



2023 Research Priority Update

Focus on five research priority areas

Executive Summary

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September 2023

**Australasian
Autism
Research
Council**



autismcrc.com.au/aarc

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ISBN: 978-1-922365-58-3

Citation: 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). *Australasian Autism Research Council 2023 Research Priority Update: focus on five priority areas*. Brisbane: Autism CRC.

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Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC participants, Curtin University, Griffith University, and Wenn Lawson.

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.

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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, 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'.

Executive Summary

Why we did this work

This project represents a continuation of work previously conducted by the Australasian Autism Research Council (AARC) in 2019, that identified the top ten autism research priorities for Australia. In 2021, the AARC produced a report that provided additional details on the views of the autistic and autism community related to five of the ten research areas. Our research team was asked to engage with the autistic and autism community to provide more detail and specific areas of focus related to the other five research priority areas. These were:

1. Choice of living and housing
2. Family and carer support
3. Gender, diversity and inclusion
4. Health and disability services delivery
5. Built environment.

Therefore, this report presents the views and experiences of members of the autistic and autism communities in relation to the five priority areas. It represents a process to co-create a snapshot of needs in these areas, presenting the autistic voice as central to the decision on research priorities.

What we did

This research was a collaborative process between two teams from Griffith University and Curtin University who conducted distinct aspects of the project. Specifically:

- **Griffith University, led by Professor Dawn Adams:** community views survey for all five priority areas
- **Curtin University, led by Professor Sonya Girder:** focus groups and individual interviews for all five priority areas.

A community views survey was conducted to ascertain research topic areas that would then be discussed in focus groups and/or individual interviews. Surveys were co-designed with members of the autistic and autism community and targeted this community as respondents. Following the collection and analysis of survey data, focus groups and individual interviews were conducted with members of the autistic and autism community to provide context and further expound on survey findings. Input from autistic researchers and consultation with the AARC and Autism CRC were used throughout the project to guide the methods used and research focus.

What we found

The surveys were completed by 43 people in total (including 25 autistic people), with between 14 and 33 choosing to respond to each domain. The research questions suggested by participants were often specific to the domain they were considering. However, there was some overlap in the suggested research questions across domains, indicating these may be considered as priority research questions. These shared questions included:

- What are the needs and preferences of autistic people (reported in all five areas; n = 5 areas)?
- What are the barriers experienced within these domains (n = 4 areas)?
- What does accessibility look like in the domains (n = 2)?
- How can accessibility be supported (n = 2)?
- What is the impact of the domain on health and wellbeing (n = 2)?
- What financial support is available (n = 2)?
- How can we educate the public to support autistic people and their families/carers (n = 2)?
- What are the experiences of autistic people in these domains (n = 2)?
- How can we support a collaborative approach between autistic people and people working within the domain (n = 2)?

All of research questions suggested by the participants were used to inform the questions within the focus groups and individual interviews.

Focus groups and interviews were conducted with a total of thirty (30) members of the autistic and autism community. Most participants were part of multiple participant groups, with 16 autistic people, 18 family members of autistic person(s), and 13 professionals. For each priority area themes and sub-themes outline the challenges that autistic people experience, their suggestions for addressing challenges and recommendations for future research in that area.

Choice and control of housing and living

The findings on choice and control of housing and living, indicated that autistic individuals may have varied preferences related to their living arrangements, however participants agreed that environments that provided a balance of autonomy or a level of separateness and support to aid with household management was most ideal. Participants noted that barriers such as the affordability and accessibility of suitable housing arrangements limits autistic people's control over their living environments. Themes related to the role of the family, limitations in National Disability Insurance Scheme (NDIS) housing support and the role of the government outside of the NDIS were also discussed as issues for consideration in this priority area. Participants suggested that research in this priority area should include the voice of the autistic and autism community as well as government stakeholders to help find solutions to challenges impacting autistic individuals' choice in housing and living.

Family and carer support

The focus groups regarding family and carer support identified a range of areas considered relevant to this topic. Awareness and acceptance of autism emerged as a strong theme in this area, with participants discussing the importance of this across contexts, including among families, professionals and the community. Participants considered the impact of autism on members of the family, discussing the different areas of support relevant to autistic and neurotypical siblings. Key areas of support identified by autistic individuals and carers included support during times of transition (e.g., between schools, finishing school, starting work, and changing jobs), financial support, improving autistic visibility and promoting positive autistic identity, as well as the importance of consistency in social workers.

Gender, diversity and inclusion

A range of themes emerged from the analysis of the focus groups and individual interview focused on gender, diversity and inclusion. Participants discussed issues with diversity and inclusion across contexts, including in education, the workplace, and health and medical services. Facilitators of inclusion and diversity were discussed alongside some of the barriers in each of these settings. The influence of gender on diagnosis was discussed, with participants discussing the impact on diagnosis for female (or assigned female at birth; AFAB) people due to the way in which autism presents in females (or AFAB) compared to males. Autistic individuals from culturally diverse backgrounds expressed that the experience could be isolating. The attitudes of others towards diversity were explored as well as the attitudes of autistic individuals and carers towards other forms of diversity, with participants expressing an open-minded approach to diversity due to their own experiences of it. Diversity and inclusion in research were discussed, with participants suggesting ways in which involvement of the autistic and autism community in research could be improved to ensure more accurate representation.

Health, disability, and education

The focus groups and individual interviews on health, disability and education service delivery explored a range of challenges, both within and across systems for autistic people and their families. For health systems, participants' responses covered the need for healthcare, being heard in healthcare, the accessibility of healthcare, and the specific areas of mental health and diagnosis. For disability services, the focus was on how a deficit focus is primarily used, difficulties with the NDIS and the need for a focus on appropriate outcomes. For education, participants discussed the needs within the school context, as well as the transition to post-secondary education or out of the education system. Finally, there were themes that discussed issues that appeared across systems: navigating systems and the availability of services, professionals providing services, and the involvement of families.

Making built environments more accessible

Themes and sub-themes coming out of the focus groups and individual interviews for making the built environment more accessible centred around challenges autistic people experience due to a lack of awareness of autism in the wider community, sensory overstimulation, interaction with neurotypical people when triggered and difficulty navigating aspects of the built environment. Participants indicated these factors contributed to autistic people being uncomfortable and avoiding participation and engagement in some spaces. Participants made suggestions about modifications that can be made to the built environment to make it more accessible for autistic people such as sensory considerations in homes and public spaces, better education of the public about autism and better use of signage. Participants suggested that future research in this area is inclusive of autistic people and considers piloting modifications to some public spaces to test their effectiveness in improving accessibility for autistic people.

Overarching themes

Six overarching themes were outlined by participants across all five priority areas. They were:

1. Awareness and understanding of autism
2. Finances
3. The role of family
4. Mental health
5. Support needs
6. The NDIS.

These themes shaped and influenced the experiences of the autistic and autism community and represented areas of central focus that participants believed that future research should prioritise across all priority areas.

What happens next?

The results presented in this report provide insight into the needs, perspectives and priorities of the Australian autistic and autism communities. The results of this survey and focus groups can be used to guide and inform future research and policy work in the Australian context. This will ensure the needs and priorities of the autism and autistic communities are being met, and help secure positive outcomes for autistic Australians.

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



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