

A Guide to Reasonable Adjustments for Autistic Adults

Developed in partnership with Kat Stapleton, Rosi Sexton and Ben Begg (Experts by Experience)(2024)

Reasonable adjustments mean changing services, so they are easier to use, accessible and effective for everyone. We hope this guide will help you to identify and implement reasonable adjustments that will help the autistic people you work with.

'In a society that works for autistic people and their families, adjustments would be built in from the start. There would be a proactive and flexible approach to individual needs, without the pressure being on autistic people or their support networks to have to ask'
(NAS 2023)

Not only is it good practice to make accommodations that will support positive outcomes for autistic people, but it is also a legal requirement under the Equality Act 2010. All support services have a duty to make reasonable adjustments, including adjustments to the environment. To ensure equitable access, 'adjustments for autism specific needs are as necessary as ramps for wheelchair users' (Hayden, C et al 2021).

Many autistic people are not aware that adjustments and adaptations can be made for them. Therefore, they don't know how to ask for the adjustments that best suit them. By keeping the conversation active, equal and ongoing, together you can agree what works best.

Watch this video on why they are needed: <https://www.youtube.com/watch?v=o1zsGZK3wzA&t=51s>

Identifying
what
adjustments are
needed

What is 'usual' service delivery?

Could reasonable adjustments help?

What adjustments are available or have been used previously?

What is the intended outcome of the adjustments?



People at
our heart

Things to bear in mind...

Although each autistic person possesses a range of different strengths and challenges, there are some common features of autism that are important to bear in mind when supporting individuals who are accessing your services:

Communication

Autistic adults are likely to have experienced many instances of being misunderstood by non-autistic others; something that can create a significant barrier to them accessing relevant healthcare and support.

Alexithymia often co-occurs with autism. Alexithymia is a difficulty with identifying, distinguishing between, and describing emotions. An autistic adult with alexithymia will likely struggle to self-report their emotional states to healthcare professionals. (NHS England 2023)

Masking refers to an autistic person's management of their social presentation to try and minimise or mask autistic traits from others. It is worth noting that masking may interfere with an autistic adult's ability to communicate their distress or symptoms during an appointment with a healthcare professional. (NHS England 2023)

It is therefore important to take the time to listen to autistic individuals, build rapport and avoid masking assumptions.

It is helpful to think about communication as a two way process. Many autistic individuals have spent their lives adjusting their interaction style in line with non-autistic expectations; something that can be highly effortful and detrimental to their overall wellbeing. Healthcare professionals therefore have a responsibility to adapt their own communication style to meet the needs of the person they are working with.

Sensory Differences

Many autistic adults have differences in the way they process sensory information. These differences impact on how they interpret, filter and respond to sensory information from their body (proprioception, vestibular and interoception) and the world around them (sound, touch, sight, taste, and smell). They may feel sensory input more or less powerfully than others or may have difficulty making sense of the sensory information that they are experiencing.

Self-stimulatory behaviour, also known as Stimming, is used (often subconsciously) as a way to cope with over or under sensory stimulation. Stimming can take a variety of forms including (but not limited to): humming, whistling, repeating the same word, tapping, fidgeting, spinning or rocking back and forth. Accept stimming as a sensory regulation tool, as long as it is not causing harm to self or others.

Sensory processing differences can greatly impact the quality of life of individuals and can be a common cause for heightened distress. These differences can vary for each individual across senses and to different levels. Experiences can also vary depending on the situation and the context.

Predictability

Uncertainty can be very anxiety provoking for autistic individuals: situations which can cause unnecessary distress or unease may include:

- Ambiguous explanations, descriptions and questions
- A lack of structure within conversations/ activities
- Being expected to engage with unfamiliar people
- Being expected to attend an unfamiliar setting
- Unexpected changes/ last minute cancellations and delays

This may result in an autistic person implementing strict routines and/or rituals which appear repetitive in nature. Such activities are often self-soothing and offer the individual significant reassurance.

Please Note...

