



HEAR ME, SEE ME

A report examining the inequalities in healthcare that impact autistic individuals in the East of England and their families.

Written in partnership with NHS East of England

Background

Autism Bedfordshire is an independent charity providing emotional and practical support for autistic children and adults with learning disabilities (and their support networks) to empower and enable them to lead enriched, more fulfilled lives.

During early 2021, Autism Bedfordshire put forward a proposal to capture the voices of autistic adults across the East of England as part of the NHS East of England Learning Disability and Autism Programme. Autism Bedfordshire proposed advocacy workshops to promote choice, access, rights, and empowerment by supporting people to have stronger voices and address power imbalances.

Autism Bedfordshire held 20 workshops regionally, across the East of England, from July 2021 to September 2021 with autistic adults and carers of autistic adults. The workshops had two focuses: the first was to empower the attendees with knowledge around advocating for themselves and their rights (understanding of the Equalities Act, knowledge of reasonable adjustments available and support details if they are finding getting what they need challenging) in a healthcare environment. The second focus was hearing experiences from these voices across the East of England in order to formulate a list of common themes and suggestions of recommendations.

Our sessions were promoted on Eventbrite and by partner organisations and sessions were held on Zoom (apart from 3 which were held in person).

Common themes in feedback

- Feeling dismissed, excluded and misunderstood
- Healthcare environments aren't sensory friendly – most hospitals set up in a way that is really challenging for someone with sensory sensitivities
- Not much knowledge of reasonable adjustments within surgeries
- Difficulty in accessing the right support for mental health
- Would like an easier road to diagnosis – quicker times and more support going through the process
- Need for different forms of communication to suit different needs
- More training needed for everyone working in healthcare environments
- Better experiences were had when people saw the same health professional regularly

Feeling dismissed, excluded and misunderstood

Almost everyone in our groups had experience of healthcare professionals who didn't have a lot of autism knowledge. A couple of people talked about autistic stereotypes influencing the care and expectation that people have:

“Almost everyone I have come into contact within my surgery has a very limited understanding of what autism is. There is still such a stereotype of it being like Rain Man.” – Bedfordshire group

The majority of adults we talked to during our focus groups don't have a learning disability and various members of our groups felt patronised and misunderstood by healthcare professionals who presumed that they would. Although autism comes under the learning disability band, some of our group members don't necessarily identify themselves as having a learning disability leading to support that doesn't fit them as an individual, or equally not knowing where to find support.

“Because I present as neurotypical (which takes a lot of energy from me), people don't believe I have autism. And this is medical professionals!” – Hertfordshire group

“I kept being told by someone my autism meant I had a learning disability – it made me feel really uncomfortable as I am high functioning and don't really consider my autism a learning disability. It felt like I was lying/accepting something that wasn't true” – Bedfordshire group

Group participants talked about how there seem to be negative connotations surrounding an autism diagnosis. One group member, the mother of an autistic adult who has several other conditions, talked about how autism is the diagnosis she is least likely to disclose.

“I sometimes use my son's blindness as a way to explain his behaviour even though it's nothing to do with that. People are much more sympathetic to blindness than autism. My son has lots of challenges but autism is always the last one I tell people about. People really discriminate when they hear autism, it feels like people become so negative about him when I reveal it” - Norfolk group

One of the people we talked to said they felt their healthcare was good but they had to leave their area to find somewhere with good support and knowledge of the LGBTQ+ community.

“I travel to London for sexual health clinics rather than stay in Luton as they seem more caring, with more knowledge and easier to access” -Luton group

Learning from these places where support seems more tailored and easy to access is going to be really important in ensuring consistent services across the country.

Lack of knowledge about sensory sensitivities

Most group members reported feeling uncomfortable in healthcare environments. It's common for autistic individuals to experience sensory sensitivities – either feeling overwhelmed by noises, smells, touch or wanting more of those sensory experiences. Typically, healthcare environments are

full of bright lights, noises of machines and people, and the need for touching or being close to others.

“Environments are set up for 95% of people but can feel hostile for my children or myself” – Hertfordshire group

One of our members talked about an experience in A&E where she was so overwhelmed by her environment on top of the asthma attack that led her to need admission.

“I’m now sitting on an A&E bed in a very small very white A&E room, it’s lined with white cupboards, flashing machines, flickering monitors, leads and wires. I am struggling to process anything I see, it is all so much. I am alone, my head is lacking oxygen so it is confused, I cannot think straight. Every part of my body is impacted... there isn’t any space left in my brain for rational thought. I am too overstimulated now with the smells, lights and unpredictable noises. I lose the ability to find the words for conversation, I just stare. I’m mute. Everything is too much. I want to give up. In my head I am screaming, but nothing comes out. Looking at me you wouldn’t know. But if I could I would bolt.” – Bedfordshire group

When asking about positive experiences, one of our Bedfordshire attendees talked about a scenario where a nurse noticed she was wearing headphones, made the connection to sensory processing and allowed her to keep them on during a procedure where it wouldn’t typically be allowed.

