





**What is most important to people who use  
mental health services in Lothian**

**A report by CAPS Independent Advocacy**

**May 2013**

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## **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 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 is set up so that the organisation and its advocates are as free as possible from conflicts of interests with the people it supports. CAPS provides collective advocacy in Midlothian and East Lothian and individual advocacy in Midlothian and East Lothian. CAPS also has several Lothian-wide experience-led projects.

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

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.

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

CAPS is a Scottish Charity, Number SC021772

# **What is Lothian Voices**

Lothian Voices is a project at CAPS funded by NHS Lothian. Since April 2012 Lothian Voices was set up to make sure that the views of people who use mental health services across Lothian were heard by the Lothian Joint Mental Health and Wellbeing Programme Board. The Programme Board is responsible for deciding on the strategy for mental health across Lothian.

Under the Lothian Voices project CAPS have been able to collect views from across Lothian and make sure these are heard when decisions are being made about mental health services.

## **LOTHIAN VOICES**



## **Why produce this report?**

This report is an opportunity to represent the views of people who use mental health services in Lothian and to make sure that the work that is being done matches what people want and what they think is important.

In these uncertain economic times where funding is tight and services need to prioritise what is offered, it is important to understand the views of the people who use the services. CAPS believes that people who have lived experience of mental health issues are most able to inform decision makers and funders about what they need in terms of their mental health.

Producing this report was also a way that CAPS could make sure it was working on the issues that were important to people. CAPS could learn more about how people wanted to have their say. The process of producing this report has given CAPS direction for its collective advocacy work. It is hoped that the report will also inform any strategic plans around mental health in Lothian.

# The process

CAPS produced a survey asking people:

- what kind of services were most important to them;
- what things they felt were missing or needed;
- important topics or issues they thought CAPS should be working on and;
- how they wanted to give their views.

There was space at the end where people could write suggestions or anything else they wanted to say.

The survey was sent to a wide range of voluntary organisations, statutory organisations and individuals in Lothian. It was included in the CAPS East Lothian and Midlothian newsletters and promoted on Eastspace, Midspace and Edspace. It was advertised via social media and an online version was made available on survey monkey. CAPS visited groups in the community and in hospital to promote the survey and collect views.

The completed surveys were collated and analysed to make up the contents of this report. There was a high volume of completed surveys from East Lothian and Midlothian and separate reports were produced for each area that go into more detail. This reflects the fact that CAPS has a dedicated collective advocacy worker in each of these two areas.

# Analysis

CAPS received **155** completed surveys. These came from:

**East Lothian**

**63**

**Midlothian**

**60**

**Edinburgh**

**22**

**West Lothian**

**10**

The responses were analysed and the main themes were identified. The views represented in this report are the topics that came up most frequently. Quotes are used from the survey to highlight the main themes.

The questions asked are written at the top of the page. The answers that came up most frequently are on the post it notes with a number below them that represents how many people said the same or similar things. Following this is more detail on each answer in order of the topics that came up the most.

Two separate reports were written for Midlothian and East Lothian, which give more detailed views from each area and are available from CAPS.

# What kinds of services are most important?

Activities and groups that brings people together

93

Independent advocacy services

22

Support from mental health professionals. Someone to talk to one-to-one.

77

Understanding and well informed GPs

16

People want services that are:

