



February 2010

February Catch Up

At our next meeting, we will catch up on the discussion we had about detention and safeguards in January. People had a lot to say about Advance Statements, Named Persons and staff dealing with detention.

As we felt it was an important topic and many improvements can be made to detention, we decided to create a sub group to look at what can be improved. The group has already met and started to work on what needs to be campaigned for. We will let people know what has been discussed and how we want the campaign to be organised.

We will also have updates on the the Care and Support at Home tendering process. It was put on hold in December to allow time for an independent investigation. EUF and CAPS staff have been attending meetings in January and we will talk about the current situation.

We will talk about the Fast Track programme and see how it has worked so far. The Fast Track programme started last year and is designed to make it easier for people who have been discharged from community mental health services to get back in touch with services if they need to in the two years following their discharge.

The North West Service User group has been involved in getting the programme started and a member of the group is now looking at how it can be evaluated.

There will be updates on the different projects CAPS has been hosting over the last year. Kirsten Maclean will give an update on the Oor Mad History project and talk about how the project has been linking with projects in Canada.

We will talk about the second phase of the Personality Disorder Resource project. Naomi Salisbury is now asking staff about their experience of working in that area.

For more information on any of the projects and topics, contact CAPS on 0131 538 7177.

Our Next Meeting:

Saturday 6 February 2010

1.30pm - doors open

2.00 - 4.00pm - meeting

McDonald Road Library, Edinburgh

For more information contact CAPS on 0131 538 7177.

Hot Topics

North West Service user Group

The North West Edinburgh Service User Group is a group for people living in North West Edinburgh who use mental health services. The group has alternate meetings between PROP Stress Centre and the Rannoch Centre.

At a previous meeting at the Rannoch Centre, someone said they would like service users to campaign for sheltered housing specifically for people with mental health problems as they feel neighbours and wardens might find it hard to deal with if they are in crisis. As sheltered housing is rented, it can put people under a lot of stress if they are worried they might get evicted because of their behaviour when they are in crisis.

People do not think campaigning for sheltered housing specifically for people with mental health problems is a good idea. There is a fear factor and if someone is really ill it might be distressing to people living near them if they don't have any knowledge of mental health.

Someone said that although it is true that people might not understand when someone is very unwell but there are two sides to the argument. It could also create stigma if people with mental health issues are not integrated in the community.

We need more monitoring by psychiatric staff to avoid problems in sheltered housing instead of putting all the people with mental health problems in the same housing scheme. Society as a whole

needs to learn to live better together.

The best way would be to keep things as they are but to make sure wardens are trained properly to understand mental health better and to know how to deal with people who are in crisis. This could also prevent people from experiencing stressful situations when the police are called in and instead be dealt with by the appropriate services.

If you have views on this issue, contact Laëtitia at CAPS on 0131 538 7177 or email laetitia@capsadvocacy.org.

Care and Support at Home Tender - UPDATE

At the moment there is still no definite news about the Care and Support at Home Tender. At the beginning of December the Council suspended the tendering process and asked Deloitte, an independent company, to review the tendering process.

The report was meant to be considered at the Finance and Resources Committee on the 21st January 2010, and although the report is ready, the Council needs more time to think about the implications of the report.

The Committee has been adjourned for a further two weeks and will resume on 4 February 2010 at 2pm. CAPS will be applying to speak at this meeting. If you would like to come along it would be great to have your support. Feel free to contact us at the CAPS office and we can meet you outside the City Chambers.

The papers for this meeting should be available on the Council website from 28th January 2010 and we will have copies of these papers available at the CAPS office.

We also held a feedback session on the 17th December 2009 about what people value in their care and support and sent letters to people who have contacted us to ask their opinions.

We would very much like to know what your opinions are about the care and support you get. If you would like to add your views please contact Naomi at CAPS.

Direct Payments

Applying for Direct Payments can be helpful to have more control over the service you receive, but they are not for everyone. The main aim of Direct Payments is to allow you to have more choice and control about the type of support you get and who you get it from.

The best thing to do is to make a well-informed choice about whether Direct Payments are the right thing for you.

For more information about Direct Payments and other forms of Self-Directed Support you can contact Lothian Centre for Inclusive Living on 0131 475 2350 or at www.lothianlcil.org.uk.

You can also ask Advocard (contact details on page 6) for support with your application.

If you would like more information or to tell us your views on the Care and Support at Home Tendering process, please contact Naomi at CAPS on 0131 538 7177 or naomi@capsadvocacy.org

Personality Disorder Project

Last year CAPS consulted with service users who have had experience of personality disorder about their views and opinions.

The project produced a resource written by service users and aimed at staff. We are now working with NHS Lothian to develop training for staff and have begun the second part of the project. We are now asking staff about their experiences of working with personality disorder.

