



ADDRESSING UNDERSERVED POPULATIONS IN AUTISM SPECTRUM RESEARCH

An Intersectional
Approach

Matthew Bennett
Emma Goodall

Addressing Underserved Populations in Autism Spectrum Research

This page intentionally left blank

Addressing Underserved Populations in Autism Spectrum Research: An Intersectional Approach

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: 978-1-80382-464-2 (Print)

ISBN: 978-1-80382-463-5 (Online)

ISBN: 978-1-80382-465-9 (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

We would like to dedicate this book to those who are interested in learning about the autism spectrum. After reading this book we hope that you will develop an awareness of the current limitations in our knowledge about the autism spectrum. We also hope you will learn and implement strategies for conducting research that can be replicated and research practices that respect the rights and dignity of autistics.

This page intentionally left blank

Table of Contents

List of Tables	<i>ix</i>
List of Graphs	<i>xiii</i>
List of Figures	<i>xv</i>
List of Acronyms	<i>xvii</i>
About the Authors	<i>xix</i>
Choice of Terminology	<i>xxi</i>
Foreword	<i>xxiii</i>
Chapter 1 Introduction	<i>1</i>
Chapter 2 Exploring the Needs of Autistic Seniors	<i>11</i>
Chapter 3 Exploring the Lack of Research About Autistic Women	<i>27</i>
Chapter 4 Addressing the Lack of Research About Fathers Raising Autistic Children	<i>39</i>
Chapter 5 Examining the Needs of Autistics With Intellectual Disabilities	<i>51</i>
Chapter 6 Researching African American Autistics	<i>75</i>
Chapter 7 Important Knowledge for Diagnosing Autistic Patients	<i>99</i>

viii *Table of Contents*

Chapter 8	Participatory Research Practices With Autistics	<i>117</i>
Chapter 9	The Reproducibility Crisis and Autism Spectrum Research	<i>177</i>
Chapter 10	Conclusion and Final Comments	<i>215</i>
	Index	<i>217</i>

List of Tables

Table 3.1.	Research Priorities, Challenges, Recommendations for Autistic Females and Implications of Recommendations of Research.	32
Table 4.1.	Examples of the Main Themes From Burrell, Ives, and Unwin's (2017) Study.	41
Table 4.2.	Examples of the Main Themes From Cheuk and Lashewicz's (2016) Study.	42
Table 4.3.	Examples of Main Themes From Pottas and Pedro's (2016) Study.	44
Table 5.1.	Availability and Distribution of Intelligence Quotient Scores Among Children Aged 8 Years With Autism Spectrum Disorder (ASD) – Autism and Developmental Disabilities Monitoring Network, 10 Sites, United States, 2016.	63
Table 5.2.	Number and Percentage of Children With Co-occurring Intellectual Disability Among Children Aged 4 Years With Autism Spectrum Disorder, by Site, Sex and Year – Early Autism and Developmental Disabilities Monitoring Network, Four Sites, United States, 2010, 2012, and 2014.	64
Table 5.3.	Children Aged 4 Years With Autism Spectrum Disorder and Co-occurring Intellectual Disability, by Site and Sex – Early Autism and Developmental Disabilities Monitoring Network, Four Sites, United States, 2016.	65
Table 1.	Estimated Prevalence of Autism Spectrum Disorders (ASDs) Among Children Aged 8 Years, by Race/Ethnicity – Autism and Developmental Disabilities Monitoring (ADDM) Network, Six Sites, United States, 2000.	86

Table 2.	Estimated Prevalence of Autism Spectrum Disorders Among Children Aged 8 Years, by Site and Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002.	87
Table 3.	Number and Percentage of Children Aged 8 Years, by Race/Ethnicity and Site – Autism and Developmental Disabilities Monitoring Network, Eight Sites, United States, 2004.	88
Table 4.	Estimated Prevalence of Autism Spectrum Disorders Among Children Aged 8 Years, by Sex and Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2006.	89
Table 5.	Estimated Prevalence of Autism Spectrum Disorders per 1,000 Children Aged 8 Years, by Sex and Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008.	90
Table 6.	Estimated Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years, by Sex and Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010.	91
Table 7.	Estimated Prevalence of Autism Spectrum Disorder Among 1,000 Children Aged 8 Years, by Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012.	92
Table 8.	Estimated Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years, by Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014.	93
Table 9.	Estimated Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years, by Race/Ethnicity – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016.	94

