Care Quality Commission

How you see me matters: perspectives of autistic people using primary care services

Introduction

CQC is committed to encouraging health and care services to provide the same good quality of care for everybody. To do this, it's vital to listen to what people say about services and learn from their experiences.

This is particularly important for us as we develop our new methods and approach to regulating. Knowing what people feel about their care services enables us to focus on the right areas and ask the right questions when we assess the quality of care.

One of our strategic ambitions is on tackling inequalities in care. This is specifically pushing for equality of access, experiences and outcomes from health and social care services.

Here, we present some perspectives from autistic people on challenges when using primary care services. We want these to help primary care providers think about how to accommodate the needs of autistic people when using services.

Background to this work

Autism is a lifelong neurodevelopmental difference that affects how people experience the world.

Autistic people see, hear and feel the world differently to non-autistic people. According to the National Autistic Society, at least 1% of the UK population is autistic. In England, that equates to over half a million people. Considering the problems around getting a diagnosis and the general level of understanding about autism, many studies estimate this figure could be anywhere from 2 to 5 times higher. Autistic people therefore make up a significant section of society. Yet knowledge about autism and the needs of autistic people is relatively low. This is even among healthcare professionals.

Autism is not a mental health condition. People may have mental health conditions as well as being autistic. So, it is important to be aware of:

- the potential diagnostic 'overshadowing' this could cause
- assumptions that people might make about an autistic person or their behaviour.

The government's National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 acknowledges that the average life expectancy for autistic people is 16 years lower than that of the general population. The reasons for this are complex, but it is widely accepted that poor understanding of the needs of autistic people is a factor.

Primary care is one area of health care that all autistic people will access at some point in their lives. The journey to diagnosis and the first step to further treatment for any health-related issue usually begins with the GP practice. Similarly, most people will visit a dentist for preventative check-ups or restorative treatment. It is therefore crucial that primary care services get care right for autistic people, as this can have a substantial impact on their health and treatment.

The aim of this particular piece of work is to raise awareness and add to the wider conversation about the care provided to autistic people. It adds to other work we have carried out in respect of care for autistic people, and our reports:

- ‘Who I am Matters’, which focused on the experiences of people in acute hospital care.
- ‘Out of sight: who cares?’, which (link) looked at the use of restraint, seclusion and segregation in care services.

We wanted to understand more about what it can be like for autistic people when they visit their GP or dentist. As a starting point, we reviewed a sample of published, peer-reviewed articles. We then spoke with colleagues in CQC who are autistic themselves to hear about their personal experiences when using these services. To corroborate what we had heard, we shared the findings and experiences from this work with:

- the National Autistic Society
- a group of our Experts by Experience.

This work has enabled us to understand specific areas that present a challenge for autistic people.

Throughout the piece, we include examples of real experiences from colleagues in CQC who are autistic. This is to try to explain what people actually feel when using GP and dental services. In doing this, our ambition is to support providers of services to:

- see things from a new perspective
- think about what they could do to make changes in their own services.

Across all our work in CQC we use ‘identity first’ language to refer to autistic people as this is generally preferred. For example, we use ‘an autistic person’ rather than ‘a person with autism’.

What we did

Reviewing published literature

We reviewed some published academic research on autism and health care. We made sure to only look at those studies that included the lived experiences of autistic people themselves and their views. We focused solely on autistic people and not specifically on people who also had a learning disability. This was because around 4 in 10 autistic people have a learning disability, so the majority do not.

Speaking with autistic colleagues and carers of an autistic person

We invited a small group of our colleagues in CQC to participate in 2 focus groups. This was to:

- give some context to our work
- enable us to develop a better understanding of the issues that autistic people face when using primary care services.

These people have lived experience of autism. They are either autistic people themselves or care for an autistic member of their family. They participate in our Carers Network or the Neurodiversity subgroup of our staff Disability Equality Network.

All the examples we quote are what they told us about their own personal experiences when using GP and dental services.

When we started this work, we were unable to open up the focus groups more widely to external people because of the ongoing pandemic. This meant we spoke with only a small number of colleagues who volunteered to participate. So we acknowledge that their experiences do not necessarily represent the wider population of autistic people.

However, our colleagues' experiences offer context. They also help our understanding of the themes that emerged from looking at the published literature. We have also shared these with the National Autistic Society and a group of our Experts by Experience to check that they reflect themes and issues more widely. Experts by Experience are not CQC employees. They are members of the public with recent personal experience of using or caring for someone who uses health, mental health or social care services that we regulate.