We are running an online survey which can be completed by going to: www.surveymonkey.com/s/G6SHMZV

The survey is also available by email or on paper and we are arranging interviews with staff members who are interested. The project has to be completed by the end of March 2010.

The aim is to provide training and resources about personality disorder that can help both service users and staff.

If you would like to get a copy of the survey, to arrange an interview or for any information, please contact Naomi at CAPS on 0131 538 7177 or naomi@capsadvocacy.org

April Meeting

Please note that because of the Easter weekend falling on the first weekend of April, the EUF April meeting will take place on the second Saturday of the month (10 April 2010)

Fast-track Evaluation

Last year members of Edinburgh Users Forum and CAPS staff worked with NHS staff to develop the 'Fast-track' system in community mental health services. Fast-track is now running in all five areas of Edinburgh.

This means that when you are discharged from a Community Mental Health Team, for two years after the discharge you can ask for the team to re-assess you if you feel you need their support again. When you are discharged from the Community Mental Health Team you should be given contact details and information about the Fast-track system and you do not have to go through your GP to contact the team.

We decided it would be a good idea to check that the system is working properly and to find out what people think of it, so we have agreed with the NHS to run an evaluation.

We are going to ask the Community Mental Health Teams to send a survey to everyone who has been discharged to find out their views on the system. We would also like to speak to some people face-to-face. We would like to hear from anyone who has any views on the Fast-track system.

At the moment we are writing the questions for the survey and if you would like to make suggestions or help us with the survey please get in touch. For more information contact Naomi on 0131 538 7177 or email naomi@capsadvocacy.org.

Information Pack

The information booklets and packs about Community Mental Health Services are finally ready. Everyone who is new to Community Mental Health Services will get a copy and current service users can also ask for a copy.

We have copies in the CAPS office. There will also be information packs available about the hospital very soon.

There will be a launch of the information packs in the spring and we would like to tell people at the launch why service users find information important.

Please let us know your views on getting information: do you think it is important to have good information and what kind of information do you find useful?

To give your views or to get more information please contact Naomi on 0131 538 7177 or naomi@capsadvocacy.org

The Mental Welfare Commission for Scotland's first service users' and carers' views survey is now available online at www.surveymonkey.com/s/MWCsurvey-easyread.

The Mental Welfare Commission also produced some hard copies of the survey. They are available from CAPS. Contact Laëtitia on 0131 538 7177 to get a copy. The survey will close on Friday 26 February 2010.

At our last meeting.....

Over the past few months, some people have mentioned how they have had very bad experiences around detention. We talked about how we can influence how detention happens and how we can campaign to improve and increase the use of safeguards and raise awareness among medical, social work and police staff about how people feel when they get detained.

The Advance Statement is a document you can write to say what you would like to happen if you are detained. It is not legally binding but medical staff have to read it. Some people said they don't feel consultants take these statements into account as much as they should. Someone was even told by their consultant that it was too early to make one when they asked about it.

A problem with the Advance Statement is where copies of it are kept. There can be some communication problems between the Royal Edinburgh Hospital and other NHS staff. Someone suggested having a specific room at the hospital where all statements are kept so that they can be accessed quickly.

A down-side of the Advance Statement is that someone might feel differently when they get detained from when they actually wrote it. Also there do not seem to be many people who can help with writing it. Apart from Advocard, people don't know where to go. It was suggested that it should be integrated into care plans by default.

We need a mechanism to make sure people know about Advance Statements and know how to use them. We also need a reminder system to

make sure people review their statement on a regular basis as their situation and needs might change over time. Should GPs have it on their notes and remind people?

People believe the Advance Statement is the best way for people to express their needs and it would work better if it was a collaborative effort between the patient and staff. Someone mentioned though that it might allow staff to veto things people might want to include in their statement.

We should remember that it is good that it exists at all and it is a first step in the right direction. However we need to make sure it is used as much as possible and that people are not put off writing a statement because it is too complicated or because they feel it will not be taken into account if they get detained. We also need to make sure People know about Named Persons and use it as a safeguard.

Someone also said that it can be very intimidating to have so many people bursting into your house. They understand it is for the protection of staff, but what about the service user's protection? People should have access to advocacy services when they are about to be detained. Advocates should be available evening and weekends. We need to find ways to make this possible.

Also, all staff involved in detention, from the police to medical staff needs more awareness of what people with mental health issues go through when they get detained.

Detention Sub Group

Following the EUF meeting, a group was set up to look at how we can campaign to improve the use of safeguards and increase staff training. The first meeting took place in January and here are the first ideas coming out of it.

We decided to concentrate on a list of issues. We will need to go through existing policies and documents such as the Mental Health Act and the Lothian Psychiatric Emergency Plan. This will allow the group to focus on ideas that have not been dealt with already.

