



August 2010

Déjà Review

The review of advocacy services has been going on for over a year and at the end of last year, services users were consulted and asked about why they value independent advocacy and what is necessary for a service to be as helpful and efficient as possible.

However everybody was concerned about the quality of services when big budget cuts had to take place as part of the review.

When the City of Edinburgh Council and NHS Lothian published the seven different options they offered, advocacy organisations and service users were concerned that most of them did not reflect the views of people consulted and that they would have a negative effect on the choice and quality of the services currently available.

Following organisations and individuals' discontent with how the review was conducted, the Council and NHS organised an event to assess the seven options being looked at and to consider the impact they would have on services.

They now want to discuss the options with as many service users, carers and services as possible.

John Armstrong, Mental Health Joint Programme Manager for the NHS and the Council, will come to the next EUF meeting to hear people's views about the review options.

John already attended a meeting in August 2009. At the time he was just gathering views about advocacy. Another person also came to a meeting to get people's views. This time, we will discuss the different options available and how they will affect services.

Join us to give your views. If you cannot attend but would like to have a say, please contact Laëtitia at CAPS on 0131 538 7177 or email laetitia@capsadvocacy.org.

Our Next Meeting:

Saturday 7 August 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

Smoking ban at the Royal Edinburgh Hospital

Following discussions at a EUF meeting, we have decided to write to the people in charge of operations at the Royal Edinburgh Hospital about the smoking ban.

A while ago, the Scottish Government decided to establish a smoking ban in hospitals and there was a consultation on what people thought about such a ban. A lot of people gave their views but it now seems that they have not been taken into account. The management at the hospital is thinking of banning smoking altogether with a proper strategy to phase this in and look at how it will affect patients.

Below is an extract of the letter EUF wrote to Tim Montgomery, director of operations. It includes statements from service users. Some information on the current situation was obtained from the Patients Council and the Acute Inpatient Forum.

“We wish to voice our concerns about this proposed move, especially as there has been extensive consultation and research in the past and it was clear for most service users that a complete ban was not practical.

We feel the proposed move is not being planned in light of people’s views and experience and in light of actual facts about smoking in the hospital. Therefore there does not seem to be a clear strategy for staff and patients to deal with a sudden ban. We understand that the Government is working on

guidance for a complete ban for hospitals that took exception when it was first introduced but the practicality of this ban is very worrying considering the current resources and plans in place.

The views of patients on the ban were sought last year but they now seem to be completely ignored. Many people have said that they want to be able to smoke but no potential solutions have been offered. There is no point consulting people if their views are not taken into account when making decisions.

The smoking cessation service is not adequate and staff do not seem to get proper training to deal with the issue on the ward and with specific patients.

While it is recognised that smoking is banned in public places and that people have to leave the premises to do so, the difference is that a typical patient who smokes, does so in a way that is intended to calm them down. Therefore, there is a medical reason.

While it might be necessary to set up some kind of process or place where people can go, the therapeutic benefits outweigh the banning benefits and these people have rights and often can’t even leave the ward.

It is understood that there is a proposal suggested or thought about that this could be overcome by the actions of a member of staff who would ‘escort’ the patient to a prescribed place. In view of the fact that there are other proposals that will affect the staffing, this is not a possibility, especially in respect of the fact that a patient might want to smoke when no member of staff is available.

It is acknowledged that the medical profession might want to do something that makes it difficult or impossible for a patient to smoke 'on the ward', however that can be overcome with the setting up of prescribed places.

A service user said that they are fully aware that smoking seems to many people a weakness but if you ask people on the wards, they would be horrified at a ban. Whether people are detained or staying overnight when they get ECT, the ban is alarming.

How will the ban be instituted? Nicotine patches are a joke. There will not be enough staff to accompany someone who wants to smoke outside. What if you are detained and not allowed to leave the ward under any circumstances. Being admitted is hardly the time to stop smoking.

We will keep you updated on any response we get and any further developments.

GP's special interests

At a recent meeting, some people thought that it would be very useful if all GP surgeries in Edinburgh could be encouraged to display and make available all the GPs' special interests. This followed talks about the experience of a service user in East Lothian. Here is his story:

"In 1998, following a period of homelessness and poor mental health, I managed to find a place in a supported accommodation unit in Musselburgh, East Lothian.

