



2023 Research Priority Update

Focus on five research priority areas

Final Report

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September 2023

**Australasian
Autism
Research
Council**



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Australasian Autism Research Council 2023 Research Priority Update

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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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Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC participants, Curtin University, Griffith University, and Wenn Lawson.

Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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Executive Summary

Why we did this work

This project represents a continuation of work previously conducted by the Australasian Autism Research Council (AARC) in 2019, that identified the top ten autism research priorities for Australia. In 2021, the AARC produced a report that provided additional details on the views of the autistic and autism community related to five of the ten research areas. Our research team was asked to engage with the autistic and autism community to provide more detail and specific areas of focus related to the other five research priority areas. These were:

1. Choice of living and housing
2. Family and carer support
3. Gender, diversity and inclusion
4. Health and disability services delivery
5. Built environment.

Therefore, this report presents the views and experiences of members of the autistic and autism communities in relation to the five priority areas. It represents a process to co-create a snapshot of needs in these areas, presenting the autistic voice as central to the decision on research priorities.

What we did

This research was a collaborative process between two teams from Griffith University and Curtin University who conducted distinct aspects of the project. Specifically:

- **Griffith University, led by Professor Dawn Adams:** community views survey for all five priority areas
- **Curtin University, led by Professor Sonya Girder:** focus groups and individual interviews for all five priority areas.

A community views survey was conducted to ascertain research topic areas that would then be discussed in focus groups and/or individual interviews. Surveys were co-designed with members of the autistic and autism community and targeted this community as respondents. Following the collection and analysis of survey data, focus groups and individual interviews were conducted with members of the autistic and autism community to provide context and further expound on survey findings. Input from autistic researchers and consultation with the AARC and Autism CRC were used throughout the project to guide the methods used and research focus.

What we found

The surveys were completed by 43 people in total (including 25 autistic people), with between 14 and 33 choosing to respond to each domain. The research questions suggested by participants were often specific to the domain they were considering. However, there was some overlap in the suggested research questions across domains, indicating these may be considered as priority research questions. These shared questions included:

- What are the needs and preferences of autistic people (reported in all five areas; n = 5 areas)?
- What are the barriers experienced within these domains (n = 4 areas)?
- What does accessibility look like in the domains (n = 2)?
- How can accessibility be supported (n = 2)?
- What is the impact of the domain on health and wellbeing (n = 2)?
- What financial support is available (n = 2)?
- How can we educate the public to support autistic people and their families/carers (n = 2)?
- What are the experiences of autistic people in these domains (n = 2)?
- How can we support a collaborative approach between autistic people and people working within the domain (n = 2)?

All of research questions suggested by the participants were used to inform the questions within the focus groups and individual interviews.

Focus groups and interviews were conducted with a total of thirty (30) members of the autistic and autism community. Most participants were part of multiple participant groups, with 16 autistic people, 18 family members of autistic person(s), and 13 professionals. For each priority area themes and sub-themes outline the challenges that autistic people experience, their suggestions for addressing challenges and recommendations for future research in that area.

Choice and control of housing and living

The findings on choice and control of housing and living, indicated that autistic individuals may have varied preferences related to their living arrangements, however participants agreed that environments that provided a balance of autonomy or a level of separateness and support to aid with household management was most ideal. Participants noted that barriers such as the affordability and accessibility of suitable housing arrangements limits autistic people's control over their living environments. Themes related to the role of the family, limitations in National Disability Insurance Scheme (NDIS) housing support and the role of the government outside of the NDIS were also discussed as issues for consideration in this priority area. Participants suggested that research in this priority area should include the voice of the autistic and autism community as well as government stakeholders to help find solutions to challenges impacting autistic individuals' choice in housing and living.

Family and carer support

The focus groups regarding family and carer support identified a range of areas considered relevant to this topic. Awareness and acceptance of autism emerged as a strong theme in this area, with participants discussing the importance of this across contexts, including among families, professionals and the community. Participants considered the impact of autism on members of the family, discussing the different areas of support relevant to autistic and neurotypical siblings. Key areas of support identified by autistic individuals and carers included support during times of transition (e.g., between schools, finishing school, starting work, and changing jobs), financial support, improving autistic visibility and promoting positive autistic identity, as well as the importance of consistency in social workers.

Gender, diversity and inclusion

A range of themes emerged from the analysis of the focus groups and individual interview focused on gender, diversity and inclusion. Participants discussed issues with diversity and inclusion across contexts, including in education, the workplace, and health and medical services. Facilitators of inclusion and diversity were discussed alongside some of the barriers in each of these settings. The influence of gender on diagnosis was discussed, with participants discussing the impact on diagnosis for female (or assigned female at birth; AFAB) people due to the way in which autism presents in females (or AFAB) compared to males. Autistic individuals from culturally diverse backgrounds expressed that the experience could be isolating. The attitudes of others towards diversity were explored as well as the attitudes of autistic individuals and carers towards other forms of diversity, with participants expressing an open-minded approach to diversity due to their own experiences of it. Diversity and inclusion in research were discussed, with participants suggesting ways in which involvement of the autistic and autism community in research could be improved to ensure more accurate representation.

Health, disability, and education

The focus groups and individual interviews on health, disability and education service delivery explored a range of challenges, both within and across systems for autistic people and their families. For health systems, participants' responses covered the need for healthcare, being heard in healthcare, the accessibility of healthcare, and the specific areas of mental health and diagnosis. For disability services, the focus was on how a deficit focus is primarily used, difficulties with the NDIS and the need for a focus on appropriate outcomes. For education, participants discussed the needs within the school context, as well as the transition to post-secondary education or out of the education system. Finally, there were themes that discussed issues that appeared across systems: navigating systems and the availability of services, professionals providing services, and the involvement of families.

Making built environments more accessible

Themes and sub-themes coming out of the focus groups and individual interviews for making the built environment more accessible centred around challenges autistic people experience due to a lack of awareness of autism in the wider community, sensory overstimulation, interaction with neurotypical people when triggered and difficulty navigating aspects of the built environment. Participants indicated these factors contributed to autistic people being uncomfortable and avoiding participation and engagement in some spaces. Participants made suggestions about modifications that can be made to the built environment to make it more accessible for autistic people such as sensory considerations in homes and public spaces, better education of the public about autism and better use of signage. Participants suggested that future research in this area is inclusive of autistic people and considers piloting modifications to some public spaces to test their effectiveness in improving accessibility for autistic people.

Overarching themes

Six overarching themes were outlined by participants across all five priority areas. They were:

1. Awareness and understanding of autism
2. Finances
3. The role of family
4. Mental health
5. Support needs
6. The NDIS.

These themes shaped and influenced the experiences of the autistic and autism community and represented areas of central focus that participants believed that future research should prioritise across all priority areas.

What happens next?

The results presented in this report provide insight into the needs, perspectives and priorities of the Australian autistic and autism communities. The results of this survey and focus groups can be used to guide and inform future research and policy work in the Australian context. This will ensure the needs and priorities of the autism and autistic communities are being met, and help secure positive outcomes for autistic Australians.

1. Introduction

1.1 Background

The Australasian Autism Research Council (AARC) in their 2019 Research Priorities Report outlined ten broad areas identified as autism research priorities for Australia. These priority areas consisted of:

1. Built environment
2. Choice in living and housing
3. Communication
4. Education
5. Employment
6. Family and carer support
7. Gender, diversity and inclusion
8. Health and disability services delivery
9. Health and wellbeing
10. Justice.

ORIMA Research was later commissioned to conduct focus groups to identify more specific areas for research focus in five of the ten topic areas: communication; education; employment; health and wellbeing; and justice. The findings of that study were reported in the ORIMA Research February 2020 report.

In 2023, Autism CRC commissioned the research team to undertake further research on the remaining five research priority areas that were not covered in the ORIMA Research 2020 report. Hence, the current project conducted surveys, focus groups and individual interviews to define and specify research questions within the priority areas of:

- Choice of living and housing
- Family and carer support
- Gender, diversity and inclusion
- Health and disability services delivery
- Built environment

1.2 Aims

The primary aim of this project was to identify ten or more important topic areas for each priority area. The research also aimed to understand the issues and challenges that affect the autistic/autism community in relation to the topic areas.

Figure 1: 2019 Research Priorities



Built environment

How can built environments be made more accessible to the autistic community?



Choice in living and housing

How do we ensure that autistic people have choice and control over where they live and who they live with?



Communication

How can we best support the communication skills of autistic Australians?



Education

How can we transition to an inclusive education system that meets the needs of students on the autism spectrum?



Employment

How can Australia transition to an inclusive workforce that provides opportunities for meaningful employment to all autistic people?



Family and carer support

How can we best support families and carers of people on the spectrum?



Gender, diversity and inclusion

How do we ensure equity for autistic individuals regardless of gender, intersectional identity or cultural background?



Health and disability services delivery

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



Health and wellbeing

How do we ensure optimal physical and mental health for all autistic Australians?



Justice

What measures can be taken to prevent discrimination, exploitation, violence and abuse of autistic Australians, and ensure equity in accessing justice?

2. What we did

2.1 General methods

2.1.1 Survey to gather initial topics for focus groups

A survey was designed to gather initial research questions for discussion in the focus groups (see Appendix B). This survey was co-produced by the research team, which included members who are autistic, are family and/or carers of autistic individuals, are neurodivergent, and/or are gender diverse. Feedback was sought from Autism CRC and the Co-chairs of the Australasian Autism Research Council. It was also piloted with members of the autistic and autism community. Each person's feedback resulted in actionable changes and improvements to the survey design and/or presentation.

The survey was designed so that participants could elect to answer questions on any or all of the five domains:

1. Built environment
2. Choice and control in housing and living
3. Health, disability, and education services
4. Family and carer support
5. Gender, diversity, and inclusion.

If a participant elected to answer the questions within a domain, they were asked to first consider the main issues autistic people face in that domain, before being asked to list "What questions should researchers ask when studying <domain>?"

To ensure that participants could share their own perspectives, text boxes (rather than predefined options or tick boxes) were provided for their responses. Participants were asked to provide up to 3 possible research questions in each domain.

Supplementary visual and written information was provided throughout the survey which participants could opt to view if they wished. Participants were encouraged to only use the supplementary visual and written information if they found it helpful; it was emphasised that it was unnecessary to view, read or use this information to complete the survey. To provide an accessible survey interface for participants using screen readers, optional information would appear on the main page if the "additional information" box was ticked. Core survey pages focused on instructions, questions, and response boxes.

- Supplementary visual information consisted of photographs relevant to each domain with image descriptions. These photographs were chosen for their neutrality and visual descriptiveness; they were neither overtly positive nor negative representations of each domain. For participants living with aphantasia (i.e., not able to create mental imagery), the photographs were intended to aide reflection on physical settings.

- Supplementary written information primarily comprised definitions of relevant terms and examples of how to frame research questions. This information aimed to be inclusive, respectful, and empathic by affirming the relevance of the participant’s frame of reference when considering concepts like family and gender.

To help the team gain feedback on the survey (including the supplementary visual and written information), participants were asked to provide feedback on various elements of the survey structure and design.

2.1.1.1 Ethics

The survey received full ethical approval from Griffith University on 14 February 2023 (see Appendix A). The survey was listed as live on Autism CRC recruitment page on 7 July 2023. The survey was closed at midnight on 23 July 2023.

2.1.1.2 Number of responses received

Responses to the online survey were sought from the autistic community and relevant stakeholders (including families, carers, teachers, health professionals). In total, 43 people responded to one or more domains to comment on questions that researchers should ask when studying that domain. Table 1 summarises the demographic details of the survey respondents. Note that respondents often reported identifying with multiple groups (e.g., autistic and a parent/caregiver of an autistic child), so the total percentage is greater than 100%. The majority of participants had completed post-secondary schooling and reported that they are just meeting, or comfortably meeting, their financial needs and responsibilities.

