



Australasian Autism Research Council: 2021 Brief Update

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Under the auspice of the Autism CRC

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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. About the Australasian Autism Research Council

The Australasian Autism Research Council (AARC), under the auspices of the Autism CRC, provides a regular and organised mechanism to:

- consult on the state of autism research in Australia;
- identify priorities for autism research in an Australian context;
- report on priorities for autism research in Australia; and
- inform funding strategies for autism research in Australia.

Its overarching goal is to ensure that the delivery of these objectives is community-led – that is, by autistic people, their families, and allies who provide services and support – for the benefit of those communities and for the broader Australian community. This purpose is changing to also include New Zealand from January 1, 2022. This change is discussed later in this report.’

The full objectives and mechanisms for the AARC can be found in its Terms of Reference via the AARC webpage (AARC, 2021c). The membership of the AARC includes representatives of the autistic and broader autism communities, including autistic people, family members, a service provider, health and education professionals, a relevant federal government employee, and researchers.

In 2021 the AARC was comprised of Charlotte Brownlow, Shelly Dival, Emma Goodall (joined April 2021), Melanie Heyworth, Katie Koullas, Wenn Lawson (co-chair), Pam Macrossan, Malcolm Mayfield, Liz Pellicano (co-chair), Rebecca Poulsen, Geraldine Robertson, Travis Saunders, Mikala Sedgwick (joined April 2021) & Lizzie Smith.

A revised AARC membership will commence in 2022 – comprising seven new members and eight continuing members.

2. Achievements and reflections in 2021

The most recent AARC Research Priorities Update was released in April 2021 in conjunction with an online webinar, hosted by Autism CRC for Autism Month, for which over 160 people registered (Lawson, Haar & Pellicano, 2021). The AARC members took the remainder of 2021 as an opportunity to reflect on where it’s come from and where it would like to focus in the future. This report is an opportunity to share some of the AARC’s activities and achievements in 2021 as well as its intentions for 2022.

Extending the AARC to New Zealand

In 2021, AARC has changed its name from the Australian Autism Research Council to the Australasian Autism Research Council in line with Terms of Reference changes, which have paved the way for the AARC to welcome its first New Zealand (NZ) members from January 2022 (AARC, 2021c). There are both important similarities and differences between the two countries and it was felt that this expansion of perspective was a valuable next step in the AARC's journey.

The AARC exists as a group of different community stakeholders with an interest in autism research, which in turn seeks the perspective of the autistic and autism communities more broadly. Up to this point that broader community has been limited to those who live in Australia. These priorities are community informed and may or may not be applicable to a range of geographic contexts. They are not the official set of autism research priorities for a particular country. As the AARC continues to increase its reach amongst a diverse tapestry of community members, it is hoped that an increasing number of researchers, funders and other influential individuals and organisations will also become aware of the AARC priorities and recognise the value of research that both listens and responds to the needs and desires of the community.

The AARC anticipate that a key part of the new NZ members' role will be to work with the other AARC members to clarify further how the inclusion of the NZ autistic and broader autism communities in the AARC's considerations and consultative work should look like as they transition to this broadened remit. The AARC recognises that there is already important work occurring in the NZ autism research community, including around making research more inclusive and consulting the community in setting research priorities. The inclusion of NZ perspectives in the AARC seeks to complement rather than compete with this existing work.

The names of the first members of the AARC from New Zealand (Aotearoa) are being announced alongside the release of this report.

Sharing what's been learned

One of the key focuses of the AARC's discussions in 2021 was the importance of sharing what the AARC has learned, and the insights the community has shared, with a broader range of people – and in particular those in a position to make a difference to what gets researched and how that research is conducted. The AARC is an important mechanism to help address the disconnect between the autism research that is done and the research that the autistic and autism communities want to be done. Research priorities are ordinarily set almost exclusively by scientific funders and academics in specialist fields with autistic people and their allies being rarely involved

in the decision-making processes that shape research and its application (Pellicano et al., 2014). This results in feelings of disenfranchisement – and also in a field that is dominated by research that fails to map the reality of autistic people’s lives.

As the AARC reflected in the commentary that accompanied the reports released earlier this year:

“Now that the questions [related to the first five of the AARC 2019 Research priorities] are identified, it is crucial that we develop a program to help researchers know what to do with these prioritised questions so that the whole process can best fulfil its potential. This point brings us directly to the issue of *how* research is conducted as well as what the research questions are.” (AARC, 2021a, p.11).

The AARC sought to start to address this critical aspect of its purpose by considering how to better communicate the outcomes of its processes and reach a broader audience. Our reflections led AARC members to consider what key messages they would want to share with different groups in the broader community to encourage them to utilise the AARC priorities, and conduct their work in a more inclusive, and community-informed way.

