

# AUTISM AWARENESS IN THE NHS

Care Opinion Project  
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**Care  
Opinion**

What's your story?

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## Introduction

Autism currently affects 1% of children and 1-2% of adults in the UK (Hey, 2022), which therefore accounts for over 700,000 people who have this spectrum disorder. People can be affected by autism in various ways and to varying degrees such as struggling with social interactions, finding it difficult to effectively communicate thoughts and feelings, routine is very important to them, and finding many sensory experiences overstimulating (Signs of autism in adults, 2022). Although someone being diagnosed with autism is becoming increasingly prevalent there seems to be a lack of understanding and awareness amongst the community and health/social care professionals. This is the focus of my project.

## Why research autism?

As well as autism being something that affects many members of the UK's population it is also a topic close to my heart. For the past few years alongside being a student I have worked as a carer for children with disabilities, the majority being autistic. I have experienced how varied the condition is in the sense of being verbal/non-verbal, physical abilities, social skills, and stimming. A person who has autism will have very individual needs and areas where they require understanding and assistance. This is something I feel is not well understood by medical professionals as I have witnessed the stress the families I work with go through when trying to advocate for their children.

## What did my research entail?

I took statements from the parents that I currently work with to find out what they think needs improved and goes well in the NHS regarding autism. This provided me with a strong base understanding on what may come up in stories on Care Opinion. I combined the positive and negative comments from both the stories on Care Opinion and the statements provided from the families I work with to collate the key problems in the NHS for autistic people and the best way to improve this.

The aim of my project was to analyse the stories on Care Opinion and combine the ideas provided by the authors to find ways to improve healthcare experiences for autistic people. I analysed 252 stories which were published after 02/03/2020. When reading through the stories on Care Opinion the same themes kept reappearing; communication, autism awareness, assessment, environment, mental health and waiting periods. In each category there was a mix of both positive and negative stories with varying criticality scores, this allowed me to identify which certain situations people were finding most difficult, and also seeing what actions could have made that experience better.

With the mix of criticality in each area of interest this raised the question of what would make a difference to someone with autism in a healthcare setting?

## **Methodology**

The data was collected from stories published to Care Opinion. The stories are for feedback which are written by or on behalf of patients which can be negative or positive. The stories are tagged by both the author and the Care Opinion staff which allows users to search using specific tag words to find stories that are on the topic of interest. The tag words I searched were “autism”, “ASD” and “autism friendly”. These tags were chosen to cover a wide variety of experiences in healthcare for people with autism.

I originally wanted to see how the pandemic affected people with autism so I only looked at stories that were submitted on or after 02/03/2020. It became evident that the problems that people with autism faced during the pandemic occurred pre-pandemic too. The issues people faced were only amplified due to various factors such as difficulty to get face to face appointment, staff shortages due to isolation and there will be reduced staff training throughout the pandemic so there will not have been any recent autism awareness training. The search criteria was kept at that submission cut off as it gave a reduced number of stories, large enough to get varied opinions but small enough to analyse in a set time frame (n=252).

The same themes came up frequently and overlapped so I decided to group the stories using tags. The tags I decided to use, were staff, environment, communication, mental health, waiting and assessment. I only tagged stories that described what made the experience positive or negative rather than just stating so. This allowed me to gather a sample of 100 stories to work from.

Due to time constraints I did not analyse all 6 topics.

