Report October 2019

Australian Autism Research Council:

2019 Research Priorities

Appendices

Australian Autism Research Council

The AARC operates under the auspices of Autism CRC.

AutismCRC

Australian Government
Department of Industry, Innovation and Science

Business
Cooperative Research Centres Program

Copyright and disclaimer

Appendices

Terms of Reference: Australian Autism Research Council (AARC)

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 is intended to be representative of the key stakeholder communities and 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 2 years. Subject to the membership terms below, a member may be re-appointed to the Council for a further term.

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.

Co-Chairs

Two members of the Council shall be appointed as Co-Chairs of the Council by the Council, that appointment subject to the ratification of the Board of Autism CRC.

At least one of the Co-Chairs is to be a member of the autistic community.

At least one of the Co-Chair positions is to be filled by an existing Member who has served at least 12 months on the Council.

Member guidelines

Initially, four members were invited by the Board of Autism CRC to form an AARC Executive Committee. The Executive Committee then invited all other positions on the AARC and all positions will be for an initial term to January 2020.

Members of subsequent Councils, the first of these from January 2020, will be appointed following an open nominations process. The nomination guidelines will be formulated by the outgoing Council and ratified by the Board of Autism CRC. Nominations shall be called for by no later than 15 October of the year prior to the January from which the new Council is to be appointed.

At least half of the membership positions on the AARC are to be called for nomination each year. Members from those positions can renominate, however at least half of the positions called for nomination should be filled by new candidates.

A person may be nominated or invited to be a member of the Council as an individual or as a representative of an organisation – in either case primarily being invited to represent at least one of the stakeholder communities identified above.

A member may resign by notifying the Co-Chairs of the AARC in writing.

A member may be removed from the AARC by a unanimous decision by the other AARC members, or by a resolution of the Board of Autism CRC, if that member is deemed to be impeding the achievement of any of the AARC objectives.

The Board of Autism CRC has the right of refusal over the proposed appointment of a member of the AARC.

Subject to Autism CRC being notified and not having refused a proposed appointment, the Council may invite someone to fill a vacancy according to these Terms of Reference.

Voting

Quorum for a Council meeting is half the number of members to the nearest whole number, plus 1.

The Council's major output, a report on current priorities for autism research in Australia, requires written approval of at least 75% of the full membership of the AARC before submission to Autism CRC for publishing.

Council Meeting Protocol

The Council shall implement a meeting protocol that maximises the opportunity for members to participate, accounting for scheduling difficulties, and social and communication preferences. This protocol shall provide for:

1. a detailed meeting agenda available via an online forum for access and contributions to be made by Council members, such as a message board;
2. the online meeting forum should be open for sufficient time to allow member contributions on agenda items, for example one week;
3. during the period that the online meeting is open, a real-time virtual meeting eg videoconference or teleconference) should be held for those members wishing to contribute to the meeting considerations by that means, the proceedings of such being recorded and subsequently made available to all members through the online meeting forum;
4. At the completion of the meeting period, contributions to and outcomes on agenda items by Council members, received by any of the means provided, shall be collated as a record of the meeting and posted via a web link accessible by Council members.

Council discussions are deemed confidential in nature.

Any formal external communications of AARC outputs will be agreed by the Council in accordance with the Terms of Reference.

Reporting

The Council shall publish a report or update in November each year on autism research priorities relevant to the Australian context. This report shall build on the foundation of the Council's previous report and will use a consultative process with the community to review and revise the outputs of the Council. That process should include:

- Seeking public feedback on the previous year's report and autism research priorities;
- Canvassing international trends in autism research priorities;
- Summarising advances in autism research;
- Updating and reporting on autism research priorities in Australia, including gap analysis.

Reports generated by the AARC shall be published by Autism CRC and be subject to the guideline principles applying to Autism CRC publications.

Autism CRC Board may refuse publication if the output is deemed to be inconsistent with the AARC objectives or the vision and mission of the Autism CRC. In such circumstances, Autism CRC will return the proposed publication to the AARC for further consideration and revision.

Review

These Terms of Reference will be reviewed annually by the Council and any revisions submitted for approval to the Board of Autism CRC.

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

Australian Autism Research Council:

Draft Research Priorities for Consultation 2019

Australian Autism Research Council
Auspiced by the Autism CRC

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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.

autismcrc.com.au

Table of contents

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.

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[1], 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[2]. The plan uses a framework of seven “consumer-focus questions”, and further subcategories of research funding have been developed for portfolio analysis[3] (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).

IACC *Strategic Plan* Research Areas[1]	Australian Autism Research Funding Commitment 2013 – 2017[2]
Screening and Diagnosis • Early signs and biomarkers • Diagnostic and screening tools • Symptomology • Intermediate phenotype/subgroups	**$2,123,000**
Biology • Developmental trajectory • Cognitive studies • Subgroups / biosignatures • Neural systems • Co-occurring conditions • Neuropathology • Molecular pathways • Computational science • Immune/metabolic pathways	**$11,819,000**
Risk Factors • Genetic risk factors • Gene-environment interaction • Environmental risk factors • Epigenetics	**$5,904,000**
Treatments and Interventions • Medical / pharmacologic • Educational • Model systems / therapeutic targets • Behavioural • Technology-based intervention and supports • Complementary, dietary and alternative • Occupational, physical and sensory-based	**$8,589,000**
Services • Efficacious and cost-effective service delivery • Practitioner training • Service utilisation and access • Family well-being and safety • Community inclusion programs	**$3,434,000**
Lifespan Issues[3]	**$3,164,000**
Infrastructure and Surveillance • Research infrastructure • Biobanks • Research recruitment and clinical care • Surveillance and prevalence studies • Research workforce development	**$8,902,000**
Total Autism Research Funding in Australia 2013 - 2017	**$43,896,000**

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

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

3. Terms of Reference: Australian Autism Research Council

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- 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 Owler	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.

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[4],
- The United Nations Convention of the Rights of Persons with Disabilities[5],
- The World Health Organisation Resolution WHA 67.8[6].

The AARC also considered recent autism research priorities developed through consultation by the Autism CRC (Australia)[7], and Autistica in the UK[8], which built on a previous study[9]. 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.

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 67th 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'[6]. 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/

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.

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’[10].

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

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[13]. Many autistic individuals have co-occurring medical conditions or disabilities[12] 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, LGBTIQA+, 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[12,14,15].

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[16]. 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[17].

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[18].

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[19] and for particular populations[20].

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[15]. In Australia, the autistic patients consult General Practitioners for mostly psychological, social or general and unspecified problems (complex needs)[21]. 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[18].

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.

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.

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.

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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Australian Government
Department of Industry, Innovation and Science

Business
Cooperative Research
Centres Programme

Autism Research Survey

We want to hear your thoughts

About this survey

The Australian Autism Research Council (AARC) was established to review and define national priorities for autism research and identify areas of research needed for the autistic and autism communities. The AARC operates under the auspices of Autism CRC.

AARC 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.

The AARC has considered domestic and international commitments, and existing global and Australian surveys on autism research priorities. AARC has identified 7 broad research priority areas through this work; now we need to know what you think.

Your involvement in the consultation process will help guide the future focus of autism research activities and research funding in Australia.

The survey can be completed by anyone 18 years or over who would like to have their say on what the autism research priorities should be.

You do not need to answer this survey. If you do answer, we will not know which answers are yours. Any results that we publish from the survey will not identify you. We will store the data from this survey for at least 7 years. It may be used to help us answer other research questions too.

This survey gives you a chance to have your say about what is important to you in autism research. Answering this survey will not benefit you directly, but we hope that the autistic and autism communities may benefit in the future from having autism research priorities that are important to them.

The survey has 17 questions and will be open until midnight (AEST), 30/06/2019.

Some questions ask you to prioritise things that are most important to you. If any of the questions or content in this survey causes distress, you can end the survey at any time. If you, or someone you know is in crisis or feeling distressed and needs support, call Lifeline on 13 11 14 or Beyond Blue on 1300 224 636.

How will my responses be used?

Responses to the survey will be summarised in a consultation report that will be made available to the public, and may be used for a scholarly report.

You will be provided with an opportunity in the survey to give permission to have quotes from your responses included in the report, but you will not be able to be identified in any reporting.

If you have any questions about this survey

You can contact Autism CRC on this email: aarc@autismcrc.com.au

If you would like to read Mind Tap Research's privacy policy, you can access it here.

You can contact Mind Tap Research on this email: contact@mindtapresearch.com.

Mind Tap Research is a member of the Australian Market and Social Research Society and adheres to the Code of Professional Behaviour. You can view our membership profile here.

Thank you for contributing your views and experiences.

Do you consent to your survey responses being used for research purposes?

You must click ‘yes’ in order to complete this survey.*

( ) Yes, I give consent
( ) No, I do not give consent and do not wish to participate

Questions about you

Before we ask you for your feedback and opinions, we have a few questions about you. This is to ensure we have received feedback from a wide variety of people. Responses to these questions also allow us to better understand the different perspectives we are gaining through this survey.

Please select ‘Prefer not to answer’ for any questions you do not wish to answer.

Which of the following options best describes you?

Please select all that apply.
*****

[ ] I am autistic
[ ] I am a parent/guardian or other family member of an autistic person
[ ] I am a carer of an autistic person
[ ] I am a support worker / work directly with autistic people
[ ] I am an advocate for autistic people
[ ] I am an autism service provider / work for an autism service provider
[ ] I work for an autism peak association or body
[ ] I employ autistic people
[ ] I am a health professional
[ ] I am a researcher
[ ] I am employed by federal, state or territory, or local government
[ ] I am a business owner
[ ] I am an interested member of the community (e.g., friend)
[ ] Other (please specify): ____
[ ] Prefer not to answer

How are you filling out this survey?*

( ) By myself

( ) With someone else helping me to fill it out or understand the questions

What is your gender?*

( ) Man

( ) Woman

( ) Nonbinary

( ) Transgender

( ) I’d prefer to describe myself (please specify):

____

( ) Prefer not to answer

How old are you?*

( ) 18-24 years
( ) 25-34 years
( ) 35-44 years
( ) 45-54 years
( ) 55-64 years
( ) 65-74 years
( ) 75-84 years
( ) 85-94 years
( ) 95 years or older
( ) Prefer not to answer

Do you identify as Aboriginal or Torres Strait Islander?*

( ) Yes
( ) No
( ) Prefer not to answer

Are you from a culturally or linguistically diverse background?*

( ) Yes
( ) No
( ) Prefer not to answer

Which state or territory do you live in? *

( ) Australian Capital Territory

( ) New South Wales

( ) Northern Territory

( ) Queensland

( ) South Australia

( ) Tasmania

( ) Victoria

( ) Western Australia

( ) I do not live in Australia

( ) Prefer not to answer

What is your postcode?

If you are unsure, please leave this blank.

____

Do you have any of the following conditions? Please select all that apply.

If you do not have any of these conditions, please select 'None of the above'.

If you would rather not answer this question, please select 'Prefer not to answer'.
*****

[ ] Depression, anxiety, or any other mental health condition

[ ] Epilepsy or seizure disorder

[ ] Intellectual disability

[ ] Speech disability

[ ] Learning disability (e.g., ADHD, dyslexia)

[ ] Other (please specify): ____

[ ] Prefer not to answer

[ ] None of the above

Which of the following best describes your current employment status?

Please select all that apply.
 *

[ ] Self employed
[ ] Employed for wages, salary or payment in kind
[ ] Working as a volunteer
[ ] Engaged in home and/or care duties
[ ] Student
[ ] Retired
[ ] Unemployed
[ ] Unable to work
[ ] Other (please specify): ____
[ ] Prefer not to answer

Autism Research Priorities

We are now going to ask you some questions about autism research priorities.

The Australian Autism Research Council has identified seven broad areas for future autism research. We would like your feedback on these.

In particular, we would like to know if you think there should be certain priority areas for autism research.

Please rate how much of a priority you think each of the following research areas should be in future.
*

	Not a priority	**Low priority**	**Medium priority**	**High priority**	**Essential**	**Don't know**
Communication research • Understanding the development of communication in autism • Evidence-based supports to help with communication	( )	( )	( )	( )	( )	( )
Buildings and other built structures research • Accessible, comfortable and inclusive spaces for autistic people	( )	( )	( )	( )	( )	( )

Health and wellbeing research • Optimal physical and mental health for autistic people, including other conditions	( )	( )	( )	( )	( )	( )
Justice research • Prevent discrimination and abuse of autistic people • Support for autistic people in dealing with the legal system	( )	( )	( )	( )	( )	( )
Employment research • Meaningful employment opportunities that are accessible and inclusive for autistic people	( )	( )	( )	( )	( )	( )
Education research • An inclusive education system that meets the needs of all students on the autism spectrum	( )	( )	( )	( )	( )	( )

Health and disability services research - Access to quality health and disability services for autistic people	( )	( )	( )	( )	( )	( )

For this question, we would like you to imagine that the government gave you $7 to give to autism research. You can choose which of the seven research areas the money goes to. You may want to give all of the money to one area, split it across two or three areas, or divide it up evenly across all seven areas.

Please enter how much of the $7 dollars you would give to each of the seven research areas listed below.

Dollar amounts must add up to $7. Totals will be automatically added up for you at the bottom.

Communication research
- Understanding the development of communication in autism
- Evidence-based supports to help with communication

Buildings and spaces research
- Accessible, comfortable and inclusive spaces for autistic people

Health and wellbeing research
- Optimal physical and mental health for autistic people, including other conditions

Justice research
- Prevent discrimination and abuse of autistic people
- Support for autistic people in dealing with the legal system

Employment research
- Meaningful employment opportunities that are accessible and inclusive for autistic people

Education research
- An inclusive education system that meets the needs of all students on the autism spectrum

Health and disability services research
- Access to quality health and disability services for autistic people

Below is a list of other potential areas for autism research. This is a modified list based on the UN Convention on the Rights of People with Disabilities.

Please select all of the potential autism research areas that are particularly important to you.

If you don't think any of the options below should be key autism research priorities, then please select the option 'None of the above'.
*

[ ] Equality and discrimination, including law

[ ] Women and girls on the autism spectrum

[ ] Children on the autism spectrum

[ ] Raising awareness and educating the Australian community about autistic people

[ ] Safe, accessible and affordable transportation for autistic people

[ ] Access to information and communication technologies for autistic people

[ ] Protection and safety of autistic people in emergencies and natural disasters

[ ] Personal freedom for autistic people

[ ] Research on the safety of autistic people, including freedom from exploitation, violence and abuse

[ ] Physical and mental respect for autistic people

[ ] Freedom for autistic people to travel and move between countries

[ ] Inclusion of autistic people in the community

[ ] Access to support to allow independent living for autistic people

[ ] Respect for the privacy of autistic people, including their homes and family

[ ] Equal access to social support by autistic people

[ ] Participation in political and public life by autistic people

[ ] Access to sport and leisure activities for autistic people

[ ] Support for carers/families of autistic people

[ ] **None of the above**

Are there any other broad areas of research, or more specific research questions, that you think should be an autism research priority in future?

Please list them in the space below.

There is an opportunity for more general comments in the next question.

____

____

____

____

Before we move on to the final question, do you have any further comments about autism research priorities that you would like to add?

Please write them in the space below.

____

____

____

____

Can we include quotes from your responses in the report summarising the findings from this survey?

(These would be anonymous)*

( ) Yes

( ) No

Thank You!

Thank you for sharing your valuable feedback and experiences.

If you would like to know more or register to receive updates about this research, please visit: www.autismcrc.com.au/aarc.

AutismCRC

Have Your Say

Autism Research Priorities

Australian
Autism
Research
Council

Autism Research Survey

We want to hear your thoughts

Easy read version

Easy Read

How to use this survey

This survey is written in an easy to read way. Pictures have been used for some questions to explain ideas.

This survey is being conducted by Mind Tap Research for The Australian Autism Research Council (AARC).

When you see the word ‘we’, it means the AARC.

This Easy Read survey is a summary of another survey.

You can find the other survey at this web address: insert link here

You can ask for help to ready this survey. A friend, family member or support person may be able to help you.

About this survey

Autism research will help us find solutions that give people with autism and their families a better life.

The Australian Autism Research Council (AARC) helps find out what autism research ideas are important.

The AARC is a group of autism experts including autistic people, parents and carers, service providers, doctors, teachers, government, policy makers and researchers.

Their ideas can be used by government, service providers, teachers and doctors.

The AARC identified 7 broad research priority areas for the future.
Now we need to know what you think.

Answering the survey questions

What people tell us in this survey will help us

- Write our report.
- Make sure that people are doing the right types of research in the future.

We want to know

- What you think of the different research topics.
- What other types of research would help to make the lives of autistic people better.
- A little bit about who you are.

By answering this survey, you are giving consent for us to use your responses to find out which autism research areas are important.

We may also use your answers to understand other research questions too.

Everybody's answers will be combined.

This means that nobody will know which answers belong to you.

We will not ask you what your name is.

You can stop the survey any time you want.

The survey will close on the 30th of April 2019.

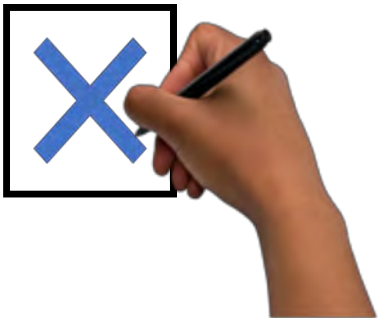
If you have any questions about this survey

You can contact Autism CRC on this email: insert email here

If you would like to read Mind Tap Research's privacy policy, you can access it here: https://bit.ly/2uw4h3Y

You can contact Mind Tap Research on this email:
contact@mindtapresearch.com.

Mind Tap Research is a member of the Australian Market and Social Research Society and follows the Code of Professional Behaviour.



When you answer questions in the survey, please mark them clearly with an X.

Example

1. Example Question

☐ Example answer A

☒ Example answer B

☐ Example answer C

If you are writing an answer to a question, please make sure your writing is

- Clear
- Easy to read.

Survey Questions

Questions about you

Are you

☐ An autistic person?

☐ A family member helping an autistic person fill out the survey?

☐ A carer helping an autistic person fill out the survey?

☐ Other? Please tell us

____

____

What is your gender?

☐ Man

☐ Woman

☐ I don’t want to answer

☐ Other? Please tell us

How old are you:

☐ 18-24 years

☐ 25-34 years

☐ 35-44 years

☐ 45-54 years

☐ 55-64 years

☐ 65-74 years

☐ 75-84 years

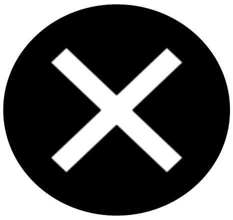
☐ 85-94 years

☐ 95 years or older

☐ I don’t want to answer

Are you from an Aboriginal and/or Torres Strait Islander background?

☐ Yes



☐ No

☐ I don't want to answer

Which Australian state or territory do you live in?

ACT	☐ Australian Capital Territory
NSW	☐ New South Wales
NT	☐ Northern Territory
QLD	☐ Queensland
SA	☐ South Australia
TAS	☐ Tasmania
VIC	☐ Victoria
WA	☐ Western Australia

☐ I do not live in Australia

☐ I don’t want to answer

Do you have any of the following conditions?

☐ Depression, anxiety, or any other mental health condition

☐ Epilepsy or seizure disorder

☐ Intellectual disability

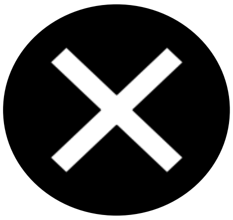
☐ Speech disability

☐ Learning disability (e.g., ADHD, dyslexia)

☐ Other – please tell us

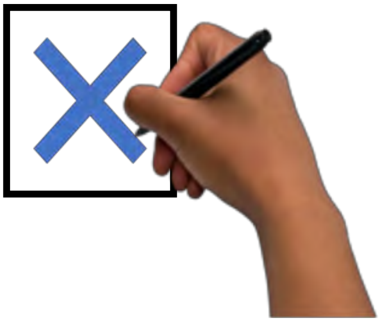
____

____



☐ I do not have any of these conditions

☐ I don’t want to answer



Now we are going to go through each of the 7 different areas of autism research.

We would like to know how important you think each of these areas of research are.

Place a mark in the box to show how important you think each area of research is.

How important do you think it is to find more ways for autistic people to say what they want?

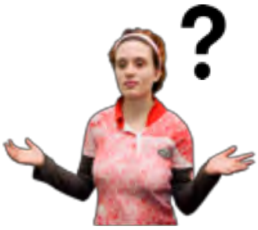
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important



☐ I don’t know

☐ I don’t want to answer

How important do you think it is to find more ways to make buildings, parks and transport more accessible for autistic people?

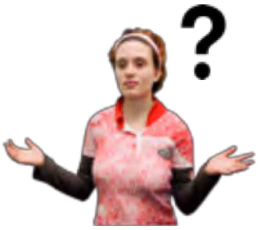
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important



☐ I don’t know

☐ I don’t want to answer

How important do you think it is to find more ways for autistic people to live healthy and happy lives?

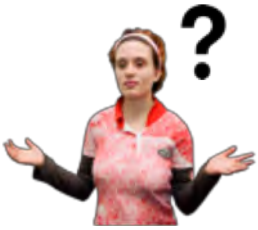
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important



☐ I don't know

☐ I don't want to answer

How important do you think it is to find more ways for autistic people to get justice and be treated equally by the law?

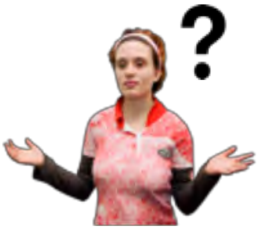
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important



☐ I don't know

☐ I don't want to answer

How important do you think it is to find more ways for autistic people to find work they like doing with equal pay?

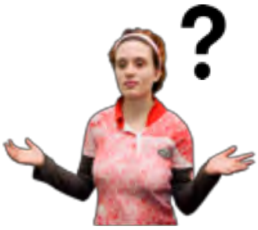
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important



☐ I don't know

☐ I don't want to answer

How important do you think it is to find more ways for autistic people to get the health services they need?

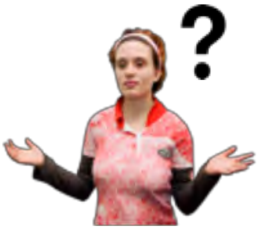
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important


☐ I don’t know


☐ I don’t want to answer

How important do you think it is to find more ways to make education inclusive for autistic people?

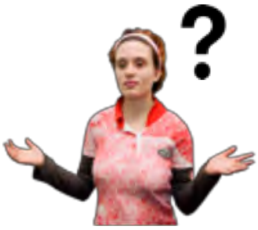
👎 ☐ Not at all important

👍 ☐ A little bit important

👍👍 ☐ Fairly important

👍👍👍 ☐ Very important

👍👍👍👍 ☐ Extremely important

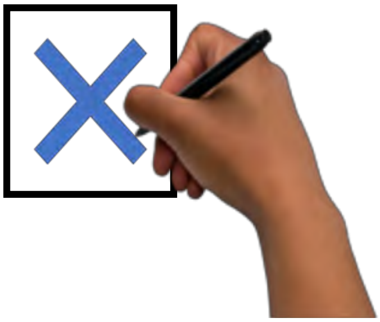


☐ I don’t know

☐ I don’t want to answer

Now we are going show you a list of other topics for autism research.

We would like to know which topics are the most important to you.



Place a mark in the box next to the topics that you think are the most important for future research.

Only select the research topics that you think are very important.

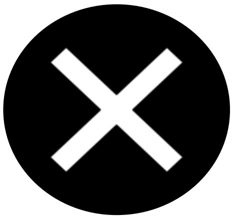
Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Autistic people being treated as equal

☐ Autistic women and girls being treated as equal

☐ Autistic children being treated as equal



☐ I don’t think any of these ideas are important for research

☐ I don’t want to answer

Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Teaching everyone about autism and autistic people

☐ Safe and accessible transport for autistic people

☐ Access to information and technology for autistic people

☐ I don't think any of these ideas are important for research

☐ I don't want to answer

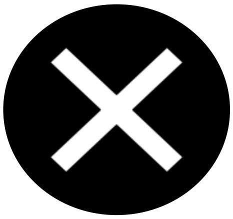
Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Protection and safety of autistic people in emergencies

☐ Making sure autistic people are free and safe

☐ Making sure autistic people are not tortured or being treated cruelly



☐ I don't think any of these ideas are important for research

☐ I don't want to answer

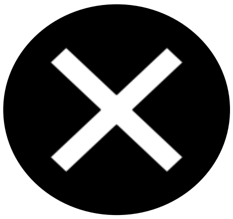
Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Respecting the minds and bodies of autistic people

☐ Freedom for autistic people to travel and move between countries

☐ Including autistic people in the community



☐ I don't think any of these ideas are important for research

☐ I don't want to answer

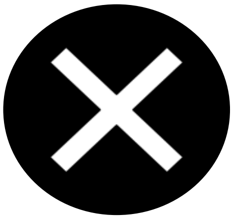
Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Support for autistic people so that they can make their own choices and get the help they need

☐ Respect for the privacy of autistic people, including their homes and family

☐ Support for autistic people so that they have what they need to live



☐ I don't think any of these ideas are important for research

☐ I don't want to answer

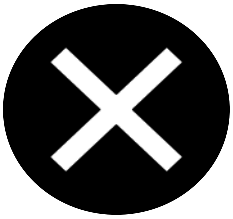
Which of these research topics are very important to you?

