Norfolk and Suffolk
NHS Foundation Trust

Reasonable adjustments for people with learning disabilities and autistic people:

A MANUAL

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About this manual and how to use it

This manual is a practical guide and reference document. It is designed to help health services make the reasonable adjustments for people with learning disabilities and autistic people that they need to. The various sections will be of interest and use to different people and it is not intended that the whole document is read, absorbed and completed by all health professionals.

Section 1 is a general introduction and section 2 contains the values associated with making reasonable adjustments and general principles. These sections should be read by all professionals and will also be of interest to people using health services and their supporters in terms of what they can reasonably expect.

In section 2 there are tables containing various reasonable adjustments with prompt questions asking 'Where are we now?' and 'What else do we need to do?' These are intended to be used by professionals, either as individuals or by groups or teams, to assess the current situation and identify any actions needed. The actions should be added to the Action Plan Template in Appendix 1, which is a tool to collate the development activities around establishing reasonable adjustments that the service needs to complete.

Sections 3, 4 and 5 cover the most important areas for reasonable adjustments in more detail; these are communication, processes/systems and the environment. As in section 2, after each suggested reasonable adjustment there are spaces to assess the current situation and any actions needed. In each of these three sections there are two tables: the reasonable adjustments that an individual professional could make and the reasonable adjustment that the service could make. Actions should be added to the Action Plan in Appendix 1. Sections 3, 4 and 5 may also be of interest to people using health services and their supporters in terms of what they can reasonably expect.

Section 6 contains links to further information for specific health service areas.

Section 7 is a review of academic research into reasonable adjustments and section 8 summarises what the law says about reasonable adjustments.

SECTION 1
Introduction

There are about 1.5 million people with learning disabilities and 700,000 autistic people in the UK. Only one in four people with learning disabilities are identified as such in their GP practice registers and those on the registers are likely to be people with more significant learning disabilities. This means autistic people and people with learning disabilities may need to access healthcare without services being aware of their diagnosis.

People with learning disabilities have overall poorer health and are at increased risk, compared to the general population, of a variety of health problems. They often have several co-existing conditions and some people have behaviour that challenges which may (or may not) be linked to a health problem. People with learning disabilities and autistic people have worse access to healthcare and are more likely to be at risk from the determinants of health inequalities than other people. People with learning disabilities die on average 25-30 years younger than the general population.

The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities and autistic people use services. This means they need to change their approach and provision of services so they are easier to use and accessible to disabled people as well as everybody else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but importantly can also mean changes to policies, procedures, systems, how health professionals communicate and behave, and changes to the environment to ensure that health services work well for people with learning disabilities and autistic people.

In the Core Capabilities Framework, Skills for Health details what practitioners will be able to do in terms of health equality and reasonable adjustments for supporting autistic people (capability 14) and people with learning disabilities (capability 8).

Like the rest of the population, people with learning disabilities and autistic people are unique individuals and come in all shapes and sizes. Some people look a little different, lots of people do not and the fact that they have a learning disability (especially a mild learning disability) or that they are autistic, may not be immediately clear.

It's important to remember that individual people will need individual, specific reasonable adjustments and while many of the reasonable adjustments, strategies and approaches in this manual will be useful for many people, there is still a need for a personalised approach.

The overall aim of making reasonable adjustments is to ensure better health outcomes for people with learning disabilities or autism. It is also essential to comply with the law and policy. In addition, making adjustments to the environment, to ways of communicating and to processes and systems to make services easier and less stressful for autistic people and people with learning disabilities to use is likely to reduce levels of distress and behaviours that challenge.

A note on the use of person first language (person with learning disabilities) and identity first language (autistic person)

Language is powerful and shapes perceptions, attitudes and actions. Person first language was initially championed as part of the self-advocacy movement to challenge the medical model which defines people by their disability. Referring to the person first separates the person from the disability to highlight both personhood and an individual's abilities. Person first language is still the preference of people with learning disabilities.

This manual does not use the term 'person with autism' because research is increasingly showing that autistic adults do not subscribe to person first language, but instead prefer identity first language. This decision has been guided by the research of Kenny et al from the Centre for Research in Autism Education, UCL Institute of Education. Kenny et al (2016) summarise some of the reasoning behind this:

"Many of our autistic adults suggested that the use of language that separates a person's autism from their identity not only undermines the positive characteristics of autism but also perpetuates the notion that autism is an inherently 'wrong' way of being."

However, it's very important to check the autistic person's view and an exception to this use of language would be where an autistic person indicates a different preference.

Also, the terms 'high functioning' and 'low functioning' should be avoided as these are colloquial language not diagnostic categories. These terms can be misleading about the myriad difficulties an autistic person may experience in their day to day lives which might be masked by cognitive or verbal strengths. The terms are disliked by some in the population and if recorded on records may mask the need for support or reasonable adjustments ('high functioning') or lead to diagnostic overshadowing ('low functioning').

A range of views on person first and identity first language can be found here: https://themighty.com/2015/08/should-you-use-person-first-or-identity-first-language2/

SECTION 2
Values and general principles in reasonable adjustments

Views of people with learning disabilities: What are the most important reasonable adjustments?

SpeakEasy NOW is a self-advocacy charity run by people with learning disabilities. As well as having a leading role in engagement, participation and empowerment of people with learning disabilities, their work with Transforming Care has been recognised nationally. SpeakEasy NOW Health Checkers are people with learning disabilities who care strongly about the quality of health services. They know that people with learning disabilities often have poorer health than other people. They want to make sure that people with learning disabilities have access to good health information and advice and that health services can meet their needs appropriately. They do this by:

- Talking with people with learning disabilities and listening to their experiences
- Visiting health settings to see if their services are good for people with learning disabilities
- Reporting on the findings from their visits and making recommendations
- Providing training to help services understand the needs of people with learning disabilities
- Helping with the production of health information and advice that people with learning disabilities can understand

Kate Brackley works for Bild and she has a learning disability. Bild have been championing the human rights of people with disabilities since 1971. Bild works to understand people's needs and improve their quality of life. Bild's approach applies a rigorous evidence base, broad expertise and long- standing experience to find and enable both short and long-term solutions that bring about lasting change.

Kate asked the SpeakEasy NOW Health Checkers to explain the most important reasonable adjustments that people with learning disabilities need in health settings. She asked the group to consider this in relation to GP practices, hospitals (clinic appointments, inpatient wards, accident and emergency departments) and community nursing.

Overwhelmingly the Health Checkers said the most important reasonable adjustment was giving people with learning disabilities enough time: time to say what they need and to be listened to, time to build up trust and confidence, and time to understand what is happening to them, what they may need to do and to make the best decisions for themselves in respect of their healthcare and treatment.

They also said that whilst making reasonable adjustments is essential to providing good healthcare and treatment for people with learning disabilities, the basic principle will always be to deliver services in the most person centred way possible. By doing this, services will always put the needs of patients first and automatically look for ways in which these needs can be best met.

The other specific responses from the Health Checkers group (which they said will apply in all medical settings) are:

"Extra time in all medical settings"

"A good listener to people with learning disabilities and their carers and families"

"Help to understand the medical letters that come through the post and what they say"

"Treat all the people with learning disabilities well"

"Have a good relationship and trust with the medical setting staff"

"Get me to understand what they are saying to me"

"Space and time to have with all medical staff"

"Having 1-1 care with the medical staff to keep it confidential if someone with a learning disability wants to be on their own in the appointments with any medical staff"

"Not to be rushed"

"To have longer appointments to give people time to talk to GP practices and other places to be able to say what is wrong with them and if there is any problems"

"Easy to read information in GP practices and in hospital settings"

"No jargon and no abbreviations and no complicated long words at all"

Overall approach of health professionals

Health professionals need to do all they reasonably can to ensure that people with learning disabilities and autistic people are provided with as good a quality health service as other people. All people with learning disabilities and autistic people have an equal right to healthcare and to be treated as individuals with compassion, dignity and to be provided with person centred care. Every step of the care pathway needs to be adjusted so autistic people and people with learning disabilities can receive equal treatment.

In addition to the practical suggestions in this manual the overall approach of health professionals involves being approachable, focusing on building trust with the person with learning disabilities or autistic person, making use of good communication (especially listening skills), trying to be flexible, not rushing and, as referred to above, providing more time. Section 3 explores reasonable adjustments to ensure more effective communication in more detail.

It may be relatively easy to identify someone with more significant learning disabilities (and information may well be passed on by health professionals, family carers or support staff). However, health staff need to be alert to the larger number of people with milder learning disabilities and autistic people who may still need some support. Staff might notice someone who has difficulty with:

- Reading and/or writing forms
- Explaining symptoms or a sequence of events
- Understanding new information or taking information in quickly
- Answering open questions
- Remembering basic information such as date of birth, address, health problems
- Understanding invisible social rules
- Eye contact
- Understanding and telling time
- Understanding colloquial language, figures of speech or sarcasm
- Crowded or busy spaces, bright lights or loud noises

Noticing these could prompt a conversation with the person to ask more questions about any communication or support needs, necessary reasonable adjustments and also to check understanding and recollection of information. Some people might not like a direct approach regarding being a person with learning disabilities or an autistic person, they may not know themselves or may be concerned about the stigma but health professionals could ask the person if they have any support with day to day things, as a way of exploring this and what adjustments may be needed.