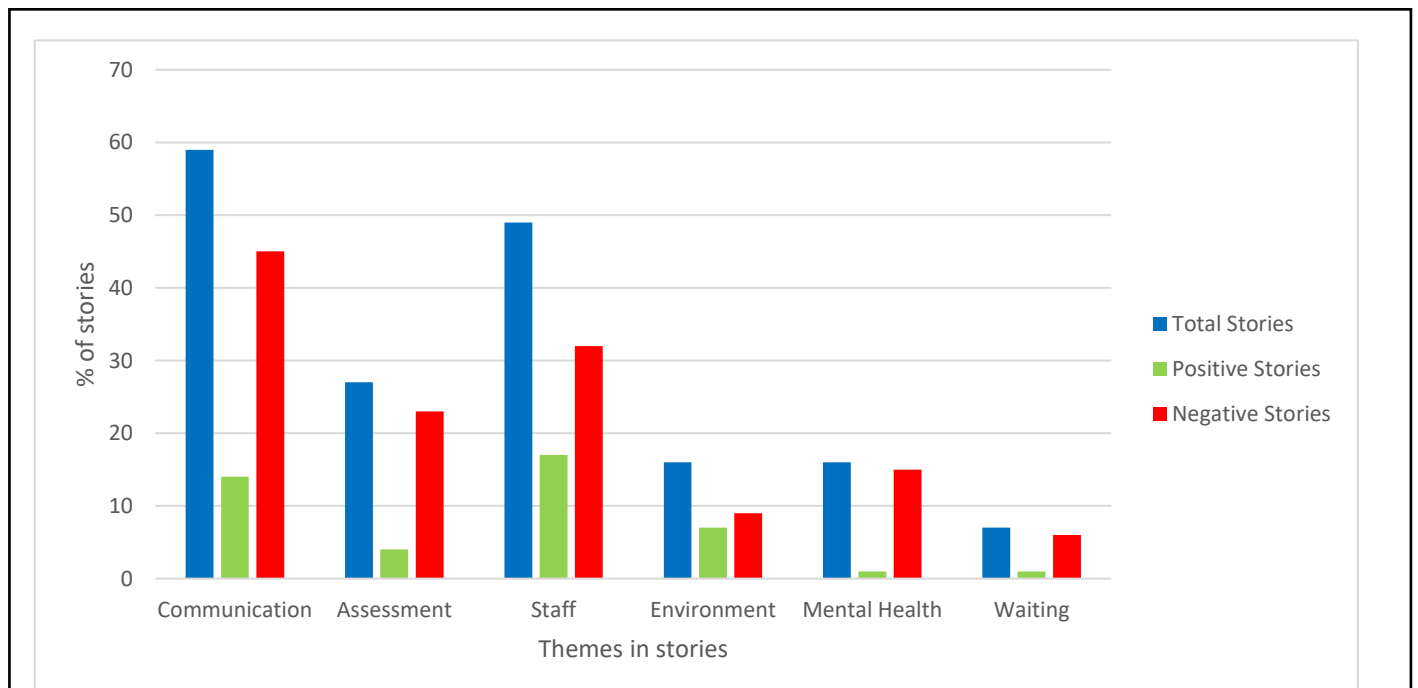
I compared the stories to find out what people found most challenging and most rewarding with their experiences in healthcare. I then cross-referenced these findings with the statements I took from the families I work with to find the commonalities but also to see if there were topics missing from the stories which should be discussed.

## Findings

Each story was tagged with at least one of the following tags: communication, assessment, staff, environment, mental health and waiting.

- The communication tag was used with regards to how well information was conveyed.
- The assessment tag refers to the initial autism diagnosis, not assessment for general health concerns.
- The staff tag refers to staff autism awareness.
- The environment tag was used in stories that had something particularly positive or negative to say about their surroundings in the healthcare setting.
- The mental health tag refers specifically to mental health concerns as well as services.
- The waiting tag refers to waiting time for referrals and appointments, not to do with waiting times in the actual practice/hospital.

Some stories were tagged with multiple tags so there is overlap in the numbers but the most prevalent topics came hand in hand with most cases was communication and staff autism awareness. This can be seen in figure 1.



*Figure 1. This figure demonstrates the distribution of themes present in the stories which are tagged with either autism, ASD or autism friendly, submitted on or after 02/03/2020. The total percentage of stories with that theme is represented in blue. Then subdivided into green and red to demonstrate the ratio of positive (green) to negative (red) stories within that theme. N=100 stories total.*

## Environment

### Problems

It is known that people with autism can find the environment within a typical medical setting to be uncomfortable and/or distressing. This could be due to various causes such as crowded waiting rooms, loud noises either electronic or from people talking, bright lights etc. All of the different elements in the environment in the medical setting can lead to sensory overload, therefore settings which seem “normal” for neurotypical people are becoming stressful and upsetting for those who are neurodivergent due to how they experience their surroundings. An example of the negative impact this can have on patient experience is;

*“There was no quiet space. I had the option of waiting in the main hall (which I wish I'd done now) or going to what they said was a quiet place. It was a waiting area a door along, and it was not quiet, it was noisy with conversations that were clear and echoed. I was in pain, but also so embarrassed, ashamed, humiliated, uneasy, on edge and frightened.*

...

*The vaccination center was way too busy and loud, and there was clearly absolutely no provision in place for autistic people, the staff didn't seem to know what to do with me, and physically I was uncomfortable too with all the standing (it wasn't for long by anyone else's standards, but I have nerve pain in my foot, and sacroiliitis).” - 850954*

Another example of this is;

*“The lighting, the people, the noise, the textures, the layout, the design, the processing system: everything is unpleasant from an autistic point of view. And the buzzer that tells you when to go to your appointment is particularly horrid.*

...

