

Inquiry into COVID-19 and its impact on matters relating to the Equality, Local Government and Communities Committee's remit

We welcome the opportunity to contribute to the inquiry into COVID-19 and its impact on matters relating to the Equality, Local Government and Communities Committee's remit.

Autism is a lifelong disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while there are certain difficulties that everyone on the autism spectrum shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK.¹

Autism and the coronavirus outbreak

The coronavirus outbreak and ensuing lockdown has changed the lives and daily routines of most people in the country. While this has been hard for everyone, it is particularly challenging for autistic people, who typically experience intense anxiety and extreme unease around unexpected change. They may also need more time to process information and instructions.

Many autistic people have contacted us to describe their experiences. Adjusting to the sudden change in their lives and routines is a huge challenge, alongside concerns about the availability of health or social care. In addition, families are often unable to visit relatives who live in residential care settings, and this causes anxiety both for them and their family members.

People say they are struggling with isolation from their families and friends, and with the rules around social distancing. This is intensified by anxiety about their health or that of family members, and fear of what might happen in the future.

Alongside these new challenges, we know that too many people on the autism spectrum, both children and adults, were not getting the support they needed before the coronavirus outbreak began.

Autism as a disability under the Equality Act 2010

The Equality Act 2010 is clear that autism is a disability, in terms of it being an impairment that has a long-term and substantial adverse effect on the autistic person's ability to carry out normal day-to-day activities. However, for many

¹ The NHS Information Centre, Community and Mental Health Team, Brugha T et al (2012), *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*, Leeds: NHS Information Centre for Health and Social Care.

people on the autism spectrum, autism is a hidden disability. This means that the wider public may not be aware of the things they struggle with and their need for support or adjustments.

It may not be obvious that a child or adult on the autism spectrum has a disability until their needs are not met to the extent that they become clearly overwhelmed. As a result, their behaviour may be perceived as 'challenging' if they are unable to follow instructions or fit in with existing rules and structures. It is important to recognise that an autism meltdown is not the same as a temper tantrum, and that 'challenging' behaviour is in fact 'distressed' behaviour.

This paper seeks to focus on areas where the rights of autistic people have been impacted by the coronavirus outbreak and where measures can be taken to ensure that autistic people aren't disproportionately affected by the pandemic.

Getting food from the supermarket

Rules around not leaving the house and social distancing have changed our high streets. Many shops are shut, there are queues to get into supermarkets and new (and often different) rules about how to behave. This is disruptive for everyone, but for autistic people these changes can feel completely overwhelming.

The current situation has put people in an impossible position – many disabled people can't get online delivery slots because they're not clinically extremely vulnerable, but they also can't go to supermarkets because of barriers they face in-store. For some, this is because they have a physical or sensory impairment that makes shopping in person impossible. For others, like autistic people, or those with dementia, a learning disability or problems with their movement, it's the fact that they can't go into the shops with their family members or unpaid carers, or at quieter times. The long queues, new rules and some staff and customers' poor understanding mean that getting food is a minefield of stress and anxiety. This is a particular challenge for those of us with mental health problems who already face difficulties in accessing supermarkets under usual circumstances. This situation is leaving some to go hungry, and we think that's unacceptable.

Supermarkets have an important part to play. We have seen them adopt great new practices to enable key workers and older people to shop in safety. However, disabled people have often been left out. It is unclear about who will qualify as vulnerable, and it often differs between shops. Priority delivery slots and "click and collect" slots are not made available. It is vital that there is consistency of fair access to food for disabled people.

We have worked with other charities across the UK and written an open letter² to supermarkets. **The Welsh Government can also play a key role to play in bringing**

²National Autistic Society, *Sign our Letter to Supermarkets*:
https://act.autism.org.uk/page/60452/petition/1?en_chan=tw&utm_source=twitter&utm_campaign=supermarkets&utm_content=open_letter

together charities and supermarkets to find a solution, to ensure that autistic people aren't further disadvantaged.

Recognising the impact of coronavirus on autistic people in Wales.

The coronavirus itself, as well as policies responding to the health and economic consequences of the outbreak, will have a varying impact on different groups of people, for a range of different reasons. In order to respond effectively to this current outbreak, and to ensure we are prepared to deal with other such significant and disruptive incidents in the future, it is crucial that we understand how the pandemic impacts people differently.

