Autism: making reasonable adjustments in healthcare

Abstract

The accompanying article set out why it is important to identify autistic people and the negative consequences of not recognising or understanding autism, including more severe illness and premature death. This article sets out what clinicians can do to help reduce those negative consequences by making 'reasonable adjustments' in any healthcare service in which they work.

Key words: Autism; Autistic; Integrated Care; Mental health; Physical health; Reasonable adjustments

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Introduction

The accompanying article (https://doi.org/10.12968/hmed.2021.0313) set out the types of presenting features that help to identify if someone is autistic and why these might cause initial confusion, as their presentation may not be typical of what a clinician might expect. Autistic people have a large number of co-occurring physical and mental health conditions (Howlin and Magiati, 2017; Cashin et al, 2018) so require input from all health services, but experience greater access barriers to health services of all types. Many clinicians, of all disciplines, receive little training in their undergraduate or postgraduate education on working effectively with autistic people. This contributes to poorer health outcomes for autistic people, including late diagnosis and treatment of co-occurring conditions. Recognising and understanding autism and being autism informed in clinical practice can improve the experience and effectiveness of healthcare for autistic people.

Terminology

Throughout this article the terms 'autism' will be used as the all-encompassing term, regardless of any sub-divisions in classification systems, and 'autistic people', a term preferred by the autism community in the UK (Kenny et al, 2016), although individuals have the right to use other descriptors by their own choice.

Challenges for autistic people accessing effective healthcare

Autistic adults are more likely to report barriers to healthcare compared to both adults with disabilities and non-autistic adults without disabilities (Raymaker et al, 2017).

Autistic people might not recognise that they are developing major symptoms or know to seek support, and are less likely to have a supportive network to give advice. They can find navigating complex health services stressful or might not want to seek support as a result of anxiety or feeling embarrassed in case the issues are seen as trivial, or because of previous negative experiences of seeking help. Uncertainty is also particularly difficult for autistic people, so not knowing what to expect or fear of getting it wrong can inhibit them from common health-seeking approaches.

In a systematic review of studies exploring the barriers and enablers to physical healthcare access for autistic adults, Mason et al (2019) identified the common barriers as patient–provider communication, sensory sensitivities, and executive functioning and planning. Patient–provider communication included communication differences, miscommunication and misinterpretation. This was partly a result of the autistic person

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communicating in atypical ways, for example finding it difficult to describe pain and symptoms in conventional ways, and partly a result of services misunderstanding or not getting the significance of the communication or not realising that autistic non-verbal communication is atypical, for example smiling despite pain.

Sensory processing differences and sensitivities contribute to autistic people feeling uncomfortable, distressed or overwhelmed in healthcare environments, especially where there is a lot of sensory information such as in busy waiting rooms, and differences in executive functioning can make the process of making and attending healthcare appointments very challenging. This can be exacerbated when there is a lack of clear guidance on where to go, what to expect and how to book in on arrival.

Another barrier identified by Nicolaidis et al (2015, 2016) and Raymaker et al (2017) was the health provider's lack of knowledge about autism in adults, which included making assumptions about the autistic person's behaviour and lacking confidence in treating autistic patients. This coincides with studies examining self-reports of health providers working with autistic people. In the USA, 79% of professionals working in adult medicine, 88% of professionals working in obstetrics/gynaecology, and 70% of professionals working in mental health rated their ability to provide healthcare to autistic patients as poor or fair (Zerbo et al, 2015). In the UK, 39.5% of GPs reported having no formal training in autism, and limited confidence in their ability to offer healthcare to autistic patients (despite having a good knowledge of the key features of autism) (Unigwe et al, 2017).

Participants in Nicolaidis et al's (2015) study called for more training and education for healthcare staff, greater consideration of the sensory environment in healthcare settings, more consideration of how the person communicates and greater awareness of the heterogeneity of people on the autism spectrum. They also suggested that resources to improve their health and healthcare self-efficacy would be helpful, including information on how to navigate the healthcare system.