*I wore noise-cancelling headphones and sunglasses, and it was still difficult. It wouldn't take much to make the place more autism-friendly, but I guess that's just not important enough.” - 862130*

This Highlights that the environment can make a significant impact on a patients experience. Although the environment can negatively impact patients who have autism there are changes that can be made that will significantly improve the patients healthcare experience. Some changes may not be possible due to funding but it is important to be mindful of what could improve a patients visit.

## Solutions

A simple way to help someone who has autism in a medical setting is to provide a separate room for them to wait in, as opposed to the typical waiting room that has other patients present. Examples of this are:

*"The nurse who oversaw the waiting room area even offered me a private room to wait in, presumably as she thought i may be more comfortable in there with my Aspergers. I've been to a few hospitals and nobody has ever done this for me, so i was really impressed that they would consider my difficulties to make waiting easier." - 862793*

*"My child has autism so cannot be in crowded or loud places as they become agitated. The nurses where very accommodating to this and brought us to an area that was quiet and comfortable. " - 909711*

This demonstrates that something as simple as having a separate room that is quiet and away from other patients can make a large impact to how comfortable and calm the person who has autism is feeling when entering the medical practice/hospital.

There are some patients who even stepping foot into the medical building can cause them to feel very distressed. This can be difficult to remedy especially in a hospital setting but in general practice (GP) some staff we able to get around this:

*"I had already discussed his needle phobia with the practice. I told my son and he was scared that it was actually going to happen but determined to be brave. We were told that the practice nurse might be able to come out to the carpark and administer his injection while he sat in the car." - 826557*

*"My son (16 with autism) was extremely anxious about having his covid vaccine but the staff went out of their way to help us, letting him have his vaccine outside and even bringing out pets to distract him!" - 855575*

These experiences illustrates that if its possible to do what needs to be done in an environment that makes the patient comfortable (even if that is outdoors), it can make a big difference to the anxiety levels the patient experiences.

Another way to improve the patient's healthcare experience is through having a sensory room accessible to people who are neurodivergent. This is not as common because having space and funding to create a sensory room for patients is not always a possibility. Even though a sensory room is more difficult to have, here is the evidence that it significantly improves the patients and families experience;

*"A&E for 4 hours usually this would be a nightmare but the nurses and receptionist sent me to the new sensory room in A&E it was absolutely fantastic he didn't even notice he was in hospital we played music he played with the toys the lights the bubbles it was perfect a completely different experience from before at hospital with him well done to all involved to make this happen parents like myself really appreciate it makes our mad and stressful lives that little bit easier" - 903555*

*"Once we checked in I asked if we could go to the sensory room and was taken straight round. This lovely relaxing space made all the difference to our experience. It had soft lighting, sensory lights and toys, bean bags as well as chairs. He received all his treatment in this room. Having this space to wait in and to be treated in cut down on stress for both my son and myself. I am so grateful that the hospital decided to create this room." - 918265*

This highlights just how being in a calm, quiet and soft lighted environment can make someone with autism more at ease and distracting things such as bubbles and toys can take away the frightening medical appearance of the building.

Lastly, many people with autism either feel more comfortable or require to have someone come with them to appointments whether that be family, friends or carers. If the patient is then required to stay overnight this can be stressful for the person who is there to support them as there is not an additional place for them to rest. Making small adjustments such as this can also improve healthcare experience for people with autism as they can have their support with them during what could be a stressful time.

*“When we eventually got into blossom, I was amazed at the facilities and the staff. The rooms are so modern and spacious and it's a luxury to have a bed in the room also for me. The staff are exceptional, my son has autism and the way they are able to adapt their communication and plan to suit him is phenomenal...” - 916260*

This demonstrates that simple changes such as having somewhere for the patients family/friend/carer to sleep if they have to have an overnight stay can have a significant impact on how the patient and others are feeling during their visit to the hospital, which will impact their interactions with staff etc.



## Communication

### Problems

One of the most common problems that is mentioned on care opinion in a variety of services on a variety of topics is communication. Communication covers a variety of issues and therefore a variety of solutions too. The first issue that was prominent was medical professionals not fully taking in what a patient has to say and responding to it appropriately. This can be demonstrated here;

*"They asked me why I was calling and when I began to explain that I think I'm autistic, they cut me off, saying very shortly that I am 19. I then tried to explain that while I hadn't been diagnosed as a child, symptoms have been present from a very young age, and my older brother also wasn't diagnosed until adulthood. The GP cut me off again, saying that they think I'm just shy. I hadn't mentioned anything about me being shy.*

...

