



2023 Research Priority Update

Focus on five research priority areas

Appendices

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September 2023

**Australasian
Autism
Research
Council**



Australasian Autism Research Council

2023 Research Priority Update

Focus on five research priority areas

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ISBN: 978-1-922365-58-3

Citation: Whitehorne-Smith, P., D’Arcy, E., Hayden-Evans, M. Malone, S., Carroll, A., Colville, O., Fitton, A., Picen, T., Vinci, B., Timms, L., Jackson, E., Simpson, K., Lawson, W., Adams, D., & Girdler, S. (2023). *Australasian Autism Research Council 2023 Research Priority Update: focus on five priority areas*. Brisbane: Autism CRC.

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Appendix A: Ethical approval survey



Human Research Ethics Approval

31/08/2023

Professor Dawn Adams
School of Education and Professional Studies
Griffith University

Dear Professor Adams,

HREC Reference: 2023/028
Project title: What do the autistic and autism communities want Australian autism researchers to focus on?

Thank you for your response to the conditions assigned by the Griffith University Human Research Ethics Committee (GUHREC) in relation to the above project.

I am pleased to advise that this research project meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 and the Griffith University Research Ethics Manual (GUREM). The Committee has granted full approval for the project.

The GUHREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007) - Updated 2018, and the Australian Code for the Responsible Conduct of Research (2018).

Project duration: 23/01/2023 – 31/08/2023

At the end of the project a Final Report must be submitted within two weeks of the end date.

Co-investigators:

Stephanie Malone, Kate Simpson, Emily D'Arcy, Sonya Girdler, Wenn Lawson

Documents reviewed and approved:

Document
Information Sheet
Questionnaire Pack
Social Media Advert

Please note the following conditions of approval:

Reporting to the HREC: The following reports are required to be submitted to the HREC. Failure to fulfil these reporting requirements may result in withdrawal or suspension of HREC approval:

Progress Reports: The Chief Investigator is responsible for the provision of a completed progress report to the HREC on an annual basis. Progress reports are due on the anniversary of the HREC approval date.

Final Report: The Chief Investigator is responsible for the provision of a completed final report to the HREC within two weeks of the end date of the project's ethical approval.

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Other project monitoring: The HREC or Ethics and Integrity Team may inquire into the conduct of any project. The Chief Investigator is responsible for the prompt provision of such information when requested.

The HREC or delegate(s) may conduct an audit of the project at any time.

Variations: Prior written approval is required from the HREC for any modification to the approved project (in accordance with Booklet 6 of the [Griffith University Research Ethics Manual](#)). Variations requests can be submitted by email to research-ethics@griffith.edu.au

Unexpected events: If an unforeseen event occurs that may have an ethical impact upon the project, or unexpected significant risk factors emerge, immediately notify the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au).

If the continuation of a participant's involvement in a project may be harmful, immediately withdraw the participant and advise the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) of this action.

If the risks associated with the project are found to be disproportionate to the expected benefits suspend or modify the research project and immediately advise the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) of this action.

Further information about the responsibilities of Griffith University researchers can be found in Booklet 3 of the [Griffith University Research Ethics Manual](#)).

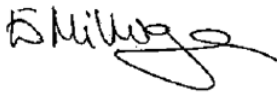
Complaints or concerns about ethical conduct: Immediately notify the Secretary of the HREC (ph: 373 52069 or research-ethics@griffith.edu.au) if any complaints are made, or expressions of concern are raised in relation to the ethical conduct of the project.

Conduct project as approved: The project must be conducted according to the application approved by the HREC including continuing compliance with the conditions outlined in this letter and with the National Statement on Ethical Conduct in Human Research (2007) - Updated 2018, The Responsible Conduct of Research policy, the Australian Code for the Responsible Conduct of Research and any other relevant regulatory and legislative requirements.

The Chief Investigator has ultimate responsibility for the conduct of the project and is responsible for ensuring all others involved conduct the research in accordance with the above.

Please contact the Office for Research Ethics and Integrity team at research-ethics@griffith.edu.au should you require further information.

Yours sincerely



Prof Eleanor Milligan
Chair
Griffith University

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Appendix B: Demographics survey

Demographics

Please complete the survey below.

Q1 Which of the following roles do you identify with?

*you can select multiple

(Note: This is not a complete list of key supporters. Please select the last option if your role has not been mentioned here.)