Key findings

From our review of published, peer reviewed articles and our conversations with colleagues, we were able to identify 3 groups of factors that contribute to the quality of primary care for autistic people:

- person factors
- provider factors
- system factors.

Person factors

Fear and anxiety

It’s important to distinguish between general anxiety as a mental health condition and situational anxiety. Situational anxiety is what autistic people can experience when the surroundings or situation cause cognitive overload or shutdown – or both.

It’s also important not to confuse situational anxiety with health anxiety. Autistic people can appear very anxious talking about their health, but this could be caused by sensory overload and environmental triggers.

When we refer to anxiety in this work, we are referring to situational anxiety. Situational anxiety is very common among autistic people. Every autistic person we spoke with reported that anxiety and a perceived lack of time to explain their concerns contributed to poor outcomes with their health. This was also reflected across research carried out in various countries – suggesting this is a universal issue. The National strategy for autistic children, young people and adults makes the point that autistic people often experience poor health outcomes because of a delay in seeking treatment. Autistic people in our focus groups told us they often felt reluctant to seek help and that they only access primary care as a last resort.

> “I [have] fear I won't be heard, fear I won't be asked the right questions so that I can tell them my whole experience.”
> (CQC colleague)

Anxiety may not always be visible. It can affect how well autistic people are able to communicate. They may become anxious in unfamiliar environments or when meeting new people. A 2021 study ‘Recognising autism in healthcare’ shows that previous poor experiences with healthcare services can be traumatising and lead to a mistrust of healthcare providers and using services.

People told us that seeing a different healthcare professional every time, rather than having the consistency of the same clinician, could increase their anxiety.

> “Fear and anxiety is more so when you’ve got multiple different GPs. I know that’s the face of general practice now, but [having the same GP] takes the edge off some of that anxiety of the unknown.”
> (CQC colleague)

In contrast, one autistic person we spoke with described how they were familiar with their dentist and always saw the same named GP. This meant they felt less fear and anxiety.

Sensory differences

Autistic people also experience sensory differences. These include:

- interoception – awareness of the internal sense of your body
- nociception – perception or sensation of pain.

> “[Being told] you need to brush your teeth twice a day is like saying to a neurotypical person you need to sandpaper your hands twice a day”.
> (CQC colleague)

Autistic people can therefore respond differently to pain. This means they may not be able to describe bodily sensations or be believed when they do. Clinical investigations need to take this into account.

Autistic people may not be able to provide an accurate assessment of the intensity of pain as a number using a traditional 1 to 10 pain score. They may see pain as a colour, or a picture. Being asked if the pain is a score of 10 – the worst they have experienced – may cause a significant delay in response. The pain may not be like anything they have experienced before. Responding literally could mean the pain is either over or under scored on the traditional scale. An autistic person may not even be able to pinpoint pain due to sensory overload from internal or external stimuli.

People in our focus groups described how:

- clinicians have not believed them when describing pain
- their facial expressions have been misinterpreted.

This can lead to developing a mistrust of clinicians and an unwillingness to access services. In turn this results in late diagnosis, trauma and anxiety for them.

> “It wasn't until the specialist nurse came in and I collapsed into a crying blubbering mess. Then I think they realised that I was probably being genuine and something was wrong. But it took that level of distress before I was really listened to.”
> (CQC colleague)

> “... if I'd gone in and said ‘I've got a broken leg’, nobody is not going to believe you. I know it sounds melodramatic, but it is traumatic in health care to not be believed again and again.”
> (CQC colleague)

Stress-related factors

We heard how autistic people also found it difficult to access services when they had to use the telephone to make appointments or book a consultation.

> “Phone calls can be very, very difficult. And phone consultations – I understand that they are a very good tool at the moment, and I don't have to see a GP face-to-face for something I can describe over the phone, but they’re still not necessarily an easy thing to do. It's a barrier, I think.”
> (CQC colleague)

The research also highlighted the stress from:

- building up to making a phone call
- the cognitive overload caused by the anticipation or planning and processing of the steps to go through to access care.

For an autistic person, this could lead to a drop in their executive functioning. Executive function is a person’s ability to perform certain tasks that they might otherwise be able to do. This then made them reluctant to ask for help.

> “I just kind of can't bring myself to do it [make a phone call] and I'm a walking, talking, ‘high functioning’ (nonsense term) autistic person. You just don't [make the call], so you just leave whatever health issue it is. That's what I find anyway. You know, unless your leg’s hanging off, I just don't seek health care.”
> (CQC colleague)

> “One of the things you get when autistic people are [feeling] low is executive dysfunction, so also just making an appointment in the first place can be... you want to do it and it just doesn't happen, you know, and so yeah those steps can be very, very difficult.”
> (CQC colleague)

Person-centred approach

It’s important to remember that autistic people are individuals with different personal preferences. Health and care providers therefore need to apply a person-centred (trauma informed) approach and ask people how they can help or support them to access the care they need.

