

Healthwatch Southwark

Summary of our engagement on mental health Date last refreshed: November 2016

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Mental health was identified as a priority area for Healthwatch Southwark (HWS) through public and stakeholder consultation. Our evidence on this topic is collated here from the many engagement activities where people have told us about their experiences, between HWS's beginning on 1st April 2013, and 8th November 2016. It is arranged thematically, roughly following a pathway through services from access to discharge. Whilst we do hear of some very positive experiences, we naturally receive more contacts from those who are unhappy. We believe that every voice counts and even one person's negative experience needs to be addressed.

All reports mentioned may be accessed using the links or via www.healthwatchsouthwark.co.uk/reports.

Public forums

Healthwatch holds quarterly public forums on different themes. At some forums, members of the public have raised mental health services spontaneously or discussed them in a more directed way:

- July 2016: <u>Parents and Families Event</u> Tabletop discussions among parents on mental and sexual health of young people.
- April 2016: <u>My Voice Counts!</u> Event with young people (joint with Clinical Commissioning Group (CCG): scenario-based discussions on mental and sexual health
- September 2015: <u>"Everyone is treated equally" Join the debate!</u> Questions raised by the public around mental health.
- June 2015: <u>"Your Care, Your Services- Issues to solutions</u>" Discussions touched on mental health topics.
- March 2015: "You said, We did!"
- Nov 2014: <u>"Healthwatch Southwark: 1 Year On"</u> Several people raised the topic of discharge, including for mental health patients.
- July 2014: "<u>Spotlight on Social Care!</u>" Questions and anecdotes were raised about the role of care coordinators for people with mental health difficulties.
- Dec 2013: "<u>Building our Network</u>" Directed tabletop discussion on each of our priorities, including mental health, amongst people with experience of relevant services.

Focus groups and surveys

Healthwatch runs **focus groups** with members of seldom-heard communities. Again, participants may discuss mental health issues spontaneously or after prompting:

• In discussions with <u>Somali women</u> and <u>Bengali women</u> (June 2014), both groups raised mental health spontaneously amongst more general consideration of primary and secondary care, cultural needs, and long-term conditions.

- Discussion with people aged 16-25 at a mental health support group (February 2015) focused on sexual health but also we also asked about mental wellbeing.
- Our focus group with <u>Vietnamese and Vietnamese-Chinese mental health service users</u> attending the Vietnamese Mental Health Services (VMHS) community organisation (October 2015) focused on different levels of mental health care.
- A <u>carers' focus group</u> (January 2015) touched on the impact of caring on people's own mental health.
- <u>Visits to talk to Travellers</u> in three areas around Southwark in 2015-16 touched on cultural attitudes to mental health.
- A <u>survey of Trans people</u> from around the UK in 2015-2016 revealed mental distress and problems with attitudes to Trans health among professionals.
- We conducted <u>extensive engagement in the summer of 2016 with 114 young people</u> <u>aged 12 to 23 years on the topic of mental health</u>, focusing particularly on education, awareness and which services they might access. This included six workshops, an online survey and a paper survey at a local school.

Information and signposting service

We run an **information and signposting service**. All contacts are logged so that we can identify themes emerging. During the period 1st April 2013, and 8th November 2016 61 contacts have mentioned mental health issues and services. Where not otherwise referenced, evidence collated below is from our signposting function.

As well as the issues discussed in detail below, we have provided assistance regarding:

- Information on where to go or where to signpost clients for mental health support, how to register with a GP in order to get help, or access mental health advocacy and legal advice
- Information on how to complain about a service
- How to access records for a mental health patient whose surgery had closed
- How to follow up on an Improving Access to Psychological Therapies (IAPT) referral into secondary care
- Contact details for Child and Adolescent Mental Health services (CAMHS) supported housing.

Engagement prior to Care Quality Commission (CQC) inspection of the South London and Maudsley Trust

Prior to the CQC's inspection of the local mental health trust, South London and Maudsley (SLaM), in September 2015, HWS collaborated with Healthwatches in other affected boroughs to actively seek feedback from the public and patients about SLaM's services. This included call-outs for comment via email, website and e-newletter, and visits to groups such as the Cuckoo Club (Southwark and Lambeth Mind) and the Dragon Café. The <u>feedback</u> was submitted to the CQC to inform inspectors' investigations.

