



HEAR US



CROYDON USER COUNCIL

Croydon User Council

Meeting at: Orchard House

1.00 – 4 pm 4th August 2009

Ruth Govan (RG)

Chair

Minutes: Jane White (JW)

Hear Us Administrator

ITEM	ACTION	WHO
1.	MINUTES, WELCOMES, INTRODUCTIONS, APOLOGIES & HOUSE RULES	
	<p>MINUTES: 7TH JULY 2009 Minutes from 2nd June, 7th and 10th July CUC meetings still to be agreed and signed off. Chair welcomed everyone to the meeting and Guest Speakers introduced themselves. Chair reminded everyone of the House rules.</p>	
2.	<p>GUESTS: DR BARRY JONES (CONSULTANT): The New Croydon Personality Disorder Service and Jamie Eccles: Service User Network (S.U.N) project</p>	
	<p>Dr Barry Jones and psychotherapist Jamie Eccles introduced the new Service User Network (S.U.N) project that is being set up in the Borough of Croydon shortly. Barry Jones acknowledged that people with a diagnosis of Personality Disorder have not always been supported and well represented by mental health services in the past.</p> <p>The organisers of the S.U.N project are looking for service users to get involved in a number of different ways over the next couple of weeks, e.g. constructing the information leaflets for the project, helping to view and choose venues for the groups etc. The project is being modelled on the existing S.U.N project that has been up and running at Springfield Hospital for about 5 years and therefore will retain the name of S.U.N project when it is launched here in Croydon (for legal reasons). Anyone interested in helping with the launch of the S.U.N project can contact Hear-Us or Barry Jones directly or Jamie.eccles@slam.nhs.uk Telephone 0203 228 0511.</p> <p><u>Summary of the S.U.N project:</u> The project is one of two new services being set up as part of the new Personality Disorder Service:</p> <p>1. The Day Service - which will be based at the Bethlem Hospital and comprises a 2 or 3 day a week intensive program for people with a diagnosis of Borderline Personality Disorder. Patients are referred to this service by their GP's or CMHT's, i.e. it is not a self referral or open access service. The program will be based on a therapy known as 'Mentalisation' therapy.</p> <p>2. The S.U.N project – This is a community based project, it is</p>	



open access, i.e. people can refer themselves, and it is designed to be as easy as possible for people to attend, hopefully with minimal/no waiting list times. **People do not have to have a formal diagnosis of Personality Disorder to attend the service.** The aim is to provide support for anyone who feels that they may benefit from the service. The emphasis is on helping those who may struggle in their day to day lives with relationships, emotions, self harm etc (i.e. a presentation similar to that of people with borderline personality disorder).

The service operates on therapeutic community principles, i.e. the group, while facilitated by staff, will be encouraged to support one another in a therapeutic way. People with Personality Disorder or those who struggle with similar difficulties, may have a lot of problems with day to day life but the service also aims to promote and share the positive aspects of peoples' experiences within the group, while supporting one another during times of difficulty or crisis. The aim is not so much a staff led group, but a partnership between service users and trained staff who will together set the program and the boundaries of the group etc within a structured environment.

Where and when?

There will be 3 groups a week initially, which will run across 2 sites. The venues are still being explored in collaboration with service users.

Times of the groups:

Monday mornings 10.00am-12.30pm

Wednesday afternoons 2.00pm - 4.30pm

Friday mornings 10.00am-12.30pm

It is hoped there will be a forth group starting up in a few months time.

The groups will be facilitated by 2 trained members of staff (e.g. Community Support Workers).

Each group session will run for 2 and a half hours (with breaks!) and will be broadly split into 3 components:

- **The first 45 minutes** will be time to check in with group members, see how everyone is doing, find out if anyone is in crisis etc.
- **The second part of group** will vary from day to day and according to what the group members decide – could be a business function session for example, to help people with letters they have received, forms they need support with (DLA, etc). It could be a support session where people can discuss any difficulties that they are experiencing in day to day living and get some support from their peers. If someone is going through a very difficult period, this time could be used as a 'crisis planning' session.
- **The third part of the day** – a group summary session to



see how people are feeling at the end of the group. Has the session adequately met their needs etc.

