



Mind Matters

A Report on Learning Disabled peoples'
experiences of Mental Health services in
Hackney

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City and Hackney
Clinical Commissioning Group

Introduction

Hackney People First is a user-led organisation for adults with a learning disability living in Hackney. The aim of this research project is to find out how easy it is, or not, for the learning disabled community to access local mental health services by gathering feedback on their experiences. The background context to this is the current consultation to do with the review of the Mental Health Act *Code of Practice* (COP) which has come about mainly as a result of the independent inquiry into the Winterbourne View scandal. One of our members is one of two adults with a learning disability who formed part of the pre-public consultation *Expert Reference Group*.

Profile of respondents

57% of the respondents were male compared to females 43%.

The age range of the respondents was as follows. The largest number of respondents was in the 40-50 years (57%) and 50-60 years (21%) age range.

43% of the respondents describe their ethnicity as White British. This is followed by Black British 36%. The remaining respondents were from various ethnic minority communities, such as Turkish/Cypriot and Jewish.

All the respondents see themselves as having a learning disability and are resident in Hackney.

Methodology

Due to the nature of the communication needs of the client group, as well as a desire to maintain a user-led approach, it was decided that the best way to gather responses would be via 1-to-1 interviews, and through the Hackney People First ‘Big Group Meetings’.

A weekly project steering group was set up which comprised mainly of ‘experts by experience’. That is, by those with a dual-diagnosis of a

learning disability and a mental health need. The questions for the interviews and for the Big Group were developed by the steering group, with support from the project coordinator, over a period of several weeks. It is important to point out at this stage that, due to the nature of people's learning disability, more time and resources are required to achieve particular tasks than might be required by a project being led by the non-learning disabled community. That is, for example, more time and resources are required to help the individual members of the steering group to understand the aims/objectives of the project, to stay on track with the project aims when formulating the questions for the interviews, and to avoid including non-relevant questions being asked and duplication. Due to needing to prioritise the user-led nature of the project, as well as time constraints, this has meant that questions which may have looked into greater detail at people's responses and therefore furnished fuller answers, have unfortunately not been included. However, by having the 'experts' responsible for formulating the questions and carrying out the 1-to-1 interviews themselves (with the supporter writing down the interviewee responses) we feel that we have avoided 'interviewer bias' and provided a more authentic collection of replies to questions than would be achieved by simply providing those interviewed with a limited choice of answers to choose from.

Once the questions were confirmed by the steering group, and an easy read version of the questionnaire was pulled together, the questionnaire was put to one of the Big Group meetings which was attended by 14 members. The responses from this meeting were gathered and put into an easy read format so that they could be presented back to the steering group. 1-to-1 interviews then took place with 4 members that had identified themselves as wanting to take part. The interviews were carried out by the 'experts' and the supporter recorded responses. The anonymous responses from these interviews were then fed back at the following Big Group meeting, as well as a reminder of what had been said at the previous Big Group. From a list of findings, a list of recommendations was put forward by the members. These were then presented back to the steering group and amended/added to and are recorded as below.

Main Findings

- Respondents value counselling services. Using a counsellor makes people feel better and helps things 'not get so bad'. 'Counselling staff are helpful as they talk to you about what your problem is and they give you guidance about what you could do'
- Some respondents value getting advice and guidance about how to manage their anger, or their mood
- Services are not always easy to use. Information provided about Mental Health services isn't always easy to understand and there are sometimes too many jargon words. Sometimes it is difficult to get through to Mental Health services. Counselling is really useful, but people don't always know how they could access counselling services
- A little support goes a long way. Some respondents said they cope very well by themselves, until there's a problem! Some said they want to get support with things like answering letters and that it is important they get the support they need. People rely on support workers and friends from the groups they belong to if they don't feel well. They rely heavily on getting good support
- Some respondents feel they will not be understood by mainstream services and that mental health staff don't listen and don't understand their needs
- People did not have good experiences of being in a mental health unit/hospital
- Having things to do helps 'to take your mind off things'

Recommendations

- Train staff that work in Mental Health services to help them better understand the needs of people with a dual-diagnosis
- Support workers should receive training so that they are made more aware of mental health issues and of what is out there to help those they support get their mental health needs met

- Provide opportunities to help people be more active in body and mind e.g. by joining a drama group
- Help people get what they need. Have better signposting to help people get their mental health needs met
- Have conferences to promote awareness of mental health services for people with a learning disability and mental health needs
- Find out what people's experiences are of being in mental health hospitals, and of using mental health services out in the community
- Carry out a Mystery Shopper exercise of Mental Health services
- Promote Counselling services
- Make sure there is easy read information of mental health services available in community settings, such as GP Practices and Libraries

Results from the Big Group meeting



Have you used mental health services before?

3 people said they had used services before



Do you know where you can go to for support if you feel sad?

