



Australian Autism Research Council 2020-21 Report Launch

Liz Pellicano

Wenn Lawson

Tori Haar

Acknowledgement of Country

I acknowledge the Traditional Custodians of the various lands on which we work today and the Aboriginal and Torres Strait Islander people participating in this webinar.

I pay my respects to Elders past, present and emerging, and recognise and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of Australia.

Australian Autism Research Council

**Research report on focus groups to identify
research questions for community informed
priority areas**

FINAL REPORT

February 2020

MELBOURNE CANBERRA SYDNEY BRISBANE
www.orima.com



Report

April 2021



**Australian Autism
Research Council:**
**2020-21 Research
Priority Update**

Australian Autism Research Council

The AARC operates under the
auspices of Autism CRC.



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program

About the Australian Autism Research Council (AARC)

- Established in April 2018 to review and define national community-informed priorities for autism research and identify areas of research need for the autistic and autism communities
- AARC includes a diverse range of representatives from the autistic and broader autism communities
- 8-14 members
- Auspiced by Autism CRC



Current Members

Co-chairs

- Dr Wenn Lawson (Esteemed wearer of many hats)
- Professor Liz Pellicano (Macquarie)



Autistic people (6), parent/carers (9) *

- A/Prof. Charlotte Brownlow (USQ)
- Shelly Dival (Enabling Spaces)
- Dr Melanie Heyworth (Reframing Autism)
- Katie Koullas (Yellow Ladybugs)
- Pam Macrossan (Autism Queensland)
- Malcolm Mayfield (Autism STAR)
- Rebecca Poulsen (PhD student)
- Travis Saunders (School of the Road)
- Geraldine Robertson (Autistic advocate)
- Dr Lizzie Smith (NDIA Research Services)

Australian Autism Research Council: 2019 Research Priorities



Built environment

How can built environments be made more accessible to the autistic community?



Education

How can we transition to an inclusive education system that meets the needs of students on the autism spectrum?



Health and disability services delivery

How is the physical and mental health of autistic Australians affected by the availability and accessibility of health, disability and education services?



Choice in living and housing

How do we ensure that autistic people have choice and control over where they live and who they live with?



Employment

How can Australia transition to an inclusive workforce that provides opportunities for meaningful employment to all autistic people?



Health and wellbeing

How do we ensure optimal physical and mental health for all autistic Australians?



Communication

How can we best support the communication skills of autistic Australians?



Family and carer support

How can we best support families and carers of people on the spectrum?



Justice

What measures can be taken to prevent discrimination, exploitation, violence and abuse of autistic Australians, and ensure equity in accessing justice?



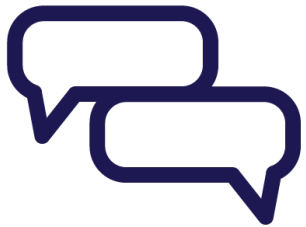
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Who are the priorities for?

- To provide the research community and funding bodies with a better understanding of what the Australian autistic and broader autism communities are interested in around research
 - Community relevance & practical outcomes
 - Engagement with research
 - Community awareness

Next steps

- Decision to conduct focus groups for 5 of the 7 original priorities:



Communication



Education



Employment



Health &
Wellbeing



Justice

- Only the highest rated of the 2 health priorities was included
- Tender process via invitation to conduct the focus groups



2020 Focus Groups



- Aged 18 or older and live in Australia
- Up to 12 members per group including, at least:
 - 3 autistic individuals
 - 2 parents or family members of autistic individuals
 - 2 relevant professionals (varies for each group)
- No one was selected for more than one group
- Priority perspectives to help ensure a diverse range of insights and experiences (2-3 per group)

Priority Perspectives: Examples

- **All Groups:** Autistic individuals who communicate non-traditionally, regional/remote and Aboriginal and Torres Strait Islanders
- **Education:** Perspectives relevant to different stages of the education journey (early childhood, primary, secondary and tertiary)
- **Employment:** Employers who currently employ at least 1 autistic staff member and professionals working to assist autistic people to obtain and/or maintain employment



Recruitment & response

- EOI process was open for ten days
- Posts on Autism CRC and Amaze social media pages
- Emails to people who had previously applied to join the AARC
- AARC members, including autistic members, conducted shortlisting and selection
- 70 EOIs were received, over 80% expressed interest in more than one group



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**Autism CRC**
Published by Vidler Brown · August 24 ·

Do you have an interest in #autism and one or more of the following areas: Communication, Education, Employment, Health & Wellbeing or Justice?