These messages were presented in September as part of a webinar hosted by ORIMA Research and jointly presented by AARC representatives, ORIMA project lead, Tamara Reinisch, and Gabrielle Hall, the autistic researcher who helped deliver the project.

Table 1. Key messages for various stakeholder groups in relation to the AARC Research Priority Areas and research questions

Autism researchers	<ul style="list-style-type: none">➤ Choose one or more of these questions to investigate➤ Further develop them into tractable research questions➤ Co-produce your research
Other researchers	<ul style="list-style-type: none">➤ Find out if similar exercises have been conducted for the community you work with<ul style="list-style-type: none">➤ If not, there’s an opportunity to do so➤ Reflect on how you’re doing your research, and how the community is part of it➤ Don’t presume to know how the community wishes to be involved and what they might have to contribute

Funders

- See the value in co-design and in working with the community in an authentic way
- Provide ways of paying co-producers and prioritise co-produced applications
- Understand that people with a lot to contribute may not come from a traditional academic background

Government

- Incorporate co-design into service design and planning and encourage participatory approaches in grants and projects
- Find ways to hear the insights, wisdom and aspirations of the community – learn about what else could be not just what isn't going well

Autistic people (and their supporters)

- Think about how you want to be involved (e.g. topics, aspects of the research process)
- Be empowered to decide which projects you wish to be part of (different projects will have different levels of participation and good things can come out of a range of approaches)
- Connect with other autistic people interested in research
- Actively listen to and amplify the voices of autistic people more marginalised than you

Another key milestone will be the publication of the first academic article arising from the AARC's work. An editorial on the importance of including autistic perspectives in determining what research should focus on and how it should be conducted, which was authored by four AARC members, will be published in 'Autism: The International Journal of Research and Practice' early next year (Poulsen et al., in press). A range of other activities relating to knowledge translation are still being explored, with the hope that they will take place in 2022

Continuing to reflect on diversity and inclusion

The AARC has also sought to increase awareness of its existence amongst the autistic community, including its purpose and how autistic people are involved. A statement explaining how autistic people contribute to the AARC's work has now been included as part of our webpage (AARC, 2021d). They also released a two-page community summary of what the AARC does and the 2020 focus group project written in plain language (AARC, 2021c). This worked continued with the

development and release of plain language versions of the AARC webpage, Expression of Interest information page and Expression of Interest form.

There are many different experiences and perspectives amongst the autistic and broader autism communities. While it is not possible for each community or experience to be represented within a group of 8 to 14 members (extending to 15 in 2022), the AARC highly values diversity and seeks to remain cognizant of its collective limitations and potential for bias, as well as continuing to use its community consultations as an opportunity to engage and learn from perspectives outside of its own expertise. Some examples of communities which have been underrepresented to this point are people from regional areas, Culturally and Linguistically Diverse communities and autistic individuals with a co-occurring intellectual disability.

3. Future aspirations

As the world continues to navigate the COVID-19 pandemic, the AARC is hopeful that 2022 will provide renewed opportunities for engaging the community to help the AARC inform what is important for autism research in Australia and New Zealand.

After the knowledge and insights gained from the definition of research questions arising from the first five of the AARC 2019 Autism Research Priorities ('Communication', 'Education', 'Employment', 'Health & Wellbeing' & 'Justice'), the AARC is intending to undertake a comparable process for the remaining five priorities (*'Built Environment'*, *'Choice in Living and Housing'*, *'Family and Carer Support'*, *'Gender, Diversity & Inclusion'* & *'Health & Disability Service Delivery'*) once resourcing has been secured (AARC 2019; AARC 2021a). It is the AARC's intention that this project would be similar to the 2020 focus groups, but would incorporate some changes in line with learnings and feedback received through the previous project.

The focus group model that the AARC has adopted, includes a small group of community members representing key communities or perspectives of particular relevance to one of the Research Priority Areas, rather than being open to all community members who wish to contribute. This complements the whole community approach taken in 2019. Both approaches provide highly valuable insights which assist the AARC in its work and achieving its purpose. Once the remaining priorities have been explored in greater depth, resulting in a list of research questions equivalent to those defined in 2020, there will be an opportunity for the AARC to consider whether the Research Priority Areas it released in 2019 are still reflective of what the AARC believes are the most relevant and important to the community.

As researchers and funders take up the research questions and priorities developed and emphasised by the AARC a plan will also need to be developed to track the progress of these projects and ensure that the community is aware of any opportunities to become involved and have access to any outcomes of research influenced by the AARC priorities.

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Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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