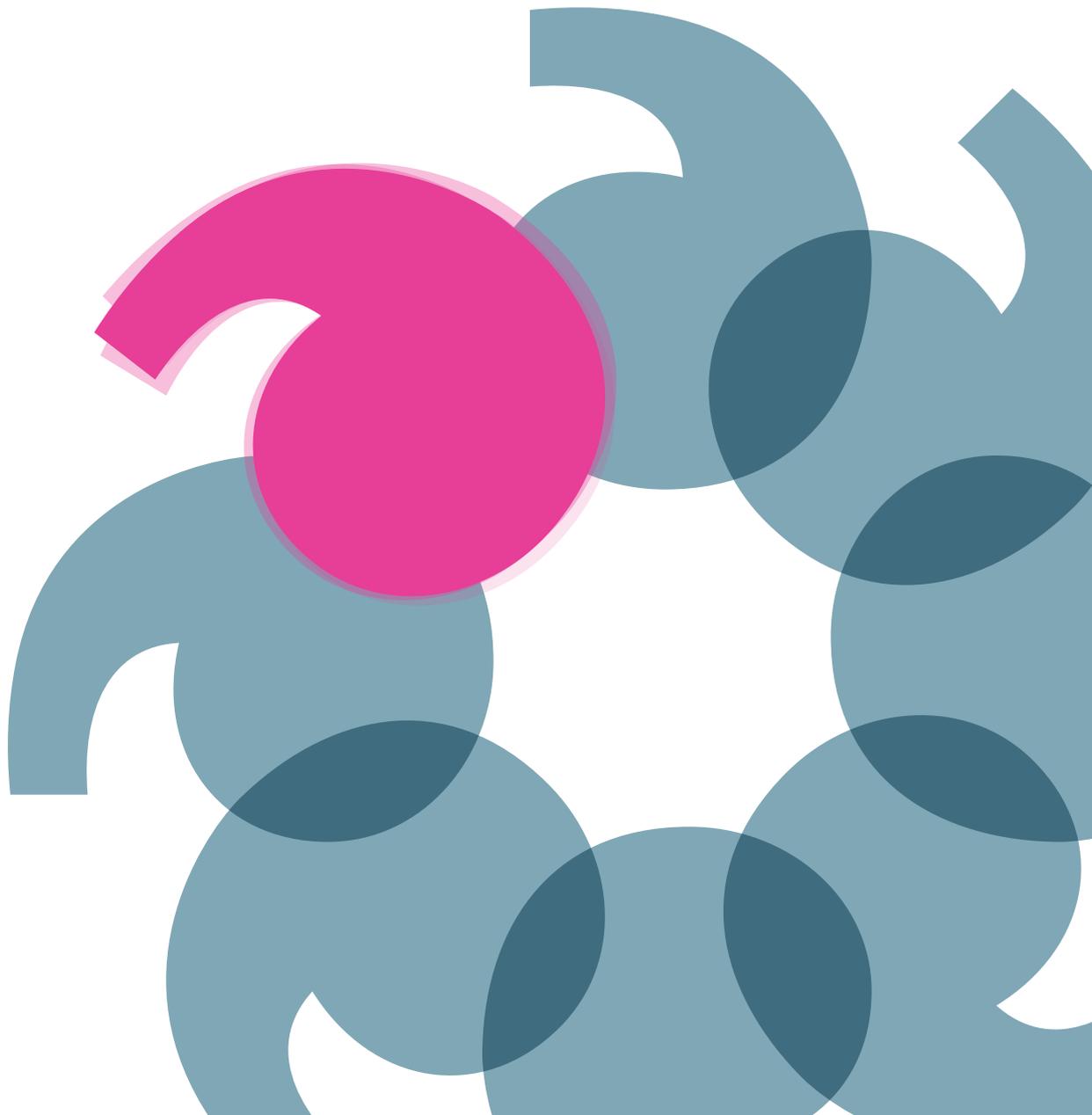


Gathering views

How well do local health and care services support the needs of people with autism?