🔔The Australian Autism Research Council (AARC) is looking for community members to join its focus groups. Participation will involve a combination of an online discussion group and short surveys. Find out more on the AARC focus groups webpage and get your Expression of Interest in by midnight on Tuesday 1 September. Find out more: <https://www.autismcrc.com.au/aarc/focus-groups>

Australian Autism Research Council

Looking for community members to join online focus groups



Communication
Education
Employment

Health & Wellbeing
Justice

[autismcrc.com.au/aarc/focus-groups](https://www.autismcrc.com.au/aarc/focus-groups)

Group rankings by number of preferences

Focus group	Overall	Autistic	Non-autistic	Parent/carer	Non-p/c
Education	1	2	1	1	= 2
Health & wellbeing	2	1	3	2	= 2
Employment	3	3	4	= 3	1
Communication	4	4	2	= 3	4
Justice	5	5	5	5	5

Discussion board composition

- 10 to 12 members per group (54 total)



Parents/family members	Autistic people	Relevant professionals
72% (58%-90% per group)	61% (33%-90% per group)	39% (25%-60% per group)

Process

- High level literature scan
- Online discussion groups
 - Mid point surveys (individual groups)
- Prioritisation survey (all members)
- Analysis



1) WHO IS ORIMA?

ORIMA is a company that does research on aspects of Australian people's lives. From ORIMA, Luke and Gabby will be contacting you about how to participate in the project. Alison and Gabby will facilitate the discussion board groups.



2) DISCUSSION BOARD TOPICS

There will be 5 online forum discussion boards, and each will look at one of the key topics of: communication, education, employment, health and wellbeing and justice.



3) WHO IS IN THE DISCUSSION GROUPS

Each discussion board will have no more than 12 people, and AARC has decided who is in them. There will be autistic and non-autistic people, and you can use a real or a made-up name.



4) DISCUSSION LENGTH AND QUESTIONS TYPES

The discussion boards will be open for 10 days, and you will be asked 4 sets of questions. The first 2 question sets will be written, the third is a survey, and the fourth set is written questions. We will give you the first 2 sets of questions before we start, and we will create the last 2 from your answers.

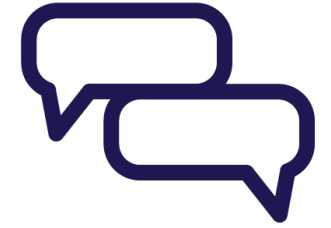


5) LOOKING AFTER YOURSELF

Sometimes talking about certain topics can bring up old or tricky thoughts, feelings or memories. For the time of the study, do connect in with your known support people, and plan for quieter days if you think you may need them.

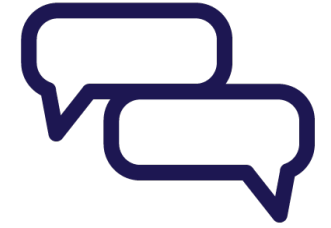
PLEASE ASK US FOR ANY SUPPORT YOU NEED

Communication



- How can the acceptance and use of diverse forms of communication (including non-verbal) in education settings be improved, to support all autistic students to participate in the educational and social curriculum?
- Identify effective ways to reframe community attitudes towards diverse forms of autistic communication, using a strength-based neurodiversity approach instead of the current deficit-based medical model.

Communication



- After an autism diagnosis (at any age), how can autistic people be supported to identify individual communication strengths, options and preferences?
How can families and professionals play a positive role in this to ensure full accessibility in education, employment, and community?
- What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility?

Education



- How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom?
- What are the most effective training and professional development approaches for educators in preparing them to support and teach autistic students? Where are there systemic opportunities for the development and implementation of educator training to be produced in partnership with autistic people?

Education



- Investigate the impact of environmental factors in the classroom and playground (e.g. sensory, layout, aesthetics, schedules) on autistic students' behaviour, learning, social and wellbeing outcomes.
- What are autistic students' preferences for flexible and/or predictable learning environments? What is the access to these and how effective are they in supporting learning and wellbeing outcomes?

Employment



- What are the flexibility and predictability needs and preferences of autistic people in the workplace and how these can be supported? This includes working hours, environment, workplace practices and processes, setting spoken and unspoken social expectations, diverse communication preferences, etc.
- What barriers do employers experience in employing autistic people, and how can these be overcome?

Employment



- How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid?
- What factors create a safe work environment and culture for autistic employees, and how can employers support and promote employees through inclusive culture, policies, practices and individual preferences?

Health & wellbeing



- What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)? Examine contributing factors to these conditions.
- How do autistic people respond to medical tests, treatments and medications? Identify what can be done to accommodate these.

Health & wellbeing



- How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan?
- How does “pretending” to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes?

