MORE THAN WORDS:

SUPPORTING EFFECTIVE COMMUNICATION WITH AUTISTIC PEOPLE IN HEALTH CARE SETTINGS

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About this report

Autism is a national priority, as highlighted in the NHS Long Term Plan[1], the Right to Be Heard report[2], National Autism Strategy (2021-2026)[3] and most recently in the 2022 Health and Care Act[4]. One significant area of concern is the striking health inequities and reduced life expectancy experienced by autistic people[5,6].

In the United Kingdom, autistic people represent at **least 1.1%** of the population[7]. Autistic people have the same health care needs as anyone, and are additionally more vulnerable to a large number of co-occurring physical and mental health conditions than the general population[5], requiring input from all parts of NHS healthcare services. Despite this, many autistic people experience barriers to accessing services that mean they struggle to get their health needs met[8,9]. In one recent study, one third of autistic respondents reported being unable to access any form of healthcare for potentially life-threatening conditions[10]. Communication difficulties with healthcare staff are frequently reported as one of the most challenging barriers[8,9,10].

Communication differences and difficulties have always been a core part of the diagnostic criteria for autism. They are also something that autistic people frequently report as finding disabling in their everyday lives, including when trying to access health services[10,11]. Historically, these communication difficulties were believed to stem uniquely from autistic ‘impairments’. However, it is now understood that successful communication and mutual understanding depend on many factors and that communication challenges are best thought of as a two-way mismatch rather than the problem of one individual (see Theme 4: The double empathy problem, below).

Aims

In the United Kingdom, the Equality Act[12] and the Autism Act[13] set out the requirement for reasonable adjustments[14] to be made in order to make services more accessible to autistic people. However, present guidance, particularly around best practice for communication, lacks detail. The aims of this report are twofold. Firstly, the suggestions below can be used to form the basis of reasonable and anticipatory adjustment standards for communicating with autistic patients. Secondly, we hope this report will provide the essential information, drawn from autistic lived-experience and high-quality research, for supporting practitioners to feel confident when communicating with their autistic patients.

In the following pages we outline seven key themes that have direct bearing on communicating with autistic patients in healthcare settings. At the end of each theme we list our recommendations. A quick-access, 'Summary of Recommendations' is provided at the start of this report (p03). Key terms are italicised throughout and explanations can be found in the 'Glossary' at the end of this report (p14).

Our approach

This report has been co-produced by a group of key stakeholders who met over several months to develop, shape and review the contents. The group has an autistic majority and includes perspectives from both service-users and service-providers with a range of professional and strategic expertise within the NHS and healthcare education. The report is further supported by extensive literature reviews and a piece of doctoral research into communication between autistic and non-autistic people. A full list of contributors, can be found at the end of this document (p13).

Neurodiversity-affirming language

In this report we have used neurodiversity-affirming (as opposed to pathologising) language and we encourage healthcare professionals to bring this into their practice[15]. We also use identity-first language throughout – e.g. 'autistic person' rather than 'person with autism'. There is a general preference among autistic people for identity-first language[16,17,18] but best practice is to observe individuals' choices and where these aren't known, to ask.

A word of caution : all autistic people are individuals

In the following document we outline a number of recommendations for supporting most effective and comfortable communication with autistic healthcare users. However, it is always important to remember that **all autistic people are individuals** and a **person-centred care approach** should always take precedent.

As you will also see, environmental factors can significantly influence autistic people's ability to communicate effectively in a given moment, so being open to different ways that communication can happen is key. If you're unsure, check with your autistic patient or when this is not possible, their advocates.

Summary of recommendations

Recommendation 1: Always consider that a patient may be autistic

Anyone can be autistic and this may not necessarily be obvious when you first meet your patient. Where you have a sense it might be a possibility, err on the side of caution and look to make reasonable adjustments: in particular to communication and the sensory environment.

