Mental Health

A local perspective by Healthwatch Croydon

August 2016

healthwatch
Croydon

"How people feel is not an elusive or abstract concept.

It is a significant public health indicator…

…as significant as rates of smoking, obesity and physical activity."

Department of Health, 2001

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Executive Summary

In Croydon 1 in 6 adults (67,000 people) has a mental health condition at any one time, this is costly to the borough and wider society (Annual Public Health Report 2015). Changes in the population size and structure of Croydon mean that the numbers experiencing mental health conditions is likely to rise, which means the numbers seeking help may also rise.

The Experience of Mental Health Services

Healthwatch is the official 'patient voice' across England. Established as part of the Health and Social Care Act 2012, we champion the views and experiences of health and social care service users, and ensure that they are heard by those who plan, deliver and scrutinise services.

Healthwatch Croydon, the local consumer champion, has researched the experience of mental health services.

Key Findings

Engaging with 90 local adults (including carers and family members) and with an additional 654 items of feedback on our database, we found that:

Service Accessibility

Residents tell us about waiting lists that exceed 18 months, and in one case, a family said they had exceeded 2 years, and were still waiting.

We said:

- *With additional funding and service redesign, it is anticipated that waiting lists will have come down during 2016/17. A wait exceeding 2 years is likely due to lack of integration, or failure of a particular pathway. Service users, families and carers should be able to 'raise the alarm' on clearly excessive waiting times.*

User Involvement

The phrase 'nobody listens' is one we have heard often. Many residents tell us they are not involved in decisions about them, or aware of what's in their care plan. People also say 'I feel like a square peg in a round hole', with many residents expressing lack of aftercare, with limited or sometimes no options.

We said:

- *Ideally, service users, families and carers will be consulted when drafting and updating care plans, and have recourse to influence, or challenge decisions.*
- *GPs and mental health professionals should listen clearly to patients before making referrals to services which may not be necessary or appropriate.*

Carer Involvement

We have heard that residents have been sectioned, and admitted to hospitals that are '2 hours away', while one family said they were 'offered a specialist bed in Scotland'. Next of kin, and main carers, tell us that they have been denied information, with providers citing confidentiality.

We said:

- *It may be assumed that the greater the distance, the less likely that family and carers will be able to visit often, with potential implications for the patient's wellbeing and recovery. As a result, this may increase the cost of treatment as a whole. More patients should be admitted locally, or if not, as close to their home as possible.*
- *It is clear that there is a regional and national under-supply of specialist beds. Given that increasing capacity will take time, resource, and collaborative planning, it may be necessary to look at practical alternatives in the interim.*
- *A main carer comments that she was able to get information from SLaM in Lambeth, but not counterparts in Croydon. Assuming that information governance protocols are trustwide, we hope that there will be regional consistency in sharing information with family and carers, and if not, this is documented and explained.*

Support

Residents tell us that calls often go unanswered, with messages not being responded to timely, if at all, by Social Workers in particular.

We said:

- *Telephones should be answered more often, and when not, messages may be left that are responded to.*

Medication

It has been commented many times that clinicians can be 'too quick to reach for the medication' and patients are concerned about side effects.

We said:

- *One patient told us that her joints had become swollen since taking medication, making it difficult to walk in particular. Although a documented side effect, the psychiatrist was 'dismissive' of her concerns. Patients should be respected when reporting side effects which cause anxiety, discomfort and potential harm.*

What Next?
It is acknowledged that the health and social care system alone cannot solve the problem – housing, education and employment, among other factors, must also play a central role. Healthwatch Croydon, and those tasked with commissioning and delivering services, must continue to work towards increasing access to mental health services, strengthening partnership working and integration of physical and mental health, promoting mental wellbeing, and improving the lives of those with mental health conditions.

1. What is Mental Health and Wellbeing?

Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices. Mental health and wellbeing is important at every stage of life, from childhood and adolescence to adulthood. Over the course of your life, if you experience mental health problems, your thinking, mood, and behaviour could be affected.

2. What Factors Influence Mental Wellbeing Locally?

Population characteristics such as size, age, ethnic make-up and levels of physical health are important factors affecting mental health in any community. Changes in the population size and structure of Croydon mean that the numbers experiencing mental health conditions is likely to rise, which means the numbers seeking help may also rise.

