



# Australian Autism Research Council:

## Draft Research Priorities for Consultation 2019

Australian Autism Research Council

April 2019



Australian Government  
Department of Industry,  
Innovation and Science

**Business**  
Cooperative Research  
Centres Programme

[autismcrc.com.au](http://autismcrc.com.au)

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# Australian Autism Research Council: Draft Research Priorities for Consultation 2019

## **Australian Autism Research Council**

Auspiced by the Autism CRC

**Citation:** Autism CRC. *Australian Autism Research Council: Draft Research Priorities for Consultation 2019*. (2019).

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## Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind support was provided by Autism CRC participants.

Additional contributions to the drafting of this consultation paper were gratefully received from Jac den Houting, Macquarie University, and Tori Haar, Autism CRC.

### **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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# Table of contents

<b>1. Introduction.....</b>	<b>6</b>
<b>2. Allocation of Autism Research Funding in Australia .....</b>	<b>7</b>
<b>3. Terms of Reference: Australian Autism Research Council .....</b>	<b>10</b>
<b>4. Membership: Australian Autism Research Council.....</b>	<b>11</b>
<b>5. Autism Research Priorities Background.....</b>	<b>12</b>
5.1. Australia's Domestic Framework .....	12
5.2. Australia's International Commitments .....	12
5.3. World Health Organisation – Resolution WHA 67.8.....	13
5.4. Previous Autism Research Priority Surveys.....	13
5.4.1. Australia – Autism CRC.....	13
5.4.2. United Kingdom – Autistica.....	13
<b>6. Australian Priorities for Autism Research in 2019.....</b>	<b>15</b>
6.1. Core Research Priority: Communication.....	16
6.2. Core Research Priority: Built Environment.....	17
6.3. Core Research Priority: Health / Self .....	18
6.4. Implementation Research Priority: Justice.....	19
6.5. Implementation Research Priority: Employment .....	20
6.6. Implementation Research Priority: Health Service Delivery .....	21
6.7. Implementation Research Priority: Education .....	23
<b>7. Call for Consultation on Research Priorities .....</b>	<b>26</b>
7.1. Primary stakeholders.....	26

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7.1.1. Autistic Australians .....	26
7.1.2. Families and Carers of Autistic Australians.....	26
7.2. Secondary Stakeholders .....	26
7.3. Proposed Consultation Format .....	27
<b>8. References .....</b>	<b>29</b>

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# 1. Introduction

The Australian Autism Research Council (AARC) was established to review and define national priorities for autism research and identify areas of research need for the autistic and autism communities. The AARC is committed to ensuring that future research priorities are developed in collaboration with these communities.

## The Council

The Australian Autism Research Council includes representatives of the autistic and broader autism communities, as well as service providers, health and education professionals, government program managers and policy makers, and researchers.

## Consultation Paper

The AARC met on several occasions throughout 2018 and synthesised the following draft autism research priorities for an Australian context. The draft priorities identified by the council in this consultation paper will be circulated for community consultation and may be changed, refined or updated prior to finalisation.

## Community Consultation

Consultation with the community will be through multiple methods to ensure the widest and most meaningful engagement possible. An online survey and online submissions will be open to stakeholders to engage with the draft priorities and to submit more detailed responses. Targeted roundtable discussions will also be convened on identified research priorities.

## Priorities

It is envisaged that the priorities established by the Australian Autism Research Council and consultation process will help guide the future focus of research activities and research funding. This will be relevant to activities and funding by government as well as research and development undertaken by non-government organisations and other industry members who provide programs and services for the autistic community.

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## 2. Allocation of Autism Research Funding in Australia

A portfolio analysis is currently underway to examine the allocation of autism research funding in the Australian context<sup>1</sup>, which will provide important information about how much has been spent on Australian autism research over a 10-year period and, critically, what kind of research the funds have been spent on. Data have been gathered on research grants relevant to autism awarded by the Australian Research Council (ARC), the National Health and Medical Research Council (NHMRC), the Autism CRC, and other relevant funders over a 10-year period, from 2008 to 2017.