- Autistic person
- Parent of Autistic person(s)
- Carer of Autistic person(s)
- Family member of Autistic person(s)
- Researcher
- Medical professional (including doctors and nurses)
- Teacher, teacher aide or school leader (educational professional)
- Allied health professional (e.g., occupational therapists, psychologist, speech and language pathologist)
- Social worker
- Disability support worker
- Government / council worker
- None of the above, but part of an Autistic person's support network (please specify) _____

Q2 What gender do you identify with?

- Man
- Woman
- Non-binary
- Prefer not to say
- Other (please describe) _____

Q3 What age bracket are you in?

- 16-25 years
- 26-35 years
- 36-45 years
- 46-55 years
- 56-65 years
- 66-75 years
- 76 years or older

Q4 What is your highest level of completed education?

- High school
- College/TAFE
- Diploma or similar
- Undergraduate degree
- Postgraduate degree
- Other (please specify) _____

Q5 Do you personally identify as any of the following?
*you can select multiple

- Aboriginal / Torres Strait / Indigenous Australian and/or Original Custodian
- Culturally and Linguistically Diverse (CALD)
- Neurodivergent
- LGBTQIA+
- Non-speaking
- Full-time user of non-spoken communication tools (e.g. Signs, Augmented or Alternative Communication; AAC)
- Part-time user of non-spoken communication tools (e.g. Signs, Augmented or Alternative Communication; AAC)
- Having a physical disability
- Having an intellectual disability
- Other (please specify) _____

Q6 Do you have any clinical-diagnosed medical conditions or disabilities?
(e.g., Physical Disability, ADHD, Learning Disability, Anxiety, Depression, Dyspraxia, PTSD, Intellectual Disability, etc.)

- Yes (please specify) _____
- No

Q7 Do you have any self-diagnosed medical conditions or disabilities?
(e.g., Physical Disability, ADHD, Learning Disability, Anxiety, Depression, Dyspraxia, PTSD, Intellectual Disability, etc.)

- Yes (please specify) _____
- No

Q8 How do you prefer to communicate?
*you can select multiple

- Speech
- Augmentative and Alternative Communication (AAC)
- Gestures
- Sign Language
- Text (typing, text messaging)
- Email
- Messenger
- Written forms (e.g. handwritten notes)
- Other (please specify) _____

Q9 What ethnicity do you identify as?

(e.g. Australian, Aboriginal or Torres Strait Islander, Asian, African, Middle Eastern, Pacific Islander, European, etc.)

Q10 In what country were you born in?

(e.g. Australia, New Zealand, America, China, etc.)

Q11 In what country or countries were your parents born in?

(e.g. Australia, New Zealand, America, China, etc.)

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Q12 How would you describe the area you live in?

- Urban (cities, towns, suburbs)
- Regional/Rural/Remote (outside major cities and towns)
- Other (please describe) _____

Q13 We would like to know if our survey has reached those with varying financial situations. Given your current needs and financial responsibilities, would you say you and your family are:

- Not able to meet basic needs and responsibilities financially
- Struggle to meet needs and responsibilities financially
- Just meeting financial needs and responsibilities
- Can comfortably satisfy needs and responsibilities financially
- Can very easily satisfy needs and responsibilities financially

Q14 Is there anything else you would like to share that may be relevant to this study?

Q15 We will be following up this survey with some online discussions.
Please provide your email address if you would like to receive information about these discussion groups.
*Note: You are under no obligation to take part just because you provide your email address

15% Complete

Appendix C: Community views survey

What do you want Australian Autism researchers to focus on?

Making Built Environments more Accessible

Survey 20% Complete

Researchers want to study how the Built Environment can be made more accessible to Autistic Australians, and those important to them (e.g. their families, their support workers).

The "Built Environment" includes all spaces for living, working and playing.

These spaces may have various types of interconnected parts, such as roads and transportation, buildings, or parks and gardens.

An accessible Built Environment means Autistic people's needs are met, without experiencing barriers.

There are multiple types of Built Environments, including:

Residential (housing) environments, Retail (shopping) environments, and Work environments.

Would you like to answer questions about Built Environments?

- Yes
 No

Q1 What do you think are the main issues (barriers) Autistic people experience within Built Environments?

*Please suggest 1-3 barriers.

This can be based on your personal experience or about Autistic people in general.

Optional Info: Helpful Images/Prompts

Optional Info: Helpful Images/Prompts

Use these images as prompts to help you reflect on your recent experiences in Built Environments.

It may help to retrace your pathways within Built Environments in your mind, from arriving to leaving.

If you can, notice how different features of the environment affected you.

Grey townhouses with flat roofs.

Green leafy trees between them.

Blue sky in the background.

Brightly lit subway station.

People standing and sitting on the platform.

White tiled floor.

Train moves fast through the station.