Table 10.	Prevalence of Autism Spectrum Disorder Among Children Aged 4 Years, by Race/Ethnicity – Early Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2010, 2012 and 2014.	95
Table 11.	Prevalence of Autism Spectrum Disorder Among Children Aged 4 Years, by Race/Ethnicity – Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016.	97
Table 7.1.	Diagnostic Agreement Between Health Professionals.	104
Table 8.1.	Description of the Seminars in Fletcher-Watson et al.’s (2019) Study.	118
Table 8.2.	The Inclusive Research Protocol Outlined by Arnold et al. (2019).	122
Table 8.3.	Autism CRC Recommendations for Focus Groups and Interview Sessions.	127
Table 8.4.	Providing Research Results to Individuals on the Autism Spectrum and Their Families.	135
Table 8.5.	Including Autistics as Co-presenters of Research.	137
Table 9.1.	Examples of Misleading Language in Peer-Reviewed Papers and Revisions Using Language of Clarity.	186
Table 9.2.	Guidelines for Successful Submissions of Qualitative Manuscripts to the Journal of Autism and Developmental Disorders.	195

This page intentionally left blank

List of Graphs

- Graph 5.1. Intelligence Quotient (IQ) of Children Aged 8 Years With an Autism Spectrum Disorder for Whom Psychometric Test Data Were Available, by Site and Sex – Autism and Developmental Disabilities Monitoring Network, Three Sites, United States, 2000. 56
- Graph 5.2. Percentages of Children Aged 8 Years With and Without Cognitive Impairment, by Intelligence Quotient (IQ) Score, Site and Sex – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. Includes only sites with cognitive functioning data for >80% of cases. 57
- Graph 5.3. Intelligence Quotient (IQ) of Children Aged 8 Years With an Autism Spectrum Disorder (ASD) for Whom Psychometric Test Data Were Available, by Site, Sex and IQ Score – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2006. Sites with psychometric test data on >70% of children identified with an ASD were included. 58
- Graph 5.4. Most Recent Intelligence Quotient (IQ) as of Age 8 Among Children Identified With Autism Spectrum Disorders (ASDs) for Whom Psychometric Test Data Were Available, by Site and Sex – Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2008. F = female; IQ = intelligence quotient; M = male. *N* = 1,981; Includes sites having information on intellectual ability available for at least 70% of children who met the ASD case definition. 59

- Graph 5.5. Most Recent Intelligence Quotient Score as of Age 8 Among Children With Autism Spectrum Disorder (ASD) for Whom Test Data Were Available, by Sex and Site – Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2010. F = female; IQ = intelligence quotient; M = male. Includes sites that had intellectual ability data available for $\geq 70\%$ of children who met the ASD case definition. 60
- Graph 5.6. Scores of Most Recent Intelligence Quotient Tests for Children Identified With Autism Spectrum Disorder (ASD) for Whom Test Data Were Available – Autism and Developmental Disabilities Monitoring Network, Nine Sites, United States, 2012. ADDM, Autism and Developmental Disabilities Monitoring Network; E + H = education and health records; F = female; IQ = intelligence quotient; M = male. Includes sites having information on intellectual ability available for $\geq 70\%$ of children who met the ASD case definition ($N = 3,353$, excluding unknown IQ). 61
- Graph 5.7. Most Recent Intelligence Quotient Score as of Age 8 Among Children With Autism Spectrum Disorder for Whom Test Data Were Available, by Sex and Site – Autism and Developmental Disabilities Monitoring Network, Nine Sites, United States, 2014. ADDM = Autism and Developmental Disabilities Monitoring Network; F = female; IQ = intelligence quotient; M = male. Includes nine sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, New Jersey, North Carolina and Tennessee) that had intellectual ability data available for $\geq 70\%$ of children who met the ASD case definition ($n = 3,714$). 62

List of Figures

Figure 5.1.	Five Steps in the Data Collection Process for the ADDM Network.	55
Figure 9.1.	Estimated financial costs of preclinical research that is irreproducible in the United States.	179
Figure 9.2.	Flowchart of the Manuscripts Handled by Miyakawa for Molecular Brain.	185
Figure 9.3.	The Relationship Between Researcher, Journal and Readership.	189

