Barriers autistic young people face when accessing primary care services

Youthwatch Cambridgeshire and Peterborough
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Background

The diagnostic criteria for autism describe three core characteristics: differences in social communication, the presence of restricted interests, and repetitive behaviours. Autistic individuals also commonly experience differences in sensory processing, which may include heightened sensitivity to sensory stimuli, reduced sensory awareness, or a strong need to seek sensory input.

While every autistic young person has a unique profile, there are shared characteristics that can make accessing primary care more challenging. These include communication differences and sensory processing needs.

In April 2025, NHS GP records showed that 1.5% of the population had been diagnosed with autism. This figure is higher among children, at 3.4%.

Over the last 20 years, autism diagnoses have increased eight-fold. This is largely attributed to improved recognition and broader diagnostic criteria, meaning individuals who may previously have been missed are now more likely to be diagnosed. This is especially true for women and autistic individuals without a co-occurring intellectual disability.

The life expectancy of an autistic person is significantly lower than that of the general population, and even shorter where there is a co-occurring intellectual disability. There are two main reasons for this: This is due to a combination of poorer physical health outcomes and barriers to accessing healthcare services.

Autistic populations are more likely to experience co-occurring health conditions across all nine organ systems (Weir et al., 2023). In 2023, researchers from the Cambridge Autism Research Centre (ARC) found that autistic individuals are more likely to experience “physical health multimorbidity”, meaning they have two or more physical health conditions. These conditions can affect every part of the body, from epilepsy in the brain to central sensitivity syndromes such as irritable bowel syndrome and temporomandibular joint disorder.

The prevalence of co-occurring conditions is estimated at 70% within the autistic population (The Cambridgeshire and Peterborough All Age Autism Strategy 2021–2026). A breakdown of common co-occurring conditions and their prevalence is outlined below:

- 28–44% have ADHD (attention deficit hyperactivity disorder)
- 14–38% have a tic disorder
- 45% have a learning disability
- Up to 79% have a motor abnormality
- 8–30% have epilepsy
- Up to 38% have immune dysregulation

- 50–80% have a sleep disorder
- 9–70% experience gastrointestinal pain

This highlights the need for more proactive monitoring of autistic patients in primary care, given their higher likelihood of physical health needs. Evidence also shows that autistic individuals are more likely to experience poorer mental health and are at increased risk of suicidal thoughts, attempts, and death by suicide (Brown et al., 2024). Primary healthcare services play a crucial role in suicide prevention, as they are designed to be an accessible point for early identification and intervention.

Despite higher rates of suicidal thoughts, autistic individuals are less likely to seek NHS support. A recent study by ARC found that one-third of respondents with an autism diagnosis did not seek support for suicidal thoughts because they felt unable to face the process of accessing a GP appointment, often due to previous negative experiences.

A key theme identified through feedback was the number of barriers to accessing GP appointments. Professor Sir Simon Baron-Cohen, Director of ARC, highlighted the "need to urgently re-evaluate current healthcare systems to improve support for autistic individuals" (2023).

A systematic review by Babalola et al. (2023), examining 24 UK-based studies on healthcare access for autistic children and young people up to age 25, identified several major barriers. These included:

- limited professional and parental knowledge
- sensory challenges
- communication difficulties
- lack of person-centred care
- stigma

The study found that many parents believed the barriers they and their child encountered could have been addressed through reasonable adjustments tailored to individual needs, recognising that every autistic child is different. Clear, unambiguous communication and effective collaboration between parents, young people, and healthcare professionals were identified as essential to good care.

Parents of autistic children should be recognised as experts in their child's needs; however, many reported having to fight to be heard, with their child's symptoms often dismissed as being "just autism". Communication barriers can be further compounded where English is not the first language, particularly when an autistic young person is expected to translate complex medical information for a parent.

Another important consideration is parental autism. Autism has an estimated heritability of around 50%, meaning that parents advocating for their child may also experience differences in communication, anxiety, and previous negative healthcare experiences. The review also highlighted that unsuccessful healthcare interactions can have serious consequences, including distress, self-injury, withdrawal from services, or increased challenges at home.

Despite good intentions, autism research has often positioned autistic individuals as subjects rather than active partners, resulting in research being conducted on autistic individuals rather than with them. Involving people with lived experience as equal partners recognises the unique strengths they bring, including intellectual curiosity, attention to detail, and deep focus, all of which enhance the quality and relevance of research.

When developing strategies to improve the accessibility of NHS services for autistic young people, it is essential to work collaboratively with those who have lived experience. This project explores the barriers faced by autistic young people when accessing GP services in Cambridgeshire and Peterborough. It does so by listening to their experiences, both positive and negative, and working with them to co-produce practical recommendations to improve access to healthcare.