Easy to access

Flexible

Focused on the individual

Non-judgemental

Fast to respond

There when you need them

Safe

Available where you live

Respectful

Able to listen to you

Able to put you first

Benefits information and advice

15

Hospital services

10

Training and awareness raising on mental health

10

Information and advice. Knowing where to go

9

Housing

10

Crisis services

9

Support for parents

9

Befriending services

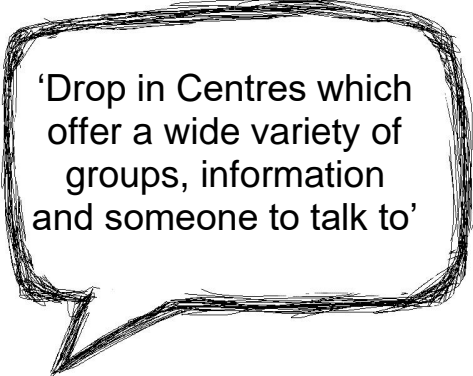
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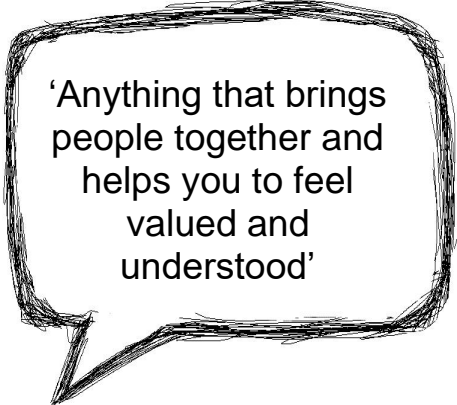
93

### **Activities and groups that bring people together**

93 people said that having places to go and things to do was what was most important to them. Getting out of the house and being around people in the same situation as you was important. The groups and activities mentioned mostly referred to ones that were organised by mental health teams and other voluntary services. Drop-ins were mentioned specifically 11 times. Sometimes people wrote the name of the service that was important to them. The services mentioned were mostly voluntary sector services that provided groups, drop-ins and activities.



'Drop in Centres which offer a wide variety of groups, information and someone to talk to'



'Anything that brings people together and helps you to feel valued and understood'

77


### **Support from mental health professionals, someone to talk to one-to-one**

People talked about having one-to-one support from mental health professionals. 13 people said that they valued the support they got from Community Psychiatric Nurses, other professionals mentioned were psychiatrists, social workers, health visitors, counsellors, GPs, occupational therapist and support workers. Having someone to talk to, one-to-one about mental health issues was very important for people.

22

### **Independent advocacy**

When people mentioned advocacy they talked about individual advocacy, collective Oor Mad History, the Personality Disorder Project and Advocacy and the Arts. People also said they value getting information through CAPS like the newsletter and people in East Lothian said they liked having monthly collective advocacy meetings and responding to consultations.



'Advocacy services that support people to find and express their voice and views'

16

### **Understanding and well informed GPs**

People said they value GPs that were well informed, listen to them and are knowledgeable about the resources in the community.

15

### **Benefits information and advice**

Services that offered Information and advice about benefits was important to people. People also mentioned being supported through the changes in welfare reform.

9

### **Information and advice. Knowing where to go**

Knowing what is available in the community was important. People mentioned the forums on the internet, informed GPs, information for carers and information and advice services coming to community groups.

10

### **Training and awareness raising on mental health**

Training that is led by people with experience of mental health issues was mentioned. People also saw this as a way to reduce stigma and increase awareness of mental health issues.

10

### **Housing**

10 people said they thought housing was most important, people who said this mainly referred to affordable housing and supported accommodation.

9

### **Hospital services**

10 people mentioned hospital services as being important.

9

### **Support for parents**

9 people in East Lothian said they value services that support parents. People also mentioned specific services that offered parental support.

9

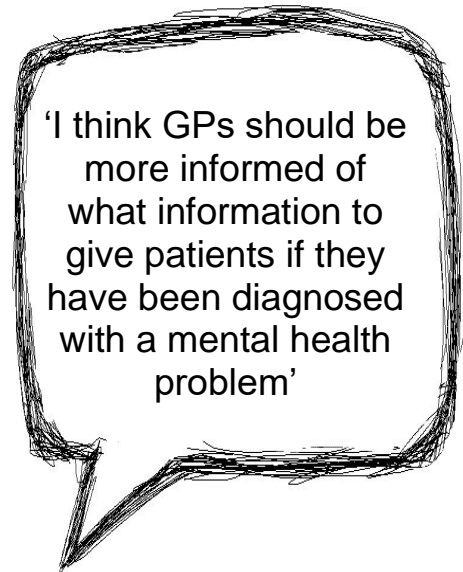
### **Crisis services**

3 people in Edinburgh and 6 people in East Lothian said crisis services were important.