“It made all the difference when a nurse noticed my headphones and asked me what they were for – made a note of it and then no one asked me to remove them as I went through procedure” - Bedfordshire group

Reasonable adjustments

As part of the focus groups we held, we taught about the Equalities Act and reasonable adjustments to empower the adults and carers we were talking to, to know what they are entitled to and what they can request. It was a complete mix; some of the individuals we talked to had made use of longer appointments, quieter waiting rooms and had been given opportunities to wear headphones to feel more comfortable but others found it hard to ask and didn’t necessarily know what to ask for.

A few people identified dentists as being particularly good at reasonable adjustments, some even stating a ticklist on arrival helping them to determine things that may be useful.

Someone mentioned they were left a voicemail by a GP surgery asking to ring them back for a phone appointment. The patient has auditory processing difficulties and was unable to phone back – this was then never followed up.

Although individuals had different preferences over appointments, one thing was clear, having different options to suit different people made such a difference to comfort levels in a sometimes already stressful situation.

“Lockdown has made things easier – maybe it should be a reasonable adjustment to keep some appointments online” – Bedfordshire

“People in hospital didn’t know what my sunflower lanyard [hidden disability] meant! Just kept commenting on how pretty it was” – Milton Keynes

One of the carers who attended our sessions is a mother caring for her 40+ year old son. She was talking about her recent experience in taking her son to get vaccinated. She was recommended a specific ward that was supporting those with sensory needs. She mentioned how much of a difference it made but was quite far to travel for lots of those making use of it as there weren’t many to be found.

“I took my son to James Padgett hospital for vaccinations – [name of disability nurse] created a specific ward for people with disabilities. It had soft lights, no sound and everyone spoke quietly. The experience was great, but it seemed lots were travelling far to make use of this”- Norfolk

*“Reasonable adjustments are **never** offered – makes you feel like a problem or being difficult asking for them. Then when you do tell them what you need, they offer something different that they have available – not the same” - Hertfordshire*

Some of the groups suggested healthcare practices offering tick lists of reasonable adjustments available as sometimes it feels difficult to think on the spot of something that would be a useful support.

Videos and plans of healthcare spaces were things individuals often cited as being helpful – so they had more of an idea what environment they were walking into and where they needed to go.

Mental Health & Autism

Mental health was one of the most mentioned points of our sessions and it’s no surprise given that 79% of autistic adults have diagnosable mental health conditions (Lever, 2016).

Quite a few people mentioned the difficulty of accessing support for mental health when autism is their primary diagnosis.

“I can’t access a mental health service because autism is my primary diagnosis and my mental health diagnosis is secondary. But I still need support for my mental health too! I’m not seen as a person who may have challenges in both these areas”- Bedfordshire

There was also a general consensus that mental health services didn’t feel confident in their knowledge of autism – and that lots of the services provided as part of mental health provisions didn’t feel accessible for autistic individuals.

“My daughter was accessing Mind services for years and there was no suggestion from them of autism – there should be more training of autism generally in mental health charities and services” – Bedfordshire

Difficulties accessing CBT was a recurrent theme for autistic adults we talked to; neurodiverse individuals think and relate to emotions in different ways and multiple people commented on CBT feeling inaccessible to the autistic community and feeling like there were no other options available.

“My son was approved for CBT but found it difficult to engage – I wanted him to try something else but he was seen as declining treatment. Now we’re stuck.”- Essex

Mental health tended to be the most talked about area in our focus groups specifically in regards to confusion from mental health professionals over whether this should be supported by the LD & Autism service, treatments and services feeling inaccessible and the lack of knowledge and misdiagnosis around eating disorders and autism.

Diagnosis

Everyone we talked to had a diagnosis of autism or was the parent of a child diagnosed with autism (one parent was on the pathway to diagnosis at the time of our discussion after going through the process with her daughter and noticing similarities). The majority of people we talked to were diagnosed as a teenager or in adulthood. There was lots of understanding around the long waiting times, especially as an impact of the COVID-19 pandemic, but difficulty in finding support in the meantime.

“Diagnosis as an adult feels really lonely, long and challenging. I would have really benefitted from talking to some who had been or was also on the same diagnosis journey” – Bedfordshire group

There was discussion about not being believed in the process of pursuing a diagnosis in multiple groups and the stereotypes lots of professionals still think of when thinking about autism.

