



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

## **East Lothian**

**A report by CAPS Independent Advocacy**

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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 East Lothian and Midlothian and individual advocacy in East Lothian and Midlothian. 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

## **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 survey was sent across Lothian, there is a main report that covers the whole of Lothian. In addition separate Midlothian and East Lothian reports were written that go into more detail. The Lothian wide work was done under a project at CAPS called Lothian Voices. 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.

## **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 newsletters and promoted on Eastspace. 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 this work has contributed to Lothian Voices which represents the voices of people from across the Lothians.

# Analysis

CAPS received  63 completed surveys from East Lothian

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.

# What kinds of services are most important?

Activities and groups that brings people together

40

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

17

Understanding and well informed GPs

12

Benefits information and advice

11

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

Support for parents

9

Crisis and Emergency services

6

Housing

6

Employment and Training

5

Hospital services

4

Transport

3

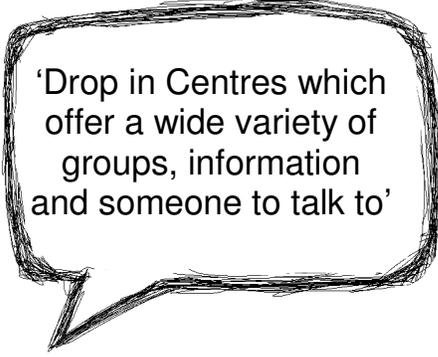
Services where you are listened to, get help and are easy to access

6

40

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

40 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 5 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'

17

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

People talked about having one-to-one support from mental health professionals. 5 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.

12

### **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.



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

10

### **Independent advocacy**

When people mentioned advocacy they talked about collective advocacy and the right to access independent advocacy. People also said they value getting information from CAPS like the newsletter and people said they liked having monthly collective advocacy meetings and responding to consultations.

9

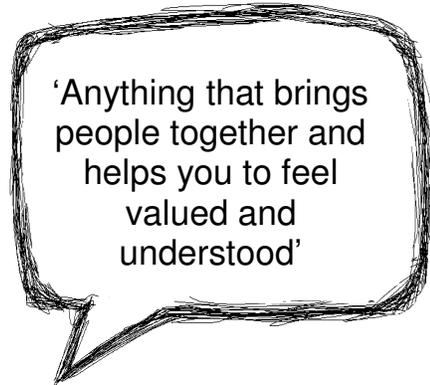
### **Support for parents**

9 people said they value services that support parents. People also mentioned specific services that offered parental support i.e., Dadsworld and Yummy Mummies.

6

**Services where you are listened to, get help when you need it and are easy to access**

People said they thought that it is important for services to help people by listening, having easy access and availability, and not to have long waiting lists.



6

**Housing**

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

6

**Crisis and emergency services**

6 people said crisis and emergency services are important, ranging from NHS 24 to respite facilities to crisis centre.

5

**Employment and Training**

People said that they need help finding supported work, accessing suitable training and more job opportunities.

4

**Hospital services**

4 people mentioned hospital services as being important.

3

**Transport**

People said they valued good bus and rail service.

## What is missing or needed?

**A fair and clear welfare system.**

**11**

**Supported places to go to meet others / Drop-ins**

**9**

**Crisis services**

**8**

**Support from mental health professionals**

**5**

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

**5**

**Fair wages and supported employment**

**5**

**Better access to services and more choice**

**3**

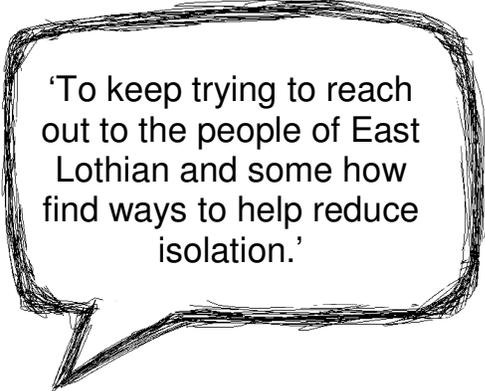
**Housing**

**3**

11

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

11 people said they need a fair and clear welfare system. They also want better communication, more support, clear information and good advice around benefits.



'To keep trying to reach out to the people of East Lothian and some how find ways to help reduce isolation.'

9

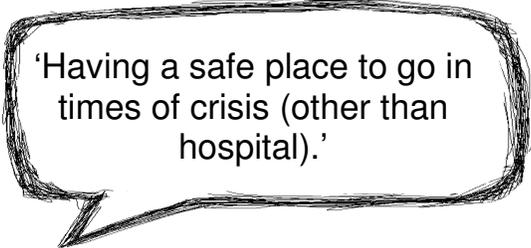
**Drop ins and informal support. Safe places to go**

People said they would like more local drop-ins. 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.

8

**Crisis services**

8 people said there was a need for local crisis services.



'Having a safe place to go in times of crisis (other than hospital).'

5

**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.

5

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

People said they need to know what is out there and to receive clear information from professionals.

5

**Fair wages and supported employment**

People 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.

3

**Better access to services and more choice**

3 people described the long waiting lists to get into services, the lack of choice and the difficulty in getting NHS appointments. People said they need more easily accessible doctor's appointments.

3

**Housing**

People said they need housing support visits, affordable housing and more housing to be made available.

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

**Safe places  
to go.  
Community resources**

**10**

**Welfare reforms and  
benefits**

**9**

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

**5**

**Crisis support**

**4**

**Mental health  
support**

**4**

10

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

10 people said they needed a place to meet. 4 people specifically mentioned drop-ins, 3 people said a safe place to go, and others said they wanted a place to go socially.

