



# healthwatch Bristol

## MISSING LINK

### SERVICE USER FOLLOW UP

03 October 2016

Healthwatch Bristol revisited the service user group for Missing Link to focus discussions on mental health support services.

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# MISSING LINK

## SERVICE USER FOLLOW UP

Healthwatch Bristol previously facilitated an informal session with Missing Link service users in June. Due to its success and the wealth of information the service users wanted to share, Healthwatch Bristol were invited back. To read the report of the first Healthwatch focus group with Missing Link see:

<http://bit.ly/2cSdmJc>

The focus of the session was in two parts:

- A general question of ‘What does it mean to be a woman in Bristol, with regards to health?’ was asked and the results will feed into the Women’s Health chapter of the Joint Strategic Needs Assessment.
- The rest of the session was an informal open discussion concerning mental health support services.

12 women took part in the session which was a mix of service users and Missing Link support workers. The Missing Link staff were invited to leave the room so that the service users could speak openly, but the Missing Link service users decided they were happy for the staff to remain and that they could speak honestly with them in the room.

### Missing Link:

Missing Link is a mental health and housing service for women in Bristol. Missing Link was established in 1982

“Trying to talk to your GP and them not hearing you is upsetting, it is hard enough trying to get an appointment but GPs are not counsellors or mental health specialists and sometimes you just need someone to talk to. Having counsellors in GP surgeries would be a really good thing.”

*Feedback shared during the session.*

to provide a range of housing and support to women who either have acute or long term mental health needs.

Missing Link support women who are homeless, or have a history of sleeping rough or whose housing is at risk because of their mental health issues.

W: <http://missinglinkhousing.co.uk/>

Some of the focus group participants had also used Next Link services. Next Link is part of Missing Link Mental Health Services and provides domestic abuse support services.

W: <http://nextlinkhousing.co.uk/>

## You Said....

### Women's Health

The key themes to come from the discussion concerned **reproductive health** and **mental health support**.

- Several members of the group talked about periods as a key issue for women and how cramps and pain can be so severe but it is not really recognised or taken seriously.
- The question of why women still have to pay tax on sanitary products was raised.
- Menopause was also discussed and there not being enough information and how it can impact your mental health. One member of the group spoke about their mother who had experienced going through the menopause quite early and because she had not been able to do what she had previously and the process had lasted several years which she had not realised would happen. She had ended up getting depression.
- Pregnancy and child birth were discussed.
- One member had experienced problems taking contraception. With one product she had bled for eight months continuously but when she questioned this it was not taken seriously and it had led to her losing weight and becoming anaemic. Eventually she asked for the implant to be removed and they discovered it had fused between the muscles and was not working properly.
- One member talked about how she had had a cyst for the last five years and has just been told it will dissipate by itself. She added that, with her

mental health issues, to be ‘brushed off’ or told it will get better makes her feel like she is wasting people’s time.

- One member talked about their mother who experienced lots of pain and sickness which turned out to be a fibroid in their stomach. They felt she had not been taken seriously and had had to get to a point of crisis before the GP did anything.
- One member also talked about taking their children to the GP and how it felt when the GP ‘shrugs you off’ as it is nothing to worry about.
- Lack of information and resources about postnatal health, Post Traumatic Stress Disorder, Bereavement and mental health support for women in general.
- Not being taken seriously or being listened too when you know your own body.
- It would be really good if there was an Accident and Emergency service for mental health where you could go and be safe. The group discussed the Sanctuary as being very good.
- Trying to talk to a GP and them not hearing you, it is hard enough trying to get an appointment but GPs are not counsellors or mental health specialists and sometimes you just need someone to talk to. Having counsellors in GP surgeries would be a really good thing.
- The group talked about the cut-off point between adolescence and being a woman, particularly young mums and the need for specialist services and support.

## Mental health support services

### 25 comments received



The group had an open discussion about their experiences of mental health support services, accessing them and the quality. Comments have been grouped by theme.