Previous negative experiences of healthcare whether personal or through media reports, such as around use of do not attempt cardiopulmonary resuscitation decisions during the COVID-19 pandemic (Care Quality Commission, 2021) can make autistic people more anxious about accessing future healthcare.

The challenges and barriers to healthcare autistic people face and the potential adverse consequences are illustrated in Figure 1.

Statutory responsibilities

Under the Disability Act 2010, reasonable adjustments are the changes the law says people or services must make so disabled people can use services as easily as everybody else. Protection under the Act does not require that a person has a formal diagnosis or even that the person necessarily considers themselves to have a disability. Disability has a broad meaning. In the Act it is defined as a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities. Autistic

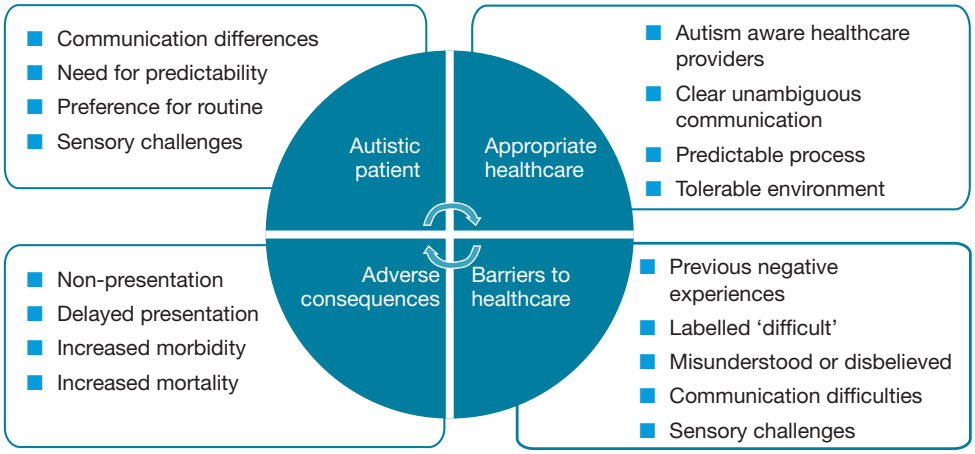

Figure 1. Healthcare challenges for autistic people: barriers, consequences and facilitators.

people presenting to health services will therefore fall within the safeguards of the Disability Act. In addition, autism has its own act – the Autism Act 2009 (in England), with the most recent strategy and guidance to deliver the act published in 2021 (Department of Health and Social Care and Department for Education, 2021). These also cover the use of reasonable adjustments for autistic people, and other jurisdictions have differing but similar policies.

Reasonable adjustments

Reasonable adjustments must be reasonable and must also be relevant to that person (often called person-centred). Healthcare and care providers must make changes or adjustments to how they provide their services if it is reasonable to do so. Whether something is reasonable depends on the size, resources of the organisation and type of service they provide. It also depends on what changes or adjustments are needed and how practicable or easy it is to do them. The courts will decide if something is reasonable or not (Citizens Advice, 2020). The practical examples discussed in this article all fall within that 'reasonable' expectation.

Once reasonable adjustments are identified with an autistic person or a person who may be autistic, best practice would be to record these on the electronic health record using a flagging or alert system, so future clinicians will know how to prepare and intervene for the consultation, appointment or examination. Autistic people may also bring a health passport with them to an appointment which lists preferences for communication and highlights issues that could potentially cause distress. Many autistic people find it easier to provide written information, especially in stressful situations, rather than trying to verbalise. It is important to ask if they have a health passport or other advance written information to share, discuss what is shared and ensure it is recorded.

Autism-friendly hospital projects are becoming more common and should be informed by the lived experience of the local adult autistic community. Awareness raising programmes such as the NHS 'Different Not Less' Campaign are also enormously helpful and should be rolled out nationwide.

Improving access to healthcare

When developing and improving services it is important to consider how accessible they are. The NHS accessible information standard is not autism specific but sets out the expected general standards for accessibility in the English NHS (similar guidance will apply in other jurisdictions) (NHS England, 2017).