Awareness of some autistic people's issues around, and responses to, touch and invasion of personal space is also important for health professionals. These will be different for each individual so finding out about them and adjusting the approach for that individual is necessary.

Some autistic people have a high threshold to pain or temperature so may not report or appear to be in pain when a condition or injury would be painful for other people. Some autistic people may display unusual responses to pain such as laughing or humming. Other autistic people may be hyper-sensitive to touch, experiencing even gentle touch or certain textures as uncomfortable or even painful, so they may withdraw from or refuse touch. Some autistic people may struggle to explain where pain is experienced and those with difficulty around body awareness may not be able to experience where different body parts are. Some autistic people are not always able to identify and name emotions. All of these need to be considered as they can impact on the ability to diagnose. In addition, close proximity to the health professional during an examination could be quite uncomfortable for some autistic people.

Learning disability and autism awareness training, including around human rights, may be useful for health staff and may help with understanding what general reasonable adjustments may be needed.

Reasonable adjustments: Overall approach	Where are we now?	What else do we need to do?
All staff have had autism and learning disability awareness training		
All staff can describe potential signs of learning disability and/or autism in people without a diagnosis		
Clinicians can describe sensory difference in autistic people and the adjustments they need to make		
Any other actions arising from this section?		

Personalisation and partnership working

The most important aspect of reasonable adjustments involves asking the autistic person or person with learning disabilities, or their supporters, what adjustments they need or want. Many people would prefer someone to ask if they need extra help because of their learning disability or autism, rather than saying nothing for fear of causing offence. The adjustments and adaptations being made should be based on that person's individual needs. Sometimes it may be necessary to offer a limited number of options sensitively and sometimes repeatedly, as some people won't know what they need or what is possible. Some of the adjustments detailed in this manual may be useful for many people with learning disabilities or autistic people, but the key point is to be committed to providing equally good alternatives and to avoid a 'one size fits all' approach. It can also help to use the person's strengths and interests to encourage them to engage in healthcare.

Getting additional information about potential reasonable adjustments from the autistic person or person with learning disabilities (or their supporter, including family) and then agreeing together what is possible is the best approach. This is about collaborative problem solving and sharing control with the person. Being clear what adjustments are not possible (or not reasonable) is part of this, but the goal is to make reasonable adjustments so that the autistic person or person with learning disabilities can access the healthcare they need.

Health professionals need a clear picture of a person's health problems but also their lifestyle and circumstances in order to be able to give helpful advice and information or to raise questions. This should include the support that is or is not available to the person with learning disabilities or autistic person. It should not be assumed that an individual will have 24 hour support, nor that any support is available from staff with health qualifications. A Summary Care Record should contain the most important medical information but could also include information about the person's wider lifestyle and support. The person themselves and their supporters will often be the best source of such information.

Family carers and supporters often hold detailed knowledge about the person's health, how this affects the person's life, successful ways of communicating with and supporting the person and what the person will or will not accept. This may be particularly relevant for people with profound and multiple learning disabilities, but remembering to always talk to the person directly not just their supporters is essential and respectful.

The person may have a health passport, health action plan, hospital traffic lights or hospital passport; these provide information about the person and their care and support needs and may be helpful in knowing what reasonable adjustments are necessary.

Reasonable adjustments: Personalisation and partnership working	Where are we now?	What else do we need to do?
All staff routinely ask the person with learning disabilities or the autistic person, or their supporters, what adjustments they need or want		
Summary Care Records contain information about the person's levels of support and wider lifestyle		
Staff routinely ask if the person has a health passport, health action plan, hospital traffic lights or hospital passport		
Any other actions arising from this section?		

Preparation

Key to ensuring people can access healthcare through making reasonable adjustments is forward thinking and planning. In general, health services should not wait and respond to difficulties as they emerge; the duty on them is 'anticipatory', meaning they have to think out what is likely to be needed in advance.

Whenever possible, health professionals should consider and plan reasonable adjustments before all appointments and treatments. Ideally, each individual's required and pre-agreed reasonable adjustments would be recorded on their Summary Care Record and would be available to be checked or flagged prior to appointments (see section 4).

Health professionals should do some research into the person's history and their physical, sensory and communication needs in advance of the appointment. For some people the only extra support they need might be as simple as providing information in a format the person understands. For other people there will need to be pre-appointment preparatory work which may involve education related to the health issue or process, capacity assessing, desensitisation work or teaching of coping and tolerating skills. This preparation may involve different health professionals to varying degrees and involve partnership working with the person and/or their supporter.

Desensitisation is a systematic, planned programme gradually introducing the person to a situation or event (in this instance an appointment or procedure) that they are anxious or fearful of. Almost a sixth of people with learning disabilities have a significant fear of contact with medical professionals to the extent that it might affect healthcare interventions. There are often reasons for many people with learning disabilities and autistic people to be afraid of specific procedures or contact with health services more broadly; these include past experiences, a lack of information and understanding about what is involved, lack of choices or even forcible treatment.

Desensitisation is about building up the person's confidence gradually until they are ready to attend the appointment or have the procedure. It might start with someone firstly getting used to the environment and then over time being exposed to the equipment and then the different steps of the process. With sufficient repetition through practice the anxiety around the appointment or procedure can be reduced. Desensitisation is a process that can mean a lot of initial input from the person's supporters and health professionals with considerable time being required but it is a reasonable, and necessary, adjustment for some people with learning disabilities and autistic people to be able to have essential procedures.

Reasonable adjustments: Preparation	Where are we now?	What else do we need to do?
Summary Care Records include individual reasonable adjustments needed		
There is a flagging system and reasonable adjustments are flagged prior to appointments		
Clinicians can describe the role of desensitisation and can contribute to desensitisation programmes		
Any other actions arising from this section?		

Capacity to consent to treatment

Knowing how much a person can understand is essential in making a decision about their capacity to consent to have a health treatment. People need clear, accessible information and simple verbal explanations in order to make decisions and consent, or not, to treatment. The Mental Capacity Act is clear that anyone is entitled to have the information relating to a decision presented in a way that means they have the best chance of understanding it. Health professionals need to have a good understanding of the process of assessing capacity and the consent process and will certainly need to contribute to the person receiving information in an appropriate format. There is more on the Mental Capacity Act in section 6.

Reasonable adjustments: Capacity to consent to treatment	**Where are we now?**	**What else do we**
All clinicians can describe how they would provide clear, accessible information and simple verbal explanations in order to support people with learning disabilities and autistic people to make decisions and consent, or not, to treatment		
All clinicians have a good understanding of the process of assessing capacity and of the consent process		
Any other actions arising from this section?		

SECTION 3
Communication

Good communication is essential for people with learning disabilities and autistic people to access healthcare. It is necessary to take an individualised approach, trying to use whatever communication methods work best for an individual, and often needing to adapt techniques for different individuals.

Many people with learning disabilities (up to 90%) have some speech, language or communication difficulties but these can often be hidden or overlooked. Around half have significant difficulties with both expressing themselves and understanding what others say. Only 5–10% of people with learning disabilities have good literacy skills and most are not able to access standard written information.

Sight and hearing impairments are much more common in people with learning disabilities and up to 40% of people with learning disabilities have a hearing loss that is often missed or undiagnosed.

Difficulties with social communication and interaction are fundamental elements of a diagnosis of autism and almost all autistic people struggle to differing degrees in these areas.

People with learning disabilities and autistic people's ability to understand verbal communication (receptive communication) is usually overestimated, especially when the same person's use of verbal communication (expressive communication) is good. There is often a significant difference in levels of receptive and expressive communication.