Table 1: Community views survey respondent demographics

Characteristic category	Respondent characteristic	% of respondents N = 43
Age of participant	16-25 years	7%
	26-35 years	16%
	36-45 years	37%
	46-55 years	33%
	56-65 years	7%
Role within autistic or autism community	Autistic individual	58%
	Parent of autistic person	56%
	Family member of autistic person	33%
	Carer of autistic person	14%
	Educational professional	19%
	Medical professional	5%
	Allied health professional	14%
	Social worker	2%
	Disability support worker	5%
	Researcher	23%
Self-reported preferred communication mode(s)	Speech	77%
	Augmented and/or alternative communication (AAC)	2%
	Gestures	12%
	Sign language	2%
	Text	60%
	Email	74%
	Messenger	37%
	Written forms	21%
Participant identifies as:	LGBTQIA+	37%
	Neurodivergent	58%
	Having a physical disability	30%
	Having an intellectual disability	0%
	Being differently abled	5%
	Non-speaking	0%
	Part-time AAC user	7%
	Full-time AAC user	0%
	Aboriginal and/or Torres Strait Islander	0%
	Culturally or linguistically diverse	12%
	Living in urban regions	74%
	Living in regional, rural or remote regions	23%

Given the absence and/or relatively small number of people who identified as:

- a. not completing or continuing with their schooling
- b. struggling to meet their financial needs and responsibilities
- c. having an intellectual disability
- d. being an augmented and alternative communication user
- e. being non-speaking
- f. being Aboriginal and/or Torres Strait Islander
- g. being culturally or linguistically diverse
- h. identifying as non-binary

It is not possible to generalise the findings from this survey to all autistic people. The use of an online survey method also automatically excludes those without access to an appropriate device or those who do not have access to the internet. Further work, using tailored approaches, is needed to learn from the experiences of these underrepresented groups.

2.1.1.3 Analysis of responses

Responses were coded using inductive Content Analysis, whereby each response from each participant was read, then systematically and objectively grouped into categories. This method allowed the findings to be derived from participant responses, as opposed to deductive analysis, in which researchers use data to test preconceived ideas. As the survey asked participants to suggest up to three research questions, if more than three research questions were provided, only three were coded. Depending on the response, the three coded questions were selected due to factors such as uniqueness of each suggestion to ensure that three distinct questions could be generated from the participants' suggestions.

For each domain, categories developed during coding were formulated into research questions, to be explored in depth in focus groups (see 3.1.2). The number of participants who elected to answer questions on the individual domains (21-41 participants), and the degree of uniformity of responses, allowed researchers to represent every participant response in the focus group questions for some domains. These domains include: built environment; choice and control in housing and living; and gender, diversity and inclusion. For the other domains (family and carer support; health, disability and education services), responses were more varied, and only the most endorsed research questions were used during focus groups.

In each domain section of this report, a table is provided which shows the research questions developed from survey data. Below each research question, further detail on the content of coded response categories is provided and was intended to support elucidation during focus groups. Where more questions were created from the survey data, a full list is provided in the appendices. The table also provides detail on:

- the proportion of participants who endorsed each research question
- the proportion of autistic participants who endorsed each research question.

2.1.2 Focus groups and individual interviews

Focus groups and individual interviews were organised to further explore the research topic areas identified in the survey for the five priority areas of:

1. Choice and control in housing and living
2. Family and carer support
3. Gender, diversity, and inclusion
4. Health, disability, and education services
5. Making built environments more accessible.

Participants for the focus groups and individual interviews were recruited via an electronic flyer circulated within the autistic and autism community across Australia. For each priority area, three groups of participants were targeted:

1. Autistic individuals
2. Family and/or carers of autistic individuals
3. Professionals working with the autistic community.

For each of the research topics in each of the priority areas, we asked participants:

1. What are the main issues experienced by the autistic and autism community?
2. What do the autistic and autism communities think should be the research priorities within these areas?

Focus groups and interviews were conducted online using Microsoft Teams to accommodate participants across Australia. Focus groups and interviews were conducted between July and September 2023. All meetings spanned 60-90 minutes in length and were recorded (audio only or audio/visual) and transcribed.

2.1.2.1 Ethics

The focus groups and individual interviews received full ethical approval from Griffith and Curtin University Ethics Committees (GU Ref No. 2023/392 & HRE2023-0159). All participants were provided with participant information sheets and gave written informed consent prior to participating in focus groups or individual interviews.

2.1.2.2 Number of responses received

A total of 30 people participated in the focus groups or interviews, including 16 autistic people. Many participants fell into multiple participant groups (e.g. were autistic and a professional). Table 2 summarises the demographic characteristics of the participants.

2.1.2.3 Analysis of responses

Responses were thematically analysed, where responses for each topic were initially organised into codes in NVivo, then grouped into themes and reviewed, followed by the defining and naming of themes (Braun & Clarke, 2006). This approach allowed the research team to capture and organise the experiences and views of participants into patterns which provided context and meaning to the data. The views of all participant groups are presented together, as it was not possible to separate the views of different participant groups due to the high level of overlap between groups.

Table 2: Focus groups and individual interviews participants' demographics

Characteristic category	Respondent characteristic	% of respondents N = 30
Age of participant	16-25 years	0%
	26-35 years	40%
	36-45 years	20%
	46-55 years	33%
	56-65 years	7%
Role within autistic or autism community	Autistic individual	30%
	Autistic individual & family member of autistic person(s)	13%
	Autistic individual & professional (education)	2%
	Autistic individual, family member of autistic person(s) & professional (coach and support worker)	7%
	Family member of autistic person	13%
	Family member of autistic person & professional (education and support worker)	13%
	Professional (allied health and education)	20%
Gender identity	Female	86%
	Male	7%
	Non-binary	7%
Participant identified cultural/ethnic group	Australian	17%
	South-East European	3%
	Oceanian	23%
	North-West European	30%
	Mixed culture	20%
	Other (not specified)	7%

3. What we found

Respondents could choose to report on 0–5 domains in the survey; 16% of respondents chose to report on one service domain, 21% on two domains, 37% on three domains, 7% of four domains, and 19% on all five domains. The domain with the most responses was the built environment, where 41 respondents provided comments. Health, disability and education services had 39 respondents, followed by choice and control in housing and living, and family and carer support which had 27 respondents each. The service domain with the least responses was gender, diversity and inclusion which had 21 respondents.

3.1 Choice and control in housing and living

3.1.1 Survey results: Research questions to be discussed in the focus groups

A total of 19 respondents answered the question, ‘What questions should researchers ask regarding autistic people's choice and control in housing and living?’ This included 13 autistic people and 25 family members or carers of autistic people.

Table 3 describes the responses provided by participants for questions researchers should ask regarding autistic people's choice and control in housing and living are reported within this section. Questions have been ordered from the most frequently reported to the least frequently reported. Percentages indicate the proportion of participants overall whose response reflected the corresponding research question, and the proportion of autistic participants whose response reflected the corresponding research question.

Table 3: Questions identified for discussion in choice and control of housing and living

Questions for the focus groups to discuss	% of respondents who suggested (n = 19)	% of autistic respondents who suggested (n = 13)
1. What are the housing and living needs and preferences of autistic individuals? (including preference for independence/social living, house/apartment/garden, urban/rural etc)	47%	38%
2. 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)	37%	46%
3. What factors impact autistic peoples' choices and control in housing and living? (including finance, transport options, location)	21%	29%
4. 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)	21%	31%
5. What barriers prevent autistic people from having their ideal housing and living situation? (including living independently, maintenance and repair work)	16%	15%
6. What do accessible living options look like across the diverse range of autistic individuals? (including current housing and living conditions)	16%	0%
7. How and where can autistic people access suitable housing and living arrangements?	16%	15%
8. What is the link between housing and living environments and the mental health of autistic people?	11%	15%
9. What is the impact on autistic individuals and their families in having choice and control over their housing and living?	11%	8%
10. How will the safe and effective level of choice and control of housing and living options for autistic individuals be governed?	5%	0%

3.1.2 Focus group and individual interview results

A total of nine participants contributed to the choice and control in housing and living focus group (3 autistic participants, 1 autistic and family member, 2 family members, 2 autistic professionals and 1 professional). Several themes emerged from analysis of participants' responses to the topics framed from the findings of the community views survey. The participants outlined themes related to the challenges of autistic people in relation to this topic and made suggestions for future research in this topic area. These themes and subthemes are presented below.

3.1.2.1 General challenges related to choice in housing and living

Participants explained that autistic people are affected by a number of challenges that bar their ability to access preferred housing. Chief among these challenges included the lack of affordable housing and the financial barriers experience by many in the autistic community: "you know, employment and money are a disadvantage for autistic people... if they are on disability pension, it's not enough" (autistic professional). Participants also discussed lack of available housing and the long waiting list for government housing as limiting their choice in housing and living arrangement. They explained that attending open houses and competing for housing was very difficult for autistic people especially those without support that can help them navigate the process.

3.1.2.2 Preferences for living arrangements

Participants noted that living preferences may vary across autistic individuals, however they all endorsed living arrangements that foster a sense of privacy and autonomy, and allowed ease of access to amenities as important to autistic people.

Living alone

Participants suggested that although some autistic people may value living alone to get a break from social interactions, living alone is often not viable and realistic due to several barriers that autistic people may face. These barriers include costs and limited support to maintain and manage a home. "living alone is often not realistic due to cost and complexity of maintaining home and responsibilities" (autistic participant).

Participants indicated that most autistic people may not be able to afford to live alone, which was attributed to them being 'unemployed or underemployed', as well as needing easy access to amenities, which means higher rental and housing costs.

"Therefore, essential services such as shops need to be walking distance (about ½ hour walk) from home. As far as location, being central and having support services nearby is important. For example, you don't want [the] majority of your NDIS funding being spent on support workers travelling to your house, which would compromise the amount of services they can provide." – autistic professional

Participants indicated that the financial barriers autistic people encountered often resulted in them living in shared accommodations or remaining in their family home despite their desire to live alone. A lack of access to support, whether from family or support workers to assist them with managing the home and decision making, was also a major barrier to living alone.

"lack of access to supports such as support worker (NDIS), case worker, or not having good family support to have help making decisions etc." – autistic participant

Other barriers to living alone included navigating transportation alone, which participants described as anxiety provoking, and the loss of social connectedness that can come about from living alone. Participants suggested that autistic people would benefit from a balance of self-contained accommodation, that would allow a measure of autonomy and independence as well as having people nearby to offer support and/or social connection.

“So, you need the balance between having the self-contained accommodation, but also some contacts.... autistic people would get that balance on having people nearby who you can call on for help or socialising, but also having your own space.” – autistic professional

Living with others

Participants explained that living with others, although necessary for some autistic people, can often be stressful, especially when facilities are shared. This was linked to the differences in sensory needs of some autistic people as well as the expectation of consistent social interaction with others which can create interpersonal challenges.

“Sensory sensitivities and interpersonal difficulties (are) common in autism. I’m sensory avoidance, so living with other people would just be a sensory nightmare as well as the interpersonal interaction.” – autistic participant

Despite the challenges, participants expressed that their need for support may require that others live with them, but explained they struggled with finding appropriate people to live with as housemates. Participants felt that autistic people were at a disadvantage in finding trustworthy people to be their housemates, which was also a source of stress and relationship conflict. They highlighted that it can be difficult to find housemates who need similar supports and that people without disabilities may be reluctant to live with an autistic person if they feel they may be treated as their carers.

“There’s nowhere to go to get help finding housemates, especially other housemates who might also need similar supports (for example organise a support worker for both people to make funding go further). If housemates don’t have a disability, it’s really hard to accidentally turn them into carers who then move out at the first opportunity.” – autistic participant

Participants described that this situation would work best when bedrooms and some living spaces are kept separate to allow autistic people to have privacy but still benefit from predictable support.

“I think that boarding with a non-family member who has a spare bedroom and love to share. For example, ‘empty nester’ middle aged or elderly people who want company and wouldn’t mind cooking for one more- they could be paid a stipend amount each week for having the person with autism stay with them (which would help host family financially).” – autistic professional

One participant suggested university models of semi-supported living as being a meaningful option for autistic people to be able to get the balance of privacy and social support. “I also think a model of community housing similar to [university] residence (available to autistic people on NDIS or outside it)- just with low level support (someone on call at all times, can help with housemate conflicts, organised social events), with people needing additional support using NDIS support workers etc. Having all-inclusive weekly rate (rent, utilities, cleaning, internet, support staff) creates more certainty reducing anxiety” (autistic professional).

