

Listening Event

Access to Mental Health Services

Thursday 15th March, 2018
The Beacon, College Street, St Helens, WA10 1TF

Report produced by the
Healthwatch St Helens Support Team



Background

Healthwatch St Helens have completed the first phase of the mental health task and finish group, which involved talking to service users about their mental health journeys. The 'Access to Mental Health Services Interim Report 2017', can be found on our website at:

www.healthwatchsthelens.co.uk.

The findings outlined in our report caught the interest of our local authority Scrutiny Committee who were starting a piece of work around looking at mental health services across the borough. Healthwatch St Helens offered to host and facilitate a listening event specifically for service users and/or their carers, so that members of the Scrutiny Committee could hear, first-hand, what people using mental health services were experiencing.

The Listening Event

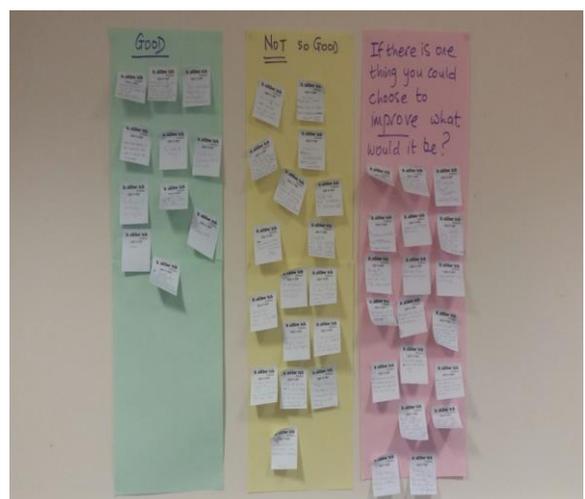
The event was attended by 20 members of the public, some of whom were services users, while others were friends, carers and family members. We intentionally excluded service providers from our invitation so that people could speak freely and openly.

Outreach & Intelligence Officer, Janet Roberts gave an introduction as to how the event came into being and what it was for. This was followed by the workshop and feedback session. Councillor Burns gave the closing remarks.

Workshops

Attendees engaged in a half-hour discussion about what works, what doesn't work and what gaps people believe there are in the service. Answers and comments were written on post-it notes and attached to the flipchart paper with the relevant heading.

Each table was asked to feed back 2 points from their discussion, which could also include questions.



Feedback

a) What is good?

- Staff try their best with very difficult cuts etc.
- Some psychologists seem to understand a person's resilience.
- Good (very) Mind friendship groups.
- Self-referral - Mindmatter.
- Helpful if you get the right person to gel with. Could possibly be a personality problem after an accessible location given.
- Some individual staff in services are respectful and knowledgeable.
- There are people in the community who want to help and volunteer.
- The work of Mind.
- We do have inpatient beds available.
- Samaritans.
- The Pharmacist at Peasley Cross Hospital.
- Nothing.

b) What is not so good?

- Help is NOT given when requested. Self-help is not suitable for everyone.
 - Too long waiting times.
 - More face to face and less telephone calls to service user.
 - Totally underfunded and understaffed.
 - Waiting times - what feels urgent to a person 'struggling' at the time has to be prioritised. Not good when anxiety levels are high.
 - Poor follow-up after discharge from inpatient. Inadequacies of Home Treatment Team.
 - Lack of listening to service users.
 - Joint working between services in mental health, hospitals, social services, schools and hospitals.
 - Diagnose far too easily and are often incorrect, causing unnecessary suffering.
 - Long time between psychiatric appointments. Understaffing serious at Peasley Cross.
 - In outpatients new meds not monitored.
 - Laundry facilities on ward. Machines in foreign language. Clothes misplaced or stolen.
 - No provision for people without family or friend support.
 - CBT - the great God. If it doesn't work for you - you are non-compliant.
 - The mental health service is not 'fit for purpose' and doesn't meet the needs of the people of St Helens.
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- Limited training of staff in Peasley Cross in basics - how to use bloods check-ups or how to take bloods.
 - Ward not secure. Frisked and bags checked on arrival but not after a day out. One lady bought wine then broke bottles to hurt.
 - Staff in Peasley Cross spend longer on computers than interacting with patients.
 - Psychiatrists that can't communicate properly with patients.