Theme 1 : Is my patient autistic? (p05)

Recommendation 2: Adapt the sensory environment to support autistic people to engage and communicate comfortably with services

Healthcare premises can often be overwhelming sensory environments for autistic people. Wherever possible, make reasonable adjustments to the sensory environment such as: turning off bright lights, offering a quiet space to wait, or permitting headphones and sunglasses on wards. Take sensory sensitivities into consideration when interacting with your autistic patients and try to avoid adding to overwhelm by giving them lots of spoken information delivered quickly. Allow autistic patients time to ground themselves and process what's being communicated: even where distress is not evident to you.

Theme 2 : Sensory challenges that affect communication (p06)

Recommendation 3: When taking a history from autistic patients, consider whether impaired interoception (a reduced awareness of bodily sensations) may be affecting how (and what) symptoms are reported.

Where autistic patients do have difficulties identifying and describing bodily sensations, enhanced clinical investigations may be appropriate and ultimately more cost-effective than relying on self-report.

Theme 2 : Sensory challenges that affect communication (p06)

Recommendation 4: Wherever possible, create a reliable, predictable environment and support 'single-focused' attention

Keep autistic patients updated with wait times and their changing place in a queue. Remember that autistic people often have a single-focused attention style and need activities to unfold one-by-one rather than simultaneously (e.g. talk to your patients before examining them, rather than at the same time).

Theme 3 : Predictability and focus (p08)

Recommendation 5: Be alert to situational mutism

Look out for signs that your autistic patient is losing their ability to speak in the moment. Provide a calm and quiet environment for them to re-regulate, be mindful of adding to overwhelm, and offer and support alternative means of communication (such as written modes). Don't assume that your autistic patient has understood what you've said just because they are using words if they seem overwhelmed. Use checking questions and active listening techniques.

Theme 4 : Situational mutism, semi-speaking and non-speaking autistic patients (p09)

Recommendation 6: Support non-speakers to use ***AAC*** and always assume capacity

Factor in extra time to allow semi-speaking and non-speaking autistic people to use ***Alternative and Augmentative Communication*** (AAC) methods. Be mindful that barriers to using speech can be related to verbal apraxia and not to a lack of capacity.

Theme 4 : Situational mutism, semi-speaking and non-speaking autistic patients (p09)

Recommendation 7: Think about communication challenges as a two-way mismatch when interacting with autistic patients and make efforts to 'meet them in the middle'.

Difficulties in social communication create significant barriers to accessing healthcare. Research now shows that these difficulties are a two-way issue (called: the double empathy problem) and not due to inherent autistic impairments. Autistic people will have spent much of their lives not being understood, so take the time to put them at ease and show that you are listening and interested. One way to bridge the double empathy problem is to imagine that the autistic patient before you may be having a vastly different experience of thinking, speaking, listening, seeing, and knowing their feelings: and begin from here.

Theme 5 : The double empathy problem (p10)

Recommendation 8: Pay attention to what autistic people ***say*** about their pain and symptoms, and resist making clinical judgements based solely on behavioural signifiers

Autistic people often have atypical body language and facial expressions which can lead to them not being believed when they report symptoms. Considering the significant health inequities that autistic people face, always err on the side of caution.

Theme 5 : The double empathy problem (p10)

Recommendation 9: Consider a ***trauma-informed care approach*** when working with all autistic patients

Autistic people are much more likely than the general population to experience traumatic experiences that can result in PSTD and this can become a further barrier to accessing services. Taking a trauma-informed care approach, built on the principles of safety, choice, collaboration, trustworthiness, and empowerment as standard practice can support autistic patients to access services.

Theme 6 : Taking a trauma-informed care approach (p12)

Recommendation 10: Offer a variety of methods for making appointments and accessing services

Having to use the telephone to book an appointment can be a significant barrier for many autistic people. To enable equitable access to services for autistic patients (diagnosed, undiagnosed and undisclosed), alternative methods of booking appointments – by text, email or an accessible online booking system – should be offered from the outset to all patients.