Themes from our engagement on mental health



Information, education and awareness

Young people

In our summer 2016 engagement with young people about mental health, more disagreed (37%) than agreed (28%) with the statement 'It is easy for young people to get information and advice about mental health'. Some said that information must be actively sought out. While some saw the internet as a helpful source, many did not feel information online was reliable, locally applicable or easy to find, or feared they might wrongly self-diagnose.¹ In an earlier discussion, young people had also said that there was not enough knowledge about what symptoms to watch out for, how to react to them and what services are available. Some suggested that hearing about people's real experiences would be a good way to educate others.² Young people agreed that adults such as parents, teachers and religious leaders needed training in how to support young people around mental health.³

The majority of participants also disagreed that their school had provided good education on mental health. While a couple of people were satisfied with information provided (via, for example, assemblies), large numbers said that they had not received anything at all. Where schools did provide information (for example around exam time), it was often inadequate - teachers were not trained in the subject and were too vague. In a few schools a potentially more effective approach had been taken, with external educators coming in. Young people suggested engaging, practically-focused education, *'Give preventative advice - for example, some people don't realise that smoking cannabis can really affect their mental health.'*4

Parents and families

At our Families forum, most parents agreed with the statement, 'If my child was having a problem with their mental health, or they were showing signs that worried me, I would know what to do', but also said that parents do not know where to go to for information and support. For instance, some people did not know about Southwark's Wellbeing Hub or any youth organisations. Lack of knowledge among faith leaders was also mentioned, 'I am a Christian but would not go to my pastor as [they] would say my child has a demon.'⁵

¹ Young Voices on Mental Health (Nov 2016)

² <u>My Voice Counts! Public Forum (April 2016)</u>

³ Young Voices on Mental Health (Nov 2016); Focus group with young people aged 16-25 (Feb 2015)

⁴ Young Voices on Mental Health (Nov 2016)

⁵ Parents and Families Event! Public Forum (July 2016)

Cultural understandings of mental illness

Understanding and interpretations of mental ill-health vary across Southwark's diverse cultural groups and this needs to be recognised in order to provide appropriate help.⁶

Stigma around mental illness

During our summer 2016 engagement with young people, we asked who they would feel able to talk to about their mental wellbeing. 61% agreed that they would be able to talk to their friends and 53% to their parents. Reasons for not talking to friends included wanting to be positive, fear of judgement or awkwardness, and fear that a problem might get 'brushed off'. In one group made up largely of young men, many said that young women are much more likely to open up to their friends. Reasons for not talking to parents included families not understanding mental health issues, focusing on practical issues, or trying to 'joke it off'. Cultural attitudes could be a significant barrier, 'My mum would say 'you've a devil inside... it's the same idea among some older traditional people.'⁷

However, in on one focus group with young people, 12 of 13 participants said that young people can access mental health services without fear of judgement.⁸ In the summer engagement, only 35% of the young people said they would feel embarrassed if others found out they had sought support with their mental health, and 44% said they would not. Yet many felt that social stigma this was still powerful, with for example television playing a role. Again, coming from certain backgrounds could exacerbate this, 'People I know from immigrant backgrounds - there is stigma. I was raised on the idea that that talking about this is very weak...If these stereotypes were broken down, people might use services more.'⁹

Participants at some of our focus groups recognised that their cultures traditionally placed stigma on mental illness: 'In Vietnam there is bad talk about people with mental health [problems]. They don't want to believe what you say. They laugh behind you'; 'We don't like to talk to strangers about our problems such as marriage problems.'¹⁰ Stigma can take many dimensions - for example Somali women told us that mental illness may cause someone's faith to be questioned, and that they are expected to suppress postnatal depression due to a cultural image of the 'strong Somali woman.'¹¹ Some people in the Traveller community told us that traditionally

⁶ Building our network! Public Forum (Dec 2013)

⁷ Young Voices on Mental Health (Nov 2016)

⁸ Focus group with young people aged 16-25 (Feb 2015)