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.

www.healthwatchislington.co.uk

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Introduction

Islington Council describes Autism Spectrum Condition (ASC) as a lifelong developmental condition that affects how a person interacts with other people. It affects their ability to understand the world around them, and adapt to new or unfamiliar situations. People with autism often experience sensory problems, particularly with bright lights, loud noises, strong smells and taste and touch. It affects people differently, though a significant proportion of adults across the whole autistic spectrum experience social and economic exclusion. Some, but not all, people with autism also have a learning disability.

There has been an increase in autism diagnoses in the borough. During 2014, Healthwatch Islington talked to local parents and picked up concerns about how the needs of children with autism, and their families, were being met.

The council established an Autism Partnership Board in 2015. Its work plan includes an aim to ensure that local health and social care services make 'reasonable adjustments' for people with autism.

Throughout the Autumn of 2016 we spoke with Islington residents with Autism Spectrum Condition, and with their families. We heard about their experiences of health and care services and asked them whether they felt those services were doing enough to accommodate their access needs.

What we did

To reach people across Islington who had autism (or were a family member or carer for someone who was autistic) we worked with organisations providing support services, such as Centre 404 and ALAG (Asperger London Area Group).

We publicised the autism project at a range of community events, such as the Cally and the Manor Gardens festivals, through social media, with flyers in local health services, and through our membership.

We offered people a wide range of ways to give their views. We attended meetings at partner organisations, hosted focus groups and created an online survey. People could also take part through a short telephone interview or by emailing us their story.

Although we were most interested in learning if and how health and care services were making reasonable adjustments to accommodate the needs of autistic service users, we were not proscriptive. We wanted to give respondents the chance to talk about what was important to them.

Participants also shared their more general experiences of autism. In addition, we asked for feedback on how easy they found it to get an initial diagnosis.

We spoke to 60 people across the borough. We wanted to hear from people of different age groups and from across the autism spectrum.

Who we spoke to

Individual with autism	15
Carer of someone with autism	33
Family member	7
Healthcare professional	5
Total	60

How people gave us their views

Focus group	12
Interviews	26
Email or website comment form	3
Online survey	12
Group meeting	7
Total	60

Group meetings followed a less structured format than focus groups. Where these meetings were attended by a mix of people from different boroughs we have only counted (and included feedback from) Islington residents.

We also received a range of queries from local residents wanting to know more about diagnosis and support available in the local community. We provided signposting in those cases.

Sex of person with autism*

Female	Male	Prefer not to say	No data	Total
21	21	1	17	60

Age of person with autism*

0-18	18-24	25-49	50-64	65 +	Didn't say	No data	Total
29	3	10	3	0	1	14	60

Ethnicity of person with autism*

Black or Black British	6
Mixed - White and Black Caribbean	5
Latin American	1
White - British	18
White - Other	3
Other	1
No data	26
Total	60

* We may have heard from the person with autism directly, or about them from others.

Findings

Accessibility of health and care services

It was felt that more could be done to make health and care services accessible to people with autism. It was also felt that the experience of accessing autism specific services was inconsistent, varying widely between individual service users.

Awareness of autism amongst health and care staff

In general it was felt that there was a lack of awareness of autism and how to meet the needs of people with autism and that more training was needed on this.

Availability of autism-specific services and information

A number of respondents called for more easily accessible and comprehensive information about autism-specific services. Several parents talked about the need for training on meeting the needs of their child.

Diagnosis pathways and processes

Many respondents spoke about the assessment and diagnosis of autism. The process was felt to be complex and lengthy, with more information and support needed. The point was also made that it was even harder to get an autism diagnosis as an adult.

Accessibility of health and care services

45 people spoke to us about the accessibility of services. Almost all these respondents felt that more needed to be done to put support in place for individuals with autism and their family/ carers.

Services are not flexible

Respondents said that it is often the patient who is expected to make adjustments when accessing services. Patients with autism can find accessing services incredibly difficult. Respondents felt that there was not enough flexibility from services to cater for the needs of these patients.

‘Surgeries aren’t very accommodating and we can’t wait in the waiting room. [My son] spits and he swears. They’re not very accommodating when I ask for a separate space... My son spat in my GPs face because he wasn’t communicating clearly and now [the GP] said he won’t examine my son.’