If there is one thing you could choose to improve - what would it be?

- Follow up after discharge is poor and needs to be improved, and the treatment from the home treatment team is not very good.
 - My daughter didn't like going to the groups as she felt they were full of old people and there was nobody around her age range. They should tailor these groups to take ages into account.
 - Sometimes service users are afraid to have their say because they are worried about the implications.
 - Mental health strategy - we need to know whether the strategy in place is really working.
 - Listen more and see the service users' perspective.
 - Psychiatrists that can communicate with patients.
 - Going to A & E when very depressed.
 - More one to one therapy and not groups.
 - To be treated as an individual and not defined by their illness.
 - Medication could be looked at by psychiatrist or similar every year so not just left on same treatment.
 - GPs need to listen to patients. Not just dismiss them.
 - Availability of information on groups to help with depression for people who don't use internet. (Put up) in waiting rooms etc.
 - Communication between mental health services and GP.
 - Need more counsellors that can actually counsel, not to ram CBT down your throat.
 - Add more job roles for people with lived experience of mental health to work alongside the professionals.
 - Too much group therapy - ineffective.
 - Communication, shorter waiting times, more funding.
 - Waiting times to be reduced (too long).
 - To improve counselling. Long waiting times, then not long enough appointment time with counsellor. Is this ever possible?
 - Put mental health back into physical health as chemicals are physical.
 - Reduction of stigma
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- Appointment system at GPs need to change - can never get one when you want one.
 - Staff training in communication skills, empathy and respect.
 - Funding: national issue but locally Hope House has had to end valuable services.

Rachel's story (summary)

Jayne Parkinson-Loftus read out a story that was sent in by email from a lady called Rachel who was unable to attend the listening event due to attending university.

She has been 'in and out of mental health services' since she was 15 and has utilised both CAMHS and adult services. She describes the poor transition between CAMHS and adult services, going from 3 appointments a week to none - meaning she was left struggling and feeling unable to cope. She gave good feedback about CAMHS but suggested that the transition should be gradual. In addition she feels she needs to have a clear, definitive diagnosis to access the support she needs.

Her experience of adult mental health services echo the comments highlighted at the workshop - from waiting times which can contribute to developing suicidal thoughts, to the need for 24/7 mental health care.

Closing remarks by Councillor Anthony Burns

Cllr Anthony Burns thanked everybody for coming along and sharing their experiences. He explained that he is the Councillor for Haydock but is also the Head of the Scrutiny Panel for health and social care.

The Panel is currently looking at mental health and access to services within the borough. He acknowledged joint work with the Healthwatch Support Team and has also attended a workshop on this subject.

He is proposing to take back all these experiences voiced within this event and compile them into a report.

At local level, the panel are going to challenge the providers and hold them to account. He hopes to share these stories and engage the Press. Their final report will also be raised politically to the new Shadow Secretary for Mental Health in Westminster.

General Conclusion

Some of the people attending the listening event gave us feedback afterwards that they valued the opportunity to have their say within a safe place, and having a Councillor present. In general, most people in the room said they felt that they could talk openly and honestly.

The themes that have emerged are:

- The long waiting times between the first appointment and treatment.
- 'One size does not fit all' approach does not work, and an individual holistic approach needs to be used. Eg. Psychodynamic counselling or other appropriate method.
- Communication between mental health professionals and GPs need to be improved, and between primary and secondary mental health services.
- Transition from children and young people's to adult mental health services is poor.
- There is still stigma attached to mental health and this needs to be reduced.