This page intentionally left blank

List of Acronyms

AASPIRE	Academic Autism Spectrum Partnership in Research and Education
ADDM Network	Autism and Developmental Disabilities Monitoring Network
ADOS Module 4	Autism Diagnostic Observation Schedule Module 4
APA	American Psychiatry Association
APC	Article Processing Charge
AQ	Autism Quotient
ARC	Australian Research Council
ASA	American Statistical Association
ASD	Autism Spectrum Disorder
ATSI	Aboriginal and Torres Strait Islander
AUD	Australian Dollar
Autism CRC	Cooperative Research Centre Living with Autism
BASP	Basic and Applied Psychology
CBPR	Community-based participatory research
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
CIHR	Canadian Institutes of Health Research
DASH-II	Diagnostic Assessment for the Severely Handicapped – II
DPR	Danish Psychiatric Register
DSM-5	Diagnostic and Statistical Manual of Mental Disorders – Fifth edition
DSM-III	Diagnostic and Statistical Manual of Mental Disorders – Third edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – Fourth edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders – Fourth edition – Text Revision
FOCUS	Focus on Autism and Other Developmental Disabilities
GMDS-ER	Griffiths Mental Development Scale – Extend Revised
IAN	Interactive Autism Network
ID	Intellectual Disability
IMFAR	International Meeting for Autism Research
INSAR	International Society for Autism Research
IQ	Intelligence Quotient
JADD	Journal of Autism and Developmental Disorders
Leiter-R	Leiter International Performance Test – Revised
NHMRC	National Health and Medical Research Council
OAJ	Open Access Journals
PDD	Pervasive Developmental Disorders
PDD-NOS	Pervasive Developmental Disorders – Not Otherwise Specified
PJ	Predatory Journals
QRPs	Questionable Research Practices
RASD	Research in Autism Spectrum Disorders
SBJ	Subscription-Based Journals

This page intentionally left blank

About the Authors

Matthew Bennett holds a PhD in Disability Studies from Flinders University, South Australia. His PhD was about the life experiences of adults who live on the autism spectrum. Specifically, he explored the education, depression, employment and intimate relationships of adults with Asperger's syndrome. He has also lectured in Disability Studies at Griffith University, Queensland. Matthew is an active advocate for the rights of people on the autism spectrum.

Emma Goodall, PhD, is an autism author, researcher and consultant in South Australia. She is reviewing programmes and developing and implementing research-based policy and programmes to enable students on the autism spectrum to flourish. Emma combines her professional and academic skills and knowledge with her lived experience of Asperger's to help people understand what it means to be on the autistic spectrum and how different life is for those on and not on the spectrum. Emma is passionate about helping families and schools to facilitate success for children on the spectrum. Emma lives in Adelaide with her dog. She is also on the executive committees of the Australian Society for Autism Research and the Autistic Self Advocacy Network of Australia, New Zealand and Oceania.

This page intentionally left blank

Choice of Terminology

There is an ongoing debate in the field of autism spectrum research, as well as in the broader field of disability studies, as to what is the most appropriate use of terminology to address members of the autistic community (Tepest, 2021; Vivanti, 2020). Some people prefer using person-first language (i.e. people on the autism spectrum) while others prefer using identity-first language (i.e. autistic person). Throughout this book we use identity-first language since contemporary research has shown that most autistics prefer this language convention (Bury, Jellett, Spoor, & Hedley, 2020; Kenny et al., 2016). Furthermore, it is our belief, as autistic researchers, that since the autism spectrum is a fundamental and an inseparable part of a person's identity that the word 'autistic' should be used instead of 'person with autism' or 'person on the autism spectrum'.

References

- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It defines who I am" or "it's something I have": What language do [autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism and Developmental Disorders*. doi:[10.1007/s10803-020-04425-3](https://doi.org/10.1007/s10803-020-04425-3)
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism: The International Journal of Research and Practice*, 20(4), 442–462. doi:[10.1177/1362361315588200](https://doi.org/10.1177/1362361315588200)
- Tepest, R. (2021). The meaning of diagnosis for different designations in talking about autism. *Journal of Autism and Developmental Disorders*, 51(2), 760–761. doi:[10.1007/s10803-020-04584-3](https://doi.org/10.1007/s10803-020-04584-3)
- Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, 50(2), 691–693. doi:[10.1007/s10803-019-04280-x](https://doi.org/10.1007/s10803-019-04280-x)

This page intentionally left blank

Foreword

Emma and Mathew's book has come at an important time for autism research. While there has always been a wealth of research focusing on autism, respectful and engaging research with the autistic and autism communities has, until recently, been lacking. What this book does is focus on diversity within and between autistic people, tackling important points of intersectionality. In doing so this text addresses myths and stereotypes, inviting readers to think about key issues such as ageing, gender, ability, and race, when reflecting on research practices.

