

# Meet the changemakers... and get involved

## Adult Mental Health services

### Self-care

## Questions and answers

Wednesday 18 July 18.00-20.30

CVA Resource Centre, 82 London Road, Croydon

In association with



**Croydon**

Clinical Commissioning Group



**South London and Maudsley**

NHS Foundation Trust

## Table 1 - Session 1: (17.08 to 17.29)

Tom Cox, Mental Health Commissioner, NHS Croydon CCG: (TC)

Resident 1

Resident 2

Resident 3

Resident 4

Resident 5

### Themes that came out of the discussions:

#### Services:

- Costs charged by GPs for essential letters which affect patients' wellbeing.

#### Knowledge and com

- Knowledge of self-care support services.
- CCG need to better market and communicate these services.
- Assessment of effectiveness of these services.
- A bigger focus on public health engagement on the street and with relevant community group.
- Need to focus service user minds towards non-medical services that will help their wellbeing.

#### Support:

- Motivation to use such services.
- Need support initiatives to maintain good personal relationships, avoid relationship breakdown and the mental health issues that follow including use of mediation.
- Using community spaces like parks to support better mental health for active sport to help wellbeing
- Facilities should relate to needs across the borough. Make parks a resource for social wellbeing for young and old.

### Full Discussions

**Resident 1:** I've got a point which Tom knows about. The benefits situation for vulnerable people is quite a crucial issue in relation to people's well-being. Somebody vulnerable, not necessarily mental health. To apply for benefits you need evidence. Often there are patients, especially adult mental health patients, who comply with the medication and have seen their psychiatrist once a year. They've found they can survive without support from secondary services, so they are referred back to the GP. In relation to some evidence, letters from the GP are needed to support their application for PIP and also ESA. I've asked Tom, in his role as commissioner, to ask this. What's come back is that this is

discretionary. My GP charges £30 per letter whether you are vulnerable or not. It is classed in a category. If you are a lorry driver renewing your license that would be £30. If you want an insurance enquiry that's also £30. There are others, I know at least three GPs in Croydon out of 62, who provide this service for free to vulnerable people. It says vulnerable people on here under the three to five years plan. Now, support for them.

**Tom Cox:** Can I pause there? That issue ties in more with the GP table.

**Resident 2:** I agree with you.

**TC:** Before we continue, first of all, so we know the context. My name is Tom Cox, I am one of the commissioning team. We have been asked on this table to think about self-care provision in the borough, what the issues are and what we need to change. What support is out there to help people care for themselves.

**Resident 1:** On that point, to help to get benefits, to help support themselves financially and not get back into hospital, and save the NHS money, they have to have evidence. To pay sometimes £30, some charge £50 for a letter.

**Resident 2:** I'm hearing what you're saying.

**Resident 3:** You don't get all that detail from the media, it's only when you're faced with these problems at your worst moment. You won't have your payment, another four weeks without any money and you need that support.

**Resident 2:** I can hear those problems but I've got a problem. You're describing difficulties in accessing different levels of care, but specifically describing an issue that arises in an area that we've been asked to not look at. We are looking at self-care. Whilst you describe something that limits the ability for some people to actually carry that out, I am also interested in what Tom has got to tell us about what the CCG sees as the current problem in either providing or asking itself whether there should be self-care.

**TC:** This is a good point. Look again at the pathway maps that we shared round before. We are looking at the left-most side of the chart, green section. This is the as-is situation at the moment.

**Resident 4:** Would self-care be more towards social prescribing?

**TC:** It would include social prescribing in terms of other services that GPs can refer onto. This chart mentions the Just Be Croydon website, where there is a range of support and information about how to be active, eat healthily. To help well-being. By being informed and helping in that kind of way, that prevents mental ill-health down the line. It might help prevent depression, anxiety. By being active, getting enough exercise.

**Resident 2:** We get that and can see how things can deteriorate if this isn't available.

**TC:** Issues include awareness around the services, not enough people know about them. Or, they know about them but they don't feel motivation to use them.

**Resident 2:** Is that the issue?

**TC:** The purpose of the table is to get your view on what the issues are.

**Resident 2:** Every time I come to one of these meetings, everybody agrees that there should be more communication. Clearly, once we've all agreed that, we need to move onto something more practical. Brands want to get their names into the marketplace, in competition. You're no different from everybody else who wants to sell their wares. Any organisation who wants to make an impact must have a highly professional marketing and selling team. CCG hasn't got that. Once you've got that, the next question is what good do these things do? We know that all these things are helpful and prevent deterioration, but I wonder to what extent there is any sort of assessment of the effectiveness of what's being done. She told us that from 2008 onwards, the world has turned and CBT became a big thing, everybody said it works. That's been the gospel for the past 10 years.