It is very difficult to predict increased demand accurately. However, using the best model currently available, local information has been used to make projections of the impact of these changes in terms of mental health.

In Croydon, the population has grown more quickly in the last ten years than was at first thought, and it is thought that some of this is due to internal and international migration (although data on migration is very unreliable). Migration can have positive and negative effects on mental health. Being reunited with family members after time apart can improve mental health, however, asylum seekers and refugees are often fleeing persecution, violence, disaster or disease and therefore have a greater risk of serious mental health problems.

There is also a relationship with ethnicity and mental health. For example, people from black and minority ethnic populations have a three-fold increased risk of psychosis. The relationship is complex. Ethnicity interacts with other characteristics and differences in the levels and prevalence of mental health across ethnic groups are due to a number of factors, including socio-economic deprivation, diagnostic bias, racism and variation in access to culturally appropriate services.

Another way in which Croydon is changing is that it is becoming increasingly deprived. Deprivation is strongly linked to some areas of mental health (such as schizophrenia and addictive behaviours). Projections made are likely to be an underestimate of demand for mental health services. (Croydon Joint Strategic Needs Assessment, 2013)

3. Mental Health Needs of Specific Local Groups

People from the following groups are at particular risk of developing mental health conditions. According to Croydon's Joint Strategic Needs Assessment, 2013:

3.1 Carers

There are an estimated 6.4 million people in the UK providing unpaid care and support to ill, frail and disabled friends and family members.

Large numbers of children and young people act as carers to their family members, a disproportionately high number of carers (10%) are from Black and Minority Ethnic (BME) communities. Croydon has about 30,000 carers, 5,000 of those providing more than 50 hours of care each week. Recent research shows that between 75% and 85% of carers

report mental health problems, predominantly depression, anxiety and stress. (Carers UK, 2011)

3.2 Offenders and Ex-offenders

Over 90% of prisoners had one or more mental health problem including psychosis, neurosis, personality disorder, hazardous drinking, drug dependence.

Dual diagnosis, that is a prisoner with a mental health problem AND a drug or alcohol dependency, is common; approximately 1 in 10 are affected by a severe mental illness. Prisoners on remand show higher rates of mental disorder than convicted prisoners. Women show higher rates of neurotic disorder than men. (Lord Bradley, 2011)

Around a third of prisoners have no accommodation on their release and a considerable proportion of people in the homeless population also have offending histories. In 2010 48% of St Mungo's clients nationally were ex-offenders. (Centre for Mental Health, 2011)

3.3 Veterans

Every year, approximately 1 person in every 1,000 regular service personnel is discharged for reasons related to mental wellbeing. Veterans' mental health has become more recognised in recent years and as a result much more is known about the subject, contributing to a reduction of stigma associated with poor mental health.

Research indicates that mental health problems are most likely to be experienced by a specific group of young single men who leave the services early. These young men may have poor social skills, limited basic education, dyslexia or dyscalculia and difficulty in adjusting to change. Because they have left the services early, they are entitled to receive considerably less support on discharge. Veterans are reported to comprise approximately 3.5% of the total prison population. (Centre for Mental Health, 2010)

The most common diagnosis is for Post-Traumatic Stress Disorder (PTSD). The veterans' mental health charity Combat Stress has reported that between 2005 and 2009, 75% of their clients (a total of 608 people) had a diagnosis of PTSD, often in association with other mental health needs.

3.4 Domestic Violence and Abuse

Evidence of the prevalence of domestic violence shows that one in four women will be affected by domestic violence in their lifetime; domestic violence accounts for 16% of all violent crime, rising to 24% in certain local authority areas. The report from Safer Partnership on Domestic Violence in Croydon shows it is an all-pervasive and continuing problem. During the 12 month period from July 2011 to June 2012, there were 5,955 allegations. Of these 30% were of serious types of violence.

The most dangerous age is from 20 through to early thirties with females most at risk, in particular they account for 83% of victims where there was serious violence.

The demands on the limited services available are of concern. Domestic violence is the major cause of injury to women under 60 years of age and a major risk factor for psychiatric disorders, chronic physical conditions and substance abuse. Women experiencing domestic violence are at greater risk of depression, PTSD, substance abuse, anxiety, insomnia, suicidality and social dysfunction as well as experiencing greater physical ill health.