An important contribution of the book is its appeal to a diverse readership. It is written in a way that considers issues that are important for autistic people, parents, professionals and researchers. This strength in diversity of readership potential is a clear signal that research needs to be a collaborative endeavour. For too long we have focused on a particular kind of 'expert', and it is only when we focus on empowering and co-produced work can we consider things from a range of perspectives, leading to clearer understandings. Emma and Matthew's book invites readers to reassess what their taken-for-granted position of 'expert' looks like and what research topic is focused on.

The reflections on the replicability crisis in psychology highlight the diversity of humans and the important influences that context, culture and historical understandings have on both the focus of research, the design framework adopted and our interpretation of the findings. It does matter what position we come from as this will influence not only the questions that we ask but also how we ask them and what we do with the answers. We have long known that research is not a neutral endeavour, and some people's interests are often better served than others. By placing a clear lens on under-researched populations, Emma and Matthew highlight the need for research to reflect the priorities of the autism and autistic communities. Additionally, the book provides practical guidance for non-researchers to engage critically with research, enabling judgements to be formed about the quality of research, allowing the reader to make future considerations about research they may encounter beyond this text.

I hope you enjoy the thought-provoking issues raised – the book encourages us all to ask questions to further knowledge, while critically considering findings in our interpretations of these.

Professor Charlotte Brownlow
University of Southern Queensland, Australia

This page intentionally left blank

Chapter 1

Introduction

1.1 A Brief History of the Autism Spectrum

In his 500-page book, *Dementia Praecox of the Group of Schizophrenia*, Eugene Bleuler (30 April 1857–15 July 1939) gave us our first, albeit brief, description of autism. In this book he framed autism as one of the four key characteristics of schizophrenia.

Bleuler defined schizophrenia with his four ‘A’s’, referring to the blunted *Affect* (diminished emotional response to stimuli); loosening of *Associations* (by which he meant a disordered pattern of thought, inferring a cognitive deficit), *Ambivalence* (an apparent inability to make decisions, again suggesting a deficit of the integration and processing of incident and retrieved information) and *Autism* (a loss of awareness of external events, and a preoccupation with the self and one’s own thoughts).

(McNally, 2016, p. 109)

The next major development in our understanding of the autism spectrum occurred during the 1940s when Leo Kanner (13 June 1894–3 April 1981) and Hans Asperger (18 February 1906–21 October 1980) independently published their first studies about this subject. In 1943, Kanner published his seminal paper ‘Autistic Disturbances of Affective Contact’. In this article he described a condition that he called ‘infantile autism’, which was comprised of three characteristics: restricted and repetitive patterns of behaviour, social limitations and restricted verbal communication abilities (Kanner, 1943). The following year, Asperger published in German his article ‘Die “Autistischen psychopathen” im Kindesalter’, which translates to ‘The “autistic psychopaths” in childhood’. He used the term ‘autistic psychopathy’ because the children he observed seemed to demonstrate an indifference towards the emotional states of others (Asperger, 1944). The characteristics exhibited by the four children in Asperger’s study closely resembled those exhibited by the 11 children documented by Kanner, although to a lesser extent (Asperger, 1944; Kanner, 1943).

2 Addressing Underserved Populations in Autism Spectrum Research

Those in the Anglosphere who study the autism spectrum typically consider Kanner a pioneer of autism spectrum research and Asperger as a latecomer. This perception was perhaps created because Kanner's research gained widespread recognition among those in the medical establishment while Asperger's work was unknown among English-speaking clinicians due to it being conducted in Vienna during World War II. However, during 1981, Lorna Wing (7 October 1928–6 June 2014) translated Asperger's first article about autistic psychopathy from German to English. Furthermore, during 1991, Uta Frith (25 May 1941) translated his doctoral thesis into English (Frith, 1991; Lyons & Fitzgerald, 2007; Wing, 1981). Frith is also credited with coining the eponym 'Asperger syndrome' to replace the term 'autistic psychopathy'. It is widely believed that this eponym removed any pejorative connotations associated with the word 'psychopathy' (Frith, 1991).

