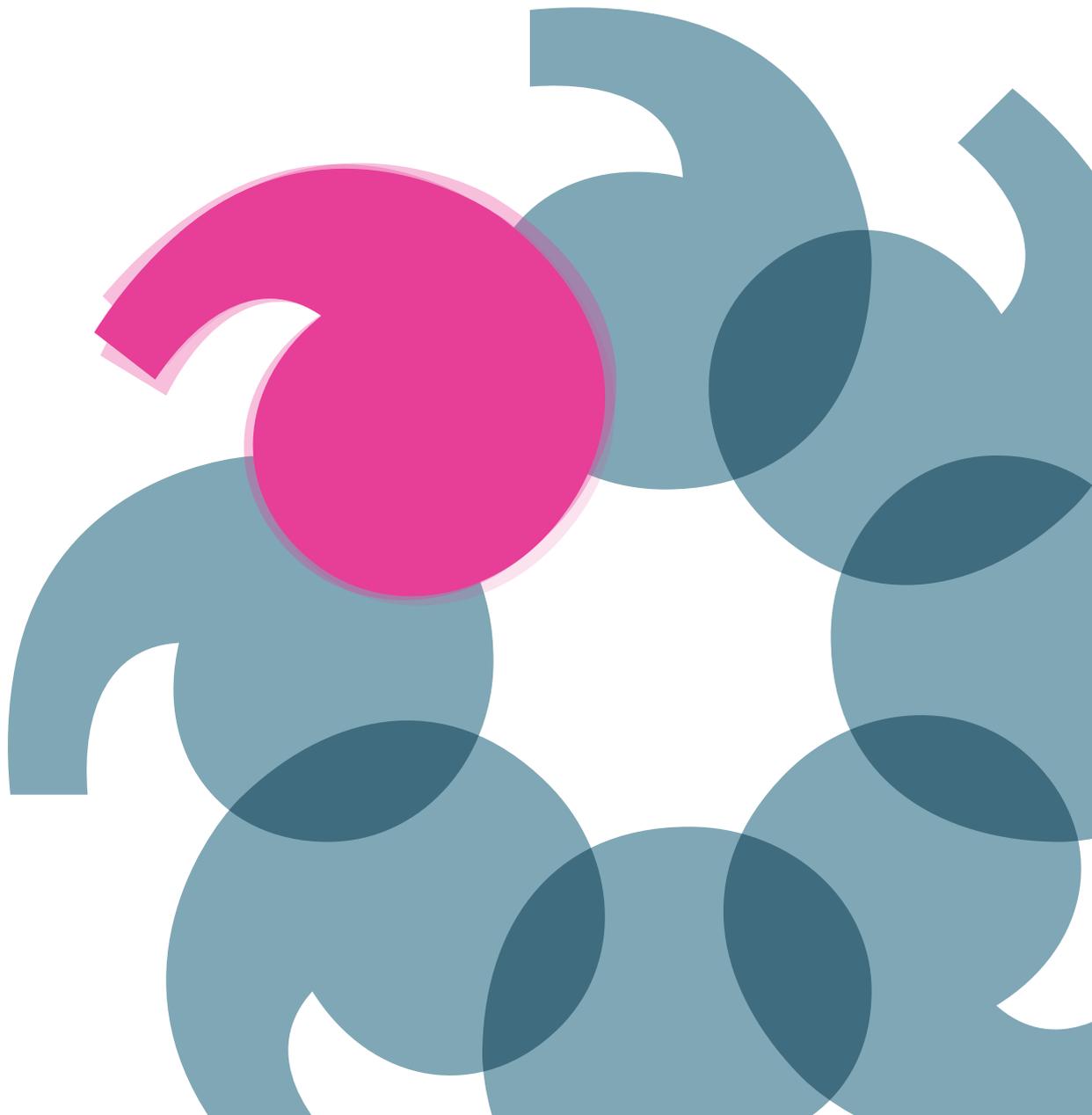


ADHD clinic for adults

Feedback on services for attention deficit hyperactivity disorder



Healthwatch Islington

Healthwatch Islington is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

Healthwatch Islington gathers local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are taken on how services will look in the future, and how they can be improved.

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Introduction

Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness. People with ADHD may also have additional problems, such as sleep and anxiety disorders.

The ADHD service for Islington and Camden residents is provided by the Camden and Islington NHS Foundation Trust. The service, which is for residents aged 18 and over, provides specialist assessment, as well as medical and psychological interventions where necessary.

