



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

Midlothian

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

Why produce this report?

This report is an opportunity to represent the views of people who use mental health services in Midlothian 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 these services. CAPS believe 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 a way that CAPS could make sure it was working on the issues that were important to people. CAPS could also 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 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 Midlothian newsletter and promoted on Midspace and through Midlothian Voluntary Action. 500 copies were sent to people who receive support from the Joint Mental Health Team in Midlothian. It was advertised through CAPS Twitter and Facebook accounts 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.

Analysis

CAPS received  60 completed surveys from people in Midlothian.

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

42

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

28

Understanding and well informed GPs

4

People want a choice in services that:

- Have no waiting lists
- Are easy to access
- Can offer support between appointments

Benefits information, advice and support

4

Information and advice. Knowing where to go

4

Housing

4

Supported Accommodation

4

Employment Services

3

Independent advocacy services

3

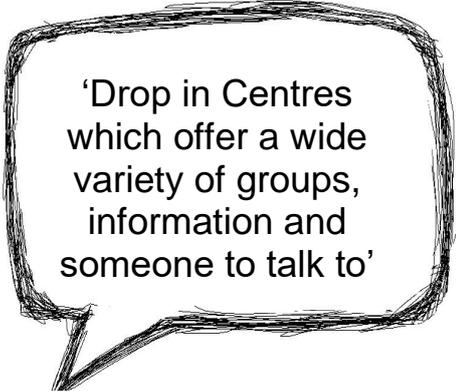
Befriending services

3

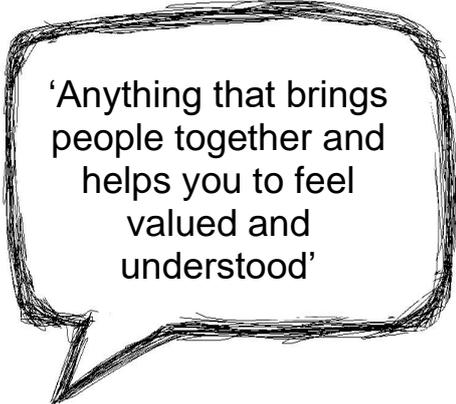
42

Activities and groups that bring people together

42 people said being able to go to groups and activities was most important to them. People value meeting others in a similar situation to themselves and getting informal support from one another. 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 4 times. Sometimes people wrote the name of the service that was important to them. The Orchard Centre was mentioned 10 times and Pink Ladies 6 times.



'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'

28

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

Having someone to talk to, one-to-one about mental health issues was very important for people and 28 people talked about the support they got from various mental health professionals. 6 people mentioned Community Psychiatric Nurses (CPNs). talking therapies were mentioned 5 times. Other people simply said one-to-one, support workers and 'someone to talk to'.

4

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.

4

Benefits information and advice

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

4

Information and advice. Knowing where to go

Knowing what is available in the community was important. 2 people mentioned the Citizens Advice Bureau that goes to the Orchard Centre and 1 person mentioned information for carers.

4

Housing

4 people said they thought supported accommodation was most important.

3

Independent advocacy

3 people mentioned independent advocacy.

3

Befriending services

3 People said they value befriending services to help them to get to groups and activities.

3

Employment Services

People wanted work experience, supported employment and help to get and keep long term jobs.

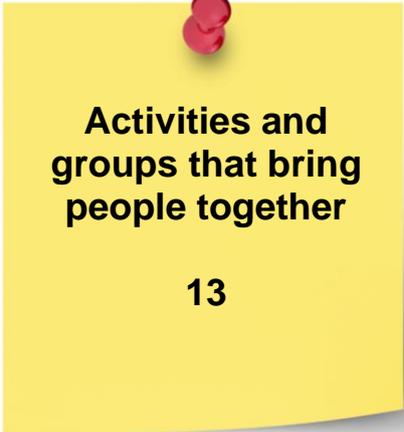


'Advocacy services that support people to find and express their voice and views'



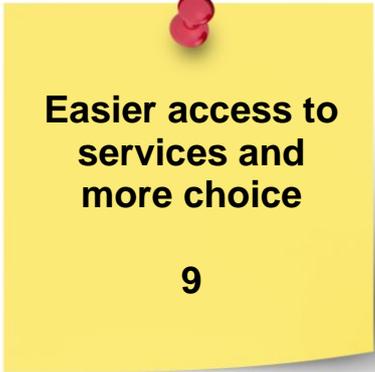
'Supported employment and assistance to get and remain in long term jobs'

What is missing or needed?