For more in-depth comments please see appendix

Evaluation

1. What was the most useful aspect of the day?

- Excellent communication on an important subject.
- The fact that it was a safe environment with no service providers here.
- The openness and honesty of the discussion.
- Listening to personal experiences.
- Being listened to, sharing experiences.
- I liked the fact the Councillor from Haydock was there.
- Having the chance to say what you had experienced and what was good - possible chance to suggest things that might help.
- Being able to say what is not working. Hearing that we are not on our own - others have the same problems.
- It helped to identify many various degrees of mental health. Many other people's experiences shared.
- Being able to talk and be listened to.
- Communication.

2. What was the least useful aspect of the day?

- I didn't find anything which wasn't useful.
 - Group dynamics but that's inevitable.
 - Nothing. It was all useful.
 - Not enough time.
 - Can't think of anything - it was good.
 - Information not about.
 - N/A.
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3. Was there anything that you would like to have seen included in the event that wasn't there?

- I think we pretty much covered it to a large extent.
- Maybe a follow-up?
- Benefits people could be there.
- A separate room where anyone uncomfortable in a group could still pass on their opinions in private.
- Issues need to be explored.
- Someone who could explain what operational policy is in place.
- No.

4. Any further comments.

- Thank you.
- The crowded room was difficult to cope with if anxious. Last year I would have run away!
- Needed more time
- The space - people can't talk if no-one listens
- Interesting event covering many aspects of problems

5. Where did you hear about this event?

- Phone call from Healthwatch. (I am a member)
 - Mind group
 - Work/leaflet
 - Carers Centre
 - Facebook
 - Healthwatch newsletter
 - Facebook - 'Friends Play for Disabled Children'
 - Post
 - Healthwatch newsletter
 - Email
 - Carers Centre
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Appendix A

Spoken stories

- As carers there is no communication from the professionals. I have a young daughter, just turned 18; she is classed as an adult, so I am no longer consulted, and she doesn't always want to talk so I have no idea how she is managing. There should be some kind of transitional service and this should be up to the age of 25 so that parents still know what is happening to their child. My daughter recently had to go to hospital (Whiston - ambulatory ward), and just sat there for over 9 hours, waiting to be seen. She finally saw the Assessment Team at 2am and the place was full of drunks. There are just not enough staff. It is now 12 months since she saw the Assessment Team and she is still waiting for Level 4 therapy. Mindmatter have sat in a meeting and told everybody that my daughter has been attending her meetings, but in reality she had only been to one meeting and wouldn't go again as she didn't like it. How can they say that when it isn't true?
 - My daughter is 16 years old and has been in CAMHS for 2 years. She has not found it useful and has since attempted suicide. She was told that she could have CBT or nothing. CBT is not always a 'one size fits all'. How can there be a service where you come out worse than you went in? My daughter felt that they were not probing enough and didn't ask enough questions. CBT doesn't work for everyone and it is very restricting. My daughter came out very despondent. I feel that you have to wait so long to get into therapy and then it is not always suitable.
 - I found that therapists need to start looking at things differently. They need to start treating the person and not the illness, as not everybody is the same. Mental health professionals don't take into account that people have had traumatic lives. They focus on the mental health condition instead of seeing it as a perfectly understandable reaction to what a person has been through.
 - "When I was in Peasley Cross I didn't find it secure. People's belongings are checked when they go in, but if they go home for a day they are not checked when they go back in. One lady brought in bottles of wine, drank them and then smashed the bottles and tried to cut her wrists. The staff were on their computers most of the time and quite often there was nobody on duty who could use the diabetes machine. There was nobody to give my laundry to and the door to the laundry room was left open at all times. Quite often people took clothes out of the machine and left them on the floor
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and items were stolen. The washing machines weren't easy to use as the instructions were in a foreign language.