Theme 7 : Supporting access (p12)

KEY THEMES AND RECOMMENDATIONS FOR SUPPORTING EFFECTIVE COMMUNICATION WITH AUTISTIC PATIENTS

According to the Core Capabilities Framework for working with autistic people[19], all health and social care professionals in the United Kingdom are required to have a good basic understanding of autism and the skills to adapt their communication to meet an autistic person's unique communication and information needs. However, feedback from both NHS staff and autistic patients indicates that clear information about how this can be achieved in practice is not often easy to find.

In the following pages we outline **seven key themes** related to communicating well with autistic patients, providing some context and practicable recommendations. Some of these recommendations may require a little extra time or thought to accommodate in the moment: but doing what it takes to support effective and comfortable communication in the present will help improve efficiency of diagnostic and treatment pathways in the future, while reducing both stress and health inequities for your autistic patients.

Theme 1: Is my patient autistic?

In the UK we know that at least 1.1% of the population are autistic[7]: but these figures are now quite dated and it is likely the number is even higher. Because of our evolving understanding of the different ways that autism can present, we now also know that there is a large number of currently undiagnosed autistic adults in the UK who missed identification in childhood[20]. Even for those who have already begun the diagnostic journey, waiting times can be astonishingly long leaving many without the supports in place that they need and deserve[21].

While aids such as electronic alerts, sunflower lanyards and Hospital Passports may help you identify some autistic patients and their needs, provision and uptake is not consistent. There will also remain a number of autistic people who do have a diagnosis but choose not to immediately disclose due to fear of perceived stigma[22].

Anyone can be autistic, and the autistic people you meet will not necessarily "appear autistic" in certain situations as masking or camouflaging behaviours – the conscious or unconscious suppression by an autistic person of their natural responses and behaviours that might attract negative attention – are common[22].

Various stereotypes of whiteness, masculinity, youth and high socioeconomic status are still often associated with autism[23]. Black and Brown autistic people, in particular, experience diagnostic biases and so are under-represented among the diagnosed autistic population[23,24]. We also know that the autistic behaviours of Black autistic people are often viewed through a systematically racist lens: perceiving them more frequently as aggressive or hostile[25,26,27]. In healthcare settings where individuals may be experiencing distress and pain this is especially important to keep in mind. Older autistic people are also disproportionately under-diagnosed[5] and may have perhaps spent a life-time masking.

Being able to identify an autistic patient is important, both for the autistic patient themselves and for helping healthcare services respond appropriately and efficiently. Characteristics such as atypical verbal and non-verbal communication, sensory sensitivities, and an increased likelihood of experiencing higher anxiety with regards to uncertainty, unexpected change, going into new situations and meeting new people can indicate that a patient may be autistic. A more comprehensive list is available in the Open Access Recognising Autism in Healthcare paper[28].

MENTAL HEALTH – HIGHLIGHT

Autistic people experience significantly higher rates of poor mental health, including depression[29], anxiety disorders[30], self-injurious behaviour[31] and suicidal ideation[32] than the general population. Research reports are now supporting the common anecdotal observations that within mental health and CAMHS services, autistic people are frequently overly represented[33,34,35,36]. Given that many of these may not yet have a diagnosis, it is especially important to consider whether both children and adults presenting with mental health conditions might be autistic and may benefit from any reasonable adjustments.

> *"All of these models we use in mental health services for understanding behaviour are in and of themselves potentially very helpful, but unless people are thinking neurodivergence first, they are possibly missing out on the key thing that might make a difference to that person's understanding of themselves…This then has a multitude of consequences for all involved: the least of which is the spending of money on inappropriate services and treatments, whilst the genuine needs of the person go unspoken and unmet, sometimes for many years at a time"* – Pete

Recommendation 1: Always consider that a patient may be autistic
Anyone can be autistic and this may not necessarily be obvious when you first meet your patient. Where you have a sense it might be a possibility, err on the side of caution and look to make reasonable adjustments: in particular to communication and the sensory environment.

