

# Autistica Action Briefing: Reasonable Adjustments

# AUTISTICA

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about reasonable adjustments for autistic people seeking healthcare. It was developed in collaboration with leading researchers and autistic people with lived experience of the topic to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, GPs, commissioners, Trusts, services and research funders to act on this information. There has been much discussion on the need to make reasonable adjustments to support autistic people to access high quality care; services must now be supported to act on this effectively.

[www.autistica.org.uk/AutismStrategy](http://www.autistica.org.uk/AutismStrategy)

“As a cancer patient, some hospital staff were dismissive about how individual pain perception can be. I was told off for ‘having a ridiculously low pain threshold’. It felt very judgemental and humiliating at a time when my defences were low.”<sup>1</sup>

## What we know

“The amount of appointments wasted because by the time I have navigated getting there, dealt with the sensory challenges, repeated my history, I am in meltdown, unable to communicate my needs.”

- **Autistic people face substantial health inequalities**, are more likely to have poorer general health than non-autistic people<sup>2</sup> and are at increased risk of virtually every cause of death that has so far been studied.<sup>3,4</sup>
- **Autistic people are less likely to be satisfied with the healthcare they receive**, and to understand and be understood by health professionals.<sup>6,7,8,9</sup> Differences in experience, expression and interpretation can mean that issues like pain are dismissed.<sup>1,6,7,10,11,12,13</sup> International evidence suggests that autistic people are more likely to end up in hospital care or using emergency services.<sup>14,15,16</sup>
- **All healthcare services should be accessible**. Autistic people's health is not the preserve of specialist units. Autistic people are more likely to develop various health conditions including cardiovascular problems, gastro-intestinal disorders and strokes,<sup>17</sup> and are therefore likely to need support from a wide range of healthcare services at some point in their lives.<sup>14,15,16</sup>
- **Adjustments should be tailored to each person**. No single set of adjustments works for all autistic people. Autistic people's communication and sensory needs vary greatly, requiring very different adaptations.<sup>16,18,19</sup> For planned appointments, services should try to identify a person's needs before the visit; various tools for communicating these needs are already being researched and developed.<sup>19,20</sup> If prior identification of adjustments isn't possible, services should try to be flexible.<sup>12</sup> Some basic steps like allowing double appointments, giving people extra time to process questions, providing clear explanations and avoiding metaphorical language can help.<sup>11,12,21</sup>
- **Where possible, services should provide information in advance** about what will happen during or before a medical appointment. Uncertainty is a known cause for anxiety amongst autistic people and can exacerbate sensory difficulties.<sup>22,23</sup> Providing information and pictures in advance can help autistic people prepare themselves for challenging physical environments and social interactions.<sup>11,12</sup> It can also help autistic people and NHS staff to identify potential adjustments.
- **There should be more than one way to access NHS services**. Giving patients a choice about how they make an appointment (e.g. online instead of over the phone) and when that appointment could be (e.g. at a quieter time of day or during a specific time in a routine) enables them to pick options that work for them.<sup>7,11</sup>

“I want to be able to tell you but you will not let me write and I do not have the verbal words I need.”<sup>1</sup>

## What we need to find out

“I have a very bad chest but I struggle to explain so they dismiss it.”<sup>1</sup>

Although there is growing appreciation of the need to make adjustments for autistic people, it is too often assumed that the same adjustments will help the entire autistic population. In reality, autistic people have varied and sometimes conflicting needs. **Science can help services to adapt to the diversity of autistic people’s needs** and provide more tailored, individualised support. Research specifically needs to address:

- What does an autism-friendly health service look like, considering the varying needs of different autistic people?<sup>24,25</sup>
- Are existing measures of pain and function valid in autistic people?<sup>24,25</sup>
- What strategies for self-advocacy and self-management of healthcare are effective in helping groups of autistic people stay well and access services when they need them?<sup>24,25</sup>
- Does a UK-adapted version of the AASPIRE Healthcare Toolkit improve the health and wellbeing of autistic adults?<sup>18,19,24,25</sup> How effective are other existing initiatives for communicating needs to health professionals, such as hospital passports?<sup>26</sup>
- What is the impact of implementing adjustments for autistic people on the clinical outcomes (e.g. missed appointments, late presentation, emergency admission, misdiagnosis) and cost-effectiveness of healthcare services?
- How do gender identity, sexual orientation, race, class, trauma, or other social factors affect the provision of healthcare services for individual autistic people?

## What we should do now

- The current Autism Strategy, Think Autism,<sup>27</sup> highlights the need for services to make reasonable adjustments as a “*priority challenge for action*”.<sup>28</sup>

**The next Autism Strategy<sup>29</sup> should focus on ensuring that public services are able to identify an autistic person’s individual needs and tailor adjustments appropriately.**<sup>1,12</sup>

- Health professionals cannot identify autistic people and the adjustments they need from sight. Few adjustments can be made universally; instead, we need to ensure health professionals have appropriate access to information about people’s needs. 95% of autistic respondents to the Westminster Commission on Autism said they wanted health professionals to have a note on their screen to tell them their patient is autistic.<sup>6</sup>

**The NHS Long Term Plan commits to rolling out “reasonable adjustment flags” for autistic people by 2023/24.**<sup>30,31</sup> NHS England, NHS Digital and NHSX should ensure digital initiatives provide health professionals with the targeted, timely and appropriate information they need to make adjustments for autistic people.

- The Long Term Plan also commits to offering all patients the option of digital GP appointments.<sup>31</sup> Further choice around how to reach healthcare services, such as alternative ways of booking appointments and double-time appointment slots, could make it easier for many autistic people to access the care they need.

**The NHS should consider implementing additional options for booking appointments across its services.**

- GPs and other healthcare professionals often lack confidence in their understanding of autistic people’s needs,<sup>8,9</sup> and autistic people often have to explain their own needs to professionals repeatedly.<sup>1</sup> Currently there are no dedicated specialisms to encourage and nurture expertise in autistic people’s health across the NHS.

**The Royal Colleges and Health Education England should recognise the expertise of health professionals who develop specialist knowledge of neurodivergent people’s health, for example by creating a GP with Extended Role (GPwER) accreditation and a corresponding specialist nurse role.**

- Autistica and the Alan Turing Institute are working in partnership to create a citizen science initiative exploring how autistic people navigate environments, such as healthcare services, which they may find difficult.<sup>32</sup>

**Primary Care Networks, Sustainability and Transformation Partnerships and Integrated Care Systems can help the project develop by providing funding and inviting local autistic people to take part. When data becomes available, PCNs, STPs and ICSs can apply to ask their own research questions and gain insight into improving accessibility for autistic people in their area.**

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