“Healthwatch and our autistic experts by experience use the phrase ‘autistic individuals’ rather than ‘person with autism’. This terminology is known as identity-first language and is often preferred by autistic individuals. Personally, I prefer this as it shows how my autism is a part of me and not something I can detach from.

Autism is a neurological difference, categorised as a disability; however, autistic individuals may feel more disabled by society. As neurodivergent individuals, we often process our environment in different ways compared to neurotypical people. Consequently, autistic individuals can experience differences in sensory processing, communication and interactions, as well as a need for certainty and routine.

We are all different and, therefore, we are all neurodiverse. Early studies separated autism and Asperger’s Syndrome. Autism described ‘low-functioning’ individuals with high support needs, whilst Asperger’s Syndrome described ‘high-functioning’ individuals with low support needs. However, over time, our understanding of autism has evolved.

We now recognise autism as a ‘spiky profile’. This explains how autistic individuals can have different strengths and areas where they need support, and how these can fluctuate. This evolving understanding also means Asperger’s is no longer used in clinical terms. However, if an individual prefers to identify as having Asperger’s, this should be respected.

For autistic individuals, co-occurring conditions are common. These are referred to as co-occurring conditions rather than co-morbid conditions. Autistic individuals are more likely to experience mental health challenges; however, autism itself is not a mental health diagnosis.”

Time to Deliver: The Autism Act 2009 and the New Autism Strategy 2024–2026

The House of Lords has asked its committee to review how effectively the Autism Act 2009 has been implemented, how it could be strengthened in the future, and what has been achieved through the current autism strategy. The Committee has also considered what the Government needs to do to develop a robust and effective new strategy, due to be launched in July 2026 when the current strategy ends. The Government has committed to using this report to inform the development of the new strategy.

The timing of this work aligns closely with the publication of our report.

Methodology

Focusing on primary care services—specifically general practice (GPs)—this study explored the experiences of autistic young people when accessing NHS services.

Participants were asked three key questions:

- To share a positive experience of their GP
- To share a negative experience of their GP
- What they would change to make GP services more accessible for autistic individuals

The questions were co-produced with experts by experience through Youthwatch. We engaged with local youth groups and charities to ensure young people were approached in environments where they felt safe and comfortable sharing their experiences.

A semi-structured interview approach was used to collect qualitative data. In total, we spoke to 16 autistic young people aged 16–25, as well as three parents of autistic young people.

Youth-Led Research Design

This project adopted a youth-led research approach. Volunteers from Youthwatch Cambridgeshire and Peterborough conducted interviews, facilitated focus groups, and contributed to data analysis. This participatory model ensured that young people were not just research participants, but active contributors, and were fully involved in the co-production of the project.

Workshops

Youthwatch organised and facilitated workshops to create a collaborative space where young people with lived experience and healthcare professionals could share insights and contribute to the development of recommendations.

Project Objectives

Youth-Led Research

To engage young people aged 14–25 with lived experience of autism in a qualitative research project exploring the barriers and opportunities they encounter when accessing GP services. This included interviews and workshops led by young people, ensuring their voices remained central throughout.

Co-Production of Recommendations

To work collaboratively with young people with lived experience to develop practical, actionable recommendations for healthcare providers, commissioners, and policymakers. These recommendations aim to address key gaps and improve access to primary care services across Cambridgeshire and Peterborough.

Deliver Health Education Sessions

- Delivered targeted health education workshops to improve understanding and awareness of neurodiversity, led by neurodivergent individuals (including The Experts On Myself (TEOM) and Speak Out Council – Voiceability).

Support Transition from Child to Adult Services

- Identified and addressed the needs of young people aged 16–18 transitioning from child to adult health services
- Explored barriers to smooth transitions and proposed solutions to improve continuity of care

Stakeholder and Community Engagement

- Engaged with key stakeholders and policymakers across local authority and health systems, particularly those with responsibility for Special Educational Needs and Disabilities (SEND)
- Worked with established groups supporting neurodiverse young people
- Gathered insights from parents and carers to understand their experiences and perspectives

Quotes

“The waiting room is too loud. I had a hard time hearing when the doctor was ready to see me. I struggled to hear the doctor during my appointment because they could hear the waiting room from the consultation room. I felt the doctor didn’t listen to my concerns.”

“I have had several difficult experiences at my local GP surgery as someone with autism. The GP is unclear, is rushed when communicating and taking notes, and lacks empathy. They have written on my notes ‘presented in clinic tearful again’.”

"Not Autism aware. More support needed on providing social story e.g. pictures and what the waiting room looks like Reception, Doctors room, Staff. This would help reduce anxiety when individuals need to attend health appointments. Easy Read information and procedures."