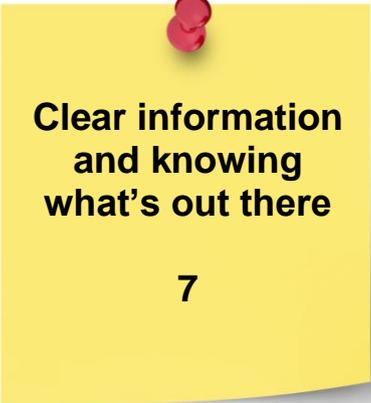
**Activities and
groups that bring
people together**

13



**Easier access to
services and
more choice**

9



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

7



Drop ins

5



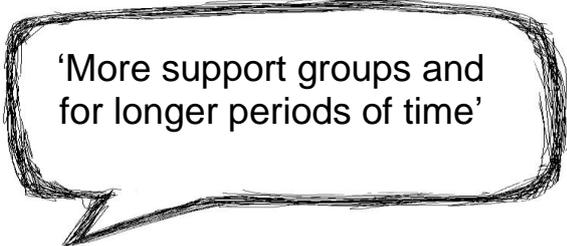
Communication

4

13

Activities and groups that bring people together

People talked about physically active groups like walking groups and gym groups. They said they needed more music groups, art activities, and bowling. People also said they want support groups that last for longer periods of time, more art based projects throughout the year, more groups like Pink Ladies, more groups that encourage people with mental health problems to go to the gym and more complementary therapies.

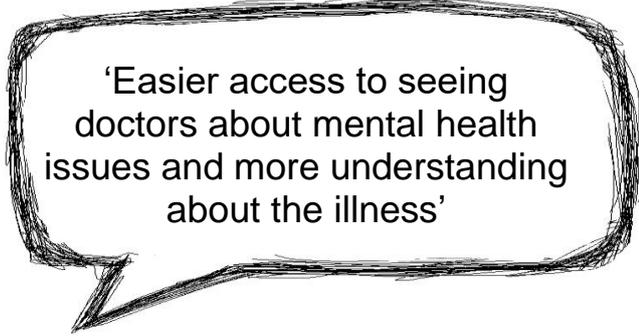


'More support groups and for longer periods of time'

9

Easier access to services and more choice

People want easier access to NHS departments, easier access to support services and easier access to seeing doctors about mental health issues. Waiting lists were said to be too long and people wanted more choice and availability for support. One person suggested longer opening hours at the Orchard Centre.



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

7

Clear information and knowing what's out there

More information about what services and groups are out there was something people said was missing and needed. People wanted help between therapy appointments or when this support ends. A suggestion was to have a more mainstream contact point for example in a shop, library or café which would benefit people who don't feel comfortable going to their GP or health visitor. Another suggestion was to have one information point for everyone that is available in GP surgeries, libraries or public centres. Other comments were about having better informed GPs and more advertising of CAPS services.

5

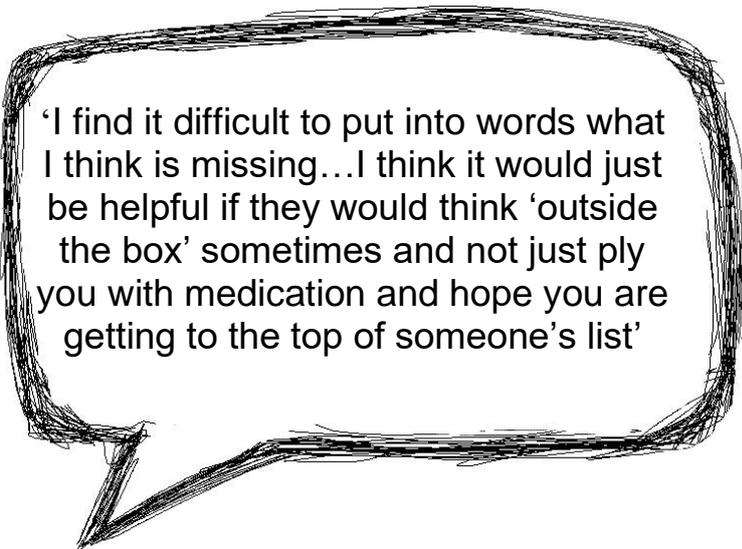
Drop ins and informal support. Safe places to go

People said they would like a drop-in for younger people and more local drop ins in every town. One suggestion was to have counselling drop in services.