Place a mark in the box next to the topics that you think are the most important for future research.

☐ Making sure that autistic people can be involved in politics

☐ Making sure autistic people can get involved in sport and leisure activities

☐ Support for carers and families of autistic people



☐ I don’t think any of these ideas are important for research

☐ I don’t want to answer

Are there any other areas of research that you think are important for autistic people?

Tell us which areas of research you think are important.

Do you have any other comments you would like to make?

Please enter your comments in the space below.

Can we use some of the things you have told us in the report we will write?

We will not use your name so nobody will know which comments are from you.

✓ ☐ Yes

✗ ☐ No

Thank you for sharing your valuable feedback and experiences.

If you would like to know more or register to receive updates about this research, please visit: www.autismcrc.com.au/aarc.

Autism Research Priorities

MINDTAP RESEARCH

Prepared for Autism CRC
August 2019

Executive Summary

MINDTAP
RESEARCH

Background & Research Objectives

Established in 2013, Autism CRC is the world's first national, cooperative research effort focused on autism. They provide the national capacity to develop and deliver evidence-based outcomes through their unique collaboration with the autism community, research organisations, industry, and government. Currently, Autism CRC has 56 participant organisations and other partners based around Australia and internationally.

In 2018, Autism CRC established the Australian Autism Research Council (AARC) to review and determine national priorities for autism research and address areas of need for the autistic and autism communities.

The AARC has developed a consultation paper, identifying a set of potential key research priorities for the future. The aim of the current research was to consult people with a lived experience of autism and the broader community to gather feedback on the importance of these research areas, and identify any additional research areas that should be prioritised.

The research priorities identified in the current research, in conjunction with those identified in the AARC consultation paper, will guide the future focus of:

- Research activities and research funding by government;
- Research and development undertaken by non-government organisations; and
- Programs and services provided by other industry members for the autism community.

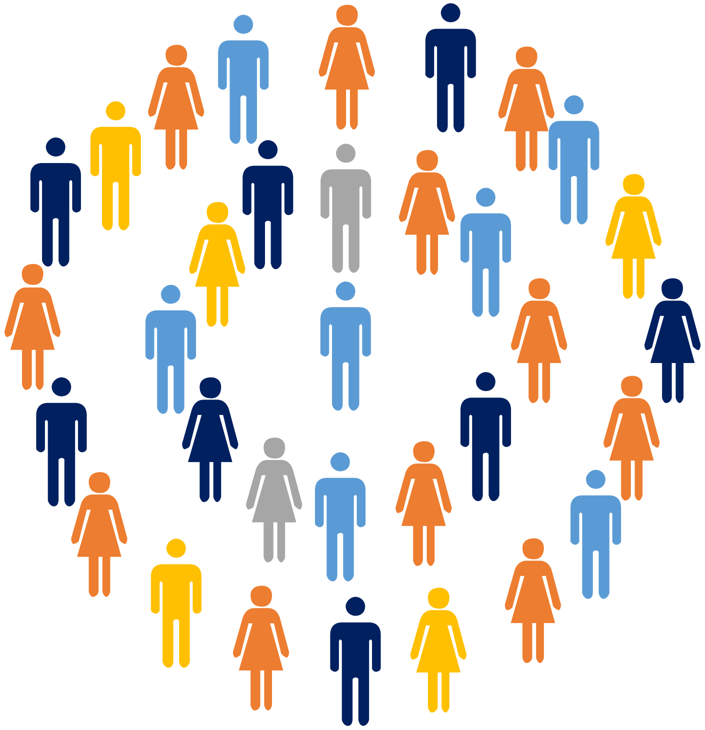
Research methodology

How was the research conducted?

To gather feedback from a large, representative sample of the community, we developed three different surveys:

1. An online survey;
2. An online Easy Read survey; and
3. A PDF version of the Easy Read survey, designed to be completed as a hard copy.

The surveys were promoted by Autism CRC (including on their website and on social media). The online surveys were open throughout all of June 2019, and were hosted on SurveyGizmo.



Who did we speak to?

A total of 1,102 respondents completed one of the two online surveys.

- 1,018 completed the standard version of the online survey
- 84 completed the easy read version of the online survey

No respondents opted to complete the hard copy Easy Read version of the survey. Overall, 22% of respondents were autistic, and 65% of respondents were parents, guardians or other family members of an autistic person.

Key findings

The majority of respondents who completed the survey were female (83%). Among autistic respondents, 22% were male and 63% were female.

Among the 247 autistic respondents, 43% were also a parent or family member of an autistic person. The majority of autistic respondents (91%) also had another comorbid condition or disability.

Only a small proportion of the respondents were from a culturally and linguistically diverse background (15%), or Aboriginal and/or Torres Strait Islander (2%).

Autistic respondents were significantly less likely to be in paid employment (43%) than non-autistic respondents (60%), but significantly more likely to be working as volunteers (10% versus 5%), studying (28% versus 9%), unemployed (10% versus 2%), and unable to work (14% versus 2%) than non-autistic respondents.

Research priority ratings

All seven of the research areas identified for future autism research in the AARC consultation paper were considered to be a high priority by respondents. Education research, in particular, was given the highest mean priority rating by autistic respondents (91% rated it as a high priority or essential) and non-autistic respondents (95% rated it as a high priority or essential).

Out of the seven research areas identified, research focusing on buildings and other built structures was given the lowest priority rating by autistic respondents (67% rated this as a high priority or essential) and non-autistic respondents (53% rated this as a high priority or essential).

> *“Education especially in mainstream schools. Teachers are unprepared for teaching special needs children. There are increasing numbers of children on the spectrum and not enough assistance in classrooms to help. Children on the spectrum are just being put into a too hard basket. These kids are too smart for special school but don't cope in main stream so get lost in the system.”*

Key findings

Hypothetical research funding allocations

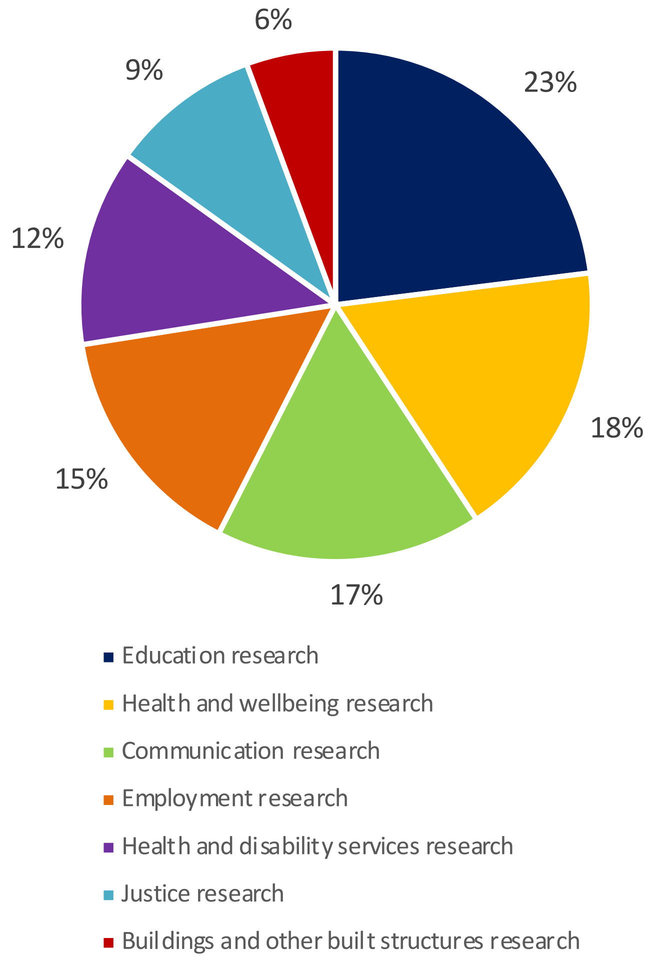
To encourage respondents to consider the relative importance of the proposed research areas, those who completed the standard survey were asked how much money they would allocate to each area if they had a total of $7 to give away. The relative percentage of funding allocated by respondents across the seven areas is shown in the figure on the right.

Among autistic respondents, health and wellbeing research was allocated the most amount of hypothetical funding. Autistic respondents also spread their allocated funding across more research areas than non-autistic respondents.

Interestingly, hypothetical funding allocations differed somewhat to the rating measures. For example, almost half of the respondents did not allocate any funding to ‘justice research’, despite 95% of respondents rating this as a medium priority, high priority or essential. For research focusing on buildings and other structures, 66% of respondents did not allocated any funding, despite 89% of respondents rating this area of research as being a medium priority, a high priority, or essential.

A comparison of funding among autistic respondents and non-autistic respondents showed that non-autistic respondents allocated significantly more to ‘education research’ and ‘communication research’ than autistic respondents. Conversely, autistic respondents allocated significantly more funding to ‘health and wellbeing research’, ‘justice research’, and ‘buildings and other built structures research’ than non-autistic respondents.

Respondents’ hypothetical funding allocation to each research area



Key findings

Other research focus areas

Respondents were asked to select other potential areas for autism research from a modified list based on the UN Convention on the Rights of People with Disabilities and/or suggest additional areas of research that should be a high priority.

One of the main themes identified was a desire to see more research identifying the causes of autism and/or research into effective and accessible treatments, interventions and cures for autism. Many respondents identified a need for treatments for specific presentations of autism and/or comorbid conditions, such as mental health conditions.

Many respondents were concerned about the efficacy of existing autism diagnostic tools, particularly for women and girls. Some respondents mentioned that there needs to be more research to prevent late autism diagnoses among women and girls, and to provide support those who have received a late diagnosis.

Many respondents (74%) indicated that research should focus on support for people who care for autistic people, and the impact on family members. Suggestions included: reliable, easy-to-access information for parents about autism and treatments; financial support; empowering parents and providing them with a positive outlook; support for managing complex needs and challenging behaviours; and support for autistic parents raising children also on the autism spectrum.

"The elephant in the room: Studying why autism and related neurological disorders are so clearly on the rise. The argument of better diagnoses and greater awareness from medical practitioners is weak when you look at the skyrocketing current trend, and at statistics for the number of older or even middle-aged people with ASD. There are clearly environmental factors afoot, and we should look at them boldly and without prejudice."

Key findings

Other research focus areas

Access to support to allow independent living for autistic people was chosen by two-thirds of respondents as an additional research priority area. Some respondents mentioned the importance of accessing quality health and disability support services, as well as government funding required to access these services. The need for quality supported accommodation was also mentioned by some respondents.

Despite already being one of the seven research priority areas identified in the AARC consultation paper, issues relating education for children on the autism spectrum was a reoccurring theme in respondents' text comments. Many respondents indicated that future research needs to focus on teacher education and training to promote better understanding and communication with autistic students. Respondents also mentioned a need for more sensory-friendly education settings, school assessments that are adapted to suit autistic students, and greater awareness and appreciation of neurodiversity among non-autistic students.

Awareness and acceptance of autistic people in the wider community was another common research theme mentioned by respondents. In particular, respondents were keen to see greater public education about autism and the diversity characteristics associated with autism. Some respondents suggested that education about autism was especially required for professionals who engage with autistic people on a regular basis, such as health professionals.

“Public Awareness. Autism is a spectrum presenting differently in each individual. The Community still holds the caricature of a person living with Autism as being like 'Rain Man'. Unless you or your child 'avoids eye-contact', 'sorts dinosaurs by colour' or 'is obsessed by cricket statistics' in the eyes of the community you are not Autistic.”

MINDTAP
RESEARCH

Detailed Findings

Demographics

Interpreting the Research Findings

A note on sample size

With a sample size of 1,018 for the standard version of the survey, we can be 95% confident that the "true" population percentage for a given question will be within 3.1 percentage points of the percentage observed in the data. For example, if 50% of respondents selected a given research area as being important, then we could conclude that between 46.9% and 53.1% of the broader population would believe that research areas is important. The margin of error for the Easy Read version of the survey (n=84) is a maximum of 11 percentage points.

Between-group comparisons

To identify research priorities among key stakeholders, we compared responses between different groups of respondents (e.g., autistic respondents and non-autistic respondents). We used parametric and nonparametric tests of statistical significance to help identify any differences between groups. To minimise the likelihood of type I errors (i.e., false positive differences), we used a conservative p-value of .01 to detect significant results. Quantitative responses were analysed using SPSS.

Free text questions and analysis

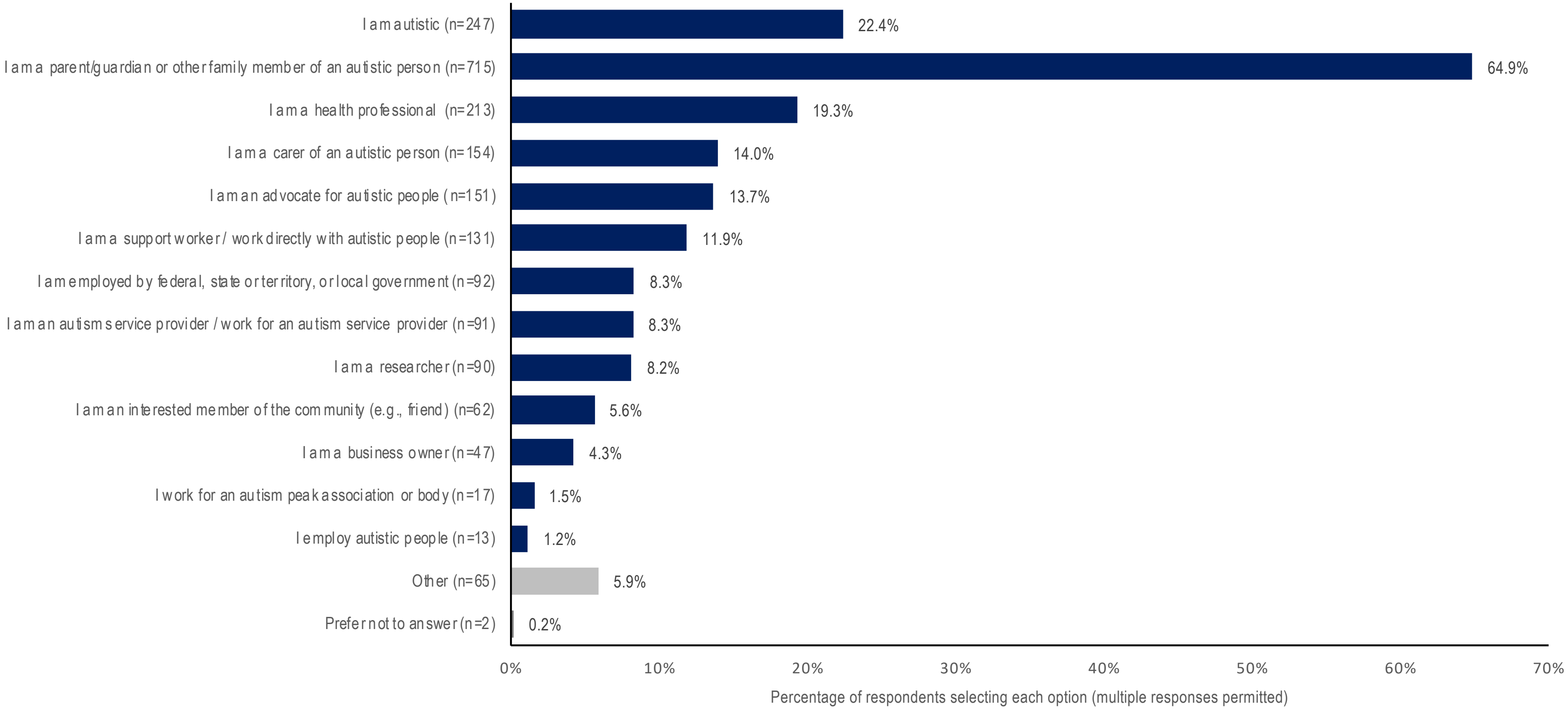
Thematic analysis (Braun & Clarke, 2006) was used to analyse open-ended text responses. Individual responses were coding into specific topics; compatible topics were then combined into a smaller number of broader themes.

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

Respondents’ interest in autism

Overall, 22% (n=247) of respondents were autistic. Sixty-five percent of respondents were parents, guardians or other family members of an autistic person. Among those who completed the Easy Read survey, less than a third were autistic (24 out of 84).

Respondents’ interest in autism (n=1,102)

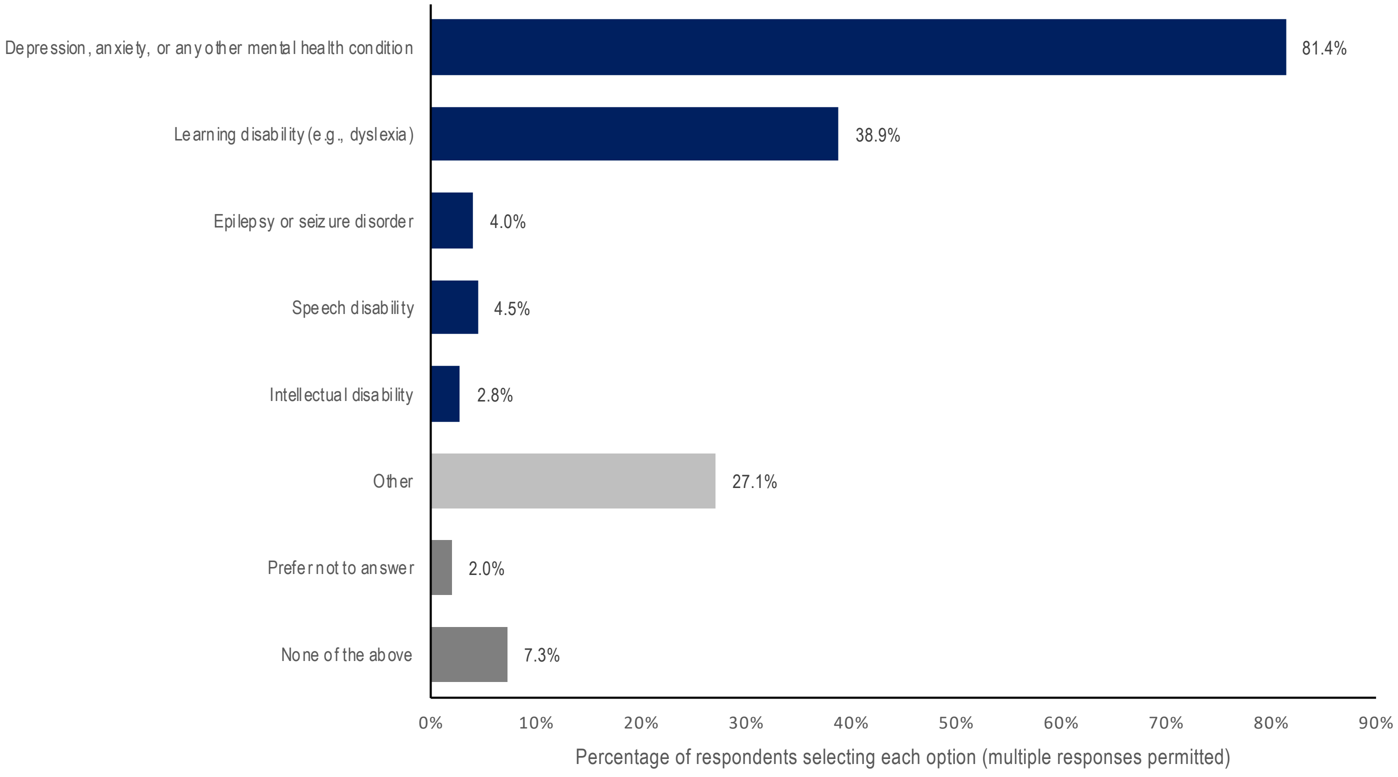


Q: Which of the following options best describes you? Please select all that apply.

Other conditions

Among the 247 autistic respondents, the majority (91%) also had at least one other condition or disability. The most prevalent conditions were mental health conditions, followed by learning disabilities. Some of the ‘other’ conditions mentioned were ADHD, autoimmune diseases, chronic illness, and sensory processing disorder.

Other conditions among autistic respondents (n=247)



Q: Do you have any of the following conditions? Please select all that apply.

Demographics – gender & age

The majority of respondents across both version of the survey were female (n=918). Although there were more female (n=156) than male (n=55) autistic respondents, autistic respondents were more likely to be male or a nonbinary gender than non-autistic respondents. As shown in the chart below, the majority of respondents were aged between 25 and 64 years.

Gender (n=1,102)

Males

12.3%

Females

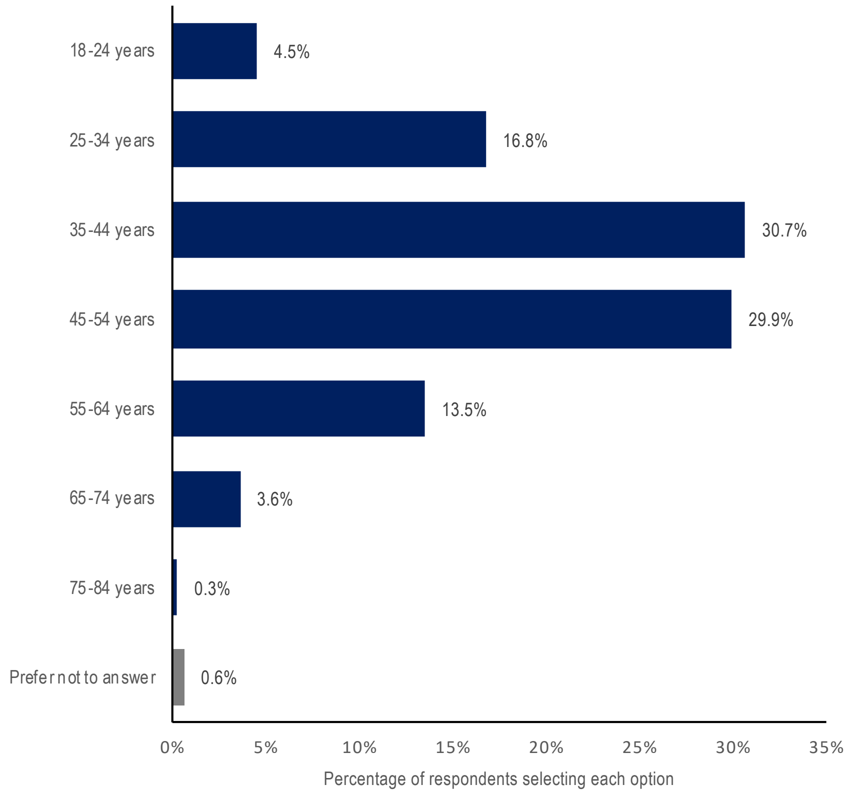
83.3%

4.4% chose a different response (i.e., nonbinary, transgender, I'd prefer to describe myself, prefer not to answer)

Gender*	Autistic (n=247)	Not autistic (n=855)
Male	55 (22.3%)	81 (9.5%)
Female	156 (63.2%)	762 (89.1%)
Nonbinary	28 (11.3%)	3 (0.4%)
Transgender	1 (0.4%)	1 (0.1%)
I'd prefer to describe myself	4 (1.6%)	-
Prefer not to answer	3 (1.2%)	8 (0.9%)

** = Chi-square test, p < .01*

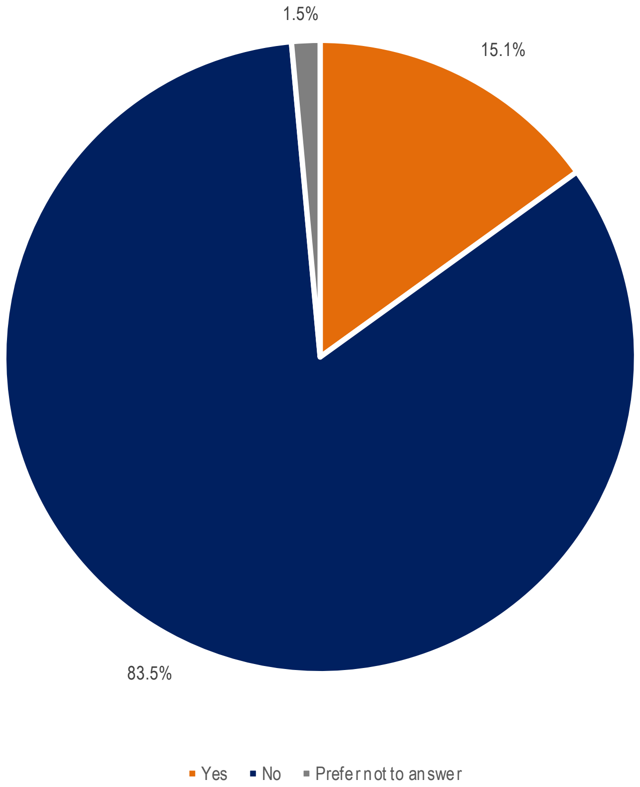
Age (n=1,102)



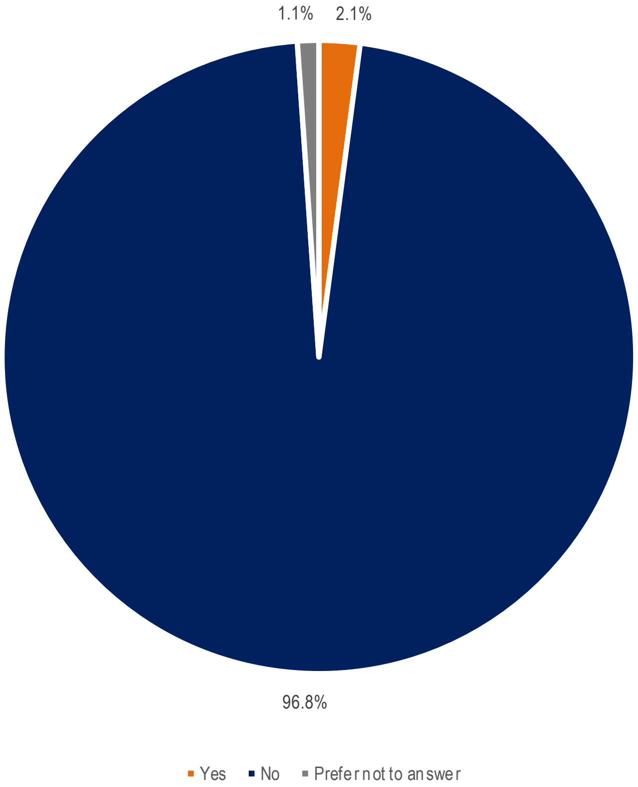
Demographics – CALD and ASTI

Across both surveys, 166 respondents identified as being from a culturally or linguistically diverse background. Twenty-three respondents identified as Aboriginal and/or Torres Strait Islander.