Respondent 40

One carer explained how the child they care for ‘refused to go back to CAMHS [Child and Adolescent Mental Health Services] as she feels they don’t change for her needs.’ [Respondent 4]. One parent mentioned that their ‘doctor knows my son has autism and he wasn’t flexible at all. He shouted at my son because he wouldn’t co-operate.’ [respondent 50 – son has a severe speech delay].

Another parent said ‘We go as little as possible to the GP because it can be a nightmare! Getting an appointment is so hard. There is a 2 week wait or I have to go in at 8am and put her name down for an appointment. Waiting for 30 minutes is doable, anything longer is a nightmare.’ [respondent 44]

Difficulties accessing GP appointments and frustrations over short appointments, ‘getting only 10 minutes per patient isn’t helpful, [respondent 25], are complaints that we also hear from people who are not on the autism spectrum. However, for individuals with autism, and their families, those frustrations can be more keenly felt.

Respondents spoke of sensory needs, anxiety and communication impacting on their daily lives. Also highlighted in responses was the need for routine, careful planning of new activities and the particular challenges of making journeys.

Waiting areas do not meet the needs of autistic patients

Parents told us that health and care providers needed to do more to make it comfortable for autistic children to spend time in their buildings, ‘He is a person. He has the same rights as another person but he’s got autism. Some people need a wheelchair, so you try to provide one. My child needs a separate room whilst waiting in hospital, so why not provide it?’ [respondent 36]

Though some existing good practice was recognised:

‘Let’s say you are number ten in the queue at the doctors - you have to wait. But at River Place Health Centre, when they see that my child is autistic, I jump the queue. But not all GPs are the same, and it’s hard to wait. At the GP there are no toys or fish like there are at the Whittington.’ [respondent 34]

‘[My son’s] GP is brilliant. But hospital out-patient departments, dentists, hairdressers, libraries and gyms all need to make reasonable adjustments if they are going to meet the needs of autistic people. It may mean [having] somewhere else to sit other than the main waiting area, or organising appointments at the very end of surgery so other people are not waiting in the room.’ [respondent 8]

A bilingual support worker [respondent 58] also told us about the stress going to the doctors can create for one of their clients. The mother finds it stressful to take her son to the GP surgery, or to any health service where she has to wait in a room full of people for a long time. There were many similar comments.

Frustrations accessing medicines

It was not as widely reported, but two parents participating in a focus group asked for easier ways to get prescriptions in cases where the treatment needed was already known:

'My son has blepharitis a recurring eye condition that comes on quite quickly and has to be dealt with straight away. The GP can't give you anything strong enough so you have to go to A&E at Moorfields and wait for three hours [very difficult with a child with autism] and then you can get the treatment which is [an antibiotic cream] you can only get at the hospital pharmacy.' [respondent 33]

'Yes, even for smaller conditions such as constipation getting repeat prescriptions can still be a huge process. It would be good to skip all the fuss and just get the medicine.' [respondent 32]

GPs are not always best placed to decide what services a child needs

Some respondents told us that medical professionals that had an ongoing relationship with their autistic child, such as their health visitor, were better placed to make good decisions about the services that they needed than their GP, with whom their child had no real relationship.

'Everything has to be accessed through the GP which is not helpful because [they don't] regularly see their doctor' [respondent 39]. 'The paediatrician or speech therapist could be the advocate' [respondent 31].

Another parent argued that having the GP functioning as the gatekeeper for services was problematic in any case. 'It's very difficult. Your GP is your first port of call. If they're not on it, or they don't know much about autism then you don't get anything else.' [respondent 29]

People had varied experiences of the accessibility of services

This point was made in reference to autism specific services in particular and arose out of discussions around diagnosis. 'It's just the luck of the draw' [respondent 29]. 'So much difficulty in getting the service. It should be easier. Nothing's straightforward and it's not consistent. The way another parent has accessed a service could be completely different.' [respondent 32].

It was also commented that services are harder to access because 'the support available is only during working hours' [respondent 38].

