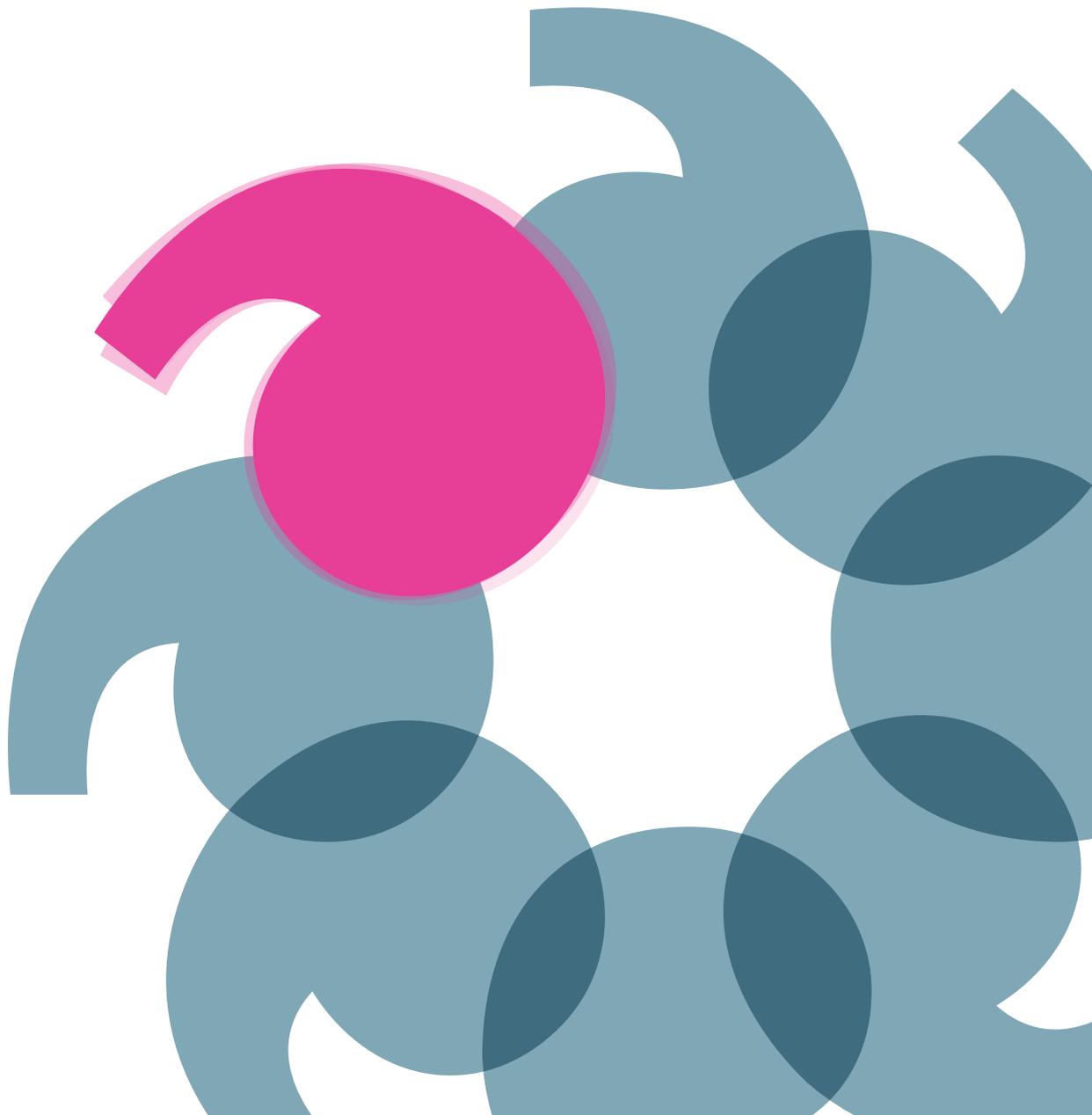


# **Support offered at GP practices in Islington for patients with autism**

## **A mystery shopping project**



## **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.

Some of our volunteers are trained as mystery shoppers. Mystery shoppers engage with health and care providers, posing as service users. This enables them to assess how well the providers perform in terms of customer service and information provision.

[www.healthwatchislington.co.uk](http://www.healthwatchislington.co.uk)

## **Contents**

<b>Introduction</b>	<b>3</b>
<b>Background and method</b>	<b>4</b>
<b>Summary of the findings</b>	<b>5</b>
<b>Findings</b>	<b>6</b>
<b>Recommendations</b>	<b>9</b>

# Introduction

In early 2017 Healthwatch spoke with Islington residents with autism and with their families. We heard about their experiences of health and social care services and whether they felt those services were accommodating their needs.