At least 750,000 children a year witness domestic violence. Children observing domestic violence can experience a range of long term effects, including physical damage, behavioural problems, mental health problems, exposure to multiple adversities, violence, mental health, substance abuse, developmental delay, academic problems leading to diminished educational attainment, and lower take up of healthcare such as risk of under immunisation.

There is a strong link between child physical abuse and domestic violence, with estimates ranging between 30% and 66% of households where domestic violence occurs. (Department of Health, 2010)

3.5 Trafficked People

Adult victims of trafficking are trafficked all over the world for little or no money – including to and within the UK. They can be forced to work in the sex trade, domestic service, forced labour, criminal activity or have their organs removed to be sold.
A report on trafficked women in support settings found that the overwhelming majority experienced physical violence and/or sexual abuse while trafficked; they reported very high levels of symptoms indicative of PTSD, of suicidal thoughts and of depression. Forced marriage, within and outside the UK, can be considered to be a form of trafficking. (Department of Health, 2010)

3.6 Gypsies and Travellers

The risk of depression and anxiety is nearly three times higher than average and the risk of depression is twice as great. Women in gypsy and traveller communities are twice as likely to suffer mental health problems. (Department of Health, 2011)

3.7 Problem Gambling

Problem gambling – that is, gambling to the extent that it impacts on the person's health and family and social relationships, can be particularly common in people who have depression or anxiety disorder. (Royal College of Psychiatrists, 2011)

3.8 Substance Abuse

Research shows that substance misuse may cause or increase symptoms of mental illness. On the other hand, mental illness may lead someone to abuse substances. Depression, anxiety and schizophrenia are more likely to be linked to substance misuse. The drug use can stop people making a full recovery. It is also more likely to lead them to becoming unwell again or to have to be re-admitted to hospital. (Royal College of Psychiatrists, 2012)

3.9 Adult Survivors of Childhood Abuse

Exposure to severe adversity in childhood and adolescence has been shown to have an impact on attainment, aspirations and emotional and mental wellbeing in adulthood. (Harvard University, 2012)

In 2012 an estimated 25,748 adults in Croydon aged 18-64 years were predicted to be survivors of childhood sexual abuse. This figure is estimated to increase by 10% to 28,399 by 2030.

3.10 Lone Parents

Research published in 2006 showed that there is a higher rate of mental disorder of all types among lone parents than for adults living as a couple with children. Lone parents are almost three times more likely than couples with children to have more serious functional psychoses (this includes disorders such as schizophrenia and bipolar affective disorder) or drug dependence, and are nearly twice as likely as couples with children to have a neurotic disorder. (Gould, 2006). Croydon has an estimated 58,000 people living in lone parent families, roughly 26,000 of whom are children. (ONS, 2010)

3.11 Living Alone

People living on their own are more likely to have worse mental health. This group is 1.6 times as likely to experience a depressive episode and is much more likely to have other kinds of mental health problems, including obsessive compulsive disorder and panic disorders. Some evidence shows that it is the transition to solo living that has the closest association with poor mental health. This is partly because relationship breakdown often leads to solo living.

Many older people living alone experience poor mental health as the result of loneliness and lack of contact with the community. People living alone over the age of 65 are twice as likely as other groups to spend more than 21 hours a day alone. (Bennett & Dixon, 2006) In 2010, Croydon had an estimated 43,000 people living alone and approximately 17,510 were aged 65 years and over. (POPPI, 2012 - 2030)

4. The Experience of Local People

As the borough's 'official patient voice', Healthwatch Croydon has listened attentively to local people's experiences of mental health services, engaging with 90 local adults in total (this includes carers and family members). Additionally, our database contains 654 items of feedback on mental health services, gathered from a range of sources across Croydon.

4.1 Case Study - 'Is it Really So Hard for People to Listen?'

While visiting the local branch of the MS Society on 21st January 2016, Healthwatch Croydon met Anthony, a visibly 'angry and frustrated' man.

Anthony stepped forward as a case study as he feels that the general public and medical profession alike simply 'don't understand mental health'. His story resonates with much of the collective experience on our database, so we have given it some prominence.

