

Introduction

The outbreak of Covid-19 has triggered profound changes to the lives of parents and carers of autistic children and young people (CYP), including school closures for most, restricted access to services and family support due to social distancing measures and changes to home routines. The Coronavirus Act (2020), no doubt necessarily rushed through parliament with scrutiny-defying haste, has reduced the rights of disabled people and their families to care, support and educational provision. These rights are hard won at the best of times.

Purpose of the study

We wanted to understand how the coronavirus pandemic, the Coronavirus Act (2020) and the lockdown impacted on families of autistic CYP, particularly in relation to their caregiving experiences and wellbeing. For families who rely on external sources of support for their autistic children, we felt it was important to gain an insight into how have they been coping with the lockdown, the restrictions on movement and the fear of ill health, if indeed it had not become a reality for some. We also wanted to consider if parents' very conceptualisation of care and support, once it was removed, had somehow shifted, and caused them to re-evaluate their needs and rights.

Procedure and participants' characteristics

Ethical approval was provided by the Institute of Education at UCL to run an anonymous survey between 1st and 30th April 2020. The survey was co-produced with three parents of autistic children, one of whom is autistic. Below we have listed key participants characteristics:

- 449 participants completed the survey: 401 mothers, 35 fathers and 13 carers (including siblings). All lived in the UK and cared for at least one autistic CYP.
- 41% of the autistic CYP were diagnosed with co-occurring conditions such as a learning disability, anxiety, ADHD and dyspraxia.
- 82% of the participants were identified as white, 18% of the participants identified with an ethnic minority background including Arab, Persian, Black, Asian, or mixed.
- 35% of the parents and family carers described their income as average, 28.6% below average, 28.5 above average and 8% preferred not to say.
- 75% of family carers who took part were married or in a domestic partnership.
- 47% of the autistic CYP were attending a primary school (mainstream or special), 27% a secondary school (mainstream or special), 4% a preschool setting and 4% a university/college or work placement. 15% stated 'other', including home-schooling and assessment and treatment units.

Key statistical findings

- 86% of family carers think that the needs of autistic people and their families have not been adequately addressed during Covid-19
- 46% of family carers stated that they consider their autistic children or themselves to be at higher risk for Covid-19 than the general population.
- 70% of family carers report that their daily routines have changed. Importantly, many participants did not want to return to the pre-Covid world.
- 58% of family carers still had access to at least one type of specialist support. However, this was not always timely nor sufficient.

Key themes

1. A sense of familiarity with life before lockdown

Social distancing was already the norm to avoid negative reactions from the general public to their autistic child

- A high level of difficulty accessing healthcare both before and during lockdown
- Some families already had to plan when to go shopping and to consider alternative ways of shopping before the lockdown

2. New struggles

Confusing and distressing information regarding access to ventilators and Intensive Care Unit treatment as well as Do Not Resuscitate status

- A strong fear of carers being ill themselves and the impact this might have on their autistic CYP
- Difficulties in explaining the loss of a close/beloved person to autistic CYP
- A strong increase in levels of anxiety, sleep difficulties, alcohol consumption
- A difficulty in communicating changes to behaviours related to hand washing, surface and packaging cleaning and social distancing
- Difficulty in accessing foods their CYP rely on
- Worries related to interrupted EHCP tribunals and lack of contingency plans for the return to school

3. New opportunities and positives

A positive impact on the mood of the child due to not having to attend school

- Investing time in leisure and play activities as a family
- Relaxed legislation on lockdown measures for autistic people¹
- Building low arousal routines at home that had a positive impact on autistic child's wellbeing
- Understanding better the value of child-led activities.
- Freedom to deviate from friends' and teachers' expectations

4. Hopes for the future

Healthcare contingency plans to ensure that medical staff can understand the needs of autistic CYP including those with co-occurring conditions

- More collaborative practices between CYP and educational professionals when deciding on homework and types of learning resources
- Support for working parents/carers by government and managers beyond unpaid leave or sabbaticals
- Allocated grocery delivery slots
- More personalised support: less reliance on online sources and more phone calls to parents
- Support from specialists who can offer positive encouragement and reassurance to autistic CYP

Key recommendations to improve the lives of families with autistic CYP in the future:

1. **Parents and carers do not feel that the government supported them during lockdown.** Future policy development related to public health crises must ensure it has input from a diversity of voices and that the needs and rights of disabled people and their families are always taken into account.

¹ <https://www.theguardian.com/world/2020/apr/14/uk-coronavirus-rules-autism-learning-disabilities-lockdown>

2. **Service providers need to devise innovative respite options.** Our data suggest that limited support is currently provided in relation to the coronavirus pandemic. A particularly big impact of Covid-19 has been the removal of respite. Employers need to also respond in more appreciative ways to the needs of working family carers.
3. **Services should work collaboratively to share ideas.** Our data show that services can still adapt and support carers, so planning and consideration into service delivery methods that can remotely support disabled people and their families need further planning. Furthermore, the government needs to request that NHS Trusts support autistic people. Each Trust should have autistic leads who can help coordinate and support such processes.
4. **Autistic people and their families must be included in the planning process for any necessary changes.** Enforced changes to daily routines have often been stressful for autistic CYP and their families, particularly if they have not received support. Moving forward, transitions and changes (which will continue to occur) need to be as clearly communicated in advance as possible so planning can more effectively take place.
5. **Support services and education providers need to try to incorporate these findings to improve educational and social services in the future.** For many families, after some time passed to allow for transitions and new routines to settle in, the changes had a positive impact on their wellbeing.
6. **We need to leverage society's realisation of what life is often like for autistic people and the wider autism community going forward.** Many families reported reduced anxiety and stress due to having to face less evident stigma and discrimination during lockdown.
7. **Future research should involve autistic people of all ages and communication styles.** More research is needed to find out what can we learn from this to ensure that in the future we do not revert back to the usual difficulties for families with autistic CYP due to lack of understanding and support.

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