The project aims to promote normal daily life through 'core activities' e.g. meeting up for coffee, going to the cinema etc. Some activities/outings will be facilitated with the help of the staff and take place outside the sessions of the 3 day program. As the group progresses the aim is that some activities etc can be organised without the help of the group facilitators, with members supporting and encouraging each other.

The Group rules will be generated between the service users and the group facilitators

Staffing of the S.U.N project: There will be two facilitators for every group. If an occasion arose where there was only one facilitator and one service user present, then that group would be cancelled (one-to-one sessions are not encouraged because of the 'group ethos' of the project. Of course if the service user was in crisis or needed to talk, they would not be turned away! Also, because the groups are open access, i.e. without referrals, risk management means that there must always be more than 2 people present at any session.

Confidentiality within the group is very important and members will not be allowed to discuss what goes on in group sessions outside of those sessions with non-members. Because of the group's open access policy and to manage level of risk – there may be circumstances when confidentiality would have to be broken, e.g. if a person is at risk of serious self harm, has taken/is intending on taking an overdose. The group would be involved, if appropriate, in any discussions, and the person's CMHT/GP etc would be contacted if necessary.

Peer support worker

A service user from within the group will be allocated (for a set period of time) to act as a Peer Support Worker for other members of the group out of group hours. Their role will be to carry a mobile phone that they can be contacted on should a member of the group need extra support, or be in crisis between group sessions. Their main role would be to talk that person through their agreed crisis plan. (Everyone who attends the group will have formulated a crisis plan with staff and other group members and will be given their own copy of that plan).

New Members

The Administration team at the Bethlem will be responsible for any new members once the groups have started. There will then be a welcome session for that new member and their crisis plan will be



drawn up.

Once a person is a member of the S.U.N project, they will remain a member for as long as they wish, i.e. members are not discharged even if they do not attend regularly or take a break from attending groups.

Questions

Will the responsibility for the peer support member not be too great?

There is no meeting up on a 'one to one' basis out of group hours. The role of the support person is just to go through the written crisis plan of the person who is in crisis over the phone. The exact set up/rules of Peer Support will be carefully discussed and agreed by the whole group and it is hoped that it will give members a sense of control over their own circumstances, as well as improve the self esteem of the Peer Supporters who are able to assist someone in crisis. If necessary there will also be support available for the Peer Support person themselves. Any crisis/difficulty that arises out of group sessions will be discussed at the next group session.

Their role is discussed and agreed by whole group, e.g. how long they have the mobile phone for etc.

In the experience of the St George's S.U.N project, the out of hours peer support works well and is not overly used, most crises are dealt with in the group.

Barry Jones and the other staff involved in the S.U.N project will be co-facilitating at some of the St Georges (Springfield) S.U.N groups that have running for about 5 years now, and some of *their* facilitators will hopefully co-facilitate at some of the groups here in Croydon when the project launches. It is also hoped that some of the service users who are involved or have been involved in the St Georges S.U.N project will come and speak about their experiences. Generally, the feedback from service users involved with the project at St George's has been very positive; they have appreciated the *open access* nature of the groups, and the fact that because no referral is necessary, they arrive with no preconceptions about them etc. They also report having benefited from the support of their peers in the group. The only negative feedback was that it can sometimes be difficult to be among other people who are having difficulties or are in distress. (Barry Jones pointed out that although this can be difficult, it could also be a useful part of the group, for members to be aware how their own actions etc, can impact on the people around them).

To what extent will this service help people to look after themselves better in life?