We think it is important to come up with a report that can be taken forward to the right people to maximise our chances of influencing change. We want this report to be based on people's views, opinions and experiences. Therefore we will be asking people who have experience of detention for their stories and ideas. This will be done at EUF meetings, in newsletters and questionnaires.

We will look at what works, what does not work and how it can be improved for the following themes:

- Advanced Statement and Named Persons: how to make sure people know about it and can write one as easily as possible? How to make sure it is used by staff detaining people?
- Extending the availability of advocacy
- Training for all staff to raise awareness of how to deal with people in crisis
- Look at how detention can happen to make it as bearable as possible from the moment a person gets taken away from home.

Contact Naomi or Laëtitia at CAPS for more information or to share your experiences.

Before it's a crisis...

Here is a short list of phone numbers you can contact for support when most services are closed. It is a good idea to have these numbers and others where you can find them when you need support or help. Services such as Breathing Space and the Samaritans offer a listening service. Social Work and the NHS are more appropriate if you need more than this.

Breathing Space

0800 83 85 87 (6.00pm-2.00am)

Samaritans

08457 90 90 90 (24 hours)

NHS 24

0845 24 24 24 (24 hours)

Emergency Social Work Service

0800 731 6969 (out of hours only)

Crisis Centre

Free phone 0808 801 0414 (24 hours)

Text phone 0808 801 0415 (24 hours)

If you get support at home, you may have an 'on-call' number to contact staff. If you have contact with a Community Mental Health Team, they may also have a number for you to contact staff.

If you require individual advocacy you may contact:

Advocard 0131 554 5307

(Monday to Friday 9-5pm)

Hospital Advocacy Service

0131 537 6004

Community Happenings

A Journey Out of Madness

On 22 of December 2009 Alistair McIntyre, a EUF member, had his second e-book published "A Journey out of Madness".

Unlike his first e-book "A Journey into Madness" which focuses on his experience of schizophrenia, his second e-book focuses on the different elements that helped his "recovery". It is a beautifully simple and moving account starting with a description of his illness, moving on to his medication, his role as a volunteer and student, as well as how pursuing his hobbies is important.

This book is one of real hope and a must read for all who have had their life touched by mental ill health. These e-books are available from www.chipmunkapublishing.co.uk. The paperback version will be available later on this year.

Lothian Bipolar Self Help

The Lothian Bipolar Self Help Group is holding meetings on the first Thursday of every month from 7pm to 9pm at The Quaker Meeting House, 7 Victoria Street, Edinburgh.

The Self-Help groups are open to anyone who has been affected by bipolar disorder. You don't need to be referred, just come along.

On 4 February 2010, there will be an open night and on 4 March, Susan Pollock from the Lothian Recovery Network will come and talk to the group.

For more information, email lothianbipolargroup@hotmail.co.uk.

Community Gardens at the Royal Edinburgh Hospital

Royal Edinburgh Community Gardens is a new initiative in 2010 to use up to fifteen acres of land owned by NHS Lothian in Myreside to grow good food and promote companionship, health and well-being. This is likely to be a phased activity over the next 2-3 years.

They are looking for people to volunteer to give practical help and expertise in establishing the site, raising money, management and strategic planning.

Community gardens have allocated growing plots for individuals or groups for vegetables, fruit, herbs or flowers but may also have common areas of grass and other cultivation. The promotion of mental and physical health, building inclusive communities and environmental sustainability are central to the project.

This is not a long term project for this specific site but if it is successful it can be used as a model for NHS sites across Lothian.

The local charity Cyrenians is starting a Development Partnership of committed groups and individuals over the next 12 months to start a demonstration project on the site.

For more information, phone 0131 475 2354, email edinburghcommunitygardens@cyrenians.org.uk or go to <http://royaledinburghcommunitygardens.wordpress.com/>

About Edinburgh Users Forum

The Edinburgh Users Forum (EUF) is an independent collective advocacy group. Our members are people who use, or have used mental health services. We were set up to give people who use mental health services a say in the services that are provided, and how services are run.

We have monthly meetings where we discuss issues and invite speakers along. We campaign on issues like services, benefits, housing, advocacy, crisis services and transport. If you would like any more information about EUF please contact us.

Contact us

Write to:
Edinburgh Users Forum
c/o CAPS
5 Cadzow Place, Edinburgh
EH7 5SN

Phone: 0131 538 7177
Fax: 0131 538 7215

Email:
info@edinburghusersforum.org
Or visit our website:
www.edinburghusersforum.org

EUF Meetings 2010

Saturday 6 February

Saturday 6 March

Saturday 10 April

(Second Saturday of April because of
Easter Weekend)

Saturday 1 May

Saturday 5 June

Monthly meetings

On the first Saturday of each month we meet at the McDonald Road Library, Edinburgh (on the corner of McDonald Road and Leith Walk). Come along from

1.30pm for a cuppa and a chat.

Meeting starts at **2.00pm**.