What a clinician or staff member can do

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Ask the person what communication techniques or methods they use or prefer and make adaptations based on those individual needs.		
Ask if they have a health passport, health action plans, hospital traffic lights or hospital passport as these should provide information about communication with the person.		
When speaking face-to-face or on the 'phone use accessible verbal communication, keep language simple, avoid using jargon and technical terms, use plain English, no abbreviations and no complicated long words. Find out what words the person uses about their own body parts so that vocabulary the person understands can be used.		
Make sure your facial expressions and tone of voice match what you say. Speak clearly, don't be patronising or use a tone of voice that you might use when speaking to a young child, but do check understanding.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Some people will be good at repeating back the information you have told them, so make sure that you probe or ask in a different way to ensure understanding. It is really important not to make assumptions that someone has understood information they have been given.		
Make use of good listening skills: listen, observe and check the person's understanding. Model actively listening to someone through body language (giving the person your full attention, stopping doing something else and being quiet while they talk). Once they have finished talking paraphrase what they have said back to them, both to check you have understood correctly and to let them know you have understood.		
Take your time and allow longer so that communication is more effective and to avoid confusion or distress. People with learning disabilities usually need longer to take in and process information, understand information they are given and to make themselves understood. Just a few extra minutes can make a big difference to many people. Some autistic people need considerable time to process information, especially when it is communicated verbally. If the person is silent and not immediately responding to a question or request they may be processing what has been said so it will be important to wait for a response and not to say more or to repeat the request or question.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Ask direct, brief questions. For some people, questions about time and frequency may be difficult to understand. Some people may give you the answer they think you want to hear. Some people may repeat back what has been asked and so appear to be agreeing. In these cases it may be necessary to check their answers or to ask again in a different way.		
People with learning disabilities may require help with appointments, and clear, simple, and possibly repeated explanations including of what is happening, or of treatments to be followed. Tell people what you are doing, explaining at every stage what you are about to do, what will happen and why. Overall, avoid the person being overloaded with information.		
Try not to rely on verbal communication. Take time to become familiar with, and then comfortable using, accessible alternatives to verbal communication. Using pictures, symbols, drawing or diagrams can be helpful for many people. Some people will find demonstration easier to understand than verbal requests, instructions or directions. Autistic people are particularly likely to find written notes and diagrams helpful as they can have a strength in visual thinking.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Tools like an accessible pain chart may help with understanding the severity of a symptoms. Having prepared body maps that the person can point to, to indicate where the pain is, might be helpful in some cases.		
Some autistic people find eye contact difficult or even painful, so don't expect eye contact as you might otherwise, and never request it. Don't shake hands.		
With almost all autistic people it's necessary to be literal, unambiguous and extremely clear; say exactly what you mean, explain and avoid figures of speech or colloquialisms. Use multiple choice rather than open-ended questions, ask direct questions with examples for the person to accept or reject. Check with the person what they understand following the assessment and ask if they have any questions.		
Autistic people will find it helpful if you focus on concrete issues and symptoms (not bigger picture), take a more structured approach and allow extra time to process new information. Autistic people often cannot predict likely consequences or think (imagine) into the future and it may be difficult for people to find solutions and to assess the suitability of these. It can be useful to be prescriptive in suggesting consequences and impacts of different courses of action.		

What the service can do

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
All NHS services must follow the Accessible Information Standard. This ensures that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support, so that communication between them and health professionals is effective. Plan how to maximise understanding by considering the communication environment and who gives information, when and where.		
Use the Health/Summary Care Record to flag specific communication needs. Appointment times may need to be longer to facilitate effective communication. This will allow for better communication, but also provide time for additional actions for the professional that come out from the appointment (ie onward referrals). Some services book double appointments where appointment slots are not able to be flexible.		
People may need additional telephone calls and reminders if they haven't attended an appointment. If someone repeatedly does not attend an appointment, or does not engage with the service, it would be worth following up with a phone call, as their learning disability or autism may not have been picked up by their GP.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment	What else do we need to do?
Many people with learning disabilities and autistic people need information presented in different formats. Services should provide accessible/Easy Read formats of letters, information and signage; good signage and directions to help people find their way easily to the appointment location and a picture of the location can help reduce anxiety.		
Written information should not be too small, too wordy or too complicated. Use larger print, a simple font and make use of different colour contrasts. Keep it simple, avoid using jargon and technical terms, use plain English, no abbreviations and no complicated long words.		

There are lots of Easy Read resources available from third sector organisations. Some examples:

- Foundation for people with learning disability: health conditionguides
- Easy Health: https://www.easyhealth.org.uk/IAPT Positive PracticeGuide
- Mencap HealthGuides
- NHSE has some helpful resources: https://www.england.nhs.uk/learning-disabilities/about/resources/
- https://www.gov.uk/search/all?keywords=easy+read&level_one_taxon=8124ead8-8ebc-4faf-88ad-dd5cbcc92ba8&order=relevance
- https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/e/easy-read

There is a Facebook Easy Read page: https://bit.ly/38b215m

These are more examples for specific areas:

- Easy Read Cancer booklets
- Hepatitis
- Type IIDiabetes
- Mental Health Resources
- Communication card

See the following pages for an example of the communication card from the link above.

Communication Card

How I like to communicate and get information

Fill in the form and take it to your next appointment

A useful resource created by CHANGE

www.changepeople.org

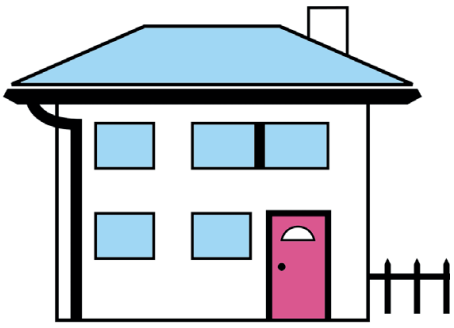
CHANGE

About me

My name is:

My date of birth is:

Date	
Month	
Year	



My address is:

How I communicate

I communicate using:

E.g. BSL, deafblind interpreter

To help me communicate I use:

E.g. hearing aid, talking mat

I need information in:

E.g. braille, easy read

The best way to contact me is:

E.g. mobile, email

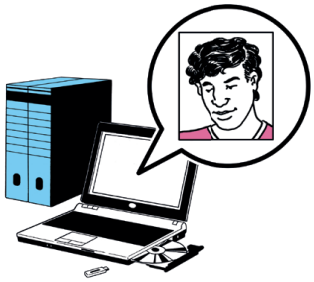
What professionals have to do

1. Ask

Find out if a person has any communication or information needs and if so what they are.

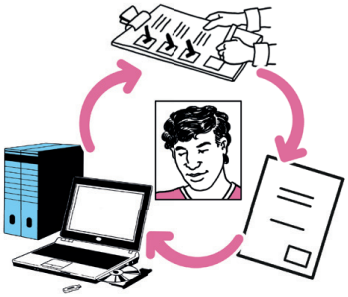
2. Record

Record those needs in a clear way. This can be done on a computer or on paper.



3. Highlight

Make sure that a person's needs stand out in their records.



4. Share

Include information about a person's communication needs when sharing other information about them.

5. Act

Make sure people get information which they can use and understand, and support if needed.

SECTION 4
Processes and systems

The duty on health services in relation to reasonable adjustments for people with learning disabilities and autistic people is 'anticipatory'. This means that services need to think out what is likely to be needed in advance rather than only responding as needs emerge. Health professionals need to adapt existing systems to meet the specific needs of individuals and this requires planning.

Key in this area is flexibility. The system and processes need to be flexible enough to ensure that autistic people and people with learning disabilities can access good healthcare.

People with learning disabilities and autistic people are 'vulnerable patients' and should be exempt from 'Did Not Attend' policies. It may be in the best interest of people who are not immediately compliant in attending appointments to remain on lists so they can be invited for treatment at a later date (recalled), enabling further education, health promotion work, desensitisation and support to be provided to make future appointments more likely to be successful.

Apparent lack of co-operation may be due to a lack of understanding or insufficient preparation, rather than a lack of motivation to engage in treatment.

What a clinician or staff member can do

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Ask the person what adjustments they need to appointment or treatment arrangements and make or negotiate adaptations based on those individual needs. Adjustments should include consideration around appointment times and duration, support required during appointments or treatments and ensuring any information provided is accessible, as detailed in the previous section.		
Record any reasonable adjustments on the patient's record clearly so it stands out and can be checked at future appointments and shared with other health services.		
On the phone, follow all relevant adjustments in this section and section 3 and, in addition, ask people if there is anything you can do to make the call easier. Offer a follow up call. Be aware it may take more time so plan in advance. Give people permission to pause. If you have limited time, explain at the start of the call. Don't sound rushed or frantic yourself. Offer to follow up the call with a written record of what was discussed, in simple, easy to read language.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Plan, with the person and their supporters, how to make processes easier to tolerate.		
This may involve providing additional information and education before treatments or appointments. Demonstrating and modelling what we want people to do, rather than telling them, can be helpful. Having a 'walk through' or 'dry run' of what the treatment or appointment will involve with the person can be useful in identifying reasonable adjustments.		
Desensitisation work, detailed in section 2, may be needed. It may help the person to visit the appointment venue before the appointment to familiarise themselves with the environment. Providing photos (for example, of staff or a building) as an object of reference can be helpful when preparing for the appointment at home.		
With autistic people it is helpful to ask about any sensory issues so that the examination and equipment can be adapted accordingly (for example, replacing a paper sheet on the examination table with a cloth one). The use of pen lights can be a problem for some autistic people and can even trigger seizures in those susceptible. Ask if it is ok to shake hands rather than automatically offering to do so.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Some people may need breaks if it is a long appointment. Some people may need a longer series of appointments to build a relationship and trust.		
For some services, one basic reasonable adjustment that can be made is a home visit. A home visit takes more time for the health professional but in the long run it can be quicker, more effective and less stressful than multiple unsuccessful attempts at a surgery or clinic. Alternatively, provide a tele- clinic service (pre-booked structured phone calls).		
It can be helpful to phone the person the day before the appointment to remind them about it and what it will involve.		
Consider the appointment location. Are there options that the person may find easier than others? Consider offering a longer appointment or offering it at a quieter time.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Let the person know who will be attending the appointment and why. Don't assume people can read an appointment letter; instead, use accessible formats or telephone with the appointment details.		
Start your appointment on time to prevent anxiety. This is especially important for autistic people.		
Be willing to adapt how you complete your assessment or treatment. Spend some time building trust and rapport. Give consideration to less invasive or aversive alternatives. Include tasks which are interesting and relevant to the person's needs – functional activities can make more sense for some people. Spend some time building trust and rapport.		
Explain what you are doing and why and show the person what you want them to do. Demonstrating on others or toys to show what will happen during a physical examination can help to reassure the person. Use clips from YouTube on an iPad to show what is going to happen. Be flexible and relaxed in your approach and don't rush; many people need more time to process information.		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
It may help to provide information visually, using flow charts, checklists or photos to explain the process and what may be involved. It may also help to use pain scales, body diagrams or charts and symptom pictures to help the person communicate the issue. 'Show me where' is a collection of simple visual tools which can help people with learning disabilities and autistic people convey the location of pain or discomfort. https://www.showmewherepain.co.uk/		