3.1.2.3 Preferences related to housing features and conditions

Participants indicated that regardless of the living arrangements, certain housing features were important to helping autistic people feel comfortable in their living space. They indicated the need for intentional planning related to sensory stimuli in living spaces, which had to take into consideration the specific needs of the autistic people living in the house. They emphasised the need for a “sensory safe space” (autistic participant) within the living environment. Ideal living accommodations would include elements such as adjustable lighting, insulated floors or walls, kitchen exhaust fans to remove strong scents from cooking, allow for pets and easy access to nature or green spaces. Arrangements like this would allow autistic people to make basic modifications to suit their needs and preferences.

3.1.2.4 The role and influence of the family

Participants indicated that sometimes there are discrepancies between the housing preferences of autistic people and what their family members may feel is in their best interest. Some participants indicated that family members often want to protect their autistic relative but may deprive them of their independence and freedom to make their own decisions. Some autistic participants explained that being compelled to live with family when that is not the desire of the autistic person can cause tension, and conflict in family relationships, and negatively affect the mental health of autistic people. Other autistic participants described a sense of pressure from family members to move out and live independently even though they didn't feel ready or capable to do so. Conversely, other autistic and non-autistic participants indicated that family members can, and many do, play a role in supporting autistic people to live independently by providing them with the financial means, helping them to navigate rental processes and helping with the general management of their homes.

“Sometimes my daughter, she thinks she can do it all. She really seriously does think and wants to do it all. But when it comes to actually executing it, she can't and so we (help) support her... if a safe space wasn't provided to her, and if she didn't have the support of her parents, then she would not be in a good place.” – family member

3.1.2.5 Housing support needs

Participants explained the importance of support for autistic people to be able to have choice and control about their living arrangement. Participants indicated that the type of housing support autistic people needed varied widely across the spectrum and age groups. However, they suggested that most autistic people need help to navigate the rental process, help navigating social elements of sharing a house, support to perform household chores, and general help to manage the household. Participants indicated that housing support needs may increase as autistic people age and may have increased reliance on family or social services. Some participants were generally unaware of where they could access organisations that would help them find suitable housing and housemates. They specified that housing support needed to be “constant and predictable” (autistic professional) and allow opportunities for autistic people to naturally increase their independent living skills. Hence, ideal, or suitable living arrangements would take into consideration autistic people's sensory concerns and provide adequate supports for them to negotiate their living environment.

“Negotiating a living environment where there is enough support (either with family, a host family/boarding arrangement, or rostered paid supports (issue of participant to staff ratios in traditional group homes, vs autistic need for quiet or less stimulating social environments).” – autistic participant

3.1.2.6 Experiences with the National Disability Insurance Scheme (NDIS)

Participants discussed that autistic people who are NDIS participants can access support through support workers to help with daily living tasks. Some participants believe that the NDIS was very helpful in facilitating autistic people’s access to housing and housing support. Yet other participants indicated that NDIS funding could be limited and inflexible about what can be covered. Some participants explained that accessing specialist disability accommodation is very difficult due to tedious processes, limited availability of housing options, constant changes, long waitlists, and high provider charges, especially in some regions.

“Inside the NDIS there is support- such as support workers (for everyday living task support etc) but accessing specialist disability accommodation is very limited even if you have funding. There are huge waitlists especially where I live in regional [Victoria]. Providers also charge exorbitant amounts (about 90% of [disability support] payment).” – autistic participant

3.1.2.7 Government housing support (not based on NDIS)

Participants discussed a lack of structured housing support by the government outside of NDIS. They noted that for autistic people who were not NDIS participants, there is no clear channel for accessing housing and other support. Participants suggested that non-NDIS participants had more challenges accessing housing and housing supports and discussed homelessness as an issue for autistic people. They further indicated their views that homeless services are not equipped to assist autistic people in finding appropriate housing options. Participants suggested that more needs to be done by the government to better support autistic people through providing a helpline to seek housing support including rental support and specific housing options for autistic people or people with disabilities.

“I think government should have a subcategory of the housing department to manage rental support (finding housemates for people) and put aside social housing specifically for people with disabilities (priority locations near facilities), and more semi-supported disability housing (available to people outside the NDIS as well). I think it should be governed outside the NDIS (as good as support coordinators are, it’s really about fairness to ALL people with autism/disabilities).” – autistic participant

3.1.2.8 Link between living environment and mental health

Participants believed there was a clear link between autistic people’s living environment and their mental health. They noted that a sense of independence and control was particularly important in autistic people’s living environment.

“If autistic people don’t feel that they have a sense of independence, it could deteriorate their mental health. That sense of dependence would massively come from where they’re living and their choices and their control and the living environments. So, I imagine the link would be strong between housing and living arrangements.” – autistic professional

Participants explained that living arrangements that are crowded, lack privacy, are overstimulating can be overwhelming and triggering for autistic people and make it difficult for them to cope and function. Still, living alone was also recognised as affecting the mental health of autistic people as it can be socially isolating for them.

3.1.2.9 Suggestions for future research

Participants discussed the high level of variability in the needs of autistic people and suggested the need for researchers to include a wide range of autistic people and their family members in their surveys and research on this topic area. They recommended research exploring; the effect of natural features or green spaces in the living environments of autistic people well-being; the relationship between living environment of autistic people and their mental health and well-being; most suitable living arrangements for autistic people across the spectrum; communication experiences of autistic people in shared accommodation; the role of family in choice and control of housing for autistic people; homelessness among autistic people and how to address it. Additionally, participants recommended incorporating comparison groups of autistic people who were NDIS participants and those who were not to assess how these factors impacts on their choice of housing and living. They further recommended the inclusion of government stakeholders in research to help build awareness of issues affecting the autism community and initiate the development of government strategies to address them.

3.2 Family and carer support

3.2.1 Survey results: Research questions to be discussed in the focus groups

A total of 21 respondents answered the question, ‘What questions should researchers ask when studying how we can better support families and carers of autistic people?’ This included 9 autistic people, 18 parents of autistic people, 5 carers of autistic people, and 8 family members of autistic people.

Table 4 describes the responses provided by participants for questions researchers should ask when studying how we can better support families and carers of autistic people. Questions have been ordered from the most frequently reported to the least frequently reported. For each question, percentages are provided to indicate the proportion of a respondent group whose response reflected the specific category. Questions have been ordered from the most frequently reported to the least frequently reported. Percentages indicate the proportion of participants overall whose response reflected the corresponding research question, and the proportion of autistic participants whose response reflected the corresponding research question.

Table 4: Questions identified for discussion in family and carer support

Questions for the focus groups to discuss	% of respondents who suggested (n = 21)	% of autistic respondents who suggested (n = 9)
1. How can families and carers of autistic people be supported across their lifetimes? (including feeling valued, what would make life easier, stress reduction)	57%	56%
2. What are the needs of families and carers of autistic people? (including complexities of a support role, special considerations, respite, what is involved)	43%	33%
3. 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, and how stigma isolation be reduced)	19%	0%
4. How can siblings of autistic people be supported? (including sibling support groups and connections)	14%	0%
5. 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)	10%	11%
6. What is currently not working for families and carers of autistic people? (including direct and indirect challenges)	10%	22%
7. What do families and carers of autistic people know about autism and how can they be supported to access information, including available support services?	10%	11%
8. What workplace education is occurring to support families and carers of autistic people? (including training allied health and health professionals)	10%	22%
9. What might lead to greater visibility and societal valuing of families and carers of autistic people?	10%	22%

3.2.2 Focus group and individual interview results

A total of 13 participants (1 family member, 3 autistic people, 3 autistic family members, 3 professionals, 2 professionals who were also family members, and 1 professional who was both autistic and a family member) contributed to the focus group discussing the topic of family and carer support. The following themes and sub-themes emerged from the analysis.

3.2.2.1 Awareness and acceptance of autism

A lack of awareness, understanding and acceptance of autism across multiple contexts was identified as a key issue affecting family and carer support. Participants highlighted the need to better inform and educate families, professionals and the wider community about autism.

By family members

Participants identified and discussed the importance of family support, understanding and awareness following an autism diagnosis. “One of the biggest needs of our family is for all family members to be on board with an autistic diagnosis” (autistic family member). Participants discussed the negative impact that may occur when immediate or extended family members do not understand or accept an autism diagnosis. They identified the need to educate family members to improve support and acceptance for the autistic individual. Participants who shared their professional perspectives on this topic suggested there was a need to inform family members about the diagnosis but that this information could be “overwhelming” due to the amount of information families are provided with during the process.

By professionals

Lack of understanding by professionals in health and educational settings was also identified by participants as an issue. Examples included over-use of medical terminology and behaviourist approaches in health, education and justice/legal settings, as well as poor awareness of early signs of autism, preventing timely access to support. In particular, participants identified a lack of support in schools as an issue. “...I could go on for hours about the education system, but how it there's just not really any supports out there.” (autistic family member). Staff were reported to have limited understanding of behaviours associated with autism and children still have a low tolerance for difference by their peers, which may be addressed by increasing education and awareness of autism and promoting acceptance of diversity.

“I think tolerance in schools could be something that would, could, make a big difference is like cause kids bully and start to exclude other kids based on, like, minor differences from very, very young. So... if there were things in schools that were like direct teaching about this, like as in, it's an actual chunk of their curriculum, not just like the kind of we have a principle of being nice to everyone that's interwoven, but it has to be really, really specifically taught.” – autistic participant

Professional participants reported that there is currently no mandatory training on autism included as part of professional development for teachers, which contributes to a lack of awareness and understanding of challenges faced by autistic students in their classrooms.

“We are required to perform some necessary like health-related PD as part of our occupation. It is, it is regulated. So, we have to do it, and in order to be in the classroom, one is on anaphylaxis, one is for asthma, none for autism. And I was like, are you kidding?” – autistic professional and family member

By the community

Participants described an ongoing lack of awareness and understanding of the wider community about the autistic experience, including poor understanding of sensory overload:

“Well, because this is the thing as a neurodivergent person, you're not even able to go out for a simple meal when the rest of the world is continually being somewhat of a sensory offence to your entire being.” – autistic family member

There remains a pressure for autistic people to conform to societal norms to feel accepted. Additionally, participants reported that a stigma remains attached to an autism diagnosis due to poor societal understanding and awareness.

3.2.2.2 Impact of autism on the family

Participants described autism as having an impact on all members of the family, particularly siblings. Participants discussed the need to use a whole family approach when supporting autistic individuals to ensure the whole family's needs are met.

Siblings

Participants discussed the impact of autism on neurotypical siblings, including greater need for support, as well as the influence an existing autism diagnosis can have on autistic siblings who may or may not yet be diagnosed.

Neurotypical siblings

Participants described the impact that being autistic can have on sibling relationships. One participant described a poor relationship with their sister, arising from a lack of acceptance of the characteristics of autism:

“Unfortunately, she doesn't want anything to do with me because...like, yeah, my unfiltered things...so we actually can't kind of be in the same, the same room...”
– autistic participant

Participants described the need for support to improve autistic and neurotypical sibling relationships. They discussed the need to conduct further research on the benefits of co-regulation for sibling relationships. In addition, there may be some resentment between siblings as one may be seen as getting more understanding and accommodations than the other.

Professionals who participated in the focus groups also discussed the importance of supporting siblings, with specific emphasis on the supports required for those siblings who are carers for an autistic sibling, or who may be transitioning into that role.

“...it's one of the things that I've thought about quite deeply because again, being a sibling, this is the longest relationship that we will have and I love my brother very much and I want him to have the best quality of life across his lifetime. So in thinking about as we age and as we get older and what are, how our, responsibilities change and how our lives change, [what] I can do as a sibling to give him that quality of life.” – autistic professional and family member

Areas of support identified for siblings included financial assistance, group support programs for siblings of autistic people, and greater mental health support, including further mental health research in this specific population.

Autistic siblings

Participants discussed how some autistic individuals will also have autistic siblings, but their experiences may not necessarily be the same. Regarding family support and understanding, the presence of one autistic sibling may be helpful in identifying potential difficulties or differences in another child or sibling (e.g., sensory processing differences observed in one child may be observed in another, facilitating a timelier diagnosis). Alternately, one participant expressed that although both themselves and their sibling have an autism diagnosis, they were not treated the same by their parents, which can have an impact on both the person and the sibling relationship.

“because I was the older, the older sibling, that is autistic. However, my sister was diagnosed first in childhood and she got a [lot of] accommodations and a lot of understanding, whereas I just got scapegoated and was treated really badly by my parents.” – autistic participant

3.2.2.3 Support needs

Participants explained autistic people and their family members may need various types of support, including support during transitions, financial support, NDIS support, promoting autistic identity and visibility, consistency of support workers and services, mental health support, and capacity building for the whole family.

