



Letter to the Editor

COVID-19 and autism: Uncertainty, distress and feeling forgotten



Depression, struggling to cope with change and difficulty interacting with others. These are some of the challenges that people with autism face at the best of times. Yet, in the midst of a pandemic, these challenges were amplified. This article highlights some of the difficulties faced by people with autism and their families. Policymakers must recognise the complex needs of this group and the mental health toll that they face. People with autism will struggle to develop new routines as the UK emerges out of lockdown, whilst localised or subsequent lockdowns may cause significant distress - particular attention must be paid to this group of people and attempts must be made to minimise and alleviate their distress.

There are 700,000 people with autism spectrum disorders in the UK, ranging from high-functioning people with Asperger's Syndrome to people with severely debilitating autism [1]. Generally, they display restrictive and repetitive behaviours and a strong preference for routines - disruption of their routines can cause distress [2]. Policies have rightly been implemented to protect those deemed extremely vulnerable, including delivering them essential supplies, their basic care needs and encouraging them to remain isolated from others. Yet other groups, such as people with autism, have largely been forgotten and left isolated, being confined to an afterthought [3]. Only in response to a legal challenge, which occurred more than two weeks after the implementation of lockdown, were the rules relaxed for people with learning difficulties and autism, allowing them to leave their homes more than once daily [4]. The only resources available are guidance and recommendations from non-profit organisations. For example, the National Autistic Society provided information for people with autism and their families about planning new routines and how to process information [5], whereas Autistica produced webinars about mental health management and coping with uncertainty. It is therefore unsurprising that the BBC reported that these people felt "forgotten" and "isolated" [3].

COVID-19 is likely to have increased distress for people with autism. First, adapting to increased hygiene and sanitation recommendations, social isolation and social distancing will have broken the daily routines of people with autism, causing distress [2]. Second, the uncertainty surrounding COVID-19 and the constant stream of new information, could overwhelm people with autism, increasing distress. Third, caregivers were unable to give warning signals of impending change, which normally allow people with autism to respond to change better and with less resistance [6]. The absence of these warning signals due to the immediate (rather than gradual) enforcement of lockdown, would have led to people with autism experiencing greater levels of distress.

For people with autism, the additional distress and trauma caused by

COVID-19 are likely to have worsened their core symptoms of autism [2] and mental health. Overall, 20% of people with autism spectrum disorders are diagnosed with anxiety, whilst 11% suffer from depressive disorders [6]. The additional distress caused by the pandemic will mean that people with autism and an existing psychological disorder are likely to have experienced a worsening of their mental health - even those people with autism who do not have a mental health comorbidity were at an increased risk of developing them, particularly anxiety [7] and depression [8]. Despite the current lack of published research, experts believe COVID-19 likely worsened the mental health of people with autism, particularly due to the uncertainty surrounding the situation [9].

The mental health and welfare of family members who provide home-care to people with autism must also be considered, especially because they suffer from increased rates of stress, depression and anxiety [10]. There may be several sources of increased stress. First, establishing new routines for people with autism may generate challenging behaviour and resistance, especially if implemented suddenly and without warning [6], increasing stress for caregivers. Second, COVID-19 placed additional demands on caregivers because they received little external support or respite from delivering care during the lockdown, factors known to increase the burden placed upon caregivers [11]. The additional stress may have worsened caregivers' mental health, with this increased burden associated with higher rates of self-reported depression and anxiety [11] - these conditions would have effected their daily functioning, preventing them from delivering optimal care.

Overall, the changing routines and uncertainty caused by COVID-19 will have brought distress to people with autism, worsening both its core symptoms and their mental health - even as the nation leaves lockdown, they will face fresh challenges and further uncertainty. Also, the additional demands of continuously caregiving without respite would have increased the caregiver burden, likely impacting their mental health and thereby the quality of care they delivered. Rather than being an afterthought, policymakers must understand that the needs of people with autism are vastly different from the general population. They must provide further mental health support for people with autism and their carers as the nation emerges from lockdown. In the event of further local lockdowns or a second wave of the pandemic, legislation must provide additional freedoms and support to people with autism. Policymakers must protect people with autism from acquiring COVID-19; however, this cannot be at the expense of the mental health needs of the population.