Justice



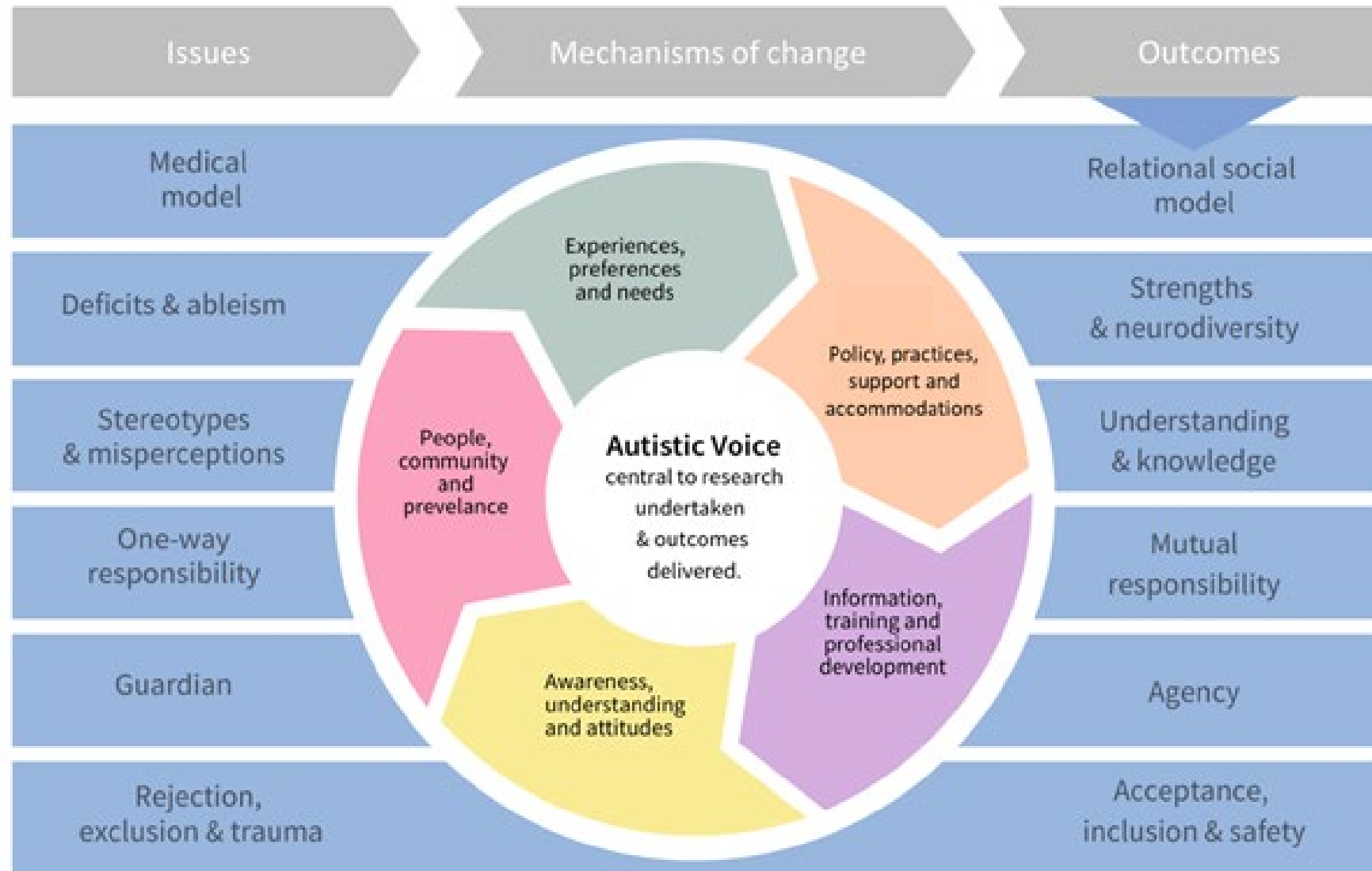
- Does police awareness of autism and interpretation of autistic behaviour and communication impact on autistic people's experience of, and outcomes in, the justice system? What awareness or training initiatives designed with autistic people could create effective change?
- What is the current level of awareness and understanding of autism amongst professionals working within the justice system?

Justice



- What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and wellbeing goals?
- Examine the number and proportion of autistic people in the criminal justice system, including rate of offending, type of offences, charges, sentencing, incarceration, parole and reoffending. Identify demographics and diversity factors.