Cultural and Linguistic Diversity (n=1,102)



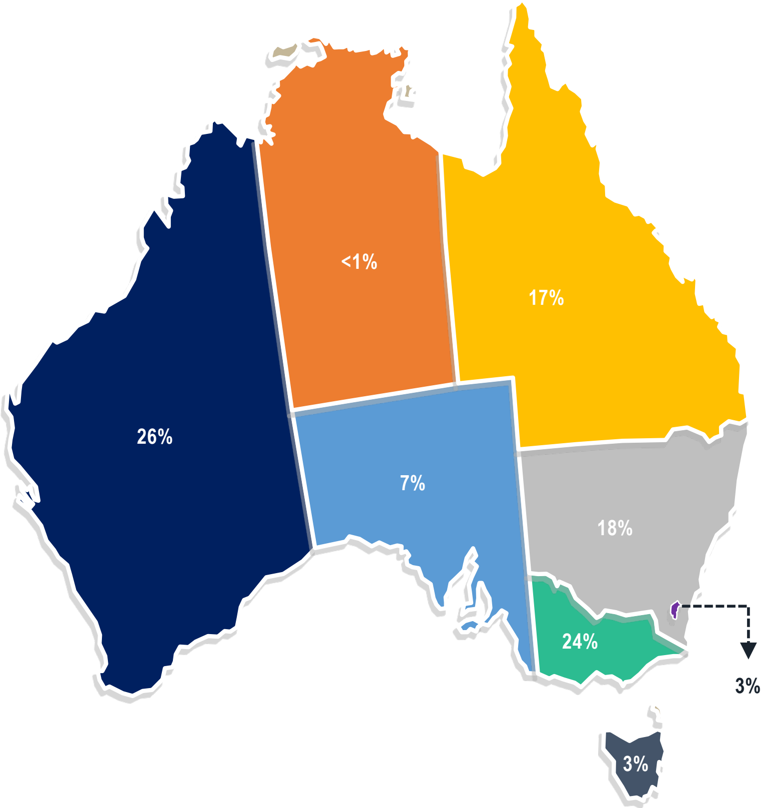
Aboriginal and/or Torres Strait Islander status (n=1,102)



Demographics – state & territory

A shown in the figure below, respondents' state or territory of residence differed somewhat to the distribution of the Australian population. Just over a quarter of respondents were from Western Australia and just under a quarter were from Victoria. Only four respondents were from the Northern Territory.

State/territory of respondents (n=1,102)

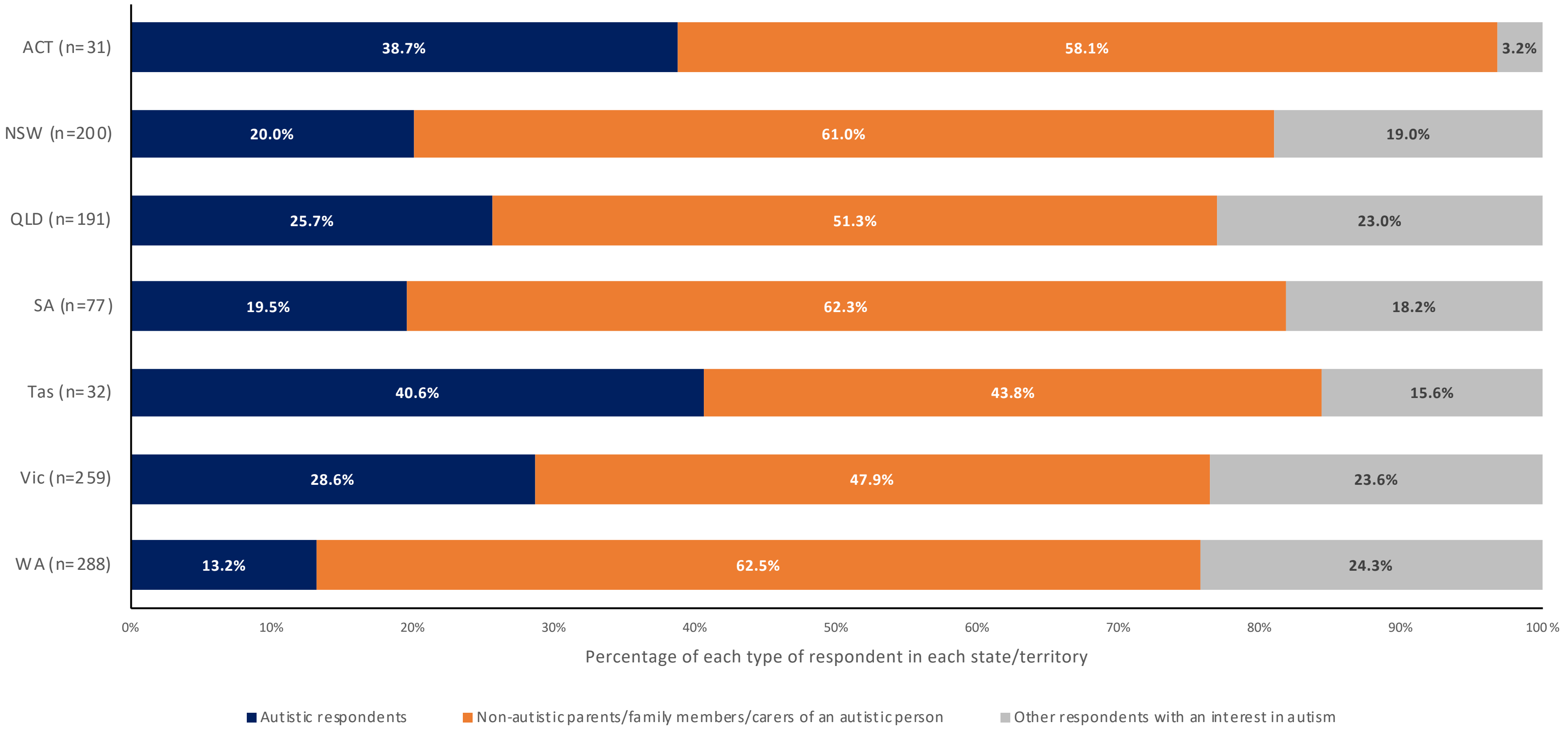


Eleven respondents lived outside of Australia and nine respondents chose not to answer this question.

Respondents’ interest in autism by state/territory

The chart below shows that respondents’ interest in autism varied significantly by state and territory. Respondents from the ACT and Tasmania were made up with a high proportion of autistic respondents (39% and 41%, respectively), whereas the majority of WA respondents were non-autistic parents, family members, or carers of an autistic person, or other respondents with an interest in autism.

State/territory of respondents, by interest in autism (n=1,102)*

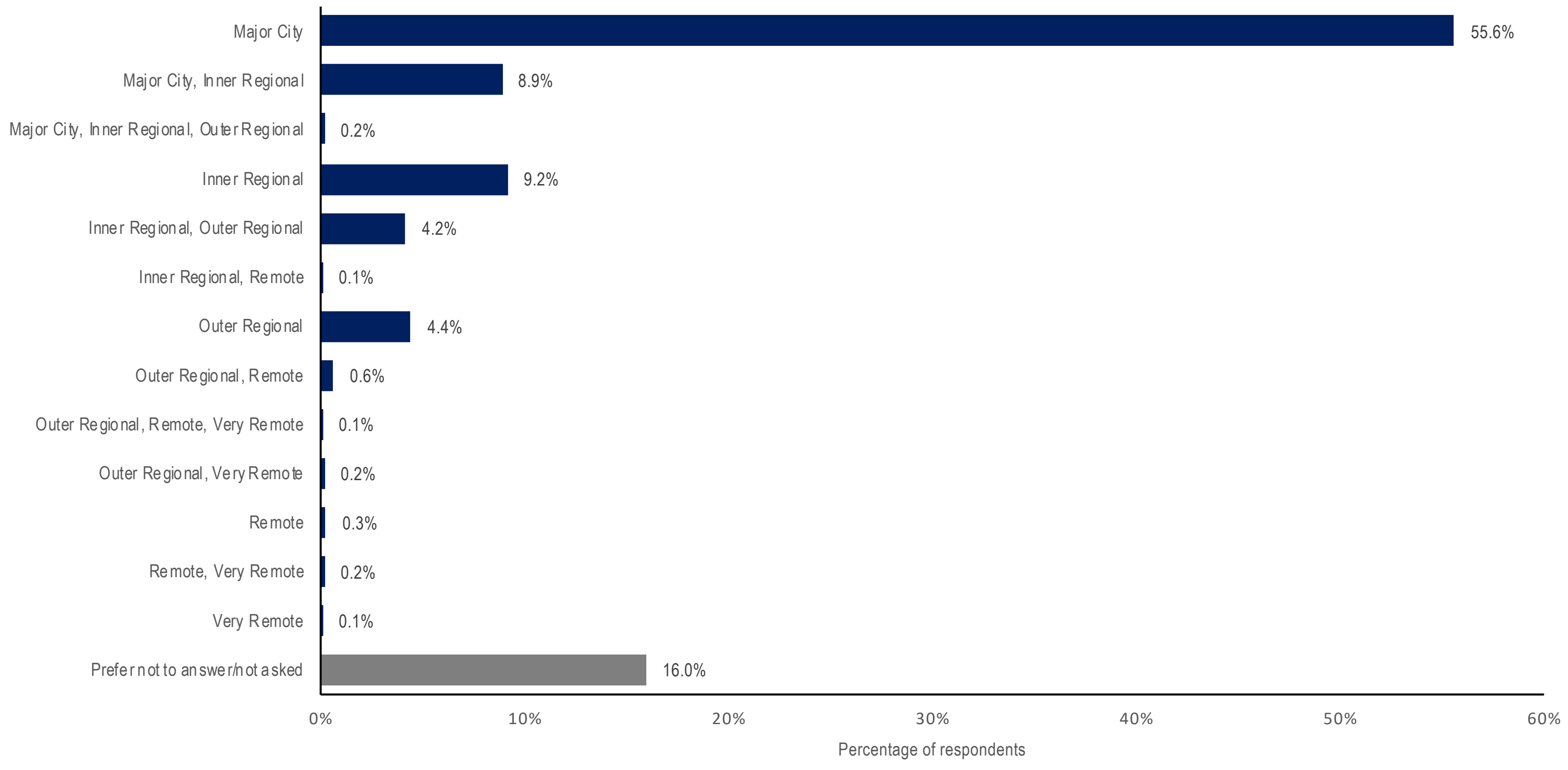


* = Chi-square test, *p* < *.01*. Respondents from the Northern Territory are not included here due to the small sample size.

Demographics – accessibility & remoteness

Postcode was used to classify respondents by the Accessibility and Remoteness Index of Australia (ARIA). Given that postcodes are primarily designed for the delivery of mail, they do map perfectly to the ARIA classification. The chart below shows that between 55.6% and 64.7% of respondents were from a major city. Between 19.3% and 28.4% of respondents were from regional or remote areas.

Geographic accessibility of respondents based on postcode (n=1,102)

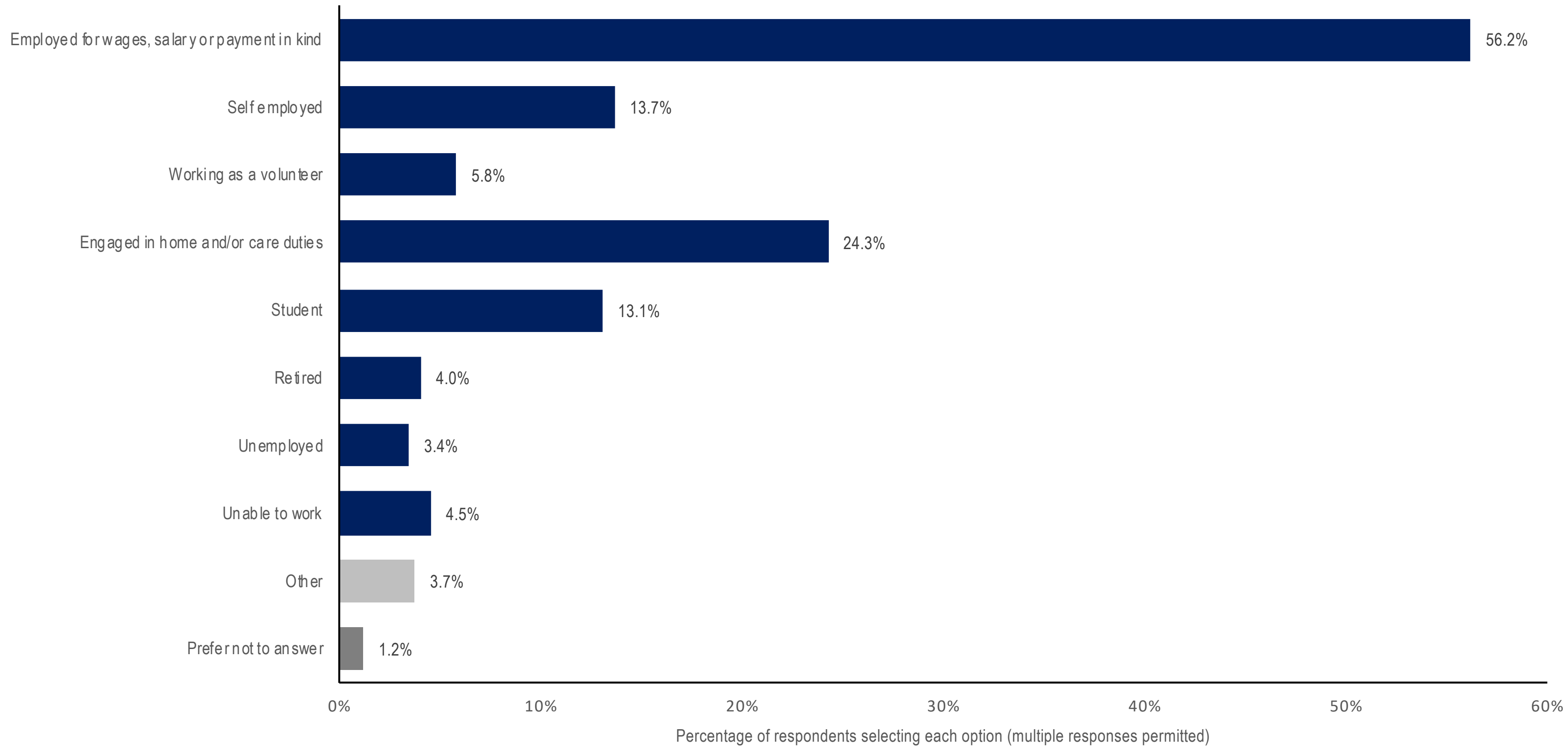


ARIA classification based on respondents' postcode (The following source from The University of Sydney was used to map postcodes to ARIA categories: http://www.pocog.org.au/aria/default.aspx)

Demographics – employment status

Respondents who completed the standard version of the online survey were asked about their employment status. Just over half of the respondents were in paid employment; approximately a quarter were engaged in home and/or care duties. Many of those engaged in home/care duties were not engaged in paid employment (173 out of 247 – 17% of total sample).

Employment status of respondents who completed the standard survey (n=1,018)

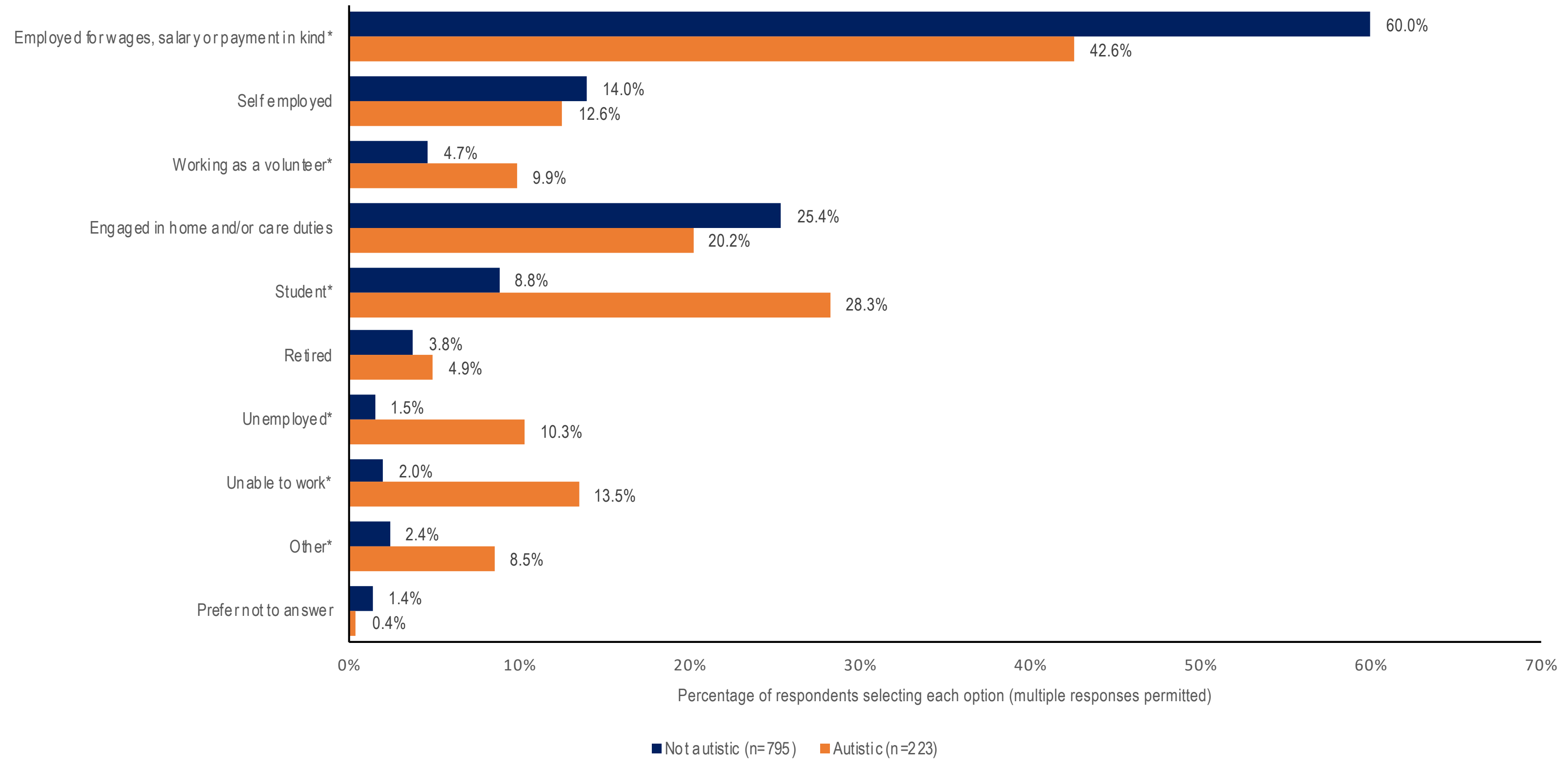


Q. Which of the following best describes your current employment status? Please select all that apply.

Demographics – employment status

Employment status varied significantly by whether respondents were autistic or non-autistic. Autistic respondents were significantly less likely to be in paid employment (43%) than non-autistic respondents (60%), but significantly more likely to be working as volunteers (10% versus 5%) or studying (28% versus 9%).

Employment status, by autism status - respondents who completed the standard version of the online survey



** = Chi-square test, p < .01*

Demographics by respondents’ interest in autism

The table below shows gender, age, and the presence of other conditions, split by respondents’ interest in autism. Although the majority of respondents across all three groups were female, there was a higher proportion of males (22%) among autistic respondents, than in in the other two groups. Other conditions, particularly mental health conditions, were much more prevalent among autistic respondents, than among the other two groups. That being said, approximately a third of ‘non-autistic parents/ family members/ carers of an autistic person’ reported having a mental health condition.

Interest in autism, by gender, age & other conditions

Demographic variable	Autistic Respondents (n=247)	Non-autistic parents/family members/carers of an autistic person (n=616)	Other respondents with an interest in autism (n=239)
Gender*			
Male	22.3%	8.1%	13.0%
Female	63.2%	90.9%	84.5%
Nonbinary	11.3%	-	1.3%
Transgender	0.4%	0.2%	-
I’d prefer to describe myself	1.6%	-	-
Prefer not to answer	1.2%	0.8%	1.3%
Age*			
18-24 years	12.6%	0.6%	6.3%
25-34 years	26.3%	8.3%	28.9%
35-44 years	24.7%	35.7%	23.8%
45-54 years	21.9%	37.3%	19.2%
55-64 years	9.7%	14.0%	16.3%
65-74 years	3.6%	3.2%	4.6%
75-84 years	0.4%	0.3%	-
Prefer not to say	0.8%	0.5%	0.8%
Other conditions [a]			
Depression, anxiety, or any other mental health condition*	81.4%	33.8%	13.8%
Learning disability (e.g., dyslexia)*	38.9%	5.5%	1.7%
Epilepsy or seizure disorder	4.0%	1.5%	0.8%
Speech disability*	4.5%	1.1%	-
Intellectual disability	2.8%	1.1%	-
Other*	27.1%	3.4%	0.4%
Prefer not to answer	2.0%	5.0%	4.6%
None of the above*	7.3%	56.5%	79.9%

* = Chi-square test, *p* < *.01*. [a] Multiple responses permitted

Demographics by respondents’ interest in autism

The table below shows cultural and linguistic diversity (CALD) status, Aboriginal and Torres Strait Island (ATSI) status, and state or territory of residence, split by respondents’ interest in autism. CALD and ATSI status did not vary significantly by interest in autism. The majority of autistic respondents in the sample were from Victoria, Queensland and New South Wales. The majority of respondents in the remaining two categories were from Western Australia and Victoria.

Interest in autism, by CALD status, ATSI status & state/territory

Demographic variable	Autistic Respondents (n=247)	Non-autistic parents/family members/carers of an autistic person (n=616)	Other respondents with an interest in autism (n=239)
Cultural and linguistic diversity (CALD)			
Yes	14.6%	14.0%	18.4%
No	83.0%	84.6%	81.2%
Prefer not to answer	2.4%	1.5%	0.4%
Aboriginal and/or Torres Strait Islander (ATSI)			
Yes	3.6%	1.8%	1.3%
No	94.7%	97.4%	97.5%
Prefer not to answer	1.6%	0.8%	1.3%
State/territory*			
Australian Capital Territory	4.9%	2.9%	0.4%
New South Wales	16.2%	19.8%	15.9%
Northern Territory	-	0.3%	0.8%
Queensland	19.8%	15.9%	18.4%
South Australia	6.1%	7.8%	5.9%
Tasmania	5.3%	2.3%	2.1%
Victoria	30.0%	20.1%	25.5%
Western Australia	15.4%	29.2%	29.3%
I do not live in Australia	1.6%	1.0%	0.4%
Prefer not to answer	0.8%	0.6%	1.3%

* = Chi-square test, $p < .01$

Demographics by respondents’ interest in autism

Employment status of respondents varied significantly by interest in autism. Autistic respondents were more likely to be students, unemployed, and/or unable to work than respondents in the other two categories. Paid employment was highest among ‘other respondents with an interest in autism’ (79%), followed by ‘non-autistic parents/ family members/ carers of an autistic person’ (53%), and ‘autistic respondents’ (43%).