The service was introduced in 2013/14 with need estimated at around 80 referrals a year. This figure was based on estimated prevalence levels provided by the National Institute for Health and Care Excellence (NICE). However, demand for the service has far exceeded these estimates. This is the case all across the country. In Camden and Islington there are around 400 referrals made to the service each year. Waiting times have increased and continue to do so. Waiting times are now running at 156 weeks (three years) for Islington residents.

Islington Clinical Commissioning Group is talking to Camden and Islington NHS Foundation Trust to discuss how waiting times can be reduced. They also asked Healthwatch to help them review the existing service. We heard from seven current users of the service. Two attended a Healthwatch meeting at the end of August 2017. This meeting gave them the opportunity to share their views with commissioners directly. Four service users that were unable to attend the meeting participated via phone interviews. One service user gave feedback by email.

Healthwatch meeting, 31 August

Background and context

Islington Clinical Commissioning Group has contacted other commissioning groups to see what waiting times for ADHD services are like elsewhere. Some boroughs (Ealing) have no local service and refer all patients to South London and the Maudsley (SLAM) for assessment. In Liverpool, which also only has a regional service, waiting times have reached seven and a half years.

Some patients from Islington choose to be seen at SLAM. There have been some delays to this pathway too, because SLAM have come back to commissioners to confirm each appointment. This has since been resolved.

Currently the service employs a psychiatrist to carry out the assessment and follow up, and a psychologist to support group work and any psychological interventions. This psychological support also has a one year waiting list.

The assessment process

Attendees included a patient who had been assessed when the service was fairly new and so hadn't needed to wait long, and a patient who had waited much longer for their assessment.

Both participants noted that they had had three appointments to get assessed. For the first these amounted to possibly 2 or 3 hours in total. He felt that it would have been useful to have more advice on how to manage the effect of the diagnosis, impacts on relationships, talking on the phone etc. He agreed the voluntary sector could provide this, and that even a leaflet would have been a help.

The second participant felt their wait had been slowed down by the need for some additional health checks before starting the medication. He noted that there is now some information given but that this feels like too little too late because you have to wait until you're assessed to access this. It would be better to have access to this whilst waiting for the assessment (as most people who are assessed do get a diagnosis).

Both noted that there were three forms (for the patient, a family member, and friend/ partner) to complete as part of the assessment and that this in itself could be a barrier.

It was suggested that the assessment process itself was not particularly 'curious', that it didn't look for what patients needed but simply went through the list. Staff could be more patient here to help explore the questions. Respondents stated that they would be happy for other staff to be involved in the process, for example, nurses to see them for their follow up appointments. Volunteers with lived experience could add something here too in terms of drawing out responses.

There was mention of the fact that services are not holistic and so whilst being treated for one thing, staff may or may not think about an ADHD assessment, for example in rehabilitation, on mental health wards and in prisons there are potentially lots of people with undiagnosed ADHD.

It was also noted that the service provider gathers user feedback on the assessment service and that Healthwatch and the CCG should ask to see this information.

Medication

There is NICE guidance around what patients should be prescribed. Following discharge from the specialist service, patients are directed to their GP if they experience side effects from the medication. However, not all GPs feel confident to prescribe changes and may prefer to refer patients back to the hospital. It was felt that this was unnecessary and needed to be addressed.

Group work

The second participant noted that the location of the group work was not ideal for ADHD patients as there was a lot of noise. There'd been 10 patients and two staff. Although the group was useful for making connections with others, the help could have come earlier. The group work addresses issues like sleep hygiene and coping techniques. Both participants felt that it would have been really helpful to have had access to this kind of support while on the waiting list.

Interviews

Interviewee 1

- ▶ On the length of the assessment process:
'The interview was distressing and confusing [because of an emotional disorder the patient experiences], but I don't remember how long it was.'
- ▶ Could nurses lead follow up appointments?
'You could see a nurse if they [the hospital] decides. The triage works at the GP [where staff decide whether you need a GP or a nurse].'
- ▶ On the group work:
'I was referred to the personality disorder service but not any group sessions, and I got re-ablement support. I would have liked group support.' [Healthwatch directed them to the local ADHD user group and Mind/ Hillside which the client sometimes uses]

Interviewee 2

- ▶ On the length of the assessment process:
'My initial assessment was for Asperger's maybe that confused things, waited around 12 months. (Didn't really recall the assessment process). The wait was excruciating and affected my mental health, the not knowing, wondering am I or not and the crisis in between didn't help.'
- ▶ Could nurses lead follow up appointments?
'My medication caused hyper episodes which I thought was standard but in the follow up I was referred to crisis support. Could a nurse have done that? I don't feel qualified to answer that.'
- ▶ On the group work:
'I had one-to-one psychology and that was great, the girl was great. It was around constructive dialogue and was very beneficial. I didn't join any groups.'

