

Winter 2008

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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Winter Newsletter

**Chair's Report**

By Peter Jones

Foundation Trust

At the time of writing this the Camden and Islington (CANDI) Trust is still awaiting the decision from Monitor regarding its application to become a Foundation Trust. The decision is expected to be made on the 4th March 2008. In my humble opinion the Trust is very likely to become a foundation trust on that date. What will it mean for us? In the short term there will be little or no change at all. At a local level services will remain the same and service users should notice no changes whatsoever. It is in the long term that things will change. The governance of the Trust should change and be far more responsive to the views and expectations of service users. The Governors will have been elected by newsletter publication date. iBUG will draft an open letter to all members with the list as soon as the results are known. I would like to thank the service users who nominated me

to become a Service User Governor, however both Patrick Dalton the CMHC Chair (my equivalent in Camden) and I felt it was inappropriate and posed a conflict of interest.

The CIP (Cost Improvement Programme).

The CIP is proceeding as expected. The largest CIP project has just got approval by the CANDI Trust board, the Islington PCT (Primary Care Trust) Board and the Camden PCT Board. Of course I am referring to the bed reduction and closure of the Mornington Unit, the South Camden PICU. AS said before many times we will have to track the closure of these beds very carefully. Although it is a less significant cut for Islington the overall effect could have an impact, if the situation is not handled carefully. Our colleagues in Camden are producing a running total of bed numbers across the Trust so it would be pointless for us to do the same.

However we should be watchful and very careful that none of us have to wait for a bed at the Highgate Centre if this is what is required. This CIP programme will be implemented over the next 12 months. My parting word is to be watchful.

IMF

Some iBUG members may know that for my sins I am also the Chair of IMF (Islington Music Forum). Well, over the last few years the funding arrangements for IMF have been very precarious. Yet again I would like to announce that IMF has found funding for another year. Once the programme of projects has been finalised I will publish a list in the next appropriate iBUG newsletter. PS: due to changes that the Trust is making around The north Islington Crisis team, both iBUG and IMF are moving to refurbished offices on the ground floor. This move is expected around AUG / SEPT 2008.

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A TRIBUTE TO ASHLEY ROAD

By Phillip Fox

In 1988, after eight years in Devon, I returned to London to support and house a woman and her three children who needed to escape domestic violence in Yorkshire.

Our situation soon became intolerable due to overcrowding and her alcoholism and instability; for the sake of the children I elected to become homeless, spending the next year moving from one location to the next until the family was rehoused.

Meanwhile my accommodation had been let out to a drugs dealer, left in a filthy condition with no rent paid, my chronic illness had worsened, my incapacity benefit was cut and I was faced with eviction.

I went to my GP with depression and felt that I was not being understood. As chance may have it I was introduced by a friend to the Mind drop in centre at Ashley Road in North Islington where I was immediately accepted without any formality.

The dedicated team workers helped me through all my problems with the courts, landlords, and Council, Benefit and Drug and Alcohol agencies.

Within the building the further advantages of counselling, healthy meals, laundry facilities, fresh clothing and most importantly companionship and complementary therapies were made freely available to me.

I can say with all confidence that, little by little, I was able to turn my life and circumstances around within the confines of the one building and the unwavering support of the staff therein.

Since then, this facility has enabled me, through its comprehensive networking, to pursue many new interests. I have furthered my activities in gardening and drawing and painting, explored the fundamentals of photography and Shiatsum, taken part in poetry and drama classes and sold artwork through an affiliated gallery.

I have been on a number of organised day trips, week long holidays and helped with the organising

of open days. I have met many worthwhile people and made some good friends.

Recently I joined the Islington Borough User Group (IBUG) where I have been able to take an active role in the mental health system. I put in a few hours each week for which I receive a small remuneration and have the satisfaction of being able to help others.

Now, and in retrospect, I can fully appreciate the value that the drop-in service has given me. I have been helped through a depressed and exhausted state. Without any diagnosis, I was mentally ill with reactive depression but was no burden to the psychiatric system; it was the warmth, patience and experience I was given that conquered my adversity and provided me with the security and peace of mind I have today.

Thanks for the opportunity to express my gratitude.



Cognitive Behavioral Therapy

By Suzy Lee

Recently I spoke to a woman I will call Sarah (not her real name), an OCD sufferer, about her experiences of Cognitive Behavioural Therapy (CBT). She attended the Bethlem Hospital in Kent where she came to understand that CBT is about changing behaviour through changing thoughts.