By virtue of having MS (Multiple Sclerosis), Anthony has a mental health problem – which has not been recognised. If there is no recognition, he wonders 'how can people be helped, or signposted to services which may assist'? He is disheartened that nobody is 'getting to grips or willing to understand' and this lack of awareness and support is widespread and affects many.

When is Medication Appropriate? Anthony feels that the government's talk of mental health 'being placed on the same footing as physical health' is a mere gesture and their heart, not to mention funding, is not behind a real change.

He suspects that it's 'all too easy for GPs to reach for the prescription pad', where perhaps other treatments and therapies may be considered. Recently he experienced this

himself – having to decline the offer of anti-depressants from his doctor. Talking therapy would have been preferred.

Perpetual Stigma. Walking with a stick, Anthony can find it difficult to get around, yet people say 'if you have MS, where's your wheelchair then'? He has even experienced this attitude at the MS Society itself, where he had to justify his attendance.

Some of these experiences leave him 'feeling irate and agitated', but not being understood or listened to, constantly, is not easy to deal with.

Anthony has befriended somebody he met at the MS Society – she has an 'associated condition' that mimics the symptoms of MS. While accompanying her to hospital she urges the staff to talk to him also as he can provide insight, but in every instance they cite confidentiality and refuse. He just wants to offer advice, which may help out, but he is always 'cut off in mid-sentence and never able to explain'. This goes 'on and on'.

This is the whole problem – Anthony is not being listened to, whether at the hospital, or the GP. He 'just wants someone to confirm what he is feeling – some kind of proof of his mental health condition that he can take back to his family'. Because of the lack of understanding he has taken to self-medicating, which has done him 'the world of good'. He says people have good reason to be weary of anti-depressants and other psychotic drugs, some people are given additional drugs 'merely to combat side effects'! Is it really so hard for people to listen?

4.2 Residents at the Rethink Support Group

On 16th March 2016 Healthwatch Croydon visited the local branch of the Rethink Support Group. A well-established charity, the group 'gives a voice to people affected by severe mental illness', helping more than 48,000 people every year nationally. We listened to local families experiences, which include:

4.2.1 – "The Medication is Hardly a Long Term Solution"

My son is 24 years old and has Attention Deficit Hyperactivity Disorder (ADHD). He has been depressed for almost 3 years, and has been on medication for much of that time. He is suicidal, gets anxious and needs help with counselling - he really needs someone to talk to, understand his problems and help. All the help given so far has been medication, that is 'hardly a long-term solution'.

4.2.2 – "My Son is Socially Isolated"

My son has episodes, on one occasion he threatened to kill himself and me. During one episode, we waited 2 hours for a psychiatric nurse - she referred us to Bethlem and they referred us to the Purley Way Resource Centre. There are no drugs for my son's condition and he cannot get help. He was referred to a peer support project, but could not stay as no-one could tolerate him – the organiser did not understand. He does not behave, but that is his condition. He is socially isolated, no-one wants to know him. He loves people and they cannot tolerate him.

> "The medication is hardly a long-term solution."
>
> 4.2.1

4.2.3 – “At Least a Year’s Wait to Access Treatment”
Our daughter has a borderline mental disorder - we referred her to psychological therapies and have to wait ‘at least a year’ to access treatment, and it may much longer than that. In the meantime she’s been referred back to our GP and medicated on anti-depressants. It’s impacted family life. She cannot access benefits (doesn’t understand the system), she had filled in a form unsatisfactorily, the phonecall from the office made her panic – she went into a state of psychosis after the call. I had to be calm. She has since hidden in her room, with no friends, just me to support her. Early intervention did not happen. We ‘waited and waited’ to get her seen and then, just as she was referred, she turned 18 and could not gain the services as she was not a child.

4.2.4 – “Sectioned, and Taken to a Private Hospital Two Hours Away”
My friend’s son has schizophenia and stopped having his depot medication. He went to Tamworth Road (Mental Health Resource Centre) and was told that they would visit him at home. After many calls, their son was still not sleeping and gradually getting worse. Two weeks before Christmas he was sectioned - no places at Bethlem so he was taken to a private hospital two hours away. This could have been avoided had Tamworth Road responded with a solution more swiftly.