⁹ Young Voices on Mental Health (Nov 2016)

¹⁰ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

¹¹ Focus group with Somali women (Jun 2014)

mental health was not discussed (terms such as 'nerves' and 'stress' are more familiar) and that this meant not everyone understood it well. One person commented, 'There is a lot of suicide in Travellers, they are too ashamed to talk about their mental health, rather than talking about things, they would rather take it to the grave with them.' However, some felt that times are changing and people were now more likely to talk about mental health.¹²

Impact of culture on mental health treatment outcomes

People's cultural background also influences their approach to self-help and their experiences of treatment. One Somali woman told us that she considered reading the Qur'an to be 'psychological therapy'.¹³ At our focus group with Vietnamese/Vietnamese-Chinese service users, many said that they felt understood and some appreciated the regular support provided by their Community Mental Health Team (CMHT) but one felt strongly that they were not understood by white British professionals: 'I don't think they understand our religious background and problems... They give medication that doesn't work; I need Vietnamese medication... I don't want to be sectioned, I want to be among Vietnamese people. They know a Muslim needs a prayer mat and to pray [but]...they don't understand my religious needs.' This person said that people's experiences as refugees impacted on the way they needed to be treated. He wanted more people from ethnic minorities to be trained as mental health staff in order to help their communities.¹⁴



Access to support via schools

As with information and education provision, several of our young people's workshop participants were critical regarding support provided by schools. Some said it was hard to access school nurses or counsellors. Other obstacles included support being predicated on the young person having academic or behavioural problems, and fears about safeguarding rules - people thought they might get 'taken away' if they sought help.¹⁵

Parents at our July 2016 public event shared experiences of the support schools had provided for their children around mental health, some being positive - '*The school counsellor is very helpful, liaises with me as well as my child. The school knows what to do...referred my child to CAMHS.*' However, we were also told about quite

¹² Focus groups with Gypsies and Travellers (Jul 2016)

¹³ Focus group with Somali women (Jun 2014)

¹⁴ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

¹⁵ Young Voices on Mental Health (Nov 2016)

negative experiences that some people had had with schools, where they felt dismissed.¹⁶

Access to GPs for people with mental health problems

We have been contacted by two people who faced different problems in accessing GP services for reasons related to their mental health. One suffered from agoraphobia and had been told that the surgery where they wished to register could not provide home visits for them. Another person said that because of their condition, they had sometimes been aggressive when at the GP surgery. However, because the police had not been involved they could not be referred to the Restart service and due to this (plus issues surrounding being homeless), were struggling to register with a practice.

The set-up of GP practices can pose challenges for those struggling with their mental health - some feel that ten-minute appointments are not enough to discuss these problems, and that the need for a long-term relationship with a named GP is not always fulfilled.¹⁷

Willingness to talk to the GP about mental health issues

Only a third of participants in our summer 2016 youth engagement agreed, and over a half disagreed, that they would be able to talk to their GP about their mental health. While some were confident in the GP and said *'they're professionals'*, others felt their relationship with the GP was not good enough or had fears about confidentiality. Some thought the GP would take extreme measures such as *'try to give me drugs, injections, or lock me up in the Maudsley!'* One person suggested that to encourage people, services should *'publicise case studies of how counselling/online services have helped people - to show that you aren't alone and it's normal.'*¹⁸

When parents at our July 2016 public event were asked if they'd trust their GP for support for their child's mental health, opinions were mixed. Some said it depended on whether the family had a relationship with the GP or if they saw a different doctor each time. Some didn't feel that GPs would have the time - *'they can only talk to you for ten minutes at a time*.'¹⁹

¹⁶ Parents and Families Event! Public Forum (July 2016)

¹⁷ Building our network! Public Forum (Dec 2013)

¹⁸ Young Voices on Mental Health (Nov 2016)

¹⁹ Parents and Families Event! Public Forum (July 2016)

Among both young people and parents, some were not aware that GPs can provide mental health services or did not think they had the expertise, *'It's like asking a doctor to be a dentist*.'²⁰