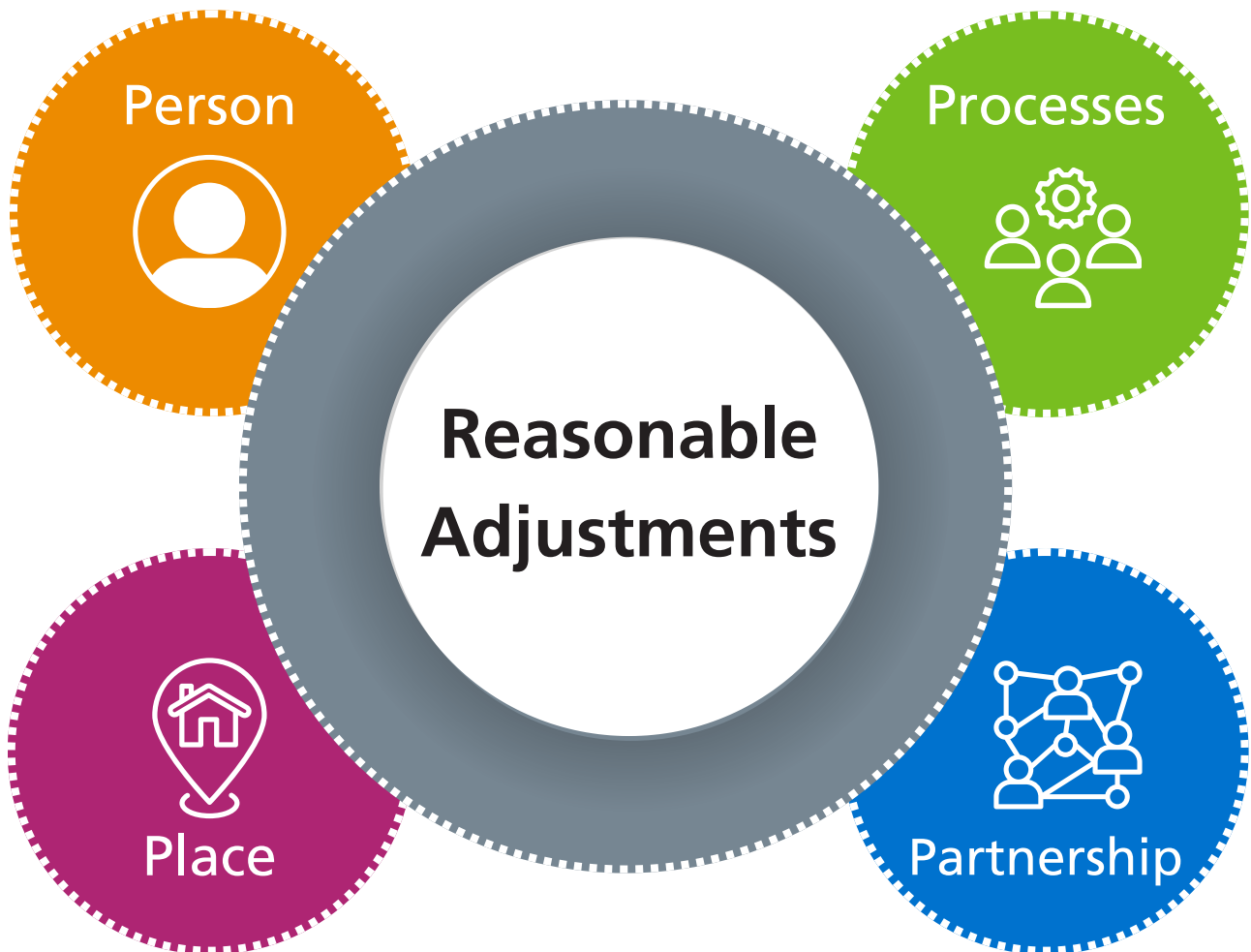
Professionals should be aware of bi-directional links between physical and mental health. Diagnostic Overshadowing of physical health conditions can occur when symptoms are misattributed to autism or a mental health condition, or when symptoms of a mental health condition are misattributed to autism or a physical health condition. If someone is autistic and has additional difficulties, it is important to:

- have an understanding of a person's experience of autism
- ensure consideration is given to making services more accessible for autistic people
- ensure that processes are adapted for autistic people
- have the skills, knowledge and confidence to adapt your approach

Introducing the 4 P's

It is important that the challenges, preferences, and needs of autistic people accessing your service are considered when thinking about the type of reasonable adjustments that might help.