The following may also be helpful to consider:

- Is there information that is readily available on health education and specific conditions, and information on when and how to seek help, with links from the hospital website?
- Can people make or amend bookings by different means (telephone, video, mail, email, text)? Having to use the telephone to access a service can be a major barrier for autistic people
- Is there information on how to find the clinic, what will happen and whether someone can or should come with you, including what options there would be if there was no one to attend or support?
- Are there alternative places to wait away from busy waiting rooms?
- Is there flexibility within clinic schedules or consultations to allow longer appointment times for autistic people?
- Are there clear instructions on how to book in for appointments?

Minimising uncertainty

Changes can be distressing for autistic people, especially unexpected changes or disruptions to usual routines. Autistic people cope best with change when they can see the logic to it and have advance warning. There are many different examples of reasonable adjustments to minimise uncertainty and change highlighted in Table 1. Being aware of the potential negative impact of changes and disruptions may help understand an autistic person's distress and presentation. Try to minimise changes with staff, appointments or interventions, and if changes are necessary, explain the reason for this at the earliest opportunity.

Table 1. Reasonable adjustments to minimise uncertainty
Provide details such as who they will see, how long for, where, will this be a one off or one of a number of appointments, what will happen if the session is late, and what will happen after the appointment. This could be included as frequently asked questions (FAQ) on your website or in appointment letters and correspondence
Offer acclimatisation visits or virtual tours of different environments that can be shared on the website
Generally autistic people will prefer seeing the same staff if possible
Prepare them for what kinds of questions they will be asked and what the intervention may consist of. Again, this could be included in FAQs on the website or in appointment correspondence
Try to ensure appointments are on time. If an appointment is likely to be delayed, offer an option for them to leave completely and return at a later agreed time
Ensure roles, rules and expectations are clear and consistent, eg treatment regimens
Be clear what is your opinion rather than a fact
Make sure you and your service keep your promises and do not promise what you can not deliver, as this could lead to disengagement
If possible, ask for preferred times to be seen, as some autistic people have routines that may be important to them. Being able to avoid disruption to these would reduce stress and increase engagement
At the end of an appointment or interaction be clear as to what has been decided and agreed and what will happen next
If you are not sure about timescales or are not sure what will happen next, for example if you are referring to another service, then it is better to be clear about that. Approximations can be precise, eg 'I do not know how long it will take for you to get the results but at the moment it is at least 4 weeks'
Ensure the written plan of any information shared, including the agreed plan and actions, is forwarded to the person as soon as possible

Hospital admission, whether as an emergency or electively, is a significant event for any patient, but to an autistic person who depends on routine, it can be an enormous challenge. While cancelled or changed appointments are upsetting for all patients, the effect on autistic patients is disproportionate; therefore, increased efforts to avoid this would be a reasonable adjustment.

Virtual tours of the hospital environment are becoming more common and these are particularly helpful to autistic people. When interventional procedures are required, it may be helpful to arrange an acclimatisation visit to the relevant department before the procedure.

Effective communication

As noted, differences in communication can lead to barriers for autistic people accessing effective healthcare. Although autism is characterised in the diagnostic criteria by social and communication difficulties, it is widely recognised that it is not solely the responsibility of the autistic person to make the necessary effort to improve two-way communication. The 'double empathy' problem, termed by Milton (2012), highlights that difficulties in communication occur in both directions rather than assuming the autistic person has communication deficits. It may be helpful to conceptualise this as an intercultural phenomenon and proceed as you would with a patient whose native language or culture is different to your own. Spoken language may need careful interpretation and non-verbal communication may be different to what you might expect.

It is vital to check for mutual understanding throughout all healthcare encounters. In general, the use of frank but precise speech and minimising reliance on non-verbal communication works best for most autistic people. Open questions and too many choices can cause difficulties, so try to break things down into more specific questions or range of options. Family members, autistic healthcare providers or local autism champions may be helpful in such circumstances and every healthcare facility should endeavour to provide access to a designated autism liaison service.