Multi-leveled shopping centre.

People walking around, and riding escalators.

Several brightly-lit shop fronts.

Large advertisement of person wearing a pink dress.

When answering questions 1 & 2, it might help you to reflect on whether any features of these images, or others that may have come to mind, stand out as:

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- Positive or Negative?
- Pleasing or Upsetting?
- Comfortable or Uncomfortable?
- Clear or Confusing?

Please return to the textbox to answer Q1

- Q2 In your opinion, what questions should researchers ask to reduce barriers / issues associated with Built Environments for Autistic people?
*Please suggest 1-3 questions.

Optional Info: Suggestions for how to phrase your questions

- Suggestions for how to phrase your questions
Researchers often use specific phrases when asking questions, such as:

- What is the link between...?
- What is the most effective way to ensure...?
- What is the best type of...?
- What might lead to...?
- Do Autistic people (and those important to them) commonly experience...?

Use these phrases if you find them helpful.

Please return to the textbox to answer Q2

Choice in Housing and Living

Survey 35% Complete

Researchers want to study how to give Australian Autistic people Choice and Control over where and who they live with.

This means:

- Empowering Autistic people to make decisions about where to live.
- Giving Autistic people different housing options that they experience as safe, accessible, healthy, and supportive of their well-being.
- Empowering Autistic people to decide whether they live with others (and whom they live with) or live alone.
- If the Autistic person needs support from others to live independently, they are empowered to decide who provides that support.

Would you like to answer questions about Choice in Housing and Living?

- Yes
 No

Q1 What do you think are the main issues (barriers) Autistic people experience regarding Choice and Control in Housing and Living? This can include where they live, who they live with, autonomy of choice as well as availability and accessibility.

*Please suggest 1-3 barriers.

This can be based on your personal experience or about Autistic people in general.

Optional Info: Helpful Images/Prompts

Optional Info: Helpful Images/Prompts

Use these images as prompts to help you consider different potential living environments, whether with people or alone.

Two people playing video games.

Both smiling and wearing headphones.

Behind them is a window and an indoor plant.

Person sits, quietly reading a book on the mattress.

String of fairy lights on the white wall.

Open window, with a green-painted trim.

Room with a red patterned sofa, red & pink cushions.

Floral paintings around.

Lamp on the side table.

Another table under a window with two wooden chairs.

When answering questions 1 & 2, it might help you to reflect on whether any features of these images, or others that may have come to mind, stand out as:

- Positive or Negative?
- Pleasing or Upsetting?
- Comfortable or Uncomfortable?
- Clear or Confusing?

Please return to the textbox to answer Q1

Q2 In your opinion, what questions should researchers ask regarding Autistic people's Choice and Control in Housing and Living? This can include where they live, who they live with, autonomy of choice as well as availability and accessibility.

*Please suggest 1-3 questions.

Optional Info: Suggestions for how to phrase your questions

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☐☐ Suggestions for how to phrase your questions

Researchers often use specific phrases when asking questions, such as:

- What is the link between...?
- What is the most effective way to ensure...?
- What is the best type of...?
- What might lead to...?
- Do Autistic people (and those important to them) commonly experience...?

Use these phrases if you find them helpful.

Please return to the textbox to answer Q2

Health, Disability and Education Services

Survey 50% Complete

Researchers want to study how the accessibility and availability of Health, Disability and Education Services may impact the mental and physical health of Autistic Australians.

In this context, availability means Health, Disability and Education Services are available to be used by Autistic people, whereas accessibility refers to services that are inclusive and accommodate Autistic individuals' needs (e.g., sensory-considerate environments) for them to be able fully engage with these services.

When thinking about availability and accessibility, consider some of the ways you engage with services, e.g:

- by telephone,
- by email,
- by video conference,
- through social media,
- from a website, or
- in person.

Would you like to answer questions about Health, Disability and Education Services?

- Yes
 No

Q1 What do you think are the main issues (barriers) Autistic people experience with accessibility or availability of Health, Disability and Education Services?

This can be based on your personal experience or about Autistic people in general.