To understand what adjustments are required, the 4 P's model will provide a helpful starting point.





"It is important to remember that all autistic people are individuals and a person-centred care approach should always take precedent"
(Williams et al 2022)

Avoid making assumptions about what autistic people need...the best way to find out is to ASK!



- Speak to the person (or the person's carer/ advocate if more appropriate)
- Ask about their previous experiences of accessing support.
- Ask what challenges they have faced and what has worked well.
- Ask about the strengths and challenges of being autistic- what does this mean for them, what support do they need?

Spend some time trying to get to know the person.



- Asking a client their preferred name and pronouns is a good place to start.
- Find out about any specific terms / language they use to refer to themselves e.g.
- Do they prefer identity first or person first language?
- Ask about the person's interests and routines.
- Find out about the person's communication and sensory needs.
- Find out what may cause anxiety and / or distress.

Asking a few questions about what someone prefers from the very beginning, can help prevent misunderstandings later.

What is the person's usual presentation when their mental health is stable?



- What does their typical day to day routine look like? E.g. sleep schedule, self-care routine, diet, household chores etc.
- How do they experience and communicate pain and distress?
- Is there anyone they like to spend time with?
- Do they usually need any support to communicate their needs and decisions?
- What do they usually do to maintain their wellbeing? Think about engagement in interests, work, family, social interactions.

Ways to gather additional information:









- Not all autistic individuals will be able to explain their needs and experiences verbally. Be prepared to use alternative methods of communication. You may need to spend time discussing and observing to build up your understanding of the person.
- Ask if they have a Communication or Health Passport, Autism Profile or Education and Health Care Plan (EHCP)





"For many autistic people, the biggest hurdle to accessing public spaces and services is anxiety. Environments can feel unpredictable, out of their control and unstructured. Not knowing which door to use, where to go, where the toilets are or how to get out of the building when required, very much adds to this stress."
(Kat Stapleton, Expert by Experience)

Things to Consider:

It is important to understand how autistic people are disabled or enabled by the environment. Considering how environments can be more predictable and more sensory aware can ensure they are more inclusive and accessible.

-  **Location:** Consider the possible impact of having to plan, navigate and travel. Is the location convenient? Is it easy to park? Is it accessible by public transport? Are there alternative venues that could be offered if needed? Is it possible to complete a home visit, if preferred?
-  **Display clear information:** Is the building clearly signposted? Is it clear where to go on arrival? Is there an internal plan of the building? How easy is it to navigate your way around? Are there clear signs for the toilets, exits, waiting room, stairs, lift etc?
-  **Reducing sensory overwhelm:** Are you mindful of the sensory environment? E.g. consider loud or repetitive noises, lighting, strong odours, visual displays.
-  **Waiting:** Is there space to wait outside or in a quieter area if needed- can they request this in advance? Is there a way to contact them when it is time for their appointment?
-  **Space:** Are rooms and waiting areas free from clutter and obstacles? Is furniture positioned for ease of access and comfort? Can they move around and use sensory tools when needed?
-  **Comfort:** Consider ventilation / heating systems- are there ways to display room temperature and alter this if needed? Is there easy access to drinking water?

Although autistic people may be more comfortable within their own environment, bear in mind that accessing virtual appointments may still be problematic. Consider the following:

-  **Environment:** Is your environment free from clutter and background noise? Is the room bright enough to see your face clearly on screen? Have you made attempts to reduce any glare/reflections?
-  **Predictability:** Have you sent clear information on how to use the specific platform you are using? Have you provided a clear plan of what the appointment will include? Have you made them aware they can use the chat function and turn their camera off if needed?