"I had an ECG and lots of blood tests at my surgery and the nurse was very understanding of my needs. She was good and gentle."

"I am very scared about getting a smear test when I am 25. I will need someone to explain what is happening. I need to see equipment. I need to know if it will hurt."

"The receptionist at my surgery always asks me for my address and I can't always remember it. All staff should be aware of my needs."

"I had to wait over six weeks to get Talking Therapy, and it was only over the phone which I didn't like. There was no aftercare. I would have much preferred to have done the talking face to face. I have ASD/ ADHD but am always fobbed off by my GP who says it is all in my head."

Youth Voice Celebration Workshop

In June 2025, Healthwatch was invited to facilitate a workshop as part of the Youth Voice Celebration event to support this project.

The group consisted of eight young people aged 14–18, including three with lived experience of autism.

Participants were asked: "What challenges do you think young autistic individuals' autistic individuals might face when accessing a health service, and what could be done to support them?"

Key themes from responses

Challenges identified:

- Feeling overwhelmed by people and noise within healthcare settings
- Overstimulation due to busy environments and high numbers of people
- Seeing different GPs and healthcare professionals and having to repeatedly explain their situation
- Delayed speech and difficulties with verbal communication

- Fluctuations in functioning throughout the day, with periods of higher and lower capacity

Suggested improvements:

- Offering alternative communication methods, such as messaging a GP instead of phoning, or using a symptom template to support clearer communication
- Providing access to a quiet, calm space or separate room to reduce sensory overload and support emotional regulation
- Having a trained champion within the service to better support autistic patients

Anglia Ruskin University – Healthwatch Live Brief Project

Healthwatch have been collaborating with Anglia Ruskin Health & Social Care students for two years. They chose our project as the focus of their Live Brief Project, which forms part of their overall qualification. The students' work provided a research-informed exploration of the barriers neurodivergent young people face when accessing GP services, particularly during key transition points into adulthood.

Across the different groups, there was a consistent finding that access to healthcare is not just about availability, but also about how services are experienced, with communication, environment, and systems all playing a significant role. A key theme identified was that communication barriers sit at the centre of unequal access. Students highlighted how traditional consultation styles often assume neurotypical communication, which can lead to misunderstandings, reduced confidence, and, in some cases, disengagement from services. Drawing on the theory of the Double Empathy Problem (Milton, 2012), students emphasised that communication difficulties should be understood as a mismatch between individuals rather than a deficit within autistic people themselves.

The findings also demonstrated the impact of sensory and environmental barriers within GP settings. Students identified that factors such as lighting, noise, waiting rooms, and unpredictability can create sensory overload, which in turn reduces engagement and increases anxiety. This reflected the social model of disability, highlighting that it is often environments and systems, rather than the individual, that create barriers to participation and access.

Another important area explored was the role of digital systems and online triage. While students acknowledged the intended benefits of these systems, such as efficiency and convenience, they identified that digital access does not always equate to accessible care. Complex forms, rigid communication methods, time pressures, and cognitive load were all identified as barriers which may unintentionally exclude neurodivergent individuals.

The students also identified transition between child and adult services as a critical period of vulnerability, particularly for young people aged 16–25. Loss of continuity, increasing expectations of independence, and fragmented support pathways were all highlighted as factors contributing to anxiety, missed appointments, and poorer health outcomes. There was a strong recognition that independence should be supported gradually rather than assumed.

Across all groups, there was a clear emphasis on neurodiversity-affirming practice, co-production with autistic individuals, flexible communication approaches, trauma-informed care, and multidisciplinary working between services. Students identified that effective collaboration between GPs, mental health services, occupational therapists, and wider healthcare teams could improve continuity, reduce fragmentation, and support more holistic care.

The students also developed several evidence-informed recommendations, including:

- adapting communication using clear, literal language and visual supports
- allowing additional processing time
- offering flexible consultation formats
- improving sensory environments within GP settings
- increasing staff training in autism awareness and trauma-informed practice
- ensuring alternatives to digital-only access systems

These recommendations align closely with NICE guidance, the Equality Act (2010), and the Accessible Information Standard, reinforcing that inclusive practice is both a legal and ethical responsibility.

Overall, the students demonstrated a strong understanding that barriers to GP access are often systemic rather than individual. Their work effectively brought together theory, policy, and lived experience, demonstrating how relatively small, practical changes can have a significant impact on participation, wellbeing, and equity in healthcare access.

Preparing for Adulthood SEND event

We spoke to many young autistic individuals' autistic individuals and parents and carers.

We asked them: "How was your visit to your GP?" and "what could make it better?"