- There were poor experiences of Petherton Resource Centre with several comments being about the service user never being given the opportunity to finish answering a question and responses being twisted.
- There was discussion about patient notes and one member had requested to see her notes only to find on reading them they had become ‘Chinese whispers’ with things she had said being taken out of context and manipulated. One example she gave was how through her own choice she had decided to live in a van, it was a fully kitted out van including a wood burning stove and she had a spa membership so could use the facilities daily and for her it was a much better place than the shared house she had been in. In her records the psychiatrist had recorded she was at risk of self-neglect.
- The group felt assumptions are made about them and diagnoses made without asking questions.
- Trusting your clinician and having a good relationship with them is key, and if you do not have that the process will not work. One member talked about their relationship with their psychotherapist through Assertive Contact and Engagement service (ACE) not being great, but there is no one else she can see so keep going back but does not feel like they are getting anywhere.
- One member talked about ACE being very good. Jenny is their support worker and she has all the time in the world for her and if she is feeling particularly low the support worker will cancel other appointments to stay with her. Only issue was she had to wait six months for a referral.
- Communication and empathy is key.

## Medication

- One member talked about how as a teenager she had been struggling due to an unhappy home life and stress of exams, her GP had prescribed Prozac but she had never been offered the opportunity to talk to someone. In hindsight she was just a normal teenager who needed someone to talk to.
- The group felt there was too much reliance on medication without clear explanation of side effects and not enough therapy or alternative



therapy. One member said she understood that in Sweden if someone goes to their GP with stress they get six weeks of massage, which they felt was surely better than pills.

- One member talked about being prescribed Temazepam which made them want to sleep all day. Unfortunately she had two small children, so wanting to sleep all day was not good for them and if she had been aware of what the side effects had been she would never have agreed to take the drug. She constantly questions whether if she had not have taken the drug would she still be with her children as they ended up being taken into foster care.
- One member talked about how when they visit their GP and tell them how they are feeling, they may say they are suicidal but the GP does not listen and they just give them more pills and say see you in a month.

### Referrals and treatment boundaries

- Several members talked about struggling between being under primary or secondary care. They wonder why you cannot access both, particularly when you hear such good things and you should be able to go where suits you best. One member was receiving treatment from a psychiatrist at Petherton which was not working that well for them so their Bristol Mind support worker made a referral to Rethink who had psychologists. Unfortunately when they finally got an appointment they discovered that as they were under Petherton, Rethink could not help. They still believe a psychologist would be much more helpful to them, but Petherton do not offer this.
- The group talked about having to be at crisis to be referred and referrals take so long. One member was referred to LIFT but have still not heard anything back.
- Several members talked about not finding LIFT particularly helpful to them.
- Another member also had a referral to Rethink while being treated under Petherton, having the referral seemed to take them off the list for Petherton, but when Rethink could not help them, they were left with nothing and had to start all over again.

- One member was taken to the Southmead Hospital's place of safety for a night, which was good. They were, however, on the waiting list for Missing Link, and when they were registered at Southmead Hospital, they were dropped from the waiting list for Missing Link so had to start the process again.
- The Missing Link support workers talked about how a key issue for them is that other services do not always get the referrals into Missing Link right and how there needs to be better understanding of what services can offer and the criteria for support. For example one worker talked about how she had met a lady whose hopes had been raised thinking she would get support from Missing Link, but as there was no housing need they could not help her.

### Treatment suited to needs

- Two members had Post Traumatic Stress Disorder (PTSD) and they both felt none of their clinicians knew anything about it so just offered pills and were told it will go away.
- There was a consensus from the group that clinicians in general will treat people as though they are from a text book. They did not feel they have the life experience to understand.
- One member talked about their experience at Brookland Hall. They felt the two workers supporting her were useless. To everything they asked for support with [the staff member] would respond 'let's think about that' and it took 10 months of them asking for the same information before they asked to see someone else. That person answered their questions in their first session. The commentator found the psychiatrist they saw be very difficult and on several occasions their not being helpful made the commentator feel worse than when she went in for her session with them.
- Most of the group felt they had a good experience of Missing Link, although one member talked about how their Missing Link support worker had been unable to help them when they asked to be sent into Callington Road for a few days. When this was not possible she asked if they could

come to get some food with them, and again this was not possible. Two days later she was admitted to Callington Road in crisis.