Theme 2: Sensory challenges that affect communication

Sensory processing differences are such a commonplace experience for autistic people that they are now a fundamental part of the diagnostic criteria for autism. In additional to difficulties integrating sensory information, autistic people often experience hyper- or hypo-sensitivity across all external and internal sensory domains. It is common for individuals to experience a range of hyper- and hypo-sensitivities across different domains. In this report we focus exclusively on the ways in which sensory sensitivities affect communication. However, we recommend an excellent recent report produced by the National Development Team for Inclusion, called It's Not Rocket Science[33], which outlines in detail the sensory differences and challenges that autistic people can experience and makes suggestions for reasonable adjustments that can be made within hospital settings that can improve the sensory environment.

There are several significant ways in which autistic sensory experiences can affect communication in healthcare settings. In the first instance, intense sensory environments create barriers to autistic people presenting for healthcare.

> *"It was so incredibly noisy in the A&E waiting room, it got to the point where I was literally about to get up and walk out before I've been triaged, without any treatment at all. I was just about to walk it out but luckily my wife walked in at the very moment I was standing up to leave, and so she was able to talk to the nurses and get somewhere quiet for me. If she hadn't turned up, I would just have gone home with the broken thumb."* – Nick

Autistic people who do remain and endure wait times in distressing and overwhelming sensory environments may present before you with reduced ability to communicate their health issues or needs. In fact, almost one third of autistic people in one study reported sensory issues as having a significant impact on their ability to communicate[10]. Autistic people maybe temporarily lose their ability to speak with words (see Theme 4: Situational mutism, semi-speaking and non-speaking autistic patients, below), or require more processing time to understand your questions and be able to respond clearly with the full information required.

Once an autistic person has begun to experience sensory overwhelm they are likely to enter flight, fight or freeze modes. Where possible, allow time to re-regulate in a calm environment and ensure your speech doesn't become a further sensory trigger (be aware of speed and volume).

Recommendation 2: Adapt the sensory environment to support autistic people to engage and communicate comfortably with services.
Healthcare premises can often be overwhelming sensory environments for autistic people. Wherever possible, make reasonable adjustments to the sensory environment such as: turning off bright lights, offering a quiet space to wait, or permitting headphones and sunglasses on wards. Take sensory sensitivities into consideration when interacting with your autistic patients and try to avoid adding to overwhelm by giving them lots of spoken information delivered quickly. Allow autistic patients time to ground themselves and process what's being communicated: even where distress is not evident to you.

Challenges with interoception and reporting pain

When it comes to communicating health concerns, an additional, highly relevant aspect of autistic sensory differences is the impaired interoception (a reduced awareness of internal bodily sensations like pain, hunger, etc.) that many autistic people can experience[37,38]. For autistic people who are hypo-sensitive to their internal senses and struggle to interpret messages from their bodies, this will have a direct bearing on their ability to identify and explain the pain, discomfort or other symptoms that they're experiencing to their healthcare providers.

Some autistic people may be aware that they struggle to identify internal signals, while others may not. When taking a history from autistic patients, it is important to rule out impaired interoception. Asking select interoceptive-related questions can help you to strengthen your appraisal. For example: *Do you find it easy to know when you're hungry or full? Do you always know when you need to use the toilet? When you feel unwell, do you find it easy to pin-point exactly how you feel in your body?*

> *"I wish I had been better at describing pain. My spinal cord injury was missed because I didn't know how to tell the doctors it hurt. I just thought the chairs were really uncomfortable"* – Jamie + Lion

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In cases where interoception impairment is an issue, enhanced clinical investigations may be appropriate and ultimately more cost-effective than relying on self-report. It may be useful to make a note on the individual's medical records and suggest that they include this in their Health Passport if one exists. Finally, impairments in interoception can also impact emotional recognition and control. Consider if this is also a relevant issue.

