

APRIL 10

EDITOR

NIKKI SHARP

RUN-UP NEWS

NEWSLETTER

**FREEDOM PASS
UPDATE**

Pass to Freedom or Chained to a System that's not working!

**IT IS WITH
DEEP REGRET**

You may remember that in our last newsletter we highlighted the Freedom Pass issue. Those of you still waiting for yours I'm sure need no reminder of the chaos this whole thing is. For those who have been lucky enough to have received yours ~ I congratulate you. For those who are still waiting I have every sympathy with you.

PAGE 3

**NEWS FROM
THOMAS
HARDY & MARK
TWIN**

users who are still waiting for their Freedom Passes. Many who had ticked the box allowing NELFT to access their computer system (Rio), but who have not yet have their letter of authorisation through, but also from many others who have not even had their renewal letters though.

PAGE 3

**KEEPING YOU
UPDATED**

This whole renewal process was meant to be much simpler than 2 years ago. Sure I understand why the changes were made, in that it was meant to save service users having to go to their GP's and pay a costly sum (though I believe it's still the case for some) for a letter about their mental health condition & also having to answer awkward & embarrassing questions from those who had no right in asking or knowing.

PAGES 4,5 & 6

**UPDATE ON
THE PROGRESS
TEAM**

We have been inundated by service

PAGE 7

**DUE TO
POPULAR
DEMAND**

PAGE 87

**NEW SUPPORT
GROUP FOR
CARERS**

PAGE 8

Early March we also attended the Redbridge Business Meeting where we specifically asked for the Freedom Pass to be put on the agenda. We raised the issues and anxieties of service users having not received their renewal letters, or if they had and had responded to that, they were still waiting for the letter of authorisation to come through. We asked if anything could be done to speed up the process and enquired (because we had heard a whisper) if the renewal deadline of the 31st of March was going to be extended. Firstly we were told that NELFT is

processing them and the hold up wasn't perhaps at NELFT's end, It was then suggested to us that if people have not received their renewal letter they should phone Community Care Advice Centre, Aldborough Road but if people are waiting for the letter of Authorisation it is being dealt with. The Operational Director said that he wasn't aware of any extension date, but then two senior mangers said they had heard there was going to be an extension date. At this point we were still waiting for clarification.

We then were asked by several service users over at Ley Street if we could meet with them. This we did and to our dismay heard about many people's plight of having to go through this, let along the stress, anxiety and concern this is causing. One gentleman showed us his rejection letter (u n s u c c e s s f u l

Pass to Freedom or Chained to a System that's not working! Cont...

application). Not only had he been rejected but there was also (what we thought) a very discriminatory paragraph in the letter which states "Sever mental disorders include psychotic disorders (e.g. schizophrenia) and bipolar affective disorder (manic Depression). It does not include 'common mental health problems' such as anxiety, depression, phobias, obsessive compulsive and panic disorders, where it is likely that a driving licence can be held". How could someone make such judgment if they are not medically informed, surely it should go on the level of someone's illness and not the illness itself.

We left the service users with the promise of highlighting this issue again in our newsletter but also to get as much information for them as possible.

We sent a strongly worded email to Peter Spelman advising him of how people felt and the sheer nightmare that this is causing and asked

him to confirm whether the deadline was to be extended or not. We also again asked Carol White (Assistant Operational Director) for clarification on what is happening. Carol informed us that NELFT get the letters, tick the boxes to the questions asked of them and then send them on to the welfare benefits advice team, who then make the decisions. In fairness (as far as we can see or how it's been put to us) NELFT seem to be doing their part, or are they? Everyone seems to be playing the blame game with each other while the services users suffer. **Surely someone is accountable for this utter mess and failure.**

I have to say that Peter was in fact on annual leave at the time the above was sent but he did respond as soon as he was back. Peter sent me a press release & confirmed that passes have an expiry date of 31st March 2010 and will no longer work on the card readers and validators as touch 'oyster-like' cards.