Access to talking therapies

People are particularly concerned with being offered the right type of support, including talking therapies. Bengali women told us they were concerned about the abundant use of medication to treat illnesses like anxiety. They felt that medication tends to make people tired, which can interfere with their responsibilities, and that talking therapy would be better.²¹ Somali women with long-term conditions told us that they are keen to be offered psychological therapies to manage pain, and it would be good to have counselling provided at the GP surgery.²² Traveller women likewise agreed that they would prefer talking therapies over medication and felt that GPs would offer the latter - *'if you go to them with a problem, they put you on medication for anti-depression.'*²³

Among young people too there is again some fear that GPs will prescribe medications rather than offer talking therapy - 'they just give pills, they don't want to talk. Pills have side effects and don't work'; 'We want to stop being prescribed drugs - they just make things worse, and the long list of side effects is really scary. We want more talking therapies.'²⁴ Parents at our Families forum likewise worried that young people would be given medication rather than a 'holistic' approach, and felt more needed to be done to promote talking therapies and peer support, and ensure proper diagnosis before treatment.²⁵

Triage has been described as a 'lottery' which can miss some people with real needs.²⁶ Some people are refused particular treatments which professionals feel will not be successful, or because they are 'not sick enough' (the person reporting this later presented at A&E).²⁷

²⁰ Young Voices on Mental Health (Nov 2016); Parents and Families Event! Public Forum (July 2016)

²¹ Focus group with Bengali women (Jun 2014)

²² Focus group with Somali women (Jun 2014)

²³ Focus groups with Gypsies and Travellers (Jul 2016)

²⁴ Young Voices on Mental Health (Nov 2016)

²⁵ Parents and Families Event! Public Forum (July 2016)

²⁶ Building our network! Public Forum (Dec 2013)

²⁷ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

Types of therapy on offer

Even when talking therapy is offered, it is not always the right kind. Participants at one forum felt that while programmes such as IAPT were helping more people access therapy, access to more specialist help might be getting worse. They said patients were often offered short-term Cognitive Behavioural Therapy (CBT), which was described as a 'sticking plaster', and that when this was not the right approach for the individual it could be damaging.²⁸ Another person contacted us for help as he had been referred to group therapy at IAPT and felt this was not suitable for the issues he needed to discuss. Many people spoke to us with high praise for the psychologists and therapists who have helped them, but it is also important that people feel able to speak up if they do not get on well with an individual therapist, as those who cannot engage with their practitioner will have poorer outcomes.²⁹

We heard from one person who had finally asked their GP for help after suffering mental health issues for some time, but had their referral to the CMHT turned down because they sometimes smoke cannabis. They were referred to the drugs service despite themselves not seeing cannabis as the issue, and felt judged and let down. When we discussed this with staff at the drugs service, they told us that many of their clients find it hard to access mainstream (non-drug-focused) services even when this might be appropriate for them.

Waiting times for mental health treatments

Concerns have often been raised about people with mental health problems having to 'jump through a lot of hoops' and wait a long time to get support.³⁰ During our engagement prior to the CQC inspection of SLaM, people raised concerns about long waiting lists to get onto developmental courses like mindfulness which were themselves seen as excellent (and the need for a good GP who could push for the patient), and long waiting times following referral to a CMHT. People cannot access IAPT treatment or be on its waiting list until their CMHT referral is accepted or rejected, so they may have no support and face two separate waiting periods.³¹ One contact referred from practice-based counselling to Southwark Psychological Therapies Services (SPTS) had not heard anything in six months, despite his counselling being discontinued. It is felt that often people do not get support until someone gets 'hurt'.³²

²⁸ Building our network! Public Forum (Dec 2013)

²⁹ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

³⁰ Focus group with Somali women (Jun 2014)

³¹ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

³² Your Care, Your Services: Issues to Solutions: Public Forum (Jun 2015)

There have also been some problems with referrals getting 'lost' or people being unable to contact a service about referral, and being discharged without care.³³ Patients would like to be involved and updated throughout the referral period.

