



# Australasian Autism Research Council (AARC)

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## Annual Report 2023

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**Australasian  
Autism  
Research  
Council**



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## Annual Report 2023

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Copies of this annual report can be downloaded from the Autism CRC website [autismcrc.com.au](https://autismcrc.com.au).

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# Acknowledgements

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## Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

[autismcrc.com.au](http://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, the AARC prefers the terms 'autistic person'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

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# 1. Introduction

## 1.1 About the Australasian Autism Research Council (AARC)

The Australian Autism Research Council (AARC) was established to review and define national priorities for autism research and identify areas of research needed for the autistic and autism communities.

In 2022, the AARC expanded to include members from both Australia and New Zealand and became known as the Australasian Autism Research Council.

The AARC operates under the auspices of Autism CRC. The AARC includes members who are:

- Autistic
- Parent/carers of autistic people
- Government representatives and policy makers
- Service Providers
- Health professionals
- Education professionals
- Researchers.

The objectives of the AARC are to:

- consult on the state of autism research in Australia and New Zealand (community-led)
- identify priorities for autism research in an Australia and New Zealand context
- report on priorities for autism research in Australia and New Zealand
- inform funding strategies for autism research in Australia and New Zealand.

The full objectives and mechanisms for the AARC can be found on the [AARC webpage](#) (Australasian Autism Research Council, 2023).

## 2. AARC key activities for 2023

The AARC engaged with two primary activities: the proposal of two projects for consideration for commissioning by Autism CRC (see section 2.1 and 2.2); and the formation of two working groups (section 2.3).

### 2.1 Research Priority Update

In 2019 the AARC undertook a broad community consultation to identify priorities for Australian autism research, gaining perspectives from over 1,100 community members. This large-scale project identified 10 Research Priorities as identified by the autistic and autism communities. In 2020 the AARC again engaged with community consultation to identify and prioritise research questions for five of the identified priority research areas (see Australian Autism Research Council, 2021).

In 2022 the AARC recommended to Autism CRC that a project be commissioned to identify specific areas of focus and research questions for the five remaining priority research areas: choice of living and housing; family and carer support; gender, diversity, and inclusion; health disability; and built environment. The project was co-led by Griffith and Curtin Universities and the work was completed during 2023 (Whitehorne-Smith et al., 2023).

Following the key co-production research principles of Autism CRC, the team engaged surveys and follow up focus groups with members of the autistic and autism communities to further understand the specific areas of focus required for the remaining five research priority areas.

#### 2.1.1 Summary of the key findings

The report can be accessed from [autismcrc.com.au](https://autismcrc.com.au). What follows is a summary of the key findings with respect to the five priority areas.

##### 2.1.1.1 Choice and control of housing and living

Priority areas of research identified were the housing and living needs and preferences of autistic individuals; current available supports to help autistic people make choices and live how they prefer; and, factors that impact choice and control in housing and living. In addition, improving the accessibility of living options, and barriers to ideal housing and living situations for autistic individuals were also identified as key areas for research.

##### 2.1.1.2 Family and carer support

Priority areas of research identified included how families and carers can support autistic people across their lifespan; the needs of families and carers of autistic individuals; and, how both autistic individuals and their carers and families can be supported by their wider community. In addition, how siblings can be supported, how families and carers can be financially supported, and current challenges facing families and carers were also identified as key areas for research.

### **2.1.1.3 Gender, diversity, and inclusion**

Priority areas of research identified included removing barriers faced by autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional; the experiences of autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional in different contexts, and; what autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional need to feel included. In addition, how clinicians can be trained to better care for and understand autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional, and how the intersections of the autistic community can be better represented, were also identified as key areas for research.

More active inclusion of the autistic and autism communities within research was suggested as a potential driver for more accurate representations.

### **2.1.1.4 Health and disability**

Priority areas of research identified what helps autistic people both access and have positive experiences in health, disability and education services; what the experiences are of autistic people and their families using health, disability and education services, and; what challenges and barriers autistic people experience in health, disability and education services. In addition, what health, disability and education services are most used and needed by autistic people, and if currently health, disability and education services currently support autistic individual's needs and wellbeing were also identified as key areas for research.

The need to change perspective from a deficit focus to a strengths-based approach was raised by participants, particularly with respect to disability service provision.

### **2.1.1.5 Built environment**

Priority areas of research identified included how we can make built environments sensory friendly for autistic people; what an ideal, or easily accessible, built environment looks like for autistic people, and; what are the best ways to reduce barriers in built environments to make them more equitable and inclusive for autistic people. In addition, how we can make built environments, including homes, more calming and comfortable for autistic people, and how can navigation signage and transport better meet the needs of autistic people, were also identified as key areas for research.

The importance of modifying public spaces to be more inclusive of autistic people, was an area for research proposed that should be co-produced with the autistic and autism communities.