5

### **Befriending services**

People in East Lothian and Midlothian said they value befriending services to help them to get to groups and activities.



## What is missing or needed?

**Drop ins.  
Informal  
support. Safe  
places to go**

**19**

**A fair and clear  
welfare system.  
Advice and  
information on  
benefits**

**15**

**Activities and  
groups that  
bring people  
together**

**19**

**Better access  
to services  
and more  
choice**

**16**

**Support from  
mental health  
professionals**

**14**

**Clear information  
and knowing  
what's out there**

**14**

**Crisis services**

**8**

**Communication**

**8**

**Education and  
awareness  
raising on  
mental health**

**7**

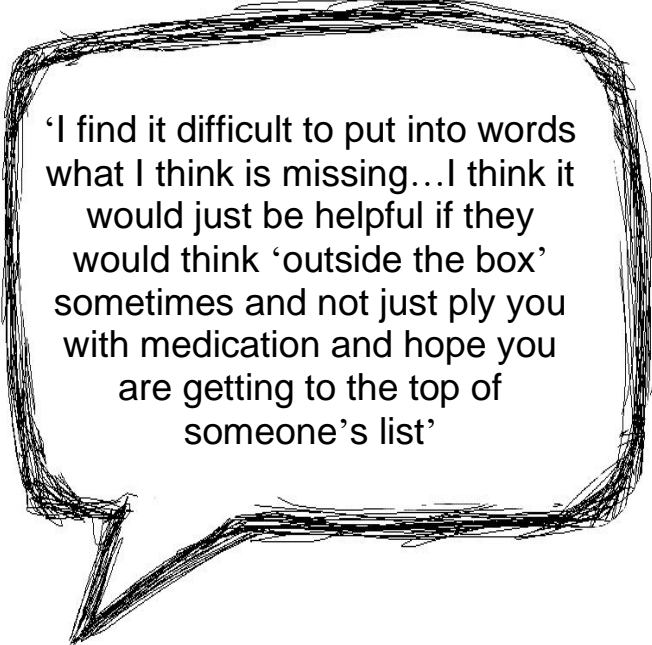
**Fair wages and  
supported  
employment**

**7**

19

### **Activities and groups that bring people together**

People said they wanted groups such as art, music, physical activities, classes, outdoor activities, groups that are for longer periods of time and things to do at the weekends and evenings. 13 people from Midlothian, 4 people from East Lothian and 2 people from Edinburgh mentioned this.

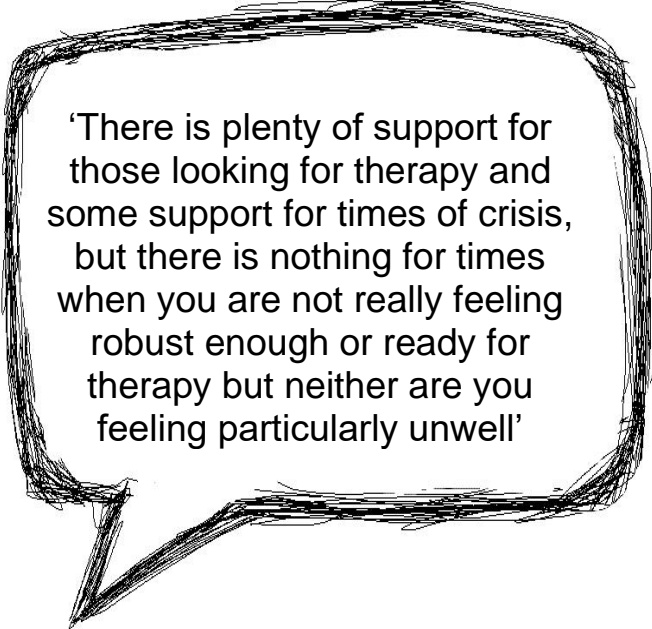


'I find it difficult to put into words what I think is missing...I think it would just be helpful if they would think 'outside the box' sometimes and not just ply you with medication and hope you are getting to the top of someone's list'