Written communication or use of communication devices (augmentative and alternative communication) may be easier for autistic patients. Anxiety reduces the ability to

communicate for most autistic people, so some who usually have access to fluent speech may not be able to communicate verbally when unwell. This is not a patient being difficult or demanding. This is a consequence of autism and therefore communication via alternative means is a reasonable accommodation. Encouraging a patient to communicate via whatever means is most suitable makes the interaction more useful for all. Information should be presented in a preferred format, for example putting key information in writing reduces risk of misunderstandings.

There is an increasing variety of apps and tools to help improve communication. These may be appropriate for one person but not for another but, in line with the accessibility standards, if they find that a particular option works well for them this should be recorded so it can be used when appropriate. Examples include PECS (picture exchange communication system) and apps such as Beyond Word or Emergency Chat. Whether and when such tools might be appropriate will be a person-centred decision.

Autistic people generally tend to avoid 'small talk' and prefer to focus on the task in hand, especially in stressful situations such as healthcare contacts. Chatting to 'establish rapport' can be counterproductive and may increase stress levels. Some autistic people may engage in a conversation about their interests, but generally excessive talking can be distracting and sometimes being quiet makes establishing rapport and completing the intervention easier and more effective.

Extra processing time may be required in conversation, and answers to questions may not be immediate. Repeating or rephrasing a question is usually unhelpful in such situations as it restarts the process again. It is better to wait, or to ask 'are you still thinking?' before trying again if they did not understand. Rapid fire questions or long questions with lots of sub-questions within them are more likely to provoke delays, increase stress and possibly lead to flight or confrontation. Keep questions focused, ask them one at a time and give pause for time to think and reply.

Generally, autistic people prefer to be told things straight and to be able to give straight honest answers, so using precise grammatically correct language works best. Very open questions or too great a choice can be difficult to process, and this could lead to autistic people relying on stock phrases, for example in answer to 'how are you?' the stock answer is often 'fine thanks' even if they are anything but fine and in answer to 'what do you want?' they use the stock answer of 'whatever you suggest' as the question is too broad. Autistic people tend not to volunteer information unless they have been asked specifically for it, but it may not be clear to them how much information to provide. They may struggle to pick up on non-verbal cues to adapt their communication or behaviour and therefore benefit from being explicitly told if they are being over inclusive of detail or need to expand on an answer.

Do not be put off if autistic people are not making eye contact or seem to be distracted and fiddling with something. Both of these can help reduce arousal levels for autistic people so they are in a more optimum state to listen and process information in the conversation. If you are not sure if they are listening or hearing then feel free just to check by asking them to repeat what you have said. If they are following the conversation, they will generally not be offended by you checking.

Reasonable adjustments that could be used to improve communication and engagement in healthcare interventions are detailed in Table 2.

Awareness of the challenges of describing pain

Communication of pain is a particular area of concern. Autistic people generally do not show the conventional non-verbal signs of pain expected by healthcare providers. Verbal descriptions of pain and associated body language may appear incongruous, leading to an assumption that the patient is exaggerating, untruthful or possibly even drug-seeking. Autistic people who are aware of this issue may attempt to simulate the expected expressions, which may or may not be successful, and often leads to further misunderstanding, distrust and deterioration of the doctor–patient relationship. In addition, a pitfall in physical examination occurs where autistic patients may not understand the purpose of such examination and may not spontaneously report subjective experiences. It may be necessary to explicitly tell a patient to report pain on palpation for example,

Table 2. Reasonable adjustments to minimise misinterpretation and miscommunication
Avoid making assumptions based on non-verbal communication, for example intonation, facial expression, gesture
Understand that an autistic person may struggle to identify or express their emotions and ask for help
Use clear and concise language
Provide information in a variety of forms, for example written or visual information in addition to verbal communication where required
Check what you have communicated has been understood and that you have interpreted the autistic person correctly
Ask specific questions and be explicit in your instructions and expectations
Supply the context to the question or why you are recommending something either verbally or in writing – do not expect the autistic person to pick up on non-verbal cues or hints
Use semi-closed questions and options in lists rather than open questions
Allow extra time for the person to process information and make decisions
Be explicit at the start as to how much time is available, for example we have up to 15 minutes for this appointment. This makes it much easier if you have to then interrupt or ask them to focus on key issues to keep to time
Check that any humour, euphemism or metaphor has been interpreted correctly and be aware of the potential literal interpretation of language
Offer strategies for allowing an autistic person to communicate when they are distressed, for example, writing notes

otherwise pain may be elicited but not reported or otherwise indicated, leading a doctor to erroneously conclude that the examination was normal. Traditional pain scales may be problematic for autistic patients, particularly those incorporating facial expressions, and an individual approach may be more useful.