What they told us:

- "More support when accessing dental appointments". "My daughter gets aggressive, and they won't treat her. She also forgets appointments. Need processes in place."
- "My son cannot access his medication via the GP for his gender medication. I have to pay private for this and the blood tests associated."
- "My GP declined my right to choose for a neurodevelopment assessment."

- “My son is autistic and agoraphobic and I cannot get the GP to do a home visit. This should be available.”
- “GPs should know more about FASD. This can be confused with autism.”
- “Barriers to requesting fit notes when my son has been under mental health services for a period of time.”
- “Processes need to be in place within waiting rooms as different noises distract.”
- “Processes need to be in place for autism assessments if the young person is mute.”
- “Quiet areas will help.”
- “I am a tutor of an autistic young person and would like to apply for a tiger card (£1.00 travel card) but cannot as it has to be a parent.”

The Expert on Myself (TEOM) – training session

TEOM young people attended a session to educate Youthwatch on their experiences.

What they told us:

- “I like to be called an autistic person or someone who is autistic.”
- “I do not want special treatment”
- “I do not like the term on the spectrum. Can use higher support needs or lower support needs depending on the environment.”
- “I do not like the term Aspergers – negative historical connotations. Always say autistic. Aspergers sound like a lesser condition so some people use this.”
- “Being neurodiverse can also be Autism, ADHD, dyslexia, Aspergers or Tourette’s.”

Misconceptions

- “People think we have no empathy. It can be cognitive empathy or can show sympathy. Some people have high empathy.”
- “People assume I am academic because I go to Uni. They assume I can do easy tasks, but I can’t. This is called a spikey profile.”
- “People expect you to be on benefits and you can’t work.”
- “When I am struggling people talk down to me like a child.”
- “I worked in a factory for a while, and I needed ear defenders. The company would not make adaptations for me or let me bring my own ear defenders.”

Co-occurring conditions

These can be:
ADHD, IBS (irritable bowel syndrome), dyspraxia, depression, anxiety, dyslexia, fatigue, myalgia, eczema, arthritis, asthma, hay fever, OCD (obsessive compulsive disorder), EDS (Ehlers-Danlos Syndrome) and hypermobility. This list is not exclusive.

Because of the amount of other physical conditions this means autistic individuals often attend several medical appointments.

What has been good about health appointments?

- "I like continuity and I always see the same nurse."
- "My rheumatologist explains everything in depth. He doesn't dismiss me."
- "I see the same GP every 3 months, and I have a good rapport."
- "I saw a medical professional for weight issues every 2 weeks."
- "I saw a physio regularly and they referred me to the pain clinic."

What has been bad about health appointments?

- "I had a very condescending Doctor."
- "When I get overwhelmed, this can bring on a non-epileptic seizure. When going to hospital I was asked if I had been taking drugs."
- "My GP is always different."
- "I was experiencing heart palpitations. I monitored this at home with an oxygen monitor and shared the results with the consultant. He was not interested. He did not examine me. Sent me away with an ECG but I am allergic to the stickers. No updates/dismissed."

Have you avoided accessing health services?

- "Yes, as I cannot call a GP at 8.00am."
- "I can't call 111 by myself."
- "I avoid A&E as its overwhelming."
- "The procedure at emergency departments is difficult."

Taking medications

- "I can't remember to reorder my medication every month."
- "Sometimes my meds are out of stock. I have to search for pharmacies that have it."
- "I was given lorazepam to take daily. This was not reviewed."

- “My medication for my mental health has to be ordered from my psychiatrist and comes weekly. I requested a weekend delivery as I was at work, and it came on a Wednesday.”

Recommendations for report

Many of these recommendations reflect those made by the accessible information standard 2025.

- “Autistic individuals should be offered an advocate when attending health appointments.”
- “Instructions should be clear on medication packets.”
- “Phoning services such as 111 should be made easier for autistic individuals. Answering the questions can be difficult.”
- “All health and care professionals should complete the Oliver McGowan training as mandatory.”
- “The process of ordering prescriptions should be made easier. Medications should be automatically processed but reviewed and monitored.”
- “Autistic individuals find accessing services such as sexual health very stressful. Professionals need to be aware and take extra time. There is a preconception that autistic individuals do not have sex.”
- “Autistic individuals need time to process information. This can be difficult over the phone. Alternatives should be offered.”
- “Busy waiting areas cause stress in surgeries and A&E. quiet areas need to be available and waiting time updates. Sometimes the screen will say 30 minutes wait and it’s a 90-minute wait. This needs to be accurate.”

Case Study – (Harry – anonymised)

This case study shares a small extract of an autistic young adult, who has faced significant challenges accessing the right support from the healthcare system during a critical time of transition. Despite having a formal autism diagnosis, there has been a significant delay/barrier to him receiving appropriate care, particularly for his mental health.