Peter suggested I wait for a response from Ruth Ezekiel (from the Welfare Benefits Team & the Freedom Pass Supervisor) to whom he forwarded my email, but at the close of play today (23/3/10) there was no response from her (I get the feeling it's like waiting for a Freedom Pass to arrive).

So there we have it. Not satisfactory by any means, but at least we have it confirmed that the renewal date is now extended. Let's hope that all who need to know this information when travelling (bus drivers, train drivers etc) know that this is the case. We sent out a full copy of the Press Release last week, however, if you would like a copy, please let me know. I would also suggest that you carry this round with you. One final note to this pitiful story is if you get a rejection letter **YOU HAVE THE RIGHT TO APPEAL.**

(Ley Street) Section 75 signed at long last

Mid February was when the section 75 was eventually signed over to NELFT. Many of you may have heard about this and like me may be wondering what this actually means.

As far as I am aware Redbridge Progress Service (Ley Street Resource Centre) now comes under the umbrella of NELFT, for staff at Ley Steet, that means they are now employed by NELFT, but as far as the service users are concerned I don't think there will be much difference.

It is With Deep Regret....

....that I have to inform you that Christine Bullivant, the Project Manager for Run-Up has taken the decision to resign. Christine will be sorely missed by so many who knew and respect her.

Because this newsletter is due out on 1st April and our Service User Network Meeting will be on the 31st March where Christine will say her thanks and goodbyes a full report on this will be included in our next newsletter.

RECOVERY/ASSERTIVENESS COURSE A SUCCESS

As you will know from the flyers we sent out early January 2010, another 8 week recovery / assertiveness course was rolled out, again facilitated by Anxiety Care. I am please to say that we have once again received very good feedback from those who participated. Our thanks therefore to not only the trainers at Anxiety Care

but to those who help fund this course.

For those of you who unfortunately missed out on securing a place on this course, we hope to have another one later this year (funding permitting).



News from Thomas Hardy Ward & Mark Twain

This was meant to go in our last newsletter, but due to the extensive cover of the Progress Team Closure and other factors it never went in. This feedback is from Kelly Beetles of Thomas Hardy Ward.

Thomas Hardy Ward and Mark Twain would like to take this opportunity to wish everybody a belated happy and prosperous new year. Thomas Hardy Ward and Mark Twain celebrated their service users Christmas party together. Service users enjoyed music which was kindly supplied by the hospital radio and later in the afternoon staff and service users participated in Karaoke thankfully there was no X Factor panel of judges to comment on the staff's attempts, but we may have found some budding singers amongst the service users. It was great to see staff and service users celebrating the festivities together and all was in the spirit of the Star wards initiative.

“KEEPING YOU UPDATED”

Anne Argent one of our User Consultants attended an away-day that was rolled out by the Redbridge Progress Service (which Anne is attached to via Run-Up). It was called an Introduction to Adult Social Services and was aimed at new staff to give a broader view of how Community Care works in Redbridge and its partnership with other services within Redbridge and surrounding Boroughs. Anne says she enjoyed the day and found it very interesting.

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Mid January, Anne Argent, Chris Day and myself attended NELFT's Single Point of Access (SPOA) workshop. This is one of a series of Change Management Project Workshops currently being held by NELFT about all different services. The purpose of this workshop was about thinking and eventually implementing a New Trust wide service that will ensure that anyone needing to make contact with the Trust can do so 24 hours a day, seven days a week, whether that's a new referral, existing service user, carer or partner organisation etc.

Though the Single Point of Access (SPOA) refers to a system that attempts to co-ordinate referrals through a single contact point/telephone number for all service users of NELFT in all four boroughs, Currently it seems all calls are made to the Goodmayes switchboard where referrals are attempted to be matched

with available staff depending upon the information given by the caller. This sometimes requires extensive questioning by the switchboard operators to gain the necessary information. This can cause great anxiety for the caller and require much patience from the receiver to get a satisfactory result that could involve more calls to other specialists.