Interviewee 3

- ▶ On the length of the assessment process:
'I was referred a year and a half ago. Getting the GP referral took time and then I always had to chase the admin at the hospital. Got a referral and then it was two months till the diagnostic test, had to call twice to chase and they told me I'd hear from them by such and such and then the day would come and go and there was nothing so I had to chase. In the end there was a bulk email saying stop contacting us, we don't have the resources, we're overstretched. It was frustrating. I was told it was an 8 month list, I waited one and a half years. I looked in to a private assessment but I couldn't afford it.'

'It was one appointment, about two and half hours, then I had to go back in because I'd not brought the form, then I needed a second visit to it to be conclusive. All the appointments were fine, they lasted around 20-30 minutes, they are still sorting my dosage [September] I was diagnosed in July.'

- ▶ Could nurses lead follow up appointments?
'This would be fine, so many of the nurses are so good. It needn't be the consultant, just someone who knows what you want.'
- ▶ On the group work:
'I wasn't offered the group sessions. I was told I was only eligible if the medication didn't work, so they'll try me on that. I'd be eligible if the drug dosage was very high. I wasn't offered group sessions.'
- ▶ Anything else?
'Just the waiting times, the impact on my ability to work, I really struggled, affected my long-term planning. It's not life threatening, but it impacts on jobs and housing.'

Interviewee 4

- ▶ On the length of the assessment process:
'The assessment was great once I got through the GP gatekeeper it was fine. I was diagnosed by a different Trust, I was already on meds etc so no, I didn't attend any group sessions or anything like that. But I had to be re-assessed, that made no sense, I had to come off the meds, it was awful. I was assessed in Lewisham and then it was really difficult going through the assessment again. I had the medication stopped, it was awful. And now my blood pressure means I can't go back on them yet so I am waiting. The system shouldn't make these barriers. This condition, ADHD, it makes it hard to overcome little things. [Was the form OK?] The form was OK, but the process, getting to assessment was difficult. The GPs are stressed, it was the same in Lewisham though, I don't think it's particular to here. I waited about 6 - 9 months and it must have been a couple of years ago.'
- ▶ Would a nurse be able to do the follow up?
'I think this is a great idea. These don't need to be done by the person who does the assessment.'

Respondent 5 (by email)

- ▶ On the length of the assessment process:
'Okay. I remember [the assessment] being at least 3 hours long, while this may have seemed like a lot of time, I was relieved and confident that I was assessed thoroughly and effectively and given an accurate diagnosis. As this is a very crucial stage for anyone concerned if they had ADHD, I strongly believe that cutting the length of the assessments might compromise on the quality and rigour of the service. Length of follow up appointments was OK. I don't think I saw a nurse, if I'm not mistaken, I was seen by a psychiatrist. This was back in 2014/15 if I recall correctly.'

- ▶ On the one to one sessions and group work:
I only attended one psychology one to one session - this was in the same year I was diagnosed. The psychologist referred me to attend a group CBT (cognitive behavioural therapy) course on Anxiety, as during this time, there were no sessions which focused on ADHD management.

I attended 2 courses... the first course on managing ADHD, and the second on mindfulness, but unfortunately was not able to complete the latter course. I really benefitted from attending these courses, they were very well planned, [the tutor] led amazing sessions. The highlight of attending these ADHD management group sessions was hearing from others who were also ADHD. Hearing about their struggles, hopes, and problems and how they found creative solutions to cope and manage the condition was extremely therapeutic and useful for me. I am very keen on attending more of these courses, and I do hope that more of ADHD focused group courses can be organised on a regular basis.

- ▶ What would you like to change about the service?
'As it is right now, I am still unsure who to contact should I have a concern with my medication. It would be really useful if we were informed of how and who to contact if we had to discuss any concerns relating to ADHD medication.'

The psychology sessions were wonderful, but it would have been great if we had a few sessions to discuss getting help with ADHD medication. It would be extremely useful if there were group sessions where an ADHD psychiatrist could come in to answer questions and discuss issues pertaining to medication (what's new in the field, should I consider other types of medication, what types of supplements should I take, should I take breaks of my medication, etc.)'

Additional thoughts from Healthwatch

1	Is there a way of making it quicker for patients to have their medication reviewed by the Trust, if their GP is unable to do this?
2	Patients were very willing to consider alternative models if this would help others (or themselves) to be seen more quickly.
3	There was a suggestion that it would be helpful to access support and advice whilst waiting for assessment. This seems like a good idea as most people who are sent for assessment do end up with a diagnosis, but even if they do not, they could benefit from the learning around issues such as sleep hygiene.

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