What the service can do

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
Establish a flagging system to support forward planning, making sure that specific needs and adjustments needed for an individual are flagged on Summary Care Record systems. This 'reasonable adjustment flag' could include: • The need for 'Easy Reads' • How to communicate • Who to involve in the person's healthcare • Things that help the treatment be successful • Preferred professionals including gender • Physical or access needs • Appointment preferences re time of day etc • Need for a phone reminder on the appointment day • What people can do for themselves (not just what they can't do) A national reasonable adjustment flag scheme has been launched by the NHS, available at: https://bit.ly/3g66CrZ		
All colleagues should be prompted to add additional information to patients' Summary Care Records as a reasonable adjustment flag.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
Consider having a named professional who focuses on reasonable adjustments for autistic people and people with learning disabilities for the service and who works proactively to communicate patients' needs with primary and secondary care colleagues.		
Provide contact lists so staff know who they can ask for advice about supporting people with learning disabilities or autistic people.		
Be prepared to provide people with learning disabilities and autistic people longer appointments and treatment time, double appointments, two appointments booked in the same week in case the first appointment is not successful, appointments at a time when the person's supporter can attend, appointments at quieter, less busy times; this might be especially important for autistic people.		
Offer home visits and tele-clinics. Appointments may need to fit around people's routines, especially if an autistic person has a rigid routine. Ensure consistency of the time in repeat appointments.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
Consider having 'fast track queues' for people who may find waiting difficult or impossible. Offer the first appointment of the session so there is no waiting, the person can avoid busy waiting rooms and be able to go straight into clinic or treatment room.		
Some autistic people may not tolerate phone appointments or assessments and may need a longer series of appointments to build trust.		
Send appointment letters (Easy Read) routinely in blue envelopes so the person knows what they are. However, a letter alone is often not enough and patients may continue to ignore the letters without support and guidance. Phone calls instead of, or as well as, letters may be needed.		
Be prepared to combine appointments and treatments, arranging for multiple professionals to be scheduled or available to assess, review, take multiple tests or complete treatment procedures which could be carried out at the same time. In addition to emphasising a multi-disciplinary approach, this may also reduce the stress or burden on the patient and, in fact, be a more efficient use of time and resources.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
At hospital, there should be a named person that the person with learning disabilities, autistic person or their supporters can talk to about any aspect of being an inpatient. There should also be clear information about what supporters (including family) can do to support the person in hospital, and what hospital staff should do.		
Allow people with learning disabilities and autistic people (and their supporters) to visit the ward before admission to familiarise themselves to help with desensitisation (see Section 2).		
The timing of operations should be carefully considered and theatre lists ordered to minimise patient wait. Being in hospital by 7.30am for a morning list may be difficult; being kept starved all morning for an afternoon list may be a challenge, so consider allowing the patient to arrive outside normal theatre arrival times. Allow pre-operative checks to be done under anesthesia if necessary. Allow supporters, including family, to be present in recovery, where possible.		
Allow supporters, including family, to visit outside of standard visiting times, including the possibility of having a supporter present at all times to support the individual, if needed.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
In A&E, prioritise triage of people with learning disabilities and autistic people and always offer a quiet place to wait rather than the usual waiting area.		
For patients who are frequently admitted, put in place a flagging system to alert hospital staff of an impending admission and help to minimise any delay in them being transferred from A&E to the most appropriate ward.		
Consider if it is possible to shorten admission and avoid overnight stay.		
There is important information around postural support when an inpatient or attending hospital for assessments in the postural care guide in Section 6.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
Plan to ensure safe discharge. Discharge processes will need to be considered carefully, with all supporters. If you believe that someone may have a learning disability or autism, but does not have any designated support, then this will need to be flagged with the social care team before discharge.		
It will be necessary to make reasonable adjustments around applying 'zero-tolerance' to verbal or physical aggression policies for some people with learning disabilities and autistic people when they are very aroused or distressed.		

SECTION 5
Environment

There are various elements or layers to the environment; as well as the physical environment there are information, communication, policy, and attitudinal/social environments. The suggested reasonable adjustments covered previously in this manual all contribute to the overall environment.

Consider the environment with reference to Universal Design principles. Universal Design aims to ensure that spaces can be used by everyone, regardless of their level of ability or disability; it means designing or arranging spaces to be usable by all people to the greatest extent possible. If a design works well for people with disabilities it works better for everyone and through applying the principles of Universal Design services can better accommodate patients with learning disabilities and autistic people.

Universal Design is based upon seven principles:

1. Equitable: The space is usable for anyone; identically whenever possible, equivalently when not. It avoids segregating or stigmatising anyone and provides privacy, security, and safety for all.
2. Flexible: The space accommodates a wide range of individual preferences and abilities. It provides choice in how it is used. It accommodates right or left-handed people, various levels of accuracy or precision and provides adaptability to the user's pace or different abilities.
3. Simple: The space is easy to understand, regardless of the user's experience, knowledge, language skills, literacy or concentration level. It avoids unnecessary complexity. It arranges information clearly and consistent with its importance.
4. Perceptible information: The space communicates necessary information effectively, regardless of people's sensory differences using different methods (such as Easy Read, pictorial, verbal and tactile). It provides adequate contrast between essential information and its surroundings, prioritising and emphasising essential information. It provides compatibility with a variety of techniques or devices used by people with sensory differences.
5. Tolerance for error: The space minimises, eliminates, shields or isolates hazards and is arranged to reduce unintentional mistakes. The most used elements of the space are the most accessible, there are warnings of hazards and errors and the space provides fail safe features.

6. Low physical effort: The space can be used efficiently and comfortably and with a minimum of fatigue. It allows people to maintain a neutral body position, uses reasonable operating forces, minimises repetitive actions and minimises sustained physical effort.

7. Size and space: Appropriate size and space is provided for approach, reach, manipulation and use regardless of the user's body size, posture or mobility. There is a clear line of sight to important elements for any seated or standing user. The space makes reaching to all components comfortable for anyone, seated or standing. The space accommodates variations in hand and grip size and provides adequate space for the use of assistive devices.

What a clinician or staff member can do

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Make people with learning disabilities and autistic people aware of the reasonable adjustments which are readily available. Ask if there are other specific reasonable adjustments to the environment they need and make or negotiate those adaptations.		
Offer people the 'reasonable adjustments box' (see below).		
Waiting room or area reception staff should make sure the clinician knows the person with learning disabilities or autistic person is waiting and if they are showing any signs of anxiety should tell the clinician.		
NSFT Waiting Room Standards will support many of the reasonable adjustments for people with learning disabilities in this manual, especially: • Staff will be trained to be aware of individuals' needs and the effect waiting may have upon them • If a visitor appears to find waiting difficult, staff will offer support • Visitors will be greeted with friendliness, respect and courtesy • Any changes to appointments should be explained to the visitor immediately, offering apologies for any inconvenience caused		

Reasonable adjustment	Do I ordinarily make this adjustment?	What else do I need to do?
Consider sensory as well as physical environmental factors. Autistic people often have very different sensory experiences and can be hyposensitive and/or hypersensitive in all of the seven senses. However, each autistic person will have a completely individual profile of sensitivities. If possible, ask about any sensory sensitivities, record them on a patient's Summary Care Record and make adjustments to your approach based on the specific individual sensitivities.		
For many people, limiting the likelihood of interruptions and minimising distractions in the environment, wherever possible, will be important. This includes minimising sensory stimulation and noise as well as removing from sight unnecessary equipment or other visual distractions such as notices from walls. Ask if there's a need to temporarily remove the clock or turn off lights.		
Transition spaces, eg halls/stairwells can be difficult for some people, so keep the use of these to a minimum.		
Try to keep consistency of appointments, eg same room, same day/time and don't be late. Many people also find waiting a long time very difficult.		