*If possible, please suggest 1-3 barriers for each type of service:

Health Services

e.g. pharmacies/chemists, doctor appointments, hospitals, psychiatrists, dentists

Disability Services

e.g. parking, employment, housing, finance and funding

Education Services

e.g. schools, kindergarten, TAFE, university

- Optional Info: Examples of Service Areas & Key Terms
 Optional Info: Helpful Images/Prompts

☐☐ Examples of Service Areas

Disability Services

Parking Employment Advocacy Housing Legal Needs Community and Social Participation Finance and Funding

Education Services

Schools Government/Non-Government Schools Specialist Schools Distance Education Schools Homeschool
Tutoring / Private Lesson Providers Technical and Further Education (TAFE) institutions Universities Adult Education
Centres Kindergartens

Health Services

Allied Health Practitioners Psychologists Occupational Therapists Speech Pathologists Emergency Departments
Public and Private Hospitals Primary Care Centres General Practice (GP) Clinics Specialist Health Providers in
Medicine Dentists Obstetricians Psychiatrists Dermatologists Cardiologists Pharmacies or Chemists

Definitions of Key Terms

☐☐ Service "Availability"

Autistic people can access the service the way and when they need to, e.g:



service answers emails.



service answers phone in working hours.



Service "Accessibility"

Autistic people can engage with the service without experiencing barriers, e.g:



workplaces and schools that embrace neurodiversity.



accessible disability support services.

☐☐

☐☐

Service "Without Barriers"

Service is equally usable for Autistic and non-Autistic people, e.g:



communication methods based on client preferences.

☐☐ Mental Health

Emotional, psychological, and social well-being, that helps us to e.g:



helps us achieve goals.



cope with stress.



engage with the community.



learn and work well.

Physical Health

Condition of our bodies and how well we're functioning, e.g:



capable movement.



absence of pain.

Please return to the textbox to answer Q1

Optional Info: Helpful Images/Prompts

Use these images as prompts to help you reflect on your recent experiences and interactions with various types of services.

Medical treatment room.

Patient wears a pink hooded jumper.

Having her blood pressure taken by a doctor.

Room has cream walls, a patient bed, and a large window.

Adult students face a large projector screen with text on it.

Teacher stands behind a lectern in the corner of the room.

Room has high, ornamental ceilings, and blue walls with panelled, arched, windows.

Gardener wearing blue, long sleeved overalls.

She looks after seedlings in trays in a large green house.

When answering questions 1 & 2, it might help you to reflect on whether any features of these images, or others that may have come to mind, stand out as:

- Positive or Negative?
- Pleasing or Upsetting?
- Comfortable or Uncomfortable?
- Clear or Confusing?

Please return to the textbox to answer Q1

Q2 In your opinion, what questions should researchers ask when studying how the physical and mental health of Autistic people is affected by the availability and accessibility of Health, Disability and Education Services?

*Please suggest 1-3 questions.

Optional Info: Suggestions for how to phrase your questions

Suggestions for how to phrase your questions

Researchers often use specific phrases when asking questions, such as:

- What is the link between...?
- What is the most effective way to ensure...?
- What is the best type of...?
- What might lead to...?
- Do Autistic people (and those important to them) commonly experience...?

Use these phrases if you find them helpful.

Please return to the textbox to answer Q2

Family and Carer Support

Survey 65% Complete

Researchers want to understand how we can better support Families and Carers of Autistic Australians.

When answering the next questions, please use the concept of Family as it applies to your own life, and what it means to you.

Autistic people can have different family structures:

- Some might have chosen families instead of biologically related families.
- Others might include pets in their families.

Your concept of Family is important, relevant and valid.

If you consider yourself as not having Family, you may think about those with whom you share a personal connection with - when writing your questions.

For example, this might include people you communicate with in online groups or in local community groups.

The important thing is to consider how to support others in their role as people connected to an Autistic person in a personal, rather than professional, capacity.

Would you like to answer questions about Family and Carer Support?

- Yes
 No

Q1 What do you think are the main issues (barriers) in support for Family and Carers of Autistic Australians?

*Please suggest 1-3 barriers.

This can be based on your personal experience or about families of Autistic people in general.

- Optional Info: Who is considered a "Carer"?
 Optional Info: Helpful Images/Prompts

Who is considered a "Carer"?

They are someone who provides unpaid care to Autistic people.

This care can include:

- Practical Support: e.g., providing transport.
- Social Support: e.g., facilitates social interactions and opportunities.
- Emotional support: e.g., acknowledges and validates the autistic individual's emotions, even during challenging moments.

Please return to the textbox to answer Q2

Optional Info: Helpful Images/Prompts

Use these images as prompts to help you reflect on your understanding of Family and Carer support.

Adult sitting beside a child, pointing to the laptop.

Open workbook in front of them.

Laptop has a floral cover.

Parent, or Carer, cuddles a toddler at the beach.

Toddler wears a green puffy jacket and a yellow beanie.

Waves are crashing on the sand behind them.

Sky is blue with a belt of white clouds.

Two customers look at products in a supermarket.

Both wear face masks and grey t-shirts.