9

### **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. All wanted CAPS to do some work around Welfare reforms and benefits.

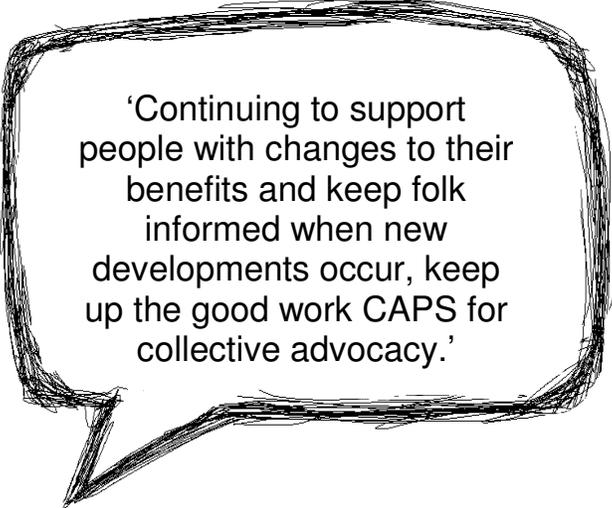


'Benefit reviews are only geared to physical health, and as such does not take into account the fluctuations in mental health.'

5

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

People talked about the value of independent 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. In East Lothian 2 people wanted CAPS to take over as the lead in consultations and advocacy in Scotland.



'Continuing to support people with changes to their benefits and keep folk informed when new developments occur, keep up the good work CAPS for collective advocacy.'

4

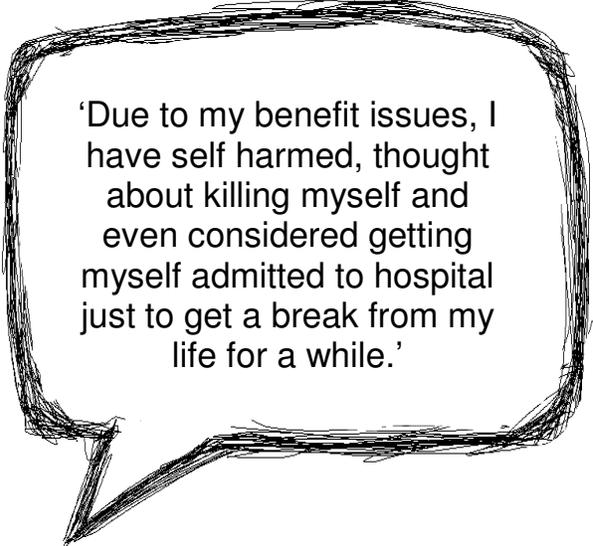
### **Crisis Support**

People said they wanted to somewhere to go locally when experiencing a crisis and to improve the provision for mental health.

4

### **Mental Health Support**

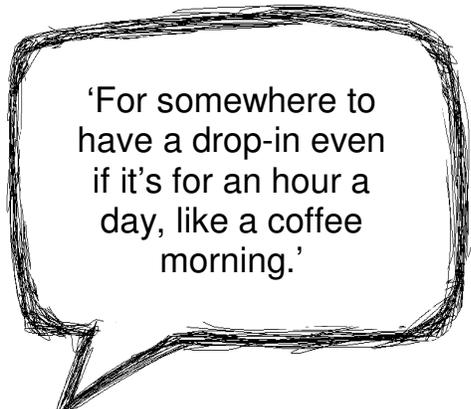
People said that they need Community Psychiatric Nurses and to increase self confidence wrapped within a supportive environment.



'Due to my benefit issues, I have self harmed, thought about killing myself and even considered getting myself admitted to hospital just to get a break from my life for a while.'



'Lobbying local authorities to move provision for mental health.'



'For somewhere to have a drop-in even if it's for an hour a day, like a coffee morning.'

# How do people want to have their say?

Within groups I  
already go to

45

By filling in  
surveys

31

By filling in  
surveys online

23

By phone or  
email

20

Through  
Facebook or  
Twitter

18

At public  
meetings

17

At creative  
workshops

16

At events and  
conferences

15

## **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.

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 whilst others would prefer email or telephone contact.

## Other suggestions and comments

'Workshops (people don't go to meetings) make it interesting for people (for CAPS).'

'Be able to live of wages and be better off than on Jobseekers'

'Fair benefit system.'

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

'Doing a good job at getting information into the community.'

'Community mental health education awareness to prevent suicide.'

# 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 said that what is missing or needed is safe places to go, where people can get support from one another as well as having activities and groups is important.
- 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. Crisis support 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.

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

- People mostly want CAPS to come to them at groups they already go to.
- Many people are comfortable filling in surveys in paper form. Some people prefer being contacted by telephone or email, whilst others are comfortable to give their views through the internet on Facebook and Twitter and by filling in online surveys.

## **Next steps**

This report will be made available on the CAPS website. CAPS will visit groups in the community to keep them updated with the progress of this work and to find out about their ideas for solutions to some of the issues raised. The report will be presented at various joint planning meetings and events. It is hoped that this report will prioritise and inform any work around mental health in East Lothian.

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.

- CHANGES Community Health Project
- Volunteer Development East Lothian
- Joint Mental Health Planning Group
- First Step – Yummy Mummies
- Health in Mind - Eastspace
- Joint Mental Health Team
- Royal Edinburgh Hospital
- Tuesday Chums
- Friday Friends
- Stepping Out
- GP Practices
- Penumbra
- Dadswork

## Contact details



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# **CAPS**

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