

Autumn 2007

Islington Borough User Group – iBUG – is a group of people who either use or have used mental health services and have come together to monitor the provision of those services in Islington

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Autumn Newsletter



PROPOSED CUTS IN MENTAL HEALTH

By Peter Jones

Why is the trust cutting so many services, nine million pounds worth?

Where did all this start? The Blair Government was adamant that the old health service could not continue in the same old way. One historic problem of the NHS was that hospitals would spend money without any real knowledge as to how much a service was going to cost. So every year around December, January there would be a crunch when hospitals started to realise that they had massively overspent. Suddenly hospitals would start cancelling operations and only treat absolute emergencies.

To combat this state of affairs the government set up Primary Care Trusts (PCT) and provider insti-

tutions like acute hospitals and mental health care institutions. The PCT of each area, in our case Islington, would be given a mass of money from the strategic health authority (London), and decide how that money was to be spent. Each year these plans would be set out and the corresponding service would be purchased.

If there was not enough money for an existing service it would have to change or be closed. This is why the trust has to cut nine million pounds over the next two years from existing services.

What if the trust refused to make the cuts? The present executive directors and non executive directors could be sacked by the secretary of state. At a minimum a hit squad of

accountants would be called in to make the cuts anyway. This would be done in the fastest way possible without due regard for local feelings or priorities.

So why am I talking about this? There are some very dangerous people in the service user movement who are arguing that the trust has some sort of choice in this matter and that all it has to do is say no to the Government, the SHA the two local PCTS and keep on spending regardless. It really cannot.

That is why with great reluctance I am supporting the Trust. There are individual decisions I still oppose but the broad strategic outline case the Trust has made I agree with. This covers the 9 million cuts.

Day Services Review

By Suzy Lee

As many of you know, the Day Services Review is ongoing. iBUG's Peter Jones is involved and will continue to monitor the situation. We will keep you posted on any new developments that occur.

“Ayo feels that iBUG has enhanced his quality of life. He believes that it has enabled him to be heard and that people act upon the things that you say.”



An Irish Story

By Gerard Greene

In Ireland recently, my brother and I got hopelessly lost in the ‘back of beyond’ as they call the wilds over there. The only living thing we could see for miles over the green rolling hills was a donkey by a gate, looking at us quizzically.

‘I don’t suppose you could tell us where the

town is near here?’ my brother asked it jokingly.

Imagine our surprise when the donkey replied ‘Sure, it’s over the hill, turn left into the first lane and go about four miles’

Bemused, we thanked it and drove on. Just over the hill, we saw a farmer

in a field, stopped, and told him about the talking animal.

He looked at us, smiling ‘Sure that will be Dobbin! But he’s an awful liar- you don’t want to believe a word he says’.

Service User Profile-Ayodeji Oyebade

By Beth Bear

Ayo describes himself as a Black British male who is 39 years old. Before becoming involved in iBUG Ayo has been employed several places, both as a paid employee and as a volunteer. For instance, Ayo has worked as a civil servant, as a consultant to an HIV aids and sexual health program, and has been very active in the gay & lesbian community volunteering his time as a helpline volunteer and serving on various management committees.

Through his work, Ayo met the Queen Mother at one event and Princess Diana at another. Ayo continued to stay involved and employed until he lost a friend to AIDS. That evening he went into crisis and less than 6 weeks later was sectioned. This even

occurred in about 1991 when Ayo would have been about 26 or 27. He was then put on maintenance medication by his GP for anxiety.

However since becoming ill and being sectioned, Ayo has not stopped being active and involved. He is heavily involved with iBUG, is a trustee at Islington Mind, works part time at Together (a mental health charity), is an active member of the Labour party in North Islington, works part time at Isledon Road as a receptionist (through the service user participation scheme), and regularly visits Ashley Road. Ayo also attends DRE, the Social Services Forum, the iBUG Patients Council, the iBUG business meeting, the Mind Management Committee Meeting, and the Umbrella Board.

Ayo feels that iBUG has enhanced his quality of life. He believes that it has enabled him to be heard and that people act upon the things that you say. He said, “Before, if you made a noise, very little would be done but now that iBUG has taken it on it is better.” Ayo strongly believes that mental health issues cannot stand alone from other health issues and inequalities.

One of his favourite things about iBUG are the snacks at Business Meetings (thanks Beverley!). He also likes the social atmosphere and the various speakers that come and address the group at Business Meetings. Ayo says that iBUG has matured him as well. He now feels he is able to say how it is without being nasty.

Smoking and the Highgate Mental Health Centre

By Suzy Lee

Recently I have been speaking to a lot of people about the smoking policy at Highgate Mental Health Centre. It is now illegal to smoke anywhere in the hospital, including the grounds. An exception has been made for inpatients, who are allowed to use the smoking garden, with limited access. Typically, there is an escorted trip to the garden every two hours, for patients who do not have leave to go by themselves. Not surprisingly, this has proved unpopular with some patients, who would like freedom to smoke when they please.