One wears a backpack and black cap.

Sign on the shelves behind them reads 'Healthy Living'.

When answering questions 1 & 2, it might help you to reflect on whether any features of these images prompt others

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Project Support



that may have come to mind, stand out as:

- Positive or Negative?
- Pleasing or Upsetting?
- Comfortable or Uncomfortable?
- Clear or Confusing?

Please return to the textbox to answer Q1

- Q2 In your opinion, what questions should researchers ask when studying how we can better support Families and Carers of Autistic people?
*Please suggest 1-3 questions.

Optional Info: Suggestions for how to phrase your questions

- Suggestions for how to phrase your questions
Researchers often use specific phrases when asking questions, such as:

- What is the link between...?
- What is the most effective way to ensure...?
- What is the best type of...?
- What might lead to...?
- Do Autistic people (and those important to them) commonly experience...?

Use these phrases if you find them helpful.

Please return to the textbox to answer Q2

Gender, Diversity and Inclusion

Survey 80% Complete

Researchers want to study how we can ensure fairness for Autistic Australians, regardless of Gender, Intersectional Identity, or Cultural Background.

Gender is considered because experiences may differ between males, females, and individuals with diverse gender identities.

Intersectional Identity is considered because the barriers Autistic people face may not be solely based on Autism itself, but other aspects of identity such as socioeconomic status, sexual orientation, disability.

Cultural Background is considered because cultural and systemic factors (e.g. stigma) may also affect the potential for equitable opportunities.

Would you like to answer questions about Gender, Diversity and Inclusion?

- Yes
 No
-

Q1 What do you think are the main issues (barriers) for ensuring fairness for Autistic Australians, regardless of Gender, Intersectional Identity, or Cultural Background?

*Please suggest 1-3 barriers.

This can be based on your personal experience or about Autistic people in general.

- Optional Info: Definitions of Key Terms
 Optional Info: Helpful Images/Prompts

☐☐ Optional Info: Definitions of Key Terms

☐☐ Equity

When barriers are removed, and supports are in place, equal opportunities can be had for all.

☐ Gender Equity

Those whose Gender Identities are marginalised are provided the same opportunities and supports, e.g:

■

workplace gender equality, including fair hiring processes.

■

gender-affirming care for transgender and non-binary individuals.

*Note: Autistic people identify as many different genders, which are not always the same as the genders they were assigned at birth.

All gender identities are valid and relevant in this survey.

☐☐ Intersectionality

Means many different social influences can combine to shape a person's experiences in the world. These aspects of our identities can include:

■

race

■

religion

■

culture

■

ethnicity

■

sexuality

■

gender

■

class

■

disability

☐☐ Intersectionality Identity Equity

Barriers are removed, supports are provided, so people have the same opportunities and experiences regardless of their Intersectional Identities, e.g:

■

addressing the unique challenges and barriers faced by Autistic individuals who may experience multiple forms of marginalisation and discrimination.

☐☐ Cultural Background

The combination of elements such as

■

language,

■

customs and traditions,

■

knowledge and stories,

■

food and drink

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■

art, drama and music,

■

religion, faith, values and beliefs.

□□ Cultural Equity

Barriers are removed, supports are provided, so people of different cultural backgrounds have the same opportunities and experiences. For example, ensuring Autistic individuals from different cultural backgrounds have equal access to:

■

autism-related support services

■

therapies

■

culturally sensitive and inclusive interventions

Please return to the textbox to answer Q1

□□ Optional Info: Helpful Images/Prompts

Use these images as prompts to help you reflect on your understanding of Gender, Intersectional Identity and Cultural Background.

Person sits in wheelchair beside a large lake.
They are smiling, wearing glasses.
Still water of the lake reflects the sky and the trees along its banks.

Family of two adults and two children walk along a road, hand in hand, towards a pride march.
Adult on the right wears an LGBTQIA+ flag as a cape.
Someone in the background holds a sign saying 'trans people belong'.

Parent, or Carer, is smiling and holding a toddler above their head.
The toddler is smiling and reaching out to touch the parent's face.

Five people pose for a photo, all smiling.
Café chairs and tables, and city buildings, in the background.

Child smiles while leaning their arms over a railing.
They have a strand of long, dark, curly hair on either side of their face, and they wear a black kippah, or cap, on their head.

Musician with white, striped body paint on their torso and chin.
Sits holding a didgeridoo.
First Nations artwork, lots of colours and patterns behind them.

When answering questions 1 & 2, it might help you to reflect on whether any features of these images, or others that may have come to mind, stand out as:

■ Positive or Negative?