Support during transitions

A significant need for support during times of transition was identified, including transitioning between schools, out of school, and between jobs. The needs of autistic people will vary depending on what stage of life they are in.

“I suppose for me transitions are really critical. So in terms of supporting families and carers of autistic people across their lifetimes there are many different transitions that they go through and they are particularly difficult for the young autistic person and for the families and carers as well.” – family member

The transition between childhood and adulthood can be difficult for carers regarding the shift in choice and control. There is a desire to facilitate independence, while also maintaining the person’s safety. One participant also mentioned the need for support for people with female reproductive organs to explore their options when it comes to the best choice of contraception to meet their unique mental and physical needs.

“another life stage being for bodies with uteruses, periods, babies, perimenopause and periods and like going on the pill or other birth control and how it can really...It's really tricky getting the right meds because of our sensory processing and our emotional processing and a lot of autistic people have a really hard time with that, and carers like cause I'm gonna be facing that, hopefully not in the next couple of years, but soonish. And it's something where there's no professional I can go to say I've got two autistic kids with uteruses. I don't particularly want them to have to try every different variety of [contraceptive]... I don't want them to go through what I went through.”
– autistic participant and family member

Financial support

Participants identified the need for financial support to enable access to services and other forms of support. They mentioned that the ways of accessing financial support could be difficult to navigate, which increased financial pressure on autistic individuals and families.

“I guess financially it's probably just all-around increase funding, increase like income, maybe making it more easy to access [Disability support pension (DSP)] which is, I know, extremely difficult. I actually used to get DSP myself and then I went off it when I got a real job which then led to me being cancelled and now I am extremely, probably more, disabled than I ever was and I don't think I'll ever be able to get back on it because of how hard they've made it to get on now.” – autistic participant

Participants discussed having to justify the need for certain supports in order to get them funded. A suggestion to improve access to financial support was the development of a specialised support service to assist individuals and families in navigating the systems required to gain access to funding.

NDIS Support

The NDIS was identified as a form of support, but participants discussed that it could be difficult to navigate and there was a lack of communication between the NDIS and other services or departments. For example, participants described issues funding supports such as travel to school, which the NDIS would not cover, but that they had difficulties accessing support from the education department. Similarly, professionals identified the difficulties experienced by families with an NDIS plan trying to access support for mental health services, elaborated in the theme below. In addition, there were some issues identified around understanding what exactly is covered by the NDIS and what is considered parental responsibility. Participants reported a disparity in what is written in the legislation and how services or supports are actually provided. Participants also commented on the difficulties they experienced navigating the NDIS:

“I think all around we would just like increases in the amounts and also making them more accessible and making the schemes like Centrelink and also the NDIS less [of a] minefield to navigate and access because I guess, I think, it's almost by design. It's like if we make it too hard to access, people aren't going to, therefore we cannot spend as much money.” – autistic participant

Autistic identity and visibility

Participants identified the need to support autistic identity and improve autistic visibility. People in the community may have their own preconceived ideas of what autism looks like, which can be a barrier to support for autistic individuals who do not fit within the stereotyped expectation. There is a need for more “out and proud autistics” to promote positive autistic identity, as well as more accurate representation of autism in the media to help improve autistic visibility. A suggestion for improving visibility included use of the sunflower lanyards and improving awareness of what this actually signifies. Participants acknowledged a recent increase in autism representation in the media.

“I’m loving the representation and a lot of media coming up in the last five years. It’s becoming a lot more diverse and a lot more actually representative. I’d like to see more of that because that would lead to greater visibility and societal valuing. I believe just having representation in media because that’s often where it starts culturally is in media representation.” – autistic professional and family member

Consistent support workers and services

There is a need for support workers to work within the family context. Participants discussed the importance of consistency when it comes to support workers, with a preference for support workers who are going to be available long-term to support the family. Similarly, participants discussed a high turnover of allied health staff, preventing the development of strong therapeutic relationships and negatively impacting outcomes.

“...there is a huge rotation of staff and what I'm noticing is that because there's a huge rotation of staff, and there's staffing issues across the board in allied health and it's not just allied health, it's in both in general, and in teaching, and a lot of these very caregiving roles, aged care is another one that comes to mind. We're not building the relationships anymore with the people that are delivering these really crucial services, and because of that, I'm seeing that a lot of like people are going backwards a bit or stagnating...” – autistic professional and family member

Mental health support

There is a need for mental health support for both autistic individuals and their families. Professionals who participated in the focus groups discussed experiences that had been shared with them by the families they work with, demonstrating a lack of urgency from emergency services when it comes to de-escalating mental health crises.

“The parent was needing lots of support and in the moment called the police and to get someone to come and help them in the house because there was lots of physical behaviours, called the police three or four times...nobody ever arrived...so in terms of getting that support from like the emergency services, even that’s not there. I think the mom got a call back later in the evening being like, oh, you still need help. And she’s like, well, I needed help five hours ago when my child was escalating and breaking things in the house and my other child and I were at risk and you actually didn’t come and help me.” – professional

Participants also identified a lack of communication between support services that acted as a barrier to accessing the help they needed. Professionals acknowledged that families were often reluctant to seek support from departments or organisations they had previously had poor experiences with.

“...and there’s often a lot of ping ponging that goes on of, you know, disability isn’t funded to support mental health. We’re support, we’re funded to support disability, so we’ll then try and link them with mental health and mental health goes, oh, you’ve got a disability, go back to the disability provider.” – professional

Capacity building as a family

Participants who contributed their professional perspectives identified the need to support families more holistically, acknowledging the need to build the capacity of the family as a whole, instead of providing only focused support to the autistic individual and offering respite to families.

“there are some service providers out there who are fantastic at that, whose focus really is on how do we build the capacity of the family. But I mean, anyone who works in this space knows that there are also a whole heap of providers there who are, let's get the kid into the clinic and do some therapy. And whatever's happening at home is sort of happening at home. We're doing this in the clinic.” – professional and family member

Participants indicated that there needs to be greater consideration of family and home context when delivering interventions and providing strategies to scaffold informal supports in the home environment. In addition, family counselling was suggested as one way in which capacity building for the family may be explored.

3.2.2.4 Suggestions for future research

Suggestions for future research relevant to the topic of family and carer support included exploring professionals' understanding of autism, exploring the economic benefits of both inclusion and sibling supports, and exploring the level of understanding of autism among the wider community. In addition, autistic individuals and family members identified a need for more research exploring the needs of autistic women and safe spaces for autistic individuals in the community.

3.3 Gender, diversity, and inclusion

3.3.1 Survey results: Research questions to be discussed in the focus groups

A total of 14 respondents answered the question: “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?” These respondents included 12 autistic participants, 8 parents of autistic people, 3 carers, 9 family members of autistic people, 7 researchers, 5 educational professionals, 2 allied health professionals, 1 social worker and 1 disability support worker. Some participants identified as belonging to more than one of these categories.

Table 5 describes the responses provided by participants for questions researchers should ask when exploring how we can ensure fairness for autistic Australians, regardless of gender, intersectional identity or cultural background. Questions have been ordered from the most frequently reported to the least frequently reported. Percentages indicate the proportion of participants overall whose response reflected the corresponding research question, and the proportion of autistic participants whose response reflected the corresponding research question.

Table 5: Questions identified for discussion in gender, diversity, and inclusion

Questions for the focus groups to discuss	% of respondents who suggested	% of autistic respondents who suggested
<p>1. How can we remove barriers faced by autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional? (including barriers to accessing community environments, workplaces, education and social inclusion, as well as barriers to reaching goals; discussion of which intersectional identities are barriers and how these barriers play out in the lives of autistic people)</p>	43%	42%
<p>2. What are the experiences of autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional, in different contexts? (Including the impact of these experiences; how these experiences can be better represented; the experiences of autistic people from CALD communities specifically)</p>	36%	42%
<p>3. What do autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional, need to feel included? (including in workplaces; including how autistic people can be supported to use their intersectional experiences to promote inclusivity)</p>	29%	25%
<p>4. 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? (including how can we teach others about intersectional autistic presentations to prevent stereotyping)</p>	21%	25%
<p>5. How can autistic people who identify as gender diverse, culturally diverse and/or otherwise intersectional, be better represented? (including in research and in clinical training; how we can 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)</p>	21%	17%
<p>6. Are autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional, believed and heard? (including by health professionals; what factors lead to autistic people with intersectional identities not being believed and what can be done about these factors; whether autistic people are believed specifically when they share their intersectional LGBTQIA+ identities)</p>	21%	17%
<p>7. What are the support needs of autistic people who identify as gender diverse, culturally diverse and/or as otherwise intersectional? (including whether autistic people’s intersectional identities impact them when trying to access support; how much money do autistic people with intersectional identities spend on needed supports; whether support services for autistic people with intersectional experiences are culturally appropriate)</p>	21%	17%
<p>8. 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? (including what aspects of communities are inaccessible to autistic people on account of their intersectional identities)</p>	14%	17%
<p>9. How can we make resources and information relevant to autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional?</p>	7%	8%
<p>10. How can we educate others about Autistic people who identify as gender diverse, culturally diverse, and/or as otherwise intersectional?</p>	7%	8%

3.3.2 Focus group and individual interview results

Nine participants (4 autistic people, 2 autistic family members, and 3 professionals who were both autistic and family members) contributed to the discussion of the topic: gender, diversity and inclusion. The following themes and sub-themes emerged from the analysis.

3.3.2.1 Issues related to diversity and inclusion

Participants indicated that there was a need for greater diversity in several key areas, including education, work, the community, health and medical services, gender and sexuality, and culture.

Diversity and inclusion in education

Participants discussed the need for greater acceptance of diversity in educational settings such as schools and universities. Some children may require accommodations to enable equitable access to education such as sensory adjustments, however, it was discussed that each child will have their own unique needs and blanket approaches to inclusivity are not acceptable or effective. Participants identified the need to educate teachers and neurotypical students about diversity and acceptance to improve outcomes for autistic students in schools and universities.

“I’m not telling him the answers. All I can do is write down, read the words on the paper and write down what he says...Why do people feel so challenged by that?...Like I said, I worked in education support and in several other types of jobs and I have been an autistic person my whole life and I don’t understand why other people are so challenged by someone getting support...” – autistic participant and family member

Similarly, participants discussed the need to embed acceptance of diversity more broadly across higher education (e.g., in TAFE and university curricula). It was acknowledged that universities could be an opportunity for further exposure to diversity, however, access to university education may be restricted by limited access to finances.

“It was like an insane eye-opening experience to go to [university] for the first time and see people of different colours and even like lots of tattoos which I hadn't seen before and people openly having different like gender expressions and different sexualities.” – autistic participant

Diversity and inclusion in the workplace

Participants discussed the benefits of working from home for autistic people. Workplaces who offered the flexibility for employees to work from home facilitated improved productivity and reduced risk of burnout due to reduced social interaction. Enabling people to work to their strengths was also considered a positive example of inclusion in the workplace. Some participants expressed difficulties relating to masking in the workplace and a lack of understanding or awareness from colleagues or employers, particularly around the need for accommodations.

Participants who shared their professional perspectives on diversity in the workplace discussed how they would choose to apply for jobs advertised by values-driven organisations known for their diversity and inclusivity. However, one participant also raised that inclusivity needs to be sincere: “We need diversity, but we need it to come from a place of sincerity and the way that you create inclusivity is to actually value a different insight, not just have a whole bunch of people who agree with the boss” (autistic participant). Participants discussed the benefits of inclusive workplaces,

reporting that staff retention is likely to be greater when employees feel included and supported in their work environment.

Diversity and inclusion in the community

Participants identified a need for further education and awareness in the broader community regarding what it means to be autistic. Participants reported that often people think they have a good understanding of autism because they know someone on the spectrum. However, there is a lack of understanding of the diversity within the autistic population, and therefore a need to continue raising awareness of different types of diversity.