Language barriers

Language is a particular barrier to accessing good mental health support. A Deaf forum participant told us about the impact of this: 'High numbers of Deaf people have poor mental health because of barriers they face with communication - they can't access services to talk about their problems. When their physical health gets worse, their mental health gets worse too.'³⁴

At our focus group with Vietnamese/Vietnamese-Chinese mental health service users, participants agreed that language is the main barrier for them in accessing services. Even some who normally or previously spoke good English may struggle to do so when unwell or may lose the ability due to their illness.

Most of the Vietnamese-speakers we talked to had not accessed mainstream health information. Some had not received help until in a crisis because of this - 'no idea, no help, no contact'; 'By the time you [get] it is when you're sectioned.' ³⁵ Two people said that if the a voluntary organisation was not there, they would rely on friends and word of mouth for information. Two said that it would be very difficult and that they did not know where they would be able to get information. Two said it would lead to crisis for them, 'I'm in hospital, definitely', 'Hospital for an emergency.'³⁶

Some GP surgeries are not meeting the need for interpretation. Making GP appointments was agreed to be a problem for many in the group, largely in connection with the language barrier. Interpreters were sometimes also required for talking therapy (as also discussed at a previous forum³⁷); we did hear a couple of examples of this being provided.³⁸

Pressure on care coordinators

There is some indication of mental health care coordinators being overstretched - one forum commentor said that coordinators do not have the time to do what they need to for people being assessed for personal budgets; another that one care coordinator failed to respond to emails and calls from a person whose mental health was deteriorating.³⁹

³³ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

³⁴ "Everyone is treated Equally" Public Forum (Sep 2015)

³⁵ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

³⁶ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

³⁷ Building our network! Public Forum (Dec 2013)

³⁸ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

³⁹ Spotlight on social care! Public Forum (Jul 2014)

Access to support in the community

People are worried that community support for those with mental health problems is inadequate and threatened. Some forum participants argued that cuts to services such as Mental Health Day Centres leave people vulnerable and undermine the prevention agenda.⁴⁰ An email contact agreed, saying that *'mental health and other invisible disabilities are being unfairly and disproportionately targeted'*, and that not everyone feels able to go to a statutory service. Another was concerned about support for minorities, saying funding for an advocacy project had been withdrawn *'because there is no concept of advocacy in Vietnamese culture/language.'*



Attitudes in primary care

Being listened to and taken seriously

People with mental health conditions do not always feel that primary care staff support them well. Whilst some people at our Vietnamese focus group felt understood by their GP, one participant told us, 'The GP doesn't have enough time to listen to our problems. I feel like they don't want people with mental health [problems]. They think we talk too much silly things, and say 'quickly, quickly'. They give medications and that's it. I feel like I don't have enough time to explain my problem...No, they don't understand.'⁴¹

In one discussion, six of eight participants were unsure whether their GP took their emotional wellbeing seriously and two disagreed that they did - people said this very much depends on the individual GP.⁴² One caller with mental health issues felt her GP was 'sarcastic'. One parent at a forum had been to their GP for their child because she had been involved in a knife incident and was suffering from panic attacks - the doctor asked, 'What do you want me to do?'⁴³

Another caller felt that both the CMHT and GP were not listening to them and talked in an unclear way about paranoia and about the GP calling them a liar.

All primary (and secondary) health care staff need to be aware of the impact of people's mental [ill] health - one person who waited a very long time at the foot clinic felt that staff there were unsympathetic to the impact on his anxiety and agoraphobia.

⁴⁰ Your Care, Your Services: Issues to Solutions: Public Forum (Jun 2015)

⁴¹ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

⁴² Building our network! Public Forum (Dec 2013)

⁴³ Your Care, Your Services: Issues to Solutions: Public Forum (Jun 2015)

Tension between mental and physical health needs

We have had three calls from people worried about physical symptoms who felt dismissed by their GP's focus on their mental health and anxiety. One of these people said that she thought racial bias was playing a role. Another person said that things were being written in her medical notes that were 'not medical' but related to her mental health and said she was a 'mad person' and felt she was being treated badly by the GP as a result - she had moved GP four times in the last few years as a result.