One of my first tasks was to register at my local GP practice. To my surprise and

delight, I was handed a leaflet from each of the GPs – seven in total – stating their areas of interest and expertise.

Two of the GPs stated mental health as one of their practice areas and I immediately thought: "What a smashing idea!" No more having to tell my life story each time I went to see my doctor and not more going to my doctor with a physical ailment and being asked "Are you sure you are not just imagining this?" or "How has your mental health been lately?".

I think being able to know a GP's special interest in mental health can help getting the right information and provide easier access to appropriate care and services – an easier time for both service users and the GPs."

Service users feel this could be a great help for them as:

- It can sometimes be stressful to talk about one's mental health issues and talking to someone who has a special interest can be helpful
- It can help people deal with dual diagnosis as a GP with a special interest in mental health is more likely to know how to deal with a dual diagnosis
- It might be a good opportunity to be referred to psychological therapies, Edspace or other activities other GPs might not know about.

We wrote to Dr John Gordon to get his views and have the idea circulated at GP forums or management groups. Three GPs got back to us and all had the same views:

In general terms, they can see it would seem a good idea but it would be hard

to enforce such as system because all GP practices work independently. In addition most GPs actually enjoy the 'generalist' nature of working as a GP such as seeing a whole variety of patients with different problems, physical and psychological. If a GP has a special interest then they tend to pursue that through a special clinic either in a hospital setting or in the practice, in which case this would be publicised within the practice.

They think some doctors' styles are more suited to dealing with emotional and psychological problems. They think the best thing to do for service users is to ask the reception staff as they are probably best placed to help guide patients appropriately.

Do you agree with these comments? Do you think we need to continue campaigning? Do you think there would be ways to make the proposed system possible? What would be the best way for GPs to let people know about their interests? Please give your views to Laëtitia at CAPS on 0131 538 7177 or email laetitia@capsadvocacy.org

Development Groups North West Edinburgh

The North West Edinburgh Development Group has now started and has had its first meeting on Tuesday 20 July. There was a good mix of staff and service users. As it was the first meeting the group looked at practical things like who chairs and takes minutes as well as how to get more views from service users and where those views get taken.

An idea that came up was to have a diagram that would show where the views raised in the group could actually

go. For example the development groups would be an agenda item for the management meetings where decisions would be made.

It is hard to get the same staff to come to all meetings as they all work on different days. It was clear that there needs to be a member of staff to lead and organise the group.

It was also raised that service users need to know that being part of a group like this is not going to affect their care. Some people are worried about being labelled as complainers. Staff reassured the group that service user input is really valued. We hope that the group can work together in a positive way to develop the service.

For more information, phone Donna at CAPS on 0131 538 7177 or your local Community Mental Health Team.

Development groups: Next meetings

Some of the five Community Mental Health Teams have a development group. Service users, carers and staff work in partnership to discuss issues and share ideas on how to develop and improve services.

South West (Cambridge Street):
30 August and 27 September, 2pm

South Central (Henderson Centre):
3 September 2010, 1.30pm

South East (Ballenden House):
To be Confirmed

North West (Inverleith Unit):
To be Confirmed

At our last meeting.....

Complaints Procedure

We looked at the EUF complaints procedure and the constitutions to see if they need to be reviewed to be useful in all possible situations. We agreed it would be a good idea to keep it simple.

There was a discussion about whether EUF needs a grievance procedure as well as a complaints procedure. It was also agreed that the 'How we behave in meetings' document should be connected with the complaints procedure.

Also people should clearly understand that they are representing EUF when they attend a different meeting and therefore they are there to represent the views of EUF. It was suggested we think about a policy that explains what is expected of an EUF representative.

EUF will set up a sub group to look at the complaints procedure. We will keep you updated on the process.

Patients opinion website

We talked about a new national website for patients available at: www.patientopinion.org.uk. Patient Opinion is a not-for-profit social enterprise.

The idea is to allow people to share their ideas and stories to try and improve the NHS. Patients and carers can find out what other people think of local hospitals, hospices and mental health services. They can also share

what happened to them or their family when they were ill.