“...it’s really hard to educate people that don’t know anything, but it’s almost harder to educate people who think they know things like if they think ohh, my sister’s cousin is autistic. I know she loves trains. Have I got a thing for you? I’ll bet you’ll love this train.”
– autistic participant

In addition, participants commented on the different types of diversity (e.g., gender, age and cultural diversity), and suggested that there is a lack of acknowledgement and understanding of sub-groups of diversity within these: “there are other groups within or separate to that who, and, deviate from the sort of a broader population and so otherwise, intersectionality is kind of those groups that crossover other groups.” (professional). One participant described the difficulties associated with being diverse: “You constantly feel like you have to, I mean, I guess fight for what’s right. Well, no. You have to fight to eat, for the right to exist constantly on all levels. And that’s not right” (autistic participant).

Diversity and inclusion in health and medical services

Although one participant acknowledged there appears to be a positive shift in the approach of health professionals towards a more client-centred approach, participants discussed that there are still issues within health and medical services regarding the treatment of autistic people. Participants expressed that they have not been believed by health professionals about their presenting health issues, or they needed another adult (such as a parent) present to assist with medical decisions, despite them being an adult themselves: “like I was a grown up person and my doctor wouldn’t treat me until my mum came to the appointments” (autistic participant). In addition, participants discussed feeling the need to keep some medical issues off their record, out of fear of being discriminated against.

“You have to be a bit careful with my health record, cause then the first thing someone sees is that you’ve had admissions for panic attacks or the psychosomatics or whatever. Even if that’s not what it is, you can’t get that removed so.” – autistic participant

Gender and sexual diversity

Participants discussed how gender remains a barrier to diagnosis for autistic women due to the difference in how autism presents in females compared to males. Similarly, female participants described experiences of feeling “infantilised” by males, made worse by the fact that they are also autistic. Participants who identified as female also discussed the “exhausting” experience of masking to try and fit in: “... being female we’re amazing actresses and we’re very good at masking and modelling behaviour to choose the correct behaviour for the correct situation” (autistic participant). In addition, the influence of female hormones associated with the menstrual cycle and pregnancy on the characteristics of autism was discussed. “I’ll just touch on like for the hormones I just was going to say that I know that my autistic traits became a lot more prominent after I fell pregnant, and then it kind of just, like, really spiked a lot of my hearing like sensory and just like a lot of my external feelings” (autistic participant and family member).

Regarding sexual diversity, participants expressed some level of internal conflict regarding their own sexuality and reported that there was a need for understanding and acceptance from others. Participants described how their sexual diversity was perceived by others as ‘attention-seeking’.

“Why can’t a person have a girlfriend? If...those two people like each other and nobody’s...being harmed, like we got enough going against this?” – autistic participant

Participants also discussed the potential correlation between neurodiversity and gender and sexual diversity, reporting there appeared to be a prevalence of these types of diversity among neurodiverse individuals.

“I know the literature has hinted at this, but it's not necessarily a I mean, it's not a universal experience, but there is a bit of a... relationship with gender can differ a bit, and with mainly it's like, OK, yeah, there's this body I have and this happens to be what I have, but it's not who I am like our body isn't necessarily who we are that's that becomes a whole thing is it's, it's it can be again not, hash tag not all autistics, and we know that, so but...there's a higher prevalence for sure.” – autistic participant

Cultural diversity

A lack of connection to culture or ability to connect with others of the same cultural background could lead to feelings of isolation for autistic people from culturally diverse backgrounds. Additionally, autistic individuals who are also from culturally diverse backgrounds may feel isolated within their own culture: “Because then it means that there's some people find solace in returning to, you know that their cultural roots and, and that's where they find that they get their recharge and then they go out into the world and deal with what's different. But you're even different within your own subgroups” (autistic participant).

Participants also acknowledged it may be more difficult for someone who does not speak English as their first language to obtain an autism diagnosis in Australia due to language and cultural differences. One participant identified that support groups for people in similar situations may be beneficial for improving connection and promoting diversity.

Mental health

Participants discussed feelings of burnout from consistently feeling the need to adjust their behaviour to fit in, which could negatively impact their mental health. In addition, cultural attitudes towards mental health were identified as a barrier to receiving support for such conditions as depression and anxiety, as participants felt these were dismissed or normalised in their culture, and therefore not considered as an issue in need of addressing: “...like depression was just you, just like, were looking for attention that there was [never] such thing as anxiety. Like you know, just get on with it” (autistic professional and family member).

3.3.2.2 Attitudes towards diversity

The broader community may have a negative attitude towards the use of labels or struggle to understand the need for these labels. However, some participants expressed that these labels were helpful for them and could enable access to supports and connection with other, like-minded people. Some participants expressed that diversity may be used against them, however, they had an open-minded attitude towards exploring the beliefs and attitudes of other people experiencing other types of diversity and could empathise with their experiences of being treated differently. The internet was identified as a means of identifying and engaging with more diverse communities.

Family attitudes

Participants discussed how family attitudes towards diversity can have an impact on how the person experiences and understands neurodiversity. Families with a history of neurodivergence, regardless of whether or not they had formal diagnoses, were more likely to accept behaviours that may be perceived as ‘unusual’ by others. “Oh, but that's just the way they are. That's just the way it is. It's just that and people say ‘oh you know I'm worried your daughter seems really anxious’ like no no she's not anxious. She's really intense. She's really focusing on this thing so she's trying to get as much done in as little time as possible” (autistic participant).

Attitudes towards NDIS users

Participants described feeling judgement from others regarding their use of the NDIS, which can negatively impact their outcomes. One participant described that they felt they shouldn't or couldn't ask for things that would improve their quality of life as they did not want to deal with having to justify themselves to others.

“I know that I felt a lot of...Ah, not asked for things I've needed, and I've felt I've hidden things and...not gotten help that I needed that would have been helpful because of the, I just couldn't deal with having to explain it to someone else, like I don't want to have to explain to them why I need this or why do I deserve it more...why do I need it? Like why do I deserve it? What's so special about me that I should get this thing that they don't get?” – autistic participant

Representation of autism

Participants identified a need to understand that autistic people will each have their own unique experiences and it is not appropriate to assume any one autistic individual or group of autistic individuals can represent all autistic people and speak on their behalf. Participants discussed how autism is represented in the media can influence societal attitudes.

“OK, this is just a character who is this, or this is a character who is this, not necessarily making...the focus of the character like it's not their identity, it's just a... so something they happen to have as a person, if that makes sense...I know in particular when I see transgender stuff done in the media, the best times I've seen it are when no one even mentions the fact the person's transgender. They're just that way. That's just who they are.” – autistic professional

3.3.2.3 Diversity and inclusion in research

Participants discussed the need for trained autistic advisors to be involved in autism research to ensure greater representation of the autistic community in research. In addition, participants suggested research involving surveys, for example, should be distributed more widely, including translated versions to enable participation by individuals from more diverse cultural backgrounds. Areas for further research relevant to the topic of diversity and inclusion included exploring the different ways in which empathy is expressed and experienced by autistic individuals, and factors associated with participation in social or leisure groups (e.g., what draws neurodivergent people to engage with particular activities or hobbies?).

3.4 Health, disability, and education services

3.4.1 Survey results: Research questions to be discussed in the focus groups

A total of 28 respondents answered the question, ‘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?’ This included 18 autistic people, 28 families or carers of autistic people, 6 health professionals, 6 education professionals, and 2 disability support workers.

Table 6 describes the responses provided by participants for questions researchers should 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. Questions have been ordered from the most frequently reported to the least frequently reported. Percentages indicate the proportion of participants overall whose response reflected the corresponding research question, and the proportion of autistic participants whose response reflected the corresponding research question.

Table 6: Questions identified for discussion in health, disability and education services

Questions for the focus groups to discuss	% of respondents who suggested (n = 28)	% of autistic respondents who suggested (n = 18)
1. 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)	43%	33%
2. What are the experiences of autistic people and their families using health, disability and education services? (including satisfaction, wellbeing, progress)	18%	17%
3. 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)	18%	22%
4. What health, disability and education services are most used/ needed by autistic people? (including services for co-occurring conditions)	14%	22%
5. 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?)	14%	17%
6. How does health, disability and education service availability and accessibility, processes and procedures, and current systems impact the health and wellbeing of autistic people?	14%	11%
7. How can funding be improved to support autistic people accessing health, disability and education services? (including NDIS, processes, free access to services)	11%	11%
8. 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)	7%	11%
9. Would quality delivery of autism support lead to better mental health of autistic people? (including autistic culture-responsive services, identified links)	7%	11%

3.4.2 Focus group and individual interview results

Thirteen participants contributed to the area of health, disability, and education services (2 autistic participants, 1 autistic family member, 2 family members and 8 professional participants). The following themes and sub-themes were identified from the workshop and interview data.

3.4.2.1 Health care and service delivery

Need for healthcare

Participants noted that there was a particular importance in accessible healthcare for autistic people due to their higher rates of co-occurring conditions and complex physical and mental health needs. Co-occurring neurodevelopmental conditions, such as Attention Deficit/Hyperactivity Disorder (ADHD) were often discussed, but participants also emphasised: “the other things like the migraines, the digestive problems, the joint issues... the odds of having some sort of dysautonomia, or some sort of heart rate [issue]” (autistic participant).

In addition to other conditions and diagnoses, participants also discussed how autistic burnout has significant effects across an autistic person’s life, and support and documentation (e.g. a medical certificate for work) were primarily accessed through general practitioners and the health system. The range of healthcare needs autistic people have (either related to autism or for other reasons) means that autistic people often need to access a range of different healthcare services. There was a need for healthcare systems to provide supports that: “should not be constrained to a time period [of an autistic person’s] life [and that were] flexi[ble] or hav[e] frameworks in place that are responsive to that” (professional and family member). Participants also discussed the impact of health difficulties going unrecognised and untreated, with potentially severe consequences on autistic people’s mental and physical health.

Being heard in healthcare

Participants also described the difficulties autistic people may have in communicating their symptoms and needs with a professional when accessing physical or mental healthcare. They described a common experience of having symptoms or needs dismissed, either through the professional apparently not believing the autistic person was able to describe and understand their own health experiences: “[You get] easily dismissed, anything you say get[s] treated as if you’re confused or something...[You’re] not taken seriously” (autistic participant), or due to diagnostic overshadowing (“autism symptoms (anxiety, poor social awareness) is assumed to be due to mental health issues and inappropriate interventions [are] used” (autistic participant).

Rather than taking a paternalistic approach, participants proposed a collaborative approach to healthcare provision. They acknowledged the subject matter expertise of health professionals but noted: “if they treat your health or your health management as a collaborative process, it’s a completely different ball game” (autistic participant). This is particularly important, because “when we exclude or devalue the experience/perspectives of populations (i.e. treating patients as unreliable narrators)... it results in a wasted opportunity to gain a genuine insight into [their] reality and results in approaches [to treatment] founded on assumptions” (autistic participant).

These factors make it particularly important that clinicians and those working in the health system are knowledgeable about and understand autism and that autistic people are trusted to be the experts in their own health.

Accessibility of healthcare

The need for increased accessibility in accessing health services was also discussed. Being able to have a range of methods available to book appointments, such as: “being able to make appointments online [be]cause some of us hate phone calls” (autistic participant) was seen as important, as the stress of making an appointment could lead to an autistic person not seeking healthcare: “[having to] go in each day for a one-day sick leave certificate, which was just about as stressful as going into work” (autistic participant). The need to have a range or even mixture of options was emphasised, as: “It’s just so hard and I think that [it’s] different for everyone” (autistic professional and family member).

Changes to the physical environment to reduce sensory input in places such as waiting rooms and treatment areas would also support autistic people to access healthcare. Having professionals who accommodated sensory needs was valued, as one participant described when their partner was in hospital: “It was so noisy, so loud, and eventually we said something. She got moved into this quiet room which was really, really good” (autistic professional).

However, there was still a need to: “desig[n] these spaces to be more accessible and to be more-friendly” (professional and family member) as many healthcare settings do not accommodate autistic sensory needs. Providing expectations was also helpful, such as being told: “what [the professional] need[s] to know, and you can write notes. That would be very helpful” (autistic participant) so they could prepare and share the information they needed to. This was particularly important for: “seeing a specialist where there might be a long waiting list and you only have one chance to try to get a diagnosis for something” (autistic participant).

Providing clear and direct instruction to autistic patients within a healthcare setting was also seen as important, as well as providing information about social expectations upfront, rather than: “hav[ing] to wait until something is done inappropriately before it gets politely dealt with” (family member).