Since Kanner's 1943 seminal article, there has been an incremental increase each year in the number of studies about the autism spectrum. This statement was supported by Beykikhoshk, Arandjelović, Phung, Venkatesh, and Caelli (2015) who found that with each passing year the quantity of studies indexed in PubMed that have the word 'autism' in either their abstract or title has increased. Happé and Frith (2020) have proposed that this increase can be attributed to the following seven major factors.

- (1) *Broadening the definition of the autism spectrum*: The American Psychiatric Association (APA) first described autism in the *Diagnostic and Statistical Manual of Mental Disorders – Third edition*. In this edition, six criteria formed the description of autism (APA, 1980). Additionally, individuals with an existing physical or mental health condition could not receive an autism diagnosis. In contrast, the *Diagnostic and Statistical Manual of Mental Disorders – Fifth edition* (DSM-5), the most contemporary edition released in May 2013, had a more elaborate description of the autism spectrum, including the options to note what conditions are co-occurring. The DSM-5 had five main criteria, seven sub-categories and a table for defining severity levels (APA, 2013; Happé & Frith, 2020). With the broadening of the diagnostic criteria, this has resulted in an increase in the number of people being diagnosed as autistic (Bennett, Webster, Goodall, & Rowland, 2018a).
- (2) *Increased recognition of autistic females*: Typically, autistic males are more inclined to be research participants than autistic females. However, there is an emerging trend in the field of autism spectrum research to acknowledge the lack of research about autistic females. For example, during 2015, the academic journal *Molecular Autism* published a special edition about autistic females. Furthermore, the academic journal *Autism: The International Journal of Research and Practice* in August 2017 published the special edition *Women and Girls on the Autism Spectrum* (Happé & Frith, 2020; Mandy & Lai, 2017). With these reputable and prominent academic journals acknowledging this lack of research, there has been a trend towards increasing the amount of research about autistic females.

- (3) *Acknowledging that autism is a lifelong condition*: Since Kanner's 1943 study, there has been a propensity to study autistic children instead of autistic adults (Jang et al., 2014). This inclination has contributed to the development of the misconception that autism is a childhood disorder and that autistic children somehow 'outgrow' their autism (Bennett, Webster, Goodall, & Rowland, 2018b). However, since 2010 there has been a trend towards conducting more research about autistic adults. This trend has partly influenced the academic journal *Autism: The International Journal of Research and Practice* to publish the special edition *Autism in Adulthood* during 2015 (Happé & Frith, 2020).
- (4) *Changing the concept of autism from a 'category' condition to a 'spectrum' condition*: When Kanner and Asperger published their studies about autism and Asperger syndrome, respectively, they were considered separate conditions. The notion that these two conditions were distinct was reflected in the APA's *Diagnostic and Statistical Manual of Mental Disorders – Fourth edition – Text Revision* (DSM-IV-TR), which catalogued autism and Asperger syndrome as two separate conditions (Linton, Krcek, Sensui, & Spillers, 2014). However, in the DSM-5, autism and Asperger syndrome were amalgamated into one diagnostic condition, 'autism spectrum disorder' (APA, 2013). The conceptualisation of autism being a 'spectrum condition' has caused a generalisation of what constitutes autism and has consequently resulted in more people being diagnosed as autistic (Bennett et al., 2018a; Happé & Frith, 2020).
- (5) *Acknowledging that autism impacts many aspects of life*: When autism was first documented, it was primarily considered a condition that only impacted children. This notion helped create the myth that autism could be outgrown (Bennett et al., 2018b). However, it is becoming more accepted that autism can impact all age groups and different aspects of a person's life (Happé & Frith, 2020). This acceptance has been reinforced by general studies about the autism spectrum, such as the spiritual beliefs of autistics (Dubin & Graetz, 2009), autistic performing arts professionals (Buckley, Pellicano, & Remington, 2021) and the impact of the COVID-19 pandemic on the production of research about the autism spectrum (den Houting, 2020; Pellicano & Stears, 2020). With the publication and proliferation of such general studies, the amount of research about the autism spectrum and autistics, regardless of their age, has increased.
- (6) *Increased recognition that autistics often have co-morbid conditions*: There is an increasing recognition that autistics often have co-morbid conditions, such as depression (Bennett, 2016a; Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2019; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006) and insomnia (Mannion & Leader, 2014). Consequently, it is becoming more common for a clinician to consider the notion that their client might be autistic (Happé & Frith, 2020).
- (7) *From regarding the autism spectrum as a purely 'developmental disorder' to embracing a neurodiversity perspective*: When autism was first identified it was portrayed as a developmental disorder (Kanner, 1943). However, as the