Respondents felt more could be done to make general health and care services accessible to people with autism.

We formulated a mystery shopping scenario based on feedback from our research, and on our conversations with ALAG (Asperger London Area Group). Mystery shoppers called GP practices posing as newly arrived Islington residents looking for a practice which could accommodate their under 18's needs. They stated that their child had a diagnosis of autism.

We contacted the 35 Islington GP practices to see:

- ▶ How many practices have specialist experience of autism,
- ▶ What kind of reasonable adjustments they would be able to make for patients with communication needs.

# Background and method

## The rights of the patient

It is a statutory requirement under the Equality Act 2010 and the Health and Social Care Act 2008 that public sector agencies make 'reasonable adjustments' to services. Further information is set out in the Accessible Information Standard which came in to effect from July 2016. These adjustments are to make services accessible and effective for all, including people with autism, learning disabilities, mental health issues, or a combination of these.

Adjustments make the service easier to use. For example, adjustments could be made to appointment times, duration and interventions with the doctor. Recording systems in GP practices should identify people with autism, learning disabilities, mental health issues, or a combination of these, and show any reasonable adjustments they require. This could include easy-read appointment letters and reminder phone calls or texts, or contact whilst waiting for an appointment, so people know they are not forgotten.

## Method

Mystery shoppers called practices posing as newly arrived Islington residents looking for a GP practice which could accommodate their under 18's needs. They stated that their child had a diagnosis of autism.

They called during a 3 week period from the end of October to early November.

- ▶ We spoke to staff at 33 out of 35 practices.

We called outside of the busiest periods (not in the first hour after a surgery had opened in the morning, nor in the first hour after the surgery had started again in the afternoon). We called back if reception staff were too busy to speak. Not all reception staff were able to answer all of our questions, some tried their best and others asked us to call back and speak to the Practice Manager.

# Summary of the findings

	<p>There is inconsistency across the borough, in terms of how patients with autism are supported.</p>
	<p>Staff knowledge - not many practices had staff with any specialist knowledge or training around autism. Some practice staff suggested sending autistic patients to a better equipped practice.</p>
	<p>Recording needs - practice staff may need support to record and identify needs, though some practices knew they had autistic patients.</p>
	<p>About half the practices said they could offer autistic patients appointments at quiet times of day. However, it was not easy for some of these practices to predict when they were likely to be quiet.</p>
	<p>There was a lack of quiet spaces for patients with autism to wait (either GP centres didn't have a room, or they just used 'whatever is available' and this would often be unsuitable e.g noisy, busy, or hard to predict if it will be free).</p>
	<p>Longer appointments - most practices were happy to give patients with autism longer appointments.</p>
	<p>Continuity of care for planned appointments - most practices confirmed that patients with autism could see the same GP each time. (Some practices didn't want to raise expectations, as many of their GPs worked part-time).</p>
	<p>About half the practices said that patients with autism would be able to email their GP prior to their appointment, to agree in advance the points to be discussed.</p>
	<p>Most practices said they could offer appointments over the phone if needed. Several said they could also offer home visits if necessary.</p>
	<p>Online services - most practices explained that appointments and repeat prescriptions can be booked online. (We know that all practices are set up to offer this in Islington.)</p>

# Findings

## Staff knowledge and training

We asked whether the practice had staff (clinical or non-clinical) with any specialist knowledge or training around Autism. Not all practices were able to answer. Of the 28 which could, five said that they had staff with specialist knowledge or training, and 23 said staff had neither specialist knowledge nor training.

## Recording autism and patients' needs

We have been told that patients with autism and their family members or carers often have to explain themselves repeatedly to professionals. We therefore asked each surgery whether they had a way of recording the child's autism on the system they use to hold patient information. (All practices do have the ability to record a communication need, such as Autistic Spectrum Condition on their system, along with the patients' individual needs. Our question was designed to test awareness of this fact.)

- ▶ 24 practices said this would be possible and would be logged using a 'medical alert'.
- ▶ Two practices said this wouldn't be possible. However, of these, one responded 'It will be recorded same as last GP. We do not give preference unless requested' so perhaps they did not understand the question.
- ▶ At two practices the individual we spoke to did not know the answer to this question.
- ▶ Five practices did not answer this question, either because we got through to an automated response, because they weren't accepting patients, because they required our postcode before they gave us information, or because they said they could not accept an autistic child as a patient.
- ▶ Four of the practices said that they already had autistic patients.

- ▶ Two practices said that they weren't able to support patients with autism, 'We don't have any autistic children at the practice and we would send you to another practice' [Practice 22].