At the time of publication of this consultation paper, a total of 136 relevant grants and investments have been identified. Based on these data, almost \$14 million was invested in autism research in Australia in the period from 2008 – 2012, and this investment more than tripled to a figure of almost \$44 million in the period from 2013 – 2017. The commitment reported here from the Autism CRC includes cash investment only and does not account for in-kind investments from Autism CRC participants.

In 2017, the US Interagency Autism Coordinating Committee (IACC) published an updated Strategic Plan for Autism Spectrum Disorder Research<sup>2</sup>. The plan uses a framework of seven “consumer-focus questions”, and further subcategories of research funding have been developed for portfolio analysis<sup>3</sup> (Table 1). Data from the Australian portfolio analysis indicates that autism research funding in the period 2013 – 2017 was distributed across all seven target areas. Biological discovery was the most-funded research area, receiving approximately one-quarter of total research funding (see Table 1).

<b>IACC Strategic Plan Research Areas<sup>1</sup></b>	<b>Australian Autism Research Funding Commitment 2013 – 2017<sup>2</sup></b>
<b>Screening and Diagnosis</b> <ul style="list-style-type: none"> <li>• Early signs and biomarkers</li> <li>• Diagnostic and screening tools</li> <li>• Symptomology</li> <li>• Intermediate phenotype/subgroups</li> </ul>	<b>\$2,123,000</b>
<b>Biology</b> <ul style="list-style-type: none"> <li>• Developmental trajectory</li> <li>• Cognitive studies</li> <li>• Subgroups / biosignatures</li> <li>• Neural systems</li> <li>• Co-occurring conditions</li> <li>• Neuropathology</li> <li>• Molecular pathways</li> <li>• Computational science</li> <li>• Immune/metabolic pathways</li> </ul>	<b>\$11,819,000</b>
<b>Risk Factors</b> <ul style="list-style-type: none"> <li>• Genetic risk factors</li> <li>• Gene-environment interaction</li> <li>• Environmental risk factors</li> <li>• Epigenetics</li> </ul>	<b>\$5,904,000</b>
<b>Treatments and Interventions</b> <ul style="list-style-type: none"> <li>• Medical / pharmacologic</li> <li>• Educational</li> <li>• Model systems / therapeutic targets</li> <li>• Behavioural</li> <li>• Technology-based intervention and supports</li> <li>• Complementary, dietary and alternative</li> <li>• Occupational, physical and sensory-based</li> </ul>	<b>\$8,589,000</b>
<b>Services</b> <ul style="list-style-type: none"> <li>• Efficacious and cost-effective service delivery</li> <li>• Practitioner training</li> <li>• Service utilisation and access</li> <li>• Family well-being and safety</li> <li>• Community inclusion programs</li> </ul>	<b>\$3,434,000</b>
<b>Lifespan Issues<sup>3</sup></b>	<b>\$3,164,000</b>
<b>Infrastructure and Surveillance</b> <ul style="list-style-type: none"> <li>• Research infrastructure</li> <li>• Biobanks</li> <li>• Research recruitment and clinical care</li> <li>• Surveillance and prevalence studies</li> <li>• Research workforce development</li> </ul>	<b>\$8,902,000</b>
<b>Total Autism Research Funding in Australia 2013 - 2017</b>	<b>\$43,896,000</b>

Table 1| **IACC Strategic Plan Research Areas and Australian Funding 2013 - 2017.**

The IACC created a classification system to allow an understanding of the autism research portfolio and funding allocation based on simple research topics that are relevant to each of the IACC Strategic Plan



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questions. A portfolio analysis is currently underway in Australia, with results reported against the IACC classification system above. <sup>1</sup>Research areas within each question are listed in order of funding allocation, from most- to least-funded. <sup>2</sup>All figures are rounded to the nearest \$1,000. <sup>3</sup>The IACC *Strategic Plan* does not provide research areas for the Lifespan Issues research question.

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## 3. Terms of Reference: Australian Autism Research Council

### Objectives

The objective of the **AARC** is to provide 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.

As the core principle for operation of the AARC, 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.

### Membership

The AARC will be composed of no less than 8 and no more than 14 members.