■ Pleasing or Upsetting?

■ Comfortable or Uncomfortable?

■ Clear or Confusing?

Please return to the textbox to answer Q1

Q2 In your opinion, what questions are important to ask when studying how we can ensure fairness for Autistic Australians, regardless of Gender, Intersectional Identity, or Cultural Background?
*Please suggest 1-3 questions.

Optional Info: Suggestions for how to phrase your questions

Suggestions for how to phrase your questions
Researchers often use specific phrases when asking questions, such as:

- What is the link between...?
- What is the most effective way to ensure...?
- What is the best type of...?
- What might lead to...?
- Do Autistic people (and those important to them) commonly experience...?

Use these phrases if you find them helpful.

Please return to the textbox to answer Q2

Final Thoughts

Survey 95% Complete

To help the team improve our understanding and make future improvements, please answer some final questions about your survey experience.

Q1 Were the "Images/Prompts" helpful in answering the questions, in the following survey sections?

	Yes	No	Did not answer this section
Making Built Environments more Accessible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice in Housing and Living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health, Disability and Education Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and Carer Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender, Diversity and Inclusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q2 Were the "Optional Info" buttons helpful in answering the questions, in the following survey sections?

	Yes	No	Did not answer this section
Making Built Environments more Accessible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice in Housing and Living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health, Disability and Education Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and Carer Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender, Diversity and Inclusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3 Were the questions clear, in the following survey sections?

	Yes	No	Did not answer this section
Making Built Environments more Accessible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice in Housing and Living	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health, Disability and Education Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and Carer Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender, Diversity and Inclusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4 Do you have any final comments or feedback? Please use the box below

08/31/2023 9:22am

projectredcap.org



Survey 100% Complete

08/31/2023 9:22am

projectredcap.org



Appendix D: Ethical approval: Focus groups and individual interviews



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03-Jul-2023

Name: Sonya Girdler
Department/School: School of Occ Therapy, Social Work and Speech Path
Email: Sonya.Girdler@curtin.edu.au

Dear Sonya Girdler

RE: Reciprocal ethics approval
Approval number: HRE2023-0361

Thank you for your application submitted to the Human Research Ethics Office for the project RECIPROCAL - Australasian Autism Research Council Research Priorities.

Your application has been approved by the Curtin University Human Research Ethics Committee (HREC) through a reciprocal approval process with the lead HREC.

The lead HREC for this project has been identified as Griffith University Human Research Ethics Committee.

Approval number from the lead HREC is noted as 2023/392.

The Curtin University Human Research Ethics Office approval number for this project is **HRE2023-0361**. Please use this number in all correspondence with the Curtin University Ethics Office regarding this project.

Approval is granted for the period **03-Jul-2023 to 30-Sep-2023**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project:

Name	Role
Girdler, Sonya	CI
Lee, Elinda	Co-Inv
D'Arcy, Emily	Co-Inv
Picen, Tanya	Co-Inv
Whitehorn-Smith, Patrice	Co-Inv
Berg, Valeska	Co-Inv
Vinci, Bradley	Co-Inv

You must comply with the lead HREC's reporting requirements and conditions of approval. You must also:

- Keep the Curtin University Ethics Office informed of submissions to the lead HREC, and of the review outcomes for those submissions
- Conduct your research according to the approved proposal
- Report to the lead HREC anything that might warrant review of the ethics approval for the project
- Submit an annual progress report to the Curtin University Ethics Office on or before the anniversary of approval, and a completion report on completion of the project. These can be the same reports submitted to the lead HREC.
- Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised

- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
- Data and primary materials must be managed in accordance with the [Western Australian University Sector Disposal Authority \(WAUSDA\)](#) and the [Curtin University Research Data and Primary Materials policy](#)
- Where practicable, results of the research should be made available to the research participants in a timely and clear manner
- The Curtin University Ethics Office may conduct audits on a portion of approved projects.

This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely



Amy Bowater
Ethics, Team Lead

Appendix E: Focus group and individual interview guides

Choice and control of living - focus group/individual interviews

Introduction

Thank you for your willingness to participate in our upcoming “Independent living” Focus Group. Below you will find a list of questions which are topics we will be discussing during the session. These topics are specific to family and caregiver support. They were taken from the results of a survey that was recently done with the autism community about what they think should be a priority for researchers.

For each topic we will ask **two main questions**:

1. What are the issues or difficulties facing the autistic and/or autism communities in the topic area?
2. What are the research priorities for this area?