- Survey results for established S.U.N projects have shown: Planned contact with CMHT's, duration of time in hospital etc has been reduced.
- Helps members form a wider social network.
- Group work based on model of therapeutic community principle - helps people to think through their problems in a less emotionally charged way, and in helping others, can help themselves.
- Members can learn from each other and share life skills/coping techniques etc.
- As the group becomes established, members get to know one another and their triggers etc, and can support one another.

How do you regulate who attends the open access groups?

We don't! New members are very important to the survival of the group. The group is shaped by its members. Since the information leaflets will describe the sorts of problems/difficulties that will be addressed in the groups, anyone who attends will probably recognise (even with no formal diagnosis of Personality disorder) that they have difficulties with such things as self harm, managing emotions, dealing with relationships etc and it is these people who will become regular members of the group.

Comments: The design of the leaflets is therefore very important so that people will know what the group is all about and can refer themselves if they think they will benefit. Word of mouth will also be very important.

(The Leaflet will have a phone number on it if people want to ring in with questions about the group).

There will be intensive staff support along side the groups, including training for staff, regular review of how the groups are going (in terms of attendance, what's been happening in groups etc). There will be clinical direction and feedback into the groups as a result of staff discussion e.g. Barry Jones will feed back into the groups from the clinical perspective.

Name of the Personality Disorder Day Service (not to be confused with the S.U.N project)

All the suggestions that have been put forward from service users have been short listed to three:

Touchstone

Discovery

Phoenix House

The names will be put forward to Steve Davidson at the next planning



	meeting.	
3.	Employment and Support Allowance What worries/concerns do people have? Any questions for Hear Us to ask Welfare and Benefits?	
	<p>A hand out (flow diagram to illustrate how the new Employment and Support Allowance works in brief) was passed round to everyone at the meeting and people were asked to voice any immediate worries or concerns/comments about the ESA benefit.</p> <ul style="list-style-type: none"> • Worries about interviews - are face to face interviews appropriate for service users? • Will the questionnaires (capability for work tests) be similar to the DLA forms, i.e. very complicated to complete and more heavily weighted towards physical rather than mental health, and will the wording of the questions be ambiguous? • Will staff at the CMHT's (Community Mental Health Teams) be trained to support service users with the new Employment and Support Allowance? • Will service users' care co-coordinators and/or key workers have been trained about ESA? <p>Suggestion: We could ask CMHT key workers/care coordinators what they know about ESA. Would it be an idea to invite CMHT's to a future CUC meeting, along with Welfare and Benefits (e.g. Sian Evans)? It would be good for staff that work at the CMHT's to hear the concerns of service users about the new benefit and could also start a dialogue between them and Welfare and Benefits to try and address some of these concerns and issues.</p> <p><u>Any other concerns regarding ESA?</u></p> <ul style="list-style-type: none"> ○ Do service users need to be at their most unwell when they are assessed to get put into the support group of ESA (i.e. the group that is not expected to undertake work or work related activities)? ○ Some people are concerned that they will 'appear too well' to qualify for ESA. ○ Will the fluctuating nature of mental illness be taken into consideration when deciding which group of ESA to put people into? ○ Are people going to be forced into work? Will service users be made to take up jobs they don't want to do. Will people be put into low paid or uninteresting jobs? ○ What will the impact on other 'benefits' e.g. freedom passes, DLA be? <p>Hear Us will be putting all these questions and concerns to the Welfare and Benefits team at the Bethlem. An article is going into the</p>	