## Making reasonable adjustments

### ▶ Appointments at quiet times of day

16 Practices said it would be possible to have an appointment at a quieter time of the day, however, only 10 practices could identify the quietest time of the day with the rest saying that it varies.

4 practices said that this would not be possible as there is no particular quiet time of the day. 13 Practices didn't or weren't able to answer this question.

### ▶ Quiet waiting spaces

Practices have limited space but we have been told that having a separate space to wait for appointments can make a big difference to some autistic patients and their families/carers.

18 practices said that they would be able to provide a quiet or separate waiting space for patients. Two practices identified designated areas for this purpose in their practice.

'We have a main waiting area and separate quiet area available all the time.' [Practice 32]

16 practices said they could offer a space if necessary, such as an empty consulting or meeting room.

'A multiple purpose meeting room could be made available if not being used - trial and error, no set time.' [Practice 9]

'We would do our best to seat him separately. We've no dedicated quiet space.' [Practice 6]

Nine practices said that there wasn't a quiet or separate space for patients to wait for their appointments, with five adding that this was because they didn't have enough space.

### ▶ Longer appointments

24 practices said that they would be able to offer patients longer appointments if needs be. 12 practices mentioned booking a double appointment and 8 said that it would be at the doctor's discretion.

Practice 2 pointed out that all their evening appointments were 15 minutes long.

### ▶ Alternatives to a face-to-face appointment

It can sometimes be difficult to attend GP appointments due to additional stress and anxiety that autistic patients may experience. We asked whether practices could offer a telephone appointment or a home visit in such cases.

22 practices said it would be possible to have a telephone appointment with three of those saying they could also arrange a home visit if necessary. (Practices 31 and 32 actually prefer to arrange telephone consultations and only arrange face-to-face appointments after a conversation between patient and GP has already taken place.)

Two practices said this wouldn't be possible with nine suggesting that this would be possible if mentioned when booking the initial appointment.

We also asked whether surgeries could offer internet call appointments. Two practices were able to offer such a service.

We were also told by family members and carers that sometimes it would be easier to attend face-to-face appointments without their autistic child. Two practices said this wouldn't be possible but 14 said this would be fine, with one suggesting that a telephone appointment might be more suitable in such situations.

### ▶ Continuity of care

We asked how likely it was that patients would be able to see the same GP for routine appointments. 20 Practices said this would be possible, with seven adding that this would need to be requested. At one practice (Practice 9) the receptionist confirmed that the child would be registered with the GP with autism training.

5 practices said they couldn't promise that you would always be seen by the same GP because many of their GPs worked part time.

### ▶ Communicating before an appointment

15 practices said that autistic patients would be able to email their GP before their appointment to list the points they wished to cover (to aid their communication when with the GP). Five practices said that this would not be possible. A number of other practices were unsure.

'Not done before - don't see why not if it's easier for patient and GP' [Practice 32]

### ▶ Last minute cancellations by the practice

Plans changing with no explanation can increase anxiety for autistic patients. We asked practices how they would communicate the cancellation of an appointment. 19 practices said they would call the patient, family member or carer as soon as possible to discuss how the patient would prefer to reschedule the appointment.

### ► Updates on waiting times

We also asked whether patients would be told how long they would have to wait to be seen, once they had arrived for their appointment. Only one practice said they wouldn't do this. 17 practices said they notify patients of any changes to waiting times on arrival at the surgery. One practice said that they would try to ensure that our child was seen as soon as possible, even if this meant skipping the queue.

### ► Online booking and repeat prescriptions

Since March 2015 GP practices in Islington have been required to provide patients with access to online services such as appointment booking and repeat prescription requests. We asked the practices whether we, as parents, could book appointments on behalf of our child.

24 practices said that we could. One practice said this wouldn't be possible. Another practice stated that parents are not able to book appointments for children under 16 online.

# Recommendations

<b>1</b>	Islington Clinical Commissioning Group to follow up with practices currently offering less flexibility to give them advice and ideas about making reasonable adjustments.
<b>2</b>	Islington Clinical Commissioning Group to offer support to practices unaware of how the IT system can record and flag need.
<b>3</b>	The Islington Autism Partnership Board partners to highlight rights and entitlements to residents with autism, and their family and carers.

**healthwatch**  
Islington

Copyright © Healthwatch Islington 2018  
200a Pentonville Road, London N1 9JP  
020 7832 5814  
[info@healthwatchislington.co.uk](mailto:info@healthwatchislington.co.uk)  
[www.healthwatchislington.co.uk](http://www.healthwatchislington.co.uk)  
[@hwislington](https://twitter.com/hwislington)