**Resident 1:** Only for some people with common problems.

**Resident 2:** Yes, and this is meant to deal with common problems. A lot of money is being spent on these online resources and I wonder what sort of effectiveness anybody is gauging of the appropriateness of these things.

**Resident 3:** You've been doing very well at talking to people as they passed you in the community. Last Saturday you did the HIV testing and approaching people. What struck me was going out there and talking to people, the thing about sexual protection. There were sometimes about 5 or 6 people all actively absorbing and asking questions, all afternoon. There were no holds barred. The information was brilliant. I was shepherding people to tables to get their HIV status test.

**Resident 1:** HIV is more in primary care.

**Resident 3:** What I'm focusing on is getting out there and giving messages in public places, so that people can actually engage in the street and public places around the borough. This could be done in Croydon High Street, wherever. It could be mental or physical health. There's nothing like neighbour telling neighbour what the thing is, and actually describing where the place is to go.

**Resident 1:** I used to a mental health day with somebody else, but there's also been a pop-up bus for the elderly people, to go round with information. They tried it that way, but are they still going?

**TC:** I just want to try to get comments from everyone. Is there anything you want to add?

**Resident 5:** Prevention methods?

**TC:** Looking at the prevention side of things, so people with no mental health needs or low mental health needs. Do you feel there are there issues with the current support available or things that may need to change or improve? To help people care for themselves better?

**Resident 4:** I think relationship breakdown is quite an important thing. It can be tense.

**TC:** That's something that can lead to mental health, yes. So, maybe something about maintaining good relationships.

**Resident 4:** Mediation or something can prevent it.

**Resident 1:** In relation to being active, you've got some active groups that do walking. They encouraged people with mental health problems who had problems with stigma. People treated them differently.

**Resident 5:** Lifestyle issues, I was thinking of. They have the largest section of open space in London, there are many uses of open space. It is scientifically shown to be a therapeutic environment. Not enough use is made of it for mental health.

**TC:** Better use of community spaces?

**Resident 5:** Yes, a therapeutic environment for mental health.

**TC:** Like parks?

**Resident 5:** Yes, there should be programmes and projects in the parks. Preventative measures as well.

**Resident 1:** On a Saturday morning in 3 places in Croydon, there is the 5K free Park Run. You just get your time later on, a lot of people with mental health problems have used it to keep their weight down or fitness up. It's a way to perhaps meet people.

**Resident 5:** I'm talking of more innovative ideas, not just walking. Innovative ideas. Projects I have in my mind.

**Resident 1:** In Lloyd Park they have fitness machines, I've never tried them. There is an obstacle sort of thing, you can climb it, pull it, jump over logs and things.

**Resident 5:** Yes, but Croydon is very big. What is there in Selhurst?

**Resident 1:** I don't know.

**Resident 5:** Exactly. It should be in proportion to the needs of the community.

**Resident 2:** In Selhurst there is a park by the railway station.

**Resident 5:** Yes, there's nothing there.

**TC:** Do you mean open spaces?

**Resident 5:** There's nothing.

**Resident 2:** Having said that, you have to know where they are. You know the Selhurst garage depot where the trains are parked. There's a park there. There's another one in Thornton Heath up on the hill.

**Resident 3:** Oh, Grangewood, but that's miles away.

**Resident 2:** I'm afraid you do have to walk to it.

**Resident 3:** The point you're making is a demand on the council who has responsibility, to make the parks or in this instance the park, more attractive as a resource that people can use.

**Resident 5:** There's a resource centre there for old people, what is there for them? Nothing in this park? People with dementia.

**Resident 1:** Young children. When I was a youngster, there was a park where I lived. All my mates used to play football, cricket.

**Resident 2:** When I was young the boys used to go out in the road because there weren't any parks. They used to play cricket and football all day long.

**Resident 3:** If I remember some of the stats at the Thrive LDN presentation, there are still a very low number of people actually accessing services, even these ones. The ones in red are that your doctor or the police send you to. These are the ones you choose yourself. When one is not feeling well, where do you go? The doctor, physically. When you're feeling depressed and down, does it naturally follow that you find these?

(Session ends)

## Table 1 - Session 2 (17.34 to 17.53)

Tom Cox, Mental Health Commissioner, NHS Croydon CCG: (TC)  
Steven Warren, Head of Commissioning, NHS Croydon CCG: (SW)  
Resident 1  
Resident 2  
Resident 3  
Resident 4

### Themes that came out of the discussions:

#### Services:

- Concern of use of psychotic drugs, based on misdiagnosis.
- Lack of home-based therapies.
- Lack of funding for autism unit in Croydon which could solve these issues, focus on autism specific needs as CBT does not work for them.
- When some people have an added complexity on top of the mental health issue, they cannot be neatly diagnosed and so fall through the gaps.

