

Left stranded:

The impact of coronavirus
on autistic people and their
families in the UK

Executive summary

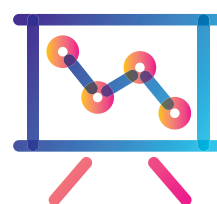
The coronavirus pandemic is an unprecedented challenge for individuals, communities and governments across the UK.

In response, each government has had to make quick decisions and set up new reviews and organisations. We need to learn from what has happened and its impact on autistic people and their families, and make sure they aren't left stranded in this way again.

Compared to the general public, autistic people in June and July were:



seven times more likely to be chronically lonely



six times more likely to have low life satisfaction

Those requiring support all of the time were **significantly more affected** by lockdown.



Nine out of ten autistic people worried about their mental health during lockdown.



One in five family members had to reduce work due to caring responsibilities.



Seven in ten parents said their child had difficulty understanding or completing school work and around half said their child's academic progress suffered.

Introduction

The coronavirus outbreak has impacted everyone's life. But for autistic people and their families, it has left them completely stranded. This report highlights the often devastating impact this has had.

Many went months without seeing their friends and families. Many of us know first-hand just how hard this was. For others, support from public services disappeared overnight, leading to impossible pressures on families and many feeling abandoned. Overall, autistic people's mental health has suffered, leaving too many at serious risk of falling into crisis.

The inequalities that autistic people and their families face aren't new. We've been highlighting them for years. But coronavirus has laid them bare and deepened them. In case of another wave or further local or national lockdowns, all governments in the UK must take urgent action to make sure the needs of autistic people and their families are better met next time. And as we rebuild our society, governments need to look beyond the immediate effects of coronavirus too and invest in the understanding, research, support and services autistic people need. Only then will we create a society that works for autistic people and their families.



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Methodology

Between June and July 2020, we ran an online survey for autistic people and their families across the UK to tell us about their experiences of coronavirus and lockdown. We received **4,232 responses** (1,810 from autistic people and 2,422 from family members). Throughout the pandemic, we also asked people to email us with their experiences.

This research was run in partnership with Mind as part of a project kindly funded by the Pears Foundation.

What is autism?

Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 700,000 autistic adults and children in the UK.

All autistic people have difficulties with communication and social interaction. These can include not being able to speak, delays in processing information or difficulty holding conversations and making friends. Autistic people also engage in repetitive behaviours, such as hand flapping, rocking or repeating sounds. They can experience intense anxiety and extreme unease around unexpected change. Many autistic people have sensory issues with noise, smells and bright lights, which can be very painful and distressing.

Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.



Impact of coronavirus on autistic people

The coronavirus pandemic has been a time of intense pressure and uncertainty for many different people across the UK.

Communities and policymakers have had to adapt to a rapidly changing situation and make difficult decisions to protect people. Although these decisions have impacted everyone's lives, they have disproportionately impacted autistic people and their families. The rapid withdrawal of mental health, social care and education services spelled disaster for many autistic children, adults and their families and has led to a nosedive in mental wellbeing. Our survey has found that compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July and six times more likely to have low life satisfaction. The scale of this inequality has not yet been matched by a serious public policy response. Significant and long-term investment in national and local programmes and support to change people's outcomes is needed.

These problems came because education, mental health and social care services for autistic children and adults were insufficient as we headed into the pandemic. As the All-Party Parliamentary Group on Autism (APPGA) found in 2019, more than two in three autistic people in England were not receiving the care they needed. According to our insights and accounts from autistic people, we know this is true across the UK.¹ The chronic underfunding and lack of focus on autistic people's lives over decades crystallised into acute suffering for autistic children, adults and their families, leaving many stranded without any support.

"I am just very isolated. The only person I see regularly is the postman."

Anonymous, autistic person in Wales

Most unfairly, our survey has also shown that the more complex the needs of an autistic person and the more support they need, the worse their anxiety and mood, and the less likely they were to receive the information and advice they needed during the pandemic.