4.2.5 – “We Cannot Help You Any Further”
There are 15 psychotherapists who offer specialist services for my personality disorder, but they are all private. Could these be publically available? I occasionally use drugs as they can ease my situation (little else does), but as a result I have been denied Cognitive Behavioural Therapy (CBT) services which may help. I received a letter from Tamworth Road saying “we cannot help you any further, so are closing the matter”. This is not good, as I can’t go anywhere in public, as long as I have this disorder.

4.2.6 – “There is No Aftercare”
There is no aftercare. My son hasn’t had any psychological therapies in hospital after being sectioned. He has lived in supported housing for eight years now (he was only supposed to be there for 2 years). To move to independence he needs to learn life skills, but the support is extremely limited. There’s just one floating member of staff to cover many blocks. On Saturday the electricity went off, it’s now Wednesday and still not restored - this is a house of vunerable adults who would respond badly and not understand fully why the power is not working. The electricity cut out has happened before. Three weeks ago in the house, two patients became violent and have since been evicted (they are now on the streets). My son has locked himself in his room for safety. He has run up ‘huge bills’, is in a psychotic state and believes people are stealing his money. We feel that the mental health care co-ordinator is not working with council contacts.

4.2.7 – “It Did Not Happen”
The mental health service requested sectioning of our daughter, on the agreement that she would have psychological talking therapies (this was promised to us). It did not happen. She spent 3 months in Bethlem and came out dosed up with no therapies. I had a carer’s assessment, but since my daughter lives seperately from me, I was classed as not compliant. Even though I am her primary carer, I am not informed of any changes.

> **“My doctor's professionalism shines through.”**
>
> 4.3.4

4.2.8 – "Having to Tell and Re-Tell the History of my Daughter"
At Tamworth Road I'm always having to 'tell and re-tell' the history of my daughter. The psychiatrist said that he had read the notes but this never happens, and I never see the same doctor twice. As for medication, it would be much easier if I could collect it locally in Purley, but no, I have to travel miles and miles, and get it from the resource centre (I am 90). She's on a medication for schizophrenia, it requires a mandatory blood test and someone has to collect the testing materials and take them to the GP. If blood levels are not correct it can be fatal. If the medication stops, my daughter will be hospitalised.

4.2.9 – "Why Not Share Information With Me – I'm His Carer!"
My son was in a catatonic state at Tamworth Road, I sat down and spoke to him and found out he hadn't been assessed. The health professionals said 'we cannot force treatment on him without his consent' but he is catatonic (in deep psychosis). He was later sectioned and spent a couple of months at Lambeth Hospital. The discharge plan was decent, but it didn't include the psychological therapies we were promised. South London and Maudsley NHS Foundation Trust (SLaM) in Lambeth did communicate with us about our son's care, but SLaM in Croydon would not share information. Why not, I am his carer?

4.2.10 – "No-one Called Back!"
People with schizophrenia are considered adults in terms of confidentiality, but they are really vulnerable adults and should be treated as such. I was concerned about my son's paranoia and contacted the Maudsley. The duty social worker said they would get somebody to call us, but no-one called back! A psychiatrist at the Maudsley said "if he wants to come and see me he can", but he is not well so how is he going to do this? They have a problem with confidentiality in Croydon, so you do not know information about your children, but you can get all the information you need when your child is in similar services in Lambeth.

4.3 Other Feedback

Healthwatch Croydon has met and engaged with many service users, carers and family members across the borough. Varying experiences include:

4.3.1 – "Top Grade Service and Care!"
I suffer acute mental issues and have alcohol and substance abuse problems, all of which causing me problems at work and at home. The GPs at Parkside Medical Centre have been superb throughout and I can't thank them enough for the help, support, advice and sympathetic and genuinely concerned attitude.

4.3.2 – "Waiting More Than 2 Years for CAMHS"
We've been waiting almost 2 years for a Child and Adolescent Mental Health Services (CAMHS) appointment. We were referred by both the school and education physiologist and have heard nothing back in almost 2 years. I have been told 1 and a half years should be the maximum wait.

> "I have to tell and re-tell my daughter's history."
>
> **4.2.8**

4.3.3 – "A Waste of Transport"
I'm a support worker and one of the things we have become aware of whilst working with clients is that some with either mental health issues, memory problems, anxiety or learning difficulties can be very reluctant to go on patient transport when it comes to pick them up. Often because they have forgotten, are very anxious, or don't know the person who comes to get them. This is a waste of the transport's time, but also we have found on occasions, has meant that people don't get the treatment that they need and it can make their health conditions worse. Also, if it happens a couple of times then they are not given any more appointments. We have on occasions gone with someone or agreed to meet them at the hospital so that they have someone with them, but it is rarely possible that we can do this as staff are always working at capacity.