#### Knowledge and Communications:

- Communications with adults and young people who have mental health problems; How mental health patients are helped at A&E.
- Lack of awareness of support services particularly talking therapies.
- Need to focus on prevention.

#### Support:

- Understanding by all services about supporting those who have mental health issues and autism and lack of therapies for this group.
- Concern about transition between child and adult services at 18. Various autism groups provide support but there is not a central place of them to voice their experiences.

**Tom Cox:** I'm one of the mental health commissioners. This is Steven Warren, deputy commissioner.

**Resident 1:** I teach drama as therapy. I worked for a cancer charity, doing a performance around various issues and bringing the issues alive. Through work I recently had to use IAPT (Improving Access to Psychological Therapies) services. I just came here to see what was going on. One of my main concerns was issues with communications with adults or young people who have mental health problems. I'm just really concerned about some areas to do with that and care receiving at A&E.

**Resident 2:** I'm a parent of a child with autism. I've found a big, big gap in Croydon with mental health. My child's just come out of a catatonia breakdown where the brain shuts

down and the limbs stop working. We've got no high-functioning autism school in Croydon, social care has to pick up the problem. I've found that NHS weren't very useful during the breakdown, everybody from GPs to psychiatrists. They knew about mental health but not mental health and autism, they admitted it. I am here to say there is a big difference between mental health and autism, they have to be treated differently, but these young adults are being sectioned, creating more problems. We've got nine beds in the autism unit at Bethlem which is gold dust if you get a bed there. He's had medication but no therapy offered at all. I'm constantly trying to find therapy for him. They wanted to section him, but I refused. I had to nurse him back to health at home, I didn't have any help or intervention.

**TC:** It's the community and GPs.

**Resident 2:** We want therapies at home. Even that young lady, she doesn't offer it. NHS doesn't offer it. He was bed-ridden for 4 months. I couldn't physically get in there. Nobody would come to the house. A crisis team said they don't deal with autism. Who does? I had psychiatrists who would have made a misdiagnosis if I wasn't there. They wanted to prescribe anti-psychotic drugs which would have made it worse. It was a complete disaster. We are in need of help when it comes to high-functioning autism. They're the ones who need help. If I wasn't there, there are three ways my son would have gone. He would have died from stopping eating, he would have been sectioned and in prison. They are still vulnerable and end up getting themselves into trouble.

**TC:** We'll feed that back to the other table. This is the self-care table.

**Steven:** It's a massive gap.

**Resident 2:** It's also education and we need to deal with it early in life.

**Resident 1:** I know you're speaking as a mother. Part of the self-care would be what is there for you?

**Resident 2:** Exactly. I know a lot of parents on anti-depressants because they can't help. After the carers act, they aren't getting the support they need. When my son was bed-ridden and I needed someone to come in and clean him up, there was a certain time they had to come in, it just didn't work.

**TC:** Why couldn't you get access to Talking Therapies?

**Resident 2:** I've been waiting for a year. I had to complain to the CCG about it. They kept going from one panel to another then it fell off the radar altogether. It was just a pattern of errors.

**Steven Warren:** That sounds terrible in terms of your whole experience. It would be good to have it as a case study to look at.

**Resident 2:** Apparently, they were supposed to set up an autism unit in Croydon. That was getting funded two years ago but the funds got taken away. My son's referral was made but then it didn't manifest. The same with social care, the autism people don't come under any banners. You don't come under learning difficulties, mental health. I



have to go from team to team. Social care is non-existent for the last 6 months. We need something for autism.

**Resident 3:** A group.

**Resident 2:** You know, there are plenty of groups, but at the top nobody is doing anything. You would free up a lot of beds and resources if you could really recognise what the problem is amongst autistic people. They are vulnerable, they need different therapies. CBT doesn't really work with autism. They need more psychotherapy but it's hard enough just getting CBT.

**SW:** How old is he?

**Resident 2:** 21, he was diagnosed at 13. I've tried to deal with education, but he's a lot better now. He's come out of his breakdown. It was inevitable, they do get traumatised and it does come out as a nervous breakdown. Early prevention would really help and make things better for mental health.

**SW:** That's a good case study of how it shouldn't happen. If you give your details afterwards we might get in touch.

**Resident 2:** I wrote to CCG and they wrote a letter back acknowledging all the errors they had made, which was fine. They admitted it, but it's not a solution. Me and my husband helped him recover but there's nothing documented. No one recognises catatonia in autistic people, they just put it down as a nervous breakdown. My GP said it was common among young adults. What are they putting in place? It's quite normal now for that to happen. How have we got to this place where we think something like this is normal?

**Resident 4:** I think it's' really unfortunately common when people have an additional complexity that they fall through the gaps, if they don't have a neat diagnostic label.