Sarah said it is about thinking logically and putting your behaviour into perspective. For example, a person may become fixated on hand washing and become very worried about the consequences of not washing.

In Sarah's case, she gets very pre-occupied with germs, so some routine tasks e.g. handling raw meat, would start her off on washing. She would become frightened that she had germs on her hands that would infect people, even that they might die, so this might provoke an orgy of washing.

She also spent hours washing up, and used CBT to break this pattern. A nurse stayed with her whilst she washed up, once, and then encouraged her to come away.

She would feel intense fear and anxiety about what would happen. She was asked to measure her anxiety on a scale of one to ten, and then she would distract herself with other activities.

Sarah said 'I knew it wasn't right, but that didn't stop the fear.' Sarah felt the fear was key in driving her OCD, but that her anxiety was reduced by exposure to new ways of doing things. She described her OCD as becoming like a bad habit, but by practising doing things differently, she broke those habits and also broke the chain of fear which kept her imprisoned.

I have had CBT myself on a one to one basis and I found it incredibly useful. I used it to overcome anxiety and still use the 'skills training' I

learnt nearly ten years ago—finding ways to rationalise my fears by focusing on reality and also reducing my anxiety through distraction techniques—a hot bath does wonders for me as it provides both distraction and relaxation. Other people use deep breathing or visualisation—whatever helps to increase relaxation and reduce anxiety.

Sarah had group therapy and is insistent that the group was a large part of what helped her - the support of other sufferers as well as her own determination to get better.

I had one to one therapy and remember forming a close relationship with my therapist. Either way is clearly able to produce remarkable results, and without depending on medication which can have unpleasant side effects. CBT offers an alternative to the medical model which can benefit many people.



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He enjoys being at the cutting edge of mental health in the borough, and feels great satisfaction that his voice is listened to.

SERVICE USER PROFILE

By Suzy Lee

Phillip is 'around 60' and has been coming to IBUG for about 15 months. He finds it very rewarding and cites being connected to society, and credibility - he says re-using old skills is very challenging, but keeps him going.

He enjoys being at the cutting edge of mental health in the borough, and feels great satisfaction that his voice is listened to. Phillip is also very sociable and enjoys meeting new people.

AN ARABIAN TALE

by Gerard Green

After our visit to Eire my brother and I dropped by Harrods to check out that monument to good taste dedicated to Mohammed Fayed's son Dodi, and Princess Diana. Suddenly the building was hurriedly

Phillip is also involved with other services such as Ashley Road, which he initially attended with an alcohol related depression.

He feels he has avoided using formal psychiatric services by attending Ashley Road. He also attends NIDS (North Islington Drugs Service) where he hopes to develop an involvement role similar to that he holds in IBUG.

Phillip plans to retire to Shaftsbury in due course, where he of-

ten visits and has a close group of friends. He says he is satisfied with his life but regrets not furthering his education or taking advantage of some of the provisions his parents made for him.

Phillip has now lost both his parents, but has a son of 27 and also has some cousins he keeps in touch with. He lives alone in a recently renovated flat in Crouch Hill.

evacuated.

It was tense outside; armed response officers, steely of jaw and eye, were looking very resolute, clutching deadly machine guns.

"What's going on" my brother nervously asked one. He turned his black

baseball-capped head to us, his voice excited "We want bed linen on the first floor"

Day Centres Review– an interview with Bianca Kokkolas

By Suzy Lee

I spoke to Bianca recently about the day services review and the first question I asked her was: why now? What had driven the day services review? Bianca replied that there have been several reviews in the last few years, including the Best Value Review in 2004, and she felt now was the right time to act.

This review was driven by the Recovery Model, of which we have heard lots recently. She felt most service users need stimulation rather than just sitting around, and help to move on to education, or employment.

I challenged the view that we are all ready to return to work and she acknowledged that this is not appropriate for everybody—but increased well-being, measured via day centre feedback forms, could be. Reduced admissions to hospital, increased confidence or improved daily living skills, for example, are positive outcomes.

Bianca acknowledged that people who attend day services often feel a strong sense of ownership, but argued that she also has to think about the people who do not currently attend day services even though they might benefit. She cited young people, and people from black and minority ethnic (BME) communities - she is concerned about social exclusion and means to tackle it through this review. Increased access is key to the review.

In particular, there is concern that those in the south of the borough get a raw deal—this is why Southwood Smith has been proposed as

the site for a new ‘super centre’. Ashley Road would merge with Southwood Smith and a new day centre would be created on this site.