Just a footnote to this; all the way through these workshops I keep hearing “This is what service users want”. Well one wonders where they evidence this and again it was mentioned that Task Groups were set up at the beginning. I don't ever remember Run-up being invited to join one of these Task Groups/Steering groups, so I mentioned this to Maria Lomas (Assistant Operational Director). Now thankfully we have been invited to take part in this particular steering group – oh you cynics – maybe after the horse has bolted I hear you say, but at least now we can Represent Service Users Views (which is what we are supposed to be doing) but I take your point. (See February in this section for a further update on this subject)

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In January both Janice and I attended the Community Development Worker Steering Group Meeting (CDW). Many items were on the agenda but the meeting focused mainly on psychological health: and a new Foundation Course for Faith and Community

Leaders.

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January was also when I first met Swati Vyas who is the Health Partnerships Officer for Redbridge Council for Voluntary Service (RCVS). Swati is planning to do a case study on Run Up for the RCVS newsletter as a best practice example of user involvement in mental health services. This will hopefully take place in May or June, but we will keep you posted as I'm sure it will involve holding a focus group with service users and providers.

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Janice attended the Integrated Governance Group meeting (RIGG) in January for the first time. One of the items on the agenda was the subject of complaints. Carol White mentioned that she was dealing with up to 15 complaints and was hoping to get the number down.

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In January Chris Day (User Consultant) attended the User Led Organisation meeting.

Members of the workshop have met a number of times since June 09 to discuss the forming of a User Led Organisation (ULO).

The workshop is to finalise the Steering group membership its Terms of Reference and elect a Chair and vice Chair. It's also to recruit a project Coordinator to work under the effective management of Redbridge Concern.

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Our Service User Network Meeting held at the end of January was when Marie Price the Assistant Director Corporate Services (PCT) came along to talk about the Consultation Healthcare for London & about Health for North East London.

Many people at our meeting were vocal and had strong view points about what changes would take place at King George’s hospital and the possible closure of its A&E department. We were told that it’s only a consultation at this stage and nothing was certain (here we go again – being cynical that word **consultation again** – decisions already been made?).

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Lastly in January, Janice and I went along to a Change Management Road show here at Goodmayes. Many changes are afoot and you only have to look around Goodmayes site to see the new buildings going up to realise that. We were told that along with many other changes there will be a 15 bed male only Low Secure unit and a 16 bed mixed sex Detox Unit is being built here.

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Early February Janice, Kate (User Consultant) and I attended an Acute Care Workshop. This was all about delivering Acute Inpatient and Psychiatric Intensive Care Units (PICU for short). Again those that attended were asked to vote on many

important things like how long should a person wait for an assessment on what will be called a Clinical Decision Bed Should it be 72 or 96 hours? The vote went for 96 hours.

You’re going to think I’m real grumpy and a real moaner but again, voting is fine and a democratic way of doing things I guess, but what about all the employees who were unable to attend (due to work) or otherwise that these changes will effect and what about all the **service users** who don’t get invited or are unable to attend.

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In Mid February Janice attended the Redbridge Integrated Governance Group Meeting again. Carol White (who is leading on complaints) mentioned 15 complaints had now gone up to 19. Janice asked if the complaints are of a recurring theme. Maria Lomas said they had looked into that, and no they were all different? We shall keep an eye on what happens with these complaints and the action taken.

Also on the agenda, which might be of interest was CQC essential standards (the Care Quality Commission), It was said that someone from the CQC could come to any NHS service at any time and check the services are following their procedures. They can talk to anyone, which includes service users. The purpose for this is to make sure that things are in place and people are working within the standards set. Bring it on we

say.

Mid February is also when Janice and I attended the Single Point of Access Task Group (you know that one we eventually got invited to). My first question was to ask how long the Task Group had been meeting for. Since November was the answer, so my second question was to ask the group whether they thought it was worth Janice and I attending at this late stage (seeing as there was only going to be one more meeting of this task group after this one). What I didn’t want was for this to be a tick box exercise so one could say they had service users input. The group agreed that our input would be very useful as they are now at the critical stage of finalising things.