A second spike and a further wave of disruption cannot be ruled out. The situation faced by autistic people in terms of mental health outcomes, care and support provision, education and public understanding was already reaching crisis point. The experience of autistic people during lockdown, and the threat of a second spike, makes the need for action now more urgent than ever before.

All four governments must prevent more distress and uncertainty for autistic people by creating an action plan covering social care, health, education, transport and shops in case of a second wave. This plan should specifically set out how the governments will avoid using the powers in the *Coronavirus Act 2020* that led to public services being withdrawn so sharply during the height of the lockdown. The Scottish Government is developing a Transition and Transformation Plan and we welcome this approach to ensuring that the experiences of autistic people are improved in the future.

Autistic people need to be a priority in future policymaking across the UK as we rebuild our economy and society. This should be on two levels. There needs to be sufficient cross-government focus and investment in specific autism policy and support, for example the future autism strategies in England and Northern Ireland and the proposed Code of Practice in Wales. Every government department needs to make sure that its plans will reduce inequalities for autistic children, adults and their families.

Equally, future reform in mental health, education and social care must have autistic people's needs at its centre. They have suffered acutely because of failings in those systems during the pandemic. It is time to make public services work for autistic people.

¹ All-Party Parliamentary Group on Autism, *Autism Act: 10 years on* (2019).



Mental health and loneliness

Autism is not a mental health condition, but many autistic people develop mental health problems. This is often avoidable, but the lack of support can mean preventable issues worsen.

Mental health problems start young and need addressing early. Research shows that more than 80% of autistic young people have experienced mental health problems.² Before the pandemic, the response was far from ideal – according to the APPGA report, 76% of autistic people in England have reached out for mental health support. But even when that support was given, 82% of autistic adults said the process of getting it took too long.³ Research suggests that 66% have thought about taking their own life.⁴

Coronavirus has made this situation considerably worse. Our new findings show that nine out of ten autistic people have worried about their mental health during lockdown. Compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July and six times more likely to have low life satisfaction.

“Mental health services stopped seeing my children. My daughter was due to start specialist therapy which has been postponed.”

Anonymous, parent

Lockdown has upended the lives of everyone in the UK, but it has undermined the essential ways many autistic people cope with daily life – through routine, structure, exercise, and time with friends or family. Without additional support, autistic people can find it more challenging to adjust. Periods of crisis are all too common among autistic people who cannot get the necessary support.

Too many autistic people end up in hospital because they fall into a preventable mental health crisis and we are particularly concerned that in recent years the number of autistic people identified in mental health hospitals in England has increased.⁵ The withdrawal of mental health and social care services left many without the support they needed to adapt to the pandemic.

The impact on mental health and loneliness was felt most strongly on those with higher support needs, who also reported significantly lower life satisfaction. This was also true of autistic women and non-binary people.

“This has had a devastating effect on my family. My husband has suffered anxiety and panic attacks due to the decline in my son’s mental health and the increase in his distress and challenging behaviour. Both myself and my husband had to take sick leave as we had all support withdrawn.”

Anonymous, family member

It’s clear that coronavirus is placing additional pressure on the mental health of autistic people, making them vulnerable. While some support has been available online or on the phone and has been vital for many, for some autistic people it simply isn’t accessible and doesn’t work.⁶ It’s vital that research is conducted to understand what digital or online support works for autistic people and what the barriers are.

Without access to personalised, evidenced, community-based mental health services, such as autism adapted counselling or low-level psychological therapy, autistic people’s mental health issues can deteriorate quickly. A second wave of the pandemic would tip more autistic people into crisis.

2 Crane, L. et al. (2017). *Mental health in young autistic adults*, Ambitious about Autism and Centre for Research in Autism Education.

3 All-Party Parliamentary Group on Autism, *Autism Act: 10 years on* (2019).

4 Cassidy, S. et al. (2014). *Suicidal ideation and suicide plans or attempts in adults with Asperger’s syndrome attending a specialist diagnostic clinic: a clinical cohort study*.