Mental health

The most commonly utilised or needed health system by autistic people was mental health services. One professional mentioned a lot of the autistic young people they work with: “are seeing counsellors pretty regularly and a lot of them... [are] seeing psychologists regularly” (autistic professional). However, lack of services, inappropriate treatments and limited understanding of autism were common limitations of mental health services for autistic people. Limited numbers of mental health providers was noted as an issue, with even fewer having experience with autistic people: “for mental health, there’s not a great deal for autism” (autistic family member). Even when services were available, participants mentioned how they might not be accessed to avoid “double-dip(ping)” (autistic family member). To partially address the lack of services, participants discussed that mental health support should have: “a focus on utilising professionals such as social workers, general counsellors, and support workers in addition to psychologists and psychiatrists. Peer supports (like ADHD coaches) are also a good idea” (autistic participant).

A lack of understanding of autism in the mental health space (including diagnostic overshadowing) was a common issue raised by participants. When describing the mental health support her child received for another mental health condition, one participant described: “the autism was part of this... she wasn’t treated properly, [it] wasn’t accepted, wasn’t understood which made all the symptoms, all the trauma much worse” (family member). While this lack of understanding or consideration about autism was not specific to the mental health space, it was seen as particularly impactful in this area by participants.

Diagnosis

The process for obtaining an autism diagnosis within the healthcare system was also discussed. Participants highlighted the importance of professionals understanding autism and the many ways it can present and avoiding misconceptions such as: “girls don’t have autism, it’s just white boys” or “[autistic children] become adults and they just suddenly gr[ow] out of it” (autistic professional and family member).

A comprehensive and contemporary understanding of autism was seen as important for believing an autistic person about their existing diagnosis, supporting a person with a referral for an autism diagnosis, and “recognising undiagnosed autistics and seeing the signs that [a] person who presents weirdly or whatever might be autistic” (autistic participant).

The immense impact of the opinion of a diagnostician was highlighted, with the potential for clinicians to miss diagnoses, particularly when only seeing the person for a short period of time or when the clinician has a limited understanding of autism. As one autistic family member described: “You met the ... kid for five minutes and you think he’s not autistic because he can look you in the eye because he’s being a good boy today” (autistic family member).

The need for access for other non-autism spectrum disorder diagnoses was also mentioned, as well as considering autism when diagnosing or treating other conditions. Beyond the difficulties and barriers to obtaining a diagnosis, the value of having an autism diagnosis was discussed. A diagnosis could help guide clinicians when providing care, and beyond this a diagnosis is also needed to access many supports: “[You] need a diagnosis to get support, then you need the funding to actually even get a diagnosis” (autistic family member).

3.4.2.2 Disability services and the NDIS

Deficit focus

Across the NDIS, disability support pensions and disability related employment services participants described how deficit focused the disability systems are. As one participant described: “The application (& planning processes) involved in getting onto the NDIS are traumatising in that they make you focus on and (essentially) exaggerate your weaknesses, failures, and the ‘burden’ you are to others” (autistic participant). As an alternative, participants described the importance of having a strengths-based approach to disability supports where autistic people could “focus on [their] positive attributes, and the goals [they’d] like to pursue, skills [they’d] like to learn or things [they’d] like to try or explore (i.e. trying out different jobs)” (autistic participant).

Disability support outcomes

Participants described the need for supports provided through disability services to improve outcomes that of importance to autistic people. This would involve research into what services are provided to autistic people through systems like the NDIS, what percentage of autistic people are accessing the NDIS, and what are the unmet needs of autistic people both accessing and not accessing the NDIS. Participants also discussed the need for outcomes from supports to be translatable into ‘real life outcomes’. The outcomes and efficacy of supports provided by the NDIS was an area of research participants discussed. One key outcome that participants discussed was autistic wellbeing. They mentioned that: “a very narrow view of wellbeing is often taken. There needs to be a greater focus on understanding a broad view of wellbeing and more appropriate ways of measuring broad wellbeing” (family member). Particularly there was a research need to explore what wellbeing looks like for autistic people, and how it should be measured.

NDIS systemic difficulties

While many participants discussed the benefits to NDIS funding and supports that it provides for autistic people, several key difficulties with the system were discussed. Many participants discussed how: “the NDIS funding process can be extremely stressful and challenging and can be a massive barrier for people on the spectrum getting services they need” (professional). The difficulty and complexity lead to families not applying for supports that they may be entitled to: “it’s a lot of time to try and go through that process so it can be somewhat overwhelming. And you put it in the two hard basket and then you, you know, and then it falls through the cracks” (family member).

The consequences of not receiving access to needed supports through the NDIS was also discussed. Autistic people and their families would either miss out on supports or must pay exorbitant amounts of money to access supports due to service providers’ response to the NDIS market. Once in the NDIS, participants also described inconsistency in decision making, or sudden changes to criteria and thresholds, for example: “One season they might be eligible for certain services and then without very much warning, all of a sudden the NDIS rules or the resubmission of a funding application results in them being stripped of the ability to [receive supports]” (autistic professional).

This lack of consistency and uncertainty impacts on autistic people's ability to receive supports, while also impacting their families: "It can be really discouraging, disheartening for parents. I've had parents crying... that they can't give their child access to services they know then need... [be]cause funding's been removed." (professional). Within the NDIS, it was described as difficult to find reliable and appropriate supports: "You get ripped off left, right and centre" (autistic family member) including support workers, cleaners and clinicians. The quality of the programs and supports that were available was also a discussed as: "they're super medicalised, super high priced, or just they're not that good" (professional). Concern that "people out there that will take advantage of the NDIS if it's just a free for all" (professional), was also raised when discussing the sector. Alongside this, having consistency in the professionals who support autistic people, and their families was valuable: "My daughter... finds it really difficulty when there's chopping and changing [of staff] all the time" (autistic family member) but often difficult to achieve.

Participants also discussed their concerns with how NDIS goals were operationalised. Autistic people felt the pressure to "pass [the] exam" of goals in NDIS, and if they did not, that their supports would be removed: "If you don't improve, they'll just take it away because you're a lost cause" (autistic participant). It was discussed that a more collaborative approach to explore: "that didn't work. Is there anything else that we could try [to help achieve goals]?" (autistic participant) was needed. There was also concern about supports being removed once a goal was achieved, rather than understanding that goals may be related to maintenance and consistency.

3.4.2.3 Education

Support in education settings

It was discussed how autistic students face greater barriers to education than non-autistic students, and that the education system was not set up to support autistic students: “mainstream [school] is meant for mainstream kids” (autistic family member). As one professional described: “we’re not creating an environment where they will flourish”. The physical environment of schools was often described as unsupportive, such as: “fluorescent lights... they’re flickery, noisy, bright light, I mean could we make it any harder for [autistic students]?” (professional) and “we’re cluttering up the environment for the kids who can’t even focus, they don’t stand a chance” (professional).

In addition to the physical environment, the social and cultural educational environments were also harmful. It was described how, in the mainstream educational context, once autistic students started to fall behind in some areas or notice that they were different, “they [start to believe] I’m the bad kid, I’m the naughty kid, I’m the, you know, the clumsy kid, the messy kid... I’m different from everyone else, I don’t fit in... then they start to feel down and it’s a self-fulfilling prophesy” (autistic family member) causing negative impacts on self-esteem and mental health. To avoid this situation, at least one family member described needing to remove their children from mainstream schooling completely, and home-school them, so that “you can have an education that suits your child” (autistic family member). For family members with children in mainstream settings, the onus to promote their child’s needs was placed on the family, often with little initiative, or even resistance from the school: “unless we are proactive, nothing happens” (family member).

The unsuitability of mainstream educational contexts for autistic students appeared to be related to a lack of understanding from teachers, and a paucity of suitable supports and strategies for schools and staff to implement. Strategies that teachers have been taught were not relevant or a good fit for supporting autistic students, as one professional described: “I see just how disjointed it is, say in schools, [with] teachers who just have no idea, using very neurotypical strategies: set boundaries, reward, consequence”. Professionals discussed how the “vast majority of teachers don’t understand and don’t have any mechanisms [to support or manage autistic children]” (professional). Where strategies were available to support autistic students (and those with other disabilities) they were not necessarily evidence-based, or had been modified from evidence-based approaches. They discussed how these strategies were often seen from: “this idea that people with autism are harder to deal with... and therefore they either need to be removed [from the classroom] or they need shortcuts to be put in place to help them without really thinking about whether or not the shortcut works” (autistic professional).

Also identified was a philosophical conflict between support strategies that could be implemented for autistic students and the structure and pedagogy used in schools. One professional described this barrier by saying “So even if I go in, what would I say? Hi guys. This stuff doesn’t work, here’s what does. And then what I’ve done then is I’ve broken their classroom. I’ve broken their worldview that just challenges everything they know to be true”. Therefore, the need to develop and test strategies, supports and programs for autistic students, and also how these can be implemented and adopted in education settings was identified as a research priority.

In cases where appropriate supports and strategies were in place, difficulties were still reported. A common example was “taking away accommodations after the accommodations start working and they are either left to mask or they’ll go back to the non-neurotypical or undesired behaviour” (autistic professional and family member). Additionally, the goals of supports and accommodations were also often misunderstood or non-neurodiverse affirming “I see so much where people [are] saying ohh, we’re neuro-affirming, we’re neuro-affirming, but the goal at the end of the day is to appear neurotypical” (autistic professional and family member).

However, participants also described positive experiences, and discussed the benefit of both supportive staff and environments in the school context for autistic students. The impact of supportive individual staff was valued, but this could be undermined by those in leadership or by school policies. However, participants felt that these supportive individuals were often limited, such as “teacher aides who work very closely with these young people who then have teachers and principals telling them that no, sorry, this is what we’re going to do” (family member).

However, it was also recognised that barriers to supporting autistic students were not solely attitudes and lack of knowledge from staff. Rather there is often a lack of funding and financial support to implement appropriate supports for autistic students within the educational context. Several family members recognised that this could be influencing the lack of supports their child was receiving: “There either not being the money there to do that, to implement [the supports] or people who are at decision making levels who are refusing to do it, or it can be a combination of both” (professional and family member). Professionals also discussed facing financial barriers to improving supports (including environmental changes) for autistic students. Despite the experiences and knowledge shared about supports in the educational context, it was highlighted that there was a need for more research into education options and supports for autistic students:

“There is little research currently that really gives autistic people and their families a clear indication regarding education choices – do we go with a fully inclusive experience or try to find an educational facility that understands and specialises in autism.” – family member

Transition to post-secondary education and out of education

Participants discussed the lack of support for autistic young adults transitioning from high school to post-secondary education, particularly university. As well as the difficulties getting into university, they noted “It is difficult for autistic people to finish their uni/higher education courses, and even if they do they are far less likely to get a job that makes use of their qualification” (autistic participant). Participants also discussed the importance of, and lack of support for autistic young people transitioning out of formal education. “I thought that the education system and the service provided in the education system was bad, and then my son left it, and I realised it’s actually not so bad compared to what is offered to adults” (family member). Participants discussed that transition services and supports were available, but these did not follow the young person through the transition: “There’s a lot of services that look at transition at school, but then once the child’s finished school, that’s it. That service is finished” (family member). Once out of the secondary education system, there were also concerns about the lack of supports and awareness within post-secondary education and employment contexts. Family members were concerned that their child “could be capable and good at that job, but ... their ability to deal with a job interview... is going to hamper their opportunity” (family member).

3.4.2.4 Common themes and impacts across systems

Navigating the system(s) and availability of services

The participants of the focus group highlighted the need for autistic people to access a range of services across their lifetimes, with fewer services and supports available for older children and adults. One participant described:

“we’ve done an excellent job at looking at ... early intervention. But you can’t do early intervention for dating, or sexual needs...it becomes really, really difficult to actually access those health and disability services that you need at [that] stage of life.” – family member

It was also noted that there were some groups, such as people living in regional and remote areas faced additional barriers to accessing services. Even where services do exist, a lack of understanding about what services are available across the health, disability and education systems was identified as a barrier to autistic people receiving care, support and access to education. Difficulties navigating and understanding the NDIS were often raised, but difficulties with other systems were also discussed. Navigating some systems were seen as too difficult and overwhelming to tackle: “you put it in the two hard basket and then you, you know, and then it falls through the cracks, so to speak” (family member). Of particular note was the difficulty experienced by autistic family members when navigating systems for their autistic children. “I find it very hard as an autistic mum... I need to be on top of all these things... organising all [this] stuff and therapy” (autistic family member). However, they persevere for the benefit of their children: “It’s great for the kids, [but] bloody hell itself for me” (family member). Difficulties described included the mental load of navigating the system, contacting services, and finding providers. Family members and autistic participants suggested a ‘case worker’ or ‘peer navigator’ type role that would provide autistic people and their families guidance and information across all systems about the range of services available to them could help address this need. Specifically, they wanted “someone to help you. Introduce you [to] what services are available and how to go about [accessing them]” (family member).

