

# Experiences of Mental Health Services 2018



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Supporting  
**NHS 70**

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Milton Keynes

# Summary of feedback

## Themes emerging through service user feedback



In 2018 we collected feedback from service users which covered experiences of Milton Keynes' main mental health services and providers: Central North West London NHS Trust (CNWL), CAMHS, GPs, Youth Information Service (YiS), MK Hospital, MK Council, Public Health and the Millton Keynes Clinical Commissioning Group (MKCCG).

Outside of our focused evidence gathering around the Primary Care Plus (PCP) pilot scheme which is accessed through GP services, we collected a further 44 pieces of feedback about mental health services and support.

While the people we spoke to about PCP were very positive about their experience of the service, on the whole, service user feedback revealed that many people continue to struggle to access appropriate or timely mental health support.

The themes that emerged from this feedback are: communication between patients and staff can be improved, access to services presents difficulties, and there is a need for more holistic support.

We also heard that relationships between the service user and their treatment professionals needed to be built on trust. It is difficult to develop this when staff changes can mean service users are seeing someone different at each appointment. Being discharged from services is not always seen as a good thing by service users as they feel the time it takes to re-enter support when needed may mean that they reach crisis point before getting the help needed.



# What's the problem?

## Timely and appropriate support

Timely and appropriate support is a big issue to both service users and their carers. People told us that unsupported mild to moderate issues are escalating to crisis point and resulting in far worse outcomes for patients.

Although the Primary Care Plus (PCP) service has gone some way to alleviating some of the access issues for those with mild to moderate mental ill health, the service is still in its infancy and has not yet rolled out to all GP practices in Milton Keynes. Patients are unable to register with a practice that carries the service if they do not live within the practice boundaries.

The waiting lists for Improving Access to Psychological Therapies (IAPT) services are listed on the CNWL website as being up to 18 weeks. However, people have told us that whilst they are being offered the phone triage service within this time, actual treatment may not be available until 6 to 8 months later.

One person shared with us that they had a phone call through IAPT offering them a move up the waiting list, as their particular case was quite complex. However, they were asked to consent to their sessions being video taped for training purposes. They declined the offer as the caller was unable to give details of who would see the recordings, or how long it would be used.

The CAMHS team can refer young people to the Youth Information Service (YiS) if they don't meet the criteria threshold or who may benefit from intermediate support while on the waiting list for CAMHS. YiS is a self-funded charity who struggle to meet the high demand, with no funding from local Health or Local Authority commissioning. The YiS waiting list has been closed since October 2018.

# Service User Voice

" My GP advised to make use of the self referral form when I first started taking anti depressants. I got a telephone appointment for an assessment quite quickly and the staff I spoke to was really friendly and seemed helpful.

I was advised about a 4-6 months waiting list. I asked if there was anything else I could do, except for going private, as I was feeling extremely low and suicidal at the time - I was told no, and to call Samaritans or a friend in those moments. This wasn't of any help for me, as I'm not in a position where I would feel comfortable speaking to any of my friends nor family, and I also hate speaking on the phone to strangers, as this makes my anxiety worse.

As of now I am still waiting for a placement, it has been over 8 months since I first had that call and I don't know what to do. I feel helpless and anxious every day and the feeling of not knowing if I will ever get help is leaving me very low and I am struggling with my day to day life more and more. I can't find another way other than calling to contact the service and I've been too anxious to do so to check on my status on the waiting list." - Service User feedback, Email

"It is extremely difficult to get quick therapeutic counselling services unless you can pay for them (which is extremely expensive). The NHS needs to be able to retain staff better to improve this." - Service user feedback, HWMK website

"I have autism and I experience mental ill health. There is no point of contact for me when I am in crisis. I need somebody who I can build a relationship with, who I can turn to when I need them. Instead I get offered support in 6 months time with a stranger" - Service user feedback - Outreach

"My relative was triaged for IAPT within the last couple of weeks and was told there was an 8 month wait." - Carer feedback, HWMK website

# Service User Voice

"Whilst I was working full time in a job that was adding to, if not creating a lot of my stress and anxiety, it was difficult (near impossible) to access support services for help when I initially realised I may have problems coping. Taking time off for appointments, groups and wellness activities etc was not really possible without my employer becoming aware of my situation.

The thought of my employer and colleagues knowing, judging, disciplining, singling me out, thinking I was not capable of doing my job was terrifying and stopped me from even approaching them for any understanding.