Council membership will comprise:

- At least 3 members on the autism spectrum;
- At least 1 parent or carer of a person on the autism spectrum (autism community);
- At least 1 representative of an autistic or autism community advocacy organisation;
- At least 1 representative of a service organisation to the autistic community;
- At least 1 representative of the Australian autism research community;
- At least 1 representative of a Commonwealth Government department or agency delivering services to members of the autistic community, preferably with a broad portfolio view, e.g. disability, education and health.

The membership term will be a maximum of 2 years. Subject to their consent, a member may be re-appointed to the Council for a further term.

A person may be a member of the Council as an individual or as a representative of an organisation.

For the first two years of operation, the AARC will be co-chaired by:

- Dr Wenn Lawson;
- Professor Andrew Whitehouse.

### Auspicing and Administration

The AARC will operate under the auspices of Autism CRC.

Management and operational support will be provided by Autism CRC, including the provision of the services of a Secretary to the Council.

## 4. Membership: Australian Autism Research Council

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 Oowler	Council member
Liz Pellicano	Council member
Geraldine Robertson	Council member
Fiona Sharkie	Council member
Samarra Toby	Council member

Table 2| **Members of the Australian Autism Research Council.**

Invitation to membership on the council was determined by the executive members as outlined in Section 3: Terms of Reference: Australian Autism Research Council, page 10.

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## 5. Autism Research Priorities Background

In developing draft research priorities for consultation, the AARC considered the importance of aligning priorities with Australia's existing domestic and international commitments and obligations. The AARC specifically considered three documents:

- The Australian National Disability Strategy 2010 – 2020<sup>4</sup>,
- The United Nations Convention of the Rights of Persons with Disabilities<sup>5</sup>,
- The World Health Organisation Resolution WHA 67.8<sup>6</sup>.

The AARC also considered recent autism research priorities developed through consultation by the Autism CRC (Australia)<sup>7</sup>, and Autistica in the UK<sup>8</sup>, which built on a previous study<sup>9</sup>. These research priorities were explicitly acknowledged and considered in the development of the current research priorities.

### 5.1. Australia's Domestic Framework

The Australian National Disability Strategy 2010 – 2020 was agreed on 13 February 2011 under the auspices of the Council of Australian Governments (COAG). It contains six key areas and the Australian Autism Research Council specifically considered the Areas for Future Action for each of the six categories:

- Inclusive and accessible communities;
- Rights protection, justice and legislation;
- Economic security;
- Personal and community support;
- Learning and skills;
- Health and wellbeing.

The National Disability Strategy can be downloaded at: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>

### 5.2. Australia's International Commitments

In 2007, Australia became a signatory to the newly drafted United Nations Convention on the Rights of Persons with Disabilities (CRPD). Australia formally ratified the convention on 17 July 2008, with declarations in relation to supported decision-making, compulsory assistance or treatment and health requirements of non-nationals seeking entry into Australia.

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The AARC specifically considered Articles 3 to 33 of the CRPD, which can be accessed at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext>

### **5.3. World Health Organisation – Resolution WHA 67.8**

In 2014 at the 67<sup>th</sup> World Health Assembly, the World Health Organisation made a resolution on the ‘Comprehensive and coordinated efforts for the management of autism spectrum disorders: WHA67.8’<sup>6</sup>. Australia is a member state of the WHO. The full WHA 67.8 can be accessed at: [http://www.who.int/mental\\_health/action\\_plan\\_2013/eb\\_resolution\\_childhood/en/](http://www.who.int/mental_health/action_plan_2013/eb_resolution_childhood/en/)

### **5.4. Previous Autism Research Priority Surveys**

There have been several previous reports that have described autism research priorities. Of these, the AARC specifically considered reports published by the Autism CRC in Australia, and by Autistica in the United Kingdom.

#### **5.4.1. Australia – Autism CRC**

In 2016 the Autism CRC published a survey of 158 participants outlining research priorities for autism research. The participants consisted of 50 autistic adults, 20 professionals, and 88 people (parent or carer) living with a person on the autism spectrum.

