Australian Autism Research Council:

2019 Research Priorities

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Australian Government
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Auspiced by Autism CRC

Acknowledgements

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.

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1. Introduction

The Australian Autism Research Council (AARC) was auspiced by Autism CRC with the objective of providing a regular and organised mechanism to:

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

A core principle of the AARC is that the delivery of these objectives will be community-led – by autistic individuals, their families and allies who provide services and support – for the benefit of those communities and the Australian community as a whole. The full objectives and mechanism for the AARC are attached in full in Appendix 1. The membership of the AARC included autistic people, parents of autistic people, stakeholders and researchers (Table 1).

Member	AARC position
Wenn Lawson	Co-chair
Andrew Whitehouse	Co-chair
Katharine Annear	Council member
Sam Bennett	Council member
Tim Chan	Council member
Adrian Ford	Council member
Katie Koullas	Council member
Jon Martin	Council member
Malcolm Mayfield	Council member
Brian Owler	Council member
Liz Pellicano	Council member
Geraldine Robertson	Council member
Fiona Sharkie	Council member
Samarra Toby	Council member

Table 1| **Members of the Australian Autism Research Council.**

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In June 2019, the AARC conducted a large community consultation with the aim of understanding community research priorities. Prior to the consultation, the AARC met on four occasions to define draft priorities and design the consultation process. The AARC considered Australia's domestic framework, Australia's international commitments and international resolutions as well as previous autism research priority surveys. From these, the AARC formulated a set of draft research priorities (Figure 1) and published a paper outlining the draft priorities and calling for community feedback (Appendix 2). The draft research priorities paper is also available at www.autismcrc.com.au/aarc/draft-research-priorities and a summary of the draft priorities is outlined in Figure 1.

Australian Autism Research Priorities

Core Research Priorities

Self/Health   Communication   Built Environment

Implementation Research Priorities

Education   Health Services   Justice   Employment

Figure 1| **Draft Australian Autism Research Priorities.**
Figure 1 shows three core research priorities: Self/Health, Communication and Built Environment, and that these should interact with and overlay the four top implementation research priorities: Education, Health Services, Justice and Employment.

The 2019 Community Consultation comprised a mixed methodology consultation including an online survey and feedback submissions. Ethics approval was received from Bellberry Human Research Ethics Committee (in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007, incorporating all updates as at 2018). The surveys were hosted and analysed by an independent consulting firm

(Mind Tap Research). The full data report from Mind Tap Research is provided as an appendix to this report. The current report provides a summary of the data analyses, a declaration about the research priorities, and recommendations for ongoing consultation.

2. AARC community consultation: objectives and methodology

2.1. Objectives

The key objectives of the 2019 AARC Community Consultation were to obtain community feedback on:

- The seven draft research priority areas identified by the AARC; and
- Other research priorities derived from the UN Convention on the Rights of Persons with Disability (UNCRPD);

2.2. Methodology

An online survey was designed to support the objectives of the consultation and to facilitate the recruitment of a large and demographically broad participant sample. Two versions of the online survey, a standard and an easy read, were offered, and a PDF version of the easy read version was also provided to allow people to print out and fill in the survey using pen and paper (Appendix 3).

The survey was designed to allow respondents to rate the draft research priorities and also to add in additional research priorities they thought were important. General demographic questions were also asked, which facilitated an understanding of the breadth of participation. The two key questions for the consultation were:

Research Question 1: Response to draft research priorities - Are the seven draft priorities identified by the AARC (Figure 1) reflective of the opinions of the broader autistic and autism community?

- To investigate the *absolute importance of each draft priority*, respondents were to rate the importance of each individual priority on a five-point rating scale (not a priority, low priority, medium priority, high priority, essential);

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- To investigate the *relative importance of the draft priorities*, respondents completing the Standard Survey were asked how much money they would allocate to each priority area if the government provided them with a total of $7 to invest in autism research. Respondents could allocate as much or as little of the $7 to each area as they deemed fit. To support answering of this question, the online version of the survey automatically calculated the accumulating total for the respondents.

Research Question 2: Identify additional research priorities - Are there any other priorities that should be included in the list of draft priorities?

- A list of *additional research areas based on the UNCRPD* was compiled, and respondents were asked to endorse any area of importance to them. Respondents could endorse as many areas as they wished.
- A *free text question* was also included to ensure that respondents were not constrained in outlining research priority areas that were important to them. Respondents to the standard survey were asked: 'Are there any other broad areas of research, or more specific research questions, that you think should be an autism research priority in the future?' Thematic analysis (Braun & Clarke, 2006) was used to analyse open-ended text response. To allow people to choose the manner of their response, and also to invite organisations to provide responses, an online submission portal was created to receive free-text responses, document uploads, or links to video responses.

