

86% of parents of autistic children felt lack of government support during lockdown

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After conducting a survey with 449 UK-based parents and family carers of autistic children and young people (CYP), academics from University of Bedfordshire, University College London (UCL) and University of East London (UEL) have published their findings to help policy-makers further understand how the Covid19 lockdown has effected autistic people and their families.

The results from this collaborative research project have highlighted that despite the relaxed legislation on lockdown measures for autistic people – brought into effect in mid-April – 86% of participants thought that the needs of autistic people and their families were not adequately planned for or addressed by officials during the pandemic.

Dr Chris Papadopoulos from Bedfordshire's Institute for Health Research, Dr Georgia Pavlopoulou of UCL's Institute of Education and Dr Rebecca Wood from UEL wanted to understand how the coronavirus pandemic, the Coronavirus Act (2020) and the lockdown had impacted on families of autistic CYP, particularly in relation to their caregiving experiences and wellbeing. They also wanted to consider if parents' very conceptualisation of care and support (once removed) had somehow shifted and had caused them to re-evaluate their needs and rights.

Although many of the 449 participants said that they often struggled to access public services even before lockdown and felt that social distancing was already 'the norm' for them, due to negative reactions, rejection and stigma they often face in public, 70% still reported that their daily routines had significantly changed since the pandemic began.

Whilst 58% of participants confirmed they still had access to at least one type of specialist support during lockdown, the survey identified a wide range of new worries and challenges that parents and family carers faced. In particular, many experienced difficulty in communicating new behaviours, such as new hand washing techniques and social distancing, and struggled to shop for key foods that their children relied upon for regulation and wellbeing reasons. These struggles, combined with a lack of respite resources and a strong fear of becoming ill themselves – given the impact this might have on their autistic CYP – led to an increase in participant anxiety, sleep difficulties and alcohol consumption.

However, many families also reported reduced anxiety and stress due to having to face less stigma and discrimination in their everyday lives whilst in lockdown, highlighting the ongoing need for public education, understanding and acceptance of autism.

"We need to make sure that we listen to the voices of our participants so that in a post-Covid-19 world, we are doing much more to protect families from the preventable anxieties, social pressures and discrimination they have endured for too long," said Dr Chris Papadopoulos, Principal Lecturer in Public Health with University of Bedfordshire's School of Healthcare Practise.

"What is important is that we leverage our findings going forwards. Our data shows that services can learn to adapt and support carers, so further planning and consideration around service delivery methods

that can remotely support disabled people and prime carers is needed. Furthermore, the government needs to request that each NHS Trust have dedicated autism leads who can help coordinate and support such processes for the wider autistic community.”

A positive finding was that many participants reported their children had benefitted from reduced anxieties due to them not having to attend school and that, instead, low arousal and low demand routines at home had an overall positive impact on their CYP’s wellbeing.

“For many families, after some time passed to allow for transitions and new routines to settle in, the changes will have had a positive impact on their wellbeing and some will feel better than perhaps they felt before,” said Dr Georgia Pavlopoulou, Senior Teaching Fellow in Psychology and Mental Health at UCL and IAPT Module Lead at the Anna Freud Centre.

“In some cases families have enjoyed unexpected freedoms by not feeling pressure to conform to pre-Covid19 world expectations. There is a lot of learning that can be had from understanding why exactly there has been some positives, and leveraging that learning to improve educational, health and social services in the future. In order to achieve this, we need to involve autistic people and their families in co-designing and co-delivering services.”

Dr Rebecca Wood, Senior Lecturer in Special Education at UEL, added: “These preliminary findings provide vital insights into the experiences of families of autistic children and young people during lockdown from which education, health and social service providers could draw important lessons.”

Considering the results, Dr Papadopoulos, Dr Pavlopoulou and Dr Wood have provided recommendations for future policy-makers to ensure families of autistic CYP feel confident in the level of support available to them during future public health crises. These include the representation of a diversity of voices in the decision-making process, to make sure that the needs and rights of autistic people and their families are taken into account from the beginning.

The full report, including these key learnings and expert recommendations for future planning, can be read online via the UCL Discovery website: <https://discovery.ucl.ac.uk/id/eprint/10101297/>

Those interested in learning more about how the autistic community and their families have been coping during Covid19 can download The Autism Podcast, a monthly community show co-hosted by Dr Chris Papadopoulos for the London Autism Group Charity.

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