What the service can do

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
Audit or review the environment using the seven Universal Design principles above and make whatever easily achievable adaptations are possible.		
Plan what further adaptations, in line with these principles, can be made, when the opportunity to re-design spaces or to re-purpose buildings or build new ones arises.		
Create a 'reasonable adjustments box' and make it available for people with learning disabilities and autistic people. The box could include: • A CD player, CDs and headphones • Ear defenders and earplugs • Coloured overlays • Communication cards ('stop/no', 'good/yes', 'explain') • Comforters/distracters: squeezies/stress balls, Chewy Tubes, Thera tubing		
Ensure physical accessibility (mobility access, a changing place toilet), so people can get into and around the service.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
As well as ensuring there are no physical barriers for people using wheelchairs or with mobility issues, also make sure signs are as easy to understand as possible.		
Try to promote familiarity for autistic people and people with learning disabilities by arranging appointments in consistent rooms or areas, using locations that people already know.		
For some autistic people sensitivity to certain lighting can be a particular problem. For instance, strip fluorescent lighting can be experienced as painful and distracting for some people. For some autistic people with hyper-sensitive hearing noisy environments can be difficult; buzzers to indicate when it is a patient's turn to see the clinician, music playing, crying babies or children can all be problems.		
Provide a separate, quiet 'low arousal' area that the person can sit in if the waiting room is too busy, or over arousing in other ways, for example through posters on walls, signage or bright lights. This is a reasonable adjustment that might be very important for many people with learning disabilities and especially some autistic people who may find the physical environment over stimulating and overwhelming. Having a quiet place to wait can prevent people getting anxious and having to leave the service.		

Reasonable adjustment	Where are we now? Do we ordinarily make this adjustment?	What else do we need to do?
NSFT Waiting Room Standards are in line with good reasonable adjustment practice, particularly: • Signs will be in place so people know where they are going • Staff working in the waiting areas will be easily recognisable • If areas are open at specific times these will be displayed effectively • Toilets will be easily accessible and easy to find • A private space should be available for visitors, if needed • There will be a minimal amount of information displayed on the walls of waiting rooms • A display booklet/stand should be used to display useful information for visitors to take away with them. All information displayed in booklet/stand should be relevant, up to date and copies available • Reasonable adjustments should be made to the information available to ensure it is in a format to meet people's needs • Waiting areas should be quiet and relaxed		

SECTION 6
Specific health service areas

Public Health England and other organisations have produced guides on making reasonable adjustments in specific health service areas so that people with learning disabilities can access services. The guides contain information, ideas, good practice examples and an Easy Read summary. They may also be relevant in relation to providing reasonable adjustments for autistic people. These guides are all available online and cover the following areas:

- Annual healthchecks
- Blood tests
- Cancer screening
- Constipation
- Dementia
- Dysphagia
- End of life care
- Epilepsy
- Eyecare
- Obesity and weight management
- Oralcare
- Pharmacy
- Postural care
- Preventing falls
- Psychological therapies
- Substance misuse

Links to the individual guides are below.

Annual health checks: https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities

Blood tests: https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities

Cancer screening: https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities

Constipation: https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities

Dementia: https://www.gov.uk/government/publications/people-with-dementia-and-learning-disabilities-reasonable-adjustments

Dysphagia: https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities

End of life care: https://www.ndti.org.uk/uploads/files/RA-End_of_Life.pdf

Epilepsy: https://www.ndti.org.uk/resources/useful-tools/making-reasonable-adjustments-to-epilepsy-services-for-people-with-learning

Eye care: https://www.gov.uk/government/publications/eye-care-and-people-with-learning-disabilities

Obesity and weight management: https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability

Oral care: https://www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities

Pharmacy: https://www.gov.uk/government/publications/pharmacy-and-people-with-learning-disabilities

Postural care: https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments

Preventing falls: https://www.gov.uk/government/publications/preventing-falls-in-people-with-learning-disabilities

Psychological therapies: IAPT Positive Practice Guide

Substance misuse: https://www.gov.uk/government/publications/substance-misuse-and-people-with-learning-disabilities

SECTION 7
Review and summary of research into reasonable adjustments

People with learning disabilities and autistic people face significant barriers to accessing healthcare (Emerson and Baines, 2010; Tuffrey-Wijne et al, 2014; Redley et al 2019; Mason et al 2019; Walsh, Lyndon, O'Dowd and O'Connor, 2020). Since the Equality Act was introduced in the UK in 2010 healthcare providers have had a duty to provide reasonable adjustments to assist people with learning disabilities and autistic people to access services and receive good quality, equitable care. Research has explored the experiences of and approaches to making reasonable adjustments and also points to the solutions or facilitators to healthcare for people with learning disabilities and autistic people.

Given the breadth of research in this area, this short review will focus on summarising how healthcare access can be facilitated by providing reasonable adjustments and the research evidence available to support this. The research evidence is organised into two key areas:

1. Communication
2. Processes, systems and environments

The review will then outline what research says in relation to the barriers to accessing healthcare for people with learning disabilities and autistic people.

Only systematic reviews and primary research from 2010 onwards (not grey literature) are included. The methods for this review are not systematic, and so should be read with a note of caution; there may be useful studies that have not been identified and the quality of the studies included has not been evaluated.

Evidence for reasonable adjustment to enable healthcare access in the area of communication

Research to explore the reasonable adjustments in the area of communication has mainly focused on communication aids and tools. Chebuhar et al (2013) in the USA conducted a pilot study of picture schedules for autistic children to depict medical procedures. The evaluation showed that the majority of staff and caregivers felt the aids decreased child anxiety and behaviours of concern during procedures. Parents/carers thought that the intervention helped make the experience tolerable for their child and also had a reduction in their own anxiety (including anxiety about future appointments).

Hollins, Carpenter, Bradley and Egerton (2017) conducted a literature review and examined case examples contributed by clinicians regularly using wordless books with people with learning

disabilities and autistic adults. The review of literature supported the assumptions underpinning the development and use of wordless books and the case analysis found that wordless books helped develop staff skills and empathy and enabled them to improve how they listened to the patient. They concluded that the books could facilitate some legally required reasonable adjustments to increase service access, though staff training would be required to use wordless books effectively.

Chinn and Rudall (2019) conducted a study which examined how Easy Read health information was used by clinicians and received by patients. She recorded 32 health checks for patients with learning disabilities and analysed these using conversation analysis. Chinn and Rudall found that Easy Read health information was visible in 22% of the primary care health checks recorded. Easy Read resources were used in conversational sequences where clinicians offered unsolicited health advice that was met with degrees of resistance from patients. She also noted the potential for shared decision-making was evident using the information in Easy Read.

Nguyen, Lennox and Ware (2014) explored the use of hand held health records, such as hospital passports for people with learning disabilities. The study found the records helped facilitate discussion about health problems, increased health-related knowledge and increased awareness of personal health issues, but did not lead to improved short-term healthcare activity.

Northway, Rees, Davies and Williams (2017) have also researched hospital passports, conducting a qualitative content analysis of 60 different passports in use in the UK. They found variation between documents in terms of terminology, length and format. Most included information regarding communication and support needs although some left out important information (including the need for reasonable adjustments). The authors conclude that the current variation in hospital passports may limit their effectiveness and suggest greater standardisation of documents is required.

Finally, Fish, Hatton and Chauhan (2017) co-produced a questionnaire about the information people received from GPs and pharmacists about medications. The questionnaire was circulated at a learning disability self-advocacy conference. The 58 self-advocates who completed the questionnaire reported that information from GPs and pharmacists was mainly instructional, and that most struggled to read the leaflets and remember information. They wanted information in an Easy Read format, pictures or diagrams.

Evidence for reasonable adjustment to enable healthcare access in the area of processes, systems and environment

Studies in the area of processes, systems and environment focus on strategic actions to promote inclusion and reduce health inequalities, the role and benefits of liaison nurses, appointment scheduling and adapting the environment to accommodate sensory needs.

McConkey, Taggart, DuBois and Shellard (2020) conducted an online international survey, with 61 respondents, who were asked to rate relevance and feasibility of 30 strategic actions and indicators to promote inclusion and reduce health inequalities in healthcare systems. The top-rated strategic actions included making available policy statements and practice guidelines on making reasonable adjustments and mandatory training of health professionals (with people with learning disabilities as co-trainers).

Another study focused at the strategic level by Marsden and Giles (2017) reported the development of an organisational framework for reasonable adjustments. To design the framework they examined

and synthesised the challenges in caring for people with learning disabilities, and conducted an evaluation using collaborative thematic analysis, reflection and a secondary analysis. The framework developed was the 4C framework: communication, choice making, collaboration and coordination.

The authors report that the framework provided a basis for delivering person centred care and was used to inform training needs analyses, develop audit tools to review delivery of care and develop competencies for learning disability champions, as well as evaluate and resolve practice-based scenarios.

In the USA, Nicolaidis et al (2016) developed the Autism Healthcare Accommodations Tool (AHAT), part of a broader healthcare toolkit. The toolkit offers a list of potential adjustments/accommodations to choose from to form an individualised plan, which can be sent to a provider in advance. From their mixed methods evaluation they reported that more than 94% of patient participants thought the toolkit was easy to use, important, and useful. Comparisons pre and post intervention showed the number of barriers decreased, healthcare self-efficacy increased, satisfaction with communication improved. Patients reported the toolkit helped clarify their needs, enabled them to self-advocate, prepared them for visits more effectively and positively influenced provider behaviour.

In the area of liaison nurses, Castles, Bailey, Gates and Sooben (2013) collected quantitative data on all patients with learning disabilities referred to liaison nurse service over a six-month period.

