



AutismCRC

Tools, strategies, and techniques developed to improve the health and wellbeing for autistic adults

EXECUTIVE SUMMARY

Katie Brooker

Pia Bradshaw

Dr Catherine Franklin

Dr Anna Urbanowicz

January 2022



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA



Australian Government
Department of Industry, Science,
Energy and Resources

AusIndustry
Cooperative Research
Centres Program

autismcrc.com.au

Tools, strategies, and techniques developed to improve the health and wellbeing for autistic adults

EXECUTIVE SUMMARY

Katie Brooker

Queensland Centre for Intellectual and Developmental Disability (QCIDD), Mater Research Institute, University of Queensland (MRI-UQ) | Autism CRC

Pia Bradshaw

QCIDD, MRI-UQ | Autism CRC

Dr Catherine Franklin

QCIDD, MRI-UQ | Autism CRC

Dr Anna Urbanowicz

QCIDD, MRI-UQ | Autism CRC | RMIT University

ISBN: 978-1-922365-42-2

Citation: Brooker, K, Bradshaw, B, Franklin, C & Urbanowicz, A (2021). Tools, strategies, and techniques developed to improve the health and wellbeing for autistics adults: Final report. Brisbane: Autism CRC.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.

Copyright and disclaimer

The information contained in this report has been published by the Autism CRC to assist public knowledge and discussion to improve the outcomes for people on the autism spectrum through end-user driven research. To this end, Autism CRC grants permission for the general use of any or all this information provided due acknowledgement is given to its source. Copyright in this report and all the information it contains vests in Autism CRC. You should seek independent professional, technical or legal (as required) advice before acting on any opinion, advice or information contained in this report. Autism CRC makes no warranties or assurances with respect to this report. Autism CRC and all persons associated with it exclude all liability (including liability for negligence) in relation to any opinion, advice or information contained in this report or for any consequences arising from the use of such opinion, advice, or information.

Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established, and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants. The authors are extremely grateful to all our participants for taking part in this project. We would especially like to thank Nick Lennox, David Harley, Kate van Dooren, Cindy Nicollet, Renae Beaumont Matthew Cadman, Joanna Granich, Dell Hele, Elizabeth Pellicano, Lyn McPherson, Matthew Sellen, Kate Sofronoff and Mieke van Driel. Thanks to students Belcita Biju, Premkumar (Prem) Brahmhatt, Heewon (Kathleen) Cheong, Matthew de Broize, Ashley Gilbert, Justin Ha, Nicole Hawkins, Lisa Kang, Kasundri Kulasinghe, Sachin Kumar, Julia Middlesworth, Jezabelle Miller, Gabriel Mullen, Imogen Page, Grace Pollard, Cecilia Shim, Cassandra Truong, Ritwika Vinayagam and Rebecca Zale. We are also very grateful to our autistic colleagues who provided input into this project as individuals or as part of the Community Council.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families, and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

1. Executive Summary

1.1. Introduction

Autism research in the adult space has been a long-neglected field, particularly in health and healthcare, despite clear health disparities between autistic and non-autistic people. Autistic adults experience gaps in healthcare provision and numerous barriers to accessing healthcare. Additionally, health professionals are also often under skilled, have low autism knowledge and low confidence when working with this cohort.

Our body of work focused on understanding and improving health and wellbeing for autistic adults by developing tools, strategies, and techniques. In our '*Understand*' area of work, we aimed to understand the health and wellbeing field in autism in adulthood through reviewing existing information and collecting people's experiences. In our '*Improve*' area of work, we designed tools, programs, and resources to improve health and wellbeing for autistic adults.

1.2. Understand

To understand the current landscape for resources, we reviewed existing information and conducted small projects to develop understanding through experiences. We reviewed academic and grey literature to establish the existing resources and training, including at the intersection of autism, intellectual disability, and health status and lastly, the barriers to accessing healthcare for autistic adults.

In working to understand through experiences, we sought to develop our understanding from autistic adults through projects that looked at the diagnostic experience for adults, oral health, diabetes, and anxiety. We also sought the experience of health professionals providing healthcare to autistic adults.

1.3. Improve

In our efforts to improve the health and wellbeing of autistic adults, we focused on three areas: access to healthcare, health and wellbeing, and improving access to health resources. Our improving access to healthcare work saw the development of a tool, the Autism CHAP, to support annual health assessments. We also investigated the utility of an American tool, the AASPIRE toolkit, in an Australian setting. We also delivered training to GPs and identified GP training priorities for future education initiatives.

We aimed to improve health and wellbeing of autistic adults through the delivery of cooking classes and a program to support the management of anxiety, ACT on your life. Lastly, we sought the view of autistic adults with intellectual disability and health professionals to understand what made an accessible and appropriate health information website.

1.4. Conclusion

This body of work consisted of multiple projects that together worked to understand and improve autistic adults' access to healthcare. This revealed that autistic adults face significant barriers to accessing healthcare, and the healthcare professionals also face difficulties in understanding how best to work with autistic adults. Further, this program worked to improve the health of autistic adults through improving access and directly through selected projects to improve aspects of health and well-being. This program has demonstrated that there are several significant areas that require further research and development and has laid the groundwork for future projects to build on.

Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



AutismCRC

Autism CRC

The University of Queensland
Long Pocket Precinct
Level 3, Foxtail Building
80 Meiers Road
Indooroopilly Qld 4068
T +61 7 3377 0600
E info@autismcrc.com.au
W autismcrc.com.au



@autismcrc



Australian Government
Department of Industry, Science,
Energy and Resources

AusIndustry
Cooperative Research
Centres Program