*I again tried to explain to this person that my issues go much further than just being socially anxious/shy but I knew they weren't listening. They asked if I had ever had a boyfriend, and when I said yes they said "Well then", as if that was the one defining factor of whether or not I was autistic. They then proceeded to ask me more very limited questions, at one point they even said they were going to reword a question and ask me again because they thought my answer "wasn't right"." - 835424*

This outlines how good communication skills are important. Whether or not this patient does in fact have autism, they should leave feeling listened to and cared for rather than dismissed and distressed (even though that will not have been the medical professionals intentions). Taking the time to let someone speak about their problems and acknowledging how they feel goes a long way with how comforted the patient will feel about their interaction with a doctor even if the outcome isn't what they desired. This should go for all consultations in general but medical professionals should take special note of how people with autism can sometimes struggle to express their thoughts and emotions so may need to be given more time to do so and asking open questions to let them speak freely in their own time, as opposed to feeling like limiting questions are being asked and being judged on their answers.

Another issue that appeared constantly within the stories was the lack of autism awareness amongst staff whether it be receptionists, nurses or doctors. There was a general lack of understanding of how people with autism express themselves in conversation but also with how they are more sensitive to sensory stimulation whether it be visual (bright lights), auditory (loud noises) or physical touch (feeling discomfort with something touching their body).

As stated on the NHS website about autism, patients may present as “seeming blunt, rude or not interested in others without meaning to” and “finding it hard to say how you feel” [2]. This is very important for medical professionals to take into account when a patient has autism or is suspected to as they may need more time and assistance finding the words they want to use to accurately describe what they are experiencing. Simple things such as giving the patient plenty of time to answer questions and asking open questions is highly important in this case scenario as it will generate a great deal of distress and upset if not done correctly, this can be seen here;

*“They were incredibly dismissive, and did not listen to my experiences. They kept interrupting me mid-sentence, not giving me the time to translate what was going on in my head into words, and kept changing the wording of the questions until I, confused and distressed, said something that seemed to fit whatever checklist they were following. Because of these constant interruptions, I was terrified of saying anything, because I felt like I was doing something wrong, like I was bothering them for trying to talk about my experiences. So I would answer in short, tentative sentences, and speak when spoken to, which is something I learned to do after years of bullying and abuse and was very much something I fell back into during that assessment. This coping strategy, which I used because I was confused and afraid and increasingly upset, was then later thrown in my face as an example of “complex social interaction”, because I was “waiting for them to ask questions”, and therefore I could not be autistic, because it was “intuitive”.*

...

*The fact that I felt the need to mask and “act neurotypical” in order to feel safe DURING AN AUTISM ASSESSMENT should reflect how terrible that experience was. I was dismissed based on the fact that I allegedly hugged people when I was a child, and because I was good at acting normal.” - 837783*

*“It feels like the “Mental Health Practitioner” hasn't had her training updated since the 1980', she told me I was “Too logical to be autistic” - 852176*

This illustrates the importance of the basics that are taught in first year of medical school; to let the patient say everything they want to say, ask open questions to give them the best opportunity to say how they feel without directing them, then moving onto closed questions but only to refine information gathered initially not to make the patient feel under distress and pressure. Also a flaw in communication here is poor word choice. Patients hold onto words doctors use for them as the reason they are seeing a medical professional is usually over a matter they care about so it is important to avoid using dismissive language as it could be taken to heart, even more so by someone with autism as they struggle with taking things very literally.

A common feature in autism is to be hypersensitive to touch, stimulation that might seem harmless to someone who is neurotypical can be very uncomfortable or even painful to someone who has autism. The National Autistic Society provides a description from someone with autism on how they feel being touched, to provide an example of how distressing just being touched can be;

*“Every time I am touched it hurts; it feels like fire running through my body.”*

(Sensory differences - a guide for all audiences, 2022).

Sensory differences between someone who is neurodivergent to someone who is neurotypical does not seem to be fully understood by healthcare staff, and they are therefore not mindful of how distressing it can be for someone with autism to be asked to do something that is out with their comfort zone. This can be seen here;

“My brother was automatically told he would need to go for a covid test. My brother asked if this was a legal requirement or a suggestion (not to be difficult, but for clear instruction due to his autism). My mother advised the nurse of this and was told that we’re all a bit autistic and they weren't getting in to politics. My brother has struggled with covid tests previously due to the intrusive sensory nature of them which again is related to his autism and was understandably reluctant to agree to go for one. The nurse then made suggestion to him that he could be going around with covid “killing people”, adding that he was putting them and their own children at risk by being there.” - 847683

“Being mask exempt from wearing a mask due to her distress and anxiety due to ASD. she has been denied access for not having a mask on, after going to get food from hospital shop and returning to ward.