4 *Addressing Underserved Populations in Autism Spectrum Research*

neurodiversity movement has gained popularity and acceptance among members of the autistic community and the general public, this perspective is changing. Proponents of neurodiversity theory assert that the autism spectrum is not a condition that needs to be treated or cured but that it is a part of a person's identity (Jaarsma & Welin, 2012). Scholars who embrace the neurodiversity paradigm position autistics as co-creators of research and embrace such practices (*Cooperative Research Centre Living with Autism* (Autism CRC), 2014; Happé & Frith, 2020).

Aside from Happé and Frith's seven reasons, the increased prevalence and incidence of autism has also contributed to more scholars studying the condition and, consequently, more research. Hansen, Schendel, and Parner (2015) examined if changes made in the reporting of medical and psychiatric conditions in the Danish Psychiatric Register (DPR) changed the prevalence and incidence of the autism spectrum in Denmark. Before 1995, only a patient's psychiatric conditions during their admission were recorded in the DPR. However, from 1995 onwards, a patient's psychiatric conditions upon exiting the healthcare system were also recorded. Hansen and colleagues measured if the prevalence of autism diagnoses changed before, during and after the reporting changes were made to the DPR. They reported that there was a 42% increase in the prevalence of autism that was caused by the introduction of outpatient reporting and examination practices. Irrespective of these differences, the increased prevalence of autism has undoubtedly contributed to an increased effort on behalf of scholars to publish research about the autism spectrum.

1.2 Summary of the Remaining Chapters

With a plethora of publicly accessible studies, one can be forgiven for assuming that every conceivable aspect of the autism spectrum has been explored. However, just because there is a large amount of research about this condition does not mean that every aspect has been comprehensively explored. There still remains many perspectives that have not been extensively researched, for instance, autistic seniors (Bennett, 2016b; Michael, 2016). The next five chapters of this book explain some gaps in our knowledge about this condition. Within each of these chapters, plausible explanations for why these gaps have emerged are provided along with an outline of some areas where more research can be conducted. This is followed by two chapters that outline specific and practical research strategies that are both respectful of autistics and able to be replicated. Below, the contents of each chapter are described in more detail.

In Chapter 2, a discussion about the lack of literature about autistic seniors is presented. It begins by presenting the results of Bebko et al.'s (2008) and Jang et al.'s (2014) studies, which conclude that few studies contain samples of autistic seniors. The allocation of public funding to studying the biological aspects of the autism spectrum and the long-term trend in reducing the age when an autism spectrum diagnosis is made are then cited as two plausible reasons for why

autistics seniors have not received much attention from scholars. This chapter concludes with a summary of the literature about autistic seniors and some of the gaps in our knowledge that could be researched more thoroughly.

The lack of research about autistic females is the subject of Chapter 3. This chapter begins with the acknowledgements of several academics (Shefcyk, 2015) and autism-specific journals (i.e. *Molecular Autism* and *Autism: The International Journal of Research and Practice*) about the lack of research about this topic. Three factors that have contributed to this lack of research are then outlined. First is the notion that healthcare professionals often do not have a proficient understanding of the autism spectrum which hinders their ability to diagnose female patients as being autistic. Second is that diagnostic instruments may not be sensitive enough to detect autistic features exhibited by females. Third is that autistic females can often ‘camouflage’ their social difficulties rendering it more difficult for them to be diagnosed as being autistic, which subsequently obstructs and minimises their availability as candidates for research. This chapter then concludes with a set of recommendations as to how more research about autistic females can be produced.

In Chapter 4, the lack of research about fathers raising autistic children is explored. This chapter begins with Braunstein et al.’s (2013) findings which showed that there is a lack of research about fathers raising autistic children. This chapter then presents the paucity of research about the experiences of fathers parenting their autistic child. Topics where more research can be conducted about fathers raising autistic children are then presented. This chapter concludes with a series of strategies that researchers can use to recruit such fathers to participate in research.