4.3.4 – "My Doctor's Professionalism Shines Through"
I suppose it's the sign of a good GP that it's hard to get appointments at short notice, but in the case of my doctor, I don't mind. I suffer from mental health issues and, over the course of ten years, have found my doctor to be insightful and understanding. Not that they always give me what I want, but their decisions have, I know, always been best for my wellbeing. The other thing I'd like to say is that this doctor seems to remember me from one appointment to the next, and this has helped me to trust their diagnoses and judgements. I think this is a great practice... my doctor's professionalism shines through.

4.3.5 – "To Make an Appointment I Have to Stay Up All Night"
For the last month at least I have been really ill with chest and ear infections, but it didn't even occur to me to try to get an appointment because it's so hard to get one. So I just tried to battle through and put up with it hoping it would all go away. You have to ring at exactly 8am in the morning to even have a chance of getting an appointment the next day, no matter how ill you are. This is very difficult for me to do, I have a severe mental health problem (schizophrenia and PTSD) am on strong medication and part of the problem I wanted to see the GP for is my sleeping disorder. I just can't guarantee I will even be awake at that time, so to make an appointment I have to stay up all night, which I did today (and tried to do yesterday) and rang at 8.30am because that used to be the time to ring at, but no, I could not get an appointment for this week. I had already called at 10am yesterday and managed to get an appointment for a week's time, so I guess I will just have to go to that. On one occasion I had to have my psychiatric nurse ring up to get an appointment for me – she 'spoke to them firmly' and magically enough they found a doctor for me and I got a prescription that day, so I know it's possible. I have cried down the phone to reception and been completely suicidal and still no joy of an appointment. I will have to phone my psychiatric team and ask them for advice on what to do next.

4.3.6 – "What Gives Them the Right to Close the Door on Me?"
I've recently ended a long period of homelessness. I suffer from paranoia (hear voices constantly) and had been sleeping rough – it's not safe as drug dealers frequent the area and I often hear bad things happening. I was getting no support at all from the mental health team, and they weren't communicating with the agency that signposted me to sheltered accommodation. What gives them the right to 'close the door on me', and leave me in a very vulnerable situation?

"Top grade service and care at Parkside!"

4.3.1

4.4 Members at the Hear Us Service User Group

Hear Us is Croydon's Mental Health Service User Group which acts as a co-ordinating body to facilitate, and ensure service user involvement in the planning, delivery & monitoring of mental health services in Croydon.

On 7th June 2016 Healthwatch Croydon attended to give a talk, but also to 'road-test' themes around mental health that have emerged from our database. We asked 20 questions, framed in various sentiment, to see if they resonated with the experiences of the 40 attendees.

Agree or Disagree?

"Doctors can be too quick to reach for the medication. What about alternatives?" *Agree*

"There is adequate funding for mental health services." *Disagree*

"Croydon spends less money per head on mental health, than its neighbouring boroughs." *Agree*

"I would like a greater choice of services. I feel like a square peg in a round hole sometimes." *Agree*

"I wasn't on the waiting list for too long." *Disagree*

"The impact of mental health on carers and family members is not fully recognised." *Agree*

"My condition was diagnosed very quickly." *Disagree*

"I got six sessions, but could really do with twice that…" *Neither agree or disagree*

"I am not too worried about the side effects of my medication." *Disagree*

"I find it easy to talk about my condition within the community." *Neither agree or disagree*

The themes were confirmed, with clear majorities in the vast majority of cases.

Most attendees cited very good quality, however waiting lists for diagnosis and treatment can be lengthy, with little (or no) support in the interim.

There is a perception that general practitioners are too focussed on the physical, and that alternatives to medication are not always given due consideration.

People also tell us that services can be a 'one size fits all', and crucially, they say they do 'not feel listened to'.

Agree or Disagree?