...

She explained she is exempt and its not been questioned all day yesterday and all night. She has a lanyard although doesn't have to show this. Anyway I called and spoke to person who sent her away and apparently hospital policy is even people who are exempt need to wear masks .. so she was not allowed back into ward. My daughter phoned me and if it didn't come up with her name I wouldn't have known who it was .... she was herself outside hospital in full blown panic attack. She couldn't speak but was very obvious the distress she was in. The member of staff was adamant that they were 100% correct and my daughter still needs to wear a mask and is not welcome in unless she wears one ...which of course she cant.” - 863213

These stories emphasise how distressing and upsetting it can be for someone with autism to be asked to do something which for them will cause over stimulation and sensory overload. The stories also show just how little some staff understand this, autism is often a condition which is not necessarily obvious at first glance so is not always taken seriously with regards to how upsetting doing something such as a covid test could be for that person. Autism awareness amongst healthcare professionals needs to improve so that they better understand their patients needs and can find creative solutions so there is minimal upset and distress inflicted.

Another issue with communication is that some places do not have something in place to make communication easier or if they do they are not using it effectively. For example something as simple as a board explaining patients basic needs;

“Upon arrival all staff where helpful, everything was explained to me by the doctors & there was time to ask any questions. There was a board on the wall to write in details, what her needs are but it wasn’t filled in. I do feel it would have been helpful if this had been done rather than me having to explain to everyone that she is autistic, won’t take medication and won’t really speak.” - 842215

Having something simple such as a board beside the patients bed explaining if they are verbal, how to communicate with them and their needs could make a drastic difference to the stress levels of the patient and their family/carers so that every healthcare staff member can see this and focus on just the medical issue at hand rather than each staff member needing to be told all of this information

repetitively. This information would also be useful to have accessible before the patient attends the appointment to make the most use out of their consultation and minimise confusion amongst staff. The better the structure and consistency in appointments, the much more comfortable someone with autism will feel about attending those appointments.

Another factor which can reduce patient anxiety is to have someone with them. This may be because they struggle to speak for themselves, they need physical support or could be just for emotional support. All of these reasons are valid, especially for someone with autism who may need help expressing themselves or have great difficulties in social situations with new people. Due to how well some people with autism are at masking their condition it can give the impression to someone that they are neurotypical. If staff do not have a good understanding of the difficulties that people with autism face then they may not understand why the patient needs someone with them. This can be seen here;

*“The person on the door told me my partner couldn't come in with me due to covid. I was crying outside in the cold for 2 hours as I couldn't go in due to anxiety and autism. They treated me horribly saying I don't seem bad and I'm capable of talking so I shouldn't need my partner with me. I tried to explain how bad my condition affects me but they wouldn't listen and kept ignoring me.” - 849063*

This kind of distress could be avoided if all healthcare staff (admin and medical professionals) had more autism awareness training to greater understand why situations like this are so upsetting for the patient.

Another element of healthcare which is distressing to people with autism is change in routine. Medical appointments are already out of the normal week routine that a person with autism has, so being mindful of this is important. It is also crucial that if the appointment needs to be changed as much notice as possible is given so that the patient can prepare for this and is not overwhelmed by any sudden changes or cancellations. This is made clear by a parent writing into care opinion here;

*“On the Monday morning I phoned Outpatients who said that putting the clinic as the location on the letter was a mistake and that it was a video call. The person on the phone was polite and helpful and I asked if they could give feedback that although this may seem like a simple mistake, for autistic families, having clear information that can be easily explained to children and as far as possible, for plans not to change, is really important.” - 858125*

Changing appointments or not communicating how the original appointment was to take place properly can impact the patients families too as they are often part of planning the patients week/organizing transport etc. Therefore it can be quite distressing to everyone involved if plans are not well communicated or are changed. This can be seen in this story;

*“However ,no one "turned up "at the arranged time. we phoned CAMHS to find out what was happening and got a phone call from the psychologist half an hour later. They explained that a decision had been made to cancel all the appointments with families related to discussing the course as the letters had gone out late ( no one had informed us that the appointment had been cancelled ).” - 911906*

In conclusion, being mindful of if the patient has autism it might be distressing and overwhelming to have the routine of the week changed if the appointment is altered last minute and how that will affect others around the patient.