Recommendation 3: When taking a history from autistic patients, consider whether impaired *interoception* (a reduced awareness of bodily sensations) may be affecting how (and what) symptoms are reported.
Where autistic patients do have difficulties identifying and describing bodily sensations, enhanced clinical investigations may be appropriate and ultimately more cost-effective than relying on self-report.

Theme 3: Predictability and focus

Autistic people often organise their lives around regular routines to provide structure and predictability. Wherever possible, asking for preferred appointment times can prevent disruption to usual routines, reducing stress and increasing engagement[14].

Knowing what is going to happen, when and with whom is often very important to autistic people: especially in situations out of their control such as in healthcare appointments and admissions. This relates, in part, to sensory processing. With high sensitivity to external stimuli and finite processing capacity, autistic people often plan out a 'rationing' of their energy and last-minute changes to plans can disrupt this, leaving them vulnerable to becoming overwhelmed and, by extension, less able to communicate effectively.

It is, of course, sometimes very hard to keep appointments running to time. Offering a first appointment of the clinic may help but where this isn't possible, keeping autistic patients updated with expected wait times and their place in a queue can be beneficial.

> *"While I was waiting for an X-ray, hospital staff kept me up to date on my position in the queue. I was 3rd, then suddenly I was 4th, then 2nd, then Next.. I was not upset someone else went before me as it was logical for them to do so and they explained the reason. I understood what was happening, rather than some mysterious period with no structure."*
> – Jamie + Lion

Autistic (and some other neurodivergent) people also often tend towards having a 'monotropic' or 'single-focused' attention style: meaning that they find it easier to focus intensely on one input channel or one task at a time, compared to the more typical attention style of attending to multiple things at once less intensely. Having a single-focused attention style can mean that managing multiple input channels (e.g. listening to a medical professional speak whilst also needing to read something, while there is a lot of background noise) can be very challenging. Keeping tasks separate (e.g. talking to your autistic patient then physically examining them), telling them what is going to happen next and allowing a moment to transition between tasks can help support your autistic patient to remain engaged and not become overwhelmed.

Recommendation 4: Wherever possible, create a reliable, predictable environment and support 'single-focused' attention.
Keep autistic patients updated with wait times and their changing place in a queue. Remember that autistic people often have a single-focused attention style and need activities to unfold one-by-one rather than simultaneously (e.g. talk to your patients before examining them, rather than at the same time).

Theme 4: *Situational mutism*, semi-speaking and non-speaking autistic patients

Many autistic people will, at times, experience significant difficulty using words to express themselves. This includes those individuals who experience situational mutism and lose their ability to form sentences or words when they become overwhelmed, and those who seldom or never use spoken words to communicate, relying instead on alternative means of communication.

Situational mutism

Situational mutism – the temporary loss of your ability to use spoken words – is often associated with high levels of anxiety: something that many autistic people experience when engaging or attempting to engage with medical appointments. In one recent study, for example, 78% of autistic adults reported that 'anxiety makes it harder to communicate' with healthcare providers[10].

In addition, for many autistic people, becoming overwhelmed by "too much information" (sensory inputs, pain, verbal information, social stimuli, etc.) can lead to a reduction in their ability to speak in a given moment. **Situational mutism** may begin gradually: with slowing or slurred speech or with individuals relying more heavily on formulaic social scripts. They may become increasingly silent and non-responsive, or you may meet your autistic patient at the point when they have already lost their ability to speak by the time they see you.

It is important to look out for these signs, and not to assume that just because someone is using words, that they understand you. Use checking questions and active-listening techniques such as repeating back what you've understood them to have said to support mutual understanding in these instances.

Often autistic people for whom this is an issue will come prepared with written notes. Wherever possible, support an individual's preferred method of communication and avoid prioritising spoken assessment over utilising pre-prepared notes. Writing can also often be easier than speaking during episodes of **situational mutism**. If spoken interaction appears to be a challenge in the moment, offer alternatives such as pen and a paper, or text-to-speech software on an individual's phone where they have this option.

