

ADULT AUTISM IN DAILY LIFE · 9.7

Autistic Adults and Healthcare: Why It Goes Wrong and How to Push Back

Healthcare goes wrong for autistic adults at a rate that is now well-documented in the UK research. The reasons are structural. Most encounters are workable with the right preparation, and the system can be pushed.

FOR

Autistic adults using UK healthcare

AUDIENCE AGE

18+

REVIEWED

17 May 2026

PART OF

The NeuroFX resource library

IN SUMMARY

Autistic Adults and Healthcare: Why It Goes Wrong and How to Push Back

What the evidence shows

- **Barriers and adverse outcomes are well-documented.** The 2022 Doherty et al. BMJ Open study of over 1,000 autistic adults in the UK and Ireland found substantial barriers to making and attending appointments, difficulty communicating with clinicians, sensory environments as a recurring problem, and a significant minority avoiding healthcare entirely after previous bad experiences.
- **The consequences are serious.** The 2016 Hirvikoski et al. British Journal of Psychiatry paper found substantially elevated all-cause mortality in autistic adults compared with the general population, driven in part by avoidable conditions caught later than they should be. The healthcare experience has measurable effects on health outcomes.
- **It is not the autistic adult's fault.** It is a structural mismatch between how clinical services run and how autistic adults engage with them. The better parts of the NHS are starting to take it seriously; progress is slower than it should be.

Why it goes wrong

- **The appointment system itself is a barrier.** Phone-based booking, time-limited slots, narrow appointment windows. The administrative load before the appointment is itself a reason many autistic adults avoid healthcare.
- **The sensory environment depletes the budget.** Fluorescent lighting, unpredictable noise, busy corridors. By the time the appointment starts, the patient is already running on a depleted regulatory budget.
- **The communication assumption fails.** Ten-minute consultations assume the patient can describe symptoms in plain language, follow questions in real time, and process clinical information immediately. None of this is guaranteed for an autistic patient.
- **Masking, interoception and diagnostic overshadowing.** Masking in clinical settings makes the difficulty look smaller than it is. Interoception gaps mean symptoms are described in ways that do not match the clinical script. Once 'autism' is on the record, unrelated physical symptoms can be wrongly attributed to it.
- **The dignity problem.** Some autistic adults report being treated as less credible or less serious once disclosure has happened. It is real, well-documented, and not the patient's responsibility to fix.

What helps and how to push back

- **Use the GP's accessibility options.** Online booking, email contact, the NHS App. Where the phone is a barrier, the surgery is required under the Equality Act 2010 to make reasonable adjustments. Ask whether the NHS England Reasonable Adjustment Digital Flag is in use.
- **Bring a written summary and ask for a longer appointment.** A one-page summary handed to the clinician at the start consistently improves the encounter. A double appointment is one of the cheapest reasonable adjustments available. Ask for it; mention complexity if you do not want to disclose.
- **Use a hospital passport for any admission.** A short document describing how you communicate, your sensory needs, what helps and does not. National Autistic Society template available. One of the better single interventions for any hospital admission.
- **Push back when it is wrong.** Practice manager first, then PALS in hospitals, then NHS complaints, then the Health Service Ombudsman. Dismissive treatment, inappropriate diagnostic overshadowing, refused reasonable adjustments are all legitimate grounds. The system needs the push.

WHEN TO SPEAK TO A PROFESSIONAL

Speak to your GP for routine concerns; bring a written summary. Private adult autism assessment with a CQC-registered provider is a legitimate parallel route where the NHS wait or quality is the gap. For complaints about healthcare specifically, the practice manager, PALS, NHS complaints and the Health Service Ombudsman are the formal routes. Seek urgent help via 111, 999 or A&E for any acute mental health crisis; the Samaritans helpline is 116 123 (free, 24 hours).

SOURCES

Doherty et al. 2022 (BMJ Open); Mason et al. 2019 (J Autism Dev Disord); Hirvikoski et al. 2016 (BJP); NHS England Reasonable Adjustment Flag; Equality Act 2010; National Autistic Society

NEXT STEPS

Speak to NeuroFX

Private ADHD and autism assessment for adults and children aged 6 and upwards.
CQC-registered. Bedford Consulting Rooms, 4 Goldington Road, Bedford MK40 3NF.

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