AUTISM AND COVID-19

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Strategies for Supporters to Help Autistics and Their Families

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INVESTOR IN PEOPLE

Certificate Number 1985 ISO 14001 First and foremost, we would like to dedicate this study to all autistics who have either lost their lives or who have experienced serious illness due to COVID-19. We would also like to dedicate this book to the parents of autistic children who have been negatively impacted by the COVID-19 pandemic. Finally, we would like to acknowledge and dedicate this research to those healthcare professionals who are providing medical care and support to autistics and their families during the COVID-19 pandemic.

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ABSTRACT

Background: The first documented case of coronavirus disease (COVID-19), a disease caused by the virus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), occurred about 1 December 2019 in Wuhan, China. By late December 2019, a cluster of atypical pneumonia cases emerged in this city. Most of the patients in this cluster had a connection to the Huanan Seafood Market, which suggests that SARS-CoV-2 was zoonotic in origin. On 30 January 2020, the World Health Organization (WHO) declared COVID-19 a 'public health emergency of international concern'. On 11 March 2020, the WHO re-classified the COVID-19 outbreak a global pandemic. This pandemic has undoubtedly had a transformative impact on our society, economy and daily lives. It has also had an impact on autistics and their families.

Objectives: This study has two objectives. First, to present a synthesis of the literature about the impacts of the COVID-19 pandemic from the perspective of autistics and their families and to highlight any gaps in this field of research. Second, to conduct an online survey that will collect the views of autistics or parents raising autistic children about the gaps identified from the synthesis. To achieve these two objectives the following three research questions were posed:

- (1) What are the experiences of the COVID-19 pandemic from the perspective of parents raising autistic children?
- (2) What impacts has the COVID-19 pandemic had on autistics?
- (3) What are the gaps in our understanding about the impact of the COVID-19 pandemic on autistics and their families?

Source and Methods: With the intention of discovering studies that could answer the three research questions, a search of PubMed, using the key terms *autis* * AND *COVID* *, was conducted on 4 July 2021. This search

Abstract

resulted in the identification of 188 citations. All of these citations were subjected to a *Preferred Reporting Items for Systematic Reviews and Meta-analysis* analysis process. Using this process, 21 studies were identified that were deemed to answer one of the three research questions. From this literature three gaps were discovered, specifically vaccine hesitancy among autistics and parents raising autistic children, the experiences of autistics living with COVID-19 disease and parenting an autistic child during the COVID-19 pandemic. To address these gaps an online survey was developed and distributed on two separate occasions to autistics and their families. During its first distribution it was open for five weeks, from 13 July 2021 to 20 August 2021, and was completed by 32 respondents. During its second distribution it was open for six weeks, from 6 March 2022 to 17 April 2022, and was completed by 34 respondents.

Findings: An examination of the retrieved literature and the results from the two online surveys revealed that autistics and their parents have experienced a considerable amount of stress during state-imposed lockdowns and social distancing requirements. The results collected also showed that autistics were generally receptive to receiving a vaccine that can prevent them from developing COVID-19. A follow-up search of the literature indexed on PubMed using the same search permutations as the previous search was conducted on 27 May 2022. This follow-up search confirmed the results collected from the two online surveys.

Conclusions: To our knowledge, this is one of the first books about the impacts of the COVID-19 pandemic on autistics and their families. It is also the first study about vaccine hesitancy among autistics and their families, the experiences of autistics living with COVID-19 disease and parenting an autistic child during the COVID-19 pandemic. However, despite these contributions to this emerging and rapidly evolving public health crisis, the results reported in this study should be cautiously adopted since they were based on a small number of participants who all had the ability to access and read an online survey that was published in English.

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LIST OF ACRONYMS

ABCAberrant Behavior ChecklistASDAutism spectrum disorderCOVID-19Coronavirus diseaseGAD-7Generalised Anxiety Disorder ScaleGPSGlobal positioning systemMERS-CoVMiddle East respiratory syndromeNHSNational Health ServicePHQ-9Patient Health Questionnaire-9PRISMAPreferred Reporting Items for Systematic Reviews and Meta-analysisRNARibonucleic acidSARS-CoVSevere acute respiratory syndrome coronavirus 2TDTypically developingUSAUnited States of AmericaWHOWorld Health Organization	AAoM	Autism Alliance of Michigan
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SARS-CoVSevere acute respiratory syndrome coronavirusSARS-CoV-2Severe acute respiratory syndrome coronavirus 2TDTypically developingUSAUnited States of America	PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
SARS-CoV-2Severe acute respiratory syndrome coronavirus 2TDTypically developingUSAUnited States of America	RNA	Ribonucleic acid
TDTypically developingUSAUnited States of America	SARS-CoV	Severe acute respiratory syndrome coronavirus
USA United States of America	SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
	TD	Typically developing
WHO World Health Organization	USA	United States of America
0	WHO	World Health Organization

ABOUT THE AUTHORS

Dr Matthew Bennett holds a PhD in Disability Studies from Flinders University, Australia. He has lectured in Disability Studies at Griffith University, Queensland. He has also advised the Australian Government's Autism CRC and has published articles for the *Journal of Autism and Developmental Disorders*. He is actively involved in supporting autistics to achieve their potential in society by disseminating his knowledge about the autism spectrum via lectures, conference presentations and publications.

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