Recommendation 5: Be alert to situational mutism.
Look out for signs that your autistic patient is losing their ability to speak in the moment. Provide a calm and quiet environment for them to re-regulate, be mindful of adding to overwhelm, and offer and support alternative means of communication (such as written modes). Don't assume that your autistic patient has understood what you've said just because they are using words if they seem overwhelmed. Use checking questions and active listening techniques.

> *"At a time in my life when I was more unregulated and more easily overwhelmed by sensory stuff, I used to 'shutdown' all the time and lose my ability to speak. I'd have the words in my head but nothing would come out, or what did come out would be slurred and not make any sense. I've lost count of the hours I've spent hidden in a public toilet cubicle waiting to get my words back…"* – Gemma

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Semi-speaking and non-speaking people

Around 25-30% of autistic people are non-speakers: having few to no spoken words[39]. However, there is an incredibly important but often overlooked distinction between being non-speaking, and not being able to understand language. Barriers to some autistic people using spoken words can be related to *verbal apraxia* (sometimes accompanied by general apraxia)– a neurological condition where the language system of the brain and the motor system involved in speech articulation struggle to connect in practice. The autistic person knows what they'd like to say but can't make it happen, which can be extremely frustrating or distressing when the message is urgent in the case of communicating acute pain.

In healthcare settings, being non-speaking can be mistaken for not having capacity. It is really important that capacity is always assumed, and that all efforts possible are made to support the individual to communicate their health needs in the best way for them. This may include involving a known and trusted advocate, but it can also include supporting the use of *Augmentative and Alternative Communication (AAC)*. AAC is a commonly used set of strategies and tools to support communication and ranges from no-tech and low-tech options such as gestures and facial expression, use of pen and paper to write, and spelling and picture boards that can be pointed at to more high-tech options such as typing on tablets or phones, and using text-to-speech software. A non-speaking individual may use a range of AAC tools and will know what best works for them. As these methods will be slower than spoken interaction, patience is required to allow the individuals to complete their message in full before attempting to read it. A note should be made on the patient record to allocate longer appointments to support this.

> *"Myself and others that experience verbal apraxia describe it as - your brain is saying, do this, and your body is doing something you didn't even predict or want to do. For example, an autistic with significant apraxia may want to say "I really don't want to be here now" but instead will come out with 'give me Pringles!!' or they might end up having total block of speech production and instead scream and jump onto a table"* – Helen

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Recommendation 6: Support non-speakers to use *AAC* and always assume capacity. Factor in extra time to allow semi-speaking and non-speaking autistic people to use ***Alternative and Augmentative Communication*** (AAC) methods. Be mindful that barriers to using speech can be related to ***verbal apraxia*** and not to a lack of capacity.

Theme 5: The *double empathy problem*

Traditionally, the difficulties with social communication that many autistic people experience have been thought to stem from inherent impairments on the part of the autistic person. In the past few years, however, research has shown support for what autistic advocates have been saying for some time: that it is more of a two-way mismatch. Contextual factors – and in particular whether the conversation partner is also autistic or not – are what most significantly shape how successful an interaction is. For example, lots of studies now have shown that in groups and interactions that exclusively involve autistic people, high levels of rapport and mutual understanding are both observed and reported, generally exceeding those experienced in the comparison groups and interactions with a mix of autistic and non-autistic people [40,41,42,43,44].

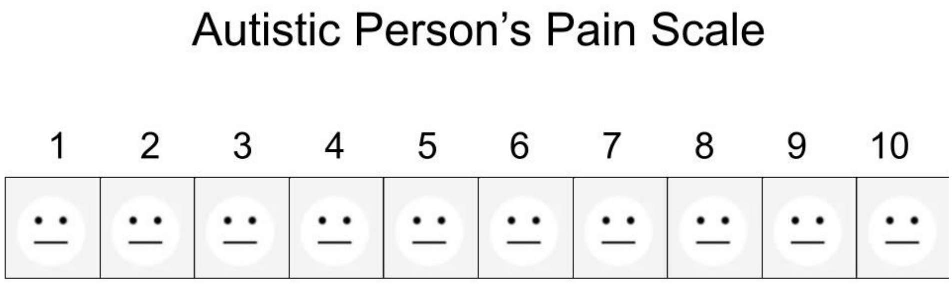
This shows us that given the right circumstances, autistic people can communicate well, and supports the idea of the '*double empathy problem*'[45]. The *double empathy problem* theory argues that because autistic and non-autistic people have very different social, cognitive and sensory experiences of the world, they may find it harder to understand one another.