“It’s a wind up” said one male patient, “you’re used to smoking when you want to, then they hit you with these two hourly breaks.” One woman said she was desperate to get discharged as she was a heavy smoker and found it very difficult. Others were getting angry and one patient described hitting a nurse when he refused to let him have a cigarette. There is also no smoking at night- the last smoking break is at 10pm and then that’s it until 8am – bad news for smoking insomniacs.

Whilst the nurses do their best to stick to the breaks, this is not always possible, particularly if there was a crisis on the ward. One

nurse described communication as essential, saying that when informed about any delays, patients were much more understanding. He did acknowledge that the opportunity to smoke was much less; “before, they would sit in the smoking room all the time - now they get 10 minutes every two hours”

It has long been commented on that psychiatric patients are often heavy smokers; this will help some to cut down but only if they continue to stick to the reduction when they leave. Also, there is the issue of freedom of choice - for smokers to indulge when they want to in what is their temporary home. Prisoners can smoke, for example, the argument being that they did not choose to be in prison - the same can be said of psychiatric patients, but they are not given the same rights—and remember that before too long, smoking will be completely banned and the smoking gardens will go.

I spoke to one of the trained smoking advisors who said that patients can get very anxious about getting their next smoke and that he advised patches to cut down on the cravings, which helped most people. He felt that cigarettes go well with negative symptoms and that those suffering from psycho-

sis often had a harder time coping than other groups. He pointed out that whilst 10 per cent had given up since the ban, others got very upset when the smoking rooms were closed and some blamed the staff. Indeed, many staff were concerned at the changes and fearful that there would be a rise in incidents, including violent incidents, by frustrated smokers.

Not all patients, however, were against the smoking ban. Some are in support of it - one woman said that she was glad her daughter and grand-daughter were being protected from second-hand smoke, (the dangers of passive smoking have been well publicised) and another said it was helping her to give up.

There is clearly a mixed reaction to the smoking policy. There is no doubt, however, that the wards are cleaner and more pleasant places to be than when smoking was freely allowed—they don’t stink of stale tobacco for a start. On a personal level, though, as a heavy smoker, I dread ending up on the wards again because my perception is that sectioned patients without unescorted leave are pretty much forced to reduce their intake of tobacco, willing or not.

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“Service user empowerment should be recognised not just as useful to the organisation, but also to the individual for recovery.”



Interview with Ros Lettman, Service Involvement Co-ordinator

by Suzy Lee

Q: What is the main focus of your job?

A: To promote service user involvement in the trust and ensure the service user’s voice is heard by management.

Q: How do you feel about service user involvement in the trust?

A: I see it as necessary—otherwise, we would be serving the community and might not know if their needs were being met or not. Those managers who regularly see service users say it is valuable and positive as they come up with a different perspective. For example, one manager changed the way he ran ward rounds due to service user involvement.

Q: Would you like to see anything change to improve user empowerment?

A: Some people are still not clear on what service user involvement is, and are not getting involved. For example, some managers are still not using service users on interview panels. It needs a broader and central focus, e.g., changing the

consultative forum to wider representation from service user groups in the community, and having a community meeting.

I also feel service user empowerment should be recognised not just as useful to the organisation, but also to the individual for recovery - the community mental health teams could include it in their CPAs, as something to do as people get better. Also, the whole question of payments needs to be clarified—there are some service users who are not getting involved because of this.

Q: How do you feel foundation status in the Trust will impact on service user involvement?

A: I hope it will make a positive difference and empower service users more. For example, some service users will become governors and they will have powers to hire and fire the board of directors, and be able to ensure fair and understandable decisions.

Q: what is your experience of iBUG?

A: My experience is limited, but I did go to two

meetings early on. I do see some members on panels, e.g. the implementation group, and that is working well

Q: Would you like anything about iBUG to change?

A: I would like to see it promoted more in the trust; not everybody knows about iBUG. Peter is quite well known but I would like to see some more of other members, too.

Q: What impact will Robert Jones (User Inclusion Manager) leaving have on your job?

A: Huge. Robert was the middleman bringing management information to me, and I took that to the service users. I have lost that feedback with Robert leaving. Parts of his job also fed into service user involvement, too, and of course he worked with carers involvement too.

iBUG would like to thank Ros Lettman for her cooperation!

Hearing Voices Conference

By Suzy Lee

Recently I was lucky enough to attend the conference celebrating Hearing Voices Day. There were some fascinating speakers and also dance performances that attempted to capture some of the thoughts and feelings of voice hearers.

The first speaker was Tasmin Knight, who spoke about voices and unusual beliefs. She asked where voices come from and concluded that there was no one answer, but lots of differing ideas – one should accept the voice hearer's own explanation, which may be anything from traumatic experiences to spirits. She also said that she accepts delusions and unusual beliefs and tried to help people to cope with them. She said that if someone was having problems with voices, it was not necessary (and not always possible) to remove the voices, but rather to help the person to learn to live with their voices. She pointed out that many voice hearers are not in the system - 43% of people experience telepathy and it is normal to have 'different' beliefs about the world. It is important that the person can cope with their beliefs - if they can't, they are likely to become an inpatient.

