Australian Autism Research Council

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

EXECUTIVE SUMMARY

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1.1 Background and methodology

In 2019, the Australian Autism Research Council released its 2019 Research Priorities Report which outlined 10 broad areas for autism research priority in Australia. In 2020, ORIMA Research conducted focus groups to define research questions and topics within five of the research Priority Areas. These five areas are Education; Health and Wellbeing; Employment; Justice; and Communication. This report presents the findings from this research.

Figure 1: Five Priority Areas

A total of 55 members of the autistic and autism communities participated in the research.

For each Priority Area, one 10-day online discussion board was conducted with up to 12 participants. Midway through the discussion board, participants completed a poll to assist with the prioritisation of topics. Topics were then refined based on feedback following this poll.

At the conclusion of the discussion boards, participants from all the discussion boards were invited to complete a final prioritisation poll for all the topics. A total of 45 participants completed this final poll. The research included a literature scan to help guide the research.

We acknowledge the significant time and effort contributed by all focus group participants.

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1.2 Priority research topics

The research identified 10 important topics per Priority Area for future research.

Communication

1	What are effective ways of challenging and correcting non-autistic people's assumptions and misperceptions about the relationship between an autistic person's communication and their cognitive capacity? Consider interpersonal relationships, employment, education, medical and community settings.
2	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? [Rated 3rd by Communication discussion board participants]
3	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. [Rated 2nd by Communication discussion board participants]
4	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? [Rated 1st by Communication discussion board participants]
5	What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility? [Rated 4th by Communication discussion board participants]
6	What barriers and opportunities are there for goods and services businesses or organisations, to offer options and accommodations for diverse communication styles?
7	How can non-autistic people be to encouraged and motivated to increase their skills and capacity to communicate with people who use diverse communication?
8	What are the current experiences and impacts of speech therapy for autistic people? From a neurodiversity relational social model, how would autistic people define speech therapy rationale, goals and outcomes; shifting from a deficit-based medical model?
9	Identify innovative and alternative solutions for autistic people that facilitate communication outcomes, and support their own preferences to form speech, visual language or increase the ease of assistive technology use. This includes those with motor planning difficulties.
10	What is the effectiveness of facilitated communication for autistic people? Research to be designed and conducted with autistic people who adopt diverse forms of communication, as well as identifying and addressing gaps in previous research.

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Education

1	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? Educators means the following people or positions: teachers, teacher aides, wellbeing coordinators and school leaders. [Rated 2nd by Education discussion board participants]
2	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? Research would cover partial attendance and flexible learning spaces (i.e. mixed attendance and distance education, micro-schools - small neighbourhood schools, quiet study spaces). [Rated 4th by Education discussion board participants]
3	How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom? [Rated 1st by Education discussion board participants]
4	Investigate the impact of behaviour support and disciplinary strategies implemented in education settings on autistic students' learning, mental health and wellbeing (e.g. self-esteem, learning, social inclusion, mental health).
5	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. [Rated 3rd by Education discussion board participants]
6	How many autistic students experience trauma at school, and why does this happen?
7	How does school culture (i.e. attitudes, behaviours) impact upon autistic students and their families' school experience?
8	How can schools collaborate with autistic students to establish a strengths-based approach to motivate and support learning?
9	Identify effective inclusion policies and practices that cultivate collaborative and respectful relationships between educators, autistic students and families to support a positive education and social experience for students.
10	To what extent do education departments and schools implement evidence-based autism inclusion practice related to developing autistic students, and what barriers exist to implementation? This includes exploring the perspectives of autistic students, their families, educators and policy makers at all education stages.

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Employment

1	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. [Rated 1st by Employment discussion board participants]
2	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? [Rated 4th by Employment discussion board participants]
3	How can recruitment processes be designed with autistic people, including those who use diverse communication methods, to demonstrate their suitability for a role (e.g. job descriptions, CV submission, interviewing and onboarding)?
4	How can the education system best support autistic students in secondary and tertiary education, to identify their career goals and support transition to the workforce or further education?
5	How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid? [Rated 3rd by Employment discussion board participants]
6	What barriers do employers experience in employing autistic people, and how can these be overcome? [Rated 2nd by Employment discussion board participants]
7	What opportunities exist to increase employers' awareness of the skills and capabilities in the autistic community, and how to source autistic employees?
8	What are the most effective approaches for changing employers' attitudes and behaviours in relation to employing autistic people (e.g. messaging, policy incentives, etc.)?
9	What are the various employment goals, needs and experiences of autistic people and how do these intersect with demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?
10	How can the autistic community's awareness of employment programs and supportive employers (across all industries) be increased?