For Trans people, there is a unique tension between mental health needs and Trans health needs. Several survey respondents commented that being Trans is often incorrectly considered to be a mental health condition in itself, and that consequently they struggle to be taken seriously and be granted self-determination over their own body - 'being referred to the mental health service rather than a gender clinic was something I found to be disrespectful.' (Some GPs are also unaware that young patients do not need to be referred to the Gender Identity Clinic (GIC) via CAMHS.) As a result, some with mental health problems might not seek help, '[1] feel I can't speak about mental issues (which are due to being Trans), because they may withhold future treatment (common).'44



Medications

Discussions at one forum revealed that many patients do not feel aware of how to manage their conditions well with medication, and about possible side effects - the one out of eight participants who said patients were aware was referring only to children. People were not sure what counted as 'a good result' from psychiatric medication. The participants all felt GPs needed more training about the drugs and their side effects, and more communication with CMHTs about how people are getting on with their prescriptions.⁴⁵ It was suggested that pharmacists could run sessions at GP practices about this, as they do in mental health inpatient wards.

One person contacted us because they had been on medication for Post-Traumatic Stress Disorder (PTSD) for ten years and wanted to change or stop it due to side effects, but the GP was 'not listening' and said they needed to stay on it.

HWS has received a few contacts about psychiatric medication errors and mistakes - one psychiatrist prescribing the wrong medication, one medication change being missed due to the patient's GP surgery closing, and one person feeling that the GP had given her the 'wrong' medication - a foreign brand. Presumably the drug is generic but this may indicate a need for patient education.

 ⁴⁴ <u>Findings from our Trans survey (Sep 2016)</u>
⁴⁵ <u>Building our network! Public Forum (Dec 2013)</u>

Crisis care

Crisis care was much discussed during our engagement around the CQC inspection of SLaM. The clinical care provided by the psychiatric liaison team at King's A&E was described as very good and helpful by four people who had presented there. One patient said the two doctors were '*very good and very sure of themselves*', which she needed when she was unsure herself. They also explained the process well. However, a couple of parents said that some staff in A&E had thought that their child was under the influence of alcohol or drugs, as opposed to being ill. ⁴⁶

However, significant unhappiness was raised around the use of A&E for mental health crisis. Common across the accounts were the long waits to be seen. Two people found it hard to sit among those who did not have a mental health crisis, and said the environment could be confusing. One person said *'the ambulance just dropped me off at the entrance hallway, nothing else'* which was daunting. A father disliked the use of police vans to escort his daughter to A&E, and the waits there, *'I was in tears the other day, watching her being escorted out of her house into the cage of a police van - the ambulance service being too busy... I didn't realize she would still be sitting in* A&E ten hours later, still waiting for a bed.'

Suggestions for improving the experience of going to A&E for mental health problems included:

- Written information to be provided after A&E presentations outlining patient details, the process and next steps. Patients may not remember the detail of what happened.
- Light refreshments of food/water as people will arrive at A&E having not taken care of themselves [and this will only increase their unwellness].
- A separate space away from other patients.
- Option of a volunteer or professional advocate to sit with or talk to patients.
- All mental health patients to have clear discharge plans and crisis plans (circulated to family members as well), to help avoid A&E where possible.



Quality of inpatient care

Many people have highlighted positive traits in staff at Maudsley Hospital, such as empathy, attentiveness, appropriate introductions, calmness and confidence. Some families feel well-involved in their relative's care and people appreciate help with practical social matters like paying bills during their stay.

⁴⁶ Parents and Families Event! Public Forum (July 2016)

However, we have heard of problems with both staff capacity and the personalisation and coordination of care in inpatient services.

One person very unhappy with her care in the Maudsley Hospital (EC1) told us that staff had too little time to help - she was given only five minutes to talk to a doctor, who was not a good listener. She had no care coordinator, and felt there was no collaboration between staff. A separate caller who had been sectioned at the Maudsley said she had been given medication but had not seen a doctor in her several days there.

Reports from a voluntary organisation about the experiences of other Maudsley patients tell us that generic care plans are used, and they are not clear to patients. Also, a lack of staff capacity means people cannot always take full advantage of their leave, causing loss of contact with family and friends. (In another hospital this impacted on people's ability to exercise, which might also be a problem at the Maudsley).