The top 3 priorities identified in the 2016 Autism CRC survey were:

1. Therapies, issues and management;
2. Understanding autism;
3. Educating.

The full report can be accessed at: <https://www.autismcrc.com.au/knowledge-centre/reports/research-priorities-survey>

#### **5.4.2. United Kingdom – Autistica**

Autistica is a UK autism research charity. Autistica led a James Lind Alliance Priority Setting Partnership with the National Autistic Society, Autism Research Trust and Autism Alliance to establish priorities for autism research. Of the 1,213 people who took part, 23% were autistic, 52% were family members or caregivers and 25% were clinicians and professionals.

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The top 10 questions for autism research identified from the alliance were:

1. Which interventions improve mental health in people with autism? How should mental health interventions be adapted for the needs of people with autism?
2. Which interventions are effective in the development of communication / language skills in autism?
3. What are the most effective ways to support / provide social care for autistic adults?
4. Which interventions reduce anxiety in autistic people?
5. Which environments / supports are most appropriate in terms of achieving the best education / life / social skills outcomes in autistic people?
6. How can parents and family members be supported / educated to care for and better understand an autistic relative?
7. How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
8. How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
9. How can sensory processing in autism be better understood?
10. How should service delivery for autistic people be improved and adapted in order to meet their needs?

The report was published in 2017 and can be accessed at:

<https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf>

## 6. Australian Priorities for Autism Research in 2019

The AARC has considered the above domestic and international commitments, and existing global and Australian surveys on autism research priorities. In identifying the priorities for consultation, these existing frameworks and publications were considered and the priorities formulated under the following **guiding principles**:

### **Autistic People at the Centre**

The priorities should be focused on assisting autistic people to discover what they want for their own lives and supporting them to achieve their goals.

### **Inclusive of all Autistic People**

The priorities should reflect the full diversity of the autism spectrum, including autistic people living without formal diagnosis. Priorities should focus on challenges and issues and positive models of care being inclusive of: age, gender, LGBTIQA+, geography, ethnicity, co-occurring disability, socio-economic disadvantage, and Aboriginal and Torres Strait Islander individuals and families.

### **Impact**

The research priorities should target areas that will create the most meaningful impact for autistic individuals and their families.

Seven broad research priority areas identified are outlined below and presented for consultation and feedback.

The first three (3) are **core autism research priorities**. They reflect the autistic person, their experience and interaction with society and the built environment:

- Communication;
- Built Environment;
- Health / self.

The next four (4) priorities are **implementation research priorities**. They acknowledge that the core autism research priorities need to be implemented systematically into many areas of society, and these are the highest priorities identified by the AARC:

- Justice;
- Employment;
- Health Service Delivery;
- Education.

## 6.1. Core Research Priority: Communication

**Research Priority:** How can we ensure that all autistic Australians have access to effective evidence-based support that meet their needs for communication?

For diagnostic purposes, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), broadly describes autism as ‘persistent deficits in social communication and social interaction across multiple contexts’<sup>10</sup>.

Further to the diagnostic criteria, up to 30% of children on the autism spectrum have been reported as non-speaking or minimally verbal<sup>11</sup> and over 35% of children on the autism spectrum in one large US study had a language disorder identified by age 8<sup>12</sup>.

**Key Considerations:**

- Inclusive and Accessible Communities (NDS, Australia)
- Article 21 – Freedom of expression and opinion, and access to information (UN CRPD)
- Article 9 – Accessibility (UN CRPD)
- Question 2 – Which interventions are effective in the development of communication / language skills in autism? (Autistica, UK)

**Example Research Questions:**

- What are the developmental pathways that contribute to minimal verbal language in autistic individuals and how can this knowledge inform evidence-based therapies and supports for communication?
- Are communication choices available for all individuals on the autism spectrum? What goal-setting protocols can be used to match the right type of communication support/s for each individual?
- How is the availability of communication supports in Australia affected by a person’s urban, regional or remote living location?
- What awareness, training and facilities are required to ensure that autistic Australians can interact with their communities on an equal basis using their required support for communication?



## 6.2. Core Research Priority: Built Environment

### **Research Priority: How can built environments be made more accessible to the autistic community?**

Up to 90% of autistic individuals may have different sensory experiences than the non-autistic population<sup>13</sup>. Many autistic individuals have co-occurring medical conditions or disabilities<sup>12</sup> which also have accessibility requirements.