5 National Autistic Society, *Beyond Transforming Care: What needs to change?* (2018).

6 Autistica, *Impact of COVID-19 on autistic people*, Action Briefing August 2020.

Care and support

For many autistic people, social care is the difference between being able to leave the house or not; being able to wash, dress and eat or not; work or not.

It is the difference between high life satisfaction and low life satisfaction. Prior to the coronavirus outbreak, the provision of basic care for autistic people was already dangerously low but the virus has reduced care provision further, leaving many parents and carers feeling abandoned.

Some autistic people will go through life needing very little support, while others will need a lifetime of round-the-clock care. Our survey found that those requiring support all of the time were significantly more affected by lockdown than those requiring only a little support. In particular, they and their families were more likely to be without adequate information and advice on how to manage in lockdown.

Many of those in residential care have gone months without seeing loved ones, due to a lack of guidance.

"The government guidance seems to have overlooked young autistic adults in specialist care provision. My daughter is in this provision and normally returns home for an overnight visit each week. This is our private family time and very important to her and us. I am concerned about the impact this will have on her mental health if this situation continues as she has been requesting to visit our home throughout this period."

Anne, parent

As someone's support needs increase, so did their worries and those of their families. According to the responses we gathered from parents and family members of autistic people, those with relatives who require more support were almost twice as likely in every case to worry about friends or family members contracting coronavirus; not getting the support they or their family needed; what would happen when lockdown ended; their mental health and social distancing than those who require little support. This has also had a profound effect on the wellbeing of autistic people as according to the families of autistic people in our survey, over half of those who require support all of the time reported higher levels of anxiety, and changes in mood and behaviour. Similarly, life satisfaction ratings also decreased significantly.

"Our son normally comes home to us every weekend and all holidays. Throughout this Covid lockdown, he has not been able to come home at all, and has found it very hard to cope with not being able to have his usual routine of coming home. We have been concerned about his mental wellbeing throughout this period. He has come for a few visits in the garden with his carers which has been helpful but he is still very unhappy."

Marion, parent in Wales

"In normal times [my son] goes for respite 36 overnights a year which gives me a chance to sleep and usually attends a day service five days a week. I am now being told there will be no respite for the foreseeable. I can't go on for much longer in this situation. My son is unpredictable, he has severe meltdowns. I have no one. My mum died in February just weeks before lockdown. If I don't get a rest soon, I really don't know how I can continue."

Sylvia, parent in Scotland

Coronavirus has placed an added strain on autistic people, the available social care services and in particular on the families of autistic people as they are often relied upon when no other options are available. Social care services are stretched and funding has been cut over many years, nor has enough research been carried out about what support works best. Experts have warned that a £3.5 billion funding gap will exist by 2024 / 2025 if action is not taken now.⁷

Families are having to fill that gap. One in five family members responding to our survey had to reduce work due to caring responsibilities, reducing their household income and overall ability to provide.

If the governments of all the four UK nations do not deliver for autistic people now, there is a serious risk that in a second wave, existing unmet care needs could become an insurmountable challenge for autistic people and their families.

Education

Education is vital for all young people to build a future, but for autistic children, schooling must meet many needs.

Although academic attainment is important, they also gain the skills they need to transition to adulthood, build relationships and cope with future challenges. Sticking to established routines is one way that autistic children make sense of the world around them and avoid anxiety on a daily basis. Without the routine of going to school, life for many autistic children has been severely disrupted. They and their families have often felt abandoned. Coronavirus has made completing school tasks more challenging, robbed autistic young people of essential social contact, and exposed the lack of autism understanding in education professionals. According to our survey, 68% of family members said their autistic child was anxious at the loss of routine and 65% couldn't do online work.

"The last ten weeks have been very up and down for us. Initially our autistic son coped with the sudden change in life very well, when his local school was closed. He seemed to enjoy having everyone at home (especially as it meant no school, commuting or unexpected changes to the day). However, as the weeks have gone on he has become more lethargic, agitated and has refused to participate in any online learning. He is not able to notice or understand his own emotions, so keeping in touch with friends has been almost impossible."