The need for continuity was highlighted

'Staff at occupational therapy change too much. It's hard for my child to get used to another person. It wastes time.' [respondent 33] 'Occupational therapy is offered in 6 week blocks and when it's finished you have to fight for the service again. You have to get someone to re-refer you and this has to be done by a professional.' [respondent 30]

Access problems due to the nature of autism

'It's an unseen disability. That makes it hard to get the services you need' [respondent 32]. 'My 13 year old boy looks completely normal. People don't think there is anything wrong with him but I know he's vulnerable' [respondent 35].

Awareness of autism amongst health and care staff

Lack of understanding

26 people spoke to us about the need for greater staff awareness and training around autism and the needs of patients with autism. Responses evidenced a lack of understanding and a lack of accommodation of needs across many health and social care services - respondents mentioned GPs, hospitals, social services, opticians, mental health services and children's services.

'You kind of expect psychologists [at Great Ormond Street Hospital] to know what they're doing. They're specialists with autism, but even they didn't seem to know how to communicate with [my son] best.'

Respondent 55

People felt that one of the biggest barriers to those with autism receiving high quality care was a lack of understanding amongst health and care staff of an autistic patient's communication needs. One respondent pointed out 'when you say "my child's got autism", training should kick in and you should be supported.' [respondent 36]. Another explained 'the optician asks [my son] a lot of very quick questions and my son's a bit slower so he struggles... could do with someone who is a clear communicator.. Sometimes they bombard him with questions and they need to pause a lot and let him answer.' [respondent 53].

Parents, carers and adults with autism reflected that professionals often do not accommodate needs; 'the GP doesn't seem to understand or help very much,' [respondent 47]; '[professionals] don't seem to have that ability to ease [my son] in and make him more open to receiving treatment... [Some] feel like they're just following the textbook.' [respondent 55].

'Getting their needs assessed was very difficult as half of the professionals in social care do not have an understanding of autism.' [respondent 7]

One respondent explained that they had given up trying to pursue a referral because it 'got too stressful dealing with people who lack knowledge and/ or an understanding of autism.' [respondent 9]. I am constantly fighting to put things in place. [respondent 48]

One respondent mentioned that 'professionals could use symbols or text so [my son's] happy and more independent.' [respondent 51]. They felt that training for professionals and a greater implementation of different communication methods would improve the care of patients with autism and other communication needs. Another parent said it feels like 'it's a long chain with so many professionals and it always breaks somewhere. Why are there so many teams and departments etc?' [respondent 28]

Some staff demonstrate good awareness of autism

There were also examples of staff being aware of needs and accommodating those needs.

'The consultant at Moorfields Hospital is very respectful and talks at the right level.' [respondent 2]

'GP always deals directly with her (and not with me the carer).' [respondent 4]

The same respondent told us how, when the GP was referring the child they care for to A&E, they wrote a letter so 'she didn't have to explain herself when she got there.' In fact a few parents spoke positively about Whittington A&E in particular, because once they know a child has autism they tend to prioritise them there.

Existing good practice in Islington

The Community Dental Service

'Wendy Bellis the community dentist has awareness about children with autism.'
[respondent 34]

Respondents spoke about how well this service makes adjustments for autistic patients. For example, it meets needs by; 'giving you longer appointments (30 minutes) and talking to him properly like a normal human... talking directly to him, he's non-verbal but he does understand things.' [respondent 43].

It was mentioned that the team use appropriate methods of communication such as Makaton [respondents 27 and 29] and sign language. Parents and carer's spoke about how challenging taking those with autism to the dentist can be - but one parent said that their experience of the community dental services had transformed that and now 'my son loves it!' [respondent 27].

Flexible approaches from some GPs

One respondent was happy that their GP service was accessible. 'My medical centre is pretty good. When we need an appointment the doctor will phone me back to find out what's going on and if it's serious they will squeeze my son in.' [respondent 45]

An adult with a diagnosis of autism, talked to us about how developments in healthcare technology had improved access for them:

'I can book GP appointments online and then I can always choose the same doctor at a time that suits me. I have a good doctor, at one point I had a specific situation that this one GP from the practice took interest in and now I always see them. I email my doctor (via the surgery reception) before appointments with a list of what's going on and I ask him to stick to that structure in the appointment. That way he's prepared before I see him.' [respondent 23].