Inclusive spaces (including classrooms, workplaces, homes and communities) increase the ability for people on the autism spectrum to live comfortably, work, socialise and contribute to the community.

### **Key Considerations:**

- Inclusive and accessible Communities (NDS, Australia)
- Article 9 – Accessibility (UN CRPD)
- Article 30 – Participation in cultural life, recreation, leisure and sport (UN CRPD)
- Question 5 – Which environments / supports are most appropriate in terms of achieving the best education / life / social skills outcomes in autistic people? (Autistica, UK)

### **Example Research Questions:**

- How can built environments be optimised to be accessible and inclusive for the autistic community (e.g., colour, lighting, sound, tactile sensation, ventilation)?
- How can autistic Australians have equal and appropriate access to cultural participation and expression, in a way that respects all aspects of their personal identity (ethnicity, LGBTIQ+, communication preferences etc.)?
- How can the current Australian Building Standards and the National Construction Code (NCC) be more reflective of the requirements of an inclusive and accessible built environment for the autistic community?

### 6.3. Core Research Priority: Health / Self

#### **Research Priority: How do we ensure optimal physical and mental health of all autistic Australians?**

Individuals on the autism spectrum have an increased chance of having additional chronic medical conditions, including sleep disorders, gastrointestinal problems, epilepsy and anxiety and other mental health issues, and incidence of these vary throughout the lifespan<sup>12,14,15</sup>.

#### **Key Considerations:**

- Health and wellbeing (NDS, Australia)
- Article 25 – Health (UN CRPD)
- Article 31 – Statistics and Data Collection (UN CRPD)
- Question 1 – Which interventions improve mental health in people with autism? How should mental health interventions be adapted for the needs of people with autism? (Autistica, UK)

#### **Example Research Questions:**

- How does the general health of autistic Australians vary across the lifespan?
- Does the physical, mental health and life expectancy of autistic Australians vary according to factors associated with autism, co-morbidities and co-occurring conditions?
- How do social determinants of health affect the Australian autistic population and influence health disparities?
- What steps can be taken to close the gap in life expectancy between autistic Australians and the broader Australian community?
- How can we work with the existing Health, Disability and Education systems to improve health outcomes for autistic Australians?

## 6.4. Implementation Research Priority: Justice

**Research Priority:** To prevent discrimination, exploitation, violence and abuse of autistic Australians, what measures can be taken across legal, educational and leisure services / activities?

In Australia, there have been recent calls for a Royal Commission into the violence and abuse against people with a disability<sup>16</sup>. There are barriers to interacting with the justice system for individuals on the autism spectrum, particularly in communication.

Australian data are lacking but, in the US, 20% of young autistic adults under 21 years have been questioned by police and 5% of young autistic adults under 21 years have been arrested by police<sup>17</sup>.

**Key Considerations:**

- Rights protection, justice and legislation (NDS, Australia)
- Article 13 – Access to Justice (UN CRPD)

**Example Research Questions:**

- How can Australia's legislative and independent authorities provide accessible and appropriate means to allow for the identification, mediation and prosecution of any abuse, exploitation, discrimination or inadequate protection of autistic people?
- How can we ensure that there is equal and effective legal protection against discrimination for autistic people in Australia?
- How can the Australian judicial system be made equally accessible for autistic Australians as it is for all Australians? How does accessibility and equality vary depending on a person's role in proceedings (e.g., as a victim, offender, complainant, defendant, witness or juror)?
- What is the experience of autistic Australians through all stages of the criminal justice system: investigative, adjudicative and correctional?
- What data are available in Australia regarding pathways to offending for autistic offenders, and can this be used to guide prevention / intervention / correctional and rehabilitation programs?

## 6.5. Implementation Research Priority: Employment

**Research Priority:** How can Australia transition to an inclusive workforce that provides meaningful work opportunities and equal remuneration to all autistic people who currently face under- or unemployment, or discrimination, exploitation or exclusion from employment on the basis of disability?