Performing painful procedures on patients is common practice in hospital medicine, from venepuncture and cannulation, to dressing changes or even bone marrow aspiration. For uncomfortable procedures, clinicians usually expect patients to moderate their reactions and stop the procedure if the patient becomes distressed. For autistic patients this may not be possible, and a strategy should be discussed and agreed beforehand. Careful attention should be paid to minimising discomfort, and it is reasonable to ask an autistic person in advance what they wish to happen should they become distressed, whether that is stopping and trying again at a different time or by providing support to tolerate the procedure, for example by holding a limb tightly. In some instances, it may be necessary to consider sedation or general anaesthesia for procedures that do not usually require it.

Environmental considerations

It is important for healthcare providers to understand and acknowledge that an autistic person experiences the environment differently to the non-autistic majority of patients and staff. A staircase is an obvious barrier to a wheelchair user, but the sensory barriers faced by autistic people are much harder to appreciate if you do not share the experience. Sensory difficulties are cumulative, and a combination of noise, light and social stress can easily cause a distressing ‘meltdown’ as a result of overload. Each person will process sensory information differently and will have different preferences, so a person-centred approach is essential. It is neither possible nor necessary to stop all sensory stimulation, but the aim should be to seek to reduce those the person feels most intrusive to the lowest level feasible in the circumstances.

Noise can be a particular challenge for autistic people and hospitals are unavoidably noisy environments. Autistic people can be hyperaware of sounds that others may be oblivious to or may easily accommodate. A squeaky wheel on a drug trolley unnoticed by staff or the beeping of an alarm on an unattended monitor or infusion device can feel like torture to an autistic patient (or staff member). Providing and encouraging the use of headphones or earplugs, especially noise-cancelling headphones, which block environmental noise but allow speech to be heard, can be particularly helpful. Placing the patient in the quietest area

available, using single room accommodation, separate waiting areas or allowing a patient to wait outside a clinic building until it is their turn are all adjustments that could reduce distress.

Lighting, particularly fluorescent lighting or flickering lighting, can also cause some autistic people to feel overwhelmed, while others find dim light very difficult to tolerate. The use of sunglasses, using dimmer switches or small lamps to allow bright overhead lighting to be turned off can all be very helpful.

Olfactory sensitivity is experienced by many autistic people and excess olfactory stress is likely in a hospital environment for such patients, especially with increased cleaning regimens during the COVID-19 pandemic. While it may be difficult to reduce the smells in a hospital or clinical setting, avoiding adding any unnecessary smells, encouraging the person to wear a scarf to shield from smells or carry an item with a preferred scent may be helpful.

Temperature can be another sensory challenge for autistic people. While preferred temperatures vary, most will struggle to cope with variations from their usual environmental temperature. This may mean the person wears more or less clothing than conventionally expected for that temperature.

Even if an autistic person is not aware of their sensory processing differences, they will know their preferences, so asking the right questions is key. Explaining what is or is not feasible can allay a lot of uncertainty and doing what is feasible demonstrates that you have listened to the person, which is very important in them trusting you.

Examples of reasonable adjustments for sensory differences and environmental adaptations to minimise distress are provided in Table 3.

Hospital care

All of the above illustrates the importance of minimising an autistic patient's exposure to environmental and social stress. Hospital admission may be avoided by improving access to primary care and using outpatient investigations and procedures where possible. If admission is unavoidable, avoid moving an autistic person from one bedspace to another. If single room accommodation is unavailable, place an autistic patient in the corner of a multioccupancy room, not the middle of an open ward, and allow the use of privacy curtains. The use of familiar comfort items and fidget tools should be encouraged.