Interest in autism, by employment status - respondents who completed the standard version of the online survey

Demographic variable	Autistic Respondents (n=223)	Non-autistic parents/family members/carers of an autistic person (n=572)	Other respondents with an interest in autism (n=223)
Employment status			
Employed for wages, salary or payment in kind*	42.6%	52.8%	78.5%
Self employed	12.6%	11.7%	19.7%
Working as a volunteer*	9.9%	5.6%	2.2%
Engaged in home and/or care duties*	20.2%	33.9%	3.6%
Student*	28.3%	9.1%	8.1%
Retired	4.9%	4.7%	1.3%
Unemployed*	10.3%	2.1%	-
Unable to work*	13.5%	2.8%	-
Other*	8.5%	2.6%	1.8%
Prefer not to answer	0.4%	1.4%	1.3%

** = Chi-square test, p < .01*

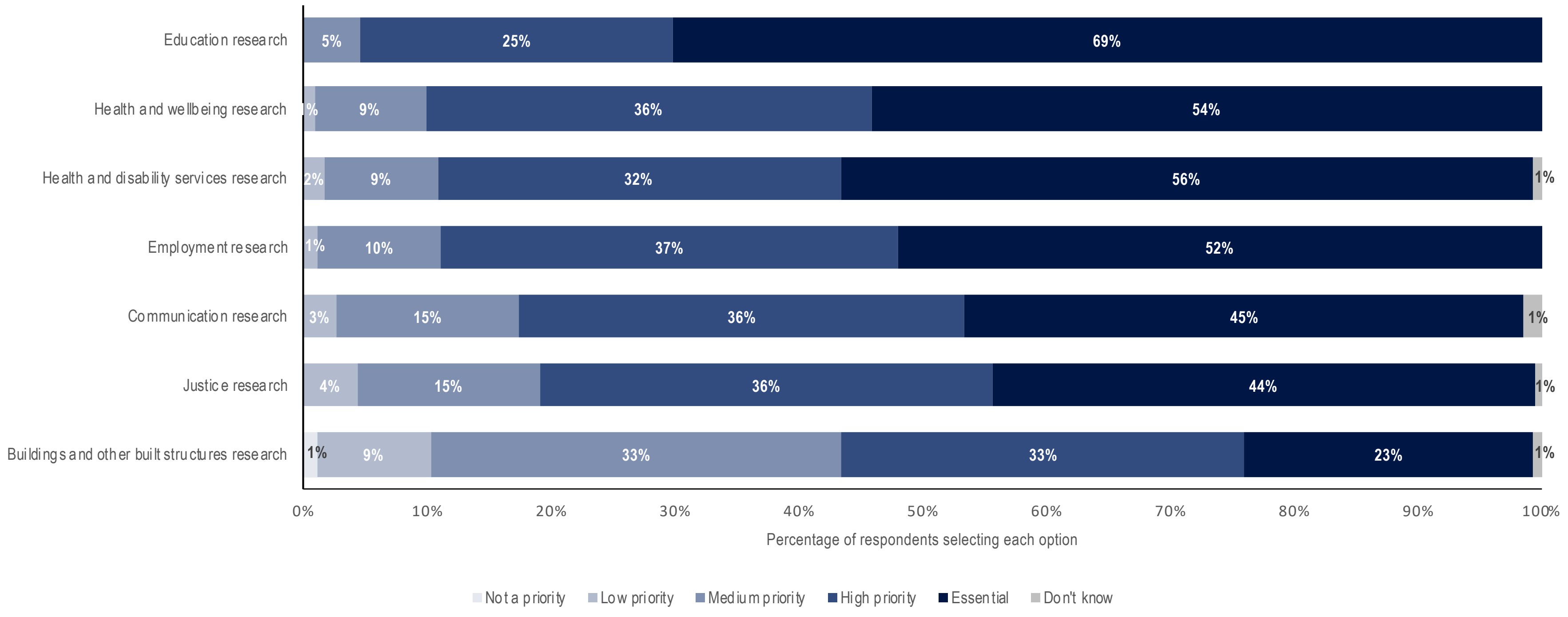
Detailed Findings

Research Priorities

Research priorities

Respondents were asked to rate the priority of the seven research areas identified for future autism research in the AARC consultation paper. Among respondents who completed the standard version of the survey, 94% rated education research (i.e., an inclusive education system that meets the needs of all students on the autism spectrum) as a high priority or essential. The next highest priority area was health and wellbeing research (i.e., optimal physical and mental health for autistic people, including other conditions). Research about buildings and structures (i.e., accessible, comfortable and inclusive spaces for autistic people) was given the lowest priority rating overall; however, 55% of respondents still rated this area as a high priority or essential.

Research priority ratings among respondents who complete the standard survey (n=1,018)



Q. Please rate how much of a priority you think each of the following research areas should be in future. (Percentages may not sum to 100% due to rounding. Percentages less than 0.5% are not shown.)

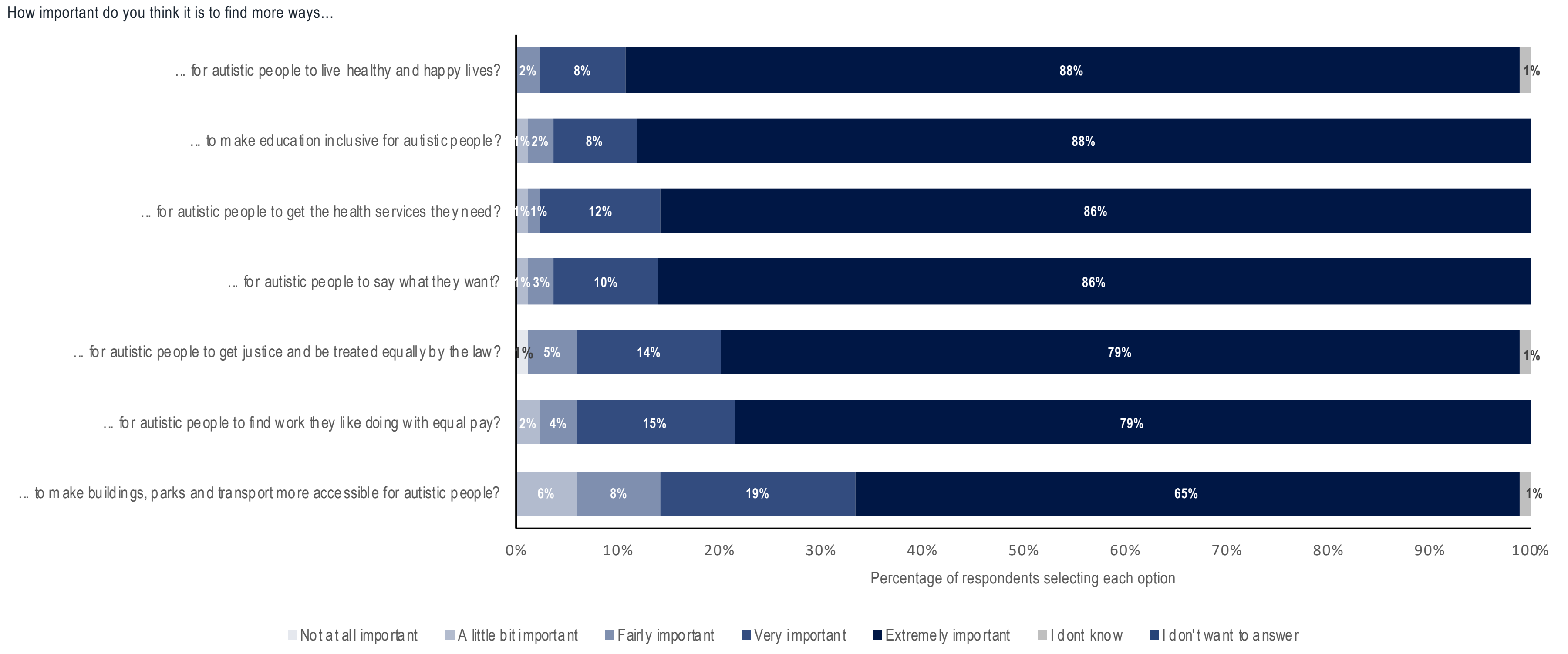
Research priorities

Among the 84 respondents who completed the Easy Read survey, the research areas given the highest priority ratings were:

- ‘finding more ways for autistic people to live healthy and happy lives’ – equivalent to ‘health and wellbeing research’ in the standard survey;
- ‘finding more ways to make education inclusive for autistic people’ – equivalent to ‘education research’ in the standard survey;
- ‘finding more ways for autistic people to get the health services they need’ – equivalent to ‘health & disability services research’ in the standard survey; and
- ‘finding more ways for autistic people to say what they want’ - equivalent to ‘communication research’ in the standard survey.

Built structures research – the area with the lowest rating – was still rated as being very or extremely important by the majority of respondents in this sample (85%).

Research priority ratings among respondents who complete the Easy Read survey (n=84)

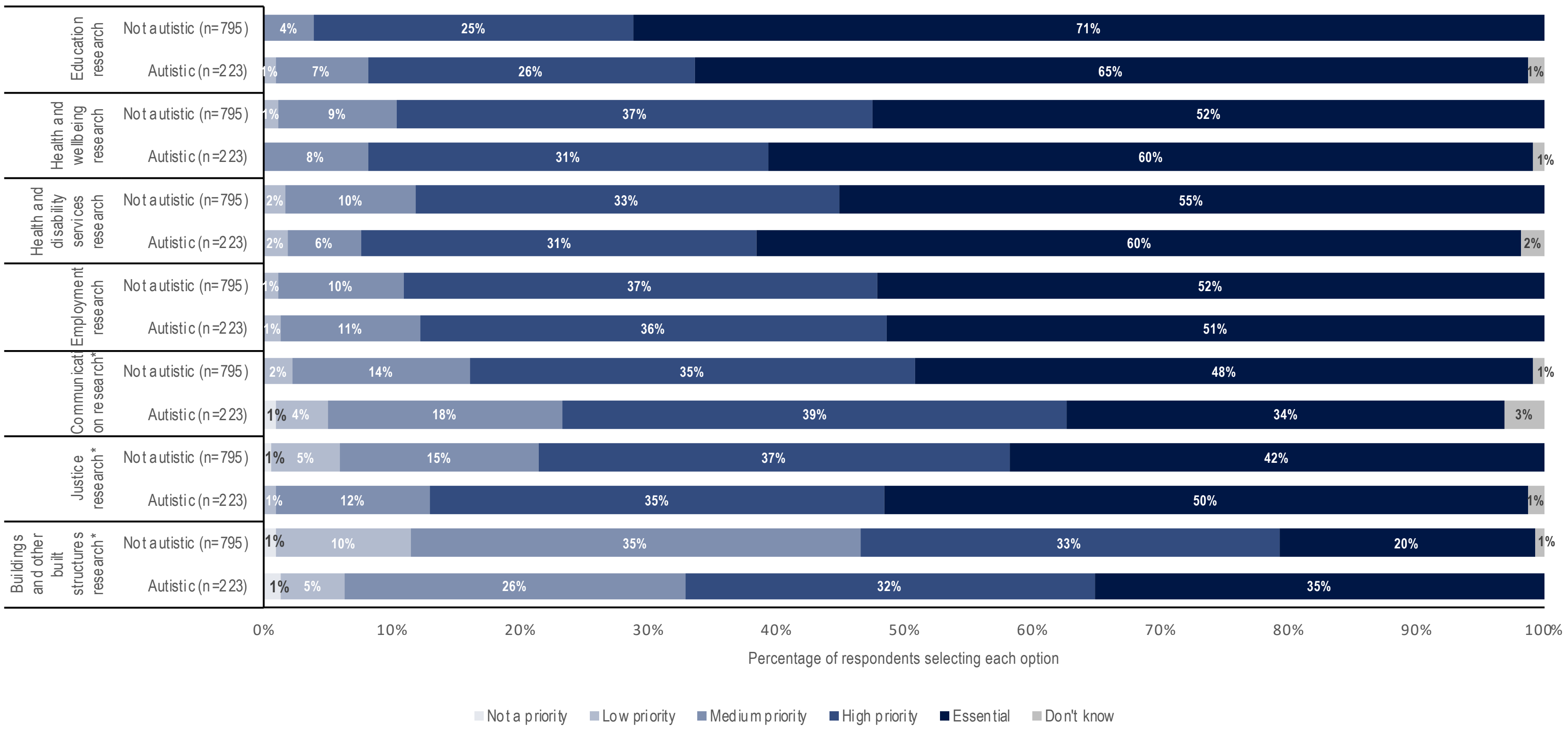


Q. How important do you think it is to find more ways….? (Percentages may not sum to 100% due to rounding)

Research priorities – by autism status

Mean research priority ratings varied by the autism status of respondents. Autistic respondents gave higher mean priority ratings to ‘buildings and other built structures research’ (*M=3.95, SD=0.97*) and ‘justice research’ (*M=4.37, SD=0.73*) than non-autistic respondents (*M=3.61, SD=0.96* & *M=4.14, SD=0.91*, respectively). Non-autistic respondents gave higher mean priority ratings to ‘communication research’ (*M=4.29, SD=0.82*) than autistic respondents (*M=4.05, SD=0.89*).

Research priority ratings by autism status, among respondents who completed the standard survey

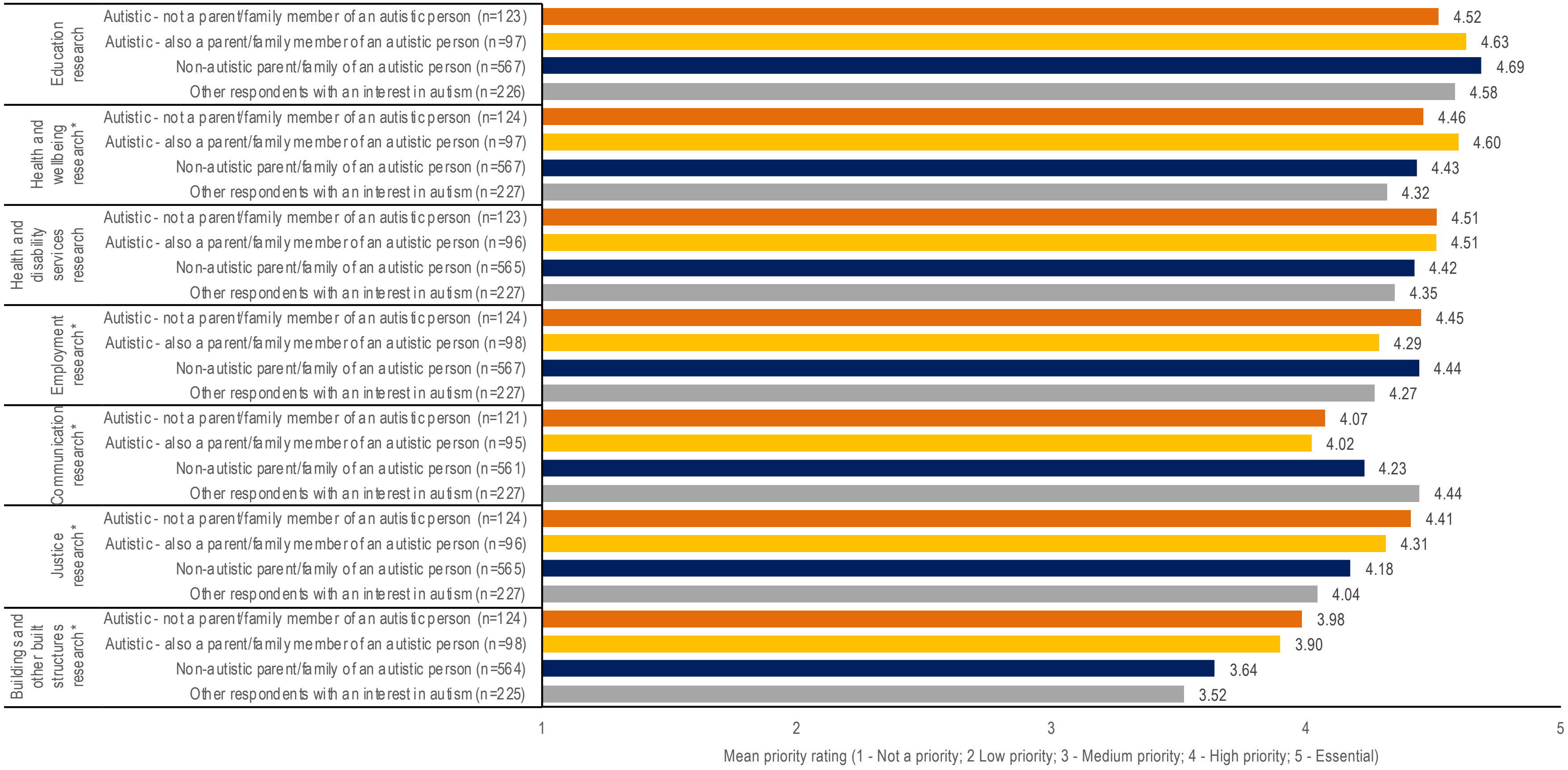


Percentages may not sum to 100% due to rounding. Percentages less than 0.5% are not shown. *=Mean rating (1-5) t-test, p < .01

Research priorities – by respondents' interest in autism

The chart below shows that mean priority ratings for some research areas varied significantly by respondents' interest in autism. Post hoc tests revealed that there were no significant differences in mean priority ratings between 'autistic respondents who were also a parent/family member of an autistic person', and 'non-autistic respondents who were a parent/family member of an autistic person'.

Research priority ratings by respondents' interest in autism, among respondents who completed the standard survey

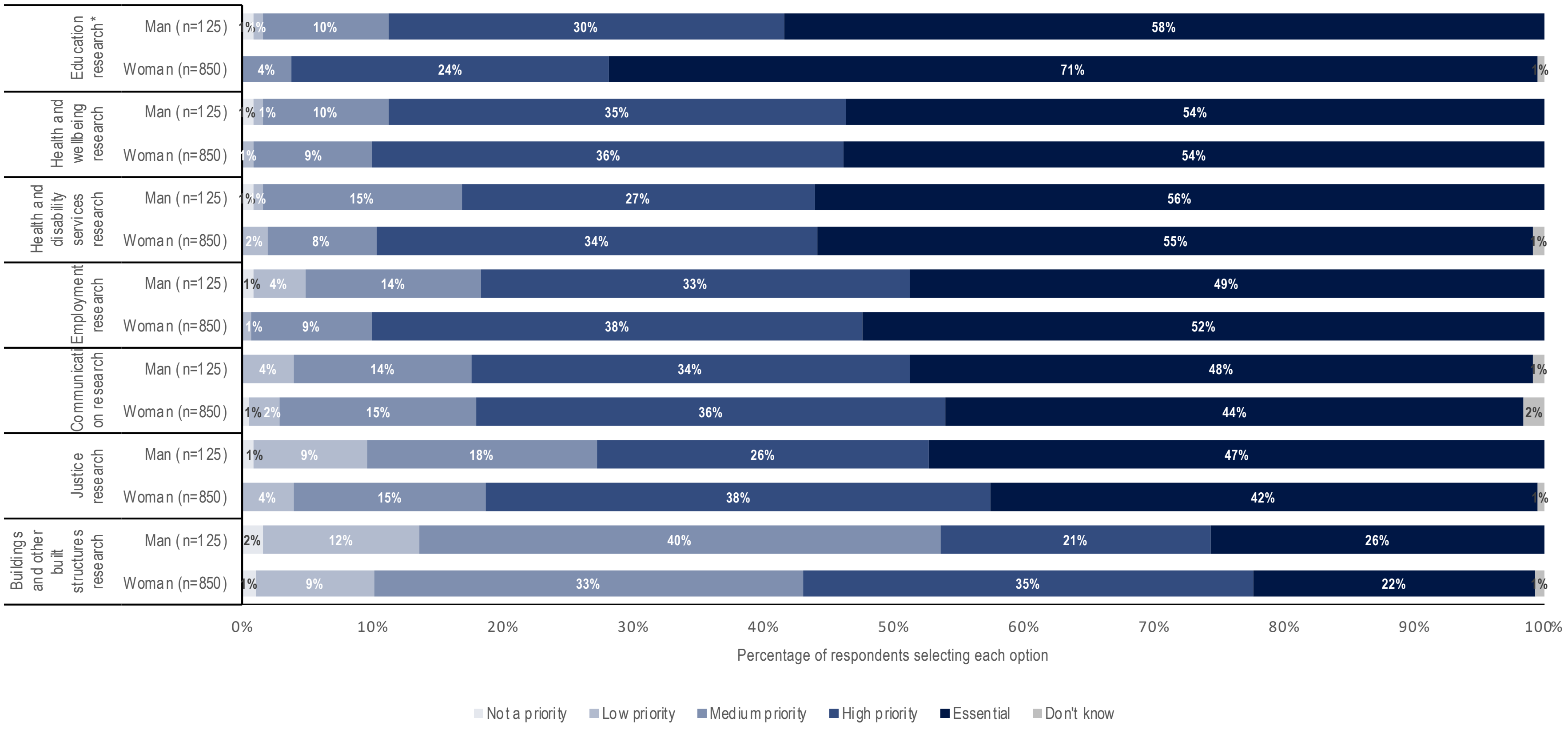


*=Mean rating (1-5) ANOVA F-test, p < .01

Research priorities – by gender

The mean priority rating for education research among women (*M=4.67, SD=0.57*) was significantly higher than among men (*M=4.45, SD=0.76*). Mean priority ratings for the remaining research areas did not vary by gender. Mean priority ratings also did not vary significantly by age groups (i.e., 18-44 years versus 45-84 years), or CALD status.

Research priority ratings by gender, among respondents who completed the standard survey

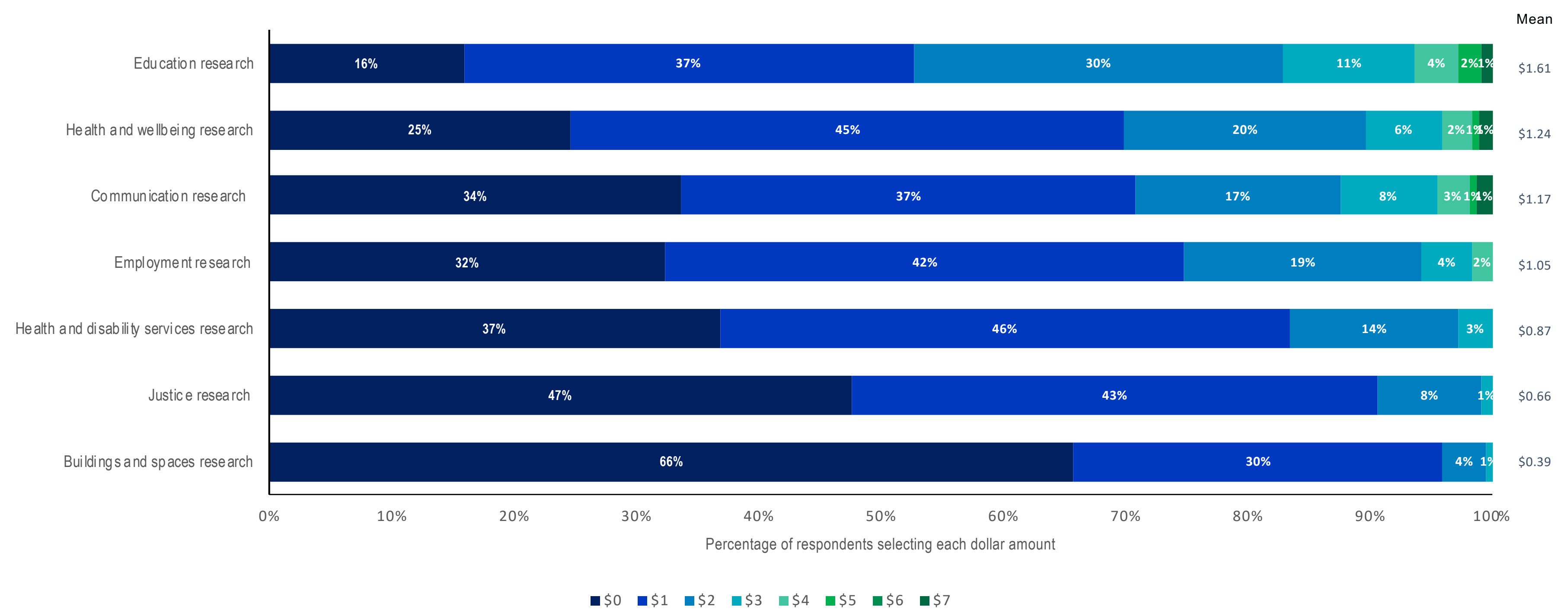


Percentages may not sum to 100% due to rounding. Percentages less than 0.5% are not shown. *=Mean rating (1-5) t-test, p < .01

Research priorities - funding

To encourage respondents to consider the relative importance of the proposed research areas, those who completed the standard survey were asked how much money they would allocate to each area if they had a total of $7 to give away. Whilst the order in which the different areas were prioritised was similar to the order in the rating question (see page 17), the *relative* important of each area was different. For example, almost half of the respondents did not allocate any funding to justice research, despite 80% of respondents rating this as a high priority or essential. Across both measures, the majority of respondents believed that education research, and health and wellbeing research were the top research priorities.