The Australian Bureau of Statistics (ABS) reported in their 2015 Survey of Disability, Ageing and Carers that labour force participation was 40.8% for autistic Australians, compared to 53.4% for people with other disabilities and 83.2% for the general population<sup>18</sup>.

**Key Considerations:**

- Economic security (NDS, Australia)
- Article 27 – Work and Employment, Article 28 Adequate Standard of Living and Social Protection (UN CRPD)
- Question 8 – How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace? (Autistica, UK)

**Example Research Questions:**

- How can the Australian labour market be made open and accessible to all autistic Australians (e.g., communication technology, changes to the built environment, flexible work arrangements etc.)?
- How can the number of autistic Australians in employment be increased?
- How can we ensure that autistic Australians have equal access to adequate food, clothing and housing including public housing, retirement and superannuation programmes?
- Are the living conditions of autistic Australians in line with those of the general population and how can we ensure that they continue to improve?
- How do autistic Australians access appropriate services in times of financial or personal hardship?

## 6.6. Implementation Research Priority: Health Service Delivery

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

Access to diagnosis and support is often challenging in more regional and remote geographical locations<sup>19</sup> and for particular populations<sup>20</sup>.

Health service needs may themselves be different in the autistic population and differences in communication, sensory and executive functioning may impact the accessibility of services<sup>15</sup>. In Australia, the autistic patients consult General Practitioners for mostly psychological, social or general and unspecified problems (complex needs)<sup>21</sup>. Whereas non-autistic patients mostly seek consultations for preventative and acute reasons, such as a cold or flu.

**Key Considerations:**

- Health and wellbeing (NDS, Australia)
- Article 25 – Health (UN CRPD)
- Question 1 – Which interventions improve mental health in people with autism? How should mental health interventions be adapted for the needs of people with autism? (Autistica, UK)

**Example Research Questions:**

- What is the state of autism-related health services in Australia, including the presence of evidence-based health care?
- Is standard health care accessible to autistic Australians? Does it vary according to where you live; if so, how can we create full accessibility?
- How aware are Australian health care professionals of the human rights, dignity, autonomy and needs of persons on the autism spectrum?
- How is timely diagnostic, treatment and access to culturally appropriate therapy, resources and educational services for autism achieved with our Aboriginal and Torres Strait Islander individuals, families and communities?
- How can health care for persons on the autism spectrum be improved in an Australian context including delivery in regional and remote areas, particularly in relation to:
  - Diagnosis / identification of all ages, particularly for minority groups and specifically Aboriginal and Torres Strait Islander individuals, families and communities;
  - Services designed to minimise and prevent further disability;
  - Recognition, health care, and services for co-occurring conditions / comorbidities?

- 
- What measures need to be taken to ensure the same access to health and life insurance across the autistic population as with their typical peers?
  - Can collection of data on the overall health of autistic Australians, including level of engagement with health services and co-occurring conditions, inform and improve nation-wide health service delivery for autistic Australians?

## 6.7. Implementation Research Priority: Education

**Research Priority:** How can Australia transition to an inclusive education system that meets the needs of all students on the autism spectrum?

The Survey of Disability, Ageing and Carers found that 83.7% of children and young people reported difficulty in education, while 48% attended a segregated class in mainstream or a segregated school<sup>18</sup>.

Australia has a number of different forms of segregated schooling and recent indications demonstrate a continued commitment to sustain that divide. Australia's Combined Second and Third Periodic Report under the Convention on the Rights of Persons with Disabilities (1 September 2018) states:

*"In respect of the Committee's comments urging States Parties to 'achieve a transfer of resources from segregated to inclusive environments', Australia's view is that a State Party will meet its obligations under Article 24 through an education system that allows for funding of different education modalities so students with disability are able to participate in a range of education options including enrolment in mainstream classes in mainstream schools with additional support, specialist classes or units in mainstream schools and specialist schools."* (page 48).