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Late February I attended the Board of Directors Meeting. The invite for this meeting usually appears in our post box after the date of the actual meeting. All the executive Directors & non executive Directors sit round a table, but others i.e. me, UQUAT Members & SURG members sit at the side of the room. Yes we are privy to what’s being said but are unable to participate until invited to do so.

I won’t go through everything as it would take far too long, but first on the agenda was Healthcare for NE London. Most comments were positive, but thankfully one person stated that Mental Health had not been mentioned much in

the document. Another person round the table said people are very confused about when to use a polyclinic as apposed to A&E – again our sentiments exactly.

Neil Collins & John Purdue gave an update about SURG and presented their 2009 Annual Report. Also raised was the concern about the pace of the Change Management Project. It was felt that at all these workshops there have not been enough Service Users or Carers invited along. **This is such an important point because actually in these workshops is where decisions are being made about future changes or new services, yet Service Users &/or Carers are not present – again it is those who it effects the most that have the least representation.**

Michael Inns gave an update about UQAT and said that changes have taken place as a result of UQAT's presence.

Strange, but interesting meeting and one I hope to go along to again.

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Last but by no means least in February we held our usual Service User Network Meeting. This group meeting was used by TEIJ Associates for our final 3 year Service Impact Review. My thanks to both Terrence and Ingrid, but also to all those who took part in both the group and individual interviews that were recently held. A report should

be out in May and will be forwarded to you.

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Early March we had a visit from three student social workers who were on placement from the organisation Restart. We shared information about ourselves and how we could work in partnership.

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Also in early March we attended the Redbridge Business Meeting. Again, many items on the agenda and we specifically asked for the Freedom Pass to be put on the agenda, which it was.

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Mid March Janice and I attended the LIT (Redbridge Mental Health Partnership Planning Group & Local Implementation Team Meeting). Many items on the agenda but I'll give a brief update on what was most relevant to us. Firstly was the subject of commissioning intentions. For you and I that means what services are decided nationally by the Department of Health that then filter down to Local level.

Jon from Concern gave a draft report put together by Jon & I that is going to be sent regarding the Consultation Healthcare for London.

It was stated that Richmond Fellowship are taking over the Mansfield road building.

Lastly but no means least was the target due to be set for

2011 regarding an 18 week deadline from referral to treatment. Also noted at the meeting was that Psychology has been given money to improve its waiting list

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One of our User Consultants was invited by Kathy Blackburn (Manager of the Recovery Team West) to attend another Community Recovery Workshop. This meeting was the first to bring together practitioners and service users to discuss the principles of recovery and the use of Action Learning Sets (ALS).

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Mid March Janice again attended the RIGG Meeting. On the agenda was The CQC Presentation and how the new system will work. There was an update on Complaints. Janice mentioned RUN-UP's Complaints Workshop we were about to roll out.

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Near the end of March two of our User Consultants attended the ReSurge Meeting (not to be confused with the other SURG). This was the first meeting of ReSURG which is Redbridge Service User Reference Group. Each borough under Transforming Adult Social Care has to form a new User Led Organisation by 2011.

For reasons of space we have shortened many of the reports we received, if you would like full details of any of the meetings mentioned, please contact me at RUN-UP.

Update following the closure of the Progress Team

As stated in our last newsletter the Progress Team here at Goodmayes has now closed. I know that we have had many concerns voiced to us via letters, emails and telephone calls about this closure and thought it only right to share with you some of the concerns raised by you. One lady (Janet) wrote in saying she used to attend one of the clubs, staffed by volunteers but was overseen by the Progress Team. Janet went on to express her concerns and felt changes (not for the better) had been made since NELFT became a Foundation Trust. Janet also pointed out that the article I printed & wrote in our last newsletter focused mainly on services that the Progress Team provided but did not cover what would be happening to the other groups that came under the Progress Team, groups like Vine Church, Craft Group and Volunteers (fair point). Well I contacted Karen Howlett (Progress Team) and she kindly provided me with some info with regards to this issue.