Table 3. Sensory and environmental considerations to support reasonable adjustments

Ask if there is sensitivity to light and whether they prefer the light on or off, or blinds open or closed
Ask if there is sensitivity to touch, whether they like to shake hands, how they prefer to be touched when being examined and make necessary adjustments
Ask if there is any sensitivity to noise and explain the different noises that may not be able to be adjusted, eg medical equipment. Adjust the equipment that may be altered according to preference, for example the volume lowered or turned off and encourage people to wear headphones or ear plugs if noise is distressing
Ask if any smells make them feel ill or cause distress, for example air freshener, cut flowers, food cooking, and make adjustments where possible
Ask if they have any sensitivity to taste or texture of food or medication and, where possible, look for alternatives
Be aware that sensory processing differences may also contribute to people preferring certain temperatures, for example wearing a coat in warm weather or disliking the temperature of medical equipment being used against the skin
People may need to move regularly or to be able to fidget, for example with a phone or fidget tool, and 'stimming' or repetitive body movements can often be calming for autistic people
Differences in interoception may result in people not recognising messages from internal organs, such as the need to go to the toilet, eat or drink. Being aware of this is important when assessing and treating autistic people. They may need more prompting, for example suggesting a break rather than waiting for them to ask for one
Most autistic people benefit from there being a low stimulus space to be away from people if possible
Specific equipment such as weighted blankets, fidget tools and earplugs can be helpful, especially in areas with high sensory stimuli, for example inpatient wards

Minimise social stress. Autistic patients will commonly prefer to be alone or with familiar people and proximity to unknown people may cause distress. Minimise contact with unfamiliar staff and, where possible, assign the same staff to the autistic patient. Avoid unnecessary contact, such as medical students seeking patients for examination practice or approaching the patient with a large entourage, which commonly occurs on teaching ward rounds. This may be a source of overload for an autistic patient and no effective communication is likely to take place as a result of anxiety. It would be preferable for the patient to be seen by one or two key members of the medical team.

Social supports available should also be considered. The healthcare system generally relies on the fact that most people have family members or friends available to support them with healthcare needs and access, whether to pick up prescriptions, take them to appointments or collect them on discharge from hospital. This may not be the case for autistic patients and it can be difficult for non-autistic people to appreciate or even believe the degree of social isolation which can sometimes be the reality for autistic people. Therefore, there may be no one available for example to bring belongings to a patient after unexpected admission or to provide support following discharge. This has implications for convalescence planning and consideration of inpatient care for procedures normally undertaken as a day case may be required. Careful enquiry is required when exploring this issue, because societal expectations of social connectedness impose value judgements on an isolated existence, whether voluntary or involuntary, and associated shame may prevent disclosure unless handled sensitively. The result may be delayed discharge, which could be avoided by arranging support from social care services in advance. Alternatively, there may be difficulties engaging with services such as rehabilitation or community providers, particularly when this requires access to a patient's home. Service providers with an understanding of autistic people will be easier to tolerate and providing consistent care staff where possible will be beneficial.

Considerations for different medical specialties

In any long-term illness with a relapsing/remitting pattern, life circumstances and emotional issues can increase frequency or severity of relapse. Autistic people are unlikely to volunteer such information unless specifically asked about it, so it is particularly important to ask when such relapses appear to be non-responsive to conventional approaches before assuming it is treatment resistance.

While autistic people experience the same range of illnesses and accidents as the non-autistic population and will therefore require access to the full range of healthcare services, there are certain specialties in which autistic people are more likely to be seen. These are illustrated in Table 4.

If an autistic person is in distress

It is stressful to experience ill health and access healthcare, especially if you are in pain. For autistic people, this stress is likely to be exacerbated by the challenges noted, so it is important to consider what may be helpful if the person becomes distressed in the healthcare interaction. A typical response to an escalation of distress and arousal is 'fight, flight or freeze' and this is commonly seen when autistic people feel overloaded, which they may describe as having a 'meltdown' or 'shutdown'. In situations of extreme distress, it is often helpful to give the person space, to refrain from touching them, avoid talking and not express judgement. Try to use a safe environment and attempt to empathise with why they may be distressed.