Another factor that significantly influenced access to services across systems was wait times for a range of services. The additional time required if the person felt they needed to seek a second opinion was quite substantial. The delays in being able to access services appears to be related to a lack of certain professionals and providers and a large demand for the subsidised pathways to access supports. Financial costs and barriers to services was also frequently discussed, with recommendations for more services (such as mental health and allied health) to be funded through Medicare. One recommendation for future research was “finding out the percentage of people who miss out on allied health services because they are unaffordable” (autistic participant).

Professionals

While the participants identified many systemic barriers and difficulties with health, disability and education services, they also discussed how individual professionals working in these systems have a significant impact on the lives of autistic people and their families. In general, participants discussed that those who interact with autistic people in these systems need to understand that autistic people can have “poor communication skills which can come across as rude. So just be understanding that it’s not deliberate rudeness” (autistic participant). It was also highlighted that knowledge about autism goes beyond “people who’ve read a textbook” (professional), rather professionals need an understanding of how diverse the autistic population is and the support needs of one autistic person may differ wildly to another. Greater awareness and understanding of individual autistic people were seen as essential to successful professional relationships: “The biggest thing has been the having the support worker or... professional understand exactly what they’re walking into” (family member).

The relationship between autistic people and the professionals they work with within these systems was also highlighted as an important factor contributing to positive outcomes. Family members and autistic participants shared both positive “really good experiences in hospitals where the nurse would come in and they’d let us know what’s happening and make sure that things weren’t too loud” (autistic professional) and negative experiences interacting with professionals which then impacted their therapeutic relationships: “the relationship would break down because you didn’t connect with them” (autistic participant). However, they have also noted that often it was “not that the individual people aren’t doing the best they can. I think it’s the systems that are really, really at fault and really let them down” (family member), and “there [are] still a lot of good people out there that ... just keep trying and really, genuinely care about the person” (family member). Because of the value and potential impact of these relationships, finding good professionals and service providers was seen as a priority for participants. As one participant described:

“when people have positive experiences, then obviously they’re feeling empowered and they’re feeling like these services are helping them to be equipped to go and achieve some of their goals that they have set out to achieve. And I think it gives them like a bit more hope and sense of purpose like because they’ve found someone that wants to work alongside them too.” – professional

Involvement of family

Autistic people’s family members are often key sources of support in accessing the health, disability and education systems, during both childhood and adulthood. The focus group highlighted that family and friends can be a powerful support and advocate for autistic people within these services. They also discussed that while the negative impacts of lack of services or poor services across systems primarily affect the autistic person, they also impact families too:

“When you are waiting for 2-3 years to find and see as a psychologist for a young person who is really, really struggling, obviously that has a really negative impact on their wellbeing and obviously that negative impact flows through to everyone in their life” – family member.

Participants also discussed that while autistic people were the experts on their own experiences, that family members also have valuable knowledge and experiences that should be captured through research and generally valued.

Another topic raised was the likelihood of autistic children having autistic parents, and the extra layer of difficulty this causes when dealing with health, education and disability systems and services. A need to accommodate the particular needs of parents and family members even when the child was the primary client or patient was expressed, as “there’s a fair chance that most of the [parents] you deal with are going to also be autistic...[it] does not help by putting them under pressure” (autistic professional and family member).

3.5 Making built environments more accessible

3.5.1 Survey to gather initial topics for focus groups

A total of 33 respondents answered the question: “In your opinion, what questions should researchers ask to reduce barriers/issues associated with built environments for autistic people?” These respondents included 20 autistic participants, 18 parents of autistic people, 4 carers, 11 family members of autistic people, 8 researchers, 2 medical professionals, 7 educational professionals, 2 allied health professionals, 1 social worker and 2 disability support workers. Some participants identified as belonging to more than one of these categories.

Table 7 describes the responses provided by participants for questions researchers should ask when exploring how we can reduce barriers/issues associated with built environments for autistic people. Questions have been ordered from most frequently reported to least frequently reported overall. Questions have been ordered from the most frequently reported to the least frequently reported. Percentages indicate the proportion of participants overall whose response reflected the corresponding research question, and the proportion of autistic participants whose response reflected the corresponding research question.

Table 7: Questions identified for discussion in making built environments more accessible

Questions for the focus groups to discuss	% of respondents who suggested	% of autistic respondents who suggested
<p>1. How can we make built environments sensory friendly for autistic people? (Including 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?)</p>	45%	50%
<p>2. What does an ideal, or easily accessible, built environment look like for autistic people? (Including what makes this environment ideal for, or easily accessible to, autistic people; whether built environments autistic people experience as accessible change across the lifespan)</p>	27%	35%
<p>3. What are the best ways to reduce barriers in built environments, to make them more equitable and inclusive for autistic people? (Including whether facilities like disability help desks make environments more inclusive; what societal attitudes are to making built environments more inclusive and equitable for autistic people)</p>	24%	20%
<p>4. How can we make built environments, including homes, more calming and comfortable for autistic people, such that their dysregulation and distress is reduced? (Including why the proposed ideas would make autistic people feel calmer and more comfortable, and reduce dysregulation and distress; whether there are any specific features of built environments that contribute to autistic people experiencing distress and dysregulation)</p>	21%	25%
<p>5. How can navigation signage and transport better meet the needs of autistic people? (Including how transport hubs could be more sensory friendly for autistic people; whether Autistic people need more infographics in built environments)</p>	21%	20%
<p>6. How can built environments meet autistic peoples' needs? (Including whether built environments that meet the needs of autistic people impact upon engagement with, or enjoyment of, activities within those environments)</p>	21%	20%
<p>7. How can autistic people be included in designing built environments? (Including how we can help non-autistic people, including non-autistic children, understand what autistic people need in built environments; how we can help non-autistic employers consider the needs of autistic employees in workplace environments)</p>	15%	10%
<p>8. What are some ways to reduce crowding, and increase private spaces, in built environments, and how would this impact autistic people? (Including when in crowded environments, how autistic people, of all communication styles and needs, can communicate their needs to others)</p>	12%	15%
<p>9. What might make built environments safer for autistic people?</p>	9%	5%
<p>10. How are autistic people impacted by the retention of natural environments and by living surrounded by nature and green spaces?</p>	6%	10%

3.5.2 Focus group and individual interview results

Eleven participants contributed to the area of making built environments more accessible (3 autistic participants, 2 autistic and family member participants, 1 family member and 5 professional participants). Themes related to the challenges autistic people experience with the built environment as well as recommendations for improving accessibility and future research are outlined below.

3.5.2.1 Challenges autistic people experience with the built environment

Participants discussed that for the most part, built environments do not adequately meet the needs of autistic people and this negatively affects autistic people's participation and enjoyment of the built environment.

Lack of awareness and empathy from neurotypical people

The lack of awareness, among neurotypical people, of autism and the support that autistic people need was noted as a concern in the built environment as this represented a barrier to accessing some spaces. Participants felt there was a lack of understanding related to the communication needs and preferences of autistic people when accessing built environments. They explained that communicating with neurotypical people in built environments can be a challenge for autistic people when they are overstimulated, especially for those who experience situational mutism. They described general attitudes of annoyance, impatience and anger directed towards autistic people when they were overstimulated and trying to access assistance. This often results in autistic people avoiding or reducing engagement with that environment.

“It’s like I literally have to scream it from the rooftop sometimes before I feel that. No, I’m not a psychiatric patient or no, I’m not asking to do something that’s above and beyond when I want you just to wait an extra 60 seconds for my [augmented alternative communication] to come out. Please just bear with me or I’m getting overstimulated.” – autistic participant

Participants explained that the lack of awareness of autism was also reflected in how many built environments are designed and do not take into consideration people who may have specific navigational needs and sensory needs. “It (building) was clearly designed by people who don’t have sensory issues, because if they did, they wouldn’t have done it” (autistic participant). Participants suggested that there is a need for education and re-education in the general population about autism to help make the built environment more accessible for autistic people.

Sensory overstimulation

Sensory overstimulation was noted as a major challenge for autistic people in accessing the built environment. Participants explained that sensory stimulation from crowding, noise, scents and lighting present in supermarkets, hospitals, stadiums, workplaces, schools and on public transportation can be difficult and triggering for autistic people and influence their avoidance of these spaces.

“Of course, you know, for like the whole grocery shopping thing. You’re not gonna like most of us seem to avoid grocery shopping because it’s such a torturous experience so something like a simple grocery shop can be extreme for me in terms of the sound of the radio blaring, buzzing lights, people everywhere, checkouts pinging, people yelling, then there’s like the different types of lighting, the different types of sounds, different types of smells, lots and lots of people everywhere and there’s just like is no escape.”
– autistic participant

Considering the impact of sensory overstimulation on the engagement of autistic people with the built environment led some professional participants to lament the barrier posed by the NDIS decision not to fund sensory items. They explained “that’s (lack of NDIS funding for sensory items) been leading to quite a big barrier for a lot of our clients who would really benefit from (them)” (professional).

Lack of spaces to ‘escape’ to and difficulty communicating needs

In instances of overstimulation participants expressed the need to “escape” to a quiet low stimulation environment. “My body starts to stim if I cannot get away from that space” (autistic participant). However, finding and accessing these spaces can be very difficult as they are not designated within the built environment. Additionally, participants explained that once overstimulated, it can become difficult to verbalise their needs to others which reduces autistic people’s ability to access help. To better respond to these situations, two participants used augmentative and alternative communication (AAC) and AUSLAN to aid them.

Participants also indicated that preparation ahead of time for what to expect in different built environment settings can be helpful to autistic people as they may take sunglasses or headphones with them so they can better cope. Other autistic participants explained that they try to scope out places that can substitute as quiet spaces they can access if needed in built environments they visit often, such as remote bathrooms and prayer rooms.

3.5.2.2 Inclusion and modifications to make built environments more accessible

The inclusion of autistic people in the design of built environments was noted as a major way to make built environments more accessible. Participants suggested general modifications that can be made to built environments to improve their accessibility to autistic people.

Modifications to the general built environment

Access to green spaces and natural elements was noted by participants to be calming for autistic people in general. Participants felt that built environments that are commonly used by autistic people should provide sensory spaces that allow them to escape overstimulation and regroup without feeling judged or exposed. They also expressed that workplaces with autistic staff members needed to be more understanding of autistic staff who may need sensory breaks and quiet time and also provide sensory reduced spaces for autistic employees.

Participants also suggested soundproofing spaces and avoiding tiles to reduce noise transfer as noise can be challenging for some autistic people. “To improve buildings is, yeah, like a lot of noise transfers between different rooms or buildings, and it’s really hard. I find it very hard to concentrate on anything if there’s lots of noise” (autistic participant). They also suggested the inclusion of disability help desks in public spaces where autistic people and people with disabilities could access help. Providing designated sensory spaces in public built environments that autistic people could access when needed through swipe access or some other specially designed strategy of identification, was also discussed as a possible solution to improving the accessibility of the built environment.

Another suggestion included built environments such as shopping centres having time slots where they reduce sensory stimulation to allow autistic people to access shops without feeling uncomfortable:

“I feel like in shopping centres they could be doing so much more to cater to diverse needs in that area. Like I really wish it was just one hour, once a week at like say, maybe 20 shops that did something about the grossly bright lighting, or the overwhelming sounds...I wish I could go grocery shopping like that. That would be the ultimate dream. And yet that’s barely even done. And I would settle for 30 minutes twice a week if that could be offered. Things like that would make it just so much more tolerable.” – autistic professional

Modifications to homes or residential spaces

For homes and residential spaces, participants indicated that sensory profiling was very important to assess the sensory needs of autistic individuals, especially when multiple autistic people were in the home. One participant noted the benefit of sharing the same Occupational Therapist (OT) with two other autistic family members as this has aided them in collaborating on their sensory needs: “[sharing an OT] has been able to integrate our sensory profiles much nicer and neater.” Other participants discussed the importance of using building materials that are noise reducing and includes adjustable lighting as well as the use of colours and layouts that are calming and comforting to autistic people, these features should be adjustable to suit the individual needs and/or preferences of autistic people.