Respondents’ hypothetical funding allocation to each research area – respondents who completed the standard survey (n=997)

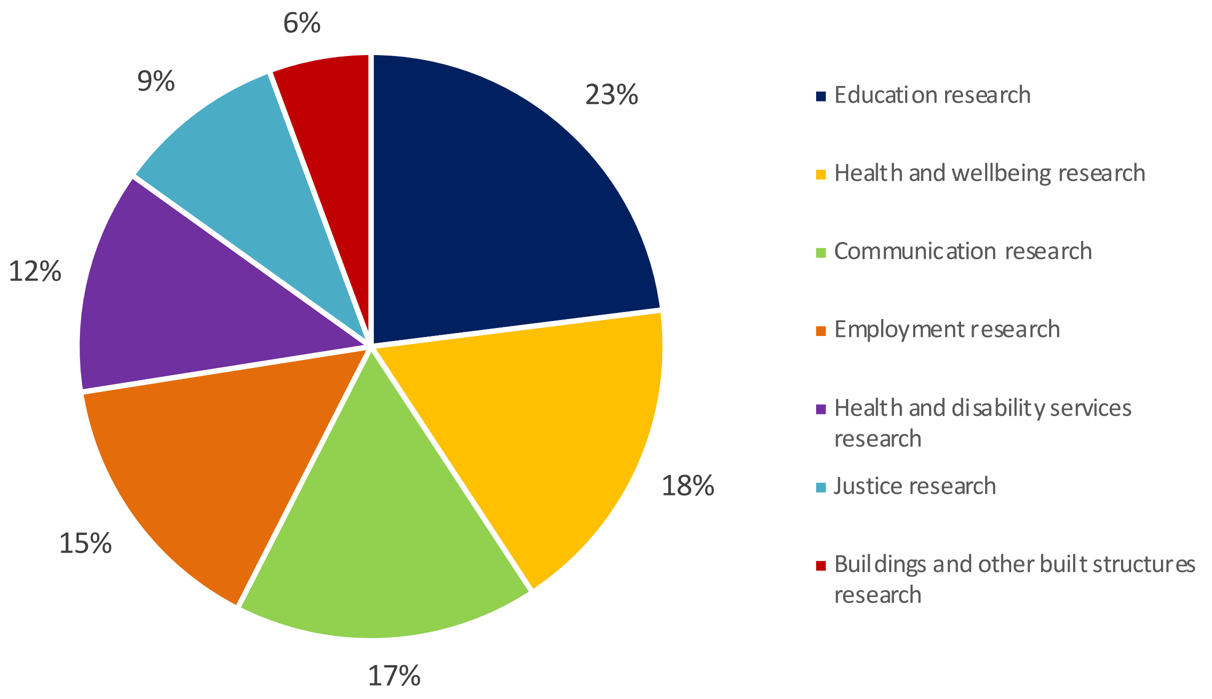


Q. For this question, we would like you to imagine that the government gave you $7 to give to autism research. You can choose which of the seven research areas the money goes to. You may want to give all of the money to one area, split it across two or three areas, or divide it up evenly across all seven areas. Please enter how much of the $7 dollars you would give to each of the seven research areas listed below. (Percentages may not sum to 100% due to rounding. Percentages less than 0.5% are not shown.)

Research priorities - funding

Using data from the funding allocation question, we calculated the relative percentage of total funding respondents allocated to each research area. Almost a quarter (23%) of the hypothetical money given to respondents to distribute, was allocated to education research. This was followed by health and wellbeing research (18%) and communication research (17%). Six percent of the total funding available to respondents was allocated to research focusing on buildings and other built structures.

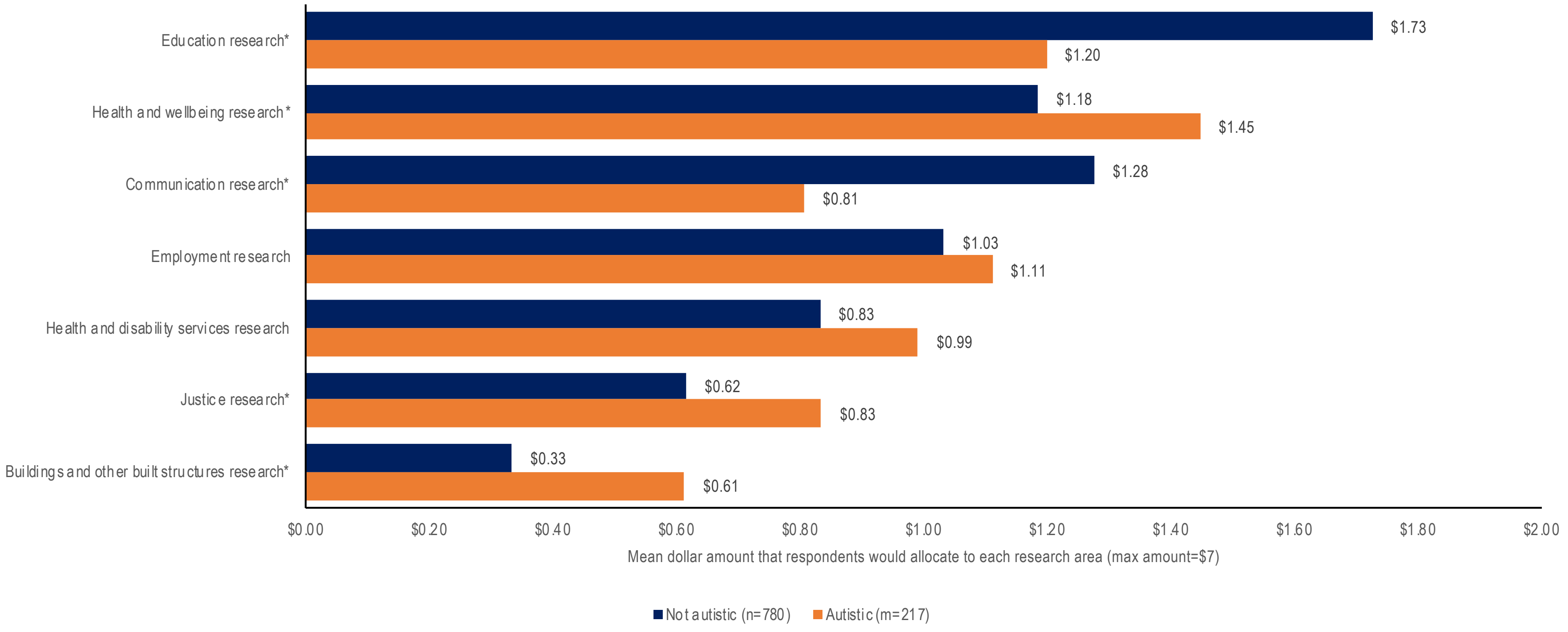
Respondents' hypothetical funding allocation to each research area – respondents who completed the standard survey (n=997)



Research priorities – funding by autism status

Hypothetical funding allocations varied by the autism status of respondents. Non-autistic respondents allocated significantly more to ‘education research’ and ‘communication research’ than autistic respondents. Conversely, autistic respondents allocated significantly more funding to ‘health and wellbeing research’, ‘justice research’, and ‘buildings and other built structures research’ than non-autistic respondents. It is also important to emphasize that among autistic respondents, ‘health and wellbeing research’ was allocated the the highest amount of funding.

Respondents’ hypothetical funding allocation to each research area, by autism status (respondents who completed the standard survey)

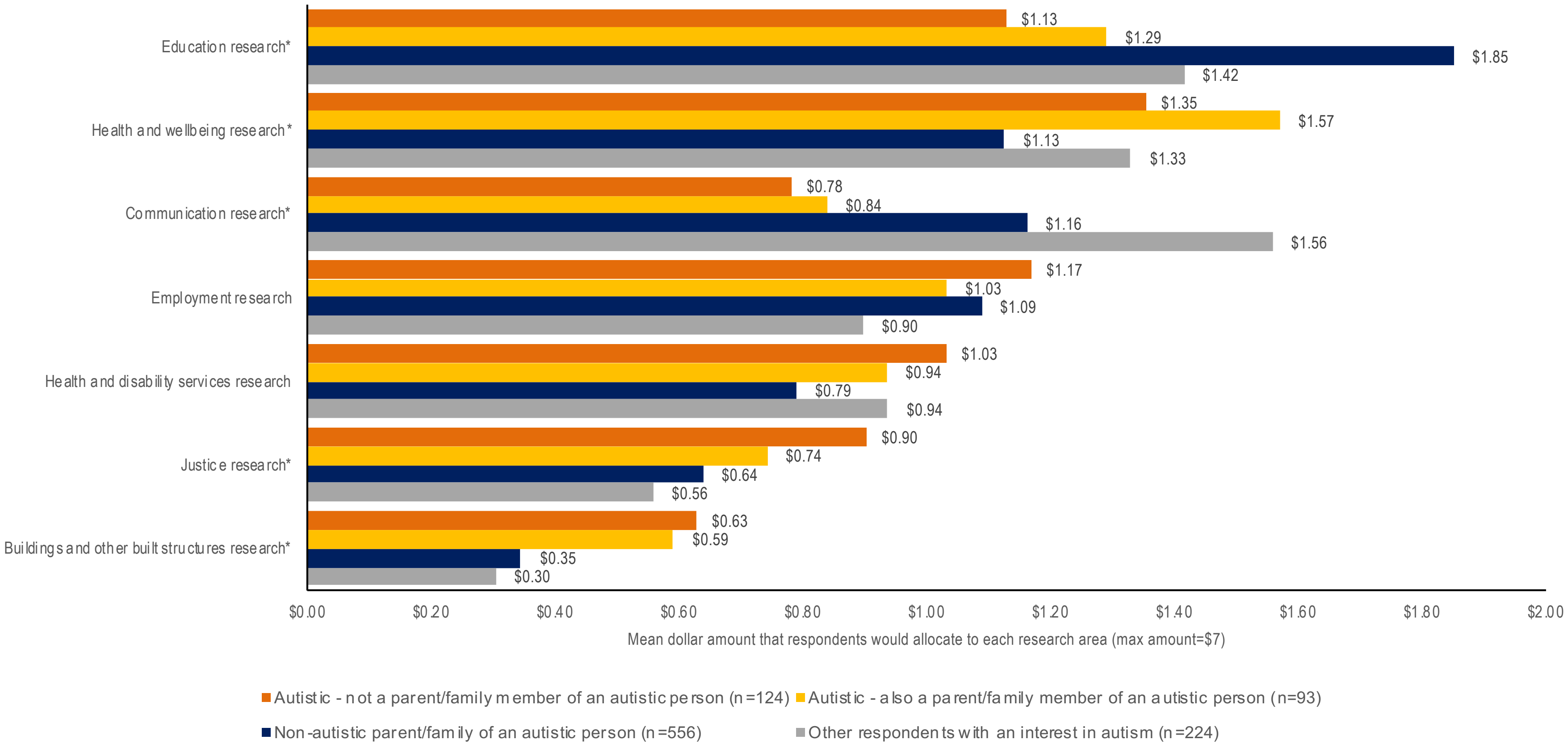


Q. Please enter how much of the $7 you would give to each of the seven research areas listed below. *=Mean rating (1-7) t-test, p < .01

Research priorities – funding by interest in autism

Hypothetical funding allocations varied significantly by respondents' interest in autism. When comparing autistic and non-autistic parents/family members, post hoc tests showed that 'autistic respondents who were also a parent/family member of an autistic person', allocated more funding to 'health and wellbeing research' and 'buildings research' than 'non-autistic parents/family members'. Conversely, 'non-autistic parents/ family members' allocated more funding to 'education research' than 'autistic parents/family members'.

Respondents' hypothetical funding allocation to each research area, by interest in autism (respondents who completed the standard survey)



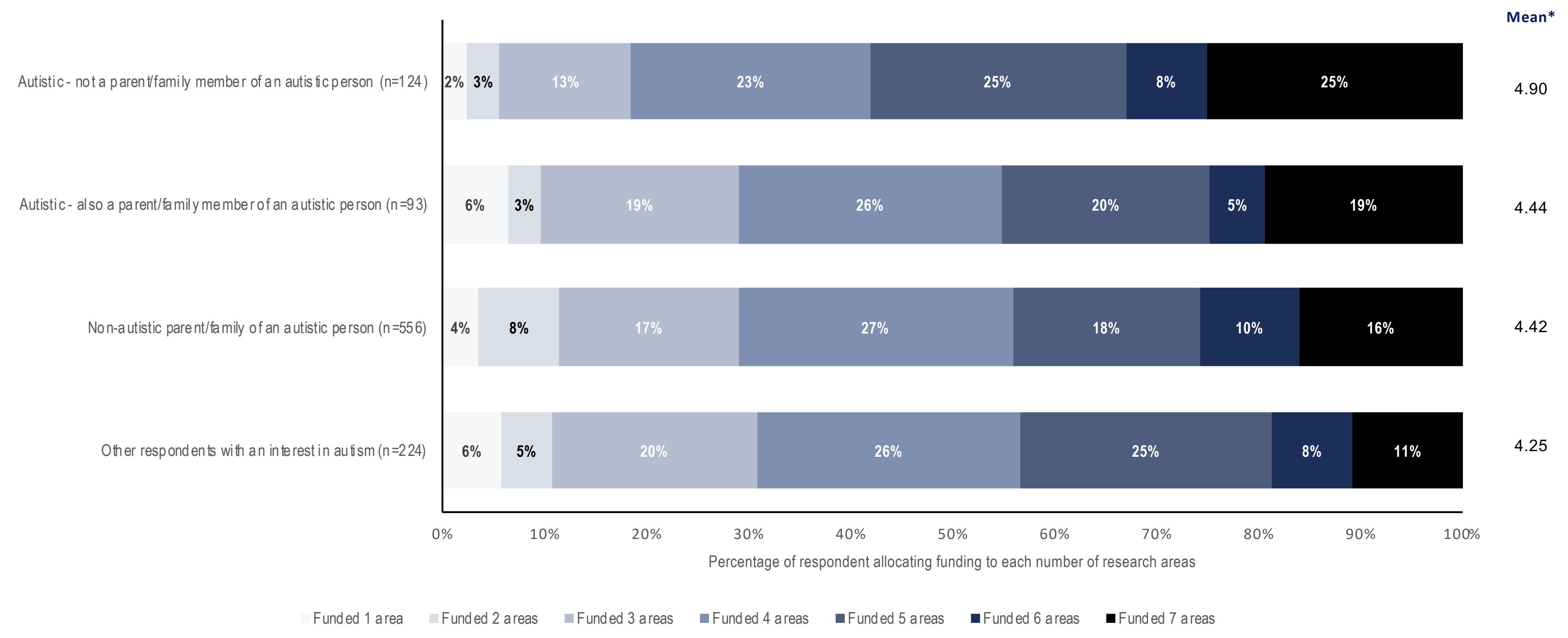
Q. Please enter how much of the $7 you would give to each of the seven research areas listed below. *=Mean rating (1-7) ANOVA F-test, p < .01

Number of research areas allocated funding

The number of different research areas that respondents allocated hypothetical funding to, varied by respondents' interest in autism.

Autistic respondents who were not also a parent or family member of am autistic person, allocated their funding to a higher number of different research areas (M=4.90) than non-autistic parents/family members (M=4.42) and other respondents (M=4.25), but not autistic parents/family members (M=4.44).

Number of research areas allocated hypothetical funding, by interest autism (respondents who completed the standard survey)

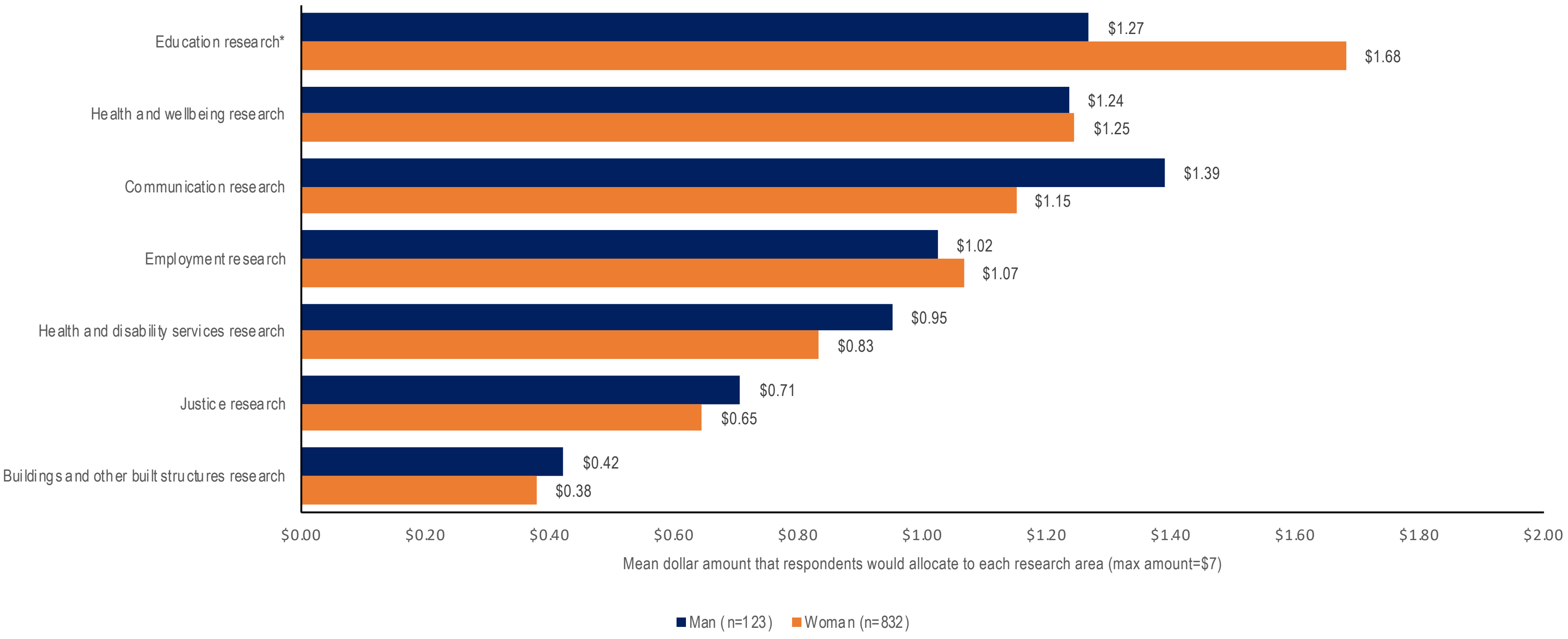


*=Mean rating (1-7) ANOVA F-test, p < .01

Research priorities – funding by gender

As shown in the chart below, women allocated significantly more hypothetical funding to ‘education research’ than men. Mean funding allocations did not vary by gender for any of the remaining proposed research areas.

Respondents’ hypothetical funding allocation to each research area, by gender (respondents who completed the standard survey)



Q. Please enter how much of the $7 you would give to each of the seven research areas listed below. *=Mean rating (1-7) t-test, p < .01

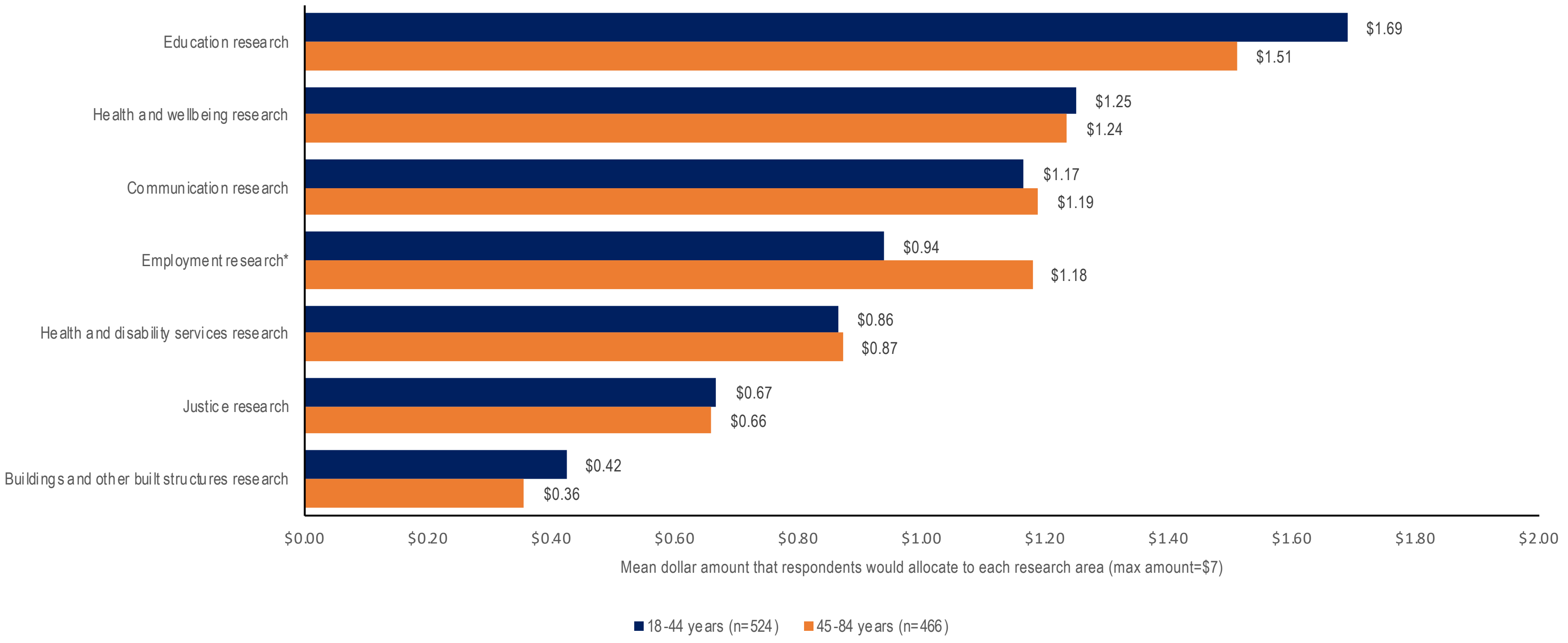
MINDTAP RESEARCH

Research priorities – funding by age

Respondents aged 45 or older allocated significantly more hypothetical funding to ‘employment research’ than those aged under 45 years. Mean funding allocations did not vary by age group for any of the remaining proposed research areas.

Funding allocations did not vary significantly by the CALD status of respondents.