"Getting a referral was a hassle, to be honest!" *Agree*

"GPs are very knowledgeable about mental health." *Disagree*

"I find that services do work together and are joined-up." *Disagree*

"Getting through to someone on the phone can be difficult." *Agree*

"I know what to do in a crisis." *Neither agree or disagree*

"I have been given a good level of advice and information." *Disagree*

"I can usually get a GP appointment without difficulty." *Disagree*

"I have a named key worker." *Agree*

"Hidden conditions are much harder to treat than physical conditions." *Agree*

"I feel listened to." *Disagree*

The response to the final question is particularly apt, as the group itself is titled *'Hear Us'*.

4.5 Healthwatch Croydon Advisory Forum

On 5th May 2016, Healthwatch Croydon hosted a Mental Health edition of its Advisory Forum. With service users and providers present, we considered:

"As a person interested in mental health needs, what support is needed?"

"How do we, as a community, continue to raise mental health awareness? What can we do to support people in the community?"

At the table discussions, delegates raised issues around information, advice and advocacy, fragmentation of the service, capacity and waiting lists, awareness within the community, training and competency within primary care, and levels of support. The following themes emerged.

4.5.1
Information, Advice and Advocacy

The provision of good information and advice, above all else, can help patients and professionals navigate what can be a complex system, with an array of pathways and services.

The Forum said:

Residents should know what is available and messages need to be simple (in plain language). Increased use of advocates could also help people around the system.

4.5.2
Centralisation

One thing that Healthwatch hears constantly is "we need a single point of access".

The Forum said:

A reduction in service access points could make it easier to get support when required. Greater responsibility for key workers could be one solution.

4.5.3
Service Capacity

Waiting lists are problematic, and will persist, as long as funding remains inadequate.

The Forum said:

It has been noted that additional resource has been secured in the interim, but this amounts to 'fire-fighting' rather than wholesale improvement. There is a perception that current services are both under-funded and under-staffed. Money is not always the solution, but a decent system cannot operate without a suitable level of funding.

4.5.4 Awareness

Greater awareness is needed within the community – working with schools, employers and faith groups (for example) has proven to be effective in disseminating information. It is perceived that Croydon is doing less of this, in relation to peer boroughs.

The Forum said:

Increased use of advertising on transport networks in particular has proven value.

4.5.5 Training

There are concerns that GPs (in particular) are too orientated towards physical conditions and are 'not knowledgeable enough' on mental health.

The Forum said:

This may only be perception, but it can deter patients from seeking treatment, so reassurance is vital (trust should not be assumed).

4.5.6 Promoting Self-Interest

We need to make people care, they need a reason to take an interest in mental health.

The Forum said:

We can learn from successful 'sloganistic' advertising campaigns, for example the cancer '1 in 3' and LGBT 'out of the closet' programmes that have done much to break down barriers, and promote openness. A '1 in 4' slogan is being used increasingly and this is an encouraging development. Positive images are important, and social media could also play a central role.

4.5.7 Support Networks

People with mental health issues don't necessarily 'form a community' and sometimes, those with mental health problems 'do not need to be surrounded' by others in similar circumstances.

The Forum said:

Social prescribing (referral to social groups such as exercise classes) has been proven to work – improving health and wellbeing, enhancing resilience, and saving money in the longer term.

5. Learning from Experience

Based on what we've heard, we have summarised 'key' improvements that may be considered to improve the service in certain areas.

It is the role of Healthwatch to influence the commissioning and delivery of services, therefore our recommendations are not prescriptive, but intended to inspire solutions to the issues that clearly exist.

5.1 Service Accessibility

Residents tell us about waiting lists that exceed 18 months, and in one case, a family said they had exceeded 2 years, and were still waiting.

Recommendations for Croydon CCG

With additional funding and service redesign, it is anticipated that waiting lists will have come down during 2016/17. A wait exceeding 2 years is likely due to lack of integration, or failure of a particular pathway.

Action: By this time next year, we hope that services will be less fragmented, with a channel for service users, families and carers to raise the alarm on clearly excessive waiting times.

5.2 User Involvement

The phrase 'nobody listens' is one we have heard often. Many residents tell us they are not involved in decisions about them, or aware of what's in their care plan.

Recommendations for SLaM and Providers

Ideally, service users, families and carers will be consulted when drafting and updating care plans, and have recourse to influence, or challenge decisions.