The consultation was open for the month of June 2019 to allow people sufficient time to consider the draft priorities and make their responses to the survey or by submission. The survey was promoted through social media, online advertising and through direct contact with key stakeholders and Autism CRC participants. All responses to the survey were confidential and anonymous. People making submissions could opt whether to make their submission publicly available.

To maintain independence in the consultation process, the data were analysed independently by Mind Tap Research. The full report provided by Mind Tap Research, including additional description of methodology and results, is provided as Appendix 4. The current report provides an over-arching summary of the results presented in the Mind Tap Research report. Where comparisons are provided in the summary below, they are based on statistical analyses conducted by Mind Tap Research, and described in Appendix 4.

2.3. Limitations

It is important to acknowledge that surveys, specifically online, can be subject to selection bias against those with limited internet access, lower literacy and cultural or linguistic diversity. Australians with a disability and who receive a disability support pension are reported to have lower access, affordability and digital ability and are more likely to be using a mobile-only internet access (Thomas et al., 2018). For this reason, the online survey was made accessible through both web and mobile platforms. However, given that the survey was hosted and completed online, the study sample may not include a large number of individuals without relatively easy access to internet.

The Consultation included an Easy Read version of the survey to support accessibility of the survey to a broader population, including those with an intellectual disability. The question on relative importance in the standard survey was not included in the Easy Read version of the survey and any reporting of relative importance is based on the standard survey alone.

3. Outcomes from 2019 community consultation

3.1. Description of survey respondents

A total of 1,102 respondents completed an online survey. The standard survey was completed by 1,018 respondents, and the Easy Read online version was completed by 84 respondents.

Respondents were asked to identify their interest in autism. Of the respondents, 22% (247 participants) of respondents were autistic, while 65% percent (715 participants) were parents or guardians of autistic individuals. Of the autistic respondents in the standard survey, 43% (105 participants) indicated they were both autistic themselves and a parent/guardian of an autistic person. Almost all autistic respondents (n = 224 participants, 91%) reported having at least one other condition or disability, with the most common co-morbidity being depression, anxiety, or another mental health condition (collectively 81%). A higher proportion of non-autistic respondents reported being employed compared to non-autistic respondents (60% v. 43%).

The majority of survey respondents were female (83%, 918 participants). Of the autistic respondents to the survey, 63% (156 participants) were female, 22% percent (55 participants) were male and 15% percent (36 participants) identified as non-binary, transgender, preferred not to describe themselves, or preferred not to answer. Respondents ranged in age from 18-24 (n = 50 participants) to 75-84 (n = 3 participants), with the majority of participants reporting to be in the 35-44 years (338 participants, 31%) and 45-54 years (330 participants, 30%) age brackets.

The respondents spanned every state and territory jurisdiction of Australia, with the majority of respondents coming from Western Australia (288 participants, 26%), Victoria (259 participants, 24%), New South Wales (200 participants, 18%) and Queensland (191 participants, 17%). We received responses from people from urban, regional and remote areas.

Of the respondents, 15% (166 participants) identified as culturally and linguistically diverse; just over 2% of respondents (23 participants) identified as Aboriginal and/or Torres Strait Islander.

3.2.   Aim 1: Response to draft research priorities

3.2.1. Importance of draft research priorities

All of the seven draft research priorities identified by the AARC (Figure 1, Appendix 2) were identified as a high priority by the majority of respondents in the community consultation, **with over fifty percent of autistic and non-autistic respondents rating all of the seven areas as either a "high priority" or "essential"**. The top three priorities were:

- Education research;
- Health and wellbeing research; and
- Health and disability services research.

These were the top three priorities for autistic and non-autistic respondents in the standard survey and also the respondents to the Easy Read survey. The ratings for each priority did not vary significantly by age, gender or cultural and linguistic diversity.

3.2.2. Relative importance of draft research priorities

To consider the relative importance of the seven draft priorities identified by AARC, respondents were asked to allocate hypothetical funding across the research priority areas. This question was not included in the Easy Read version of the survey and the results reported below are based on the respondents to the standard survey only.

Non-autistic respondents allocated a significantly greater proportion of their funding than autistic respondents to "education research" (25% v. 17%) and "communication research" (18% v. 12%) than autistic respondents. Autistic respondents allocated a significantly greater portion of funding than non-autistic respondents to "health and wellbeing research" (21% v. 17%), "justice research" (12% v. 9%), and "buildings and other built structures research" (9% v. 5%). There was no significant difference between autistic and non-autistic respondents in the amounts of funding allocated to "employment research" (16% and 15%, respectively) and "health and disability services research" (14% and 12%, respectively).