The lack of research about autistics with intellectual disabilities is examined in Chapter 5. In this chapter the reader is first introduced to the condition of intellectual disabilities, followed by several studies about the prevalence of intellectual disabilities among members of the autistic population. This chapter then describes the findings from the *Autism and Developmental Disabilities Monitoring (ADDM) Network* about the proportion of the autistic population in the United States from 2002 to 2016 that also have an intellectual disability. The ADDM Network is operated by the United States Government’s *Centers for Disease Control and Prevention (CDC)* and is considered one of the most reliable and authoritative measures of the characteristics among the autistic population. Despite these studies and data from some of the ADDM Network data collection sites showing that typically 25% of the autistic population also has an intellectual disability, most of the research has been conducted with autistics without an intellectual disability. The stress that caregivers raising autistic children with intellectual disabilities encounter and that autistics with intellectual disabilities are a small cohort within the autistic population are then described as two factors that are responsible for the lack of research about autistics with intellectual disabilities. Several areas about this topic that would benefit from more attention conclude this chapter.

Chapter 6 brings to the reader’s attention the lack of research about African American autistics. There is also a lack of research about autistics from other

ethnic minorities, such as indigenous Australians. However, for brevity, Chapter 6 will only focus on the lack of research about African American autistics. It begins by explaining the CDC's statistics from the ADDM Network about the proportion of the autistic population in the United States who are African American. It then explains some of the reasons why there has been a lack of research about this ethnic minority in research about the autism spectrum. This chapter concludes with four recommendations as to how more research about African American autistics can be produced.

Unlike the previous chapters that explain 'what' aspects of the autism spectrum require more research, the last three chapters explain 'how' research about this condition should be conducted. Chapter 7 describes strategies that clinicians can use to ensure that their patients are diagnosed as autistic. Diagnosing such patients can ensure that there is a large pool of potential candidates for research. Chapter 8 outlines how to conduct participatory research with autistics. Examples of these practices include adjusting the physical environment to ensure that autistics are not sensorially overwhelmed. In Chapter 9, strategies that can be implemented to mitigate a potential reproducibility crisis in the field of autism spectrum research are explained; for example, publishing datasets so that the results reported in a study can be confirmed by repeating the analysis of the data collected and documented in the dataset.

1.3 The Intended Audience for This Book

1.3.1 Academics Who Research the Autism Spectrum

Discovering and then disseminating knowledge are two tasks that academics perform. They accomplish these tasks by identifying gaps in our knowledge about a subject and explaining why more research should be conducted to address such gaps. The ultimate outcome of this activity is to create new understandings about a topic. This book has been designed to assist academics in their research activities. Chapters 2–6 present various gaps in our knowledge about the autism spectrum. After reading these chapters, scholars should understand some areas where more research is required. This book also provides researchers in Chapters 7 and 8 with the tools needed to engage with autistics in a mutually respectful and ethical manner. Additionally, after reading Chapter 9, researchers should develop the skills needed to produce robust and credible research that can be repeated to verify that the results stated are credible.

1.3.2 Autistics

This book provides autistics with two benefits. First, they can learn about topics that require more attention from researchers, such as research about autistics with intellectual disabilities. Such insights can allow them to understand the extent of our current knowledge about the autism spectrum. Second, after reading Chapter 8, they can develop an appreciation for appropriate research etiquette that is 'autistic friendly'. Equipped with this knowledge they will be able to identify situations in

which there is a heightened possibility of them being exploited, or conversely, situations where they may be able to contribute more widely to research about the autism spectrum.

1.3.3 Professionals Who Support Autistics

After reading this book, professionals can obtain several insights about the autism spectrum that may help them improve their professional practice. For example, after reading Chapter 3, some professionals will develop an awareness that females are often not diagnosed as autistic because of their innate abilities to conceal their social difficulties and that instruments may not be sensitive enough to identify the subtle autistic characteristics that females typically exhibited. With these insights in mind, clinicians might be able to improve their diagnostic practices. Additionally, Chapter 8 outlines several strategies that can help researchers facilitate the participation of autistics in studies. Although this chapter is pitched at researchers, it can also help those who support autistics by giving them advice about how to support their inclusion in research. For example, it is mentioned that autistic participants might feel comfortable in rooms that do not arouse their sensory sensitivities.

