

What can we learn from the pandemic?

The mental health needs of autistic
people and their families

What we already know



Autism is not a mental health condition but many autistic people develop mental health problems. This is often avoidable with the right support early on.



autistic adults told us they reached out for mental health support in the last five years.



autistic people said there were enough mental health services in their area to meet their needs



autistic adults said the process of getting support from mental health services took too long.

The pandemic has only made this worse.....

Left Stranded 2020 report



Our report, supported by four other leading autism organisations, highlights the often disproportionate and devastating impact the pandemic has had on the mental health of hundreds of thousands of autistic people and their families.

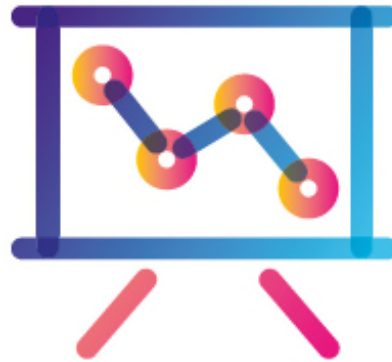
Between June and July 2020, we ran an online survey for autistic people and their families across the UK exploring experiences of lockdown.

We received 4,232 responses (1,810 from autistic people and 2,422 from family members). We also asked people to email us with their experiences.

We think this is the biggest database about autistic people's experiences of lockdown.



We found...



six times more likely to have
low life satisfaction



seven times more likely to
be chronically lonely

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

Anonymous, autistic person in Wales

"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 Both myself and my husband had to take sick leave as we had all support withdrawn."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



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

Lack of support has led to many autistic people being unnecessarily sectioned in mental health hospitals due to a **lack of intervention** in the first place.

This is particularly concerning as in recent years the number of autistic people in mental health hospitals in England has **increased** and the latest Assuring Transformation data shows us that **over 1,100 autistic people** are still in inpatient settings.

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

Anonymous, parent

Recommendations



Investing in mental health and social care services is vital. We want to see a plan to improve this in the upcoming **National Autism Strategy**.

Change the law so it works better for autistic people which is one of the proposals in the recent **Mental Health Act** White Paper.

Recommendations



Government has to make sure these services **actually work** for autistic people

To do so they need:

- A **better understanding of autistic people's needs**
- To make reasonable adjustments so that autistic people **can actually benefit from** therapy



Our project



Our Mental Health project, run in partnership with Mind and funded by the Pears Foundation, looks at creating a **process of seeking and gaining mental health support** that works better for autistic adults and children in England.

This is aims to:

- **Give practitioners the information they need**
- **Work with the NHS to make sure these are put into practice**
- **Understand what information and advice is currently missing and how to provide it**

Research parts



Mental Health Survey asking autistic people what they prioritise in therapy, how they support their own mental health and what information and advice is currently missing.

Interviews and focus groups with autistic people and mental health professionals. This has shown what practical changes can be made to services to make them better for autistic people as well as what reasonable adjustments autistic people benefit from.

Reviews on current mental health practice evidence base according to each mental health condition showing the most up to date practice and evidence-based therapies.

Focus groups and Interviews



- Autistic adults , autistic young adults, parents of autistic children and autistic parents of autistic children
- Mental health professionals – IAPT, private practitioners, community, inpatients

Early findings show



An understanding of an **individual's autism** is essential as every autistic person is different

“Start off with what makes you tick, what are your drives what are your states that you really enjoy. Have a deeper dive with that person.”

Autistic Practitioner

More **autism training** is needed for Mental Health Professionals

**“They did try to help, they just
didn’t know how”**

Autistic adult

The importance of **advocacy** for autistic people

“Involving family helps make sure what we learnt in sessions moves into the real world.... when someone is anxious about meeting new people having someone there until they feel comfortable helps. We need to think a bit more creatively.”

Clinical Consultant Psychologist

Outcome measures and screening assessments are not made for neurodiverse population

“One thing that is helpful with scales like that is to give examples of what you can manage .. like can you do most of your normal daily tasks ...that to me helps”

Autistic adult

The importance of **environmental adaptations**

Also that there a number of **practical changes and adjustments**
that therapists can embed in their therapy for autistic people

**“We need information before the session
about what will be expected of
you and what will happen, it is so stressful
walking in and not knowing what is going to
happen”**

Autistic young adult

Outcomes?



- **Resource** for Mental Health Professionals
- **Reasonable adjustments** work with IAPT
- **Information and advice** for autistic people and families in the form of digital content on both the NAS and Mind's websites