- There was nowhere to go on the wards if you are spiritual and somebody only comes in once a week to give communion. There is no holistic approach and spiritual health is just as important as mental health.
 - Staff training was a big issue. Also there can be issues with accessibility as the hospital is not easy to get to.
 - It is also important that you trust the person that you are receiving therapy with otherwise it doesn't work.
 - Even longer waits if you can't cope with working in a group.
 - Self-help is not always suitable and they can't do it, therefore they are not getting the help that they need. Peoples' anxieties mean that they can't physically access self-help. My wife was continually put into CBT groups and she can't work within a group, she needs one-to-one therapy sessions. The waiting times are even longer if you require one-to-one.
 - I had to have the GP act on my behalf as I found Harry Blackman House to be a blockage and communication was just one-way.
 - I am on a number of different tablets and the GP won't take me off the medication that I feel is no longer working for me. The need to be more careful around the usage of some antidepressants, and this is stated in the NICE guidelines.
 - There should be a multi-disciplinary approach.
 - Services won't talk to you on behalf of somebody else if you are not an appointee. My brother will not pick up the phone if he doesn't know who is ringing and they always insist on ringing him up instead of ringing me. This means that he is missing out on help that is vital to him.
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Appendix B

Written statements /stories

- I have lived in St Helens over 20 years. I started taking anti-depressants at the age of 16 and have never been off them since so that's about 44 years I've been on the medication. In the past I was put on Section 3 and in Winwick Hospital, there have been times I've attempted suicide.

At the present time I'm much better than I was a few years ago. For many years I was on Dotheipin at increasingly high doses probably from age 16 to 57. It was obvious for a lot of those years it was doing me no good. I started having severe headaches and nothing was helping. I was constantly at the Doctors but since I'd been in Winwick about 30 years before it was much more difficult to get help. Suddenly you had to go to A&E if you were depressed (I haven't family around or a car but a number of times had to go in the night to A&E) so it was very definitely not helpful. Then there were appointments with the Assessment Team which was constantly going over what had happened in your life and then sent home. Finally after years and years I got to see a psychiatrist again who put me on Prozac and an anti-psychosis medication. It changed my life, I could sleep, talk to people, just survive a lot more easily.

But why was it so hard to get to see a psychiatrist - I feel years of my life were ruined just because instead of access to help there were barriers. For a physical illness you don't have to go to A&E to try and see a specialist and you don't have to be interviewed by an assessment team whose job seems to be to persuade you to go home and cope even though you can't. Shouldn't there be a system in place where people with persistent depression eventually just get to see a psychiatrist to give advice about the medication. With physical conditions doesn't this happen.

At one time you could have a nurse visit you at home that seems to be rare now.

So there should be support available in the community. I think in the town centre there should be a Mind Café where people who otherwise get sent to A&E in the middle of the night could call in and chat to people. The café could be very basic - just coffee/tea or toast available. It could be run by volunteers or people with mental health problems who are stable. Information about activities available could be around, not everyone uses the internet.

I also think people with mental illnesses have difficulty finding work and keeping jobs - and they are often found in charity shops. For some that is probably okay but where are the alternatives? Some people just want to be outside. Sherdley Park has potential to be much more. There is rubbish everywhere and a café which is never open.

I think it would be easy to establish a 'Friends of Sherdley Group' maybe one morning or afternoon a week.

The café building might be used or just a shed. From this volunteers who are just on their own, have mental health problems or learning difficulties could meet. The Council could provide large recycling containers for glass bottles, plastic bottles, just paper and people who are volunteers or dog walkers could be given recyclable bags to collect bottles etc. It would keep people active. There could also be an area that was a community garden where the public could plant and weed as a community. Perhaps there should be cheap drinks available to buy just to encourage people to mix (stocked from pound shops).

The psychiatrists I've seen in the last few years have been amazing. I just wish it had been easier to access their help. I've only seen two but it was the help I needed and had been needing for years.

Job Centre

At the job centre you are interviewed by people with no understanding of severe depression (often). You can feel like you are seen as putting it on and the fact that you turn up for an interview means you can turn up for jobs. No account is taken of the amount of medication you are on or your life experiences which have taken your confidence.

I think the job centre needs to be a bit more supportive. People with mental health problems often get bullied, lack confidence at work or when becoming ill again become happier away from other people.

When you are well you can seem very well but mixing with other people who put people down can make the depression come back. I've been bullied in a number of jobs because I'm not confident.

Acknowledgements

Healthwatch St Helens wishes to thank everyone for attending and give special thanks for those people who bravely shared their stories with us.

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