Additionally, patients with learning disabilities, their carers and hospital staff who had experience of the liaison service were interviewed. Their data suggest a rise in referrals to the service over time, few inappropriate referrals, referrals from hospital staff and community services were 'similar'; however, some patients with learning disabilities were not referred to the service. Participants interviewed understood the role of the liaison nurse and reported improved communication and more holistic care.

Tuffrey-Wijne et al (2014) have also researched liaison nurses; theirs was a mixed methods study of interviews, questionnaires and participant observation (conducted between July 2011 and March 2013) in six acute NHS hospital trusts in England. This was a large-scale study (n=1,251), including senior hospital managers, clinical staff, ward managers and 33 people with learning disability and their carers. The conclusions they drew from their research were that that where adjustments are complex, a highly skilled liaison nurse service was key in ensuring that preventable harm and preventable deaths were avoided in a number of cases. However, there does need to be easy access to the post holder, and liaison nurses need authority and managerial support. The authors also report that ward managers had a strong influence on ward culture, which in turn affects the flexibility to provide person centred care.

Another study, by MacArthur et al (2015), reporting on semi-structured interviews with stakeholders about the role of the liaison nurse, found outcomes associated with this role included improved individual patient outcomes (via co-ordinated care, successful investigations and treatment, reducing and managing challenging behaviour, increasing staff confidence, fostering autonomous decision-making and ensuring compliance with capacity and other safeguarding legislation). Carers also valued adjustments that promoted understanding, safety, comfort and reduction in anxiety. They reported liaison nurses' influencing adjustment of outpatient appointment times and waiting areas. Primary care staff reported reasonable adjustments that ensured environments of care in hospital and preparation for admission, which allowed the individual to make the decision to attend.

General hospital staff described support they provided to make reasonable adjustments (eg securing additional nursing resource, advanced preparation for admission and using specific assessment and communication tools).

Pratt et al (2012) conducted an audit of experiences of families and hospital staff, providing them with a checklist asking about particular aspects of behaviour and communication utilised for pre-admission planning. They concluded that patient experiences were improved by awareness of the child/young person's communication needs and behaviours, good pre-planning by all staff involved, having a team member allocated to ensure that the care plan is carried through and admitting children to hospital as late as possible, discharging as early as possible; and minimising time nil by mouth.

Cermak et al (2015) carried out a pilot and feasibility study to examine the impact of a sensory adapted dental environment (SADE) for autistic children. The study concluded that adapting the sensory environment ameliorated anxiety of the children and resulted in lower pain and sensory discomfort.

Barriers to accessing healthcare for people with learning disabilities

In their report on health inequalities and people with learning disabilities, Emerson and Baines (2010) summarise the barriers to accessing healthcare services as:

- scarcity of services
- physical barriers to access
- failure to make 'reasonable adjustments' in light of literacy and communication difficulties
- variability in the availability of interpreters for people from minority ethnic communities
- 'diagnostic overshadowing' (symptoms of physical/mental illhealth wrongly being attributed as factors inherent in the person's learning disability)
- disablist attitudes in healthcare professionals (HCPs)

Tuffrey-Wijne and colleagues, in a large scale study in 2014, reported other major barriers, including

- lack of effective systems for identifying and flagging patients with intellectual disabilities
- lack of staff understanding of the reasonable adjustments needed
- lack of clearlines of responsibility and accountability for implementing reasonable adjustments
  lack of allocation of additional funding and resources

In a more recent study by Redley et al (2019) the views of medical professionals on quality of care reasonable adjustments for people with learning disabilities were obtained through semi-structured interviews. Participants attributed difficulties in providing care to communication problems and/or behaviours seen as non-conforming for a hospital ward. A minority reported that, as people with learning disabilities have multiple health conditions, these patients were seen as more complex. Half of the respondents reported minimal use of reasonable adjustments to improve care.

Barriers to accessing healthcare for autistic people

The barriers autistic adults face in accessing healthcare has been the subject of two recent systematic reviews (Mason et al, 2019; Walsh, Lyndon, O'Dowd and O'Connor, 2020). The former reviews six mixed methods studies (published in English, adult population aged 18–65, some studies also included carer and healthcare professional perspectives); the latter is a review of 31 mixed method studies (of international research with child, adult, carer and healthcare professional participants).

The 2020 review offers a taxonomy of four thematic barriers and for brevity the findings from both reviews are synthesised under these themes:

1. **Challenges associated with autism-related characteristics** (sensory sensitivities or communication and social difficulties and difficulties handling waiting rooms and lengthy waiting times, slow processing speed or executive functioning affecting processing information in appointments and self-management of care, such as medications, highly variable needs of individuals)
2. **Healthcare provider-based issues** (lack of autism training and knowledge, lack of flexibility/unwillingness to make adjustments, perceived stigma and reticence about disclosing regarding diagnosis owing to concerns about the impact on treatment)
3. **Healthcaresystemissues** (lack of supports to navigate the system, scarcity of resources to support people to navigate the system, problems with continuity of care and collaboration, location of services)
4. **Patient-related factors** (dynamic and length of the consultation altered owing to presence of caregivers, familial lack of acceptance of diagnosis, attitudes toward healthcare by autistic people and caregivers, eg caregivers may wish to explore alternative medicines and approaches, may have had negative experience resulting in lack of trust, socio-economic factors, problem not seeming serious enough/temporary and wanting to handle the problem themselves/having other priorities)

In conclusion

This short review of research into reasonable adjustments for people with learning disabilities and autistic people is by no means exhaustive; however, it does provide an overview of findings, which supports the need to implement reasonable adjustments to improve both the access to and quality of care. The studies reviewed demonstrate that the provision of reasonable adjustments is everyone's business within healthcare systems.

Reasonable adjustments require a culture shift, strategic planning and organisation, as well as awareness of responsibilities and the skills for implementation, especially for communication and ensuring capable and accessible environments. Further details of research in this review are set out in Appendix 2.

SECTION 8
Summary of what the law says about reasonable adjustments

The Equality Act 2010, Autism Act 2009 and Health and Social Care Act 2012 say that services must make 'reasonable adjustments' for people with learning disabilities and people with autism. The Equality Act 2010 also strengthens the law in important ways to help tackle discrimination and inequality. In the Health and Social Care Act 2012, section 250 is the Accessible Information Standard which says that people who have a disability or sensory loss should get information in a way they can access and understand. It also says that they should get support with communication if they need it.

The Care Act 2014 places a strong focus on wellbeing and prevention and provides a new safeguarding framework to protect from abuse and neglect. The Mental Capacity Act 2005 was designed as both a protection for people who may lack the capacity to make their own decisions and as a way to empower more people to have the right to make their own decisions. It is very clear that people need all possible support to make their own decisions, which includes making reasonable adjustments.

Equality Act 2010

The Equality Act 2010 is a legal framework to support disabled people to access employment and public services in the UK. So as not to disadvantage disabled people, public services have a duty to make reasonable adjustments under the Act. In the context of health and social care, professionals should consider in advance the type of adjustments disabled people require. Public bodies should not wait for difficulties to occur before making adjustments. Adjustments may be considered:

a. Collectively – considering adjustments that would benefit all
b. Individually – specific adjustments any one person needs

The Act outlines three requirements in relation to delivering reasonable adjustments:

1. Changing policy, practice or procedure
2. Changing a physical feature
3. Providing additional aids or services

Failure to comply with the duty outlined in the Act would be considered as discrimination against a disabled person. More information about the Equality Act 2010, and making reasonable adjustments can be accessed at: https://bit.ly/3g4NP0k and https://www.gov.uk/guidance/equality-act-2010-guidance

Easy Read: https://bit.ly/2VoOIJm

Autism Act 2009 and Think Autism – Fulfilling and Rewarding Lives, The Strategy for Adults with Autism in England: An Update (April 2014)

The Autism Act was established in in 2009 to make provision for meeting the needs of autistic adults and sets out actions for local authorities, NHS bodies and NHS Foundation Trusts that must be taken to meet the needs of autistic people. The statutory guidance for implementation of the Adult Autism Strategy outlines key areas where local authorities and NHS organisations have a duty, and this includes reasonable adjustments and equality. In his ministerial foreword, Sir Norman Lamb said:

"Autism should also not be seen as an add on to services and with over half a million people on the autism spectrum in England, mainstream services will already be seeing or in contact with many people who have autism. By encouraging more innovation in the way services are delivered and through services making more reasonable adjustments, individuals can go to their local council office, GP or hospital feeling confident that those services are aware of their autism and knowing that adjustments can be made for them. Training and awareness of autism are key here."
(Department of Health, 2015, p2)

In relation to reasonable adjustments the strategy sets out potential general adjustments:

- premises – providing quiet or lower-light areas
- processes – scheduling appointments at less busy times, on time start and end to appointments, allocating extra time, being flexible about communication methods, flexibility to swap appointments around
- face-to-face communications – accommodating preferences to communicate non-verbally, avoiding ambiguous questions, asking follow-up questions, being aware of sensitivity to touch, providing written information in advance of meetings
- written communications – ensuring essential documents and forms are available in accessible formats (Easy Read versions and formats that take account of sensory issues in their choice of colours), supportive written information to take away can enable adults with autism to process it
- planning and preparation – opportunities to visit settings in advance to familiarise themselves

The Autism Strategy, published in 2010, was reviewed and updated in June 2014. In 2018, arrangements for overseeing implementation of the Strategy were refreshed to clarify the implementation activities.

