

# **Addressing Underserved Populations in Autism Spectrum Research**

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# Addressing Underserved Populations in Autism Spectrum Research: An Intersectional Approach

BY

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*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.*

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# 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

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## 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.

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# 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'.

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# 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  
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