

Written evidence from the National Autistic Society (COV0155)

Introduction

1. 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 1 in 100 people in the UK.¹
2. The National Autistic Society is the UK's leading autism charity. Since we began more than 50 years ago, we have been pioneering new ways to support people and understand autism.
3. We have noted the Committee's terms of reference, and this submission focuses specifically on the disproportionate impact of Covid-19, and measures to combat it, on autistic people and their families. The issues outlined are complex and we have expressed them briefly. We would be happy to provide the Committee with further evidence – written or oral – if that would be helpful.

Autism and the coronavirus outbreak

4. The coronavirus outbreak and ensuing lockdown has changed everyone's lives and daily routines, but for many autistic people and their families, life has been turned upside down.
5. Many autistic people and their families have contacted us to describe their experiences: adjusting to the sudden change in their lives and routines, and worrying about getting their social care, mental health and special educational support. Research by the All Party Parliamentary Group on Autism in [2017](#) and [2019](#), found that even before coronavirus, people were not getting the support they needed. Now, autistic people are struggling more than ever because so many of the services they rely on have been stopped or reduced.

Impact of COVID-19 measures on autistic people

6. The pandemic has highlighted the inequalities faced by autistic people in this country. All too often, autistic people have been forgotten about in Government policy since the start of the outbreak, from decisions about

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.

access to life-saving treatment, to being able to get exercise or vital services. The impact has been devastating, and from available – albeit partial – data, it looks like many have also died from the coronavirus.

Disproportionate number of disabled people dying from COVID-19

7. The most recent figures published by the Office for National Statistics show that two thirds of COVID-19 deaths from March to mid-May 2020 were disabled people.² Given this, we were concerned that Public Health England’s review into factors impacting health outcomes from coronavirus didn’t include the impact on disabled people. We need to better understand what’s happened in the first phase of the coronavirus outbreak, as it’s crucial to protecting people ahead of a second wave. **The Government must urgently commit to a review of disabled people’s health outcomes – otherwise we risk seeing more lives lost.**

8. We don’t fully understand the number of autistic people who have died of COVID-19 because the data only show a partial picture. Available NHS data suggests at least 514 autistic people or people with a learning disability have died in hospital. There are also reports of significant numbers of deaths in social care, which is a major warning sign. The Government said in a response to a written parliamentary question that it is “urgently considering” research into the impact of coronavirus on autistic people. **The Government must move forward with this urgently, so we know what’s really happened and how to prepare for the coming months.**

Access to life-sustaining treatment

9. Lots of autistic people and their families were understandably extremely worried that they or their autistic family member would not get the treatment they needed if they became seriously ill with COVID-19.

10. There were reports of GPs telling autistic people and their families that they were unlikely to be prioritised for life-sustaining treatment or that they would be subject to ‘Do not attempt to resuscitate’ (DNACPR) orders. Guidance from the National Institute of Health and Care Excellence (NICE) on ‘frailty’ also allowed for disabled people to be refused treatment. While we welcomed NICE and NHS’ clarification that none of these decisions should be blanket one based on a diagnosis like autism, it is unacceptable that these happened in the first place.

Reductions in social care support

11. The COVID-19 outbreak has laid bare the ongoing crisis in the social care system.

² Office for National Statistics (19 June 2020), Coronavirus (Covid-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020.

12. Despite the “easements” to the Care Act duties contained in the Coronavirus Act only being implemented for a short time in a few areas, we have heard from autistic people across the country whose care was immediately stopped or reduced, leaving them completely stuck and isolated. We also know that many struggled to find PPE, without which their support workers couldn’t visit. This is completely unacceptable, and suggests that legal duties have been set aside without scrutiny during lockdown.
13. We have been deeply worried that autistic people have been left behind in the Government’s testing programme in social care. While we welcome the commitment to test and re-test in care homes, this has not been rolled out across all supported living settings, in spite of the risks of transmission being similar. **We want to see the Government commit to rolling out its plans for care homes to supported living as soon as possible to tackle this inequity.**
14. The Government must set out how they will reopen social care. Many of the services and support autistic people usually get have temporarily closed because of the outbreak, especially day and respite services. These services are important parts of people’s lives and crucial in preventing their needs from escalating. **The Government must ensure these vital services reopen and autistic people are fully supported.**
15. Many autistic adults in residential have been unable have visits since lockdown. This is a cause of great anxiety for individuals and their families, and could lead to long-term mental health problems. **The Government must urgently publish guidance for providers helping safe visits to happen.**
16. **To ensure the social care system can return to providing support to autistic people and safeguard their rights in a potential second wave of the virus, the Government must urgently invest in social care.**

Withdrawal of support for children with special educational needs and disabilities (SEND)

17. The impact of lockdown and school closures on autistic children and their families, has been huge. Autistic children across the country have been left without the educational support and therapies they need, and families increasingly struggled as the lockdown continued. Under a temporary modification to the law enabled by the Coronavirus Act 2020, local authorities’ duties to deliver the support in a child’s education, health and care (EHC) plan was downgraded to ‘reasonable endeavours’ to provide it. This sends a message that this support is not crucial and can be de-prioritised. However, we know from experience that if support for children with SEND is not a legal requirement, it is unlikely to be provided and children’s needs will escalate as a result.

18. The impact of lockdown and school closures on autistic children and their families should not be under-estimated. Many schools were closed with little or no support for parents and children at home. We are also concerned that children with the most complex needs will be barred from returning to school because of their needs (for example if the sometimes display distressed behaviour). It is vital that children with complex needs are not *de facto* excluded from school and left behind because of coronavirus.

Problems getting food

19. Since the beginning of lockdown, we've had thousands of autistic people and their families get in touch with us because they've been very worried about how they're going to get food. The rules around leaving the house, many shops being shut and supermarkets changing how they operate, have been disruptive for everyone. But it's disproportionately affected autistic people and their families, who've often fallen through the cracks of Government policy.

20. The Government and supermarkets have left autistic people behind. Because autistic people are not *clinically* vulnerable to COVID-19, they weren't included in plans for priority delivery slots or food boxes, so have had to go to supermarkets. This ignores many of the barriers autistic people face – including social distancing rules and restrictions on people going to shops with their family member or carer. Unfortunately, we still hear that reasonable adjustments are not being made for autistic people in shops, despite the Equality Act remaining in full force.

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