	<p>next issue of the Hear Us newsletter, which will just include a simple introductory outline of the new ESA. A more detailed document is also being put together for anyone who wants more information. This is a topic to be continued at future CUC meetings.</p>	
4.	DAYCARE	
	<p>A hand out was passed around; "Adult Mental Health Social Inclusion Day Services in Croydon, A Guide for Service Users and Carers". Everyone currently/recently using Lantern hall, Enterprise House, Fairfield club and the Social Development Team is in the process of having a 'Review of Needs'. For now, only this group of people will have immediate access to the new services when they launch. All the CMHT's (Community Mental Health Teams) should have leaflets on each of the new services for people to take home, at the resource centres. Each service will also be providing their own fliers and leaflets. These are all being put together at the moment. (Please note: MIND Fairfield club is NOT closing down)</p> <p><u>Questions and Comments</u></p> <ul style="list-style-type: none"> ○ Are all these separate initiatives knowledgeable about what each other are doing or is there no co-ordination between the different services? ○ Service users would benefit from a single contact number. ○ What happens if my care co-ordinator does not know about all these new services? ○ This document gives you information about some of the services, is there a document that gives ALL the information? <p>TO: It should be the job of the Key Worker/Care co-ordinator to provide services users with all the information about what is available to them.</p> <p>The Mental Health Directory, commissioned by the PCT (Primary Care Trust) should be available shortly and all key workers should have access to this book. However, many of these services are very new and as yet some do not have a venue or contact numbers. Venues for the new day services are currently being explored in collaboration with service users.</p> <p>FA: Comment: maybe it is also our responsibility, as human beings who want to improve our own lives, to let our GP's etc know about what is going on in Croydon for service users and in doing so, help improve the lives of other service users.</p> <p>Comment: There are no contact details (telephone numbers etc) in the 'day service guide'</p> <p>There is going to be a big event when all these services come together. (October/November time).</p>	TO



HEAR US



<p>5.</p>	<p>ANY OTHER BUSINESS</p> <p>Is Hear Us going to have a Summer party? This was raised at an earlier CUC meeting and there are only 3 weeks left in August!! We don't need to just get together as an organisation at Christmas! How about on or around world mental health day – in October?</p> <p>Opportunity for Hear Us to apply for fundraising with Healing Waters (offered by SLAM) to put on events for mental world health day (10TH October) Millie to e-mail detail to TO.</p> <p>Dissolving the CUC group – Should this meeting be a Hear Us open meeting instead. It was tabled that the CUC be dissolved and the meetings be held as Hear Us meetings in the future, basically still functioning in the same way. To be followed up at future meetings.</p>	<p>TO</p>
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HEAR US



MEETING TYPE	DATE	TIME	VENUE	Guest
Closed	Tuesday 6th January	1 – 4 pm	Hear Us Office	None
Closed	Tuesday 3rd February	1 – 4 pm	Hear Us Office	CANCELLED
Open To All	Tuesday 3rd March	1 – 4 pm	Fairfield Club*	John Clarke, from the Home Treatment Team & Psychiatric Liaison Service
Closed	Tuesday 7th April	1 – 4 pm	Hear Us Office	None
Open To All	Tuesday 5th May	1 – 4 pm	Fairfield Club*	Welfare Benefits here to discuss the New Benefit; Employment and Support Allowance (ESA) & Permitted Work & A researcher from the IOP (Institute of Psychiatry)
Closed	Tuesday 2nd June	1 – 4 pm	Hear Us Office	None
Open To All	Tuesday 7th July	1.30 – 4.30 pm	Fairfield Club*	SNAP Team & CroyCILL
Open To All	Friday 10th July	1.30 – 3.30 pm	Hear Us Office	Personality Disorder Service
Open To All	Tuesday 4th August	1.30 – 4.30 pm	Hear Us Office	Personality Disorder Service
Open: AGM*	Tuesday 1st September	1.30 – 4.30 pm	Fairfield Club*	Depression Alliance & Active Minds
Closed	Tuesday 6th October	1.30 – 4.30 pm	Hear Us Office	None
Open To All	Tuesday 3rd November	1.30 – 4.30 pm	Fairfield Club*	TBC
Closed	Tuesday 1st Decen	1.30 – 4.30 pm	Hear Us Office	None

Please send apologies to Tim Oldham or Jane White on 020 8681 6888

Email: tim@hear-us.org or <mailto:jane@hear-us.org>

Hear Us User Group

Orchard House

15a Purley Road

South Croydon, CR2 6EZ

Website: www.hear-us.org