**SW:** Yes, also in the transition between children to adult services.

**Resident 2:** As soon as the day he turned 18, that was it, he was in adult services and then you're waiting. I was mentioning medication. This is what I don't understand. Why are we prescribing medication without therapies? Really, you should give therapies, then if they don't work, do it side by side. We've got young OCD kids who they are prescribing anti-depressant tablets to without the therapies in place. We don't help wean them off, it's left to the family. The times that I've had to wean off and no one wants to help. They're happy to put him on there.

**Resident 1:** In terms of your self-care and support, what is it that you're doing?

**TC:** Just briefly, we're looking at this pathway map that we've got here. Looking particularly in the green section, the no to low level of need. This is what services are currently being provided. My head of team gave an overview earlier on. Some of the issues that have come up in previous events are the lack of awareness, for example in terms of self-care. Being active, eating healthily, having healthy lifestyle choices and approaches. Sometimes the support that's available in terms of the Croydon Talking

Therapies, that's something that there's a capacity for. Opening it up to you, what are your views on the current provision?

**Resident 2:** The NHS are wonderful people but you only know when you access it, when you really need it, that you know all the flaws. When it came to my son, the help is not there. What surprised me was that the top psychiatrists had not a clue. I know autism is still quite new, people are learning about it and it's varied, but I was still surprised at how they are mixing it with mental health. That is a big danger.

**Resident 1:** Are they doing that in your communities?

**Resident 2:** Yes because there are no provisions for autism so they've got no choice. They need special help and attention. They cannot be put into a mental health facility, all you're doing is traumatising them more.

**Resident 3:** We need to address it because the diagnoses of autism are going up. I think what you were saying about that transition time, it's a really tough time. Young people experience such a difference between the services under and over 18. Your son has got a supportive family but some people do not. Navigating that is key.

**Resident 2:** They have usually fallen off the cliff by then. They need to really be strong, and get the support. I think the prisons are full of autistic people.

**Resident 4:** There are well-established support groups.

**Resident 2:** There are autism groups, adult services at Chatsworth Hall. They are very small groups, everyone gets together and talks but they are all having the same problems.

**Resident 4:** Is there a national society as well?

**Resident 2:** There is the National Autism Society, that's where I found out about catatonia. To get it to the psychologists and the specialists, it's about education.

**SW:** Yes, we were talking about different communities and community groups to get feedback more systematically.

**Resident 2:** Aren't the CCG the top, main people who can make the changes?

**SW:** Yes.

**Resident 2:** I know there are many people who have similar experiences but they're not documented. How are we supposed to make changes? I feel like I had to document it and write to the CCG just so it's out there, so people know the difficulties I had and the gaps in the system. The gaps are very big all the way through.

**Resident 4:** The other thing around prevention, I know there has been some discussion about how we connect better to communities and get messages out. There are lots of ways to do it. That's key.

(Session ends)

## Table 1 - Session 3: (17.58 to 18.17)

Tom Cox, Tom Cox, Mental Health Commissioner, NHS Croydon CCG: (TC)

Resident 1

Resident 2

Resident 3

Resident 4

Resident 5

### Themes that came out of the discussions:

#### Services:

- Need for a personal approach. Some may use acute service for a short while, but then spend the rest of their time in self-care. Users should not be defined by a condition or the services they use or are offered.
- There are issues in the way the psychiatrist talks to the patient, language issues but also ways of relating. More information needed on medications and their side effects given by the psychiatrist, with pharmacists having a role here.
- The good benefit of community gardening to help people turnaround.

#### Knowledge and communications:

- Careful with the messaging as providers don't want to bombard people and put them off.
- People know they have issues but don't want to show it due to stigma that needs to be overcome.
- Need for a leaflet distributed across Croydon for all services at various stages.
- Better promotion of IAPT services.

#### Support:

- Boredom and loneliness - how can this be overcome?
- The sense that other people with mental health issues are weird, so why does someone with mental health issues want to spend time with another person in a similar way?
- Success with the Recovery College in helping those with mental health issues, more promotion and knowledge about this is needed.
- Helping people recognise they need help early on - mental health first aid.
- Mental health telephone support and advice is needed, or if it exists better promoted.
- Talking positively about mental health - taking care of the mind as well as the body.



**Resident 4:** Yes, especially from close friends and close relations. Social psychologists don't necessarily help all the time.

**Resident 2:** In our case, our loved ones need medication as well, but in addition to that.

**Resident 3:** I think the point you're making is that people can be here in the red area and be diagnosed, but they live most of their life like the rest of us. The stigma prevents them from living their lives in the way they ought to. That's an interesting conundrum. That needs family members to advocate, access to appropriate services. Why should you have to go for services for people like you? Why can't you go to services for people who like the same music as you, or art? We are not defined by our conditions but ourselves. What the system tends to do is see things through a service lens but not a personal lens, that's where we need to actually see the world through the eyes of the person. Not what services we think they need, but how they would like to experience their lives.