4

Communication

People wanted better communication between GPs and mental health teams. To be listened to more especially by GPs and also for concerns about medication to be taken seriously.



'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'

Important topics and issues for CAPS to work on

**Welfare reforms and
benefits**

12

Employment

10

**Community
resources**

7

Stigma

6

Short Breaks

3

12

Welfare reforms and benefits

People wanted CAPS to do some work around the welfare reforms, the support that is provided during the reforms and the way people are treated within the system. One suggestion was to have a user friendly guide on all the changes.

10

Employment

Help to get back to work, help to keep jobs and making employers more aware of mental health issues was something people would like CAPS to work on.

7

Community resources

People talked about funding Pink Ladies, making sure there is support in the community, more drop-ins, an ongoing befriending service, local gyms and family support services.

6

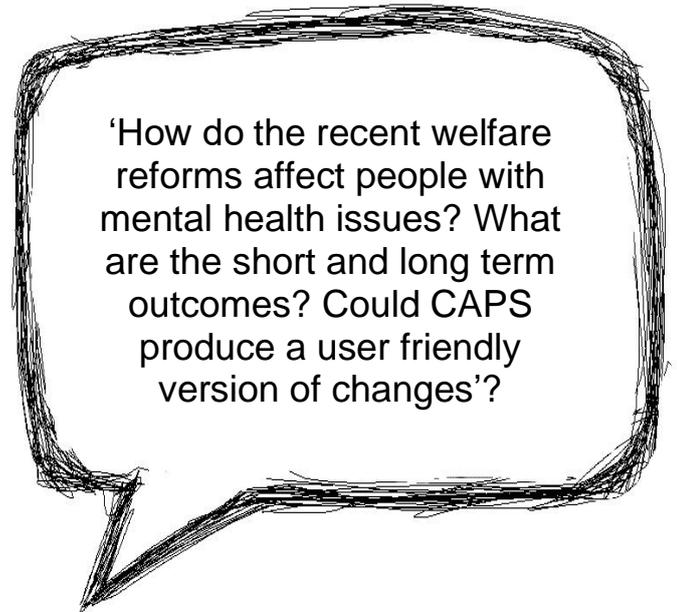
Stigma

Stigma about mental health issues came up and people wanted CAPS to do some work on reducing the stigma around mental health.

3

Short Breaks

Making sure that the Short Breaks scheme continued was something 3 people wanted CAPS to work on.



How do people want to have their say?

**Within groups I
already go to**

36

**By filling in
surveys**

31

**At creative
workshops**

14

**By phone or
email**

12

**At events and
conferences**

11

**Through
Facebook or
Twitter**

9

**At public
meetings**

9

**By filling in
surveys online**

7

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 a public meeting or event were comfortable to give their views in many other ways. Many people who said they preferred CAPS to come to a group they already go did not fill in other options.

In Midlothian going to public meetings came out as one of the least favourite options. Paper surveys and having CAPS come out to groups were the most popular options. Some people also seem keen to go to creative workshops and 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'

'I'd like to suggest having some nice biscuits in the office (caramel wafer logs) I understand the response may be funding issues but it's the little things that really count'

'Work places should be more understanding and aware of mental health issues'

'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'

'It's good to have contact with CAPS so you can ask questions and have things explained'

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.

What's missing or needed?

People want easy access to help and support without having to be put on a waiting list. They also want more choice in services available. Information about community resources is needed so people know what is available. People want the activities and groups to be offered in the area they live. They want more activities, groups and drop ins as well as a drop-in for younger people. Well informed GPs that are able to listen to people and understand mental health is something that there needs to be more of.

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 important in Midlothian.

How do people want to have their say?

The majority of people want to give their views by having CAPS come to groups they already go to. 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. One of the least favourite options for people to give their views is coming to meetings.

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 Midlothian.

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.

Contact details



The Consultation and Advocacy Promotion Service
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>

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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 Midlothian’ Copyright 2013

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