### **Key Considerations:**

- Policy Area 5: Learning and Skills, Areas for Action (NDS, Australia)
- Article 24 – Education (UN CRPD)
- Q5 – Which environment / supports are most appropriate in terms of achieving the best education / life / social skills outcomes in autistic people? (Autistica, UK)
- Priority 3 – Educating (Autism CRC, Australia)

### **Example Research Questions:**

- What are the minimum, and optimum, requirements for built environments for learning (including lighting, acoustics, temperature, sensory considerations)?
- What training, including whole of education sector (administration / staff / teacher / students), diversity and social skills programs are required to implement an inclusive social environment?
- How should Alternative and Augmentative Communication be used in teaching for non-speaking students and also students with gross and fine motor accommodation requirements?
- How can Australia include all autistic students in 'mainstream schooling' in the Disability Education Standards?

- 
- How can Australia have equality of employment for autistic teachers and support staff?
  - How can Australian classrooms be built and redesigned to meet minimum required learning environments at every school (lighting, acoustics, temperature)?
  - Can the Exemplars of Practice be expanded to include a broader range of students on the spectrum including those with complex needs and co-occurring conditions or disabilities?
  - What criteria are used for allocation of resources to inclusive education for students with communication support needs and how can available resources be used to best match students' learning profiles?