Availability of autism-specific services and information

Differences in availability of services

Differences in the availability of services for those with high functioning Autism Spectrum Condition compared to those with a Learning Disability was an area that was highlighted.

One parent explained 'There is nothing available for high-functioning people...It would be hard for [my son] to be grouped with those with a more obvious disability. He's very sensitive to that.' [respondent 55]

Differences in the availability of services for under 18s and over 18s was also a theme. Several respondents stated that more services were available before they turned 18. 'NHS services are non-existent for Adults with ASD in Islington' [respondent 19]. One mother told us that 'when [my son] turned 18 and left school - it was like having to start all over again. That part is quite stressful.' [respondent 43]

Crisis Services

One respondent suggested that there was a need for crisis services: 'There are no services for people with autism who are having a crisis and might need or benefit from more specialist intervention from a care coordinator and social services for adults.' [respondent 18]

It is difficult to find information about autism and autism specific services

'I've heard of CAMHS but I don't know where they are [respondent 53]

11 respondents spoke to us about how hard it is to find information about autism and the services on offer in the borough, and that no one practitioner or clinician really has the whole picture. It was felt that this increases the workload of parents and carers. They also said that communication about service provision and support needs to be consistent as information gets lost easily.

'The problem is that information [about autism services] is not all in one place, you have to really look for it. If you weren't well informed already, you wouldn't find it...there's no joined up thinking or integrated service.'

Respondent 4

'Islington is flooded with too many services and it's really complicated.' [respondent 46]

Carer's and family members also spoke about wanting training and clearer information on how to better meet the needs of their loved one. They felt that this would in turn make accessing services and care easier.

One respondent (a support worker) mentioned that as part of the speech and language therapy service, parents can have a few sessions with therapists in which they are given practical tips on how to manage their child's behaviour.

Support services based in the community have their limits

Some parents spoke to us about the new Family Action Islington Special Education Needs Community Support and explained that now 'the service is just a phone call. It's not a community. Even to access it you have to be called back.' [Respondent 34]

In one of the focus groups one parent explained how they were 'offered the early bird course [a support service for parents] soon after diagnosis' [respondent 25] but others explained that it was only offered to parents of children under 5 and another parent explained that the course didn't offer childcare so some parents were unable to attend as they had other children to care for too.

Diagnosis pathways and processes

35 of those we spoke to during this project spoke about diagnosis pathways and processes.

Waiting times

15 respondents said that the process of receiving an autism diagnosis took a long time. 'There was lots of waiting involved' [respondent 25]. 'We were waiting for eight months for an appointment' [respondent 52], 'It was very difficult. It took a long time between appointments,' [respondent 53]. 'The diagnosis was over several months and such a stressful time...I had to take time off work for [the appointments]' [respondent 38].

Respondents spoke about there not being clear explanations for the long waits or any details at the beginning of the process to what to expect. '[there were] no updates as to how long the delay would be' [respondent 14]. 'It felt like a long process but it was an average time I think after speaking to other parents' [respondent 47].

Difficulties with the process

A number of respondents said they had found it difficult to get referred, or had found the process itself difficult. 'Getting the diagnosis is always a battle... compared to others, I didn't have much of a problem.' [Respondent 48].

Some respondents believed this was to do with funding, 'some children only get diagnosed with 'autistic traits' I think it's to do with money.' [respondent 40]. At the focus groups parents and carers spoke about their children being diagnosed with 'autistic traits' as a way of reducing spending, then the child would have to come back in 12 months' time and could be diagnosed in the next year. An adult who had experienced going through the assessment process themselves said, 'The council were reluctant to make the diagnosis official and add it to my care plan. I found out later that this was due to funding. That, and the resources that would follow my diagnosis.' [respondent 13]

Having to repeat the assessment process

Parents and carers also spoke about having to go through the assessment process more than once, 'we've been through the same process twice. It was really hard work...' [respondent 46], 'The first diagnosis found [my son] not to have autism because he made eye contact. I then had to wait another year before getting the diagnosis' [respondent 48]. One mother mentioned that 'my son had to go through two assessments. His first was through the Child Development Team which is for under 5's and they were supportive. The one he had this year was through Child and Adolescent Mental Health Services and they are less supportive and it felt far less official.' [respondent 44]. One parent mentioned that they 'went through the whole process and they said "come back in a year"... we were told he had autistic traits.' [respondent 39].