Action: By this time next year, we hope that service users, families and carers are familiar with the contents of care plans, and involved at every opportunity in decision making. We know that SLaM has launched a two year programme to strengthen care planning, and this is welcome.

Another common phrase we hear is 'I feel like a square peg in a round hole', with many residents expressing lack of aftercare, with limited or sometimes no options.

Recommendations for GPs, SLaM and Providers

GPs and mental health professionals should listen clearly to patients before making referrals to services which may not be necessary or appropriate.

Action: By this time next year, we hope that patients will be able to choose a greater range of holistic services, with increased utilisation of user peer and support groups.

5.3 Carer Involvement

We have heard that residents have been sectioned, and admitted to hospitals that are 'two hours away'.

Recommendations for Croydon CCG

It may be assumed that the greater the distance, the less likely that family and carers will be able to visit often, with potential implications for the patient's wellbeing and recovery. As a result, this may increase the cost of treatment as a whole.

Action: By this time next year, we hope that more patients will be admitted locally, or if not, as close to their home as possible.

One family said they were 'offered a specialist bed in Scotland'.

Recommendations for NHS England

It is clear that there is a regional and national under-supply of specialist beds. Given that increasing capacity will take time, resource, and collaborative planning, it may be necessary to look at practical alternatives in the interim.

Action: By this time next year, we hope that patients will not be given options that are clearly impractical, or unreasonable, with all possible alternatives explored.

Next of kin, and main carers, tell us that they have been denied information, with providers citing confidentiality.

Recommendations for SLaM

A main carer comments that she was able to get information from SLaM in Lambeth, but not counterparts in Croydon.

Action: By this time next year, assuming that information governance protocols are trustwide, we hope that there will be regional consistency in sharing information with family and carers, and if not, this is clearly documented and explained.

5.4 Support

Residents tell us that calls often go unanswered, with messages not being responded to timely, if at all, by Social Workers in particular.

Recommendations for Social Workers

More than one family has said it can be difficult to reach social workers by phone, with messages not responded to timely, if at all.

Action: By this time next year, we hope that telephones will be answered more often, and when not, messages may be left that are responded to.

5.5 Medication

It has been commented many times that clinicians can be ‘too quick to reach for the medication’ and patients are concerned about side effects.

Recommendations for GPs and SLaM

One patient told us that her joints had become swollen since taking medication, making it difficult to walk in particular. Although a documented side effect, the psychiatrist was ‘dismissive’ of her concerns.

Action: By this time next year, we hope that patients are respected when reporting side effects which cause anxiety, discomfort and potential harm. We hope that alternative medicines or treatments may be considered before concerns are discounted.

6. What Next?

The Croydon ‘Integrated Mental Health Strategy for Adults (2014-19)’ states challenges as:

- An increasing demand for mental health services (led in part by demographic changes and population growth), which has led to significant pressures on inpatient beds for Croydon’s population.
- A challenging environment in terms of financial resources available to commissioners
- A service system that is imbalanced with a significant number of people in secondary care in the community that could be better managed in primary care, and an over reliance on inpatient provision.
- A low baseline for community services e.g. Improving Access to Psychological Therapies (IAPT) services.
- A need to develop further health and social care integration with the aim of promoting a whole person approach.

The health and social care system alone cannot solve the problem – housing, education and employment, among other factors, must also play a central role. Those tasked with implementing the strategy, must continue to work towards:

- Increasing access to mental health services.
- Strengthening partnership working and integration of physical and mental health.
- Promoting mental wellbeing.
- Improving the quality of life of people with mental health conditions.

While acknowledging the significant challenges of mental health commissioning and provision, we must ensure that local services are adequate to meet local needs.

7. Glossary of Terms

BME	Black and Minority Ethnic
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
MS	Multiple Sclerosis
PTSD	Post Traumatic Stress Disorder
SLaM	South London and Maudsley NHS Foundation Trust

8. References

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Croydon Annual Public Health Report 2015
https://www.croydon.gov.uk/sites/default/files/articles/downloads/Annual%20Public%20Health%20Report%20for%202015.pdf

Croydon Integrated Mental Health Strategy for Adults (2014-19)
https://www.croydon.gov.uk/democracy/dande/policies/health/imh-strategy

“Is it really so difficult for people to listen?”

Resident of Croydon, 2016