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Autistic respondent

- Education research 17%
- Health and wellbeing research 21%
- Communication research 12%
- Employment research 16%
- Health and disability services research 14%
- Justice research 12%
- Buildings and other built structures research 9%

Non-autistic respondent

- Education research 25%
- Health and wellbeing research 17%
- Communication research 18%
- Employment research 15%
- Health and disability services research 12%
- Justice research 9%
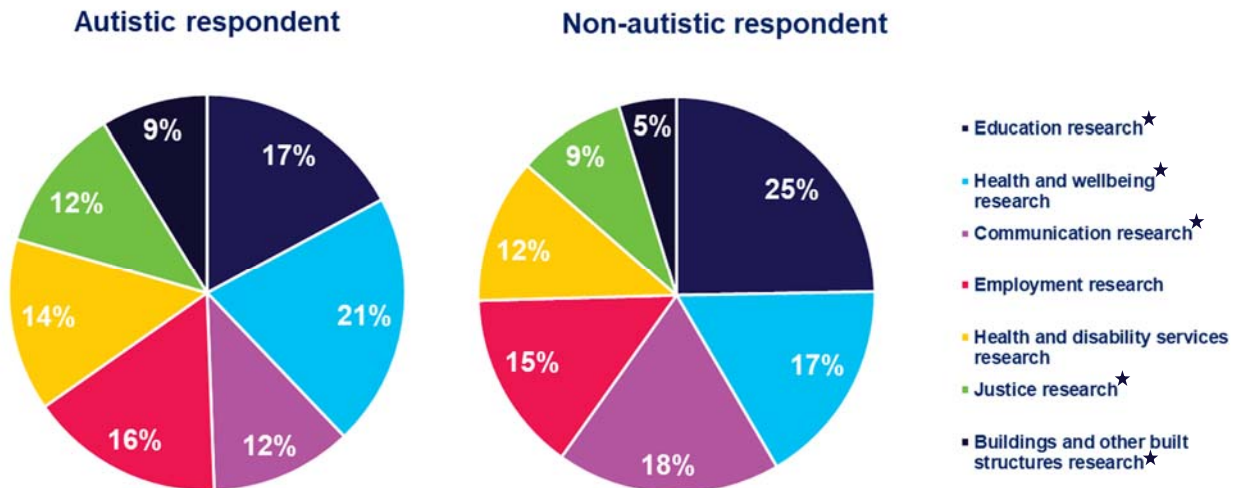- Buildings and other built structures research 5%

Figure 2| **Relative importance of draft AARC research priorities**. Participants were asked to allocate a hypothetical pool of funding to the seven draft research priorities outlined by the AARC. The figure describes the proportion of funding allocated to each of seven draft research priorities by autistic and non-autistic respondents. There were some small but significant differences in the relative importance of priorities between autistic and non-autistic respondents (*= mean dollar amount t-test, p<.01). Autistic respondents allocated the highest percentage of funding to "Health and wellbeing research" (21%) whereas non-autistic respondents allocated the highest amount of funding to "Education research" (25%).

3.3. Aim 2: Identifying additional research priorities

3.3.1. Additional research areas based on the UNCRPD

In addition to the draft research priorities identified by the AARC, respondents were provided with a list of potential research priority areas based on the UN Convention of the Rights of People with Disabilities. Respondents were asked to endorse the areas that were important to them. The top three areas selected by autistic respondents were:

- **"Women and girls on the spectrum"**
  "Women and Girls" was the most commonly selected additional priority area by autistic respondents (79%). The AARC also noted that 15% of the autistic population did not identify as either male or female (or preferred not to answer) and also the importance of specific demographics and intersectionality raised in free text responses below.
- **"Raising awareness and educating the Australian community about autistic people"**
  Both autistic (70%) and non-autistic (69%) respondents selected this area as a high priority.
- **"Access to support to allow independent living for autistic people"**

"Access to support to allow independent living for autistic people" was selected as an additional priority area by 70% of autistic respondents. It was also the second most selected additional priority for respondents over the age of forty-five after "support for carers and families of autistic people".

The top three areas selected by non-autistic respondents were:

- **"Support for carers/families of autistic people"**
  "Support for families and carers of autistic people" was endorsed by 81% of non-autistic respondents. AARC noted the significant difference in importance of family and carer support between non-autistic respondents, and autistic respondents (81% and 48%, respectively).
- **"Raising awareness and educating the Australian community about autistic people"**
  As mentioned above, both autistic (70%) and non-autistic (69%) respondents selected this area as a high priority.
- **"Inclusion of autistic people in the community"**
  Non-autistic people also selected "inclusion of autistic people in the community" as an important potential autism research area (69%).