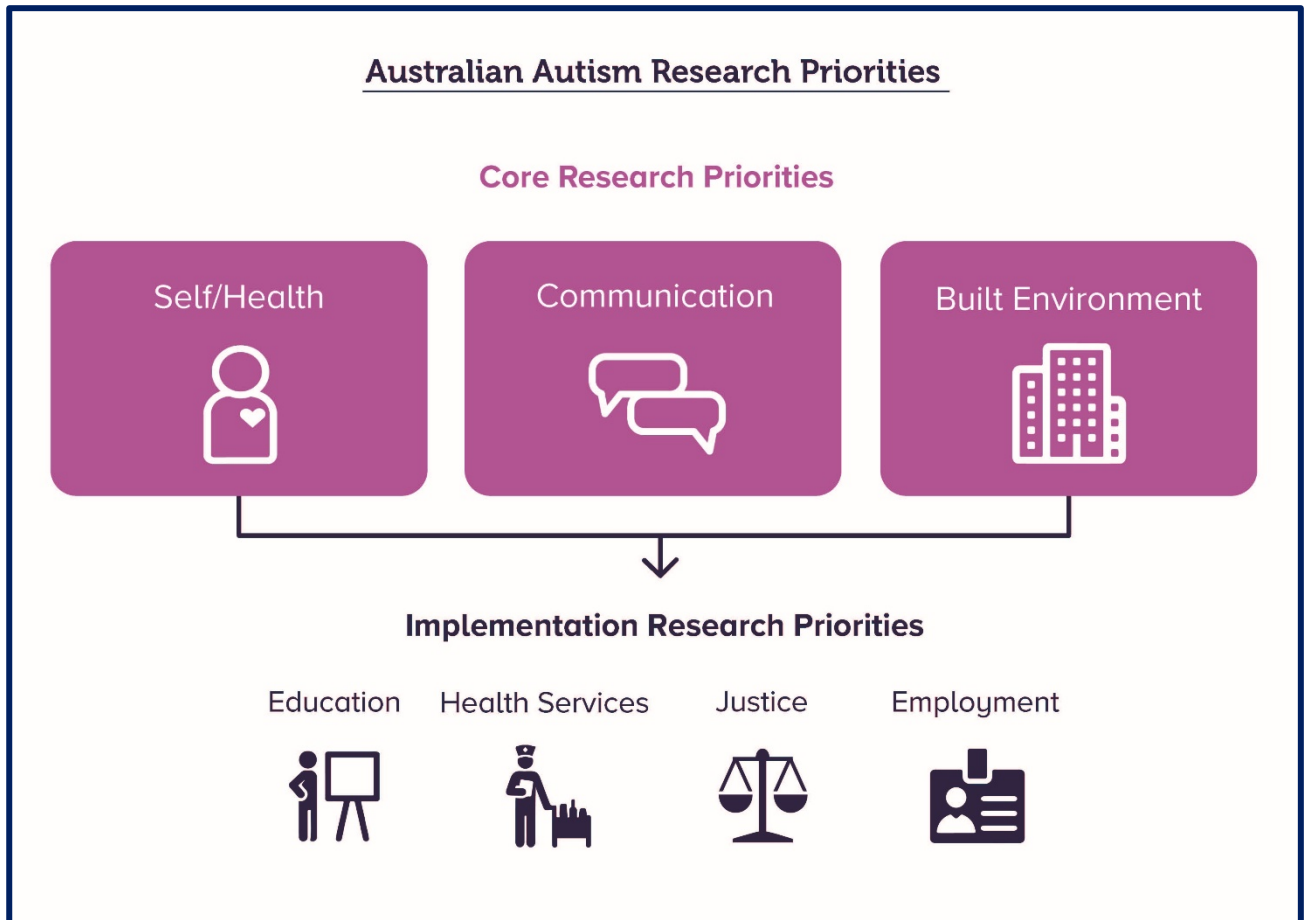


Figure 1| **Draft Australian Autism Research Priorities for Consultation.**

Figure shows 3 core research priorities: Self/Health, Communication and Built Environment, and that these should interact with and overlay all of the 4 top Implementation Research Priorities: Education, Health Services, Justice and Employment.

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## 7. Call for Consultation on Research Priorities

### 7.1. Primary Stakeholders

#### 7.1.1. Autistic Australians

Autistic Australians are the key primary stakeholder in this consultation. That definition encompasses at least 1 in 100 Australians, or currently over 250,000 people. The autism spectrum is broad and the views of its members on research priorities are expected to be diverse. It is crucial that any consultation is co-designed with autistic people, including those on the AARC, to ensure that it is accessible to a broad cross-section of the autistic community. In the consultation, stakeholders will be asked questions to provide demographic information, including:

- Age
- Diagnostic status
- Gender (including gender diversity)
- Postcode
- Annual income
- Employment status
- Co-occurring conditions (e.g., epilepsy, GI symptoms, anxiety, depression, difficulties with spoken communication, intellectual disability)

#### 7.1.2. Families and Carers of Autistic Australians

The experience of families and carers is also important in determining autism research priorities. The consultation will seek to hear from families of autistic Australians and also people in caring and / or support roles. We will ask questions of the person answering the survey and also about the autistic person they are related to or care for, to again identify the breadth of the autistic and autism communities responding to the survey.

### 7.2. Secondary Stakeholders

Secondary stakeholders, being individuals and organisations involved in the provision of services and supports, as well as managing policy, that affect the primary stakeholders, are also to contribute to this consultation.

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Secondary stakeholders include:

- Educators
- Medical and health professionals
- Service planners and providers
- Law enforcement officials
- Employers
- Architects and urban planners
- Technology providers
- Policy makers and program managers
- Researchers.

### 7.3. Proposed Consultation Format

#### Survey

A survey will be conducted in 2019 for **primary and secondary stakeholders** who would like to give their opinion on the importance, accuracy and relevance of the proposed draft research priorities in autism. To ensure broad engagement with the stakeholder community, it is contemplated that the survey methods will be through a mix of methods including online.

#### Submissions

There will also be an opportunity for submissions in free text commentary to be made in addition to or in preference to the survey for **primary and secondary stakeholders**. Submissions will also be available for **primary and secondary stakeholders** and other interested parties around the draft autism research priorities and / or other new areas of priority. Those making submissions will be asked to identify the subcategory of stakeholder they represent, and to give permission to publish their submission and name should their submission be used as part of a subsequent consultation report.

#### Targeted 'Virtual' Roundtables

The AARC will convene virtual round table discussions around the 7 core research priorities and implementation research priorities to engage **primary stakeholders** with **experts in the research priority area** including researchers and research funders. Invitations will be determined by the AARC.

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The structure of the surveys, submissions, roundtables and any other recommended forms of engagement will be co-designed with autistic people, to maximise accessibility of the consultation. All contributors to the survey, submission or roundtables will be able to provide contact details if they would like to receive a copy of the outcome of the consultation.

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**Autism CRC**

The University of Queensland  
Long Pocket Precinct  
Level 3, Foxtail Building  
80 Meiers Road  
Indooroopilly QLD 4068

**T** +61 7 3377 0600

**E** [info@autismcrc.com.au](mailto:info@autismcrc.com.au)

**W** [autismcrc.com.au](http://autismcrc.com.au)



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