Georgie, parent in England

It has fallen to parents to home school or support their child's education, often while juggling work and other commitments. Two in five parents or carers did not feel they could adequately support their child in their education needs. Seven in ten parents said their child had difficulty understanding or completing school work and around half said that their child's academic progress was suffering.

When asked how their children's education could be improved, they suggested giving work in smaller amounts and providing better links to other students for social interaction. But for around half of families, it's also been harder to contact school staff, who could provide vital help and advice.



⁷ Local Government Association (2018). *The lives we want to lead: the LGA green paper for adult social care and wellbeing*. London, UK.

"I feel completely alone and unsupported with a child who is regressing further into his own bubble on a daily basis. I haven't got him outside in 11 weeks and I haven't had a break in as long. He has not been able to do any schooling as home is home and school is school, causing massive meltdowns and trauma."

Anonymous, parent in Northern Ireland

The return to school has been equally fraught. Some schools have refused to allow autistic young people to come back for risk reasons, even when schools have re-opened. Others haven't put in place the individual plans that autistic children need to cope with another massive change to their routines. This needs to happen for each autistic pupil. While schools are under huge pressure, there are other simple steps they could take that will help. They could provide visual guides showing the changes that have been made to the school and early tours for autistic children before term starts so they can understand changes to handwashing or playtime.



Fundamentally, the pandemic has laid bare the lack of understanding of autism within our education systems. The inclusion of autism in training for new teachers in England has been withdrawn, without consultation. The Scottish Government's very welcome commitment to improving teacher training on education has been delayed due to the pandemic. All four UK nations need to make sure that the people teaching autistic children have basic understanding of their needs. This will help educational professionals better support autistic learners to return to school and to deal with any future closures.

Going out of the house

Even before the pandemic, getting out and about was hugely challenging for some autistic people due to a lack of understanding or reasonable adjustments in public places.

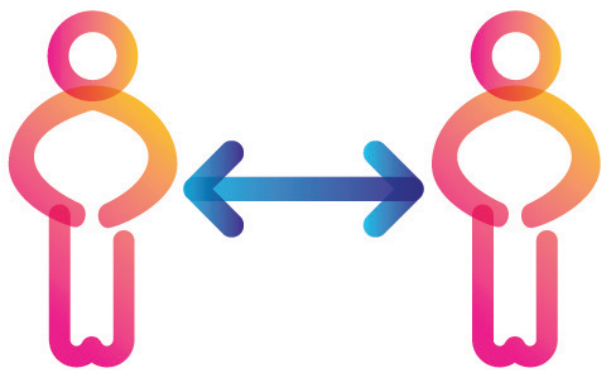
In 2019, one in eight autistic people and one in six family members said they had been asked to leave a public place as a result of autism associated behaviour.⁸ Unfortunately, since lockdown restrictions have come into force, public spaces have become even more inhospitable to autistic people.

During lockdown, many new rules and restrictions were brought in to protect people. Exercising outdoors was limited, shops and businesses had to adapt their stores and face coverings became mandatory. Although these changes were intended to control the virus, they caused fear and anxiety among autistic people, who felt overwhelmed by rapidly changing and unclear advice. In our survey, 78% said they were concerned about following the Government's rules.

"I find it hard to shop for essentials as queues are too long and in some you can only shop alone. I have been using click and collect but often items are missing and substitutes are bad so don't always have enough ingredients to make a meal, also certain things have been out of stock since Covid began."

Anonymous, autistic person in Wales

⁸ National Autistic Society (2019). Survey of 7,789 autistic people and their families on public attitudes towards autism, August to September 2019, unpublished.



The growing fear about using public spaces meant that many autistic people and their families struggled to get food because they couldn't access supermarkets. In our survey, autistic people said that buying food was their biggest difficulty during lockdown. Long queues, unclear rules and a poor understanding of invisible disabilities among staff meant that shopping became a minefield of stress and anxiety. Because of rules limiting the number of people in a shop, carers and family members were prevented from going into the store with their autistic relative to help with shopping. Being unable to shop meant that not only were some autistic people deprived of food, they were also deprived of their independence as they had to rely on others to do their shopping.