It’s also important to check how the person would like to be referred to in respect of their autism diagnosis. For example, people may prefer to be referred to as either:

- an autistic person
- a person with autism
- not autistic at all, despite their diagnosis.

Provider factors

People in our focus groups described how providers of primary care services sometimes do not do enough to take the ‘person factors’ into account to make their services accessible. This can then create a barrier to getting access to care in the first place and reduce the likelihood of a good experience of care.

Understanding and awareness of autism

The level of knowledge and awareness of autism among clinicians and others who work in health care affects how autistic people experience care and treatment.

Appointments and communication can go well when autistic people are able to:

- see the same GP or dentist
- have an appointment with a clinician with experience or understanding of autism.

However, staff with a poor understanding of autism may have stereotypical views and not understand how autistic people experience the world. They may also misinterpret a person's style of communication as being rude, aggressive or blunt.

The autistic people we spoke with in our focus groups who don't have a learning disability described how providers do not always believe they are autistic. They told us that not having a learning disability often meant they were not believed when they told services that they needed support. This was despite expressing needs that were often the same as autistic people with a learning disability.

> "The default position is for people not to believe you."
> (CQC colleague)

From 1 July 2022, all health and social care providers registered with CQC must ensure that their staff receive training on autism and learning disability at a level appropriate to their role. This requirement includes:

- all health and care staff
- ancillary staff who may have contact with people with a learning disability and autistic people. For example, staff in administrative and support roles.

Training staff appropriately will help to improve the experience and outcomes for all people using services.

Communication

Autistic people are more likely to communicate differently to non-autistic people – both verbally and non-verbally. Some autistic people are semi-speaking or non-speaking. Others may lose their ability to speak (situational mutism) because of increased anxiety and sensory overwhelm.

They may find it hard to communicate concerns about their health. This can be due to:

- situational anxiety
- finding it difficult to describe what they experience because of sensory differences.

Alexithymia is an inability to recognise or communicate emotions. Because of this, some autistic people may not realise they have an issue that needs attention or be able to accurately communicate this. Annual health checks are therefore vitally important.

Many autistic people find it very uncomfortable to make eye contact and will try to avoid it. This may mean their efforts to communicate with healthcare professionals are misunderstood or appear less genuine.

> “GPs make deeply sincere eye contact, which if you know anything about autistic people, is the worst thing in the world. It's positive body language for neurotypical people. Um, but I hate it. I'm aware [of] somebody staring at me and also possibly judging me for not looking at them or they think looking at me and thinking ‘well, this person is obviously lying to me because I'm not meeting their eyes’ and so that's a challenge for me.”
> (CQC colleague)

Autistic people told us that it’s harder to communicate when healthcare professionals:

- aren’t aware of their diagnosis
- don’t make reasonable adjustments to how they communicate.

> “I personally just want ‘autistic’ at the top of all of my medical notes. It would make life easier.”
> (CQC colleague)

The research we reviewed shows that difficulties in communicating are not due solely to a person being autistic. It is more likely that autistic and non-autistic people jointly mis-communicate. This is because of a lack of understanding on both sides about what the other person is experiencing.

It’s important that providers make efforts to understand how autistic people may communicate differently. Indeed, if an autistic person’s ability to communicate is deteriorating in a conversation with a healthcare professional, this may signal a need for more support to maintain communication.

Fact-based or blunt responses should not be taken personally. An autistic person may speak louder than others, but this does not mean they are shouting. They may not be aware of or be able to control the tone or volume of their speech, particularly when over-stimulated.

It may encourage an autistic person to seek medical attention earlier than they may otherwise have done if providers:

- support them to ask for reasonable adjustments
- proactively offer such support and adjustments.

This could help to address late diagnosis and delayed treatment.

Demonstrating genuine compassion and willingness to help reduce cognitive load, sensory overwhelm and other barriers to health care can really help an autistic person to feel supported.

It is also important to communicate with an autistic person in a way that's appropriate to their age and ability, and not to assume a learning disability.

> "I have found that once they know I am autistic, medical professionals often speak 10 octaves higher and as if I have a learning disability. This feels uncomfortable and disingenuous, but also high-pitched voices are very triggering and painful for me, which means communication breaks down very quickly. When I say I am autistic I am often met with a blank stare as if they do not know what I mean, what help I might need or worse they don't believe me."
> (CQC colleague)

The physical environment

Buildings and the physical environment of primary care services can provide challenges to autistic people – they can be disempowered by the environment that surrounds them. For example, waiting areas are often busy and can have:

- noises such as background music
- many other people present (patients, families and staff)
- a lot of visual stimulation such as posters and television screens
- an overwhelming range of smells
- intense lighting.