19

### **Drop ins and informal support. Safe places to go**

In Midlothian people said they would like more local drop-ins and a drop-in for younger people. In East Lothian people talked about the preventative nature of drop-ins, the closure of Tyne Park and the benefits of having somewhere safe to go and being able to socialise with peers. In Edinburgh people talked about informal peer support as well as having somewhere to go to maintain your mental health. This was mentioned 6 times in Edinburgh, 9 times in East Lothian and 4 times in Midlothian

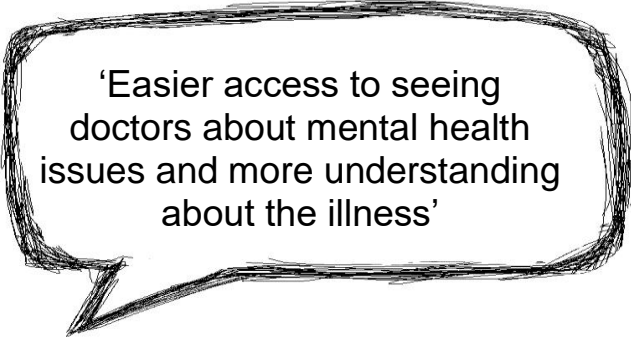


'There is plenty of support for those looking for therapy and some support for times of crisis, but there is nothing for times when you are not really feeling robust enough or ready for therapy but neither are you feeling particularly unwell'

16

### **Better access to services and more choice**

People often described the long waiting lists to get into services, the lack of choice and the difficulty in getting NHS appointments. People in East Lothian said they need more easily accessible doctor's appointments. 9 people from Midlothian, 3 from East Lothian, 2 from West Lothian and 2 people from Edinburgh talked about access to services and more choice.



'Easier access to seeing doctors about mental health issues and more understanding about the illness'

15

### **A fair and clear welfare system. Advice and information on benefits**

People want a fair and clear welfare system. They also want better communication, more support, clear information and good advice around benefits. 11 people from East Lothian, 2 people from Edinburgh and 1 person from Midlothian mentioned this.

14

### **Support from mental health professionals**

People often spoke about having mental health professionals to talk to like a Community Psychiatric Nurse, a therapist and support workers. In West Lothian people said they wanted these kinds of services to be based away from the hospital. This topic was said 5 times in East Lothian, 4 times in West Lothian, 3 times in Midlothian and 2 times in Edinburgh.

14

### **Clear information and knowing what's out there**

People in Midlothian had the most to say about this and said they need information about where to go between appointments or when the support they receive ends. They also asked for a mainstream contact point for finding out about the resources available. People across Lothian said they would like GPs to be more knowledgeable about community resources. 7 people from Midlothian, 5 from East Lothian, and 2 people from Edinburgh mentioned this topic.

8

### **Communication**

People talked about wanting to be listened to by GPs, not being told about changes in services, the lack of communication in hospital and poor communication between GPs and mental health teams. Communication was mentioned 4 times in Midlothian, 2 times in East Lothian, 1 time in West Lothian and 1 time in Edinburgh.

8

### **Crisis services**

8 people in East Lothian said there was a need for Crisis Services,

7

### **Fair wages and supported employment**

People in East Lothian said they want decent wages that are better off than being on benefits. Other people wanted more jobs, support to find work and supported employment. 5 people in East Lothian and 2 people in Midlothian mentioned employment.

7

### **Education and awareness raising on mental health**

The 7 people who mentioned this were all from Edinburgh. People said that GPs need to be more educated about mental health. There should be more initiatives in schools to combat stigma at an early age and more awareness raising and training in general on mental health.