**Resident 4:** I started telling my friend, it's a cycle, start with medicine then reduce treatment.

**Resident 2:** We did that, in the beginning you don't believe it, they get better and then they get ill again.

**Resident 1:** You have to trust the professionals.

**Resident 4:** There is the clinical psychiatrist and the social one. The clinical one. This guy was in an acute situation, within 15 minutes he was out of there. There are problems, the language problem, the way they speak and are coming across. There are a lot of problems between the psychiatrist and the patient.

**Resident 2:** The other thing about medication, there's been a lot in the press about sodium valproate which is given for epilepsy. It's now been found that it affects women with children, it affects the foetus very badly. They are going to take people and tell them, but they weren't told this a few years ago.

**TC:** So, there's not enough information about side-effects. There needs to be more information out there.

**Resident 2:** A lot more. The pharmacies need to guide the psychiatrists.

**Resident 5:** One thing that occurs to me is that quite often the person with the problem doesn't admit to it, but friends and family are living with it. They don't have a way to find out what they can do to help.

**Resident 3:** Maybe a more generalised approach to mental health first aid, being able to recognise what positive mental health is.

**Resident 2:** There's lots out there, but you don't get it at the beginning.

**Resident 5:** Yes, you have no source of information, no way to find it.

**Resident 3:** I think that's true at different stages, for parents with children, for people with an older loved one with signs of dementia. There is support there but it's finding it.

**Resident 5:** There's no single point to find it.

**Resident 3:** You can phone Healthwatch.

**Resident 5:** That hasn't got a good reputation.

**Resident 3:** It's a new provider, we have an information signposting service but people don't know it exists. There isn't enough knowledge. Sometimes you need to know what the question is to ask. There is a dearth of telephone support. You need to phone someone up and say you're worried.

**Resident 5:** It's even worse when you're saying, 'My family member is doing some strange things, what can I do?' It's difficult to do anything even if you have the details and are the husband or wife.

**Resident 4:** They can become very defensive.

**Resident 5:** The easiest one to find out about, is if your child is diagnosed on the spectrum when they're at school, but if they're teenagers or older you are on your own.

**Resident 4:** I was wondering. You know there are a variety of leaflets from IAPT, I have not seen anything.

**Resident 2:** It's in this month's IAPT, and there has been a leaflet.

**Resident 4:** Perhaps there is one leaflet alongside one about the bins, but we need to tell people the resources available. If CCG give money to Croydon they can get the leaflets out there. A small one, nicely designed.

**TC:** Of all the services available?

**Resident 4:** Yes, at different stages. I don't know. You have to monitor to see how many people respond.

**Resident 2:** I wanted to ask a question. When it said 1 in 4 adults have a mental health problem, 4,500 have serious problems, was it in Croydon?

**TC:** In the borough.

**Resident 5:** In the population, 1 in 1,000 are very serious.

**Resident 2:** I think the 1 in 4 is not serious.

**Resident 5:** No it can be anything, reactive depression.

**Resident 2:** So, it's 4,500 people with a serious problem going to Jeannette Wallace House, it's no wonder it's quite busy.

**Resident 5:** Totally anecdotal, gardening therapy. It's amazing how effective it is. It kicks them enough to get out of a rut.

**Resident 3:** I know someone, exactly that, had depression and started volunteering in the community garden. It absolutely turned him around.

**Resident 2:** There is a group in Croydon.

**TC:** In terms of the stigma, I wanted to mention that there one way of addressing it, in terms of promoting awareness and moving away from thinking of mental health as a negative. More talking about taking care of your mind as much as your body. If something happens you need to care for your mind to prevent worse conditions. One other thing than promoting that is also talking about services available. One suggestion has been to still have the services provided as they are but not label them as mental health services as such, as one way of getting around that stigma.

**Resident 1:** Yes, it is a stigma, isn't it?

**TC:** Has your son ever tried them?

**Resident 1:** He used to join gyms and play football but he can't afford it regularly. I said, 'I am sure there must be some services.'

**TC:** It might be worth looking at that leaflet in terms of things they suggest, the websites.

(Session ends)

## Table 2 - Session 1: (17.10 to 17.29)

**James Du Bray:** South London and Maudsley NHS Foundation Trust <<role>>

**Paris Cosgrave:** Lead for IAPTS (talking therapies) for long term conditions, South London and Maudsley NHS Foundation Trust

Resident 1

Resident 2

Resident 3

Resident 4

### Themes that came out of the discussions:

#### Services:

- Services for those whose English is not their fluent language.
- Concern that cancer psychotherapy services may be closing - what is happening to the service?
- Self-referral pathways: People can self-refer, but for long-term conditions it is easier to go by GP - hard to do by self-referral.
- Charging process: This means GPs charge each other in Croydon to see patients from other surgeries. This is not true of other services - mental health should be seen like these.