Autistic people we spoke with described how the discomfort they feel in waiting areas can lead to a lower executive function during the appointment. Some patients find the waiting room unbearable and will need reasonable adjustments such as waiting in a quiet room or in their car until their appointment.

> “Waiting rooms tend to be quite noisy. They have music, they have TV... But I can't put my headphones on because most places call the patient by coming out and calling their name. So, I have to make myself deeply uncomfortable even prior to the appointment, which then throws my ability to actually deal with the appointment.”
> (CQC colleague)

A recurring theme from the literature review was the effect of the built environment on autistic people. This can be challenging because of sensory sensitivities and the impact on people’s ability to communicate effectively at any one time, for example during a health consultation.

Autistic people are entitled to reasonable adjustments under the Equality Act 2010. They may need adjustments to:

- the time or length of appointments
- how information is delivered
- the environment.

Executive dysfunction, attention to detail, processing delays and anxiety can all make it difficult for autistic people to explain clearly and concisely why they need an appointment.

Time factors

People in our focus groups told us about difficulties with the length of appointments. For example, during a short GP or dentist appointment it is difficult for them to:

- fully discuss all the concerns that led to the appointment
- make shared decisions about ongoing care and treatment.

“...the dentist was very clear that he was very busy, and he was hurrying my son and said ‘you need an injection to stop the feeling, I'm gonna do it now’. He didn't give my son time to process the information. He didn't ask him, didn't explain what was going to happen and although my son didn't disagree, the dentist then gave him an injection to numb his gum without explaining. My son then completely panicked and was tearful because he had never experienced that sensation before. And then he refused to have any treatment and it was just an awful experience.”
(CQC colleague)

“... you know if you've only got a sort of 10-minute appointment...you then spend half the appointment explaining to the medical professional how to interact with the person, and so then there wouldn't be the time [to discuss what you came in for].”
(CQC colleague)

System factors

The way healthcare systems are organised can provide challenges to autistic people. The process of changing from one service to another can pose challenges. This includes physically moving around an environment through to changing to a different type of healthcare provider.

We found from both the literature review and our own focus groups that people described themselves as “being pushed around the system” from one service to another without a clear explanation of the reasons why. When we looked at the academic research about these issues, we found reports that described the concern and anxiety expressed by autistic people. This was felt particularly by parents and carers whose child was transitioning from children’s services to adult services. In this case, good preparation is key to ensuring a seamless transition. Unfortunately, services do not always match the expectations and needs of autistic people or their families.

Diagnosing autism and providing support

The diagnostic assessment process should be the starting point for a lifelong understanding between the autistic person and the professionals supporting them.

However, research shows that many autistic people find it difficult to access a diagnostic assessment. They may also not receive any follow-up support because there are no appropriate services or agreed care pathways.

Women and girls can find it more difficult to obtain a diagnostic assessment. Even then, they are often under-diagnosed or misdiagnosed. This is because their behaviour does not always match the stereotype of autistic behaviour more commonly seen in young males.

If people find it difficult to access services and communicate, their physical and mental health conditions may go unrecognised and untreated. Integrated care boards need to listen to the views of local autistic people and take these into account when developing and commissioning services.

Autistic people and carers in our focus groups described difficulties in accessing support services as they were not commissioned or available to autistic people. We heard examples of how children and young people in some areas were unable to access specialist mental health support because they are autistic.

> “Once you have a diagnosis of autism, that automatically rules out the ability to be diagnosed or to be even assessed for other things. So [in our area] as soon as you got a diagnosis of ADHD or autism, you can't have an assessment for auditory processing disorder.”
> (CQC colleague)

People also described how there was very little or no post-diagnostic support, both for adults and children. This can make it difficult for autistic people to know how to navigate healthcare systems and how to ask for reasonable adjustments.

> “It's like you get given this present of ‘here you go, this is your diagnosis’. It's up to you to do everything now.... There is no check and there's nothing to say ‘are you doing OK?’”
> (CQC colleague)

What we're doing in CQC

We want the findings from this work to encourage discussions about health care for autistic people and to result in real improvements.

All autistic people will need to use primary healthcare services at some point.

We're already using the findings of this work to improve the way we assess how healthcare providers deliver care for autistic people. In developing our new approach to regulating, we're incorporating specific aspects to ensure we ask the right questions to get to the heart of people's experiences. We can then use this to speed up much-needed improvements.