# Important topics and issues for CAPS to work on

**Welfare reforms and  
benefits**

**27**

**Safe places  
to go.  
Community resources**

**20**

**Advocacy.  
CAPS Projects.  
Campaigns and  
consultations**

**14**

**Employment**

**11**

**Stigma**

**6**

27

### **Welfare reforms and benefits**

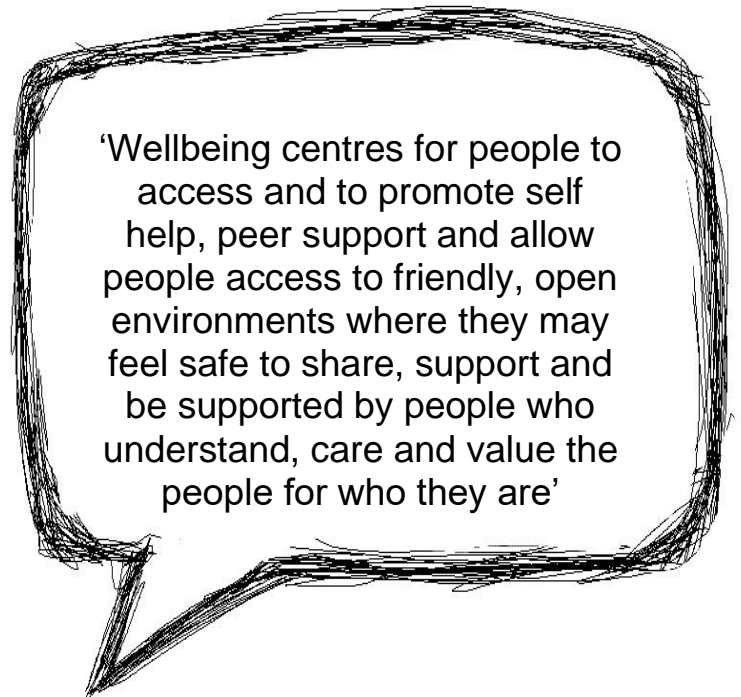
People talked about self directed support, the negative impact of welfare reforms, Employment Support Allowance, Personal Independent Payment, Work Capability Assessment and cuts to benefits. There were also comments saying that people who receive benefits should be treated better and should be more involved in decision making processes. 9 people from East Lothian, 12 people from Midlothian, 5 people from Edinburgh and 1 person from West Lothian all wanted CAPS to do some work around Welfare reforms and benefits.



20

### **Safe places to go and community resources**

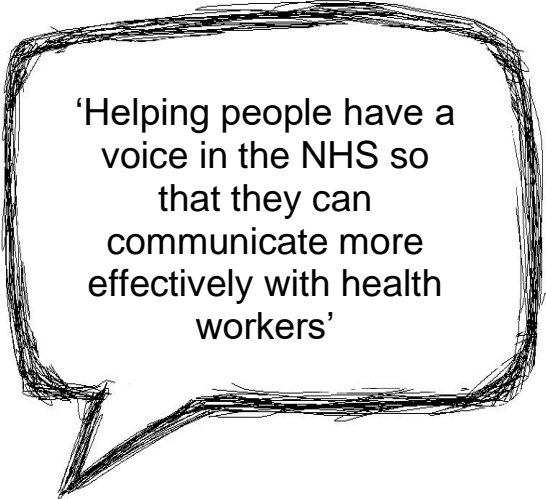
The majority of people who talked about this were from East Lothian with 10 people mentioning this. 6 people from Midlothian, 3 people from West Lothian and 1 person from Edinburgh mentioned this as well. 4 people from East Lothian specifically mentioned drop-ins, 3 people said a safe place to go, and others said they wanted a place to go socially. In West Lothian people said they wanted informal support and groups in the community and emphasised that they did not want services to be based in hospital and not necessarily run by the NHS or local authorities. In Midlothian people said they wanted more community resources and more drop-ins.



14

### **Advocacy, CAPS Projects, campaigns and consultations**

People in Edinburgh talked about the value of collective advocacy projects like Oor Mad History, Art as Advocacy and the Personality Disorder Project. Others would like clearer information on where to give their views. This topic was mentioned 7 times in Edinburgh, 5 times in East Lothian, 1 time in Midlothian and 1 time in West Lothian. In East Lothian 2 people wanted CAPS to take over as the lead in consultations and advocacy in Scotland.



'Helping people have a voice in the NHS so that they can communicate more effectively with health workers'

11

### **Employment**

Employment came up mostly in Midlothian with 10 people mentioning this. 7 people wanted help to get back into employment and 3 people wanted to make employers more aware of mental health issues.