We are concerned that sufficient data isn't being recorded and published to fully understand the impact that the current pandemic is having on autistic people, and disabled people more generally.

For example, we don't know enough about autistic people contracting COVID 19 in care homes in Wales, and those that have died as a result. Data published in England shows a 134%³ increase in the number of deaths of those with a learning disability and/or autism in care homes. This is extremely concerning and it's important that we can see comparable data for Wales.

There are similar issues in relation to mental health hospitals. We have concerns that a lack of appropriate social care support, exacerbated by this crisis, has led to more autistic people being inappropriately placed at mental health in-patient units. And again, we don't have information about the number of cases and subsequent deaths of autistic people in such settings. This data is available from NHS England⁴, in the weekly published table of all announced deaths.

We also aren't aware how many autistic pupils have been left without the educational support, social care or health services they need.

We have lots of anecdotal evidence that supports the view that autistic people, and disabled people more generally have been significantly and sometimes disproportionately affected by the coronavirus outbreak. However, it is crucial that more information is collected so that we can better understand the real impact of the pandemic on autistic people.

Not only will this information be an important factor in responding to the existing crisis, it will be crucial the recovery process. It is only by monitoring and understanding the way in which this crisis has impacted on different groups of people within society that we can develop policies and support that address the challenges that people face.

³ Care Quality Commission, *CQC publishes data on deaths of people with learning disability*: <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

⁴ NHS England, *COVID-19 deaths by type of pre existing condition*: <https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-daily-deaths/>

We urge the Welsh Government, along with health and care bodies to ensure that information is captured to identify the impact that the coronavirus outbreak is having on autistic people, and those with other disabilities,

Availability of medical treatment

Many people have contacted our charity to express concern that they or their autistic family member will not get the treatment they need if they become seriously ill with Covid-19. On the basis of their own experiences of using health services, or what they see reported in the media,^{5,6} they have been worried that health professionals will decide on the basis of their autism diagnosis that they should not receive the same treatment that would be offered to non-autistic people. This is causing extra stress at a very difficult and uncertain time.

It is vital that clinicians avoid any kind of blanket policy on which groups of people are entitled to particular types of treatment. Whilst we recognise that guidance⁷ is clear that each person should be considered and assessed as an individual, with their individual needs and circumstances – rather than their diagnosis or disability – **we would like to see autism explicitly included in this guidance to provide additional reassurance.**

Other issues

We have also written contributed to the inquiries currently being undertaken by the Children, Young People and Education (CYPE) Committee and the Health, Social Care and Sport (HSCS) Committee. These responses focus on the specific policy areas relevant to the respective inquiries. However, some issues will be of interest to this committee, such as guidance on leaving the house and exercise rules for autistic people as well as concerns about accessing education, social care or medical help.

Our [CYPE](#) and [HSCS](#) committee inquiry responses are available online should the committee require any further information on the impact that the coronavirus outbreak has had on autistic people and families in these policy areas.

We are grateful for the opportunity to contribute to this inquiry. This submission seeks to address how the coronavirus outbreak, and the measures taken to combat it, have affected people on the autism spectrum in relation to autistic children and young people's health and wellbeing, and access to education provision and other support services. The National Autistic Society Cymru is happy to provide any further information that the Committee would find useful, or to provide oral evidence if required.

⁵ Financial Times (13 April 2020), *NHS 'score' tool to decide which patients receive critical care.*

⁶ ITV Wales (1st April 2020), *Apology after patients with life-limiting illnesses asked to sign 'do not resuscitate' form if they get coronavirus:* <https://www.itv.com/news/wales/2020-04-01/surgery-asks-patients-with-significant-life-limiting-illnesses-to-sign-form-waiving-cpr-if-they-get-covid-19/>

⁷ Welsh Government, *Coronavirus: Ethical values and principles for healthcare delivery framework:* <https://gov.wales/coronavirus-ethical-values-and-principles-healthcare-delivery-framework.html>



This consultation response has been submitted by [REDACTED] External Affairs
Manager, National Autistic Society Cymru, [REDACTED]