Overarching themes from the research





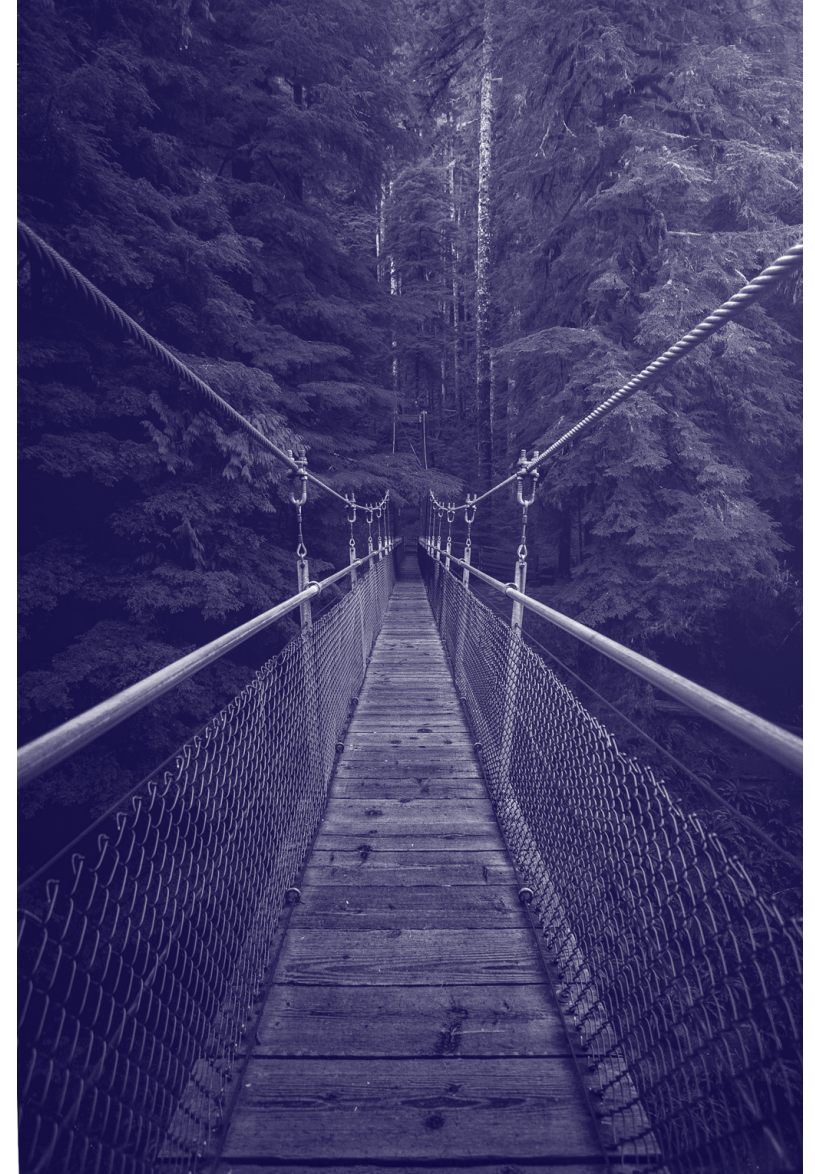
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AARC 2020-21 Research Priority update

- Commentary by AARC members to be read alongside the ORIMA report:
 - ***describes*** the process and ***summarises*** the findings (including their ***limitations*** and the ***opportunities*** they offer)
- It's important ***how*** research is conducted as well as ***what*** the questions are
- Autistic people and allies want to be involved in decisions around research
- Opportunities for better quality research and building trust between researchers and the broader community

What's next?

- Reflection
- No focus groups or surveys this year
- Brief report released in November



Remaining 2019 AARC Priority Areas



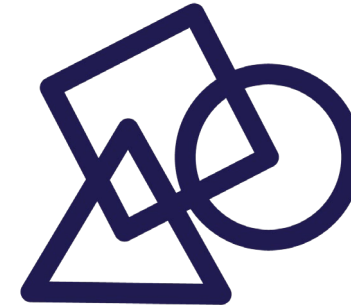
**Built
Environment**



**Choice in
Living and
Housing**



**Family and
Carer Support**



**Gender,
Diversity and
Inclusion**



**Health and
Disability
Service
Delivery**

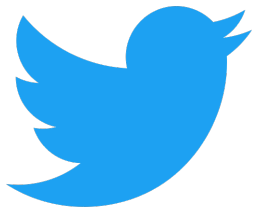


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Recruitment for 2022 AARC

- EOI process didn't occur in 2020
- Will open in August for ~one month

Register for updates



eNewsletter



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Recruitment for 2022 AARC

- Offers will be made in November, and announced later that month alongside the AARC's 2021 brief update
- New members will commence in January 2022



Extension to New Zealand

- From January 2022 the AARC will be renamed the Australasian Autism Research Council
- At least 2 members from each country – including at least one autistic individual or parent/carer



Thank you

Questions?

www.autismcrc.com.au/aarc

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