All humans rely on shortcuts and assumed, shared understandings when we speak with one another: this is a very natural part of communication. One way to bridge the *double empathy problem* is to imagine that the autistic patient before you may be having a vastly different experience of thinking, speaking, listening, seeing, and knowing their feelings: and begin from here.

Recommendation 7: Think about communication challenges as a two-way mismatch when interacting with autistic patients and make efforts to 'meet them in the middle'. Difficulties in social communication create significant barriers to accessing healthcare. Research now shows that these difficulties are a two-way issue (called: the ***double empathy problem***) and not due to inherent autistic impairments. Autistic people will have spent much of their lives not being understood, so take the time to put them at ease and show that you are listening and interested. One way to bridge the ***double empathy problem*** is to imagine that the autistic patient before you may be having a vastly different experience of thinking, speaking, listening, seeing, and knowing their feelings: and begin from here.

Recognising difference: atypical body language

Apparent discrepancies between the words that autistic people say and their body language or facial expressions is one area which can feed into the **double empathy problem** and lead to misunderstandings with non-autistic healthcare providers. Many autistic people describe not being believed when they've tried to report their pain or physical symptoms: often because what is being verbally reported doesn't match with expected body language or facial expressions, as depicted in the 'Autistic Person's Pain Scale':



AutisticSciencePerson.com

Ira Kraemer, @AutSciPerson

Sensory differences, social differences and **masking** behaviours can all result in different ways of presenting oneself in an interaction. It is important to listen to what autistic people say about their pain and symptoms, and resist making clinical judgements based solely on behavioural signifiers. It is also important to remember, however, that some autistic people may be hypo-sensitive to pain so a person-centred approach is required.

Recommendation 8: Pay attention to what autistic people say about their pain and symptoms, and resist making clinical judgements based solely on behavioural signifiers. Autistic people often have atypical body language and facial expressions which can lead to them not being believed when they report symptoms. Considering the significant health inequities that autistic people face, always err on the side of caution.

Theme 6: Taking a *trauma-informed care approach*

All autistic people are at higher risk for experiencing abuse and trauma than the general population[22, 47]. In addition to adverse life experiences and victimisation, many autistic people may have had poor experiences trying to engage with health services in the past and feel guarded or untrusting[48].

A **trauma-informed care approach**, built on the principles of safety, choice, collaboration,trustworthiness, and empowerment, is recommended in the NHS Long Term Plan[1] when working with patients who experience severe mental health issues. We strongly recommend that this approach is extended to all autistic patients, or any patients you suspect may be autistic (as per Theme 1: Is my patient autistic?) in order to support engagement and reduce the risk of re-traumatisation.

Recommendation 9: Consider a *trauma-informed care approach* when working with all autistic patients.
Autistic people are much more likely than the general population to experience traumatic experiences that can result in PSTD and this can become a further barrier to accessing services. Taking a ***trauma-informed care approach***, built on the principles of safety, choice, collaboration, trustworthiness, and empowerment as standard practice can support autistic patients to access services.

Theme 7: Supporting access

Finally, this report largely addresses issues that are important when communicating with an autistic patient in attendance. However, one of the greatest barriers to accessing services reported by autistic people are the challenges to using the telephone for booking an appointment or talking to service providers[10,46, 49]. In one survey, nearly two thirds autistic adults (62%) reported significant difficulties booking a GP appointment by telephone, compared to only 16% of non-autistic respondents[10].