If the distress has not escalated to a significant level, it is important to 'check' with them if possible what is causing the distress and what may be helpful and for you to 'check' that you have applied reasonable adjustments. Figure 2 shows a checklist that can be used in clinical settings, which may help with prompting.

Conclusions

Autistic people will present to hospital at all stages of life and to all medical specialties. It is vital that clinicians recognise this vulnerable minority so that the patient journey can

Table 4. Different medical specialties where autistic people may be seen

Specialty	Consideration
Neurology	Epilepsy is a well-known association with autism, and recent evidence shows an increased prevalence of Parkinson's disease in autistic people
Cardiology and endocrinology	Autistic people have increased rates of diabetes, obesity, thyroid disease, hypertension, and cardiovascular disease. Morbidity and mortality from these conditions are increased therefore relevant specialists should be alert to possible autism
Surgical specialties	Autistic patients are more likely to present late in the natural course of an illness or with advanced disease. Unexplained late presentation may be a clue to underlying autism. Surgical intervention may be refused for unexpected reasons and careful exploration may be required to address concerns
Orthopaedic surgeons and chronic pain specialists	Ehlers–Danlos or hypermobility syndromes are increasingly recognised as associated with autism. Therefore, joint problems such as dislocations and chronic pain commonly occur
Emergency department	Autistic people are three times more likely to present to the emergency department, have increased admissions into hospital and are more likely to die post admission (Vohra et al, 2016)
Psychiatry	Between 7.3 and 15% of patients admitted following a suicide attempt may be autistic (Segers and Rawana, 2014). This is not something that would usually be considered by intensive care or medical teams, for example when someone is admitted following an overdose
Gastroenterology	Symptoms of gastrointestinal type are more common in autistic people and may have a variety of causes. These can range from the effects of restricted dietary choices to conditions such as irritable bowel syndrome. Precise questions are often needed to clarify the nature of abdominal symptoms when autistic people report that things do not feel right

be optimised and their healthcare outcomes maximised. Although autistic patients are all different, there is a consensus about the challenges and barriers in accessing and engaging in healthcare, what questions to ask and which reasonable adjustments to apply. As illustrated, these changes can easily be embedded within clinical practice.

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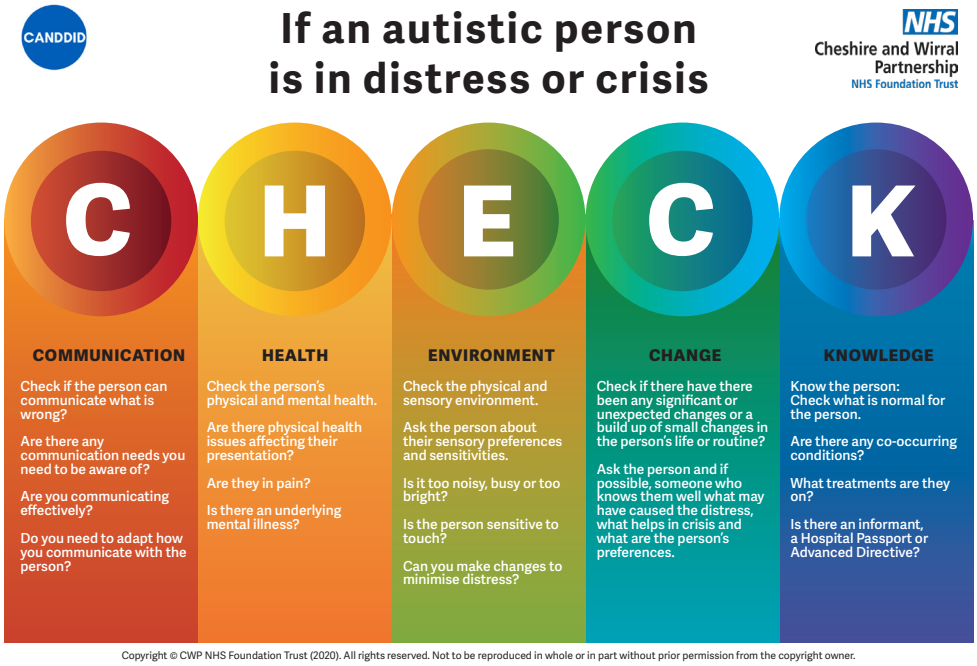