“I’m on the diagnosis pathway at the moment. I was told I can’t have autism because I have a university degree. I feel confused, frustrated and like no one is listening” – Bedfordshire group

“Scary assessment environments – feel like a headteacher’s office, feeling like you’ve done something wrong” - Hertfordshire

Group discussions suggested peer support groups within surgeries for the diagnosis process and more resources and guidance for support in the meantime.

Communication

Communication was a big talking point, especially in light of the pandemic and how appointments changed. Some really enjoyed not having to go into a GP surgery physically and being able to have video calls. However most found the shift to more telephone calls challenging.

“I find it difficult to remember things [in phone conversations] and nothing is written down. My partner was really mentally unwell. I am his carer and I am autistic and there hasn’t been any checking in with me and my needs.” – Bedfordshire group

This was something that was discussed a lot throughout the sessions; lots of the autistic individuals we talked to were also carers to autistic partners, children and other family members and phone calls allowed less time to ask more general questions, or see from someone’s appearance they may be struggling.

The actual language used by professionals was commented on a lot during our sessions. A lot of our adults commented on a need for questions to be more specific as broad questions leave them confused and unable to answer.

“Big open questions are hard! Doctors often say ‘What do you want me to do?’ and I have no idea!” - Milton Keynes group

Use of particular words was also triggering for some of our focus group attendees. ‘High functioning’ was a word discussed a lot in one of our Bedford sessions and again with some adults in Hertfordshire. Our adults felt high functioning was used as a way of saying “you don’t need any support”.

“I may seem high functioning in some situations, where I’m using lots of energy to appear ‘normal’. But if I’m in an environment with loud noises and lots of people, I don’t see myself as high functioning at all – I don’t speak, can’t process anything, and lash out. They take me as they see me that day which isn’t an accurate version” – Bedford group

“I hate the word “high functioning”... also challenging when talking about behaviour... distressing would be a much better word to use as the reason someone is behaving like that isn’t because they are challenging, but distressed” – Hertfordshire group

Communicating before or during procedures was really important – a lot of the adults we talked to felt a lot calmer if someone was explaining what was happening and what they needed to do.

“Communication is what I struggle with the most. I was in hospital and suddenly a porter took me somewhere else without telling me where or why I was going. I didn’t feel like a human and felt really confused and worried’ ‘Almost like they’re saying, I’m going to trigger you and then get really angry at you for being ‘challenging’”
Hertfordshire group

The majority of the adults we talked to found a lot of hospital communication lengthy, confusing and not easy read. Although adults acknowledged seeing easy read versions of more general healthcare advice, more specialised areas were really lacking in easy to understand content.

“There’s a definite misconception of autistic people not having sex – no thought for easy read formats around contraception/sexual health resources/family planning”-

Luton

Positive experiences

Members of our listening groups cited particularly positive experiences, where they had felt understood and supported. A few mentioned how useful it was seeing the same GP multiple times; more of an opportunity to build trust and less energy spent introducing themselves and their support needs.

“Because the staff at my GP surgery know my son, his appointment times are always kept to time even if others can’t as they know what a difference it makes” – Norfolk group

“My GP is brilliant. Seeing the same GP consistently makes all the difference and I automatically get double appointment slots because I’m a carer” – Hertfordshire group

The other positive examples were linked to reasonable adjustments – either adults feeling confident in asking for support or their stress being recognised by a professional and help provided.

“After she was born [her baby], the hospital staff saw I was getting overwhelmed and moved me to a side room. Their communication was great and I felt so much happier” – Bedford group

“Flexibility on how you book appointments is really useful – different people find different ways easier depending on the day” – Hertfordshire group

The common theme in positive feedback was adults being listened to, communicated with and believed. Although creating easy read documents and creating an environment that is more sensory friendly are great, talking to each adult as an individual, believing their experience and supporting their unique needs is vital in giving autistic adults a more positive healthcare experience.

Our Recommendations:

- Make healthcare environments more accessible
 - Easy read information more readily available
 - Adapted wards or part of the ward to have a better sensory environment for those accessing services
 - Visual guides and videos for healthcare spaces available before appointments
 - Disability nurses (with increased knowledge of autism) available to support – more than just one per facility

- Autism specific training mandatory
 - More than just healthcare practitioners – reception staff and support staff
 - Training made/held/supported by autistic adults
 - Knowledge away from autism stereotypes

- Reasonable adjustments available
 - More information about flagging to autistic individuals and more use generally
 - Tick list options/notes of where someone may be supported

- Support for mental health practitioners
 - Specific autism training for mental health practitioners
 - More research and support into eating disorders and autism
 - More understanding of mental health action plans and support for autistic adults – acknowledgement that different approaches may be needed for the neurodiverse population and supporting mental health practitioners with this

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