Talking on the telephone is a distilled form of verbal communication, with the additional challenges of not being able to see a person's lips move when they speak, peripheral sensory issues (like a crackly or quiet line, or background noise) and an absence of visual cues to help identify when to take a turn to speak. Pre-recorded, automated systems can be hard to navigate.

> *"I ended up having to change GP surgeries because at my old surgery, I used to ring them up and they would give literally about 10 options. Like, 'press one for this thing, press 2 for this thing…' and I just couldn't. I just, I didn't fit into any of these options. So I'd put the phone down and I couldn't ever get an appointment"*- Ria

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Worryingly, difficulties using the telephone to book an appointment have been found to be significantly associated with almost all adverse health outcomes for autistic people[10]. Wherever possible, alternative methods of booking appointments – by text, email or an accessible online booking system – should be offered.

Recommendation 10: Offer a variety of methods for making appointments and accessing services.
Having to use the telephone to book an appointment can be a significant barrier for many autistic people. To enable equitable access to services for autistic patients (diagnosed, undiagnosed and undisclosed), alternative methods of booking appointments – by text, email or an accessible online booking system – should be offered from the outset to ***all*** patients.

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About the cover artwork

"As an autistic person I see and experience the world differently. I'm also always on the look for patterns which is often an autistic strength and to transform the 'ordinary', words, shapes or images into artwork both digital and as lines on paper. This image originated from a photograph of rucked bedsheets, very small scale but seemingly geological with contour lines added while imagining a flow of time or meanings" – Jon Adams

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GLOSSARY OF TERMS

Augmentative and Alternative Communication (AAC): Strategies and tools used by non-speaking and some semi-speaking people to support communication. These can be both low-tech (e.g. paper and pen or picture boards) or high-tech (e.g. text-to-speech software).

Double empathy problem: a theory that argues that people with very different experiences of the world may find it harder to understand one another. It relates specifically to interactions between autistic and non-autistic people and challenges the traditional view that difficulties in social communication (between autistic and non-autistic people) are due to inherent autistic impairments.

Identity-first language: ways of talking about people that leads with their disability or neurodivergence (e.g. autistic individual). The alternative is ***person-first language***, which leads with the person (e.g. a teenager with autism). Preferences vary between different disabled communities and individuals.

Interoception: the sense that identifies the internal states of the body (e.g. things like hunger, thirst, temperature, the need for a bowel movement and pain).

Masking / Camouflaging**:** the conscious or unconscious suppression by an autistic person of their natural responses and behaviours that might attract negative attention. An example might be resisting ***stimming*** behaviour, or making eye contact despite it feeling extremely uncomfortable to them.

Monotropism: an attention style whereby attention is focused more acutely on one thing to the exclusion of others. Autistic people tend to have monotropic attention styles. This is contrasted with polytropic attention which best supports less intense focus across multiple areas (i.e. having a conversation whilst crossing the road whilst being aware you're feeling hungry). Non-autistic people tend to have polytropic attention.

Neurodiversity: a perspective that embraces the range of ways that people can experience and interact with the world around them as neurologically-based differences, not deficits. It is often associated with the social model of disability.

Reasonable adjustments: adaptations to services to ensure individuals with protected characteristics aren't disadvantaged in accessing services. Adjustments must be reasonable and relevant to each individual.

Situational mutism: moments when autistic people are **unable** (not unwilling) to speak with words, or their ability to use words is significantly impeded. It is often associated with overwhelm, anxiety, or reduced processing capacity due to sensory overload.

Stimming: repetitive actions or movements (e.g. hand-flapping or leg-bouncing) that help an autistic person to self-regulate.

Trauma-informed care: an approach to healthcare provision that realises the wide ranging impact of trauma on a person's physical and mental wellbeing, and systematically integrates knowledge about trauma into policies and practice.

Verbal apraxia: a neurological condition affecting speech-production and articulation, thought to stem from a difficulty within brain pathways that translate from the language system into the motor system controlling speech.

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