3.3.2. Free text responses and submissions

Free text responses were received by 645 respondents. The thematic analyses identified seven key areas from these free text responses:

- Research into causes, treatments and specific presentations of autism;
- Awareness and perceptions of autism;
- Support for autistic people and the people who care for them;
- Education and employment for autistic people;
- Specific demographic groups and intersectionality;
- Upholding the rights of autistic people and the people who care for them; and
- Specific research strategies.

In addition to the survey results, a total of 21 submissions were received, including 12 from individuals and nine from groups (parent groups, organisations, government bodies etc.). Submissions ranged from short emails to formal submissions of up to 10 pages. Some submissions also referred to their website or to third-party reports and documents. Given the open and non-prescriptive nature of the process, there was diversity in the approach and content of the submissions. A number of submissions provided commentary on the seven research areas

proposed in the draft consultation paper (n = 4) and others shared aspects of their personal story or shared that of one or more autistic family members (n = 4). A detailed breakdown of topics from the submissions will be provided to all the working groups. Where consent was provided, submissions made on behalf of a group or organisation are included as Appendix 5.

4. Australian autism research priorities 2019

AARC considered the consultation outcomes and noted that all of the seven draft research priorities were endorsed by the community as important research priorities. This was observed in questions looking at both absolute importance in the online and Easy Read survey and relative importance in the online survey. There were some differences noted between the autistic and non-autistic respondents in terms of relative importance, which can be seen in the allocation of hypothetical funding in Figure 2 above.

In addition to the seven draft priorities, there were a number of additional research areas identified by the consultation. In considering the additional priorities, the AARC noted that "access to family and carer support" and "access to support to allow independent living for autistic people" were considered in the top 3 additional priorities by the non-autistic and autistic populations, respectively. The AARC also noted that independence of living may not be a goal for all people, and that "choice in living and housing" may be more appropriate across the autistic spectrum and the lifespan. The other top priorities centred on gender (particularly women and girls), diversity and inclusion. In considering the research priority, AARC noted the gender sampling bias of survey respondents, both autistic and non-autistic. Equality and inclusion were also the two top additional research priorities identified by respondents to the Easy Read survey. While noting that gender, equality and inclusion are included in the AARC guiding principles for all research areas, given the responses received the AARC considered that gender, diversity and inclusion should be recognised as an area requiring specific research, and that this should specifically encompass "women and girls" and also acknowledge the importance of the broader gender spectrum. The AARC considered these three additional priorities, "choice in living and housing", "family and carer support" and "gender, diversity and inclusion" should be added to the endorsed draft priorities, to make a total of ten Australian Autism Research Priorities in 2019.

From these considerations, AARC has formed a list of 10 priority areas consisting of the seven priority areas confirmed by the consultation and three additional areas highlighted by the consultation. The three additional areas were arrived at by considering the areas of highest research priority by respondents and taking into account the mix of stakeholder views.

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The top 10 research priority areas identified through this community consultation for autism research in Australia are:

- Built environment
- Choice in living and housing
- Communication
- Education
- Employment
- Family and carer support
- Gender, diversity and inclusion
- Health and disability services delivery
- Health and wellbeing
- Justice

5. Towards ongoing community-driven research priorities

5.1. AARC nominations for January 2020

The AARC has recommended that community consultation and engagement around autism research priorities be an ongoing and iterative process. The Australian Autism Research Council is calling for nominations for new members to commence in January 2020. The Application process is outlined at Appendix 6 and the Updated AARC Terms of References are in Appendix 1. The call for nominations will open from 16 October to 14 November 2019 and the new members of the AARC will be announced on or before 15 December 2019 to commence their two year term from January 2020 to December 2021.

5.2. Targeted working groups

The AARC has recommended that future consultation involve targeted working groups to identify more detailed research questions under the identified priorities. The format of the working groups is under consideration by the AARC and a recommendation will be made regarding the format and timing of a call for members, likely to be early 2020. It is envisaged that members of the working group will draw on the analysis in Appendix 4, consultation submissions and their own personal, professional and/or lived experiences to outline relevant topics in each research priority.

6. References

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101.

Thomas, J, Barraket, J, Wilson, CK, Cook, K, Louie, YM & Holcombe-James, I, Ewing, S, MacDonald, T, (2018), *Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2018*, RMIT University, Melbourne, for Telstra.

7. Appendices

See addendum

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