



news

healthwatch
Islington

There are more than 500,000 people with **autism** in the the UK, around 1 in every 100 people. As part of Healthwatch Islington's research into the health and social care challenges of autism, we spoke to Islington parent Virginia Bovell (pictured) whose son Danny was diagnosed when he was three. He is now in his early twenties and living independently. [The interview is up on our website](#), and there's more on the autism project inside.

Earlier in the year we carried out phone interviews with Islington residents who receive council funded **care in their own homes**. We heard some really interesting stories. We've collected them together into a [report](#) that offers a snapshot of what it is like for people receiving this care and support, told in their own words.

We've also finished visiting all the centres in Islington providing **mental health day services**. Local voluntary and statutory organisations had

suggested these services were under threat and vulnerable to funding cuts. On our visits we had service users queuing up to tell us how good they thought the service was. They were anxious that it was going to be taken away. When these mental health day services are recommissioned it is very important that conversations around the re-tendering process be carefully and clearly communicated, and that service users are involved every step of the way. Thanks to everybody who shared their views.

All our reports (we've published 16 in the last 12 months) are available to download [from our website](#). Remember, if you don't have access to the internet we're always very happy to post out copies. Just give us a call if there's one you're interested in reading. Our phone number is on the back. And if you've got [an opinion to share on any health or social care service](#) you've used in Islington, we'd love to hear what you have to say.

Spotlight on **Autism**



What adjustments could your GP make to ensure good communication with anybody with autism, especially people who are high functioning or may not yet have a diagnosis?

Centre 404, on Camden Road, recently celebrated 65 years supporting people with learning difficulties and their families. It is well known in north London for offering shared housing, practical clubs for all ages as well as advice for carers. But if you have autism, and are high functioning, there is much less on offer. All this is about to change – in part due to the Autism Act of 2009.

That's why Centre 404 is working with Healthwatch Islington to encourage adults with autism, but who are high functioning, to **share their experiences** about going to hospitals and doctors' surgeries in a bid to improve services for this sizeable group of people.

'Autism is a spectrum,' explains Bob Dowd, Centre 404 Family Services Manager (top right) who grew up in Islington and now lives in Archway.

'At Centre 404 all of our families meet statutory requirements for a service. The Autism Act of 2009 has put the onus on the local authority

to provide services to all people with autism, including those with Asperger's or who are high functioning. Until now this group has been denied access to services because there was no clear pathway for them. It's an unseen disability and can have a serious impact on an individual's mental wellbeing. With the right support people will be able to use universal services, they won't need special services.'

Emma Whitby, Chief Executive of Healthwatch Islington (left) reckons the feedback could usher in big improvements for between 2,500-4,000 adults in Islington. "Coming in this year is the Accessible Information Standard which requires any NHS provider or local authority service to record the communication needs of the people using that service. We want to maximise the impact of this by collecting feedback from people with autism that we can share with the Partnership Board,"

'There are a lot of assumptions about autism, like people are non empathetic which isn't true,' adds Whitby, 38. "But if you are autistic you may experience needs differently and find taking in information hard at the GP or a hospital appointment. The provider should be aware of that from your notes, but then the information needs to be tailored to the individual, by checking it's understood, not assumed.'



Danny'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 training the receptionists, having longer appointment times, or 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.

Islington parent Virginia Bovell on how services should adapt to better meet the needs of autistic people, such as her son Danny.

'We're not expecting any local provider to make changes yet,' she adds. 'First we want to listen to people who have autism, or who know someone who is autistic, and hear their solutions in their own words.'

The plan is to collect information this autumn - via face-to-face interviews, phone, email and focus groups - to create a report that will be published in January 2017.

'All the information will be confidential,' reassures Dowd. The anonymous feedback will then be shared with health and social care providers, such as Islington GPs and Whittington, Moorfields and UCH hospitals.

'We want people to encourage friends and family to join in,' says Dowd who already has more than 1,600 families on the Centre 404 database, adding that 'you don't have to have an autism diagnosis to talk to us.'

Dowd, 62, who has been working in social care for 35 years, and Whitby, who is passionate about helping people take control of their health needs, have high hopes that the information will lead to increased awareness about the ways health and social care providers can adjust what they do when a person has autism. For example it could see organisations appointing an autism champion able to give tips to staff about dealing with clients

with autism. It should also see organisations improve relevant policies and procedures.

Whitby is clear that there is no predetermined agenda though and the report 'will be led by what people want to tell us.' Questions to answer might include:

- ▶ Experience of using health and social care services - what worked well and what worked better?
- ▶ Feelings about the assessment process for their autism diagnosis, and whether it happened in a timely way?
- ▶ As a bonus everyone who offers feedback will be entered into a **prize draw**.

If you are autistic, or know someone with autism, you can share your insight and help us all think differently by contacting healthwatchislington.co.uk/autism or call 020 7832 5814.

Events coming up

Islington Patient Group

The next meeting of the Islington Patient Group is on Tuesday 15 November, from 2 to 4pm at the Lift Centre, 45 White Lion Street, N1 9PW.

This patient group was set up by Islington Clinical Commissioning Group to talk to the local community about the quality of local services and about future plans. In the last meeting in June, participants also provided feedback on the factors that influence how they decide whether they need to be seen in a hospital emergency department, at their GP, or at their local pharmacy. You can read the [published report](#) that came out of everyone's contributions on our website.

Everyone is welcome on 15 November. Please let Healthwatch Islington know if you are planning to come along so we can make sure there are enough seats and refreshments.

Free training for volunteers

Healthwatch Islington's training programme has been designed to meet the needs of those working, volunteering, and using health and social care services.

- ▶ 5 October, An introduction to Healthwatch
- ▶ 19 October, Health and social care in Islington
- ▶ 9 November, Health and social care in Islington
- ▶ 23 November, Health and social care committee training

Each training session will be run from 10am to 2pm at Manor Gardens and repeated at 6pm the same evening at the Healthwatch Islington office on Pentonville Road. For more details or to book a place on any of the courses listed above, [visit our website](#) or contact [Sarah Lee](#), our Information, Learning and Development Manager on 020 7832 5828.

Training for Healthwatch volunteers and staff/ volunteers in small community organisations is free (but charges apply for larger and statutory organisations, each session is charged at £70).



Healthwatch steering group meeting

The next meeting of the steering group is on 18 October from 6 till 8pm at Resource for London, 356 Holloway Road, N7 6PA.

We'll be looking in detail at the newly introduced Accessible Information Standard, and exploring what it means for patients and providers in Islington. This meeting is open to the public. Please let us know if you intend to come along.

Our contact details

You can visit our website to give feedback on any health and social care services you use, and get information about other services that are available. If computers aren't for you, you can call us, or write a letter. You won't need a stamp.

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