#### Knowledge and communication:

- Difficulty in raising awareness of mental health with certain cultural groups, with only 66 referrals from the Asian community.
- Too many people go to GPs, but they are seen as the reliable place to go
- Different language and approach depending on age, ie focus on isolation for older people.

### Full Discussions

**James:** What did you discuss on the other table? This session is on psycho-therapy.

**Resident 1:** Trying to find something that's even better than talking therapy. Thinking about different languages. You have to have practitioners who are fluent in the language when dealing with patients.

**Resident 2:** I'm a resident. I volunteer for the NHS. I've used psychological services and other services. I think the cancer psychology services may be going in Croydon which really disappoints me. I don't know how that impacts on community services.



**Paris:** I don't know if James knew about that but I certainly didn't know about the cancer service closing down. We certainly have the resources to deal with that, to help those people.

**Resident 3:** Which service was that? I'm not sure it's closing. I think there's just a discussion about it.

**Resident 2:** Oh okay, that's good.

**Paris:** One third of people with a long-term illness have a mental health issue.

**Resident 4:** Can anyone self-refer for help?

**Paris:** Yes, anyone can self-refer.

**Resident 4:** If someone with a long-term condition phoned up and asked for a service, would they then have to go back to the GP?

**Paris:** We'd suggest that they go to the GP first. I have someone at the moment who's been referred without such a form, which is often very difficult.

**James:** We know if you have one long term health condition that you're very likely to have one alongside it. You still need the ability to treat both at the same time, which is very challenging.

**Paris:** If someone did call through with a long-term condition, there's no reason they can't self-refer if their issue isn't related to that condition.

**James:** We want to encourage others to use the service.

**Resident 4:** The list you gave was quite helpful in understanding what the different things are that can help.

**Resident 1:** You want to say that we have this fabulous way of helping your wellbeing in Croydon. We were talking about how within some cultural groups the stigma is so great that they won't even admit that they have a mental health issue, so you're expected to interpret that that's what they're talking about.

**James:** Only 66 referrals were made to the service last year from the Asian community. That's woeful in a society as diverse as Croydon. Too many people are heavily reliant on their GP's.

**Resident 1:** Traditionally, the only gatekeeper for the mental health society is the GP and if you go they tell you go to walk in centres anyway. To try to get people to go to A&E who don't really want to go is very tough.

**James:** Croydon is quite unusual in the sense that a lot of GP surgeries charge to run a service out of them. Others won't actually see patients from other practices at their surgery, which is ridiculous. Mental health should be brought more into the mainstream.

**Resident 2:** Having it in different centres makes it more accessible.

**Paris:** People do find accessibility hard if they have long-term conditions. Like James says, it's important to destigmatize what we're doing and to make it available in the same building. We do work with interpreters so any therapist we have that don't speak certain languages, we can do telephone or online interpreters.

**James:** There are some specialist services for people who are hard of hearing too. There was a service at St George's.

**Paris:** Any tips that we should take away and consider?

**James:** Shouldn't we be thinking about different age groups?

**Resident 1:** I think it's essential that for older people the attitude changes. Maybe the language should change from mental health and therapy to something like better wellbeing. I find it heart breaking when people still can't let go of the negative thoughts that make them miserable when they don't need to be. It's the isolation too. It doesn't need to be terribly complicated.

**Paris:** Other services do have older groups. We don't run that at the moment but it is something we need to focus on more really.

**James:** There are more and more students who are recognising mental health issues so that is something that does need focus on too.

(Session ends)

## Table 2 - Session 2: (17.34 to 17.53)

James Du Bray: South London and Maudsley NHS Foundation Trust <<role>>

Paris Cosgrave: Lead for IAPTS (talking therapies) for long term conditions, South London and Maudsley NHS Foundation Trust

Resident 1

Resident 2

Resident 3

Resident 4

### Themes that came out of the discussions:

#### Services:

- 18-week wait for therapy.
- GP said they would refer but said it would take so long that patient should go private. Mental health issues of those with autism compounded by the wait.
- Telephone service to support after initial home visit for those house-bound.
- Tailoring anxiety and depression services for those with autism - risk of sectioning if there is not the right support.

#### Knowledge and communications:

- Need to GPs to be better informed of mental health services so they can refer better, for those with and without autism.

#### Support:

- Need to know range of services - a more integrated approach.
- It takes courage to make a self-referral, so waiting times need to be shorter.

### Full Discussions

**Resident 1:** I've had leaflets through the door but only in the last year or so. My son was waiting for therapy for 18 weeks.

**James:** How old is he?

**Resident 1:** He's over 18.

**Resident 2:** My son was diagnosed late as having autism. The GP said she could refer him but that it would take so long that we should go private, which cost a fortune.