Topics

- A. What are the housing and living needs and preferences of Autistic individuals? (including preference for independence/social living, house/apartment/garden, urban/rural etc)
- B. What supports are available and can effectively help Autistic people make choices and live in the way that they prefer? (including legal clarity, processes/paths, support workers, staff training)
- C. What factors impact Autistic peoples' choices and control in housing and living? (including finance, transport options, location)
- D. How can individual needs be considered in providing living options for Autistic people? (including communication options, ensuring Autistic peoples' autonomy and rights are appropriately met, location, proximity to facilities)
- E. What barriers prevent Autistic people from having their ideal housing and living situation? (including living independently, maintenance and repair work)
- F. What do accessible living options look like across the diverse range of Autistic individuals? (including current housing and living conditions)
- G. How and where can autistic people access suitable housing/living arrangements?
- H. What is the link between housing and living environments and the mental health of Autistic people?
- I. What is the impact on Autistic individuals and their families in having choice and control over their housing and living?
- J. How will the safe and effective level of choice and control of housing and living options for autistic individuals be governed?

Gender, diversity, and inclusion - focus group/individual interviews

Introduction

Thank you for your willingness to participate in our upcoming “Gender, diversity, inclusion” Focus Group. Below you will find a list of questions which are topics we will be discussing during the session. These topics are specific to family and caregiver support. They were taken from the results of a survey that was recently done with the autism community about what they think should be a priority for researchers.

For each topic we will ask **two main questions**:

1. What are the issues or difficulties facing the autistic and/or autism communities in the topic area?
2. What are the research priorities for this area?

Topics

- A. How can we remove barriers faced by Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional?
E.g., barriers to accessing community environments and workplaces; barriers to reaching goals.

Related follow up questions

- Which intersectional identities are barriers to education, employment, and social inclusion for Autistic people?
- How do these barriers play out in the lives of Autistic people?

- B. What are the experiences of Autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional, in different contexts?

Related follow up questions

- What is the impact of these experiences?
- How can these experiences be better represented?
- What are the experiences of Autistic people from CALD communities specifically?

- C. What do Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional, need to feel included? E.g., in workplaces?

Related follow up question

- How can Autistic people be supported to use their intersectional experiences to promote inclusivity?

- D. How can we train clinicians to better care for and understand Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional?

Related follow up question

- How can we teach others about intersectional Autistic presentations to prevent stereotyping?

E. How can Autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional, be better represented? E.g., in research and in clinical training?

Related follow up question

- How can we ensure that Autistic representatives have voice in various contexts, to improve the likelihood that other Autistic people are included (no matter the diversity of their presentation)?

F. Are Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional, believed and heard? E.g., by health professionals?

Related follow up questions

- What factors lead to Autistic people with intersectional identities not being believed and what can be done about these factors?
- Are Autistic people believed when they share their intersectional LGBTQIA+ identities specifically?

G. What are the support needs of Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional?

Related follow up questions

- Have Autistic people's intersectional identities impacted them in any way when trying to access support?
- How much money do Autistic people with intersectional identities spend on needed supports?
- Are support services for Autistic people with intersectional experiences culturally appropriate?

H. Are Autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional, able to access the accommodations they seek and/or need?

Related follow up questions

- What aspects of our communities are inaccessible to Autistic people on account of their intersectional identities?

I. How can we make resources and information relevant to Autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional?

J. How can we educate others about Autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional?

Health, disability & education - focus group/individual interviews

Introduction

Thank you for your willingness to participate in our upcoming “Health, Disability and Education” Focus Group. Below you will find a list of questions which are topics we will be discussing during the session. These topics are specific to family and caregiver support. They were taken from the results of a survey that was recently done with the autism community about what they think should be a priority for researchers.

For each topic we will ask **two main questions**:

3. What are the issues or difficulties facing the autistic and/or autism communities in the topic area?
4. What are the research priorities for this area?

Topics

- A. What helps Autistic people accessing health, disability and education services and having positive experiences in these settings? (including at hospital, the dentist, the classroom etc, making appointments, supporting transitions between services, workplace accommodations)
- B. What are the experiences of Autistic people and their families using health, disability and education services? (including satisfaction, wellbeing, progress)
- C. What challenges and/or barriers do Autistic people experience in health, disability and education service settings? (including any unmet needs, accessing the services, traumatic experiences)
- D. What health, disability and education services are most used/ needed by Autistic people? (including services for co-occurring conditions)
- E. Do current health, disability, and education services support the individual needs and wellbeing of Autistic people? (including receiving the appropriate medical care and education, were needs met?, are individual specific accommodations made?)
- F. How does health, disability and education service availability and accessibility, processes and procedures, and current systems impact the health and wellbeing of Autistic people?
- G. How can funding be improved to support Autistic people accessing health, disability and education services? (including NDIS, processes, free access to services)
- H. What strategies will support a more collaborative approach with Autistic people to care and decision-making in health, disability and education services? (including increasing the Autistic workforce, supporting communication preferences, creating safe environments, exploring and refining approaches with Autistic patients)
- I. Would quality delivery of autism support lead to better mental health of Autistic people? (including autistic culture-responsive services, identified links)