1 person said the NHS Alcohol Counselling service called 'Lifeline'. Also, that you could get counselling through your housing and support service provider. Your provider could help to make a referral to counselling. Someone else said that you could go to St Leonards hospital to see a nurse or psychiatrist. Someone said they had counselling through their housing and support provider. Another said they would go to *Mind*. Someone else said the police should be trained to know what to do if they come across someone with a learning disability who also has a mental health need. Another said they would go to their support provider. Another person said they would make contact with Hackney People First. Someone else said that they

would go to friends. They also said that they were confident that they have friends that they feel they can trust. Someone else said that they were in hospital for 9 months and they did not know that they were unwell. Someone else said that they would turn to their relatives and that they feel they have people that they can turn to. Someone else said that they might go to the Hackney i-Care website to find out about services that could help.

Do you find mental health services easy or difficult to use?



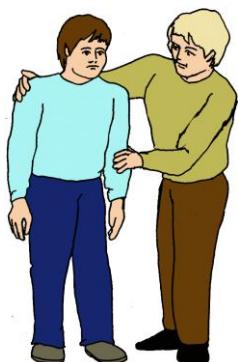
One person said that they would find it easy and that the location is easy to get to. However, this is only if you have been through the system. You might get support from your support workers.

i Information



Is the information they use to describe services easy to understand?

Someone said they are not sure if the information out there is easy to understand. They would need to see it first. Someone else said that the 'Looking After Me' booklet at St Leonards is easy to understand.



If you have used mental health services, did you find the staff helpful?

Someone said 'Sometimes...my counsellor was very good, but I felt my psychiatrist was not very good. Someone else said that they felt counselling to be helpful. Another person said they found the counsellor from the learning disability services to be very nice



Have you ever used 'talking therapies' as a way to make you feel better? Another name for this is 'counselling'?

5 people said that they used counselling services



Do you think it would be easy to get a counsellor?

5 people said they thought that it would be easy. 1 person said no because you would have to go on a waiting list and this would take a long time. Another person said that it would be difficult, especially for those with dementia or behaviour problems. One person said sometimes they would make an appointment to see a counsellor and then they wouldn't go. Or they might go, wait outside, and then leave



If you have used a counsellor, did it make you feel better?

1 person said 'Yes, very much!' Another said that it made them feel comfortable. 1 person said that sometimes it did and sometimes it did not. The same person said that it took them a year to understand what the issue was. Another person said 'it definitely made me feel better!' and that 'it's a fantastic thing to have!'

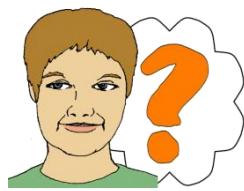
Your doctor and other professionals



Are you comfortable telling your doctor if you feel sad?

1 person said 'No. Because I like to keep my problems to myself' in case they pass my information onto other people. Another person said that they too would keep their problems to themselves. One person said they would feel comfortable. Another person said 'it's all about trust. It depends on how you felt about your doctor'. Another person said they did not know if they would. They would tell their doctor about their weight or about their physical well being, but not about their mental health. This is because 'they might give confidential information to others, and that 'in my opinion they would do

this!'. Someone said 'not everyone can trust their doctor'. Another 8 people said they would go to their doctor if they felt sad.



If you are not comfortable, why do you think that is?

(See answers above to previous question)



Do you feel your doctor listens to you?

7 people said 'Yes' and 2 people said 'No'



Do you feel that your doctor understands you?

7 people said 'Yes' and 1 person said 'No'



Do you feel that your doctor can help you when you don't feel well?

2 people said 'Yes' and 1 person said 'Maybe'. One person said 'female doctors are more caring. They are more compassionate...more sensitive'.



Does your doctor ask you if you feel happy or sad when he gives you a health check?

9 people said 'Yes'. 1 person said 'Maybe'

Being in hospital



Have you been in hospital because you feel sad?

3 people said 'yes'.



What was the experience like?

1 person said they were in hospital for the weekend, but that the security bullied them. 1 person who said they had spent 9 months in hospital said that 'the experience was horrible. They just drug you up. They drugged me up so much that I couldn't feed myself...you would get injections if you kicked off!' Another person said that the experience was bad for them and that they 'kept having nightmares...I just went in for a talk'.



Have you ever been to St Leonards because you have not been feeling well?

2 people said 'Yes'



What was the experience like?

1 person said the experience was good. Another person said that the experience was good and that it helped them to cope with stress.



Do you feel that you were supported well during your stay?

- (no answers provided)



Do you feel that you were supported well after your stay?

- (no answers provided)

Making things better



What would help you when you feel sad?

1 person said 'talk about it'. Another person said you should make an appointment to see your GP. One person said you should talk to someone. Another said you should go out for a walk. Another person said you should 'go to the park to take your mind off anxiety'



Do you think that you get enough help at the moment?

2 people said 'Yes'.



How would you like things to change and be made better for you?



and

1 person said 'have more group meetings'. Another person said 'stop all the Cuts from happening'. Another person said 'do more socializing. Play more snooker



Do you know what to do if you want to complain about health services?

4 people said 'yes'



Are you happy with the help that you got?

1 person said 'yes it worked'



Do you know about PALS. This stands for the ‘Patient Advisory Liaison Service’ and they help you to complain.

2 people said ‘Yes’

Collection of results from the 1-to-1 Interviews



Have you used mental health services before?