As time when my anxiety and depression took a stronger hold and became overwhelming resulting in my taking intermittent time off, not being able to face the day and hiding in bed. Ultimately I was questioned on my time off which exacerbated the situation.

At work one day I collapsed and this brought things to a head. The diagnosis was malnutrition, stress, and possible alcohol related symptoms. My employers decided that it was "best" that I stay at home until further tests were carried out. This time off led to my isolation, boredom, loss of identity (without work who was I?), increased anxiety, depression, self medicating using alcohol to block everything out and ultimately not wake up.

Had I felt able to safely say something to someone earlier, ask for help and get speedy access to much needed help and support, I probably would not have lost over 3 years of my life sinking deeper until I hit bottom (close to death) before finding the courage (or being desperate enough) to ask for help.

I would suggest, request and plead that services and support are made available "out of hours" even 24 hours a day if possible - desperation does not clock in and out or wait until you can get an appointment."

- Service User feedback, HWMK website

# What's the problem?

## Who can help me?

An issue that a number of people have told us about while speaking to both professionals and service users, is that the criteria for accessing services is perceived to vary depending on who triages the referral, and information on what services are available is not easily found.

There has been some discussion about developing a mental health service directory in both the voluntary and professional sectors for some time, as the information on the Council, the MKCCG, and CNWL websites is incomplete and not joined up.

People with Autism who are also experiencing mental ill health are experiencing a particular gap in services and struggle when professionals are unable to provide coherent pathways or advice.

Service users have told us that, while GPs tend to be their first port of call, they did not always know what was available. In a number of cases, gaps in the GPs own knowledge and understanding meant that the patient felt they did not receive appropriate treatment.

Another barrier to treatment that people have talked to us about is the loss of community advocates. We have heard from people who had staff from the previous advocacy provider attend appointments with them have been informed that this service is no longer available. We researched this and found that the service offered by the previous provider was not a contracted service, but something delivered 'above and beyond' contract, not within the scope of commissioning. This has created a gap in support services, which may prevent people accessing the mental health support that is available to them.

# Service User Voice

"There is a lack of communication between departments. As a result I am required to re-tell my story my story over and over again. This is particularly traumatic when it comes to mental health. The information I give should be recorded accurately and should be read by my doctors before an appointment" - Service user feedback, HWMK Website

"One of the Drs in particular is very prescription happy when it comes to anti-depressants. Even when I told them I wasn't depressed and didn't want anti-depressants, I came away with a prescription for them." - Service user feedback, Outreach

"I used to have someone from PoHwer come with me to talk to the Council about social care. Now there is noone - seAp don't do it. I can get angry and the council won't help." - Service user feedback, HWMK Website

"I have autism and experience mental ill health. I was offered very little support during my pregnancy. I didn't fit the specific criteria so I was offered no mental health support. Instead, I was passed around from one department to the next. Police and Health professionals need more training surrounding autism and mental health." - Service user feedback, Outreach

"I called the new advocacy provider to ask for someone to attend an appointment with me and they told me I was no longer eligible for support. Why? Nothing changed for me - I still have the same problems!" - Service user feedback, Email

"Milton Keynes has lost the community advocacy support. SeAp, the new providers are unable to provide this - I have seen this patient today and he said SeAp contacted him as my colleague had spoken with them yesterday. They can't help him but are referring him on to an ex-veterans charity who may be able to help with advocacy. There are now a lot of people struggling to access support at health, social care or other appointments." - Support Worker feedback, Email

# Service User Voice

"When I was 17 I had a counsellor at CAMHS who made transphobic comments, saying "you'd never be a real man" and that doctors would rather operate on someone else than me." Service User feedback, Healthwatch LGBTQ+ project

"My friend did not have a good experience with CAMHS after seeing them to help with self-harm and suicidal thoughts, she said she had 6 sessions done together with mum and she sat in the room but it was more a conversation between mum and counsellor about her. She did not feel she could speak up and she was treated as a case of anxiety and given some CBT tools. She has returned to YiS as she felt she needed better support than CAMHS could offer and felt listened to and valued here." - Friend of Service User feedback, Outreach