Figure 2. The CHECK list – useful prompts to assist assessment in poster form

Key points

- When clinicians recognise that someone might be autistic, they should ask about preferences and reasonable adjustments.
- If autistic people have a positive experience of accessing health interventions, they are more likely to access health services in the future when needed.
- Autistic people have high rates of co-occurring health conditions and are at increased risk of premature mortality from preventable and treatable illness.
- Owing to difficulties accessing health services autistic people are less likely to receive early or preventative interventions resulting in greater acuity, more emergencies and more hospitalisations.
- Recognising autism and making adjustments for autistic people in healthcare settings can reduce barriers and delays in getting appropriate treatment thus improving health outcomes and reducing health inequalities for autistic people.

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Conflicts of interest
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References

Care Quality Commission. Improved oversight and reform needed as pressures of pandemic shine light on inconsistent and concerning approaches to DNACPR decisions. 2021. https://www.cqc.org.uk/news/releases/improved-oversight-reform-needed-pressures-pandemic-shine-light-inconsistent (accessed 3 September 2021)

Cashin A, Buckley T, Trollor JN, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. J Intellect Disabil. 2018;22(1):96–108. https://doi.org/10.1177/1744629516665242

Citizens Advice. Discrimination in health and care services - duty to make reasonable adjustments. 2020. https://www.citizensadvice.org.uk/health/discrimination-in-health-and-care-services/health-and-care-services-what-are-the-different-types-of-discrimination/discrimination-in-health-and-care-services-duty-to-make-reasonable-adjustments/ (accessed 22 October 2021)

Department of Health and Social Care and Department for Education. The national strategy for autistic children, young people and adults: 2021 to 2026. 2021. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf (accessed 22 October 2021)

Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. Curr Opin Psychiatry. 2017;30(2):69–76. https://doi.org/10.1097/YCO.0000000000000308

Kenny L, Hattersley C, Molins B et al. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. 2016;20(4):442–462. https://doi.org/10.1177/1362361315588200

Mason D, Ingham B, Urbanowicz A et al. A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. J Autism Dev Disord. 2019;49(8):3387–3400. https://doi.org/10.1007/s10803-019-04049-2

Milton DE. On the ontological status of autism: the 'double empathy problem. Disability Soc. 2012;27(6):883–887. https://doi.org/10.1080/09687599.2012.710008

NHS England. Accessible Information: Implementation Guidance v1.1. 2017. https://www.england.nhs.uk/publication/accessible-information-standard-implementation-guidance/ (accessed 14 October 2021)

Nicolaidis C, Raymaker DM, Ashkenazy E et al. Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism: Int J Res Practice. 2015;19(7):824–831. https://doi.org/10.1177/1362361315576221

Nicolaidis C, Raymaker D, McDonald K et al. The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. J Gen Intern Med. 2016;31(10):1180–1189. https://doi.org/10.1007/s11606-016-3763-6

Raymaker DM, McDonald KE, Ashkenazy E et al. Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. Autism: The Int J Res Pract. 2017;21(8):972–984. https://doi.org/10.1177/1362361316661261

Segers M, Rawana J. What do we know about suicidality in autism spectrum disorders? A systematic review. Autism Res. 2014;7(4):507–521. https://doi.org/10.1002/aur.1375

Unigwe S, Buckley C, Crane L et al. GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. Br J Gen Pract. 2017;67(659):e445–e452. https://doi.org/10.3399/bjgp17X690449

Vohra R, Madhavan S, Sambamoorthi U. Emergency department use among adults with autism spectrum disorders (ASD). J Autism Dev Disord. 2016;46(4):1441–1454. https://doi.org/10.1007/s10803-015-2692-2

Zerbo O, Massolo ML, Qian Y, Croen LA. A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. J Autism Dev Disord. 2015;45(12):4002–4014. https://doi.org/10.1007/s10803-015-2579-2