You can find out more about the Autism Act at: https://bit.ly/3i8kiVj

The Autism Strategy is available at: https://bit.ly/3dGXHMa

The following link will take you to a download of a document from the National Autism Society (NAS), *It Involves Us, Enabling Meaningful Inclusion of Adults with Autism in the Development of Local Autism Plans*: https://bit.ly/31rj5CK

Easy Read: https://bit.ly/3dBPkBn

Health and Social Care Act 2012

A focus of this Act is reducing health inequalities and the establishment of Public Health England, a

dedicated body to improve the health of the nation. The act provided an extensive reorganisation of the NHS, including:

- removing the Secretary of State for Health's 'duty to provide' a national health service throughout England, replacing it with a duty to promote a comprehensive health service
- transferring the commissioning of services to Clinical Commissioning Groups run by GPs in England, with a role of providing services to meet patients' needs

Full details are available at: http://www.legislation.gov.uk/ukpga/2012/7/contents/enactedhttps://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets

Accessible Information Standard 2016

This standard came into force by law (section 250 of the Health and Social Care Act 2012) in 2016 and aims to ensure that people who have a disability or sensory loss get information they can access and understand, and any communication support that they need. Organisations providing NHS care and adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to:

- identifying
- recording
- flagging
- sharing
- meeting the information and communication support needs

More information is available at: https://www.england.nhs.uk/ourwork/accessibleinfo/

Animated video of the standard by Sense: https://bit.ly/3g5Vo6R

Summary document for patients in a variety of formats: https://bit.ly/2CGxznJEasy read: https://bit.ly/2VnfnWM

Care Act 2014

The Care Act sets out the how local authorities should be meeting needs for care, care standards and their wider responsibilities, including:

- promoting individual wellbeing
- preventing needs for care and support
- providing information and advice
- promoting diversity and quality in provision of services

The Act outlines information that should be provided to people and importantly says that information and advice must be provided in formats that help people to understand. Full details are available at: https://bit.ly/3dGYhJQ

Care Act fact sheets: https://bit.ly/31r12g2

Easy Read: https://bit.ly/3icyr3F

Mental Capacity Act 2005

People with learning disabilities and autistic people may need help with managing issues of consent related to their care and treatment. Under the Mental Capacity Act a person with a learning disability should not be assumed not to have capacity to make decisions and people should be helped to make their own decisions whenever possible. In relation to reasonable adjustments the Act says that people should be provided with:

- the relevant information needed to make a decision
- information about alternatives
- information explained or presented in a way that's easier for the person to understand
- alternative methods of communication, including non-verbal communication
- support for communication, eg from family member, carer or advocate
- support at times of day when the person's understanding may be better
- support in locations where the person may feel more at ease
- time – the decision could be delayed until the person may be better able to make the decision

You can find out more about the MCA at: https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

Guidance and law related to the MCA can be found at:

Independent Advocacy: https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/someone-to-speak-up-for-you-advocate/

Lasting Power of Attorney: https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/giving-someone-power-of-attorney/

Advance statements: https://www.nhs.uk/conditions/end-of-life-care/advance-statement/Court of Protection: https://www.gov.uk/courts-tribunals/court-of-protection

Deprivation of Liberty Safeguards: https://www.gov.uk/government/publications/deprivation-of-liberty-safeguards-forms-and-guidance

Easy read: https://bit.ly/31opSwQ

References

Bieber, C, Nicolai, J, Hartmann, M, Blumenstiel, K, Ringel, N, Schneider, A, Härter, M, Eich, W and Loh, A (2009) Training physicians in shared decision-making: Who can be reached and what is achieved? *Patient Education and Counseling*, 77(1), 48–54. doi:10.1016/j. pec.2009.03.019

Bordini, D, Lowenthal, R, Gadelha, A, Araujo Filho, G, Mari, J and Paula, C S (2015) Impact of training in autism for primary care providers: A pilot study, *Brazilian Journal of Psychiatry,* 37, 63–66. doi:10.1590/15164446-2014-1367

Carbone, P S, Norlin, C and Young P C (2016) Improving early identification and ongoing care of children with autism spectrum disorder, *Pediatrics,* 137: e20151850

Castles, A., Bailey, C., Gates, B and Sooben, R (2013) Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: A service evaluation. *British Journal of Learning Disabilities,* 42(4), 272–281

Cermak, S A, Duker, L I S, Williams, M E, Dawson, M E, Lane, C J and Polido, J C (2015) Sensory adapted dental environments to enhance oral care for children with autism spectrum disorders: A randomized controlled pilot study, *Journal of Autism and Developmental Disorders,* 45(9), 2876–2888

Chebuhar, A, McCarthy, A M, Bosch, J and Baker, S (2013) Using picture schedules in medical settings for patients with an autism spectrum disorder, *Journal of Pediatric Nursing,* 28(2), 125-134.86

Chinn, D and Rudall, D (2019) Who is asked and who gets to answer the health-care practitioner's questions when patients with intellectual disabilities attend UK General Practice health checks with their companions?, *Health Communication,* 1-10. doi: 10.1080/10410236.2019.1700440

Department of Health (2015) Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy. London: DoH. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/ 422338/autism-guidance.pdf (accessed 28 June 2020)

Emerson, E and Baines, S (2010) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory. Department of Health

Fish, R, Hatton, C and Chauhan, U (2017) 'Tell me what they do to my body': A survey to find out what information people with learning disabilities want with their medications, *British Journal of Learning Disabilities,* 45(3), 217–225

Health Education England (2019) Core capabilities framework for supporting autistic people and/or people with a learning disability. Available at: www.skillsforhealth.org.uk/services/item/945- capabilities-frameworks (accessed 28 June 2020)

Hollins, S, Carpenter, B, Bradley, E and Egerton, J (2017) Using wordless books to support clinical consultations. *The Journal of Mental Health Training, Education and Practice,* 12(4), 260–271

Kenny, L, Hattersley, C, Molins, B, Buckley, C, Povey, C, and Pellicano, E (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. Autism, 20(4), 442–462

MacArthur, J, Brown, M, McKechanie, A, Mack, S, Hayes, M and Fletcher, J (2015) Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'getting it right' for people with learning disabilities receiving general hospitals care, *Journal of Advanced Nursing,* 71(7), 1552–1563

Major, N E, Peacock, G, Ruben, W, Thomas, J, Weitzman, C C (2013) Autism training in pediatric residency, *Journal of Autism and Developmental Disorders,* 43(5), 1171–1177. doi:10.1007/s10803- 012-1662-1

Marsden, D and Giles, R (2017) The 4C framework for making reasonable adjustments for people with learning disabilities. *Nursing Standard,* 31(21), 45–53. doi: 10.7748/ns.2017.e10152

Mason, D, Ingham, B, Urbanowicz, A, Michael, C, Birtles, H, Woodbury-Smith, M, ... and Parr, J R (2019) A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults, *Journal of Autism and Developmental Disorders,* 49(8), 3387–3400

McConkey, R, Taggart, L, DuBois, L and Shellard, A (2020) Creating inclusive health systems for people with intellectual disabilities: An international study, *Journal of Policy and Practice in Intellectual Disabilities.* doi.org/10.1111/jppi.12341

McIntosh, C E, Thomas, C M, Allen, R A, Edwards, J A (2015) Using a combination of teaching and learning strategies and standardized patient for a successful autism simulation, *Clinical Simulation in Nursing,* 11(3), 143–152. doi:10.1016/j.ecns.2014.11.008

Mencap (nd) Treat me well: Reasonable adjustments for people with a learning disability in hospital. Available at: https://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf (accessed 28 June 2020)

National Autistic Society (nd) Visiting the doctor. Available at: https://www.autism.org.uk/about/health/doctor.aspx (accessed 28 June 2020)

Nguyen, M, Lennox, N and Ware, R (2014) Hand-held health records for individuals with intellectual disability: A systematic review, *Journal of Intellectual Disability Research,* 58(12), 1172–1178

Nicolaidis, C, Raymaker, D, McDonald, K, Kapp, S, Weiner, M, Ashkenazy, E, Gerrity, M, Kripke, C, Platt, L and Baggs, A (2016) The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers, *Journal of General Internal Medicine,* 31(10), 1180–89. doi:10.1007/s11606-016-3763-6

Northway, R, Rees, S, Davies, M and Williams, S (2017) Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK, *Journal of Clinical Nursing,* 26(23-24), 5160–5168

NSFT (2020) *Waiting Room Standards.* Norfolk and Suffolk NHS Foundation Trust (internal document)

Pratt, K, Baird, G and Gringras, P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: A continuous quality improvement and change management programme, *Child: Care, Health and Development,* 38(6), 789–797

Public Health England (2016) Reasonable Adjustments: A Legal Duty. Available at: https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable- adjustments-a-legal-duty (accessed 28 June 2020)

Redley, M, Lancaster, I, Pitt, A, Holland, A, Thompson, A, Bradley, J R, ... and Holme, A (2019)