You can tell people what happened to you, as well as reading what others think. Your own story can be used to make services better for other people. Professionals are also contacted and they can post replies saying how they have improved a particular service.

At the meeting, someone said that there is now a similar website specific to Scotland. The address is www.bettertogetherscotland.com.

Better Together is a Patient Experience Programme. It supports NHS Boards, frontline staff and patients in driving forward service improvement.

The programme will also help best practice to be shared between different services and lead to changes at a national level.

To start with, it will cover three main areas: people who are inpatients in hospital, people who receive primary care, especially from their GP and people with long-term conditions.

Royal Edinburgh Hospital short term changes

At our last meeting, we talked about the latest in the review of acute services. Here is a summary of the current situation.

Over the past two years, there has been a review of acute mental health services in Edinburgh and the Royal Edinburgh Hospital. The introduction of

Intensive Home Treatment Teams (IHTTs) in 2008 has led to a wider review of all services in the hospital and the community and involving a partnership of health, local authority, service users, advocacy and carer organisations.

The idea is to improve care across the board and improve the patient experience and the safety of patients and staff.

When someone has an acute episode of mental illness they are cared for by a variety of teams, services and as their care needs change, they need to be transferred to a different team in a smooth way. This requires a lot of planning.

For an integrated acute care service to work, inpatient wards will be aligned with the two IHTT teams (two wards for the North and two for the South, plus a ward for East Lothian and Midlothian). The wards will go from twenty five to twenty and eventually fifteen beds.

There will be single sex wards to give more support to vulnerable people but with common activities across wards. Acute in-patient wards should become non-smoking and patients will be offered support to aid smoking cessation.

Intensive treatment at home should be available 24/7 to all patients considered for admission to hospital and throughout any necessary hospital stay.

A review of how medical staff are organised is also necessary and posts working across team and service boundaries need to be developed.

We will keep you updated on the progress of the review.

Before it's a crisis...

Here is a list of numbers you can phone for support when most services are closed. It is a good idea to keep these numbers 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

08454 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)

Royal Edinburgh Hospital Advocacy Service

0131 537 6004

Community Happenings

Bipolar Self Help Group

The Lothian Bipolar Self-Help Group normally meets on the first Thursday of each month from 7pm to 9pm in the Quaker Meeting House on Victoria Terrace. The group is for people affected by bipolar disorder including friends and relatives of sufferers.

Please note that there will be a one-off change of venue for the meeting on Thursday 5 August. It will take place at the Central Library, George IV Bridge from 7pm to 8pm. The topic will be CBT and other Talking Therapies.

Personality Disorder Trainers Required

Do you have experience of personality disorder? Either as someone who has been given the diagnosis or someone who works in the area?

Are you interested in developing your training and facilitation skills in a supportive team environment? Are you committed to recovery values in mental health practice? This means, for example, living well in the presence or absence of symptoms. If you can answer 'yes' to these questions, please read on!

Over the last year, Naomi at CAPS has developed a new resource about personality disorder called Much More Than a Label. This toolkit is a collection of information and reflective experiences about the experience of personality

disorder based on people's lived experience of it.

Now a training course will be developed and facilitated by people with lived experience of having the diagnosis and people who work in the field. There is an exciting opportunity to become a trainer for this course.

An information event will take place on the 26 August 2010. There will be information on the training and how to become a facilitator. It is open to people who have lived experience of personality disorder, who have been given the diagnosis or who work in the area.

If you apply and are successful in becoming a facilitator, you will be given training and ongoing support. The people that you train will have the opportunity to build on what they have learned through reflective practice groups.

To find out more about the training and to receive information about applying, please come along to an information event on 26 August 2010 from 1pm to 4pm (lunch provided at 12.15pm) at the Edinburgh Royal Infirmary.

For an application form for the event, please contact Sarah Cairns on 0131 537 6761 or email Sarah.Cairns@nhslothian.scot.nhs.uk.

For more information on the Personality Disorder project "Much More Than a Label", contact Naomi at CAPS on 0131 538 7177 or email naomi@capsadvocacy.org.

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 7 August
Saturday 4 September
Saturday 2 October
Saturday 6 November
Saturday 4 December

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**.