Even harder for adults

Respondents said that the process of getting a diagnosis is even more difficult for adults.

'Getting a diagnosis for my kids was very hard. Getting diagnosed as an adult is virtually impossible - I had to pay for private assessment.'

Respondent 9

Another adult with ASC explained that they 'got a private diagnosis but [are] still on the waiting list for the NHS to rubber stamp it having been referred for a diagnosis in September 2015.' [respondent 12] One professional explained 'the vast majority [of adult patients] feel that earlier diagnosis would have been helpful to them... there is a wait of almost a year for a full assessment with them.' [respondent 16]

Lack of information and support

Six respondents mentioned a lack of information and support during diagnosis. 'The diagnosis was very long. I had to wait from initial referral for two years. [My son] didn't receive any services or support during this time.' [respondent 50]

'Whilst we were waiting for the diagnosis, or before the process started, I could have done with some support (specifically targeted at children without a diagnosis yet). This could have been from other parents explaining what might happen and what we might need to know. That's when you need the most support.'

Respondent 44

One respondent commented 'I was just given the diagnosis and left' [respondent 25]. 'I didn't know what autism was so I went to the library and read like a mad woman. I think things would be different now.' [respondent 43]

But not everyone reported difficulties

Three respondents said that the diagnosis process was fine. One had found the counselling offered helpful.

'I was offered counselling when I was going through all this [their child's diagnosis]. It was really helpful.' [respondent 24]

What respondents told us would help

40 people spoke to us about good examples or aspirations for services. Some of those we spoke to spoke about some of the good experiences and services they've used:

Better preparation for appointments

Respondents spoke about how services could be more prepared and better equipped to manage the needs of their service users with autism:

- ▶ Professionals should be familiar with the 'patient notes that flag up the needs of individuals, and take it seriously' [respondent 4] and that this should affect the whole care of the individual from arranging the time of an appointment (at the quietest time of the day) to providing slightly longer appointments.
- ▶ Services should provide points of contact that are autism friendly. Professionals could encourage patients to use 'alert cards' or 'autism passports' or provide autism friendly clinics [respondent 9].
- ▶ It could help prepare children for appointments if 'when you are sent an appointment letter they should send you something saying here is the social story of what the premises is like, what it looks like, how long you can expect the wait to be' [respondents 12 & 10]
- ▶ 'People who are vulnerable should receive reminders and calls, they should never be expected to initiate a consultation because this is a challenging role for them.' [respondent 51]

More support for parents and family carers

Parents and carers spoke about wanting more support and clearer, more accessible information

around caring for their children with an autism diagnosis:

- ▶ A specific page on the council web-site or directory.
- ▶ A specialist autism co-ordinator should be provided, 'a neutral person who could advocate for you, saying "yes, you should have this service"'. [respondent 31]
- ▶ 'A route diagram would be useful'. [explaining how to access all autism specific services] [respondent 32]

Adjustments to appointments and waiting times

Parents and carers spoke about the importance of 'having a quiet space when attending appointments' [respondent 7] or a 'separate waiting room' [respondent 36] with toys or a 'sensory environment' [respondent 31]. Some suggested that 'greater ability/ willingness to have home visits [would make health services easier to access], the surgery and clinical settings are very intimidating' [respondent 8]. Professionals could take their time and use symbols or text to communicate with patients [respondent 51]. Respondents said that sometimes services prioritised patients with autism, but it was felt that this should happen more across the board.

The need for continuity and routine

People told us that continuity and routine was especially important for service users with autism. This was mentioned in the context of perceived high staff turnover within speech therapy and language services. Others noted the disruption caused by the rescheduling of appointments, 'Dentists (not the community dental services) keep calling and rescheduling - it's really hard!' [Respondent 38].