6

### **Stigma**

Stigma about mental health issues came up 6 times in Midlothian but was not mentioned in other areas.



# How do people want to have their say?

Within groups I  
already go to

92

By filling in  
surveys

77

By filling in  
surveys online

47

By phone or  
email

43

At creative  
workshops

41

At events and  
conferences

37

Through  
Facebook or  
Twitter

35

At public  
meetings

37

## **How do people want to have their say continued....**

In this part of the survey people could fill in more than one option. People who were willing to go to an event, conference or a public meeting also said they would give their views in other ways. Many people who said they preferred CAPS to come to a group they already go to or to fill in a survey did not fill in other options.

In Edinburgh people said they would go to a public meeting but, in Midlothian going to public meetings came out as the least favourable option. Surveys and having CAPS come out to groups were the most popular options. Some people also seem keen to do things online with the option of online surveys and Facebook and Twitter.

## Other suggestions and comments

'GP attitudes to mental health are still not good enough. They can't seem to recognise when a patient is REALLY in need of help. There is a vast difference between their approach and that of the mental health specialists'

'Just thank you for all the brilliant work you do. I feel you are a real champion of our rights'

'Having an advocacy service is essential and very effective'

'I am interested in the promise of a safe place to go'

'I've been asking for a drop-in service since Tyne Park closed down. I feel there's a great need for this'

'Keep up the good work. Even with SUM (Service Users Midlothian) suspended, it is really important that service users have access to information, advice and support. In these uncertain times we need to be kept up to date by an organisation which is user led/friendly'

# Summary

## **What's most important to people**

Having places to go to, things to do and people to see came out as most important. People want safe places to go where they can get support from their peers, attend a variety of groups and activities, and get one-to-one support from people who understand mental health. Knowing where to go and having good information and advice about what is available is also important. People valued advocacy so they could express their views and be listened to.

## **What's missing or needed?**

People want easy access to help and support without having to be put on a waiting list. They want more choice in services available. Knowing what's available and information about services and community resources is important. People valued well informed and understanding GPs. Safe places to go, where people can get support from one another as well as having activities and groups is important. In East Lothian crisis services and drop-ins are what people say they need. More advice and information on benefits and welfare reform is needed throughout Lothian.

## **Important issues and topics for CAPS to work on**

People are most keen to see CAPS doing some work around the recent welfare reforms and benefits. Campaigning for community resources like drop-ins, safe places to go and activities and groups for people was also important. Tackling Stigma about mental health and work around employment were most important in Midlothian. People in East Lothian want safe places to go and drop-ins. People in Edinburgh are keen to see CAPS continue the projects like Oor Mad History, the Personality Disorder Project and Art and Advocacy.

## **How do people want to have their say?**

People mostly want CAPS to come to them at groups they already go to. People in Edinburgh are more comfortable to come to public meetings, events and conferences. Many people are comfortable filling in surveys in paper form. Some people are comfortable to give their views though the internet on Facebook and Twitter and by filling in online surveys.

## **Next steps**

This report will be made available and launched at the 'Year Two- Taking Stock' event on the 9 May 2013 about the mental health strategy; 'A sense of belonging" – A joint strategy for improving the mental health and wellbeing of Lothian's population 2011 – 2016'. It will be presented at the Lothian Joint Mental Health and Wellbeing Programme Board and other local strategic and planning meetings. It is hoped that this report will prioritise and inform any work around mental health.

The results of this survey will also be used as the topics for a series of events across Lothian looking at solutions to some of the issues raised.

What people said they thought CAPS should be working on will inform the work CAPS does and our annual target plans.

# **Acknowledgements**

CAPS would like to thank everyone who took the time to complete the survey.

We would also like to thank all the organisations that helped us to arrange visits and distribute the survey to get people's views.

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‘Things to do, Places to go, People to see – what is most important to people who use mental health services in Lothian’ Copyright 2013

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The Consultation & Advocacy  
Promotion Service

## **LOTHIAN VOICES**