Making built environment - focus group/individual interviews

Introduction

Thank you for your willingness to participate in our upcoming “Built Environment” Focus Group. Below you will find a list of questions which are topics we will be discussing during the session. These topics are specific to family and caregiver support. They were taken from the results of a survey that was recently done with the autism community about what they think should be a priority for researchers.

For each topic we will ask **two main questions**:

1. What are the issues or difficulties facing the autistic and/or autism communities in the topic area?
2. What are the research priorities for this area?

Topics

- A. How can we make built environments sensory friendly for Autistic people?

Related follow up question

- How can Autistic people avoid overwhelm in sensory environments? E.g., do Autistic people benefit from quiet rooms, quiet hour at the supermarket, and sensory rooms?

- B. What does an ideal, or easily accessible, built environment look like for Autistic people?

Related follow up questions

- What makes this environment ideal for, or easily accessible to, Autistic people?
 - Do the built environments Autistic people experience as accessible change across the lifespan?
- C. What are the best ways to reduce barriers in built environments, to make them more equitable and inclusive for Autistic people? E.g., One way to make built environments more inclusive might be to provide disability help desks.

Related follow up question

- What are societal attitudes to making built environments more inclusive and equitable for Autistic people?

- D. How can we make built environments, including homes, more calming and comfortable for Autistic people, such that their dysregulation and distress is reduced?

Related follow up questions

- Why would the proposed ideas make Autistic people feel calmer and more comfortable, and reduce dysregulation and distress?
- Are there any specific features of built environments that contribute to Autistic people experiencing distress and dysregulation?

- E. How can navigation signage and transport better meet the needs of Autistic people?

Related follow up question

- How could transport hubs be more sensory friendly for Autistic people?
- Do Autistic people need more infographics in built environments?

F. How can built environments meet autistic peoples' needs?

Related follow up question

- Do built environments that meet the needs of Autistic people impact upon engagement with, or enjoyment of, activities within those environments?

G. How can Autistic people be included in designing built environments?

Related follow up question

- How can we help non-Autistic people, including non-Autistic children, understand what Autistic people need in built environments? E.g., how can we help non-Autistic employers consider the needs of Autistic employees in workplace environments?

H. What are some ways to reduce crowding, and increase private spaces, in built environments?

Related follow up question

- How would this impact Autistic people?
- When in crowded environments, how can Autistic people, of all communication styles and needs, communicate their needs to others?

I. What might make built environments safer for Autistic people?

J. How are Autistic people impacted by the retention of natural environments and by living surrounded by nature and green spaces?

Family & carer support - focus group/individual interviews

Introduction

Thank you for your willingness to participate in our upcoming “Family and Caregiver Support” Focus Group. Below you will find a list of questions which are topics we will be discussing during the session. These topics are specific to family and caregiver support. They were taken from the results of a survey that was recently done with the autism community about what they think should be a priority for researchers.

For each topic we will ask **two main questions**:

1. What are the issues or difficulties facing the autistic and/or autism communities in the topic area?
2. What are the research priorities for this area?

Topics

- A. How can families and carers of Autistic people be supported across their lifetimes? (including feeling valued, what would make life easier, stress reduction)
- B. What are the needs of families and carers of Autistic people? (including complexities of a support role, special considerations, respite, what is involved)
- C. How can Autistic individuals and their families be better supported by their wider communities across their lifetimes? (including how can care be shared in a community? support and social group opportunities? how can stigma isolation be reduced?)
- D. How can siblings of Autistic people be supported? (including sibling support groups and connections)
- E. How can families and carers of Autistic people be financially supported? (including addressing systematic gaps in financial support, different funding models to support medical costs)
- F. What is currently not working for families and carers of Autistic people? (including direct and indirect challenges)
- G. What do families and carers of Autistic people know about autism and how can they be supported to access information, including available support services?
- H. What workplace education is occurring to support families and carers of autistic people? (including training allied health and health professionals)
- I. What might lead to greater visibility and societal valuing of families and carers of Autistic people?

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



AutismCRC

Independent national source of evidence for best practice



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