Harry was diagnosed as autistic at a young age. Professionals at the time recommended additional support at school, but no formal plan was ever implemented. When Harry was in primary school, his family reached out to their GP for help and support as Harry’s school had limited understanding and lack of resource to help. The GP wrote to children’s services at the hospital to ask for their input and support. The referral was sent back with advice for the family to work with the school, the hospital service was not in a position to support.

Throughout his education, Harry remained quiet, compliant, and non-disruptive traits that often led to his needs being overlooked. However, the challenges and difficulties that were overlooked were creating mental health challenges and social anxiety. As he moved into secondary education and then post-16 studies, the lack of structured support became more evident. The stress and lack of support had taken a toll on his wellbeing. Harry eventually left college due to anxiety and low mood, triggering a period in which he actively sought help, but found it difficult to access the right services.

Challenges accessing healthcare support

Initial attempts to get help

After leaving college, Harry began experiencing severe anxiety and depression. It took several weeks to get a GP appointment. A first responder suggested referring him to hospital mental health services, who advised he did not meet the threshold for crisis intervention. In addition, a social prescriber referred him to the Learning Disability Team, despite clarification that Harry did not have a learning disability.

Referral pathways and long waits

The Learning Disability Team conducted a phone assessment but said he didn't meet their criteria. He was then referred to the Adult Autism Team. Meanwhile, Harry was given a list of self-referral services for mental health support. He reached out for mental health support with a youth support charity, and requested talking therapy following an in person visit—but heard nothing for over 8 months.

Ongoing uncertainty

In August 2024, the Adult Autism Team carried out a telephone screening and placed Harry on their waiting list, nearly a year later there was still no assessment.

Impact on Harry

Without the structure of an Education, Health and Care Plan (EHCP) or a named care coordinator, Harry and his family found themselves left to navigate a complex system by themselves with no support. The combination of repeated referrals and lack of follow up meant that Harry remained unsupported for a prolonged period, during which his mental health worsened. His experience is not uncommon and reflects the need to strengthen the links between autism diagnosis, mental health care, and post-education support.

Final Workshop

The purpose of the online workshop was to bring together individuals with lived experience of autism and healthcare professionals to share patient stories and reflect on current practice, with the aim of improving patient experience within GP surgeries.

The workshop was widely promoted through the Primary Care Newsletter, Healthwatch social media channels, professional networks, and Integrated Neighbourhood Teams.

Attendees included:

- six young people with lived experience
- two parent/carers
- two GPs
- one social prescriber
- two practice nurses
- one PhD researcher
- one representative from Cambridgeshire County Council Adult Autism Team
- three Healthwatch professionals

At the end of the workshop, attendees were invited to make a pledge, identifying a specific improvement they would take back to their practice and implement.

The workshop opened with young people sharing their personal experiences, providing powerful insight into the challenges they have faced and setting the context for discussion and reflection.

Anecdotes from our 'Experts by Experience'

The below statements have been written by some of our Autistic experts, explaining their experiences accessing NHS GPs. Not all of these were shared verbally during the workshop and were added later. These have been kept anonymous.

Anecdote 1

"I would like to summarise some of my experiences accessing my GP surgery. I believe that raising awareness can support collective change, help reduce some of the barriers to healthcare faced by autistic individuals, and ultimately reduce associated health inequalities.

To book an appointment, I can either call the surgery or complete an online form. Calling the surgery must be done at 8am and relies on me being able to verbally explain my symptoms, which can be challenging. Alternatively, identifying the specific part of the body on the map in the online form can also be difficult.

Previously, when my mum tried to book an appointment on my behalf, this was questioned, as it was perceived that I should be able to advocate for my own needs given that I am in my early 20s. After booking an appointment, I can become anxious, especially if I do not know what to expect.

Face-to-face appointments can be helpful, as they enable me to write down my concerns to show the clinician and allow for any necessary observations to be taken. However, the waiting room is often overwhelming due to background noise, which can impact my ability to verbally communicate. At times, my symptoms can become masked, which has previously meant that some of my health needs have been missed.

I also struggle with hyposensitive interoception, which means I can find it difficult to notice when I am thirsty. This has previously led to UTIs and kidney stones.

Since receiving my autism diagnosis, there have been some positive changes. For appointments booked in advance, I have been able to see the same nurse, which supports continuity and reduces anxiety, as they understand sensory sensitivities and information overload. I have also been given longer appointment slots, which support my processing time.

The nurse takes my observations at different points during the appointment, which helps me process each task separately—for example, using the cold thermometer or the tight blood pressure cuff. Due to co-occurring health conditions, I sometimes need to discuss multiple health challenges, which can be difficult within restricted timeframes.

