

# How can I help?

# Running Autism-Friendly Surgeries: A Guide for MPs and Staffers

**There are over 700,000 autistic people in the UK**. Together with their families, they comprise a significant portion of the constituents you represent. This guide will help you to understand autism, the issues autistic people are facing, and how to run an autism-friendly surgery in your constituency.

# What is autism?

Autism is a developmental disability which affects the way a person understands the world around them. Autism is...

- Lifelong,
- A spectrum condition,
- Different for everyone.

Communication differences, restricted and repetitive behaviours and interests, and sensory differences are common in autistic people. When overwhelmed, autistic people can experience distressed behaviours (commonly known as meltdowns), shutdowns, and burnout.

### **Communication Differences**

Autistic people can communicate differently from neurotypical people in various ways. This can include:

- Preferring not to make eye-contact.
- Struggling to interpret non-verbal cues like body language or facial expressions.
- Literal thinking about idioms.
- Preferring written communication.

Autistic people may try to "behave neurotypically". This is called masking, which can feel exhausting and lead to burnout.

#### When running a surgery, you can...

- Communicate directly, avoiding superfluous details and potentially confusing turns of phrase.
- Provide written copies of information.
- Allow for extra-processing time when speaking with autistic people.
- Be understanding about differences in eye contact, intonation, gesticulation, etc.
- Be open to autistic people's preferred ways of communicating.



## **Rigidity and Routine**

Restrictive and repetitive behaviours and interests (RRBIs) are a core characteristic of autism. They include...

- Repetitive movements (known as stimming), like hand-flapping or hair twirling. This can be a form of self-regulation.
- Rigid routines like eating the same meals or taking the same route to work or school.
- Resistance to change this can range from big changes like moving house to smaller changes like a new recipe for a favourite food.
- Intense interests often an easy topic of conversation!

#### When running a surgery, you can...

- Give plenty of notice when plans change (e.g., surgery dates getting rescheduled or cancelled, venue changes).
- Maintain a familiar environment in your office.
- Make sure not to negatively comment on repetitive movements (e.g., accusing someone of being distracted because they are "fidgeting").



### **Sensory Differences**

Autistic people may experiencer hyper- or hypo-sensitivity to sensory input. This occurs across the five main senses (sight, sound, touch, smell, and taste) and the other senses: vestibular (balance and movement), proprioception (body awareness in space), and interoception (awareness of internal states, e.g., hunger). This isn't uniform across the senses – some autistic people may be hypersensitive to sound but hyposensitive to interoception. Sensory differences include:

- Being overstimulated by overlapping noises (e.g., in a shopping centre or an office).
- Avoiding the feeling of some fabrics while enjoying the feelings of others.
- Lack of awareness of hunger or stress.

Autistic people may be more sensitive to overstimulation due to stress and anxiety, exhaustion, hunger, or prolonged periods of masking.



#### When running a surgery, you can...

- Have a quiet space available at your constituency office for autistic people to use when overstimulated.
- Create a low-input environment. This can include:
  - using softer lights or natural light rather than fluorescent light;
  - turning off radios/music;
  - using an advance booking system rather than drop-in sessions to avoid busy queues.
- Be understanding of constituents using aids like noisecancelling headphones or stim toys.

# Meltdowns, Shutdowns, and Burnout

When autistic people are experiencing acute stress from overstimulation, exhaustion from masking, and/or disruption to their RRBIs, they can go into meltdown, shutdown, or burnout.

- A meltdown is the temporary loss of control of behaviours and can include crying, shouting, and kicking.
- A shutdown is the temporary withdrawal from any interaction of activity. This can include an inability to communicate or move.
- Burnout is characterised by exhaustion, loss of function, and reduced tolerance to stimulus. The frequency of and duration of burnout can vary.

It's important to remember that these are **not** bad behaviours or "tantrums". They are involuntary responses to being completely overwhelmed.

#### When running a surgery, you can...

- Make sure not to judge or be rude to an autistic person (or their parent/carer) when they have a meltdown in public.
- Have a quiet space or a sensory room available.
- Calmly and non-judgementally offer help. If the answer is no, give them space!





# Prejudice

Due to misconceptions and stigma surrounding autism, autistic people often face prejudice. This can come in many forms, like:

- Barriers to employment.
- Hurtful comments.
- Refusal to make changes and adaptations.

Autism awareness is important because it increases understanding, highlights prejudicial behaviour, and empowers bystanders and allies to intervene.

#### When running a surgery, you can...

- Challenge misconceptions about autism when you encounter them.
- Support and advocate for autistic people facing prejudice.
- Offer accommodations to autistic staff, or to constituents wishing to contact you.
- Be an active bystander and intervene when you witness the mistreatment of autistic people.



As we enter a new parliamentary term led by a new government, we ask that autistic people are not left behind. At present, thousands of autistic people are being let down by a lack of appropriate support and services from education and employment to mental health, social care, and access to diagnosis. We're calling on all parliamentarians to work toward the following goals:

- Reform the education system so all autistic children have a suitable school place.
- End the autism diagnosis crisis.
- End the scandal of autistic people being stuck in mental health hospitals.
- Halve the autism employment gap by getting 55% of autistic adults into work by 2030.
- Introduce mandatory autism training for all public services staff by 2030.

To read more about what truly autism-friendly society would look like, read our <u>Moonshot Vision</u>.

#### We look forward to working with you to create a society that works for all autistic people.

