

AUTISM AND COVID-19

This page intentionally left blank

AUTISM AND COVID-19

Strategies for Supporters to Help Autistics and Their Families

BY

MATTHEW BENNETT

Independent Researcher, Australia

And

EMMA GOODALL

University of Southern Queensland, Australia



United Kingdom – North America – Japan – India
Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2022

Copyright © 2022 Matthew Bennett and Emma Goodall.
Published under exclusive licence by Emerald Publishing Limited.

Reprints and permissions service

Contact: permissions@emeraldinsight.com

No part of this book may be reproduced, stored in a retrieval system, transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise without either the prior written permission of the publisher or a licence permitting restricted copying issued in the UK by The Copyright Licensing Agency and in the USA by The Copyright Clearance Center. Any opinions expressed in the chapters are those of the authors. Whilst Emerald makes every effort to ensure the quality and accuracy of its content, Emerald makes no representation implied or otherwise, as to the chapters' suitability and application and disclaims any warranties, express or implied, to their use.

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN: 978-1-80455-034-2 (Print)
ISBN: 978-1-80455-033-5 (Online)
ISBN: 978-1-80455-035-9 (Epub)



ISOQAR
REGISTERED

Certificate Number 1985
ISO 14001

ISOQAR certified
Management System,
awarded to Emerald
for adherence to
Environmental
standard
ISO 14001:2004.



INVESTOR IN PEOPLE

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.

This page intentionally left blank

CONTENTS

<i>Abstract</i>	ix
<i>List of Tables, Images, and Figures</i>	xi
<i>List of Acronyms</i>	xv
<i>About the Authors</i>	xvii
1. Introduction	1
2. Methodology	11
3. Results	25
4. New Perspectives about the COVID-19 Pandemic for Autistics	69
<i>Choice of Terminology</i>	83
<i>Appendices</i>	85

This page intentionally left blank

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

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.

LIST OF TABLES, IMAGES, AND FIGURES

Table 2.1.	Overview of the Arksey and O'Malley's Six-Step Methodological Framework for Conducting a Scoping Review.	12
Table 2.2.	Inclusion Criteria.	14
Table 2.3.	Exclusion Criteria.	15
Table 2.4.	The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Analysis Process in This Study.	16
Table 3.1.	Characteristics of Studies about Parents Raising Autistic Children.	26
Table 3.2.	Examples of Questions Asked during the Telephone Interviews.	28
Table 3.3.	Studies That Contain Parental Accounts of Their Autistic Children and the COVID-19 Pandemic.	29
Table 3.4.	Psychosocial and Behavioural Impact of the Emergency Outbreak.	30
Table 3.5.	Responses to the Open-Response Question about What Could Be of Help to Deal with the Ongoing Emergency.	35
Table 3.6.	Studies that Contain Accounts from Autistic Adults about the COVID-19 Pandemic.	39
Table 3.7.	COVID-19 Pandemic-Related Change in Depression and Anxiety Symptoms.	43
Table 3.8.	Mean Scores per Group Regarding Eleven General and Three Pandemic-Related Topics of Worry.	44
Table 3.9.	Mean Scores per Group Regarding the Impact of the Pandemic on Topics Related to the DSM Criteria of Autism Spectrum Disorder.	45
Table 3.10.	Responses to Questions Related to Help and Guidance.	46

Table 3.11.	Themes Identified From Responses of Autistic Adults to the Following Open Question: <i>What Measures Could Be Taken to Help You Manage Your Mental Health during the Current COVID-19 Pandemic?</i>	47
Table 3.12.	Themes Identified from Responses of Autistic Adults to the Following Open Question: <i>What Changes, Due to the Effects of the COVID-19 Regulations on Your Everyday Life, Are the Most Difficult for You (If Any)?</i>	48
Table 3.13.	Themes Identified from Responses of Autistic Adults to the Following Open Question: <i>What Changes, Due to the Effects of the COVID-19 Regulations on Your Everyday Life, Have Caused the Most Stress/Anxiety (If Any)?</i>	50
Table 3.14.	Themes Identified from Autistic Adults' Responses to the Following Open Question: <i>What Changes, Due to the Effects of the COVID-19 Regulations on Your Everyday Life, Have Made Life More Pleasant for You (If Any)?</i>	52
Table 3.15.	Studies that Contain Mixed Samples of Autistic Children and Adults.	53
Table 3.16.	Parent-Reported Information of COVID-19 Related Understanding and Problems for Autistic Children and Adolescents.	54
Table 3.17.	Behaviour, Sleep Quality, and Hypersensitivity Differences before and during the COVID-19 Pandemic.	55
Table 3.18.	Limitations of Studies about Parents Raising Autistic Children.	57
Table 3.19.	Limitations of Studies about Autistic Adults During the COVID-19 Pandemic.	58
Table 3.20.	Limitations of Studies about Autistic Children during the COVID-19 Pandemic.	60
Table 4.1.	Age of Participants.	70
Table 4.2.	Country of Residency.	71
Table 4.3.	Restrictions Related to the COVID-19 Pandemic.	72
Table 4.4.	Techniques and Strategies Used to Cope with the Restrictions Associated with the COVID-19 Pandemic.	73
Table 4.5.	Reasons for Wanting to be Vaccinated Against COVID-19 Disease.	76

Image 1.1.	Image of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) Virions Taken by the National Institutes of Allergy and Infectious Diseases.	2
Figure 1.1.	Cross-Species Transmission Pathways for Three Coronavirus Virions.	3
Figure 1.2.	Transmission Pathways for Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2).	4
Figure 1.3.	Common Symptoms of COVID-19 Disease.	5
Figure 2.1.	Results from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Analysis Process.	17

This page intentionally left blank

LIST OF ACRONYMS

AAoM	Autism Alliance of Michigan
ABC	Aberrant Behavior Checklist
ASD	Autism spectrum disorder
COVID-19	Coronavirus disease
GAD-7	Generalised Anxiety Disorder Scale
GPS	Global positioning system
MERS-CoV	Middle East respiratory syndrome
NHS	National Health Service
PHQ-9	Patient Health Questionnaire-9
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
RNA	Ribonucleic acid
SARS-CoV	Severe acute respiratory syndrome coronavirus
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
TD	Typically developing
USA	United States of America
WHO	World Health Organization

This page intentionally left blank

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.

Dr Emma Goodall is an adjunct research fellow at the University of Southern Queensland, holds a PhD in Education, focused on teaching students on the autism spectrum. She is an executive member of the Australian Society for Autism Research, independent researcher through Healthy Possibilities, a published author and keynote speaker in the areas of autism, sexuality and relationships, education and interoception.