I do not experience health anxiety; however, being autistic means I can struggle with uncertainty. Appointment summaries can be particularly helpful, especially when there are several instructions to follow.

In the past, I have been perceived as a difficult-to-engage patient, as I can struggle to process my feelings and may communicate in a direct way. However, since being diagnosed as autistic and with the GP surgery implementing some reasonable adjustments, most of my appointments are now positive."

Anecdote 2

"I find going to the GP as an autistic person a hostile experience. I feel I am treated with annoyance, or even outright contempt when I go, and GPs do not try to understand what I am saying. As a result, many of my medical records are inaccurate, and if I challenge them, I am treated as being difficult or simply ignored.

In my most recent visit to the GP, I saw in my records that it was noted—in an aggressively large font—that there needs to be a chaperone in my appointments because I've made 'too many' complaints, without any consideration for the medical negligence that has led to me needing to make those complaints. These chaperones sit in the corner and silently watch and judge, making me feel like a criminal for standing up for myself.

Many of my medical records also make negative judgements about me personally, which then leads others to treat me poorly because they read these stereotypes and stigmas and do not even give me a chance. GPs and other medical professionals do not communicate with me in ways appropriate to my autism or learning difficulties and instead accuse me of lying when I misunderstand.

In my most recent appointment, I asked for a written summary from the GP, and the receptionist told me I was wrong and refused to speak to me any further. Not being communicated with in a way I can understand means I do not fully understand what is wrong with me, what treatment options are being explored—or why others are not—how to follow aftercare instructions, or even how to take medications properly.

Alongside my autism, I have a number of other disabilities and chronic illnesses, but I do not receive treatment for these, which makes much of daily life feel unbearable. Even when I experience distressing and potentially dangerous symptoms, such as random temporary blindness or bouts of temporary paralysis, my GPs seem annoyed when I try to tell them about it. As a result, I often do not bother anymore.

I find going to the GP as an autistic person such a hostile experience that I avoid it most of the time, often waiting until things become severe enough to attend an Urgent Treatment Centre instead. Whilst that is not an easy experience for my autism either, I at least find it less hostile than a GP surgery.

When I moved to where I live now, I did not register with a GP for about a year because of my previous experiences. Before I eventually registered with my current surgery, a support worker contacted them to ask what Reasonable Adjustments they could make to help me communicate. Despite Reasonable Adjustments being a legal requirement for disabled people, the surgery stated that they would not make any."

Public transport where I live is so limited that I cannot travel to other GP surgeries within the catchment area, and any surgeries I could travel to have refused to register me because I am outside their boundaries. In practice, this leaves me unable to access GP-provided medical treatment unless I move.

I find going to the GP as an autistic person such a hostile experience that any interaction can trigger meltdowns, shutdowns, anxiety, and other medical flare-ups. Even simple tasks—such as asking for a medical form to be completed or a referral to be made—feel like going into battle. What should be a five-minute task often turns into months of back-and-forth, which I simply do not have the energy for.

Autistic individuals should be able to access healthcare just as easily as any non-autistic person, and it should not feel like a hostile experience.

Anecdote 3

“Around mid-December of 2025, I had begun to find bright red blood on my tissue paper after going to the toilet and later began to regularly see it appear in the stools themselves daily. I want to preface this all by saying that I’m a 23-year-old, with a father in his late 60s currently fighting stage 4 colon cancer, and my gran on his side who also passed away from a fight with bowel cancer before I met her.

One of the pre-requisites I had to get on the 2WW (two-week-wait) pipeline to rule out cancer was the familial connection, in addition to the blood found in my stool samples. Fast forward to the colonoscopy results, and an 11mm polyp was found and removed (which is just big enough to be considered ‘large’ or marginally higher risk, apparently). Luckily, this was found to be benign, and now I am referred to have a colonoscopy every 3–5 years going forward.

My anxiety is around this and future health complications for me and other young people, especially those that are neurodivergent and without the familial history. Would I have been seen with such urgency? I’m not so sure. By every other factor, I was healthy on paper and in tests. So that polyp could just as well have been left to sit there and potentially get a lot worse down the road if it had not been addressed when it was.

Something I want to highlight that I found particularly difficult to understand was the dietary restrictions pre-colonoscopy in preparation. There were unclear aspects to me that I don’t think are necessarily a neurodivergent-specific problem. For example, instances of having ‘milk puddings’ on the dessert list, and cereals like ‘cocopops’ and ‘rice crispies’, but with no indication in the drinks/liquids section that directly said ‘you can drink XYZ milk, dairy, etc.’ When it comes to my personal wellbeing—and a time-sensitive appointment that I couldn’t afford to risk messing up and having to reschedule, I don’t want to have to read between the lines.