Related work

Westminster Commission on Autism

The Westminster Commission (2016) found that 83% of respondents felt that professionals don't listen to them. The Commission concluded that several small changes could be made to improve services for those with Autism. They suggested that the Care Quality Commission (which regulates health and care services) include autism-specific questions in their inspections; that all health and care professionals should receive autism training and that GP's should record the needs of autistic patients and make reasonable adjustments to meet these needs (this would be in line with the requirements of the Accessible Information Standard. The report also suggested that the NHS create Autism Champions.

Think Autism Strategy

Similar themes were to be found in the Think Autism Strategy such as; increasing the awareness and understanding of autism, developing clear consistent pathways for the diagnosis of autism, improving access for adults with autism to services and support, and enabling local partners to develop relevant services to provide support.

Recommendations

1 Reasonable adjustments from all health and social care providers

Respondents asked that health and social care providers make reasonable adjustments to better meet their access needs. They should offer somewhere else to wait for patients with autism, or appointments at times of the day when the service is less busy. Home visits might be considered in certain cases. Respondents also asked for easier ways to access repeat prescriptions, slightly longer appointment times, and more assistance in preparing for appointments.

- ▶ Commissioners should support health and social care providers to make these reasonable adjustments. Existing good practice in the borough (some of which has been identified in this report) should be highlighted and shared, as part of this effort.
- ▶ The Accessible Information Standard requires that providers talk to patients and carers, to understand their communication needs. Where particular needs are identified, for example in the case of patients with autism, providers are required to formally record those needs, and ensure that staff are aware of them, and meet them. We recommend that this be acted upon immediately as providers were required to meet this standard as of July 2016.

2 A more integrated approach to care from autism specific services, in line with NICE guidance

Respondents complained of inconsistent access to autism specific services, difficult referral pathways, and a lack of continuity within services. There was a perception of lack of integration between services. Respondents spoke of the need for a central information point or contact person, and of the need for support and advocacy.

- ▶ Commissioners should examine existing models for delivering integrated care for patients with higher levels of need, such as the Multi-Disciplinary Teams, Integrated Care Ageing Team, and the Locality Navigators. Where possible, lessons learned about what works for patients should be brought in to the delivery model for autism specific services, so as to make the service user experience less fragmented.
- ▶ Commissioners should also explore whether specialist nurses and specific autism friendly GP practices could be set up within the borough.
- ▶ The Autism page in the Directory on the Islington Council website needs to be more comprehensive if it is to meet the needs of service users calling for a central information point on autism. For example, it should include information on all related health and care services supporting people with autism, how to access them, and how long you might reasonably be expected to wait for a referral.

3 Better autism awareness amongst health and care professionals

Respondents felt that there was a general lack of understanding of autism amongst health and care staff, particularly regarding autistic patients' communication needs.

- ▶ The Map of Medicine Tool (also used by GPs to provide information for residents with a Learning Disability) should be maintained so that healthcare professionals can use it effectively.
- ▶ Autism training should be provided for Islington's health and care staff. Ideally, first hand experiences from service users and carers will be included in this. This training should also make all staff aware of the Map of Medicine tool, to enable them to provide effective signposting.
- ▶ In recognition of the fact that this change will take time the council could fund some additional support from local organisations already working with residents with autism to create a short-term 'hub' where peer support, and information about rights and entitlements of residents with autism and their carers could be accessed.

Two suggestions from the Autism Partnership Board

Islington's Autism partnership board brings together different organisations, services and stakeholders and sets a clear direction for improved services. Responding to the content of this Healthwatch report, they put forward two additional suggestions:

4 Commissioners could explore how we might work with the Royal College of GPs or Department of Health to pilot an 'Autism Friendly Practices' project to help bring in investment and resources to share learning and raise the standard of support.

5 Commissioners to consider whether liaison nurses could be appointed to share good practice around working with patients with autism who have complex needs. They could work across GP practices, in the same way that liaison nurses work across care homes.

Appendix

NICE guidance

<https://www.nice.org.uk/guidance/CG142/chapter/1-Guidance#interventions-for-autism>

1.1.13 In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

healthwatch
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