This option is not, however, problem free. Ashley Road is very popular and there has been some overcrowding, but users are up in arms as they love the Victorian house it is based in, and do not want to travel so far to the new site. In response to requests during the review, a feasibility study is now being done to see if it can be made compliant with the disability discrimination act as, at present, wheelchair users cannot access the centre.

There is also another problem in that a community mental health team may have to move to Southwood Smith, in which case there will not be room for Ashley Road clients. Bianca has been looking around at other options for another day centre in the south of the borough, for example, Pine Street, but says there is a shortage of available buildings.

Bianca is hopeful that they will get Southwood Smith, and also that the needed repairs to the centre, costing about £200,000, will be undertaken by the Care Trust, but acknowledges that this has not yet been agreed.

The Lambo day centre also faces upheaval under the preferred ‘option two’. Under the proposals, Bianca stated that the building would be closed and services would be moved around the Borough. Bianca is keen to see the Lambo community moved to Isledon Road and said she is considering having a BME day, in at least one centre.

However, the Lambo workers would become outreach workers, trying to contact BME users and link them to day centres to aid their recovery. This will be done via community mental health teams. There would also be a BME

worker linked to Hanley Road as there are distinct issues around education and employment that affect BME communities.

There would also be a worker linked to Highgate Mental Health Centre so patients know what is available when they leave. Bianca argued that this system will increase access for service users as, under the new system, they would have capacity to work with a hundred service users at any time.

Bianca is keen to point out that, whilst they are hoping to improve services, this is not a cost cutting exercise and they are not looking to save any money. At one point they did think that they would have to save £30,000 but this money has already been found from other sources. So no day centres should face a cut in their budgets.

The consultation period finishes in March, after which decisions will be made. We will of course keep you informed.



Edit—an Introduction

By Edit Szarvas

I would like to introduce myself to you all in a few sentences.

I appreciate the opportunity to work for IBUG as I have been searching for a position exactly like this.

I started my career at the age of 17, at Rudolf Steiner Camphill School, Aberdeen, Scotland, where I worked as a volunteer for a year with autistic children.

Returning to my country, Hungary, I worked with children and adults with learning disabilities and mental health problems in different settings. In the last couple of years I have worked with asylum seekers, especially with women facing mental distress, as a European Project Coordinator in a refugee reception centre.

Richard Blackmore

By Suzy Lee

Richard Blackmore was a valued member of IBUG who died recently. Richard was a Canadian and very

Since coming to London, I have worked in a residential care home as a support worker with adults with learning disabilities. It was a great opportunity for me to learn about the English social care system.

I graduated as a legal administrator in Hungary, but spent a couple of months studying the English legal system and my special fields of interest are mental health law, human rights, and asylum and immigration law.

My long term goal is to carry on with my studies, to become a legal expert on human rights and mental health law.

Working as the administrator of IBUG gives me the opportunity to learn all about the problems people have to face daily, to identify the gaps in the system, to learn about service users' needs and expectations.

popular with his fellow members. He was 50 years old and is survived by three children. There has not yet been a funeral but a memorial service

I consider myself to be an open-minded, optimistic person, who is always interested in other people and ready for a chat, so please don't hesitate to come and talk to me about anything that you feel like. (I work on Mondays, Tuesdays and Wednesdays between 10am and 5pm)

There are lots of very good professionals around you, but there might be something that you still miss.....

Looking forward to working with you to make the mental health and social care system even better in Islington!

Edit Szarvas

IBUG administrator

was held before Christmas by the Salvation Army. He will be greatly missed.

I consider myself to be an open minded, optimistic person, who is always interested in other people and ready for a chat,



Demystifying User Focused Monitoring

*Audit asks the questions:
‘What should service users expect when using the service? What are they actually experiencing? And, how can service standards and service user satisfaction be improved?’*

By Maggie Lay

I suspect that although many readers are already familiar with the term ‘User Focused Monitoring’ (UFM for short) and what it is all about, there are even more who are totally mystified by it! Therefore, as the new Coordinator of the local UFM project, I welcomed Suzy Lee’s invitation to write an article about it and to introduce myself.

Firstly, a few words about me. I started working as the UFM Coordinator in November 2007. Previously I have worked as a university researcher, a Clinical Governance Facilitator for a Primary Care Trust and as a Clinical Improvement Facilitator for a mental health NHS Trust. My base is in Highbury at Peter Bedford Housing Association offices.

