

# Background to this work

Autism is a lifelong neurodevelopmental difference that affects how people experience the world.

Autistic people see, hear and feel the world differently to non-autistic people. According to the National Autistic Society, at least [1% of the UK population is autistic](#). In England, that equates to over half a million people. Considering the problems around getting a diagnosis and the general level of understanding about autism, many studies estimate this figure could be anywhere from 2 to 5 times higher. Autistic people therefore make up a significant section of society. Yet knowledge about autism and the needs of autistic people is relatively low. This is even among healthcare professionals.

Autism is not a mental health condition. People may have mental health conditions as well as being autistic. So, it is important to be aware of:

- the potential diagnostic 'overshadowing' this could cause
- assumptions that people might make about an autistic person or their behaviour.

The government's [National Strategy for Autistic Children, Young People and Adults: 2021 to 2026](#) acknowledges that the average life expectancy for autistic people is 16 years lower than that of the general population. The reasons for this are complex, but it is widely accepted that poor understanding of the needs of autistic people is a factor.

Primary care is one area of health care that all autistic people will access at some point in their lives. The journey to diagnosis and the first step to further treatment for any health-related issue usually begins with the GP practice. Similarly, most people will visit a dentist for preventative check-ups or restorative treatment. It is therefore crucial that primary care services get care right for autistic people, as this can have a substantial impact on their health and treatment.

The aim of this particular piece of work is to raise awareness and add to the wider conversation about the care provided to autistic people. It adds to other work we have carried out in respect of care for autistic people, and our reports:

- [‘Who I am Matters’](#), which focused on the experiences of people in acute hospital care.
- [‘Out of sight: who cares?’](#), which (link) looked at the use of restraint, seclusion and segregation in care services.

We wanted to understand more about what it can be like for autistic people when they visit their GP or dentist. As a starting point, we reviewed a sample of published, peer-reviewed articles. We then spoke with colleagues in CQC who are autistic themselves to hear about their personal experiences when using these services. To corroborate what we had heard, we shared the findings and experiences from this work with:

- the National Autistic Society
- a group of our [Experts by Experience](#).

This work has enabled us to understand specific areas that present a challenge for autistic people.

Throughout the piece, we include examples of real experiences from colleagues in CQC who are autistic. This is to try to explain what people actually feel when using GP and dental services. In doing this, our ambition is to support providers of services to:

- see things from a new perspective
- think about what they could do to make changes in their own services.

Across all our work in CQC we use 'identity first' language to refer to autistic people as this is generally preferred. For example, we use 'an autistic person' rather than 'a person with autism'.

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