### Getting back into work

- The group talked about how someone's mental health can impact on work and getting back into work could help their recovery. One member spoke about how she had just undergone seven days of training with 'Your Lifestyle' to become a support worker. She completed the training but due to pre-screening checks has been told she does not have a job and told she has to pay for the training.
- One member applied to be a volunteer receptionist at The Terrance Higgins Trust for a few hours a week. Before starting she had to undergo four full intensive days of training which ended up being too much for her. The issue she had with the experience is the way her psychiatrist wrote up the situation very negatively, when actually the training had not really been appropriate for the role she had been going to take on.
- The group discussed Bristol Disability Benefits Centre at Flowers Hill. They feel the assessors do not understand mental health and the criteria are only designed for those effected by physical health. One member spoke about the stress she feels at having to go every six months, not sleeping and how she spends the whole time in the assessment trying to keep control, only for her on one occasion be scored zero. She took this to tribunal and with all the GP and support worker evidence was scored 39.
- One member spoke about how her mother attends the Personal Independence Payment (PIP) appointments with her as otherwise she would not be able to say anything and the way the assessment is carried out it has no concern for how her mental health impacts her life. For example, while she can walk, when she is feeling low she cannot leave the house or even her bed, and this is not taken into account.
- There was real concern that if the assessor does not understand mental health and are only selecting what they think is important, which is then interpreted by someone else, that is missing the whole person and what is actually going on under façade they may be putting on.



## Key themes

### Services included in this report:

- ❖ Avon & Wiltshire Mental Health Partnership NHS Trust:
  - Petherton Resource Centre
  - Callington Road Hospital
  - Brookland Hall
  - Southmead Place of Safety
- ❖ Bristol Mental Health: Greenway Centre
- ❖ Rethink
- ❖ Missing Link
- ❖ Assertive Contact and Engagement (ACE) service
- ❖ Sanctuary
- ❖ Bristol Disability Benefits Centre at Flowers Hill
- ❖ LIFT

### Key themes:

- ❖ Being listened to and taken seriously in mental health settings. There were several accounts of experiences where member of the group felt they had not been heard by their clinician and what they had said was interpreted incorrectly.
- ❖ Reliance on medication was felt to be a negative aspect to mental health support instead of spending the time to get to the cause of the problem and 'solve' it. Having counselling sessions or alternative therapy would be more useful.
- ❖ The fitness for work assessments are thought to discriminate against those with mental health.
- ❖ Being able to access the right support for an individual's mental health was thought should be priority regardless of whether that comes under primary, secondary or community care.

## Healthwatch will....

All the feedback Healthwatch Bristol gathers is analysed and used to inform the Healthwatch Bristol quarterly reports which are shared with Healthwatch Bristol partners including Bristol Clinical Commissioning Group, the Bristol Health and Wellbeing Board, Bristol City Council, the Care Quality Commission, NHS England and Healthwatch England. The quarterly report is also presented to the Healthwatch Bristol Advisory Group to propose further uptake of the issues identified in the report. The report will be available on the Healthwatch Bristol website ([www.healthwatchbristol.co.uk](http://www.healthwatchbristol.co.uk)) and circulated to our mailing lists via the monthly e-bulletin.

## Looking forward....

Healthwatch welcomes and encourages service users of Missing Link to continue to contribute their feedback to us using the communication methods included at the end of this report.

Healthwatch also supports members of community groups to become Volunteer Champions so that they can represent the experiences and needs of their community group. If you would like to find out more about volunteering with Healthwatch, please contact us using the details below.

## Tell Us Your Story...

Healthwatch Bristol wants to hear from you about your experiences so that we can tell services your needs to create the best local services.



Text us - text bris followed by your message to 07860 021 603



Email us at [info@healthwatchbristol.co.uk](mailto:info@healthwatchbristol.co.uk)



Call us: 0117 2690400



Write to us at: Healthwatch Bristol,  
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