Appropriateness and safety of inpatient and supported accommodation environments

Being admitted to hospital is obviously stressful and some people find the ward environment can make the experience scary and possibly harmful. A former Maudsley inpatient recounted her experience where she felt 'frightened' on the ward and alleged she had been attacked many times by other patients.⁴⁷ We have heard from a person who found Maudsley EC1 a scary environment, with verbal abuse and door slamming from other patients. Another said that the Maudsley Intensive Care Unit was an 'inappropriate environment' for her daughter, due to constant loud reggae music making her daughter feeling isolated as the only white person present. Another mother informed us of her son being given illegal drugs by other patients in Maudsley AL3.

Relatives of patients in Maudsley AL3 said that the inside garden was 'neglected, with dead plants and rubbish' which was interpreted this as implying the inpatients' 'life was less valued.' However, the activity room at this ward was praised as helping take the pressure off relatives and giving families a place to spend time together.⁴⁸

We also heard from a previously homeless person with mental health difficulties who found the environment in his supported accommodation (for people with mental health or substance misuse problems) very distressing. He said he was surrounded by drugs and alcohol and felt it was bad for him.

 ⁴⁷ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)
⁴⁸ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

Themes from our engagement on mental health

The Mental Health Act, Deprivation of Liberty, and restraint

Fears as an inpatient can be exacerbated by the use of restraint. One contact was upset at nurses allegedly shouting, throwing her on the bed, twisting her arms and holding her wrists tightly enough to leave bruises for two weeks.

A voluntary organisation has also told us that there is inconsistent practice on hospital wards with not all staff aware of patients' rights under the Mental Health Act. As mentioned above, a patient who had been sectioned was unhappy at being prescribed medication and not having seen a doctor. The patient unhappy with the use of restraint said that her sectioning kept being extended, but that she and her family didn't know why. Communication with patients on this matter is very important.



Discharge and ongoing support

In one forum discussion, discharge was recognised as an crucial period. It is important to look at how carers are involved at the point of discharge.⁴⁹ We have heard cases which indicate possible failings in risk assessments and in aftercare.

Discharge from hospital

During engagement around CQC inspection, a family told us that their relative with schizophrenia was inappropriately discharged from Maudsley Hospital in 2012 without them being informed. Another family said that when their son was transferred from the Maudsley to Ladywell Unit, there was little information or willingness to involve relatives.⁵⁰ Three individuals also contacted us independently about issues around their discharge from Maudsley Hospital AL3. One had not had their records sent to their GP and so could not be prescribed medication; one had had a discharge meeting without an advocate/friend present; another implied that if discharged he intended to kill himself as he was not ready to leave but was not being listened to (it appears his stay was extended).

Discharge from the Community Mental Health Team (CMHT)

A distressed and possibly suicidal person contacted us about his discharge from the CMHT in Camberwell as he had missed an appointment for which he had not had the invitation in time. He felt '*I am crying for help and no one is helping me*.' We

⁴⁹ Healthwatch Southwark one year on! Public Forum (Nov 2014)

⁵⁰ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

confirmed that he had been discharged but the team agreed to contact him for further support.

Support after discharge from hospital or the CMHT

We have heard from a voluntary organisation that many service users do not have enough support after discharge from hospital, and return on a regular basis. Some people have complained of abrupt discharge from the CMHT, lack of clarity about postdischarge support (and long waits) and time-limited interventions without any follow up.⁵¹ One person told us that after discharge from the CMHT she had been waiting a month so far for contact from the Wellbeing Hub.⁵² Support needs to be in place before discharge and stepped down gradually to ensure patients can remain stable. Those who have received support from community care nurses and the Home Treatment Team often say this is very helpful, with staff listening to them and helping with social issues.



Integration and coordination across services

Our engagement work prior to the CQC inspection of SLaM highlighted that patients find it stressful and frustrating to have to repeat information and assessments when accessing different services. More coordination across local services would help with this issue. One father told us his daughter had presented to services from St Thomas' A&E to triage wards in Lambeth, Bethlem and Bromley, to inpatient wards in Lambeth and Maudsley, to the local home treatment team - each involving a new assessment. It was confusing in terms of who to call, and highlighted fragmented and siloed working structures. We raised in our response to SLaM's Quality Accounts 2015 the lack of consistency of service across the four boroughs where SLaM operates.