The AARC thanks the project leads Professor Dawn Adams (Griffith University) and Professor Sonya Girder (Curtin University) and broader team for their inclusive engagement with both communities in delivering this project. We hope that the outcomes from the project will shape research foci for researchers on areas of research priority as identified by the autistic and autism communities.

## 2.2 Quality of life and wellbeing of autistic individuals with complex support and/or communication needs

In 2022 Autism CRC asked the AARC to develop project specification on what research should be considered to better understand the needs and priorities of autistic people who have complex support and/or communication needs. The AARC drafted a proposal for consideration by Autism CRC to commission the research.

Members of the AARC discussed at length the key issues that would need to be considered as part of this proposal including appropriate methodological approaches, the need to utilise respectful language, and the complexities in engaging this marginalised group. The AARC therefore proposed an investigation of existing literature, specifically a systematic or scoping review and thematic synthesis to understand the experiences of a diverse range of autistic people identified as having significant support or complex communication needs. The review would identify and understand the building blocks for a flourishing life for these individuals.

Through rigorous review, key themes underpinning conditions for an autonomous and flourishing life could be identified and scoped for further investigation in a larger-scale future project. Importantly, the review could also help identify gaps in the academic and lived experience literature which would determine which groups are truly underrepresented to appropriately prioritise them in future work.

The findings of the review, including the gaps identified, could then be taken out the community for consultation for future project possibilities. However, the most appropriate next steps and groups to prioritise would not be known without first undertaking this foundational work.

The project was led by Griffith University and the work was completed during 2023 (Simpson et al., 2023).

### 2.2.1 Summary of the key findings

The report can be accessed from [autismcrc.com.au](https://autismcrc.com.au). What follows is a summary of the key findings.

The review identified 236 research studies that met the inclusion criteria set in the protocol that was co-designed with the autistic and autism communities. The majority of studies were conducted in the United States, with fewer focusing on Australian understandings and only one study being conducted in New Zealand. While there was an identified growth in the number of studies being conducted in recent years (50% being published in the previous five years), it was clear that more research needs to be undertaken within our region to understand the challenges from an Australasian perspective.

Of note was the large number of studies who drew on proxy reporting for data collection (83%). This indicates that researchers may need to further consider inclusive approaches to researching with particular groups, including the design of measures appropriately validated for use with autistic people. This was compounded by few studies reporting engagement with the autistic and autism communities in the design and execution of the research. Future research needs clearer adherence with co-production principles to respectfully and inclusively involve autistic people with complex needs and their families.



The AARC thank the project leaders and broader team for their inclusive engagement with both communities in delivering this project. We hope that the outcomes from the project will shape research foci for researchers in focusing on the under-researched area of quality of life for autistic people with complex support and/or communication needs and the implications of this for autistic people and their families.

### **2.3 AARC working groups**

With the new committee formed at the beginning of 2023, priorities for the AARC were discussed. Two key priorities were raised following extensive discussions. The first reflected terminology and the importance of the use of empowering and respectful terminology and the second the engagement with Human Research Ethic Committees (HRECs).

Two working groups were established to discuss format for impact and relevant research. This work will be ongoing.

## **3. Closing remarks**

The two projects proposed by the AARC, which were completed in 2023, provide important foundational evidence for future research needs and focus, drawing on methodologies that are inclusive of a range of autistic voices. The work produced by the two working groups may be continued by the 2024 AARC members.

The co-chairs for the 2023 AARC would like to thank each of the AARC members who dedicated time and interest to engage in collegial discussions in supporting and promoting excellence in co-designed research. The 2023 AARC was fortunate to have broad representation of voices from a diverse range of stakeholders, which were reflected in discussions and outputs.

We wish the new 2024 AARC committee well in furthering this research agenda.

## References

- Australian Autism Research Council (2021). *Australian Autism Research Council: 2020- 21 research priority update*. Brisbane. Autism CRC.
- Simpson, K., van der Meer, L., Adams, D., Bowen, R., Chandran, H., Gable, A., Heyworth, M., Heussler, H., Hogg, G., Patrick, L., Paynter, J., & Westerveld, M. (2023). *A systematic review of how quality of life and well-being is measured in autistic individuals with and without complex support and/or communication needs*. Brisbane: Autism CRC.
- Whitehorne-Smith, P., D'Arcy, E., Hayden-Evans, M. Malone, S., Carroll, A., Colville, O., Fitton, A., Picen, T., Vinci, B., Timms, L., Jackson, E., Simpson, K., Lawson, W., Adams, D., & Girdler, S. (2023). *2023 Research Priority Update: focus on five priority areas*. Brisbane: Autism CRC.

## Our values



### **Inclusion**

Valuing lived experience



### **Innovation**

Solutions for long term challenges



### **Evidence**

Truth in practice



### **Independence**

Integrity through autonomy



### **Cooperation**

Capturing opportunities together



# AutismCRC

Independent national source of evidence for best practice



[autismcrc.com.au](https://autismcrc.com.au)