1.3.4 Students

This book has two benefits for students studying the autism spectrum. First, they can obtain several insights into where more research can be conducted. Such insights can help them develop an awareness as to the limits of our knowledge about the autism spectrum. Second, some students who read this book will pursue a research career. For these students, they might obtain some benefits after reading Chapters 8 and 9. Chapter 8 gives them some suggestions about how to engage autistics in the research process, from designing the study to disseminating its results. Chapter 9 brings to a student's attention some practices that they should implement to ensure that their research is reproducible. It is anticipated that after reading this book students will learn the limits of our knowledge about the autism spectrum, several strategies about engaging with autistics in research and conducting studies that can be reproduced.

1.3.5 Parents

After reading this book some parents who raise autistic children can develop a better understanding of the autism spectrum and appropriate research practices. Several chapters can give them an appreciation of the current limits of our knowledge about the autism spectrum. For example, there is currently a lack of research about autistics with intellectual disabilities, fathers raising autistic children and autistic seniors. Additionally, this book will hopefully help some parents understand suitable and ethical research practices so that they can be aware of practices that might exploit their autistic children.

References

- American Psychiatry Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: DSM-III.
- American Psychiatry Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: DSM-5.
- Asperger, H. (1944). Die “Autistischen psychopathen” im Kindesalter. *Archiv für psychiatrie und nervenkrankheiten*, 117(1), 76–136. doi:10.1007/BF01837709
- Bebko, J. M., Schroeder, J. H., Weiss, J. A., Wells, K., McFee, K., & Goldstein, G. M. (2008). The face of autism research as reflected in the IMFAR looking glass. *Research in Autism Spectrum Disorders*, 2(3), 385–394. doi:10.1016/j.rasd.2007.06.005
- Bennett, M. (2016a). The importance of interviewing adults on the autism spectrum about their depression and suicidal ideation experiences. *Journal of Autism and Developmental Disorders*, 46(4), 1492–1493. doi:10.1007/s10803-015-2674-4
- Bennett, M. (2016b). “What is life like in the twilight years?” A letter about the scant amount of literature on the elderly with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(5), 1883–1884. doi:10.1007/s10803-016-2710-z
- Bennett, M., Webster, A. A., Goodall, E., & Rowland, S. (2018a). Exploring the identity of autistic individuals: Reconstructing the autism epidemic myth. In *Life on the autism spectrum* (pp. 17–35). Singapore: Springer. doi:10.1007/978-981-13-3359-0_2
- Bennett, M., Webster, A. A., Goodall, E., & Rowland, S. (2018b). Supporting self-efficacy and self-determination on the autism spectrum: Refuting the “autism can Be outgrown” myth. In *Life on the autism spectrum* (pp. 213–232). Singapore: Springer. doi:10.1007/978-981-13-3359-0_11
- Beykikhoshk, A., Arandjelović, O., Phung, D., Venkatesh, S., & Caelli, T. (2015). Using Twitter to learn about the autism community. *Social Network Analysis and Mining*, 5(1), 1–17. doi:10.1007/s13278-015-0261-5
- Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 7(7), 858–865. doi:10.1016/j.rasd.2013.03.005
- Buckley, E., Pellicano, E., & Remington, A. (2021). “The real thing I struggle with is other people’s perceptions”: The experiences of autistic performing arts professionals and attitudes of performing arts employers in the UK. *Journal of Autism and Developmental Disorders*, 51(1), 45–59. doi:10.1007/s10803-020-04517-0
- den Houting, J. (2020). Stepping out of isolation: Autistic people and COVID-19. *Autism in Adulthood*, 2(2), 103–105. doi:10.1089/aut.2020.29012.jdh
- Dubin, N., & Graetz, J. E. (2009). Through a different lens: Spirituality in the lives of individuals with Asperger’s syndrome. *Journal of Religion, Disability & Health*, 13(1), 29–39. doi:10.1080/15228960802505213
- Frith, U. (1991). Asperger and his syndrome. *Autism and Asperger Syndrome*, 14, 1–36.
- Hansen, S. N., Schendel, D. E., & Parner, E. T. (2015). Explaining the increase in the prevalence of autism spectrum disorders: The proportion attributable to changes in reporting practices. *JAMA Pediatrics*, 169(1), 56–62. doi:10.1001/jamapediatrics.2014.1893