"Staff questioned them both like they were criminals and asked personal questions about [our son's] disability in front of everyone. As you can imagine, he is now deeply upset and it will take some time before we can get him to leave the house again due to this incident."

Matt, parent in England

Being thrown out of public places is a very real threat now that face coverings are mandatory in shops, public transport and other venues. Many autistic people struggle to wear a face covering, for example due to sensory overload – 70% told us that they were worried about this. Although disabled people who are not able to wear a mask are exempt, this is not always acknowledged by staff and customers or the public, meaning autistic people can feel vulnerable to being confronted or asked to leave. Better awareness of these exemptions would spare autistic people and their families much anxiety every time they go out.

"I experienced the first instance of someone pointing an infrared thermometer at my head over the weekend. No warning and held like a gun, it started a minor panic attack... far too scary. This is an incredibly difficult time and I cannot wait for things to return to a more 'normal' time."

Anonymous

Governments can help to improve public understanding. They have invested in the past in campaigns to improve awareness of dementia and of mental health. But autistic people so far have not seen a full-scale government campaign to educate the public about their needs. In April 2019, the Secretary of State for Health and Social Care in England said he wanted to see this, but it has not yet been delivered. Scotland has plans for a campaign, which is expected later in the year. Wales and Northern Ireland have no public plans. The pandemic has reinforced the need for more of the public to understand autistic people's challenges so that they can safely go to shops, parks and live their lives as freely as anyone else.



Recommendations

All four governments in the UK should create an action plan to protect autistic people and their families in case of a second wave, covering social care, health, education, transport and shops.

This plan should specifically set out how the governments will avoid using the powers in the *Coronavirus Act* that limit duties to assess and meet disabled people's needs.

England

- Publish the new all-age national autism strategy with an action plan to tackle the inequalities faced by autistic people, embedding understanding, research and support, as outlined here and in the All-Party Parliamentary Group on Autism's report: *The Autism Act: 10 years on*.
- Make sure autistic children and young people's needs are specifically covered in the national SEND Review and that no autistic child ends up wrongly held back from going back to school.
- Focus future social care reform on autistic adults as well as older people, and on social care in the community as well as care homes.
- Focus future mental health reform on autistic adults and children.
- Roll out a national public understanding campaign, as announced in World Autism Awareness Week 2019.
- Give autistic people and their support the funding it needs in the upcoming Budget and Spending Review.

Northern Ireland

- Publish the new Northern Ireland autism strategy tackling all the issues outlined here and in the joint National Autistic Society and Autism NI report: *Broken promises*.

- Increase funding for social care for autistic children and adults and make that sustainable.
- Make sure autistic children and young people's educational needs are met and that no autistic child ends up wrongly held back from going back to school on a full-time basis.
- Make sure mental health services are expanded and are accessible to autistic people.
- Fully implement the duty outlined in the *Autism Act NI 2011* to implement an effective autism awareness campaign.

Scotland

- Ensure that the Scottish Government's forthcoming review of social care and the pandemic includes the impact on autistic people and families, as well as older people and care homes.
- Implement the commitment to introduce a baseline of autism awareness within Initial Teacher Education as agreed following the *Not included, not engaged, not involved report*.
- Move forward with plans for a national public awareness and understanding campaign due for the autumn.
- Take forward the recommendations from the Independent Review into Learning Disability and Autism within the *Mental Health Act*.

Wales

- Prioritise the development of the Code of Practice on the Delivery of Autism Services as soon as possible to ensure it can be agreed during this Senedd term, strengthening the legal rights of autistic people and their families in Wales.
- Publish the Additional Learning Needs Code ahead of moving to the new support system in 2021, and implement the commitment that all teachers receive mandatory autism training as part of their initial teacher education.
- Roll out a national public awareness campaign on autism.



The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people.

We transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work.

We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum. With your help, we can make it happen.

Find out more at:
www.autism.org.uk



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