"A flexible patient centred approach will be more beneficial than a one-size fits all approach"

Legal Requirements



Be aware of your legal requirements in relation to your setting.

For example:

The Equality Act (2010)

Autism Act (2009)

NHS England Accessible Information Standard (2017)

Things to consider:

Clear, structured, and consistent processes may help autistic people engage. Allowing for individual differences is also important, however. Processes should be adaptable to accommodate individual needs where required.

Be aware that making and receiving phone calls can often be a barrier for autistic people in being able to access services and support.

Are there a variety of contact methods people can use to access the service? E.g. email, online booking platforms etc.

Are you able to provide appointment reminders?

Are you able to offer flexibility with regards to the timing of appointments?

Can you amend non-attendance processes?

Can you provide detailed information about the service and what to expect? E.g. ward welcome booklets, service aims etc

Have you explained any 'unwritten rules' of the service?

From the first point of contact you should establish:

How they prefer to be contacted and the best way to send information.

Their preferred method of communicating with the service.

Start conversations about adaptations and adjustments. Provide examples of what these could be.

Reiterate that they can request any adjustments throughout the process.

Helping people prepare:

Do you provide detailed information on what to expect from appointments, in advance?

Face to face:

Photos / a map of the venue, with directions.

Information about parking / public transport.

Where to go on arrival and what to do.

The name and a photo of the clinician / the receptionist(s) / other staff.

For virtual appointments:

The video calling platform, including visual step by step instructions.
What to do / who to contact if they cannot connect to the call on the day.
What to do if the call gets disconnected.
The different communication options available to them e.g. text chat, microphone, options to have camera on / off.



Additional considerations for Assessment and Intervention:

Have you offered: time for additional breaks, movement breaks, processing time etc?

Have you clearly explained the purpose and intended outcome of the assessment and/or intervention?

Have you considered how accessible your 'usual' way of working is?

Are there adaptations required to assessment tools routinely used or more appropriate ones available?

Have you thought about how to increase your knowledge and use of visual tools?

Can you add increased structure to sessions and/or set an agenda for how the time will be used?

Consider how you can incorporate interests into sessions meaningfully.

Have you considered whether your communication style is meeting the person's needs?

Have you considered how risk may present differently in autistic individuals?



What happens next?

Do you routinely provide a written summary of what was discussed and answers to any important questions?

Have you made actions clear? What will happen next? Who will do what and when? How will this be arranged? Are there any actions for them?

Be honest and transparent if you are unable to complete actions as planned.

Do they know how to contact the service, if needed?

Can you give realistic timeframes in how long it will take for any queries /communications to be answered?





Partnership

Working in partnership requires professionals to make adaptations rather than the responsibility being solely on the autistic person.

"All too frequently what I express is perceived through a neurotypical lens. I see red, most people see blue and no matter how much effort I put in I need reciprocity to get to purple."

(Stephen 2003)

Compassion, Acceptance and Respect:

Acceptance leads to appropriate accommodations, including understanding that so called challenging behaviour is usually a response to autistic needs not being adequately met.

(McDonnell et al, 2015)



Don't make assumptions because the person doesn't fit the social norm. Many autistic people have felt judged throughout their whole life.

Avoid making assumptions about a person's intellect.

Be accepting of unconventional gestures, differences with volume, tone and pace of speech, quick escalation of emotions, neutral / exaggerated facial expressions, differences with eye contact and stimming.

Look for cues that a client might be anxious or overwhelmed. Agree together how they can request a break.

Openness, Honesty and Trust:

"By the time people get to us, it can be really difficult for them to trust/ think we can make a difference because of their previous experiences. Taking a lot of time to build up that therapeutic relationship and understanding, really makes a difference."

(NAS 2021)



Many autistic people will take you at your word. They may struggle or become agitated if things do not go as expected, which can lead to a breakdown in trust.

Do not make promises you can't keep!

Make decisions in partnership.

Be open about changes- seeing a different staff member, delays, challenges.

Accept and acknowledge own mistakes.

Education – engage in CPD:



Increase your knowledge of autism and know what the requirements are for your role <https://www.skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/>

Watch Ted-talks, You-tube videos and read books/ blogs by autistic adults.