**Resident 3:** Because there's no help it develops into mental health issues. There's no help all the way down the line.

**James:** The issue is that you as members of society only see one service.

**Resident 1:** You say that, but the service isn't there. I've had psychiatry say to me that they know about mental health but not enough about autism.

**James:** We have to work towards a more integrated approach.

**Resident 1:** I heard there was going to be a university in Croydon specialising in it. Going back to therapies, if a person is house bound, where do they go as in Croydon there is no help for those who are house bound?

**Paris:** Although we don't offer home visits, we did initially actually go out to a lady and then continued on the telephone with her, which was something that works very well.

**Resident 1:** Then you don't offer therapy for people with autism

**Paris:** We actually do but their prime problem would be anxiety and depression.

**Resident 1:** It is still anxiety and depression but it's not exactly the same. Until the NHS realises that there is a big difference between mental health and autism then it is going to carry on. When we're talking about mental health we're putting vulnerable children and adults into mainstream psychiatric wards. It's a big problem, you're sticking them in there and traumatising them even more as they don't belong there.

**James:** Yes, I do agree.

**Resident 1:** A lot of people on the spectrum are shut down.

**Paris:** In terms of psychotherapy, we have Cripps, which offer longer term treatments.

**Resident 1:** It is really hit and miss. It doesn't work for them with how their minds work. My son had 6 sessions. He was offered CBT.

**Paris:** It seems like you're saying that there's still a gap?

**Resident 1:** There's a big gap. My son had a catatonic breakdown with autism and no one understood it. They misinterpreted it as a mental health issue and tried to prescribe a drug that made it worse. Time and time again there are people who end up being sectioned which actually makes them worse before they can get better. The information just isn't out there.

**James:** Maybe things are slowly changing. It's a horrible thing to be on the receiving end of.

**Resident 1:** I was at the point over choosing whether to get my son sectioned or try to manage it myself. I nursed him back at home myself. It's not something that's even documented.

**James:** The National Health Service must commission a service.

**Resident 1:** We're traumatising a bunch of people and the majority even end up in mental institutes or prison or, are dying. When I needed the help, I had a GP come round and he said to me when he's in and out of consciousness, just call for the ambulance.

**James:** I think we need to educate our GP's more.

**Resident 1:** The GP knew that he couldn't advise me as he was aware that there wasn't the help out there.

**Paris:** The waiting times have dropped. At the moment waiting times are actually quite good. We're not talking about months anymore.

**James:** There are specific standards that we hold them to account. 75% of all people must have their first treatment within 6 months. If you think about how much courage it takes to make their own referral, 6 months is still too long but the idea is to have 6 to 12 sessions. It's not a long-term panacea. It is to give you a brief solution at that particular time.

**Resident 3:** When you offer therapies, do you offer therapy and medicine?

**Paris:** We only offer therapies but we do have that conversation with people. If they say they're not on medication, we usually point them in the direction of the GP. It takes quite a while for medication to kick in sometimes.

**Resident 2:** Yes, I'm on the highest one and it's working now. I had a bad point last month with anxiety and panic attacks.

**Paris:** Have you ever considered talking therapies?

**Resident 2:** The doctor said CBT might be helpful but I don't know. I feel like there's a stigma with it.

**Paris:** It's a massive barrier we try to overcome. It's completely confidential so even if you come along and think, 'no, it's not for me,' then you're able to leave. What we're trying to do is break that stigma. It depends on the type of therapy you're put forward for. They draw out a cycle for you and they might draw out different techniques.

**Resident 2:** When I get anxious, I can't breathe and I yawn a lot. I keep taking deep breaths. I think I'm scared and then I get frightened because I can't breathe.

**Paris:** We can talk you through the thought process and what we can do. Counselling would talk more about your past history and childhood, but CBT focuses on the here and now, so you don't have to discuss your history.

**Resident 4:** I think you need motivation for CBT to work. My son just doesn't have any motivation needed for it.

**Paris:** Yes, for CBT, you do need some motivation. You need it to turn up really.

**Resident 4:** Also, to do the homework in between sessions?

**Paris:** Yes, with CBT there's quite a lot of thinking in between sessions. There's a level of motivation but if we can get someone into the service we can talk it through. We would hope the GP would make contact and once they are in our system we can discuss what's wrong and how we can get that motivation back for them. It's a bit of a vicious cycle otherwise.

**James:** How can we make the service more appropriate to your needs?

**Resident 3:** After a year I had to make a complaint as my son got lost in the system. Social care is non-existent at the moment and they don't even respond to my emails. Nobody is talking, which needs to change.