An example of much of an impact a mix of poor communication between healthcare professionals, between medical staff and patient, and also changing routine can affect a patient to a life-threatening extent:

*"In the morning I was moved to a&e waiting where I had NO blood sugar checks despite being a type 1 diabetic! I was finally moved to IAC in the afternoon, no drinks or food were offered all this time, I was not even put on a fluid drip to stop me dehydrating, when I got to IAC my sugars were checked for the first time along with ketones. I discussed with the ward staff I am autistic among other conditions I explained I needed to keep as close to my normal routine as much as possible, I was told there was no issue and the care of my medication was allowed to be my responsibility, when I was transferred to AMSS I was told I was not allowed to take any epilepsy medication (you can NOT stop epilepsy medication) I was also not allowed to administer my Insulin which I was moaned at for poor diabetes control this happened because the doctor who listed my insulin forgot to sign the authorisation. So 3 days no insulin, Ketones started building! When I explained to staff that I was Autistic and it had been agreed with the doctor on IAC that I was allowed to administer my own meds to keep my routine as normal as possible, they said they didn't care! That they are sick of patients dictating that we want things that are away from the normal routine of the ward! I was FINALLY authorised that I was allowed my epilepsy meds, 6 hours late! This is likely to have contributed to the 2+ seizures on ward as well as the extremely long run of seizures which resulted on the home transport ambulance which also landed that an emergency ambulance needed to be called while I was on the transport!" - 865331*

This story was rated 4 on the criticality scale (0 is not critical and 5 is extremely critical) on Care Opinion. It illustrates just how detrimental to someone's health a lack of communication can be.

Incorrect communication can also affect other elements of a patients life not just their healthcare, this can be seen here;

*"Following autism assessment of our son we received a letter confirming diagnosis through the post.*

...

*The letter had bullet points outlining strengths and weaknesses and also had other information.*

...

*However, we did not recognise our son from the description, and it seemed like some sections had been copied and pasted from a letter describing another child. This was very upsetting for us both. For example, the letter stated that our son has hyperacusis and wears ear defenders, which is not the case. The letter also stated that our son has autistic siblings, whereas he only has 1 sibling, and that his dad has autism! (which is untrue)." - 911907*

This family received a letter that did not depict their son, which gave them a lot of stress and anxiety as they worried the letters were going to be passed onto the school their son attends. Parents go through many emotions when their child is diagnosed with autism, the last thing they need is the diagnosis letter being wrong and being handed out to different areas of their sons life.

Overall, communication is the route of many problems, but there is multiple different ways communication can be improved to benefit a patient who has autism.

## Solutions

One of the most simple yet effective ways to improve communication and rapport between healthcare professional and patient is to look at the patient as a whole rather than just a symptom. A brilliant example of this can be seen here;

*“We went away a walk to let the drops work, (it was a sunny day, so he was finding it quite difficult) once we came back, he was still unsettled and not keen to go into the clinic again. Richard the optician came out to collect us. He could see my son was upset at having to go back to the clinic, but he was so patient and engaged my son asking about what dinosaur was his favourite (he noticed his Jurassic world socks!). Once in the room he explained everything to him clearly and encouraged him throughout the examination, he managed to calm my son down so much that he was laughing with him by the time we left.” - 843130*

Engaging with a child with autism does not need to be scary and intimidating, this socks example is a brilliant way of interacting in a friendly way to encourage a response from the patient and building a bond. This simple but effective way of engaging with someone can really help let someone with autism bring you into their world and be comfortable with that. Using something familiar to them to start the conversation/interaction can be very calming and settling for them, and may encourage them to engage in the consultation more. Seeing the patient as a whole person rather than a symptom is a very helpful way of working with every patient but can make a significant difference to the quality of experience for someone with autism who struggles with social interaction.

As explained previously, routine and environment are both factors which can make or break a situation for someone who has autism. An example of how some simple communication and creative thinking improved a patient experience is;

*“After I explained everything about my son to him, to our relief, he called back in the afternoon to say they could vaccinate him at home that night. I can’t believe how quick he worked to get this sorted and all in a day. We got pictures of the nurses, so my son knew who was coming to the house. Jackie & Naomi were absolutely fantastic to do this. They were amazing at explaining everything to us and keeping him calm. He was so relaxed with them.” - 877096*

Providing pictures of the nurses who were going to come to the house and organizing for the vaccination to occur in the patients home makes a huge impact on their stress levels as they are in their safe place and have photos to get familiar with the staffs faces before them come to allow them to prepare for this change to routine. Picture cards are a common method of communication for some people who have autism as it simply lets them know what is happening at what point in the day and who they will be seeing at that time. The GP practice implementing this into how they interacted with the patient to make the change in routine have as small an impact on their wellbeing as possible was very important.