Karen's update was; The Vine Church group is being wound down, Anne has managed to relocate the craft group to Age Concern at Wanstead. The Tea bar volunteers and internet café are continuing as normal but from the 31st March volunteers will be co-ordinated by Redbridge Concern for Mental Health. Another service user emailed Pam Lloyd (Assistant Director Mental Health, PCT) and

registered her comments about the closure and many others I believe have taken this issue to their local MP's.

As I put in our last newsletter there was an Advice and Information event for service users and carers held on 8th February. Janice and Kate (user consultant) attended on Run-Up's behalf along with many more (some who feed back to us directly including John Purdue) who gave their thoughts and views to us. Present on behalf of NELFT were Bob Edwards and Carol White. Many questions were raised. Questions like; The issue of lack of Service User/Carer consultation before the decision to close the Progress Team was made, the point made to Bob was that as part of the 'Mission Statement' the Trust declares: 'Service Users At The Heart Of Everything We Do', the fact that there was no prior consultation undermines the Trust's position in this respect. Bob agreed and took the point on board.

Reference was made to the recently set up Intake Team. It was pointed out to Bob, that, NELFT's advertising of this important support service was at best sketchy or non-existent. As a result of the proposed RPT closure it's quite likely that due to raised anxiety levels and general unease about this situation, that some Service Users may well feel the need for extra advice and guidance. Intake can provide this but people have to know that it exists! He

said that NELFT had sent laminated cards out to GPs and had really tried to keep people informed. It seems that this isn't working. Indeed, a visit to NELFT's website won't enlighten anyone either. There were a lot of personal stories and how the Progress Team had played a big factor in people's recovery.

The recovery teams will take on some of the things the progress team offered. There was also a possibility of Ley Street being updated and changes being made there.

Another question to Bob was who would take over the EVO role from Rhian Farnham after 31/3/10 and he expressed the hope that Rhian would stay with the Trust and that she would be able to continue with her EVO responsibilities as part of her new role.

Anyone wanting a list of Volunteering Opportunities, Day Activities & Groups or Employment Advice & Support please feel free to contact us here at Run-Up.

A foot note to this article; just before going to press we heard a whisper that the Goodmayes Allotment Project was also under threat of closure. I contacted someone from what was the Progress Team and the latest information we have is that the Bridge Rehab unit is considering financing this particular project. – Like always we will keep you updated.

Registered office:
Redbridge Concern for Mental Health
98-100 Ilford Lane, Ilford, Essex, IG1 2LD
Registered Charity No. 1065770
Company Limited by Guarantee No. 3115971

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EDITOR
NIKKI SHARP

RUN-UP
GOODMAYES HOSPITAL
BARLEY LANE
GOODMAYES
ESSEX IG3 8XJ
Phone: 0844 600 1201 ext 7888



Due to popular demand

Late last year the User we gave our first one to the Consultants and I spent a long staff at the Redbridge Progress time putting together a Service (Ley Street). The presentation together about feedback we had was RUN-UP, who we are and what encouraging and a plan is now we do. The idea came from underway to give many more 2008/09 service impact review that stated Run-Up needed to promote itself more. It proved to be a timely exercise but a very worthwhile one. Now finally (having got used to the I.T equipment and building all of our confidence in rolling this out, I am really pleased to say



presentations, not just to staff from all different services but to User Groups and Community groups as well.

Janice has been inundated with requests since putting an email out there asking for anyone interested and I know at our February's Service User Network Meeting it was requested we did one there as well. This we will do at our next Service User Meeting.

New support group for carers

As mentioned in our last newsletter I am happy to report that at least 4 people attended this new group and more are welcome. So here are the details again:

The group will be held on the first Wednesday of every Month at 6.15pm – 7.30pm at the Acute Day Treatment Service. If you are a carer for a service user on Acute Day Treatment Service, Mark Twain, Thomas Hardy and the Home Treatment Team you are welcome to attend.

If you would like further details or are a little unsure about joining such a group, please contact Sandra Sullivan on 0844 600 1206.