(Session ends)

## Table 2 - Session 3: (17.58 to 18.17)

**James Du Bray:** South London and Maudsley NHS Foundation Trust <<role>>

**Paris Cosgrave:** Lead for IAPTS (talking therapies) for long term conditions, South London and Maudsley NHS Foundation Trust

Resident 1

Resident 2

Resident 3

Resident 4

### Themes that came out of the discussions:

#### Services:

- A GP doesn't like referring because it costs her surgery. Due to this some people don't ask to be referred.
- A walk-in might work, but it depends how far it is from people who need it.
- Need for a more instant service when someone is in crisis.

#### Knowledge and communications:

- Lack of knowledge of service, particularly for those with dementia.
- Need for GPs to know more about services, or to point to nurse who can provide the service just as well for the patient.
- However, there is an expectation that a patient should see a doctor, which needs to be managed.

#### Support:

- Bibliotherapy - link between learning and well-being.

### Full Discussions

**Resident 1:** My task is to follow the patient experience.

**Resident 2:** I'm from the Inaspectrum autism group. We did have some information given to us about IAPT. A friend of mine was referred to it.

**Paris:** Did he find the process quite helpful?

**Resident 2:** Yes, he said it was helpful.

**Resident 3:** I'm shadow deputy to the Counsellor. I'm here in that role but also because I've been around and am interested in Healthwatch.

**James:** Do you get people go up to you and talk about mental health issues?

**Resident 3:** No, strangely not. Most of my patients are older.

**James:** I think part of it is not necessarily the stigma but the lack of education and the understanding that the service is available to everyone. We know that there are lots of people out there with dementia who haven't actually got a diagnosis.

**Resident 4:** We have a GP in our area who doesn't like referring because it keeps down her figures and expenditures. The thing that gets to me the most is that someone in crisis won't necessarily make a phone call.

**James:** So, do you think we should just make it a walk in?

**Resident 4:** The issue with that is how far it is between the residents and centres.

**Paris:** We're trying to reach out to surgeries. We did have a point of time where we would call the person and you'd call and they wouldn't be in, or the person wasn't particularly motivated. It was very difficult to get hold of them and by the time that's passed you could have seen someone for treatment, so we found it was easy for people to call in rather than the other way around. That's why we changed it.

**Resident 4:** The difference is that if people make a booking they actually expect something to happen.

**Paris:** We would make exceptions for people at the stage of really making an effort to get in touch, but the majority would call in. We're dealing with people with mild to moderate mental health issues.

**Resident 4:** I got your point about referring yourself online but then I'm not sure that having to make a phone call works with the person in crisis.

**James:** I suppose it is very much a structured programme. There are times when people will need a more immediate response.

**Resident 4:** But it's about flexibility above the approach.

**James:** When I first started, the GP's weren't educated enough to know how it could support them. Maybe there needs to be an exercise of educating GP's. The problem again is that there's too much tendency to think the GP is the answer to all of your problems. You could talk to a practice nurse or someone else.

**Resident 4:** I think if people go to seek help, they should expect to see a doctor though.

**Resident 1:** My wife, Carol did have a heavy panic breathing attack. The doctor did recommend talking therapies. The doctor didn't say anything that I hadn't told her already but once the doctor told her her breathing and everything was alright, she was fine an hour or so afterwards. I thought, 'Geographically, where is this place, is it going to take a long time to get there?'

**Resident 4:** My frustration is that my husband can't get into the local practice, so he has to travel far despite hardly being able to walk at the moment.



**James:** My last job was working for a service provider online. A therapist was available as you typed.

**Resident 4:** So not talking, just texting?

**James:** Yes. A lot of people were having therapy in that way.

**Resident 2:** What about more old-fashioned bibliotherapy? I did see on your website that there were references to it.

**Paris:** We have leaflets that we hand out. In terms of our self help, that tends to incorporate a lot of bibliotherapy. They'd come back in a week or so and talk through what they've learnt which helps consolidate what they've learnt.

**Resident 2:** I think there's a strong connection between learning and well-being. That in itself probably makes you feel better.

**Paris:** Yes, and you can take that with you and keep learning and going over it.

**Resident 3:** I'm diabetic. My daughter was 7 when she was diagnosed and I was only diagnosed 10 years ago. My granddaughter struggles with it as she's different to her peers. What's interesting is that we are all different in how we deal with things.

**James:** Different generational things too. The younger generation seem to be more anxious.

**Resident 3:** Yes, social media and the internet make you know more and you might be better off not knowing it.

**Paris:** The younger generation have too much knowledge about what's normal and what isn't.

**Resident 1:** There's a will for conformity.

**Paris:** It goes back to that cycle of the thoughts you have over a situation.

**Resident 4:** In my father's generation you wouldn't talk about it at all.

**Paris:** You'd just get on with it, that stiff upper lip attitude.

**Resident 4:** I often think we don't support each other as we are all too busy.

**Paris:** Yes, definitely. It goes back to that discussion about social media.

(Session ends)