<https://doi.org/10.1016/j.puhip.2020.100034>

Received 21 May 2020; Received in revised form 20 July 2020; Accepted 26 July 2020

Available online 31 July 2020

2666-5352/© 2020 The Authors. Published by Elsevier Ltd on behalf of The Royal Society for Public Health. This is an open access article under the CC BY-NC-ND

license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Declaration of competing interest

None declared.

References

- [1] Autism Facts and History - National Autistic Society [Internet]. [cited 2020 Apr 18]. Available from: <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>.
- [2] S. Fuld, Autism spectrum disorder: the impact of stressful and traumatic life events and implications for clinical practice, *Clin. Soc. Work. J.* 46 (3) (2018 Sep 1) 210–219.
- [3] S. Clare, J. Reed, Coronavirus: the Struggle of Living in Lockdown with Autism [Internet], BBC News, 2020 [cited 2020 Apr 29]. Available from: <https://www.bbc.co.uk/news/health-52398144>.
- [4] Bindmans, Government guidance changed to permit people with specific health needs to exercise outside more than once a day and to travel to do so where necessary [Internet] [cited 2020 Apr 29]. Available from: <https://www.bindmans.com/news/government-guidance-changed-to-permit-people-with-specific-health-needs-to-exercise-outside-more-than-once-a-day-and-to-travel-to-do-so-where-necessary>, 2020.
- [5] National Autistic Society, Tips for autistic people and families [Internet] [cited 2020 Jul 1]. Available from: <https://www.autism.org.uk/services/helplines/coronavirus/resources/tips.aspx>, 2020.
- [6] L.E. Bull, C. Oliver, K.A. Woodcock, Signalling changes to individuals who show resistance to change can reduce challenging behaviour, *J. Behav. Ther. Exp. Psychiatr.* 54 (2017 Mar 1) 58–70.
- [7] A. Gillott, P.J. Standen, Levels of anxiety and sources of stress in adults with autism [Internet], *J. Intellect. Disabil.* 11 (4) (2007 Dec 21) [cited 2020 Apr 18], <http://www.ncbi.nlm.nih.gov/pubmed/18029412>, 359–70. Available from: .
- [8] X. Liu, M. Kakade, C.J. Fuller, B. Fan, Y. Fang, J. Kong, et al., Depression after exposure to stressful events: lessons learned from the severe acute respiratory syndrome epidemic, *Compr. Psychiatr.* 53 (1) (2012 Jan) 15–23.
- [9] S.A. Cassidy, C. Nicolaidis, B. Davies, S.D.R. Rosa, D. Eisenman, M.G. Onaiwu, et al., An expert discussion on autism in the COVID-19 pandemic. Autism in adulthood [internet] [cited 2020 Jul 1];2(2):106–17. Available from: <https://www.liebertpub.com/doi/10.1089/aut.2020.29013.sjc>, 2020 Jun 1.
- [10] Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: the roles of parenting stress and parenting self-efficacy [internet] [cited 2020 Apr 18]. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3420762/>.
- [11] A.L.R. Souza, R.A. Guimarães, D. de Araújo Vilela, R.M. de Assis, L.M. de Almeida Cavalcante Oliveira, M.R. Souza, et al., Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study, *BMC Psychiatr.* (2017 Oct 25) [cited 2020 Apr 29]; Available from: <http://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-017-1501-1>.

J.A. Patel*

*London School of Hygiene and Tropical Medicine, United Kingdom
University of Southampton School of Medicine, United Kingdom*

A.A. Badiani

University of Liverpool School of Medicine, United Kingdom

F.B.H. Nielsen^b, S. Assi^a, V. Unadkat^a

^a *University of Southampton School of Medicine, United Kingdom*

^b *London School of Hygiene and Tropical Medicine, United Kingdom*

B. Patel, C. Courtney

University of Liverpool School of Medicine, United Kingdom

L. Hallas

London School of Hygiene and Tropical Medicine, United Kingdom

* Corresponding author. London School of Hygiene and Tropical Medicine, United Kingdom.

E-mail address: mail.patel.jay@gmail.com (J.A. Patel).