Respondents’ hypothetical funding allocation to each research area, by age (respondents who completed the standard survey)

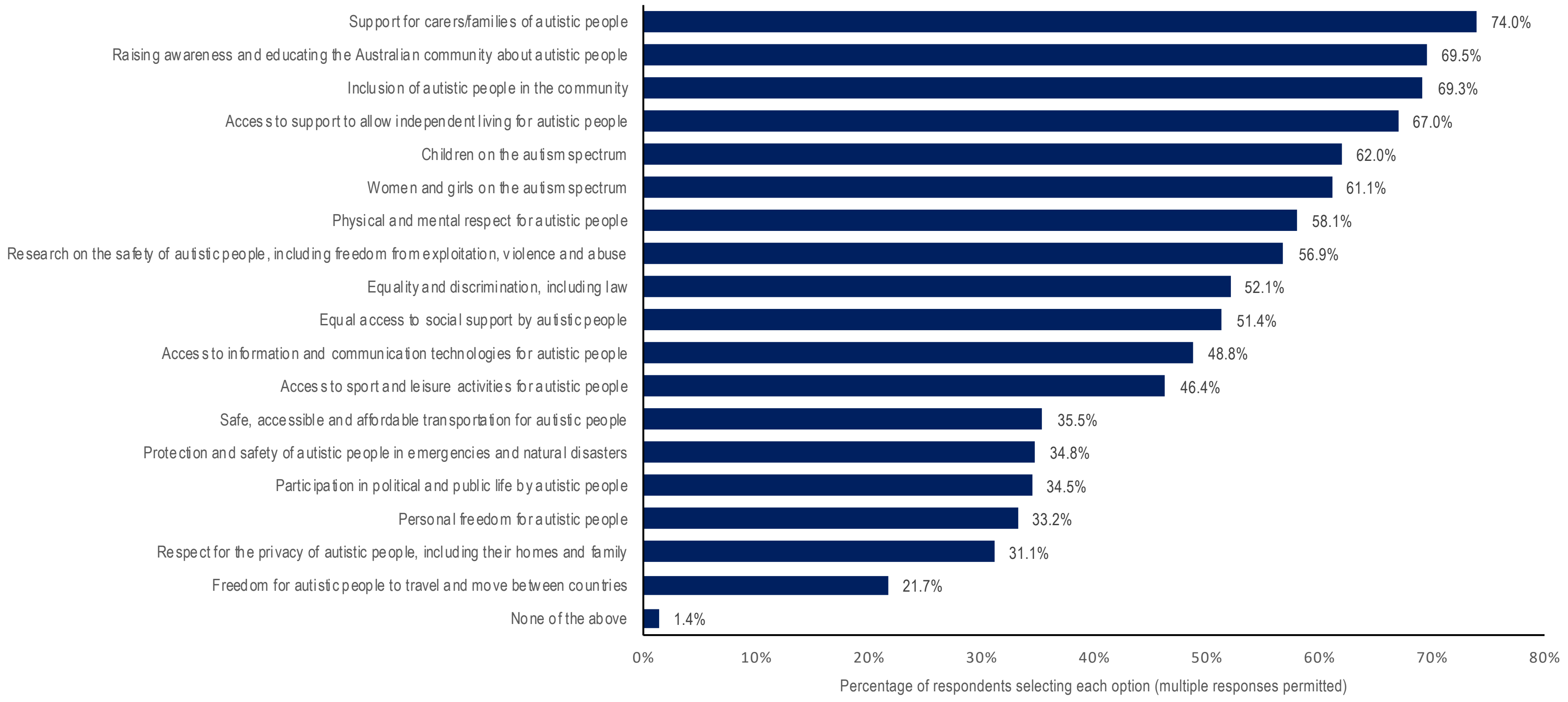


Q. Please enter how much of the $7 you would give to each of the seven research areas listed below. *=Mean rating (1-7) t-test, p < .01

Research priorities – additional areas

Respondents were asked to select other potential areas for autism research from a modified list based on the UN Convention on the Rights of People with Disabilities. The top priorities selected by respondents who completed the standard version of the survey were: ‘Support for carers/families of autistic people’; ‘Raising awareness and educating the Australian community about autistic people’; and ‘Inclusion of autistic people in the community’.

Other research priorities from the UN Convention on the Rights of People with Disabilities – respondents who completed the standard survey (n=1,018)

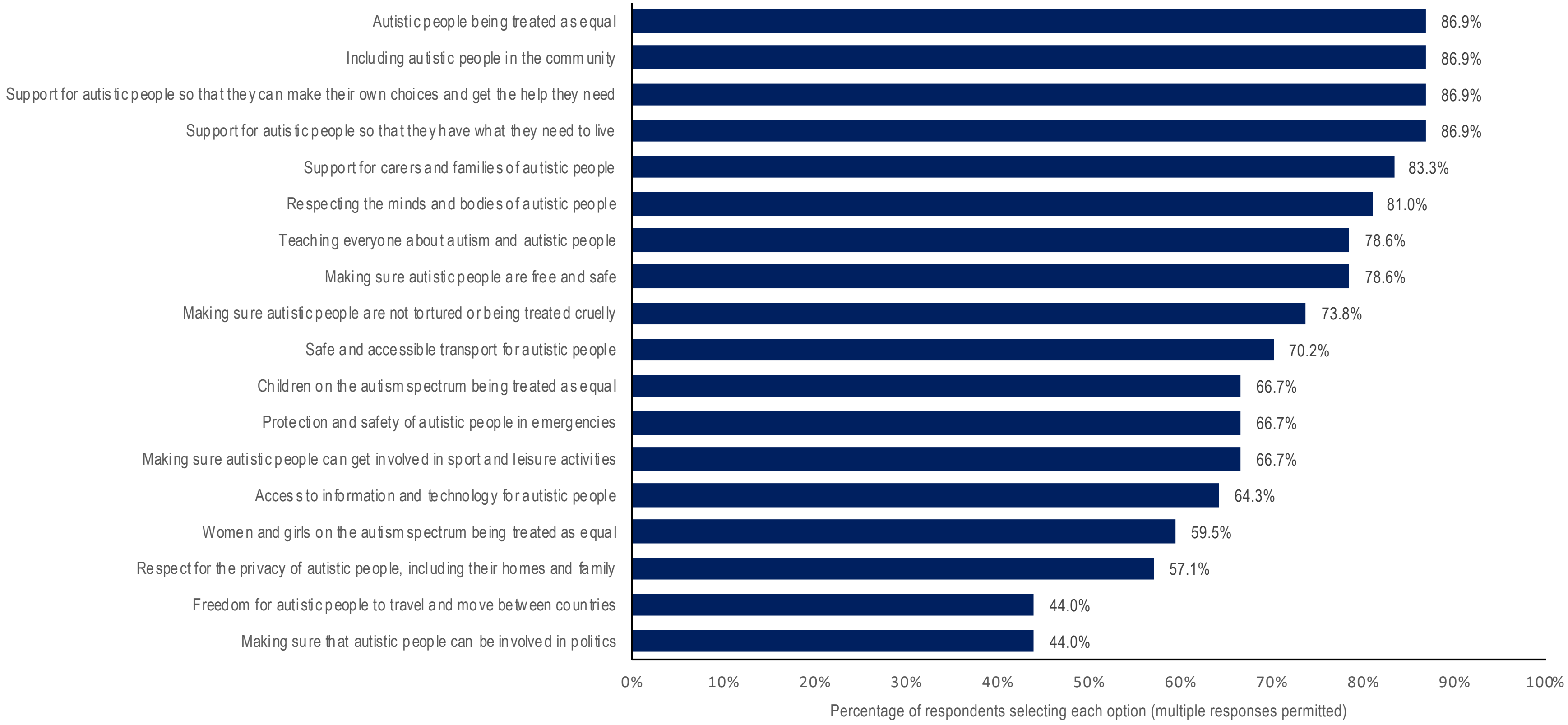


Q. Below is a list of other potential areas for autism research. This is a modified list based on the UN Convention on the Rights of People with Disabilities. Please select all of the potential autism research areas that are particularly important to you.

Research priorities – additional areas

Top research priorities from the UN Convention on the Rights of People with Disabilities, for respondents who completed the Easy Read survey, were: ‘Autistic people being treated as equal’; ‘Including autistic people in the community’; ‘Support for autistic people so that they can make their own choices and get the help they need’; and ‘Support for autistic people so that they have what they need to live’.

Other research priorities from the UN Convention on the Rights of People with Disabilities – respondents who completed the Easy Read survey (n=84)

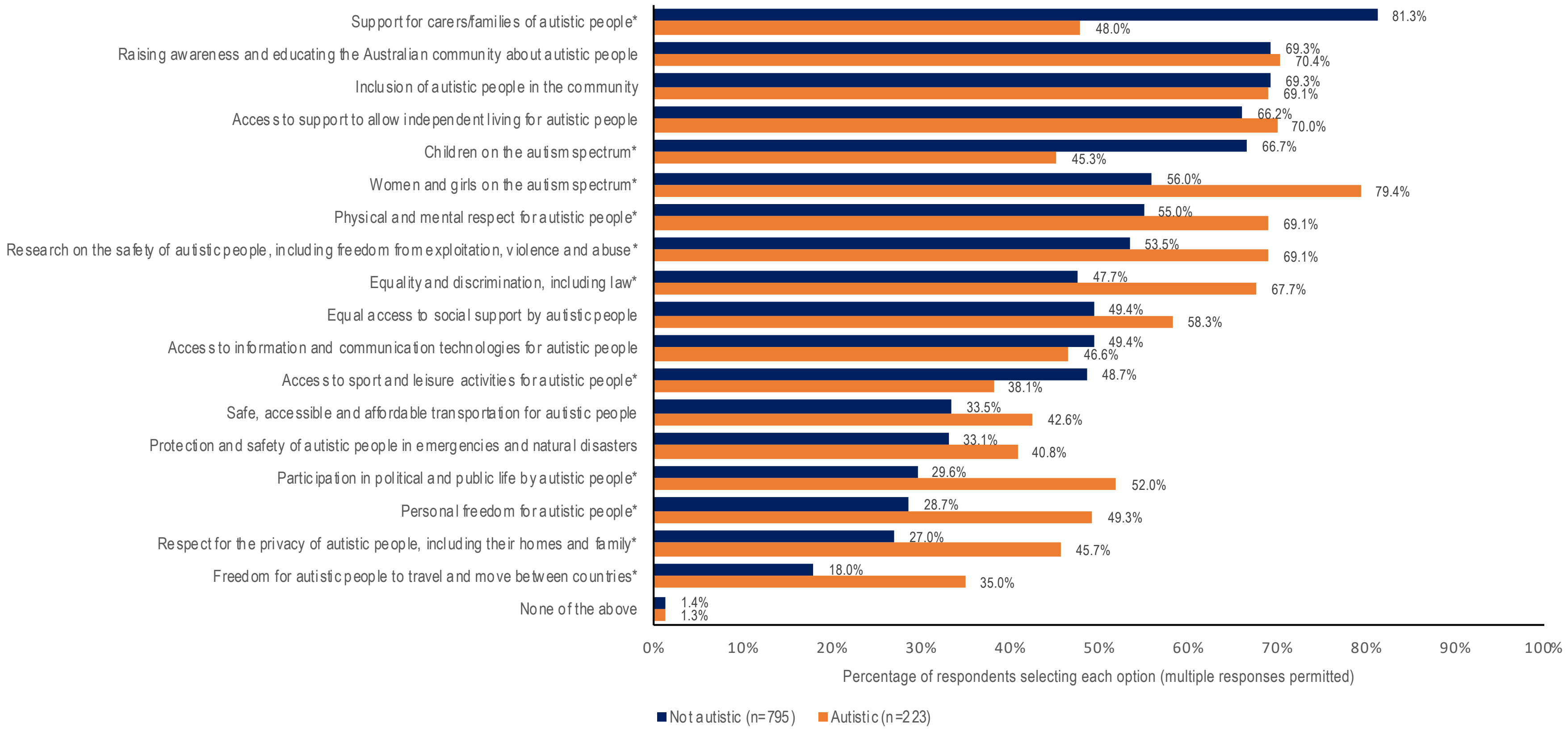


Q. Which of these research topics are very important to you?

Research priorities – additional areas

The proportion of respondents selecting additional research areas varied by autism status. Among autistic respondents, research focusing on women and girls on the autism spectrum was the most frequently selected additional research area. Among non-autistic respondents, 'Support for carer/families of autistic people' was the most frequently selected additional research area.

Other research priorities from the UN Convention on the Rights of People with Disabilities, by autism status – standard survey respondents

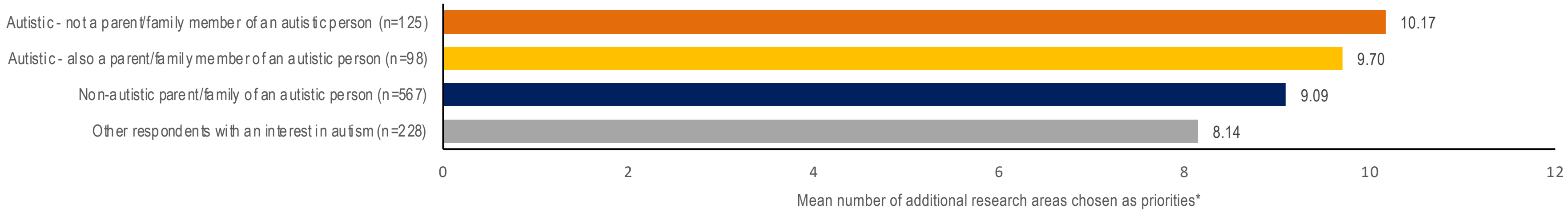


Q. Please select all of the potential autism research areas that are particularly important to you. * = *Chi-square test, p < .01*

Number of additional research areas chosen as priorities

‘Other respondents with an interest in autism’ selected significantly fewer additional research areas than ‘autistic respondents who were not parents/family members of an autistic person’ and ‘autistic parents/family members of an autistic person’. There were no other significant pairwise differences.

Number of other research areas chosen as priorities, by interest in autism (respondents who completed the standard survey)



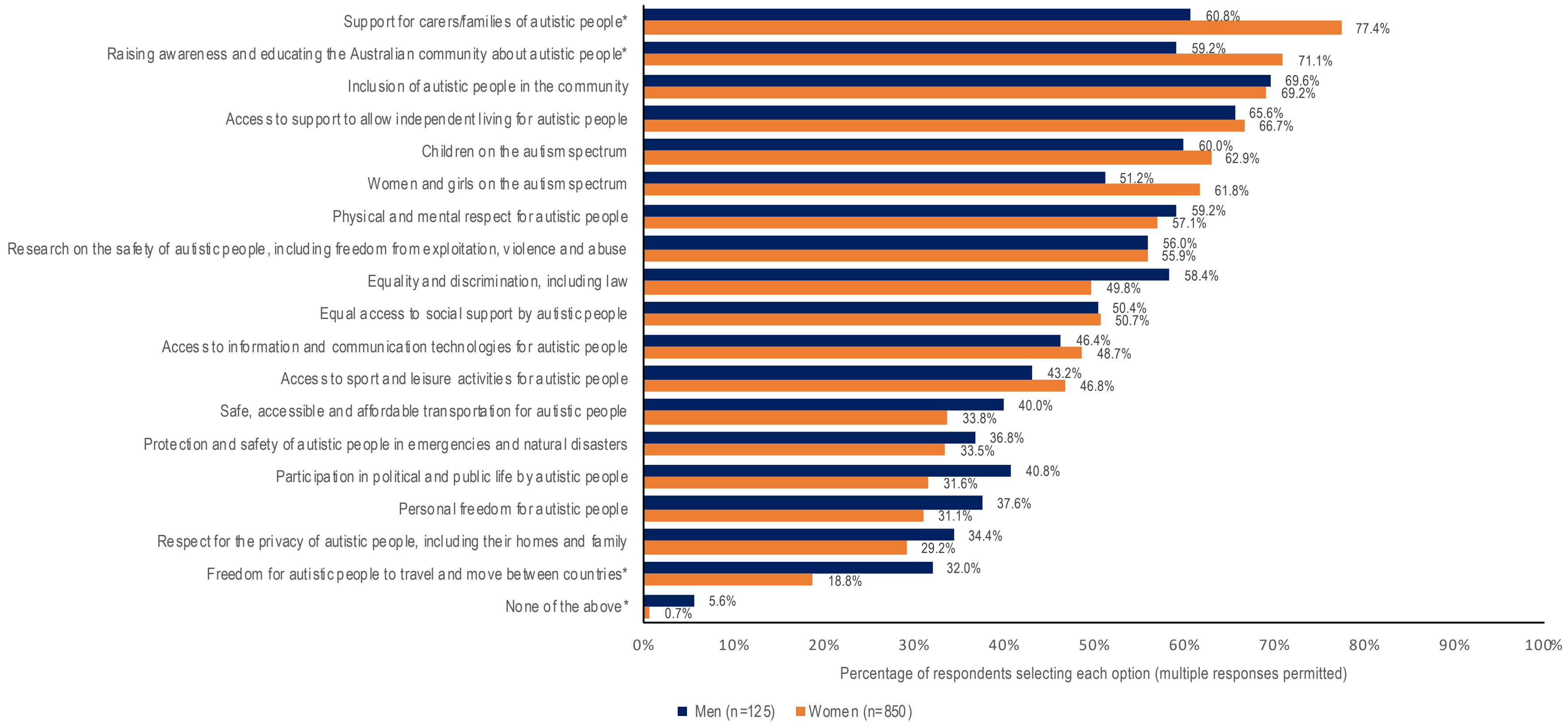
Number of additional research areas chosen as priorities	Autistic - not a parent/family member of an autistic person	Autistic - also a parent/family member of an autistic person	Non-autistic parent/family of an autistic person	Other respondents with an interest in autism	Total
0	2.4%	-	1.2%	1.8%	1.4%
1	0.8%	2.0%	1.6%	1.8%	1.6%
2	1.6%	1.0%	3.4%	3.9%	3.0%
3	4.0%	8.2%	4.9%	7.0%	5.6%
4	4.0%	-	6.2%	9.2%	6.0%
5	8.0%	11.2%	7.6%	8.3%	8.2%
6	5.6%	7.1%	9.2%	8.3%	8.3%
7	4.0%	9.2%	10.4%	11.4%	9.7%
8	8.0%	8.2%	8.6%	7.5%	8.3%
9	12.0%	7.1%	7.6%	5.7%	7.7%
10	5.6%	7.1%	6.0%	8.8%	6.7%
11	6.4%	6.1%	5.5%	4.4%	5.4%
12	6.4%	6.1%	3.9%	5.7%	4.8%
13	4.0%	3.1%	2.8%	3.1%	3.0%
14	3.2%	1.0%	3.2%	1.8%	2.7%
15	4.0%	4.1%	2.1%	1.8%	2.5%
16	1.6%	3.1%	1.6%	1.8%	1.8%
17	5.6%	3.1%	3.7%	0.9%	3.2%
18	12.8%	12.2%	10.6%	7.0%	10.2%

*=Mean rating (0-18) ANOVA F-test, p < .01

Research priorities – additional areas

Research focusing on ‘Support for carers/families of autistic people’ and ‘Raising awareness and educating the Australian community about autistic people’ were more significantly more likely to be selected by women than men as additional research areas. Men, on the other hand, were more likely to select ‘Freedom for autistic people to travel and move between countries’ as an additional research area than women; however, this areas was still only selected by about a third of men.

Other research priorities from the UN Convention on the Rights of People with Disabilities, by gender – standard survey respondents

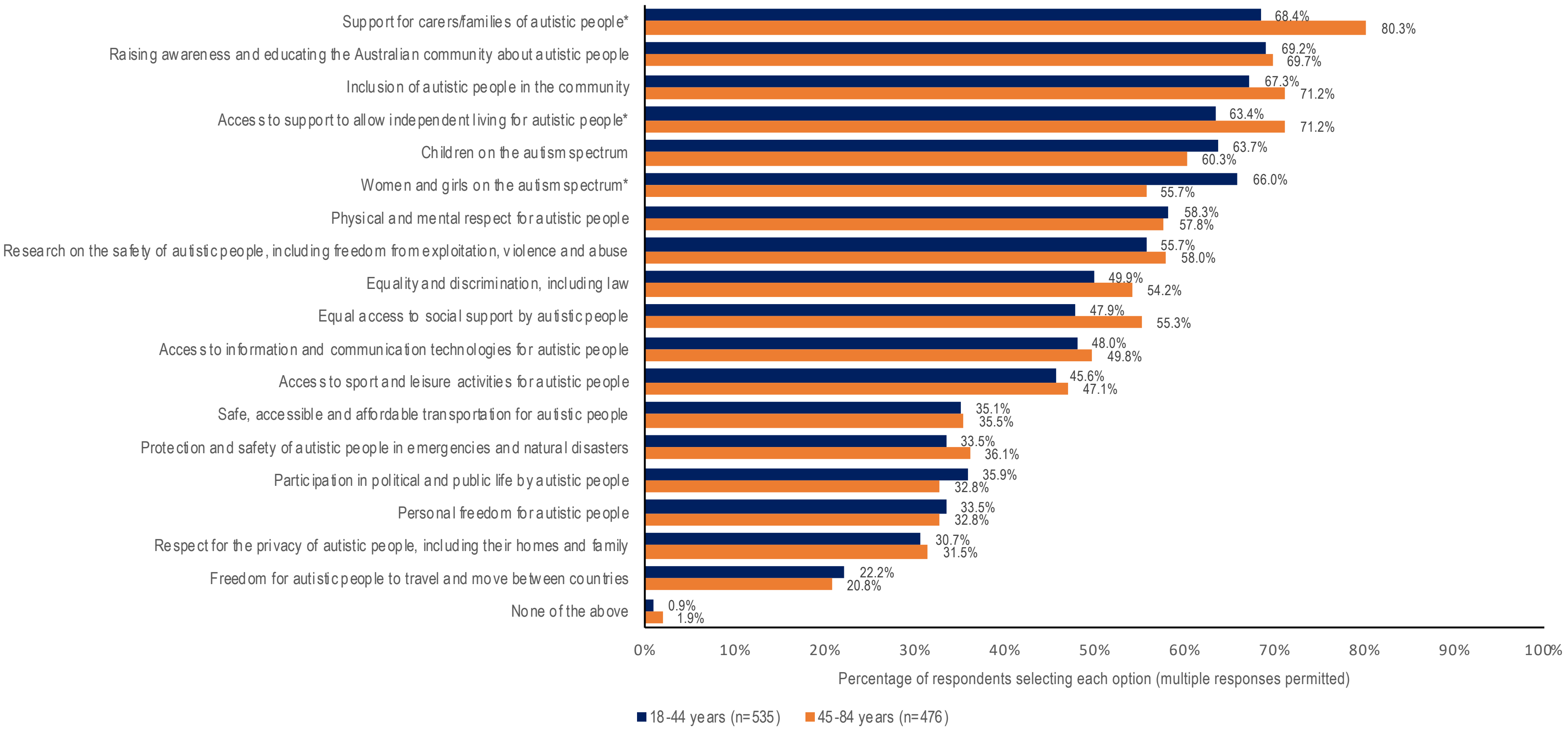


Q. Please select all of the potential autism research areas that are particularly important to you. * = *Chi-square test, p < .01*

Research priorities – additional areas

Respondents aged 45 or older were more likely to select ‘Support for carers/families of autistic people’ and ‘Access to support to allow independent living for autistic people’ as important areas of research, than respondents aged under 45 years. On the other hand, those aged under 45 years were more like to select ‘Women and girls on the autism spectrum’ as an important area of research, than those aged 45 years or older.

Other research priorities from the UN Convention on the Rights of People with Disabilities, by age – standard survey respondents

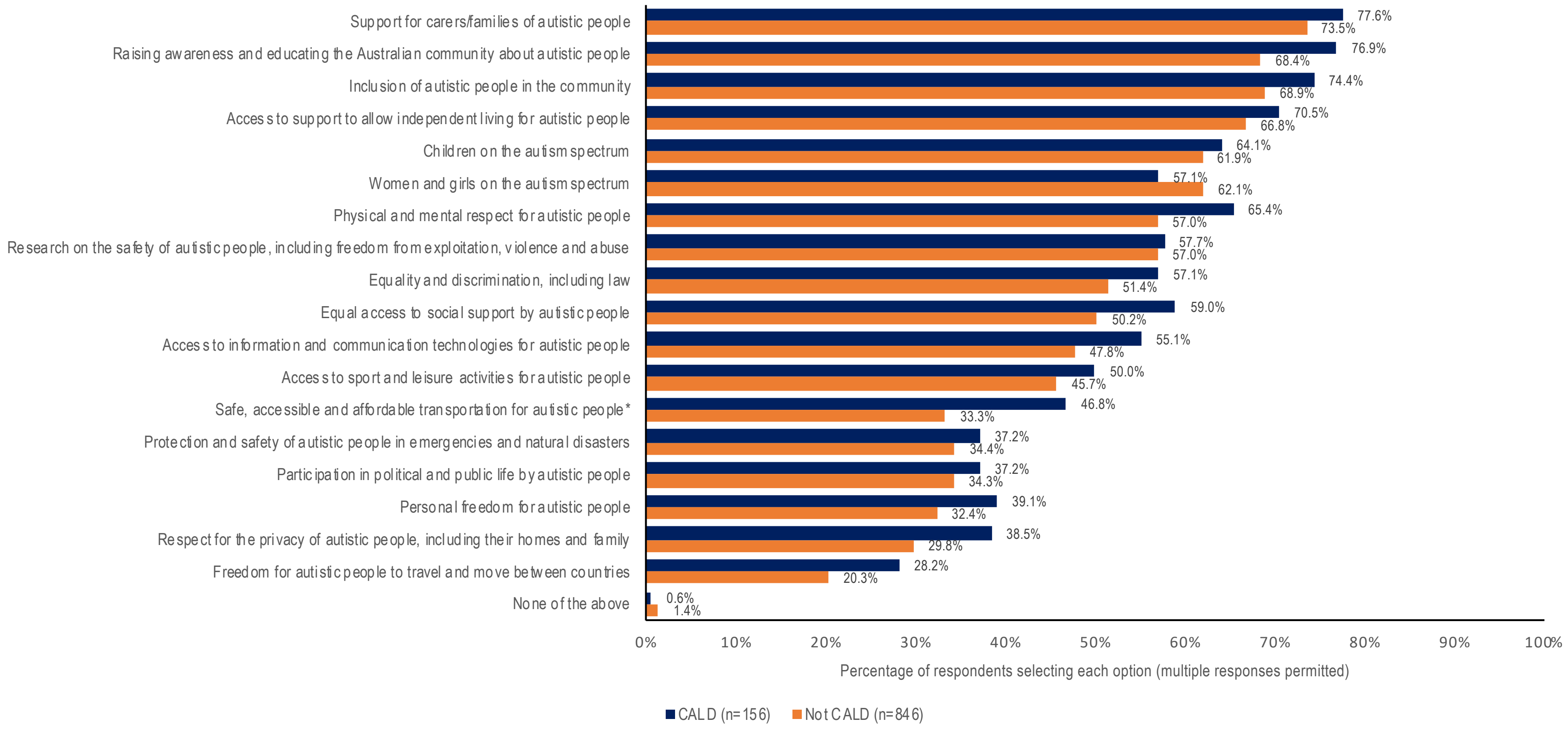


Q. Please select all of the potential autism research areas that are particularly important to you. * = *Chi-square test, p < .01*

Research priorities – additional areas

Respondents from a culturally and/or linguistically diverse background were more likely to select ‘Safe, accessible and affordable transportation for autistic people’ as an important area of research, than respondents who were not from a CALD background.