Preparation and planning:




To avoid repetition of story- read what is already available.
Consider in advance any possible adjustments that can be made and what might be more difficult to implement.
Plan your appointment but be willing to be flexible. Have a back-up plan.

Communication:

“Any unavoidable or unexpected changes will be more easily accepted if explained clearly and openly”

(Doherty, 2023)



Be prepared to adapt your communication style.
Reiterate that they are free to communicate, in their own way, what makes them feel distressed or uncomfortable.
Listen with genuine interest to what they are communicating.
Use concise and concrete language. Speak in a calm and unhurried manner.
Repeat key information and check that it makes sense. Ask ‘Am I making myself clear?’ rather than ‘do you understand?’
Are you supporting their individual communication style? Do they like social chit-chat? Do they relish talking in length about an interest?
Offer visual cues alongside spoken language.
Break down complex information into smaller chunks.
Use specific and closed questions. Ask each part of a question in turn.
Be conscious of ‘masking’ and the impact this may have.

Time:



Be aware of the need for additional processing time. Be comfortable with silence.
You may need longer appointments or you may need to reduce them due to the possibility of ‘burn out’.
Allow time when expecting important decisions to be made.
Try to make sure appointments start on time; delays can increase anxiety.

Be aware of, validate and support sensory needs:




I can't THINK if you are tapping on your keyboard, talking too loudly, I can smell your perfume, or you're wearing dangly earrings...

Be aware of your own contribution to potential sensory overwhelm. When an autistic person is anxious or overwhelmed, they may become more distressed by sensory stimuli than they ordinarily would.

Each autistic person's sensory profile will be different and what is problematic for one person may bring sensory joy to another.

Things to consider:



Be mindful of the volume of your own voice, and any other auditory distractions, like clicking your pen, or typing when they are trying to think.
Are you wearing strong smelling perfume/ aftershave. Have you smoked a cigarette or eaten strong smelling food?
Think about your use of touch, your proximity / positioning- the person might not want you to be too close to them / directly opposite them.
Avoid wearing clothing or jewellery that might cause a visual distraction.
Provide access to sensory tools.

Implementation:

Ask Listen Do

Making conversations count

in health, social care and education

The *Ask, Listen, Do* framework also provides a helpful way of considering how to approach implementing reasonable adjustments by responding to feedback, concerns or complaints. [NHS England » Information for organisations and practitioners](#)

Ask people about their experiences and make it easy for people to share these.

Listen to feedback about adjustments that would be helpful.

Do consider changes that need to be made and timescales needed and then inform the person what is being done and by who, or why these changes cannot be made.

Record:



Have you identified reasonable adjustments that have helped?

Have you recorded relevant identifying information and communication needs?

Have you gained consent to record reasonable adjustments within records?

Have you captured these within care plans?

Have you considered how and when these will be reviewed?

Have you ensured that you have recorded identified preferences and needs in a way that is accessible to all who are working with them?

Can you support the person to create or review an autism passport or one page profile?

Feedback and Audit:

Have you completed audits and sought feedback from those who use your service to see what is working and what needs to change?

Consider completing the green light toolkit for your service

<https://surveys.ndti.org.uk/site/assets/files/1290/08-autism-only.pdf>

<https://www.ndti.org.uk/resources/green-light-toolkit>

Remember



'Having to tell my story and explaining what adjustments make a difference over and over again is frustrating and distressing'

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Our Values



Compassion

We are compassionate, kind and caring to everyone, including people who use our services and people we work with.

Respect



We are civil and respectful. We celebrate diversity and always appreciate the views of other people.

Excellence



We always do our best and seek to achieve excellence in all we do. We innovate and try out new things, and when things don't go to plan we embrace this as an opportunity to learn and improve.

Collaboration

We take pride in involving people and working together as an inclusive team, both within our organisation, and in co-production with service users, carers, partners, local community groups and others.



Integrity



We do the right thing and people can trust us. We are open, honest and transparent, even when things go wrong.



People at
our heart

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