I also didn’t want my mum buying groceries that I couldn’t actually use because we were uncertain whether they were safe to have or not. In my mind, the language of these documents really needs to be re-assessed and done so with neurodivergent people across the spectrum to make sure that it is 100% clear to all readers.

A secondary problem, loosely related, is to do with some ongoing back problems I still have, which I was then assuming the worst about and worrying were somehow related to my colon issues. I’ve seen the local NHS physiotherapist twice now, and both times quite robotic language was used when speaking to me. For example, I get asked, ‘what are your expectations from this appointment?’—which I can only reasonably answer as a paraphrased version of ‘help, I am in pain; I’m not a doctor.’

It’s very jarring, and it makes me feel a little bit stupid for reaching out for help. It makes me feel like I should be putting on a performance—exaggerating or being more hyperbolic instead of simply being honest about my symptoms, just so I can be taken a bit more seriously. I don’t think anyone should have to do that.

On my second visit post-colonoscopy, I’ve been signed up to an 8-week wait for a physio referral. I was apparently meant to receive advice on exercises that could help, but it never found its way to me via the NHS app, texts, or any other communication. So, I’m pretty much entirely in the dark for six weeks while my back remains consistently stiff, without any context or guidance.”

Anecdote 4 – Masking

Masking

Masking is used to describe how some autistic individuals or those with other learning needs don't display their disability. It can also be applied to a medical setting where someone does not tell anybody how they are really feeling when they're unwell. This can also be attributed to difficulties interpreting one's own internal body signals due to sensory processing differences associated with autism.

"It's hard to tell if the symptoms are that of a cold, influenza or something else. I have in the past found it hard to communicate with others and explain how I am feeling, one instance had resulted in the GP thinking that I had a condition (arthritis) when I was just tired."

Anxiety going to the GP

"In the past I have seen a medical student or a new Doctor, they might be inexperienced or lack the right training with people with additional needs. Although my GP surgery is good for appointment bookings for some, others have had to wait or they may not be able to see the Doctor they are familiar with, there might be other Doctors or Nurses that are at the practice. Appointments have often overrun; this can be expected."

"Even if I was to feel anxious, it is important that I go to the Doctor or Nurse if I am feeling unwell", where needed chooses to take a family member with him to "advocate on my behalf, just as a support."

"A few years ago, I was in Hospital for a week because I was masking symptoms of Pneumonia and a chest infection, this later resulted in borderline sepsis. At first, I thought that I'd just had a cold or a short illness, but after a short while I'd felt much worse and I should have rested more.

The care that I got in Addenbrookes required better communication as they almost gave me the wrong medication and spoke quickly. Since this happened, I've had long term chronic fatigue, which is now well controlled with the right amount of rest and learning to pace myself. I was also told that recovery would take a while and am still taking steps to get myself back to some sort of normal."

Pledges from surgeries in attendance

Boroughbury Medical Centre will take this feedback back to the practice to share the patient perspective and highlight the barriers experienced with colleagues.

- They will propose offering double appointments where needed for patients with multiple conditions and explore how this can be flagged on the system home screen.
- They noted that requesting a same-sex clinician is not always possible due to capacity constraints.
- Health Passports could be attached to patient records and made visible on the system home screen. The practice will take this learning into team meetings to raise awareness and discuss implementation.

Granta Practice will review and discuss potential adaptations to improve the waiting room environment within their practice.

- They also expressed strong support for the use of Health Passports, which could be uploaded to patient records.
- The importance of continuity of care—particularly while waiting for referrals—was highlighted, alongside the need for longer appointments for patients managing multiple health conditions.

The Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) Youth Group is developing a booklet focused on supporting neurodiverse young people. Youthwatch has expressed an interest in supporting the co-production and design of this resource.

Thistlemoor Medical Centre acknowledged that some of these issues had not previously been considered.

- They will take this feedback back to the practice and propose increased awareness of communication needs, alongside introducing more specialised staff training.
- These issues will be raised in practice meetings.
- The practice will also explore introducing double appointments and improving continuity by offering follow-up appointments with the same practitioner, reducing the need for patients to repeatedly share their experiences.

Recommendations

- Provide access to quiet or low-sensory spaces within GP surgeries to support patients who may feel overwhelmed.
- Offer the option for young people to wait in their car (or another preferred space) until the clinician is ready, with a phone call or text to notify them.
- Keep patients informed of expected waiting times and any changes to the healthcare professionals involved in their appointment.
- Be flexible in communication methods, including accepting written descriptions of symptoms where verbal communication may be difficult.
- Focus on individual needs rather than assumptions about a diagnosis, recognising that every autistic person has different preferences and requirements.
- Appoint a trained autism champion within each practice (for example, someone trained in the Oliver McGowan Mandatory Training on Learning Disability and Autism), aligning with the government's autism strategy.