Another impressive form of communication that some medical settings have implemented is care passports;

*“She showed me a care passport I could fill out for my daughter to make interactions with care professionals in the future easier.” - 855687*

Care passports are a brilliant idea, to have a quick and easy way to explain someones needs and requirements whether it be they are nonverbal, or only speak through Makaton or if they struggle to take medication etc. This would mean the majority of the consultation can be used to focus on the

issue at hand rather than a parent or carer using half of the time explaining the needs of the patient to every doctor and nurse they encounter.

Lastly, the way in which healthcare professionals choose to interact with someone who has autism can either leave them feeling cared for and understanding the outcome of the consultation or can leave them confused and distressed. The first example of this is:

“the GP spent time listening to me and even wrote a diagram explaining the dosage of medication.” - 896444

Providing visual information as well as verbal is a really positive way to simplify things so that patients can understand what is going on. This can be good to reinforce what you are saying to the patient, especially if a lot of what they use for their day to day routine is picture based.

Another example of good communication is:

“Its great when our son is spoken to directly and we as parents are not the focus or point of communication. It's fabulous that he is given the time to communicate at his own pace and encouraged to express his choices and feelings about what's happening to him.” - 856079

This demonstrates a very important element of communication, speaking to the patient. This may sound like a basic and simple thing to do but it is common that when a healthcare professional reads that the patient has autism and then sees them come in with family or carers they may instinctually go to directly speak to the person supporting the patient. In some cases this may be required, such as if the patient is non verbal or does not have capacity to understand the doctor but this should not be assumed. This doctor speaking directly to the child with autism and letting him engage in his own time will have made a difference to that child's confidence for social interactions and for attending medical appointments in future. Giving that patient that little bit extra time and focus will significantly improve their healthcare experiences.

Although it is important to speak directly to the patient if possible, its important to take input from the parents/carers and be mindful of how stressful the situation is for them;

“as soon as we arrived she introduced herself and asked how I was. I wasn't the patient but I haven't eaten and slept since the day before. She brought us some toast, coffee and milk. She read my son's folder and she was aware that he is on spectrum. She asked what's the best way to communicate with him and she was talking to him in the kindest and in a manner that he will respond to her based on what I've told her. She listens and responds with compassion. She visited us often and ensure that doctors sees us when needed. I didn't realise that she's a student nurse. Her confidence, professionalism and compassion is beyond exemplary.” - 853673

The healthcare professional in this story was amazing for both the mum and child. Recognising the stress and fatigue the mother was experiencing and doing something to try and make her feel a bit better was impressive as often people forget how draining it can be for parents who have children with additional needs, especially when that child is sick. The very simple yet important part of this story was that the healthcare staff member asked the best way to communicate with her son. This is such a simple question but it allows the staff member to enter that child's world in the way they will engage and best understand what is happening. This is a question I think is underrated and should

be used regularly in healthcare settings when the staff member does not know the patient but is aware of their difficulties.

Overall, finding the most effective way to communicate with a patient will make a significant difference on their experience of healthcare and hopefully decrease distress and anxiety that may be brought on by having a medical appointment.



### **What else could be studied?**

There are many topics that could be researched from these stories about autism, but this project focused directly on communication and effect of environment. Other possible topics would be mental health services, autism assessment/diagnosis and doing more in depth comparisons.

While reading the stories it became very evident that mental health services in particular was where there was a lack of communication, long waiting times and a lack of support for the person with autism but also their family. More in depth research could be conducted to see how this affected people with autism in particular and how it could be improved.

Autism assessment/diagnosis also has long waiting times but also there was a lot of stories that mentioned the diagnosis criteria itself as it is based off of male patients. Females are very good at masking which makes them more likely not to get a diagnosis even though they do experience the difficulties that come with having ASD and therefore get no support.

There is also various comparisons that could be conducted such as

- Comparing problems with geographical location
- Comparing GP, hospital and additional services to see if problems are the same across the board or if they are service specific
- Comparing stories submitted by/on behalf of adults and children with autism to see if they experience the NHS differently depending on their age

This could give a greater insight to where either more funding is required or more training for autism awareness is required.

### **What was missing from the stories?**

A lot of what I read in the stories on care opinion coincided with the information I received from the families I work with but there were many topics that were not discussed in the stories. This could be for many reasons such as people not being aware of the care opinion platform but also these families do have difficult day to day routines so finding time to sit and write in about NHS experiences may not be their top priority. The main topics missing from stories on Care Opinion are lack support after diagnosis, reviews post diagnosis, dual specialty appointments and covid-19 testing.