'Reasonable adjustments' under the UK's Equality Act 2010: An enquiry into the care and treatment to patients with intellectual disabilities in acute hospital settings, *Journal of Applied Research in Intellectual Disabilities,* 32(6), 1412–1420

Royal College of Speech and Language Therapists (2013, reviewed 2016) *Five Good Communication Standards.* London: RCSLT

Tuffrey-Wijne, I, Goulding, L, Giatras, N, Abraham, E, Gillard, S, White, S, and Hollins, S (2014) The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: Evidence from a mixed-methods study. *BMJ Open*, 4(4). Available at: https://bmjopen.bmj.com/content/4/4/e004606 (accessed 28 June 2020)

Walsh, C, Lydon, S, O'Dowd, E and O'Connor, P (2020) Barriers to healthcare for persons with autism: A systematic review of the literature and development of a taxonomy, *Developmental Neurorehabilitation,* 1–18. doi: 10.1080/17518423.2020.1716868

Appendix 1. Reasonable adjustments action plan template

What do we need to do?	By whom?	By when?	How will we know this is achieved?
Overall approach of health professionals			
Personalisation and partnership working			
Preparation			
Capacity to consent to treatment			

What do we need to do?	By whom?	By when?	How will we know this is achieved?
Communication			
Processes and systems			
Environment			

Appendix 2. Further details of evidence for reasonable adjustments to enable healthcare access from research

Evidence for reasonable adjustment to enable healthcare access in the area of communication

Author/study year	Methods and participants	Findings/implications for reasonable adjustments
Chebuhar et al, 2013	• Picture schedules for hospital medical procedures • Literature review • Pilot study: staff trained to use picture schedules (physicians, nurses, child-life specialists, medical assistants, and students. Six nurses, one child-life specialist, and one medical assistant from four clinical units, along with nine parents/caregivers) • Children | Autism | USA	• Literature review: pictures helpful for communicating to children with autism; good for transitions and aiding independence in school, home and community settings • Majority staff and caregivers felt the aids decreased child anxiety and behaviours of concern during procedures • Parents/carers thought that the intervention helped make the experience more tolerable for their child • Reduction of parent/carer anxiety (including anxiety about future appointments)
Nguyen, Lennox and Ware, 2014	• Handheld health records, such as hospital passports • Systematic review, 7 studies included • Learning disabilities	• Facilitate discussion about health problems • Increase health-related knowledge • Increase awareness of personal health issues • Did not lead to improved short-term healthcare activity
Hollins, Carpenter, Bradley and Egerton, 2017	• Sought to examine the theoretical and clinical basis for using wordless books • Literature review identified peer-reviewed English articles relating to the neuroscience of information and emotion processing • Case examples contributed by clinicians regularly using wordless books • Adults with learning disabilities | autistic adults	• Review of literature supported the assumptions underpinning the development and use of wordless books • Wordless books are reported to help develop staff skills and empathy, better listening to the patient • The books facilitate some legally required reasonable adjustments to increase service access • Staff training is needed for effective use of wordless books
Chinn and Rudall, 2019	• Study examined how Easy Read health information was used by clinicians and received by patients	• Easy Read health information was visible in 22% of the primary care health checks
	• Video recordings were made of 32 patients with learning disabilities attending a health check with primary care clinicians, nine attending a health appointment with a specialist learning disability nurse • Recordings were analysed using conversation analysis	• Easy Read health information was used in sequences where clinicians offered unsolicited health advice and met with degrees of resistance from patients • Potential for shared decision making also evident

Northway, Rees, Davies and Williams, 2017	• 60 hospital passports in use in the UK were reviewed against a coding frame • Qualitative content analysis	• Considerable variation was found between documents in terms of terminology, length and format • Most included information regarding communication and support needs • Some left out important information (eg allergies, risk assessment and need for reasonable adjustments). • Variation may limit effectiveness • Greater standardisation of documents is required
Fish, Hatton and Chauhan, 2017	• Co-produced questionnaire about the information people received from GPs and pharmacists about medications • Questionnaire circulated at self-advocacy conference • 58 self-advocates completed the questionnaire • Learning disability	• Information from GPs and pharmacists mainly instructional • Most respondents struggled to read the leaflets and remember information • Information wanted in Easy Read format, pictures ordiagrams • Some not told about medication side effects

Evidence for reasonable adjustment to enable healthcare access in the area of processes and systems

Author/study year	Methods and participants	Findings/implications for reasonable adjustments
McConkey, Taggart, DuBois and Shellard, 2020	Strategic actions: • Online international survey (61 respondents): rate relevance and feasibility of 30 strategic actions and indicators to promote inclusion and reduce health inequalities in health care systems • Learning disability	• Top-rated strategic actions included: o availability of policy statements and practice guidelines on making reasonable adjustments o mandatory training of health professionals (with people with learning disabilities asco-trainers)
Marsden and Giles, 2017	Developing a framework for reasonable adjustments: • Examine and synthesise the challenges in caring for people with learning disabilities to develop a framework for making reasonable adjustments • Evaluation, collaborative thematic analysis, reflection and a secondary analysis were used to develop a framework for making reasonable adjustments in the hospital setting	• The 4C framework was developed: communication, choice-making, collaboration and coordination. • Provided a basis for delivering person centred care • It has been used to: o inform training needs analyses o develop audit tools to review delivery of care o develop competencies for learning disability champions. o evaluate and resolve practice-based scenarios
Tuffrey-Wijne et al, 2014	Liaison nurses: A mixed-methods study of interviews, questionnaires and participant observation (July 2011– March 2013) • Conducted in six acute NHS hospital trusts in England • Total number of participants was 1251, including senior hospital managers, clinical staff, ward manager, 33 people with learning disability, carers	• Intellectual Disability Liaison Nurses (ILDN) have a specific remit to improve hospital care for patients with learning disabilities • Where adjustments are complex, a highly skilled IDLN service was key in ensuring that preventable harm and preventable deaths were avoided in a number of cases • Need to have easy access to the post holder, and IDLN needs authority and management support • Ward managers had a strong influence on ward culture which, in turn, impacts flexibility to provide person centred care
Castles, Bailey, Gates and Sooben, 2013	Liaison nurses: • Quantitative data were collected on all patients with learning disabilities referred to liaison nurse service over a six-month period • Patients with learning disabilities, their carers and hospital staff who had experience of the liaison service were interviewed	• Quantitative data suggest rise in referrals to the service over time, few inappropriate referrals, referrals from hospital staff and community services were similar, some patients with learning disabilities were not referred to the service • Participants interviewed understood the role of the liaison nurse • They reported improved communication and more holistic care

MacArthur et al, 2015	Liaison nurses: • Qualitative, semi-structured interviews with stakeholders about the role of the liaison nurse	Outcomes of the liaison nurse service included: • HCPs and carers described individual patient outcomes directly influenced by the liaison nurses (co-ordinated care, successful investigations and treatment, reducing and managing challenging behaviour, increasing staff confidence, fostering autonomous decision-making and ensuring compliance with capacity and other safeguarding legislation) • Carers valued adjustments that promoted understanding, safety, comfort and reduction in anxiety. They reported liaison nurses influencing adjustment of outpatient appointment times and waiting areas • Primary care staff reported reasonable adjustments that ensured environments of care in hospital and preparation for admission, which allowed the individual to make the decision to attend • General hospital staff described support they need to make reasonable adjustments (eg securing additional nursing resource, advanced preparation for admission and using specific assessment and communication tools)
Pratt et al, 2012	Appointment times: • Audit of experiences of families and hospital staff • Checklist asking about particular aspects of behaviour and communication was developed and utilised for pre-admission planning • Learning disability | autism | children	Patient experiences improved by: • Awareness of the child/young person's communication needs and behaviours • Good pre-planning by all staff involved • Team member allocated to ensure that the care plan is carried through • Admitting children to hospital as late as possible, and discharging as early as possible, even if this means at irregular time • Nil by mouth time is minimised

Evidence for reasonable adjustment to enable healthcare access in the area of environment

Author/study year	Methods and participants	Findings/implications for reasonable adjustments
Cermak et al, 2015	• Pilot and feasibility study examined the impact of a sensory adapted dental environment (SADE) • Children | autism	• Adapting the sensory environment has been shown to: o reduce anxiety o lower pain and sensory discomfort in the SADE environment
Nicolaidis et al, 2016	• The Autism Healthcare Accommodations Tool (AHAT), part of the AASPIRE Healthcare Toolkit, offers a list of potential adjustments/ accommodations to choose from • Choices and thus an individualised plan can be sent to the HCP in advance • Cognitive interviewing and test–retest reliability studies to develop the toolkit • Mixed-methods evaluation • Autistic adults | USA	• More than 94% of patient participants thought the AHAT toolkit was easy to use, important, and useful • Comparisons pre and post intervention showed: o number of barriers decreased o healthcare self-efficacy increased o satisfaction with PCP communication improved • Patients reported that the toolkit: o helped clarify their needs o enabled them to self-advocate o prepare for visits more effectively o positively influenced provider behaviour

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Written by Tom Evans and Lisa Richardson, with thanks to Kate Brackley and SpeakEasy Now