- Consider access to free prescriptions for autistic individuals, who may require multiple medications to manage complex or co-occurring conditions.
- Offer double appointments where needed, particularly for patients with multiple or complex health concerns.
- Allow additional time for procedures such as blood tests or health checks to reduce anxiety and sensory overload and ensure that all procedures are clearly explained in advance.
- Provide more flexible options for booking same-day appointments, rather than limiting access to early morning (e.g. 8:00am) call times.
- Introduce alternative booking methods, such as text-based services, for patients who may find verbal communication challenging.
- Simplify and improve processes for reordering repeat prescriptions.
- Enable patients to bring an advocate to appointments without challenge or unnecessary questioning.
- Introduce a system prompt or code to alert reception staff and clinicians, encouraging them to ask: "I am an autistic young person—please ask me what my needs are today."
- Implement an autism spectrum disorder (ASD) flag within patient records, including personalised support strategies. This should be developed collaboratively with the patient in a dedicated appointment, so they do not need to repeatedly explain their needs.
- Ensure autistic adults are routinely offered annual health checks

Conclusion

This project set out to understand the barriers autistic young people face when accessing GP services across Cambridgeshire and Peterborough. A co-production approach was central throughout, ensuring that autistic young people, the focus of the project, were meaningfully involved at every stage.

Through interviews, three key barriers were identified: challenges in communication between healthcare professionals and patients; inflexible systems and processes; and sensory difficulties within GP environments. While the workshop highlighted examples of good practice, with some healthcare professionals already creating welcoming and supportive environments, young people's experiences showed that this was not consistent across services.

By bringing together autistic young people with lived experience and healthcare professionals, the project created a valuable opportunity to share best practice and deepen understanding of the barriers encountered. Autism Health Passports were identified as a practical tool that could be implemented across GP surgeries to support more personalised, person-centred care.

In addition, the introduction of a designated autism lead within GP practices was recommended. This role would help ensure that staff remain informed about current best practice and appropriate language, enabling knowledge to be shared more effectively across teams and improving consistency of care.

Finally, the project recommends that autistic individuals are routinely invited to annual health checks, recognising the growing evidence of higher rates of co-occurring physical and mental health conditions.

Together, these recommendations have the potential to improve trust, accessibility, and health outcomes for autistic patients.

A key impact of this project has been the growth in young people's confidence in advocacy and participation in research. The project's success, and the impact achieved, would not have been possible without the meaningful contributions of autistic experts by experience.

This work highlights the importance and clear benefits of involving neurodiverse individuals at every stage of research design and delivery. Their insights ensured the research remained grounded in lived experience, resulting in more relevant findings and practical recommendations.

By creating accessible and inclusive opportunities to take part in research, we can better understand the realities people face and drive meaningful improvements in services. As a direct outcome of this project, we have recruited additional neurodiverse young people to Youthwatch, who will continue to contribute to research focused on health inequalities in our local area.

This report will be distributed to the following:

- Central East Integrated Care Board – Primary Care Commissioning Sub Committee
- Central East Integrated Care Board – Mental Health, Learning Disability and Autism Accountable Business Unit
- North Cambridgeshire & Peterborough Care Partnership (North Place Board)
- Cambridgeshire South Care Partnership Joint Strategic Board (South Place Board)
- Healthwatch England
- Healthwatch Non-Executive Directors
- Healthwatch East of England Network
- The ASD club

- The Expert On Myself (TEOM)
- A North London NHS Talking Therapies Service
- Cambridge University Autism Research Centre

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Primary beneficiaries and co-researchers of the project.

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A key partner in engaging young people and promoting their voices.

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- Autism Research Centre Cambridge University
- Voiceability and Speak Out council
- Circles, Peterborough
- ASD Club, St Neots
- Preparing for Adulthood SEND event
- Unloc young people – Celebration event workshop
- Students at ARU Peterborough Campus
- Health Inequalities, Learning Disability and Autism Programme, Cambridgeshire and Peterborough ICS
- Boroughbury Medical Centre, Peterborough
- Thistlemoor Medical Practice
- Granta Practice
- Adult Autism team, Cambridgeshire County Council
- Waterbeach and Cottenham Surgery

Appendix

- Neurodiverse booklet
- Neurodivergent Support Pack (Print)
- Neurodiversity - Pinpoint
- 2025 Autism Strategy.pdf
- Autism Strategy Summary list of recommendations.pdf
- Ten top tips on autism-friendly consultations _ Nursing in Practice.pdf
- 10352388 - Cambridgeshire Local Area Partnership - Area SEND - Final Report-165734.pdf
- National autistic society (2017), “My Health Passport” Health_Passport_A4_2020.pdf

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