Other research priorities from the UN Convention on the Rights of People with Disabilities, by CALD status – standard survey respondents



Q. Please select all of the potential autism research areas that are particularly important to you. * = *Chi-square test, p < .01*

Research priorities – additional areas

To ensure respondents were given ample opportunity to provide feedback on the direction of future autism research, they were asked if there are any other broad areas of research, or more specific research questions, that they think should be an autism research priority in future. Overall, 645 respondents provided an answer to this question. Responses were coded into specific topics and then combined into broader themes. Across the 645 responses, there were 1,444 coded suggestions. The seven main themes were:

- 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.

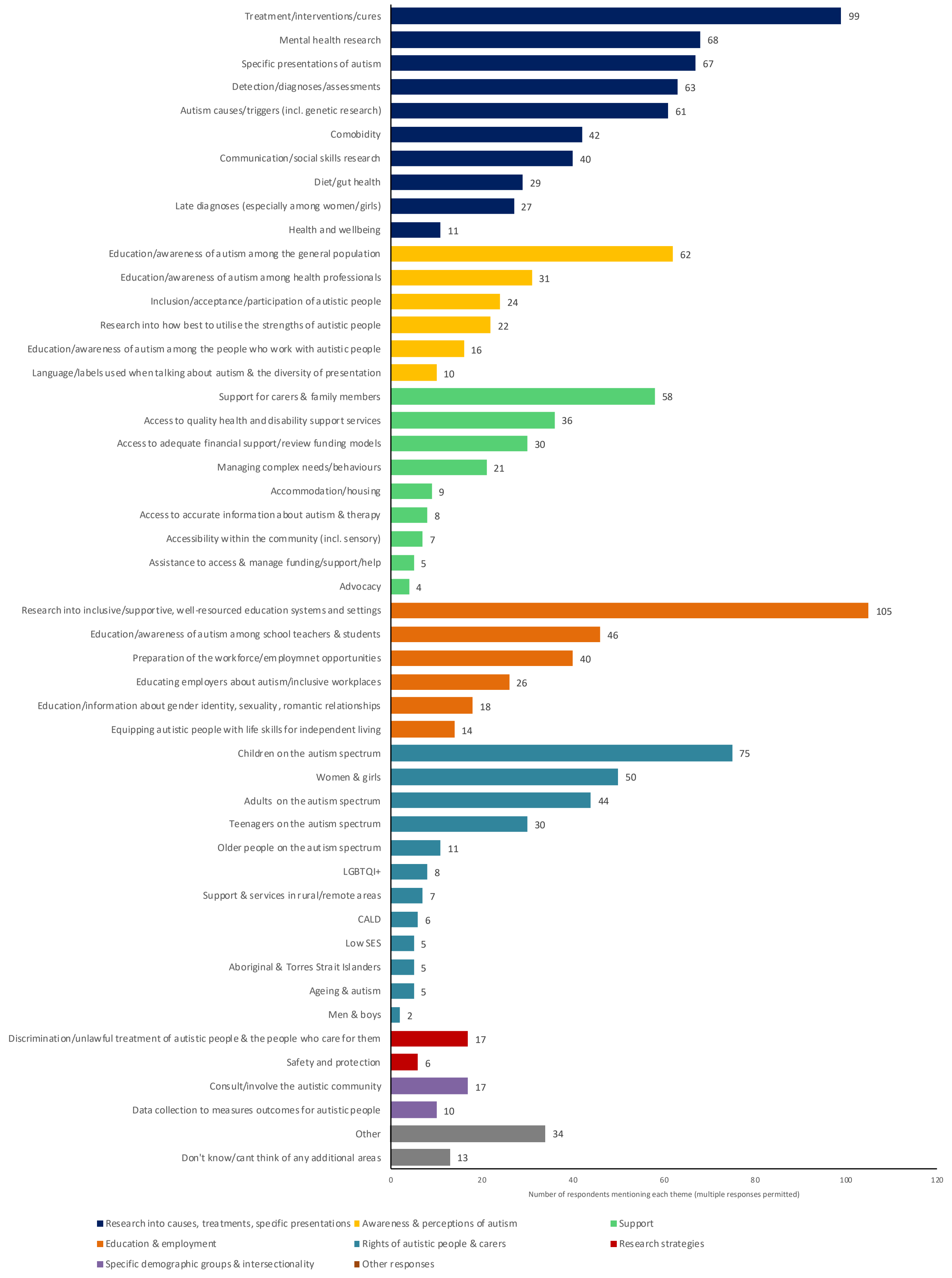
The frequency of coded responses is presented on next page.

> *“Different ways that girls on the autism spectrum may present. For example, some professionals told me my daughter 'couldn't have autism because she makes eye contact'. She's good at masking in *some* situations. And she doesn't present like boys with autism, but she definitely has autism. It's a part of her and we love every part of her - we don't wish to change a thing :)”*

> *“The elephant in the room: Studying why autism and related neurological disorders are so clearly on the rise. The argument of better diagnoses and greater awareness from medical practitioners is weak when you look at the skyrocketing current trend, and at statistics for the number of older or even middle-aged people with ASD. There are clearly environmental factors afoot, and we should look at them boldly and without prejudice.”*

Research priorities

Other research priority areas suggested by respondent (n=645)



Q. Are there any other broad areas of research, or more specific research questions, that you think should be an autism research priority in future?

Research priorities – additional areas

Research into causes, treatments and specific presentations of autism

Many respondents were eager to see more research into effective and accessible treatments, early interventions, and possible cures for autism. Some respondents believed that future research should focus on determining the cause(s) of autism; some suggestions were diet and gut health, genetic determinants, and environmental factors. A small number of respondents were still concerned about a possible link between vaccines and autism.

Many respondents were keen for greater understanding of, and treatment for, specific presentations of autism (particularly mental health conditions, communication skills, and Pathological Demand Avoidance). Respondents were also interested to know why autism tends to be associated with other comorbid conditions.

Respondents were concerned about the efficacy of autism diagnostic tools, particularly for women and girls. Some respondents also mentioned that a lack of funding for diagnostic assessments was a barrier to some people receiving an early diagnosis and subsequent interventions provided by government funding. Lastly, some respondents believed that there should be more research on appropriate supports for people (particularly women) who receive an autism diagnosis later in life.

> *"My observation and my personal, family experience suggests that mental health and related problems, lack of meaningful employment and difficulties within the education system at all levels can have the most negative impacts on autistic individuals. To improve these areas involves research and community training and awareness at many levels, including supporting communication and social skills development, prevention and intervention research across a range of areas, and educational and vocational supports and training. This needs to involve the person on the spectrum, their family or other supportive others, and the community, particularly including educators and employers. I think that within our working silos we miss that many issues are interconnected, for example poor mental health may interact with poor social communication skills and lack of employment. Thus solutions need to be multi-disciplinary and multi-faceted and collaborative in their approach. As a researcher, my observation is that the Australian research community needs to be more collaborative and less competitive in helping address these issues, and it needs to be innovative and consultative across a broader range of researchers. And we must be in touch with and involve the autism community we hope to serve, if we are to be maximally relevant."*

Research priorities – additional areas

Research into causes, treatments and specific presentations of autism

"Research into the causes of autism should be a big priority. Many people with autism, including my son, suffer terribly due to the severity of their symptoms and they cannot get relief without the understanding of what is happening on scientific and medical level."

"More research into different causes of autism, including genetic, environmental and other causes, maybe even further immunization research."

"Recognition of the existence of Pathological Demand Avoidance (PDA) in Australia, and research into coping strategies for both people with PDA and their families and carers, including schools. PLEASE!!! Personally I'm not interested in 'achieving a diagnosis' for my son, I'm just desperate for evidence-based strategies for this. The stock standard autism and mental health strategies don't work!!! PLEASE HELP."

"Also I'm an undiagnosed mum, desperately need support, but can't afford a diagnosis. To my knowledge there is no bulk-billed or cheap diagnosis options."

"Research into improving accurate diagnosis - a brain scan or blood test - something more concrete than subjective paper testing."

"The impact of ASD on adults mental health, and what is the most appropriate treatment for their mental health and if it differs from non autistic peoples treatment. The ability for autistic adults to access good mental health care/clinician's who are appropriately trained in autism and how they may differ in the treatment they need compared to non autistic patients. (Many autistic people are turned away from mental health services as they don't feel they are appropriately equipped to deal with people with co-morbid autism and mental illness diagnosis. There are also no figures or research on suicide and Autism in Australia which I think there needs to be."

Research priorities – additional areas

Research into awareness and perceptions of autism and autistic people

Many respondents mentioned that future research should focus on educating the general population about autism and the wide variety of characteristic associated with the condition, to foster inclusion and acceptance. There was also a desire for increased awareness of autism among health professionals and other professions who are likely to engage with autistic people.

Some respondents mentioned that they would like to see research that focuses on the strengths, rather than impairments, of autistic people and how such strengths can benefit society.

A small number of respondents thought that there should be more research into the various labels used to describe autism to better capture the broad range of characteristics associated with the condition.

“Public Awareness. Autism is a spectrum presenting differently in each individual. The Community still holds the caricature of a person living with Autism as being like 'Rain Man'. Unless you or your child 'avoids eye-contact', 'sorts dinosaurs by colour' or 'is obsessed by cricket statistics' in the eyes of the community you are not Autistic. My child's Autism presents as Pathological Demand Avoidance, and his level of discrimination in the community is extreme because he doesn't fit the community's vision of what an Autism. Research into the Community's understanding of Autism, matched against the range of Autism would be helpful for government and peak bodies to educate the community, which would be very helpful in improving the quality of lives people living without the 'typical autism’.”

“Positive attributes of autistic persons, and education of the public about these (people in my life, including relatives say to me that I am not autistic (I guess because I am high functioning) and mostly I feel that they think they are complimenting me and NOT denying my genius!”

“As a mother of a child with autism, I feel social isolation in the community. People do not have a good understanding in the condition because the condition varies quite significantly between individuals. As a carer, I want be more included in the community and for individuals with autism, I want them to have a support network and where they meet and socialize.”

Research priorities – additional areas

Research into awareness and perceptions of autism and autistic people

“Community education on what autism actually is, not stereotypes based on externally observable traits.”

“Communication difficulties hamper most people with ASD. Wider society often does not understand the 'literal' approach of some people with ASD.”

“You have probably covered it in other areas, however I find that education for people about people with autism is critical and adapting that information to their specific involvement with autistic people, say for example, I work at an organisation that is being very proactive in providing opportunities for people with autism which is great, but the people that will be dealing/working along side the autistic person need awareness of autism so that they know how to build relationships and support the autistic person. Additionally, all of the seven goals need to ensure that education and awareness is given to the day to day person having interactions with the autistic person, eg the bus driver, the doctor, the work colleague, the interviewer, the police man etc. A national education and awareness campaign targeted at ordinary Australians. I bet they don't even know how many people there are in Australia who are autistic and that they probably come in contact with someone who is autistic quite often.”

“Education of medical professionals regarding ASD. There is a huge bias in the medical and mental health professions against accepting functional autistic women or not accepting that a functional woman may have autism. Many middle aged women have potentially slipped through the cracks in being diagnosed because they are not being diagnosed until much later in life. This seems in part due to the symptoms of autism being put down to 'hormonal or other mental health problems'. It seems that it is acceptable by many medical professionals to excuse autistic symptoms as simply the way women function, until their functionality is so degraded that they can no longer function well in society.”

“Defining sub-categories - autism is a very broad condition which makes it hard to describe and differentiate different types of people with autism ie. I prefer to use the term Aspergers for myself (as I am high IQ) and have found some people don't believe me or simply tell me I don't have autism when I say I have been diagnosed with Aspergers/AD.”

Research priorities – additional areas

Research into support for autistic people and the people who help to care for them

Many respondents mentioned that there should be more research into support for people who care for autistic people, and the impact on family members. Suggestions included: reliable, easy-to-access information for parents about autism and treatments; financial support; empowering parents and providing them with a positive outlook; support for managing complex needs and challenging behaviours; and support for autistic parents raising children also on the autism spectrum.

Some respondents mentioned the importance of accessing quality health and disability support services, as well as government funding required to access these services. Supported accommodation that prioritises the health and wellbeing of autistic people was also mentioned.

"...Also something about educating parents to - empathise with their child - enjoy their child - understand that autistic adults are their best resource for advice and education about autism. - recognise that just because an autistic adult is able to communicate verbally or in writing , does not mean that they were not once exactly like their own non-verbal child."

"...empowering parents to understand the importance of their role in maximizing a child's development."

"More assessment and support for parents of ASD people as often they are also on the spectrum, understanding themselves could help them support their child better."

"The mental health of people with ASD and of their families is so important and lacking under NDIS."

Research priorities – additional areas

Research into support for autistic people and the people who help to care for them

"Availability of services and supports. There seems to be many families in crisis and I have often felt some sort of inpatient service where a number of medical and allied health professionals could work as a team with the person with disability and their parents / carers to resolve challenges e.g. challenging behaviours, feeding issues, sleep issues, toilet training etc"

"Carers of autistic people are really struggling. We are often isolated from our communities. We manage challenging behaviours, violent outbursts and a whole range of other challenges and we just don't get anywhere near the support we need to avoid getting our own mental health problems. Autistic carers need the help of a 'village' to support them. But often when there's a kid on the spectrum with extra challenges - everyone disappears! It just feels impossible! More research needed into how to create a financially sustainable way to provide substantial and ongoing support for carers of autistic people (allowing them to enjoy the same social, emotional, financial, physical and mental health as their non-autistic caring peers). Also, The ndis has put even more pressure on carers. It has been great for some autistic people but it's a lot of hard work and stress for carers. We need research into the impact of managing/ coping with ndis as a carer."

"Specific research on the impact on siblings of living with a person with autism. The needs of carers and families subsume the siblings need. We need to focus specifically on the sibling as they have the longest relationship with the person with autism and often attend the same school and witness or are subjected to bullying. Education system often places responsibility of care on the siblings at school. Not enough support or research on siblings. By labelling siblings as carers you assume they will provide care. But this is not the case, many siblings do care but many siblings move countries to get away from the caring role. why? and how can we support them and include them in this research."

Research priorities – additional areas

Research into inclusive and supportive education and employment opportunities for autistic people

Inclusive, supportive, and well-resourced education systems and settings was the most commonly mentioned research priority among respondents. It is important to recognise that the number of respondents who mentioned this topic is likely to be an underestimate of interest in this area, as respondents were asked to list any "other" research areas, and the topic of education had already been covered in the survey as one of the seven main research priorities identified by the AARC.

Some of the specific research topics relating to education mentioned by respondents were: teacher training about autism to promote better understanding and communication with autistic students; sensory-friendly education settings; assessments that accurately measure the learning of students on the autism spectrum; and bullying with schools.

Some respondents also mentioned a need for research that focuses on employment opportunities and workplaces that are inclusive of people on the autism spectrum. Some respondents mentioned that there needs to be greater awareness among employers of how to build relationships with employees on the autism spectrum, and how to create autism-friendly workplaces. The transition from education to the workforce was seen to be a critical stage in people's lives that also required additional support.

Some respondents also mentioned that more support and education is required for autistic people regarding gender identity, sexuality, and romantic relationships.

"The complete lack of appropriate training for school teachers in Australia in ASD is unacceptable, especially considering the numbers of children on the spectrum. It adversely effects not only ASD kids but neurotypical kids in classroom as well. Appropriate support for ASD kids through learning, truly understanding the differences and his to best communicate and educate all children in the Australian community. ASD kids have the same rights as everyone."

"Ways to encourage organisations to create autism-friendly workplaces and flexible roles for people with ASD"

Research priorities – additional areas

Research into inclusive and supportive education and employment opportunities for autistic people

“Sensory differences and how they affect our life & what can be done to make the environment more sensory friendly e.g. more natural light in buildings instead of fluorescent lights, lower 'maximum volume' of audio producing equipment in classrooms (school & uni) so that when videos are played they're not painfully loud. Also whether individuals feel able/confident enough to speak up for their sensory sensitivities, otherwise possibly there should be more limitations put in place within schools and employment environments (where possible) so that individuals with ASD aren't forced to suffer in painful/distressing sensory conditions.”

“What do employers currently understand about Autism and universal access/accommodations that can support better inclusion in the workplace.”

“research on how well the policies (eg inclusion/employment) are implemented and how that has changed outcomes (mental/physical) as well impacted their quality of life.”

“School refusal due to low capacity and standard of inclusive education. Schooling practices that leads to trauma that is life long and sets up a maladaptive trajectory with further education and employment. Many homeschool and do distance education so just ensure the holistic care of children are being met whilst trying to gain some education. This impacts families who loose earning capacity in the short, medium and long term which further disadvantages the family.”

“Alternate methods to assess students on the autism spectrum within educational institutes.”

“Research into school suspensions of children on the autism spectrum”

“Education especially in mainstream schools. Teachers are unprepared for teaching special needs children. There are increasing numbers of children on the spectrum and not enough assistance in classrooms to help. Children on the spectrum are just being put into a too hard basket. These kids are too smart for special school but don't cope in main stream so get lost in the system.”

Research priorities – additional areas

Research into inclusive and supportive education and employment opportunities for autistic people

"You have probably covered it in other areas, however I find that education for people about people with autism is critical and adapting that information to their specific involvement with autistic people, say for example, I work at an organisation that is being very proactive in providing opportunities for people with autism which is great, but the people that will be dealing/working along side the autistic person need awareness of autism so that they know how to build relationships and support the autistic person."

"I really want there to be more research on employment, especially concerning whether the use of psychometric testing in recruitment discriminates against autistic applicants."

"Benefits of employing an autistic person (with or without a support worker) in mainstream employment other than Disability Employment."

"primary and high school suspension rates in children and adolescents with autism to inform i). prediction of entry into criminal justice system of this population (as in literature) and ii). identify areas of professional development and system /policy changes in Department of Education and iii) evaluate need for integrated multiagency support system to include allied health (OT, ST, psychologists) in the education setting (not done in NSW)."

"Supports needed for ASD adults to navigate partnerships and relationships"

"Supports for Autistic people in romantic relationships."

"Promotion and education around safe intimate relationships; education and skill building around keeping yourself safe from harm i.e. reducing chance of STDs, recognising unsafe situations and what to do, etc"

"Research in helping Autistic people to lead fulfilling sex lives."

Research priorities – additional areas

Specific demographic groups and intersectionality among autistic people

Some respondents emphasised the need for research that takes into account intersectional disadvantage among specific demographic groups of autistic people. The main minority groups mentioned by respondents were: women and girls; people who identify as LGBTQI+; culturally and linguistically diverse groups; people with a lower socioeconomic status; and Aboriginal and/or Torres Strait Islanders. Many respondents also mentioned specific age groups that should be the focus of future autism research, particularly children (in relation to schooling and therapies), and adults (in relation to employment, mental health, relationships, late autism diagnoses, and parents on the autism spectrum).

Women and girls

When considering the number of respondents who mentioned women and girls on the autism spectrum as a future research priority, it is important to realise that this number is likely to be an underestimate of interest in this area, as respondents were asked to list any “other” research areas, and the topic of ‘women ang girls’ had already been covered in the survey as one of the additional potential research themes.

Respondents who mentioned ‘women and girls’ as a research priority, indicated that research should focus on: suitable diagnostic tools and therapies for women and girls on the autism spectrum; support for women who have received a late autism diagnosis; the impact of ‘masking’ autism characteristics; and greater education within the broader community about the presentation of autism in women and girls.

“Much more support for teenage girls on the spectrum is needed. They don't fit anywhere. They are very aware that they have limitations and this isolation leads to mental health issues. They don't fit in the general (boy dominated) autism camps and groups they don't fit the younger age group yet they are not ready to be put in the open adult groups either. They mask much better and yet explicit sex education and social situations are not readily available for high functioning teenage autistic girls.”

“Gender bias inherent to diagnostic tools and general clinician perceptions of autism, particularly in women. Supports post adult diagnosis.”

Research priorities – additional areas

Specific demographic groups and intersectionality among autistic people

"Diagnosing girls and women - and changing the common, but inaccurate, belief by the general population as well as professionals and authorities, etc.) that there are many more males than females who are autistic. World leading experts (such as Professor Tony Attwood) have come to understand that girls and women present differently than males and are generally much better at trying to fit in, masking and trying to pass as 'normal', because they are so misunderstood (to the detriment of their mental and physical health and well being) and, it seems that many in the medical profession, in education, in the government, etc. have not caught up with the latest understanding of this. Education and understanding of the latest research on autistic girls and women needs to much more widespread and accessible to those who affect the lives of autistic girls and women and their families and carers … It is a huge problem that I can see at the moment - from first-hand experience, as well as observations."

"I am appalled that your draft priorities don't include women and girls on the spectrum. We talk about inclusion but girls and women are so commonly misunderstood and misdiagnosed that they are even excluded from their autism community!!!"

"Women and girls on the spectrum - supporting adult women to seek diagnosis and create the opportunities for their kids that they never had. All of the topics mentioned are important - but this one isn't considered the top 7????!? I think the impact of more understanding in this area will impact the path forward for the 7 areas - let's stop this gender stereotype of autism - if we want some validity in outcomes for autism research it has to start here!"

MINDTAP
RESEARCH

Research priorities – additional areas

Specific demographic groups and intersectionality among autistic people

"Support services for fathers with children on the autism spectrum. The predominant population is male and yet there are very limited supports targeted specifically to fathers and how they can best support their child. Similarly, the therapy services and education sector is predominantly female. I think this is because traditionally woman are generally more nurturing than men, however, I would want to know if having strong male role models with sound autism knowledge would further support children to learn essential developmental skills."

"More support for children on the spectrum in schools Research into the impact on families/primary carer in terms of mental health, impact on relationships with siblings who care for a person with ASD and support needed Supports needed for ASD adults to navigate partnerships and relationships"

"Research related to effective treatments for ASD adults with mental health disorders, including eating disorders, especially innovations in service delivery for rural areas. Evidence based guidelines for mental health clinicians regarding medication use for ASD adults."

"Intersectional access to diagnosis, care, and supports (e.g., barriers to access due to race, economic factors, poverty, geographic location, etc)."

"Broadening research in CALD and Aboriginal communities to ensure that unconscious bias is not in play and skewing diagnosis and supports"

"1. The growing health inequities (including growing gaps in health outcomes) between regional/rural communities and metropolitan communities, as it pertains to people with diagnoses of (or those undiagnosed with) autism. 2. Aged care services for people with autism (especially with Australia's ageing population) 3. Palliative care for people with autism"

Research priorities – additional areas

Upholding the rights of autistic people and the people who help to care for them

A small number of respondents mentioned research focusing on the safety and protection of autistic people, and reducing discrimination and unlawful treatment. The main topics that were mentioned were abusive relationships within families and couples, and exploitation, abuse and discrimination from the community.

Research strategies

A limited number of respondents included suggestions for research strategies. Some respondents emphasised the need to consult and involve a broad range of autistic people in all areas of research. Some respondents also mentioned that research should involve population-level data collection to measure outcomes for autistic people.

"Educating non-autistics on slurs, discrimination, unconscious negative behaviours toward neurodiverse people - Educating autistics on self-advocacy, including when non-autistics are overstepping their authority to the detriment of one's self"

"Research into Autistic people in an abusive relationship/ that are being abused"

"Also the level of family and community violence towards Autistic people is hidden and needs to be exposed and challenged. People with autism need genuine advocates across all sectors of the community and services."

"There are also no figures or research on suicide and Autism in Australia which I think there needs to be."

"Research on how well the policies (eg inclusion/employment) are implemented and how that has changed outcomes (mental/physical) as well impacted their quality of life."

"Longitudinal studies of outcomes for subgroups of people on spectrum"

"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?"

