What we did

Reviewing published literature

We reviewed some published academic research on autism and health care. We made sure to only look at those studies that included the lived experiences of autistic people themselves and their views. We focused solely on autistic people and not specifically on people who also had a learning disability. This was because around 4 in 10 autistic people have a learning disability, so the majority do not.

Speaking with autistic colleagues and carers of an autistic person

We invited a small group of our colleagues in CQC to participate in 2 focus groups. This was to:

- give some context to our work
- enable us to develop a better understanding of the issues that autistic people face when using primary care services.

These people have lived experience of autism. They are either autistic people themselves or care for an autistic member of their family. They participate in our Carers Network or the Neurodiversity subgroup of our staff Disability Equality Network.

All the examples we quote are what they told us about their own personal experiences when using GP and dental services.

When we started this work, we were unable to open up the focus groups more widely to external people because of the ongoing pandemic. This meant we spoke with only a small number of colleagues who volunteered to participate. So we acknowledge that their experiences do not necessarily represent the wider population of autistic people.

However, our colleagues' experiences offer context. They also help our understanding of the themes that emerged from looking at the published literature. We have also shared these with the National Autistic Society and a group of our Experts by Experience to check that they reflect themes and issues more widely. Experts by Experience are not CQC employees. They are members of the public with recent personal experience of using or caring for someone who uses health, mental health or social care services that we regulate.