Tasmin also said that anxiety management could be helpful in gaining reassurance and helping the person feel safer. She had looked at books on the topics of their beliefs ,e.g., psychic self-defence against spirits. Support from others could also be very important - she explained how one person believed in alien abduction and joined a support group for alien abductees, and was then able to get on with his life. She said this type of problem solving could be very useful - one person, for example,

wore tin foil on his head to protect his mind and got stared at a lot because of his odd appearance, so she suggested that he wore a hat, which worked very well.

Tasmin also said that improving self-esteem was very important - it helped people to cope with fear and their preoccupation with voices. The voices might still be talking, but the hearer was not so disturbed.

Next came some workshops - I attended one on hearing voices and self-harm which looked at the stigma attached to self-harm and the negative experiences that many self-harmers experienced. I found this to be a little disappointing, to be honest - as an ex-voice hearer and self-harmer, I did not feel that I learned anything new, but rather heard my own experiences echoed by others in the group.

The next speaker focused on negotiating with your psychiatrist about medication. He talked about how diagnosis became tied to medication and mentioned some of the powerful interests here from psychiatrists to pharmaceutical companies. He argued that antipsychotic medication is not antipsychotic - it helps with anxiety and sleep, but not psychosis.

He argued that people are often left on medication for too long and cited the NICE guidelines for gradual withdrawal. He argued that relapse was often not a return of the original illness but could be due to different reasons. He went on to discuss the rapid onset psychosis which occurs when people stop taking their meds and said this was due to a number of reasons, including discontinuation syndrome or drug withdrawal syndrome, rapid onset (especially linked

to clozapine) due to super sensitivity and neurological disturbance, psychological, or a genuine relapse caused by withdrawal.

He argued that it is good practice to involve the patient and listen to them, to engage with them and advocate on their behalf, and to offer choices and respect them. He advised patients to use the CPA process to get what they want.

The next speaker also focussed on coming off medication and recommended the MIND website on coming off meds. He advised people to talk to their allies and get them on board, then go to negotiate with the doctor or CPN. He stated that it took as long to come off meds as one had been taking them - for example, if you took them for a year, it should take a year to come off them.

The last speaker talked about speaking to people's voices. He said that he could find out what troublesome voices wanted, where they came from and when they first appeared. He told the story of one patient who heard voices and coped with them, but then joined a Christian sect who told her that her voices were evil and she should try to fight against listening to them. Six months later she had a breakdown and ended up in hospital. He spoke to her voices and they said they were quite benign, but did not like being ignored. Over time, the patient managed to have children, got married and eventually her voices disappeared.

I found this conference fascinating, informative and stimulating. It was also encouraging to see how many of the speakers were users and ex-users -there is hope for us all yet!



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Get Involved With The iBUG Newsletter

By Beth Bear

Are you aware of an issue that you believe more people should know about? Do you have knowledge of a service or project that you think other people would benefit from? Are you just looking for an outlet to your creative ideas?

If so, you could contribute to the iBUG Newsletter. We encourage ideas for contributions and will help you to develop your idea into an item for our newsletter. iBUG members in particular are encouraged to contribute, but all are welcome.

For more information please contact Beth Bear or Suzy Lee at the iBUG office on 0207 561 4140.

Changes To iBUG Payments

The iBUG Board of Directors has reluctantly decided to reduce service user payments from £20 to £10. The Board had to reduce payments due to financial constraints. This change is effective immediately and is for all iBUG made payments.

iBUG DIARY

The iBUG Business Meeting and the iBUG Patients Council are held monthly. Please contact the iBUG office for further meeting dates.

Highgate User Forum
 5/11/2007, 2.00pm
 HMHC, (Highgate Mental Health Centre) Jaffa Kareem Seminar Room, Contact Beth Bear 020 7561 4140. iBUG Patient's Council members may attend

Foundation Trust Committee
 09/11/2007 3.00pm St Pancras Hospital. Contact Peter Jones 07950229007. Only designated members

may attend.
iBUG Patient's Council
 13/11/2007 2.00pm
 HMHC, Contact Beth Bear 020 7561 4140. iBUG members from Camden and Islington may attend.

Service User Implementation Group
 16/11/2007 1.00-4.00pm,
 2nd floor East Wing St Pancras Hospital. Contact Ros Lettman 020 7530 3340.

Service User Research Forum
 21/11/2007 3.30-5.00pm
 Seminar Room, Department of Health Sciences, Hampstead Campus, University College London, 2nd Floor, Royal Free Hospital.

iBUG business meeting
 27/11/2007 2.00pm Hanley Road Day Centre, 75 Hanley Road Contact Beth Bear 020 7561 4140. Open to all iBUG Mem-