“Counselling services”

“I went into Homerton Hospital because of my behaviour. The paperwork took a long time”

“I used Mental health services a very long time ago. It was okay. I didn’t know what was going on. Later on I thought about getting counselling”.



Do you know where you can go to for support if you feel sad?

“Support workers”

“my support workers and my nurse”

“I would go to my doctor. Before things get too bad, the doctor is my first port of call. I would also go to my friends at Hackney People First”

“I would stay in touch with people. I would ask my support workers to support me”



Do you find mental health services easy or difficult to use?

“Sometimes. But when I try to ring up they keep you waiting”

“I find it easy if they tell me the procedure”

“When I used counselling services it was excellent. Now I know there is no counsellor specifically for people with a learning disability I don’t know if mainstream services would be able to understand me”

“It is difficult to use services without getting support”

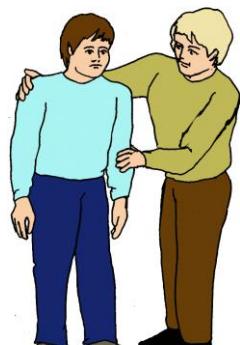


Is the information they use to describe services easy to understand?

“Sometimes”

“Definitely Yes”

“For me it is, but I’m not sure about others. It is in jargon sometimes”



If you have used mental health services, did you find the staff helpful?

“Yes. They talk to you and give you guidance”

“Sometimes, but not all the time. They go against you sometimes”

“I didn’t. Not in the hospital. I found counselling very helpful”



Have you ever used ‘talking therapies’ as a way to make you feel better? Another name for this is ‘counselling’.

“Yes I have. It is ongoing at the moment”

“Yes I have. For 4 years”

“No I haven’t used this”

"Yes. It was really helpful. It's like all the tight elastic bands in my mind come loose and I could think clearly again. It's like a light bulb comes on. I found it really helpful"



Do you think it would be easy to get a counsellor?

"In my case yes!"

"There isn't one at St Leonards anymore as he has gone"

"No!"

"Probably not as I don't know if I would meet the criteria. I haven't tried because I have felt okay. I know how to cope"



If you have used a counsellor, did it make you feel better?

"Yes it does"

"Yes it did"

"It helped me to come to terms with my anger. It was like a kind of road rage. It's about learning of ways to cope. Now I have learnt of ways to cope with society. It's really important that people get the support that they need to function in the community. Now when I get angry I can ask myself 'Why am I angry?'"

Your doctor and other professionals



Are you comfortable telling your doctor if you feel sad?

"Yes, no problem. I'm happy to do that"

"Yes I am"

"Yes"

"Yes"



If you are not comfortable, why do you think that is?

“I feel that woman GP’s understand me better”

Do you feel your doctor listens to you?



“Yes”

“Woman GP understands me very well”

“Yes he does”



Do you feel that your doctor understands you?

“Yes, at least the doctor I go to”

“Yes”

“Yes”



Do you feel that your doctor can help you when you don't feel well?

“Yes”

“Yes”

“I don't know”

“Yes”



Does your doctor ask you if you feel happy or sad when he gives you a health check?

“Yes he does. He asks me how I feel”

“Not recently, but it did happen”

“He doesn't ask me that, no”

“I don't like changes”

Being in hospital

Have you been in hospital because you feel sad?



“No”

“Yes. I felt sad when I was in a mental unit”



What was the experience like?

“It was bad.”

“Last time I was in there for 9 months”

“Terrible, as I mentioned earlier”



Have you ever been to St Leonards because you have not been feeling well?

“Yes. I am still going there”



What was the experience like?

“It’s a nice area, but the psychiatrist and the nurse don’t listen to me. They don’t respect my point of view”



Do you feel that you were supported well during your stay?

“No”



Do you feel that you were supported well after your stay?

“Not really”

Making things better

What would help you when you feel sad?



“Get help from a support worker. Listen to music. Read a book. Do gardening and take my mind off it”

“Staying calm”

“Someone to talk to like a counsellor so that it doesn’t get so bad. I think there’s a lot of people that don’t get the help that they need”

“Listen to a tape or read a book”



Do you think that you get enough help at the moment?

“Fifty-fifty”

“Yes”

“Yes, because I’m so busy”

“Yes”



How would you like things to change and be made better for you?

“For the psychiatrist to listen to me and don’t jump to conclusions”

“Get more support to help with housing issues and with letters”

“If I got a service from the learning disability team, someone to come and make sure letters are being dealt with and support with any accidents I have in my car. I cope very well, until there’s a problem”

“No sure. More listening by professionals”



Do you know what to do if you want to complain about health services?

“Write a formal letter”

“Yes. And if I had a problem with my GP, I would go above them”

“I would speak to my support worker”



Are you happy with the help that you got?

“Yes”



Do you know about PALS. This stands for the ‘Patient Advisory Liaison Service’ and they help you to complain.

“No”

“I’ve heard of them. I wish things could be better at the Homerton Hospital”

“I do. When my partner was in hospital they were quite helpful. They were very helpful”

“Yes. It’s an advocacy body. You can go to them if you’re not happy about the service you’re getting”