Transitions from children's to adults' services

During our engagement work prior to the CQC inspection, transitions between child and adult services were consistently raised as an issue. The treatment and environment for children and adults is significantly different and there is a lot of understanding and trust to be rebuilt after transition. Relatives and patients highlighted a lack of robust handovers and became less confident in the care received as an adult.⁵³

⁵¹ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

⁵² Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

⁵³ Engagement prior to Care Quality Commission (CQC) inspection of SLaM (Aug 2015)

Themes from our engagement on mental health

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Privacy and confidentiality

Given the stigma that still surrounds mental illness, privacy and confidentiality for patients is particularly important. We have been informed of two concerns about this, with one visitor to King's College Hospital having overheard someone's mental health assessment taking place at ward level, and one woman's GP having passed information about her mental health to housing officers.



Consultation and complaints

Healthwatch aims to promote the public voice, and sometimes people do not feel they have been listened to. There has been recent widespread concern about the closure of voluntary-sector-run mental health services and day centres and their replacement with a Wellbeing Hub, as described above. Some feel that the changes were made too rapidly and without consultation, and announced in a way that would shock many vulnerable people relying on the services.

We have also heard from a person who complained to SLaM but the complaint was not accepted as it did not contain the word 'formal'; even after it was resent no response had been received within 28 days. One person told us about a contact who required advocacy support to make a complaint about their treatment in hospital - they said 'they won't take you seriously if you don't get support.'



Social causes and exacerbators of poor mental health

Whilst we are not able to delve deeply into the social and root causes of mental ill health, the public are concerned that these are addressed - we have heard particularly about the impact of housing problems, difficulties with finances and benefits, the experiences of refugees, and digital exclusion.⁵⁴ Several young people also referred to declining mental health around exam time because '*Very ambitious people take getting good grades seriously and are stressed*.'⁵⁵

Failure to resolve social issues can mean that mental health treatment is not as successful as it could be, and mental health services sometimes fail in this regard. One pastor told us about a member of their congregation who was in hospital but felt that they were not being listened to, because fundamental issues around their housing situation and need for advocacy were not being addressed. As a result their mental health was not improving. Another person was in conversation with the CMHT and GP but needed more help at home (being a wheelchair user), and to deal with paperwork and

⁵⁴ Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties (Oct 2015)

⁵⁵ My Voice Counts! Public Forum (April 2016); Young Voices on Mental Health (Nov 2016)

£15,000 of debt when they were in a 'muddled' state. They were not able to attend an advice centre due to being housebound.

Some root causes of mental ill health can be addressed within the health and social care system itself:

- Discussion at a focus group highlighted that carers' health and wellbeing can suffer greatly due to the overwhelming pressure of caring, and lack of time.⁵⁶ We also heard from young carers who felt, poignantly, that they did not want to burden their families with their own mental health concerns, 'I could talk to them but... I wouldn't want to put them through it, because I know it can be hard to know about someone else's mental health troubles'; 'I wouldn't want to bother them because they have their own problems.' ⁵⁷
- We have heard from three people whose poor experiences in maternity and obstetric care had led to mental health deterioration. This is a pertinent issue especially given the increased focus on perinatal mental health.
- Trans people told us of the impact that struggles to access gender identity treatments had on their mental health, '*The rates of suicide of Trans people who aren't able to transition are so high.*' One person described waiting a very long time for their first GIC appointment, which then did not involve a blood test or hormone prescription despite psychiatric recommendation. During this period the person was self-medicating with unsafe hormones, and had '*disintegrating mental health*' and suicide attempts. The emotional impacts of exclusion, and difficulty trusting medical professionals, were apparent throughout the survey responses.⁵⁸
- A forum attendee questioned how much education about mental health and drugs was provided in schools.⁵⁹

⁵⁶ Social support for carers focus group (Jan 2015)

⁵⁷ Young Voices on Mental Health (Nov 2016)

⁵⁸ Findings from our Trans survey (Sep 2016)

⁵⁹ "Everyone is treated Equally" Public Forum (Sep 2015)