Feedback from Autism Queensland on the Australian Autism Research Council: Draft Research Priorities for Consultation 2019

- Further research is needed on the quality of life and happiness of people on the spectrum especially those with high support needs who have tended to be somewhat neglected. For example, this may include improved models of supported accommodation. Many people on the spectrum are expected to share accommodation with other people that they don't get along with, and who have challenging behaviours that they can find to be distressing. Models of supported accommodation that offer a better quality of life should therefore be explored. The current focus of research appears to be primarily on meeting health needs of people with high support needs, but there is more to quality of life and happiness than health.
- Further research is required into better ways to support the families of people who are minimally verbal and/or who have high support needs and challenging behaviours, as these families are currently some of the most disadvantaged people in our society. As 30% of people on the spectrum who are minimally verbal cannot speak for themselves, the research council should include a greater representation by family members of people who are minimally verbal, so as to avoid inadvertent discrimination against this group.
- Research translation should include greater consideration of the real-world costs of implementation of autism interventions by service providers, including training costs. Currently, the implementation of many interventions includes exorbitant training costs for clinicians in order to meet fidelity requirements that are difficult to achieve in real-world settings. This includes some early intervention and social skills programs. As a consequence, some services claim to be delivering interventions but do not provide the required training, while others pay exorbitant costs for training at the risk of some programs becoming financially nonviable. Developers of interventions should therefore consider more realistic training requirements and offer less expensive online and train-the-trainer options.
- Research into the development of autism-specific interventions should include participants with a broad range of cognitive, speech and language abilities. Service providers have an obligation to provide services to people with a wide range of abilities. Some early intervention and social skills interventions have been developed for people who are cognitively very able. As a consequence, service providers often find that they need to adapt programs, exclude some participants, or develop their own programs for participants who have cognitive, speech or language delays.
- The experience of many service providers is that people on the spectrum with mental health difficulties are often excluded from community mental health services. This relates to the perception that intervention for mental health difficulties must occur through a specialised autism service, and/or a lack of confidence among community mental health professionals in their capacity to work with individuals on the spectrum. Further, intervention for people on the autism spectrum with co-occurring mental health difficulties is often restricted to pharmacological treatments. This is despite a lack of evidence to support these treatments and despite evidence existing for the effectiveness of psychotherapeutic interventions. As such, some individuals on the spectrum fail to receive much-needed mental health support. Research is needed into improving existing mental health services to be inclusive of individuals on the autism spectrum. This could include exploring (1) the willingness and confidence of mental health professionals in working with individuals on the spectrum with co-occurring mental health difficulties, and (2) the need for upskilling mental health professionals in their knowledge and understanding of autism and the interaction between autism and mental health difficulties.

Australian Autism Research Council:

Draft Research Priorities for Consultation 2019

A Submission by Autism West June 2019

Autism West welcomes the opportunity to submit on the draft research priorities for the Australian Autism Research Council. As an independent community organisation that works with our community to increase self-determination, become aware of their own voice and how they can be empowered to make a difference and have a voice, it is timely that we address what areas the community wants.

We are not therapeutic in our approach, however, our work revolves around creating opportunities to demonstrate strengths and build a sense of belonging both of which are critical to enhancing quality of life. Therefore we are involved in research around strengths and co-participation.

This submission follows the priority areas identified by the council but acknowledges and welcomes that the council have identified that "priorities should be focused on assisting autistic people to discover what they want for their own lives and supporting them to achieve their goals."

6.1. Core Research Priority: Communication

Research Question

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?

Comment:

Understanding how individuals prefer to communicate is a key factor and they need to be offered that choice by societal systems and institutions. Understanding that this may change relative to an environment is also important. This may be related to typical communication challenges but also needs to reflect the social challenges of individuals. Options to provide multiple avenues to communicate, a decent time line to enable processing, and getting thoughts together as well as working on individual therapy align to social norms.

6.2. Core Research Priority: Built Environment

Comment:

Built environment is a narrow focus. There is a need to look at what the challenges are (unintentional bias) that exist in societal systems that act as barriers for the autistic community. A purpose built environment will help address sensory issues, but what about social issues which create anxiety? This challenges individuals with executive functioning issues to navigate systems. How can these barriers to participation, for autism and other invisible disabilities, be identified and accommodated at a macro institutional level.

6.3. Core Research Priority: Health / Self

Research Question

Does the physical, mental health and life expectancy of autistic Australians vary according to factors associated with autism, co-morbidities and co-occurring conditions?

Comment:

Similarly, as to the point in 6.2 above, is anxiety resultant from "factors associated with autism" or "factors associated with environmental challenges (social, built and systemic). Inaccessibility to a building is not a factor associated with being unable to walk, it is associated with an environmental challenge, can this concept be championed as a right when it deals with invisible challenges.

6.4 Implementation Research Priority: Justice

Comment:

This is restricted to legal justice and needs to reflect that if that is the case but perhaps the council can reflect on broadening the theme. It is an opportunity to expand this out to "'a concern for justice, peace, and genuine respect for people", a definition in its broader terms which reflects the NDS and, in line with this submission, reflects the need for equity for our community. By using this broader more encompassing definition it becomes a preventative priority. The current focus on legal justice could be seen as assumed and reactionary resultant from challenges our community have as a result of environmental challenges, misunderstandings, and abuse and exploitation.

6.5. Implementation Research Priority: Employment

Research Question

How can the number of autistic Australians in employment be increased

Comment:

Much of our work has aligned with developing resilience for our community given the stark reality of unemployment among youth and confounding this among autistic youth. How do we become preventative in educating about the meaning and purpose of work and how do we fill the gap given reality also. How do we also prepare our young generations around how the future of work looks and what that may mean to them?

6.6. Implementation Research Priority: Health Service Delivery

Research Question

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?

Comment:

What proactive strategies can be developed to aid the recruitment of autistic individuals as well as research into specific strategies for the treatment of mental health issues for autistic individuals.

6.7. Implementation Research Priority: Education

How can Australia include all autistic students in 'mainstream schooling' in the Disability Education Standards?

Autism West would welcome a research focussed on identification of where the barriers are within the schooling systems and processes which inhibit engagement for our students, rather than a focus on the individual

Teacher training, reflective practice and awareness of the environment and sensory issues.

CRC Autism
Community consultation process
June 2019

1. HELP Enterprises.

HELP is a social enterprise that exists to **enhance the lifestyle and independence of people who live with disability**. HELP is a registered charity and not-for-profit organisation.

HELP operates a range of commercial businesses that are uniquely designed to employ people with disability as part of our diverse workforce. We have a completely integrated HELP team in excess of 900 staff, of which some 350 are individuals with a disability. Our businesses complement our HELP Disability Care services, which provide a wide range of direct support to our communities.

As a modern social enterprise, we strike a balance between our commercial operations and our support services to ensure that we can provide ongoing support both now and well into the future.

2. HELP Enterprises supports approximately 250 people on the spectrum: either employed and using other services at HELP Enterprises, or supported in the community.

3. Research areas of importance to HELP Enterprises

From the seven research priority areas mentioned in the CRC document, HELP has a particular interest in the following two areas:

- Built Environment
    a. As an innovative provider in the areas of housing, day services and employment for people with disability HELP Enterprises is focused on making their facilities as accessible and “user-friendly” for their participants as possible. HELP is aware of the sensory challenges faced by people on the autism spectrum and would greatly value a deeper understanding of the possible improvements it could make to its facilities to address these challenges. This applies to domestic as well as work spaces.

- Employment
    a. HELP Enterprises has a long history of providing successful employment to people with a disability, many of whom are on the autism spectrum. Recently HELP was awarded the 2019 National Excellence in Disability Award for Supported Employment. Continued success in employing people with disability will depend on a continuous improvement of the understanding of the specific needs people in a disability in general and people on the autism spectrum in particular, have to operate successfully in a work environment. This applies to both the infrastructure (covered under the previous heading), the type of work and the human interactions.

    b. For the employer the key will be to understand how to successfully combine the challenges of coaching people with disability and the pressures of operating in a commercial environment.

    c. Specific areas HELP feels should be included in further research are:
        i. The interview process. Interviewing for a job is a major challenge for people on the autism spectrum and we suspect in many cases is the reason for not getting a job at all. Research into how to address this “hurdle” could lead to a significant increase in work participation in the target group.
        ii. Many workplaces are full of noise, movement and other unplanned situations leading to sensory defensiveness of people with autism impacting on their success in the workplace. Understanding how to develop strategies to minimise the impact of these events would enhance the workplace experience significantly. Training for employers on structuring sensory supporting environments within the workplace may also assist in this success.
        iii. In the workplace, it is paramount that all employees understand and correctly interpret health and safety messages and instructions. We need to better understand how to ensure this is happening with employees on the autism spectrum.
        iv. How to best prepare people on the autism spectrum for future employment: when to start the discussions and how to best coach them towards the first job.

For most people the ultimate goal in employment is to participate in open employment. Other than direct employer, HELP is also a major employment placement service for people with disability into open employment.

d. To be successful in the transition from supported to open employment the following areas need further research:

    i. The type and length of support needed and choosing the right moment to complete the transition.
    ii. How to best prepare standard employers for the integration of people on the autism spectrum in their work force.

HELP would welcome any further discussions about the above-mentioned research areas.

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Australian Autism Research Council:
Autism Research Priorities

Submission from Plumtree Children's Services, Inc.

Servicing the inner west and south east regions of Sydney, Plumtree Children's Services, Inc. (henceforth, 'Plumtree') is an early childhood intervention (ECI) service providing support, therapies and education to very young children with disability and developmental delay, and their carers, parents, and families. Approximately 65% of the children supported by Plumtree have been diagnosed with autism.

Plumtree applauds the release of the AARC draft research priorities, with its move away from a focus on causes, cures and interventions, towards creating a more inclusive, just and equitable society for individuals with autism and their families. As an ECI service, however, Plumtree has 'first contact' with many families newly introduced to autism, and our empirical evidence shows that more must be done to address the needs of families of very young children at the earliest moment post diagnosis to ensure the best quality of life for these families, particularly with regard to mental health.

Parents of young children identified with disability and developmental delay are at a high risk for developing mental illness, including stress, anxiety, and depression (Neece, 2014). This fact is especially true for autism (Vasilopoulou & Nisbet, 2016). In addition, mothers in particular are often susceptible, and are excluded from the workforce because of their intensive duties caring for their child with autism (Baker & Drapela, 2010; Scott, 2010), which in turn exacerbates decreased family quality of life outcomes. Moreover, a predictor for child mental illness is poor parental (especially maternal) mental health (Bayer et al., 2011; Siegenthaler, Munder & Egger, 2012).

Research suggests that a diagnosis of autism can negatively impact parental mental health and quality of life outcomes, and that parents of children with autism are especially susceptible to experiencing many stressors in their daily lives that are detrimental to their mental health, resilience, and feelings of self-worth (Weiss et al., 2013). Indeed, research consistently shows that these families face a variety of physiological and psychological stressors that can result in mental illness (Lee et al., 2009).

Just as alarmingly, children and adults with autism are far more likely than their non-autistic peers to experience psychiatric conditions, and to find accessing appropriate mental health support more challenging (Autistica, 2016; Maddox & Gaus, 2018). Suicide in the autistic community is a significant risk (Autistica, 2016). In a recent article, Hwang and colleagues (2019) found that mortality rates for the autistic population were 2.06 times that of the general population, with poor mental health a significant factor in these figures. Importantly, recent research also suggests that mental illness in the autistic population is not derived from autism itself, but rather from lifelong exposure to stigmitisation, discrimination, and concealment or 'masking' (Cage, Di Monaco & Newell, 2018). It is Plumtree's position that at least some of these factors are experienced in the home context, as well as in the broader community. Autism is thus associated with poor mental health in both families and autistic individuals themselves, although arguably stigmatising attitudes to autism are more detrimental than autism itself (Pachankis et al., 2018).

It is vital, therefore, to provide families of young children with autism appropriate ECI services to build parents' acceptance of, and respect for, their child's autistic neurology and establish healthy inclusive practices in the home environment from the earliest possible moment. The provision of genuinely family-centred ECI can help in this endeavour, and can have a positive impact on family mental health and outcomes (Davis & Gavidia-Payne, 2009; Gavidia-Payne, Meddis & Mahar, 2014). Ideally, then, ECI should support not just the child but the whole family, to the benefit of both (Sukkar, Dunst & Kirby, 2017).

One crucial aspect of this kind of effective ECI is to build the leadership and capacity of parents by explicitly giving parents the skills and tools to navigate their own, as well as their child's, mental health needs across the lifespan (Dykens et al., 2014). Plumtree is achieving just this goal by embedding positive psychology principles in its award-winning, internationally recognised capacity and leadership program, *Now and Next*. By using evidence-based positive psychology techniques, explicitly grounded in the theories of prospection, post-traumatic growth, and mindfulness, families of children with autism can experience positive mental health outcomes, including contributing to wellbeing, and developing resilience to the mental illness through fostering constructive approaches to challenges (Moore, Fong & Rushton, 2018).

Providing families of young children with autism with access to preventative, proactive mental health supports from the earliest possible time through coordinated, family-centred and evidence-based positive psychology supports within an ECI framework is one important factor which can mitigate the poor mental health outcomes for this vulnerable population. Not only does positive psychology help families to recast their challenges as opportunities for growth, but equally it teaches families how to vision and hope for the future, which is vital for subjective wellbeing ('happiness') and mental health (MacLeod, 2016).

Through the provision of respectful and positive family-centred ECI, we have the opportunity to impact positively the narrative surrounding autism to the mental benefit of both families and autistic individuals across the lifespan (Hutton & Caron, 2005). Improving parents' mental health and resilience can have corollary positive impacts on children's mental health and resilience, and build skills for the future.

We call on the AARC to recognise the mental vulnerability of families of young children with autism, and ask it to prioritise the preventive mental care of this population to the social and economic benefit of the families, their children, and the communities in which they live.

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Australian Autism Research Council

Autism Research Priorities

Submission from Reframing Autism

Reframing Autism (RA) is a non-incorporated organisation run by and for Autistic people, and their families and allies. RA's vision is to create a world in which the Autistic community is supported by their families and allies to achieve genuine acceptance, inclusion and active citizenship, and in which Autistic culture and identity are celebrated and nurtured. RA and its members thus have a deep interest in the draft research priorities released by the AARC for consultation.

It is heartening to see a concerted effort in the 2019 priorities to move away from research into causes, cures and interventions, and towards achieving the basic human rights of Autistic individuals across the lifespan. As they stand, each of the broad research priority areas reflects the lived experience needs of the Autistic community, and RA applauds the emphasis on intersectionality in the priorities and example research questions.

Broadly, however, we would like to have had more clearly communicated information about how the research priorities were determined, and how deeply the Autistic community was involved in their development. That is, whilst we appreciate that the AARC used national and international frameworks and existing surveys to form its priorities, understanding how the AARC decided upon and articulated its priorities would be helpful information in assessing the relevance and urgency of those priorities.

In response to Core Research Priority 1. Communication

RA would like to encourage the AARC to consider adopting the terminology of 'non-traditional communicator' or 'non-traditional communication'. The reference to 'non-speaking' or 'minimally verbal' contributes to a narrative which asserts the primacy of spoken communication over other forms of communication, which is both reductive and harmful. If the Autistic community is to experience genuine inclusion, all types of communication must be equally valued and valid.

It is encouraging to see that the final example research question implies a reciprocity of responsibility for communication: too often, research focuses on the ways in which the Autistic community can learn to communicate better with the non-autistic community. RA urges more concerted and direct research into the ways in which the non-autistic community can learn to communicate better with the Autistic community, and more explicit acknowledgement of the requirement for the reciprocal responsibilities of the Autistic and non-autistic communities to 'meet halfway'.

In response to Core Research Priority 2. Built Environment

The provision of inclusive and accessible built environments is crucial to an Autistic individual's ability to be a full, active and participatory citizen, which is our human right. In order to become self-determined civil, political and social participants in our lives and communities across our lifespan, Autistic individuals must have access to more inclusive physical spaces. RA thus fully supports this core research priority, especially given its focus on changing the environment, rather than changing the Autistic community.

In response to Core Research Priority 3. Health / Self

Whilst the inclusion of a core research priority on improving the physical and mental health of the Autistic community is most welcome, there are some areas of concern in this priority area.

We note that the example research questions do not acknowledge the latest research linking Autistic mental health with Autistic concealment and prolonged exposure to stigmatisation and discrimination (e.g., Cage, Di Monaco & Newell, 2018). Surely if the research priority is to ensure optimal mental health for all Autistic Australians, we must not only acknowledge but actively tackle the roots of such mental illness, and not assume that mental illness is an unavoidable element of an Autistic neurology. It seems a striking and disappointing oversight that interrogating the ways in which Autistic Australians experience exclusion, and explicating the causal relationship between such exclusion and mental health outcomes (including impact on mortality rates), is missing from this research priority.

We are particularly disappointed that the example research question 2 is limited to exploring factors 'associated with autism, co-morbidities, and co-occurring conditions' and does not commit to exploring the broader community responsibility for Autistic mental and physical health (beyond the social determinants of health outlined at question 3).

Moreover, we would like to note our overarching unease with the Autism Biobank. Whilst the Biobank is not specifically referenced in this priority research area, we would like to caution the use of its data without the full and informed consent of its donors (including children whose data have been stored without their permission at their parents' request).

In response to Implementation Research Priority 4. Justice

We hope that any research into justice will work to facilitate the full, active sociopolitical citizenship of Autistic Australians by putting equal emphasis on making the legal and judicial system accessible and equitable for the Autistic community, and on ensuring robust protective measures to prevent discrimination, exploitation and abuse of Autistic individuals.

In response to Implementation Research Priority 5. Employment

We encourage the AARC to ensure its priority remains firmly focused on providing 'meaningful work opportunities', not simply on providing 'open and accessible' work arrangements. Too often, Autistic individuals are forced to accept menial or unskilled employment placements that do not relate to their skillset or interests. Meaningful work opportunities do not correlate directly or simply to 'employment'.

In response to Implementation Research Priority 6. Health Service Delivery

This implementation research priority seems ill distinguished from the core research priority 3. These priorities need further definition and explication to help us to understand the ways in which they are distinct and differ.

In response to Implementation Research Priority 7. Education

We note the AARC's assertion that Australia has a number of different forms of segregated schooling and that there is a continued governmental and departmental commitment to sustain such segregation. However, this reality does not mean that segregated education is optimal for the Autistic community, that it is best practice, or that it is evidenced to result in the best educational experiences for Autistic individuals. We are disappointed that the AARC priority accepts the status quo in Australia, rather than exploring evidence which might challenge it. It behoves the AARC to interrogate Australia's commitment to segregation, especially given international moves away from such segregated schooling. Simply adhering to this commitment does not seem concomitant with the AARC research mandate.

Comments on the consultation process

Commenting on the consultation process more broadly, Reframing Autism would like to register our dissatisfaction and unease with the Standard Online and Easy Read Online survey forms relating to this consultation (available at https://www.autismcrc.com.au/aarc). In the first place, the Easy Read version is not, in fact, easy read (its reading grade does not accord with Easy Read guidelines), which renders it inaccessible to many key primary stakeholders. Moreover, the Easy Read survey differs significantly from the Standard English version (which itself was written in more academic than plain English, also undermining its accessibility). Surely, the data collected from the two surveys will be compromised since these surveys are distinct and do not parallel each other adequately.

Perhaps more importantly, concepts vital to this consultation are not defined and therefore are rendered obscure and abstruse for many readers. This inaccessibility is amplified because so many of these concepts are highly subjective or jargonistic (for example, 'research', 'evidence-based', 'justice', 'inclusive' and 'inclusion').

Finally, our team felt that asking us to prioritise and monetarise our human rights within a $7 equation trivialised and diminished both our human rights and our struggle to achieve them. Such reductive thinking seems unnecessarily distressing to the Autistic community, and we would like to register our view that its appearance in the survey demonstrated poor judgement, undermining this otherwise important opportunity for genuine and respectful collaboration and consultation.

Xceptional

Australian Autism Research Council (AARC) Autism research priorities submission

28th June 2019

To whom it may concern,

We are delighted to have the opportunity to contribute to the AARC priorities and to shape the future of research for autistic people. Seeking input from a wide range of individuals, families, researchers, experts is a wise and welcome step.

Xceptional, a technology platform, that matches people with autism to IT jobs, is particularly interested in the area of employment. We have worked with more than 100 amazing individuals on the spectrum in 2019 alone. More than 50% of our management team are on the spectrum, or have an autistic sibling or child.

Employment is such a crucial area. Given that autistic people spend more of their life as working age than school age, we would argue that employment should be one of the most important areas for research. Far more research has been focused on children and education; this posits employment as a significant research opportunity.

Retention conditions and barriers to employment

Much of the existing body of research on employment of autistic people focuses on the barriers they face. This makes sense, given how locked out this group are from the workplace, but needs to be broadened and deepened.

We need to understand these barriers in more detail. For example, we know that the job interview process is especially tough and does not allow autistic people to perform well. More can be done to understand the specific challenges of the interview process such as recruitment assessments, test performance under stressful conditions and job interview adaptations such as work sample tasks.

Furthermore, by focusing the majority of our research on barriers, we are finding that there is insufficient research focused on retention, and only limited understanding of success factors for long-term employment. We would welcome research questions focused on these two areas.

Leadership conditions and media portrayal

The autistic and neurodiversity inclusion efforts are lagging behind the race and gender discussions. This is a new frontier, so it will take time to catch up. To accelerate this process of understanding, autism employment research can learn a lot from other diversity areas that are leading the way.

For example, other inclusion fields are looking at the lack of diversity at CEO level. This reminds us we need to do more to understand how to better understand how to support autistic people who want to start new companies or lead companies. Who is researching the barriers and conditions for autistic leaders to thrive?

Other areas of diversity are learning that an effective approach to progress is to change stereotypes in the media. Employable Me, the Good Doctor and other shows are having an impact on portrayal of people on the spectrum. We can certainly be doing more to research and better understand the positive and negative sides of this impact.

Too often, we see people working in laundries and cafes; what about studying the story of leaders such Temple Grandin or Xceptional staff working at some of the leading tech firms?

Research changes in technology companies
The AARC priorities suggest the research question, “how can we the number of autistic Australians in employment be increased”. This is a good question but is ignoring the fascinating and very relevant shift in corporate Australia.

Increasing numbers of companies, especially technology firms and those that heavily utilise technology, such as banks and financial firms, are seeking to transform their workplaces to be more accessible for people with autism. We are seeing this happen at some of the biggest technology companies in the world, from both the US and Australia. Several hundred contacted us after Xceptional appeared on ABC’s Employable Me, for example.

In a sense, these companies are asking us to help them transform; it is like there is a need for an NDIS for corporations. Alongside employment supports for individuals, we are now providing employment support for companies. This is a field ripe for research.

A systemic transformation is needed
The wording used in the AARC priorities document for education refers to an “inclusive education system”. The focus of the comparable sentence for employment is “meaningful employment opportunities”. Why are we looking at opportunities and not looking at a systemic change in the workplace, as with education?

At Xceptional, we would like to see an inclusive employment system that meets the needs of all autistic adults both for opportunities and long term success.

Regards,

Mike Tozer, Founder and CEO
Xceptional
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Australian Autism Research Council nominations process

Expressions of interest will close at 11:59pm (AEST) on Thursday 14 November 2019. We will advise people whether they have been selected or not via email by 5pm AEST on Wednesday 27 November 2019.

The new members of the AARC will be announced on or before 15 December 2019 to commence their two year term in January 2020 (ending December 2021).

If you would like to know more about this expression of interest, please read our Privacy Policy.

Important things to note:

- Please read the AARC Terms of Reference before submitting your application.
- Submitting an expression of Interest does not guarantee that you will be invited to be part of the Australian Autism Research Council. The Council has a minimum of 8 and a maximum of 14 members.
- The decision about who will become members of the AARC will be considered by the current AARC membership. We will try to include the broadest and most diverse representation possible from across key communities with an interest in how research can improve the lives of autistic Australians.

Below is an overview of the questions from the 'Expression of Interest' form which needs to be submitted online (https://www.tfaforms.com/4761689).

Your details (First name, Last name, Email address & Postcode)

Your communities

Please tick as many as apply

- I am autistic
- I am a parent/guardian or other family member of an autistic person
- I am a support worker / work directly with autistic people (this is for people who are employed to work with autistic people)
- I am a representative of an organisation which provides services to the autistic community (please specify the name of the organisation)
- I am a representative of an autistic or autism community advocacy organisation (please specify the name of the organisation)
- I am a researcher
- I am employed by federal, state or territory, or local government (please specify the level of government and you areas(s) of expertise: policy, transport etc.)
- I am a health, education or legal professional (please specify: General Practitioner, Speech Pathologist, Kindergarten teacher etc.)
- I am a member of a minority group (please specify)
- Other (please specify)

Why would you like to be part of the Australian Autism Research Council? What skills and experiences would you have to offer the communities you have selected?

Please answer the question in 50-250 words. Please email aarc@autismcrc.com.au if you would like to submit a voice recording or video as your response to this question.