We've identified some key points that primary healthcare providers, and those who commission services, can reflect on to ask themselves what changes they can make.

What changes can providers and systems make?

Have you thought about the impact of your service on autistic people and their families?
What effect could your processes have on people's anxiety, and how they communicate with you?

Increasing your awareness, understanding and skills

One of the main contributory factors that affects people's experiences and outcomes from services is a poor understanding about autism among healthcare providers. This includes understanding:

- how autistic people feel

- the difficulties they face:
    - getting access to care
    - communicating when they do.

This work shows how people can see and feel things from a different perspective. There are a number of areas where making small changes and meeting existing regulations and standards can have a positive impact for autistic people using primary care services.

Training staff

Does your training meet the requirements of the regulations?

Autistic people have the right to expect that all staff in primary care:

- understand autism
- use that understanding to enable autistic people to use their services.

The Health and Care Act 2022 introduced a new legal requirement for providers. This is to ensure that all their staff are trained to understand autism at a level appropriate to their role. This is also a legal requirement to meet Regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. It includes:

- all health and care staff
- ancillary staff who may have contact with people with a learning disability and autistic people, such as administrative staff.

We want to see that training put into action.

Alongside any formal training, think about what else you can do to support autistic people who use your services, for example:

- making sure that staff are aware of anxiety and how situational anxiety may affect people
- being aware of how the environment may affect people and taking steps to reduce sensory overload
- understanding how your systems and processes affect autistic people
- providing reassurance and giving people enough time to speak
- just asking how you can help the autistic person to access your services confidently and reliably.

Taking a trauma-informed approach builds trust, collaboration and empowerment. This improves people's access, experience and outcomes. Showing compassion and helping to reduce cognitive load, sensory overwhelm and other barriers to health care can really help an autistic person to feel supported.

Communication

Do you make reasonable adjustments when communicating with autistic people?

It's important to understand that some autistic people may have very different communication styles and needs when communicating. Remember not to make assumptions. Make adjustments to allow autistic people to communicate in a way that meets their individual needs.

In line with the Accessible Information Standard, think about the different ways to support autistic people to hear and be heard effectively. This might include:

- supporting alternative ways to communicate. These could be written formats, or Augmentative or Alternative Communication boards or devices (AACs)
- using checking questions and active listening to make sure that autistic people have understood you and you have understood them

- allowing extra time in consultations to accommodate people's additional communication needs and questions. An autistic person may have many more questions they need answered
- providing information in advance of appointments
- enabling autistic people to submit information before and after a consultation
- providing a written plan of action and information following a consultation.

Adapting your processes and environment

What adjustments could you make to the environment of your service or the way you do things?

The physical environment of a building or premises can have a huge impact on autistic people and their executive function.

Think about what you can do to improve access and be more welcoming to autistic people. Enabling and supporting people to ask for reasonable adjustments, like waiting in a quiet room for their appointment, can encourage them to seek medical attention earlier than they may otherwise have done.

To improve access to health care, consider:

- offering different ways to book appointments with clear instructions, such as by text, online form or email
- quiet or alternative waiting areas
- flexible or longer appointments

- allowing autistic people to make sensory adjustments, for example:
    - turning off bright lights and screens in waiting areas
    - wearing sunglasses indoors
    - wearing ear-protectors or headphones.

But it’s not just about what providers can do. Commissioners need to be creative and flexible when developing new services and ensure the views and choices of autistic people are central to new developments.

Improving autism diagnosis and support

Do people have timely access to diagnostic assessments for autism and support after diagnosis?

People need to be able to access diagnostic assessments for autism quickly and have support following a diagnosis. Integrated care boards should commission and develop services that support people to receive an autism assessment within the timeframe recommended in NICE Quality Standard QS51.

For healthcare professionals:

- think about how you identify that a person may be autistic. Remember that autism may present differently in different age groups, genders and ethnicities
- do you know how to refer that person for a diagnostic assessment if appropriate?
- do you know what support services are available once a person is diagnosed autistic?

It’s important to ensure people have access to these services so that their care is joined up and they feel supported.

Delivering joined-up primary care

Do you work together with other services to co-ordinate people's care?

Thinking about the care in your area, is there more that you can do with other primary care services and ensure that the care for autistic people is joined up and co-ordinated? In particular, when:

- people's care moves from one service to another, for example when a child transitions to using adult services
- care moves between adult services such as from community to inpatient services
- people move to a new area, which risks losing continuity of their care – or not receiving care at all.