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Health and wellbeing

| 1	How do autistic people respond to medical tests, treatments and medications? Identify what can be done to accommodate these. This would include peoples' general experiences, communication of pain / symptoms, and experience of different types of treatments. [Rated 2nd by Health and Wellbeing discussion board participants]
2	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 (e.g. lifestyle, socioeconomic status, social, physiology, stress, access to health services, culture, location, trauma). [Rated 1st by Health and Wellbeing discussion board participants]
3	How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan? [Rated 3rd by Health and Wellbeing discussion board participants]
4	What are health professionals' understanding and attitudes regarding autism and its co-occurring health conditions? How can gaps in autistic-informed evidence-based practice be improved?
5	Examine the impact of the accessibility of appropriate and informed health services for autistic health on wellbeing outcomes (including trauma) with consideration of location and other demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?
6	How do autistic people want to communicate and collaborate with health professionals, and how can autistic people effectively contribute to health professional training to support this?
7	What are the most effective ways to optimise self-advocacy capacity for autistic people within the health care system? Research would consider knowledge, skills and tools for self-advocacy.
8	How does "pretending" to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes? [Rated 4th by Health and Wellbeing discussion board participants]
9	When services are provided by, or in collaboration with autistic professionals within a multidisciplinary team, does this influence an autistic people's health and wellbeing? Does a neurodivergent perspective influence outcomes?
10	How would autistic people define wellbeing and research the barriers and enablers of people living this definition?

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Justice

1	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? [Rated 1st by Justice discussion board participants]
2	What information do autistic people need to best understand their rights and responsibilities in relation to the law? Partnering with autistic people, identify what are effective information and delivery approaches to minimise risks of criminal offending or victimisation.
3	What is the current level of awareness and understanding of autism amongst professionals working within the justice system? [Rated 2nd by Justice discussion board participants]
4	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 (e.g. age, ethnicity, culture, identity, LGBTQIA+) and diversity factors (e.g. co-occurring disabilities, mental health). [Rated 4th by Justice discussion board participants]
5	What are the barriers to autistic people reporting crime and pursuing conviction? This would include comparison to barriers faced by the general population or other demographic groups (e.g. age, ethnicity, culture, identity, LGBTQIA+)
6	What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and wellbeing goals? [Rated 3rd by Justice discussion board participants]
7	What are autistic peoples' perceptions and experiences of their interactions with police and the justice system (as victim or perpetrator)?
8	Are there are specific autistic traits or characteristics that make people more vulnerable to being victims of different types of crime?
9	What are the most effective screening processes, practices and tools; that have been designed with autistic people; for use at different stages within the justice system?
10	What are the social and demographic factors across the lifespan (social determinants) that may place an autistic individual at increased risk of criminal offending? This would include employment, poverty, housing, education, gender, age, culture and health factors.

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1.3 Broader themes

In addition to the research questions identified for each topic, the research identified a range of broader themes (that summarise the changes that participants were hoping that research would contribute to across all Priority Areas. These are represented in Figure 2 and described below:

1. The widespread acceptance of a relational social model of autism;

2. A strengths-based and neurodiversity framework of autism;

3. Improving recognition of the diversity of the autistic;

4. Increased responsibility of the broader community to accommodate autistic people and their families;

5. Promoting the agency of autistic people to make decisions about their own lives; and

6. Improving autistic people's experiences of society, through widespread acceptance, inclusion and safety.

Figure 2: Overarching themes from the research
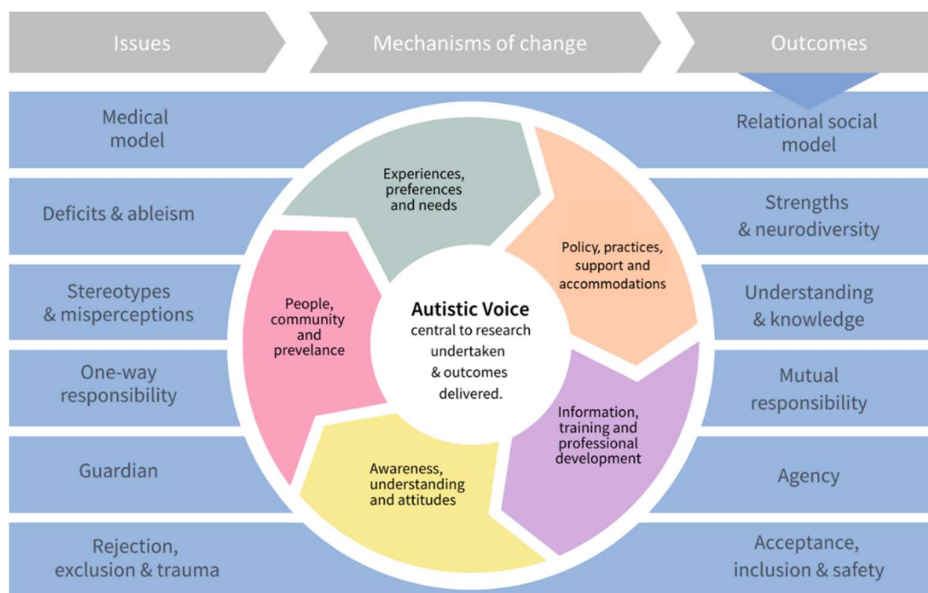
As such, the majority of the topics that participants identified as important for future research related to:

♦ Improving understanding of the diverse experiences, preferences and needs of autistic people;

♦ Developing knowledge, understanding and approaches to inform policy, practices and supports;

♦ Informing information, training and professional development, particularly for professionals;

♦ Informing opportunities to increase awareness and understanding about the autistic community, and changing attitudes in the general population; and

♦ Identifying the prevalent factors, characteristics and trends amongst the autistic community.

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Participants also consistently raised how important it was that research, programs and policies about autistic people, be led and co-produced with people from the autistic and autism communities.

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