#### **Support after diagnosis**

The families I work with were handed a book/leaflet when their child was diagnosed with autism and sent on their way without any more information such as what the next few years may bring, what to do if their child isn't coping with mainstream nursery etc. One of the children I work with attended mainstream nursery when he was pre-school age. At this mainstream nursery he was strapped to a chair by staff to try and get him to eat which left marks on his body. If there was more guidelines and support in place, then maybe this would have been changed before reaching that point.

#### **Post diagnosis reviews**

Post diagnosis reviews aren't very regular therefore there isn't a great deal of help with milestones throughout childhood and teenage years but also the parents themselves would like reviews to see how everything is affecting their mental health. There are emotions of grief and shock that can occur when your child is diagnosed but yet there isn't much support for the parents, which is important as parents need to keep well to care for their children.

#### **Dual specialty appointments**

It is impossible to get appointments with more than one specialist which creates issues. An autism consultant can only do so much but if the patient has autism and ADHD for example then psychologists get involved but don't interact with the autism specialist, so it feels like never ending cycles of not getting a well-rounded consultation.

#### **Covid-19 testing**

There hasn't been any support for covid testing in home or at school for people with special needs so some have been isolating when unnecessary and that will bring great distress especially if they don't understand why their routine has been impacted.

## NHS Autism training

There is an NHS training document which works through the key considerations for positive practice with regards to autism (KEY CONSIDERATIONS IN PROMOTING POSITIVE PRACTICE FOR AUTISM SPECTRUM DISORDERS, 2022).

The overview of this document states:

### **KEY CONSIDERATIONS FOR PROMOTING POSITIVE PRACTICE: OVERVIEW FOR ALL HEALTH AND SOCIAL CARE STAFF**

- i **ATTITUDES AND ASSUMPTIONS:** Being aware that attitudes can be affected by knowing that an individual has a diagnosis of autism and that we must be careful about making assumptions based on a diagnostic label or past experience of someone else with autism
- i **INDIVIDUALISED APPROACH:** Recognising that those with autism will vary across a range of skills, needs and circumstances
- i **PREPARATION:** Thinking about what staff can do to prepare in advance and how they might support individuals, families and carers in preparing for appointments
- i **PRACTICAL ARRANGEMENTS:** Considering the physical setting of appointments/contact and how these are arranged as well as timing and frequency
- i **COMMUNICATION:** Understanding the range of communication needs for those with autism and ways of supporting communication
- i **KNOWLEDGE, UNDERSTANDING AND SIGNPOSTING:** Having the right level of knowledge and understanding for your role and an awareness of other resources and sources of support

This demonstrates that healthcare staff do have access to a document that describes many important factors and states what they can do to promote positive practice in these areas. It is not clear if this is mandatory to read or if it is optional and does state that there is E-learning resources available. Just because information is available online does not mean that it will be used in practice or even reviewed by staff at all.

My opinion is that the NHS should run in person training sessions on autism, and how they can alter their practice to benefit someone with autism so that it has more chance of setting in, spreads autism awareness and can be interactive so it is something staff can enjoy and engage with.

This would hopefully lead to a better understanding of people who have autism in healthcare and make healthcare more accessible and inclusive.

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## **References**

[1] Hey, L., 2022. *Autism in the UK: prevalence, assessment and the impact of the Covid-19 pandemic*. [online] Hogrefe.com. Available at: <[https://www.hogrefe.com/uk/article/autism-in-the-uk-prevalence-assessment-and-the-impact-of-the-covid-19-pandemic#\\_ftn2](https://www.hogrefe.com/uk/article/autism-in-the-uk-prevalence-assessment-and-the-impact-of-the-covid-19-pandemic#_ftn2)>

[2] nhs.uk. 2022. *Signs of autism in adults*. [online] Available at: <<https://www.nhs.uk/conditions/autism/signs/adults/>>

[3] Autism.org.uk. 2022. *Sensory differences - a guide for all audiences*. [online] Available at: <<https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences>>

[4] Knowledge.scot.nhs.uk. 2022. *KEY CONSIDERATIONS IN PROMOTING POSITIVE PRACTICE FOR AUTISM SPECTRUM DISORDERS*. [online] Available at: <[https://www.knowledge.scot.nhs.uk/media/12413447/nesd0565%20autismguide\\_web.pdf](https://www.knowledge.scot.nhs.uk/media/12413447/nesd0565%20autismguide_web.pdf)>