So what is User Focused Monitoring? UFM was established as a method for evaluating service users’ satisfaction with mental health services about 10 years ago. Peter Bedford Housing Association has managed the Camden and Islington UFM project since June 2005. There are several UFM projects across the country. Each project has a Coordinator and a team of trained service users who undertake the work.

We use a method called ‘auditing’ to find out how well local mental health services are performing from the service users’ point of view and to find out how they might be improved. Audit asks the questions: ‘What should service users expect

when using the service?

What are they actually experiencing? And, how can service standards and service user satisfaction be improved?’ This is known as the ‘audit cycle’, as after improvements have been made to the service the cycle begins again providing a continuous cycle of standard setting, evaluation and service development.

Auditors with the UFM Project are themselves current and previous mental health service users. They contribute to all aspects of audit including collecting data from other service users; entering data onto the computer; data analysis; helping write reports; making recommendations for management; presenting audit results to them and discussing any action needed.

All auditors undergo thorough training for the role and get support from other auditors and myself when undertaking an audit. Nobody is expected to do tasks they do not feel prepared for or happy about.

We can audit any mental health service in Camden and Islington, including those provided by voluntary organisations. Our programme of work is overseen by a Strategic Steering Group, which includes service user representatives. Since Peter Bedford has been managing local UFM we have done audits of service user satisfaction with mental health advocacy services, and patient satisfaction with in-patient treatment and care at the Grove Centre. We are going to do the same at the Huntley and Highgate

Centres during 2008.

Being an auditor with the UFM Project is an exciting and sometimes challenging role. Auditors get a lot of job satisfaction, and working with others can help develop self-confidence. It can help get people back on the road to employment, training or education.

Small fees also are also paid to auditors for work undertaken in line with benefit limits. In future we aim to find ways of involving carers of people with mental health problems in the project too, as their perspective is extremely valuable to service development.

If you are a past or current user of mental health services and live in Camden or Islington you can apply to become an auditor with us by contacting me at the address below. We welcome people from all social and cultural backgrounds and seek to reflect the local population. Importantly, we need people who care about local mental health services who want to make a difference.

Maggie Lay at: Peter Bedford Housing Association, Legard Works, Legard Road, London, E5 1DE. Telephone 0207 226 6074; email Maggie.lay@peterbedford.org.uk





ISLINGTON BOROUGH USERS GROUP

Highgate Mental Health Centre
Dartmouth Park Hill
London

Phone: 020 7561 4140

E-mail: ibug@hotmail.co.uk

By Edit Szarvas

Do you have enough of winter?

Have you started realising the first signs of spring? We tend to be too busy to notice the beauties of nature.

But Miss Spring is definitely knocking on the door; you can already smell it in the air.

People in my country have a very old tradition of celebrating spring, which became a festival during the years in a little village. It is called "Busojaras" and only certain people are taught how to lead the celebrations.

It starts in the end of February and lasts for a week. People dress up in scary masquerades, take their drums and other equipments and make loud noises while they dance and walk through the whole village knocking on each door on their way to the great square of the village.

They do this because it is said that spirits of winter have to be scared away in order for spring come in peace.

They even make a huge witch-poppet out of hay and burn it in the great square, having a huge bonfire.

They dance and sing, calling the spirits of spring. Here, in London, we can celebrate spring with a smile on our face in the morning looking in the early sunshine. Let our souls warm up, winter is over soon!

iBUG DIARY



CIP Stakeholder Meeting

05/03/2008 1:45-3:15pm

2nd Floor, East Wing, St Pancras Hospital. Contact Linda McDonald, 020 7530 5347. Only designated iBUG members should attend

Patients Council

11/03/2008 2:00-5:00pm

Highgate Mental Health Centre, Dartmouth Park Hill, London N19 5NX. Contact Edit 020 7561 414 0
iBUG members from Cam-

den and Islington may attend.

Service User Implementation Group

14/03/2008 1:00-4:00pm

2nd Floor, East Wing, St Pancras Hospital. Contact Ros Lettman 020 7530 3340. Only designated iBUG members should attend.

iBUG Business Meeting

25/03/2008 2:00-5:00pm

Hanley Road Day Centre, 75

Hanley Road, N4 3DY. Contact Edit on 020 7561 4140. Open to all service users.

Service User Consultative Forum

28/03/2008 1:00-4:00pm

St Pancras Hospital, 4 St Pancras Way, NW1. Contact Ros Lettman 020 7530 3340. Open to all service users from Islington and Camden