"I have been referred from one service to another. I don't fit the specific criteria for certain services, and there is no-one to fill the gaps. I have been left with no support. I was referred to Primary Care Plus but despite constant calls to them, they never got back to me. I was told by my psychiatrist that I would get therapy but it never happened - professionals tell you one thing, and set the expectations, but then it is never delivered. I was also told that I would be suitable for MBT (an Art Based Therapy). However, despite being suitable this wasn't offered to me because the rest of the group was made up of girls. I was denied therapy that could have helped, just because I was male." - Service User feedback, Outreach

"I experience Mental Ill Health amongst other problems, and I never know where to go when something happens (e.g. when should I call 999, when should I go to A&E or urgent care, or when I should go to my Pharmacy or call 111). I cannot find any clear, simple information." - Service User feedback, HWMK website



# What's the Problem?

## Medication and Medicine Reviews

People have told us they are concerned that they are not having regular medicine reviews.

According to the Thames Valley Strategic Clinical Network, people living with severe mental illness face one of the greatest health inequality gaps in the UK. In the Thames Valley, life-expectancy is reduced by an average of 15-20 years mainly due to preventable physical illness.

A combination of factors including the side effects of anti-psychotic medication, lifestyle, diagnostic overshadowing and difficulties accessing mainstream health services can all contribute to the reduced life expectancy.

People with Autism or Learning Disabilities alongside mental ill health are also at a greater risk of developing gastric and bowel cancers.

The long term health of Service Users is placed in jeopardy because they are struggling to get an appointment with their GP, or have bad experiences once they do get an appointment. Service users have told us of being banned from their GP practice due to the challenging behaviours that are part of their illness.

**"Recently, when I explained to my GP that I was having some violent thoughts, he banned me from the surgery. I felt like they were just looking for an excuse to get rid of me because I am a difficult patient. They just want to discharge me as soon as possible, and then there's no support available. Every time a doctor leaves, I have to start again on my 'Care Plan', so it never achieves anything. My medication has not been reviewed in years, and I am worried about the side effects" - Service User feedback, Outreach**

# Service User Voice

"I suffer from mental health problems. Despite trying to make appointments, there is nobody at my GP who will talk to me about mental health, so can't get help even when I'm asking for it. I have been on the same medication for a long time. It is now causing problems, my doctor is refusing to review it. There are also no posters about mental health at my GP and no signposting available through the doctors." - Service User feedback, HWMK Website

"It is no good putting someone in crisis on a 6 month waiting list. When medication is given, it is never reviewed. I also never get to see the same doctor twice, this means nothing ever gets sorted." - Service User feedback, HWMK Website

"I went to my GP to discuss my mental health. I was in a very bad state (panic attacks crying etc.). The queue was very long, and it was very busy. I asked the receptionist if I could sit somewhere quieter whilst I was waiting to get an appointment. She put me in the 'broom cupboard'. They then forgot about me, so by the time I came out to get in my place in the queue (near the front) they told me that there were no appointments left that day. It is vital that doctors surgeries have quiet place to wait for people with bad mental health. Once I had seen the doctor he told me to get another appointment within a week, but when I tried, the nearest was 1 month away." - Service User feedback, Outreach

"I am currently experiencing mental ill health, and have been for a long time. There is nobody at my GP who specialises in it. This means they never understand me when I go to them. Every GP should have a trained Mental Health specialist. Due to my mental ill health, I find it very stressful waiting in long queues at the GP to get an appointment, if I try and phone to make an appointment, they never pick up." - Service User feedback, HWMK Website

# What would help?

## Healthwatch Milton Keynes recommends:

- \* Accessible information about mental health conditions and treatments available locally, the criteria and pathways of care, as well as what other options are available to empower service users and their carers to make informed choices.
- \* The local system reviews, with service users and their carers, its use of the Care Plan Approach (CPA) with a view to ensuring a consistency in how these are approach and used with the key groups and how they are implemented across Primary Care Networks.
- \* More support is provided to Health Professionals working with people with challenging behaviours as this could help to reduce the health inequalities experienced by this group

## Service Users suggested:

**If all the support available was joined up, and the pathway clearly signposted to all, it would save time, money and resources. The internet should not be relied upon; many who need to be informed do not or can not use IT.**

**Having a Sponsor to build a rapport and share problems with would help save on the number of assessments, interviews, meetings with a variety of parties to be put on various waiting lists. This would also help to build a support plan that would ideally be aligned between the services.**

**Milton Keynes should be proud of the initiatives it puts in place to help its citizens so why not shout about it. A good number of people using these services like to become involved and often volunteer, equating to more staff/resource in the long run.**

# healthwatch

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