Improve signage and symbols in built environments

Poor signage was highlighted by participants as a major concern for autistic people and negatively affected their ability to navigate spaces and respond appropriately in the built environment. Participants expressed confusion when reading maps and worded signs and suggested that visual illustrations, assigning colour codes and revising some symbols may be more helpful for some autistic people to independently navigate spaces.

“Unless I can see it (maps) drawn or I have some sort of another landmark or a prior experience in which I’ve already learnt and scripted in my mind, I don’t know where to go or what to do or how that should be. And so, if I just had those sort of visual markers, whether they’d be known landmarks or a little mud map or some pointers that were just not verbally given then I think I would have been more successful.” – autistic participant

This was also applicable to emergency evacuation procedures that often involve glaring noise as the symbol for evacuation which is often triggering for autistic people. One participant suggested the use of visual illustrations and “arrows on the ground pointing to where your emergency exit is” (professional) to aid autistic people navigate how to exit the building.

Another aspect of signage that was highlighted related to the symbols for disabilities such as Australian Council for Rehabilitation of Disabled (ACROD) parking which has a wheelchair as the symbol of disability. Participants pointed out that people with autism and other physical or mental health conditions may not have visual disabilities and this symbol is not inclusive for them and suggested revising it to be more inclusive. One participant indicated how this affects her:

“I have to have ACROD parking at times and I get the strangest of looks when I utilise this and although I understand a lot of people are looking for a physical disability which involves a wheelchair thanks to the symbolism that’s been attributed to ACROD parking.” – autistic professional

Participants further discussed that because autism is invisible it can be difficult for neurotypical people to identify autistic people which can contribute to their unwillingness to accommodate them. A few participants suggested that the autistic and autism community create a symbol for autism that can be publicised, that autistic people can wear or use to indicate that they are people who may need additional support in built environment settings.

“A sort of a quieter, more discrete way of saying: I have an invisible disability, and can that be somewhat understood, and can you bear with me and give me that extra moment that I might need? Or can you try and look to understand me within that scope?” – autistic participant

Modifications to public transportation

Public transportation was highlighted as an aspect of the built environment that was very challenging for autistic people. This was linked to sensory stimulation associated with public buses and trains but also to challenges in understanding signage. Participants indicated that buses were the least accessible kind of public transportation while trams and regional trains were the most accessible. The high accessibility of regional trains was linked to the provision of visual colour coded signage, the presence of a conductor onboard the train, and audio recording that announced stops:

“On (trams) all you have to do is remember that I’m supposed to be getting off at stop 42 and you can ask as many people as possible. You can watch the numbers. Buses don’t have that. Buses have weirdo numbers of routes that mean...they’re rather confusing as well” – autistic participant

To improve the accessibility of buses for autistic people, participants suggested having visual maps of the bus route posted on buses, have bus stops with distinctive names and audio recording that call out the names of the next stops.

3.5.2.3 Dignity and safety

Participants felt that modifications to the built environment could help autistic people maintain their dignity and safety. This was expressed especially in situations when they become overstimulated:

“It’s not just safety (from physical harm), but it’s safety in terms of our dignity and public image as well, because if you’re in a workplace where you have to go down 6 flights of stairs to get to a toilet, but you’re autistic, that’s not safe. That doesn’t feel psychologically safe” – autistic professional

Participants explained that knowing that there are quiet spaces or other supports available to them in built environments would reduce their sense of discomfort and increase their sense of safety and dignity. Hence, they noted that an ideal built environment would foster inclusivity, independence and sensory comfort for autistic people.

3.5.2.4 Role of carers and supports in the built environment

Some participants highlighted that some autistic people may need support to negotiate and participate in the built environment. They discussed the important role that family members and support workers who understand the triggers of the autistic individuals they care for, play in helping autistic people in built environment settings. This was especially true for autistic people with high support needs. Several participants noted the role that technology can play as a support for navigation and tracking in case autistic people get lost and need assistance. The role of social stories was also discussed as a strategy that carers can use to help autistic people prepare for new built environments.

3.5.2.5 Future research

Participants expressed that research related to making the built environment more accessible should be inclusive of the voices of autistic people from surveys and qualitative engagement to capture a wide range of experiences and needs. This was considered especially important in the designing process for places that may have high volumes of neurodivergent people “...having an autistic consultant, having lots of research to back the decisions in the design process” (autistic professional). They also suggested that developers and businesses could pilot changes to aspects of the built environment such as sensory features and green spaces to see how it improves accessibility for autistic people and other populations. They further suggested exploring the differences in experiences of autistic people in learning environments and teachers understanding of sensory needs of autistic students; further research into the most accessible and least accessible built environments for autistic people; exploration of the experiences of autistic people who live in cities versus those who live in rural or remote areas with access to built environments. As one participant explained: “We’re asking for equity, we’re asking where can we find the slots in this world where it might be suitable for us to have a bit of an easier run at it” (autistic participant).

4. Overarching themes and conclusion

Several overarching themes were identified across all five priority areas. These represent areas of central focus for the autistic and autism community and warrant research prioritisation across the five domains. These areas and their applicability to each domain area are outlined below.

4.1 Awareness and understanding of autism

Participants believed there was a general lack of awareness about autism among the public and understanding of autism as being a spectrum. There is a need to improve awareness of different types of diversity, including neurodiversity, across multiple settings, including educational facilities, health and medical services, and in the workplace. Systems were not designed to accommodate the needs of autistic people (such as sensory overwhelming environments and lack of communication options) which prohibited or reduced access to services. Participants explained that awareness and understanding facilitated positive experiences in these environments, while ignorance and judgement contributed to negative experiences and poorer outcomes for autistic individuals and their families. There is a need to acknowledge the impact of intersectionality, where individuals who are neurodivergent may identify with multiple diverse identities including gender, age, or cultural diversity.

Participants called for an increase in education for family members, health and education professionals, and the broader community. The lack of awareness and understanding of autism was considered a major barrier to receiving both formal and informal supports for autistic individuals and their families. The impacts of poor awareness and understanding of autism could have far-reaching consequences, ranging from lack of acceptance within the family and bullying at school, to delayed diagnosis and ongoing stigma within society. There is a need to increase diverse representation of autism in the media to help improve awareness and promote diversity at a societal level.

4.1.1 Research focus

Research into building awareness and understanding that is inclusive of the autistic voice and autism community to co-create strategies to assess levels of awareness and understanding across sectors; create and implement interventions geared at building awareness and understanding; and evaluate interventions that seek to build autism awareness among the wider community. Awareness building initiatives should be intersectional and inclusive of relevant stakeholders in each priority area.

4.2 Finances

The challenges autistic people experience in accessing adequate financial resources was discussed in some way by participants across domains. This was often connected to the difficulty experienced by autistic people in gaining and maintaining gainful employment as well as the costs associated with the services accessed by autistic people. Hence, financial support was considered essential for facilitating access to family and carer supports, housing, and education. The financial costs of accessing health, disability and education services were described as a barrier and source of stress for autistic people and their families. This was particularly relevant when systems, such as Medicare or the NDIS were not providing supports as they should be (or at least perceived to be responsible for). Difficulties accommodating the needs of autistic students in schools were also attributed, in part, to financial constraints on schools. Participants also noted that financial support systems could be difficult to navigate, and limited finances could be a barrier to accessing necessary supports and services.

4.2.1 Research focus

There is a need for cross-cutting research that examines the financial challenges experienced by autistic people and how this impacts them in each priority area. There also needs to be research identifying strategies to reduce poverty and homelessness among autistic people. There is a need for research exploring the economic benefits of improving inclusion and access to parental and sibling supports. Participants also suggested the development of a specialised support service to assist individuals and families in navigating the systems required to gain access to funding.

4.3 Role of the family

Across all domains, the family was recognised to play an instrumental role in the lives of autistic people. Family play an important role in facilitating access to supports for autistic individuals and other members of the family (e.g., siblings). Families were identified as a key support for autistic people in all systems, including health, disability and education. They were guides, advocates, and administrators, helping their autistic family member navigate systems to receive the supports they needed. Families can influence how autistic people view their own neurodivergence, with some autistic individuals reporting that they grew up accepting their own autistic characteristics due to the attitudes and experiences of their family members.

This could be beneficial, promoting self-acceptance, or harmful, where support was not sought or provided due to family or cultural beliefs relating to disability and mental health. For example, as it related to the priority area of choice and control of housing and living, the family was noted as either exerting control and restricting the housing and living choices of autistic people or playing a supportive role that enabled autistic people to live independently.

However, a lack of support for family members supporting their autistic loved one was identified, with many parents and family members facing high levels of stress, anxiety and burnout due to the barriers and complexities within these services and systems. These negative effects on family members were exacerbated when considering that many of these family members may be autistic or neurodivergent themselves and in need of accommodations or support. Family members also noted that although they may not necessarily be autistic, they also had valuable expertise that should be acknowledged and considered when attempting to improve these systems.

4.3.1 Research focus

Participants discussed that there is currently limited support for siblings and other family members funded by the NDIS. There is a need to use a whole family approach when supporting autistic individuals, including building the family's capacity to function within their own environments, beyond the therapy context. Research exploring the support needs of other family members, particularly siblings, was identified as an important area for future research.

4.4 Support needs

While participants acknowledged the support available, the consensus among participants was that these supports could be increased or improved, and there were some areas, particularly around periods of transition, where support was limited or absent. In the priority areas of choice and control of housing and living, participants indicated support needs for autistic people in navigating the process of acquiring housing as well as supports that would help them with key aspects of household management. This was noted to vary based on whether autistic people had supportive family members or access to NDIS. Support was also viewed as important in helping autistic people to successfully navigate the built environment, whether through support workers, family members, employees, or the use of technology.

Promoting diversity and inclusion across multiple contexts, including educational facilities, workplaces, and the community, was identified as an area of need for autistic individuals. A need to educate teachers and students in schools was identified as necessary for improving outcomes for autistic children. Autistic individuals from culturally diverse backgrounds may need additional support in the form of support groups to connect with their cultural background, which can be made difficult by cultural attitudes towards disability. Family and carers of autistic individuals were also recognised as have specific support needs which included support during times of transition, financial support, NDIS support, promoting autistic identity and visibility, consistency of support workers and services, mental health support, and capacity building for the whole family.

Across health, disability and education systems, many autistic people are receiving a range of supports. However, these supports are not always sufficient or appropriate if they are received at all. These included not receiving appropriate physical or mental health care due to biases or lack of understanding about autism. In the disability sector, supports often were hard to find, and even if available, may be of questionable quality or reliability. Due to the demand for services in the disability sector, participants also described long waitlists as a common experience when trying to access services. Within the education sector, a lack of understanding, willingness or ability to support autistic students, with many school systems and individual staff not given the training or resources to support students. However, despite the limited or flawed support provided by schools, participants described how post-school supports were even more scarce. Little to no support or pathways were identified for autistic people transitioning to adulthood, including for employment or post-secondary studies.

4.4.1 Research focus

There is need for more research including the autistic voice and those of autism community to identify the support needs of autistic people across the spectrum and priority areas. Research in this context should include identifying the unique support needs of autistic individuals belonging to multiple sub-groups of diversity. For example, researchers conducting surveys should consider distributing these more widely, using translators, to ensure the perspectives of individuals from diverse cultural backgrounds are also being captured.

4.5 Mental health

Mental health was identified as a key area for support for both autistic individuals and their families. Participants believed that the living and built environments greatly affected the mental health of autistic people. This was connected to sensory factors and the quality of interpersonal interactions in these environments. Autistic individuals who felt the need to mask or modify their behaviour to fit in with their peers identified that burnout could be an issue. In addition, attitudes towards mental health, particularly in individuals from diverse cultural backgrounds, could have an impact on the support available to individuals. Often, mental health issues were dismissed and therefore unsupported due to cultural attitudes towards mental health.

Families felt unsupported by services in relation to mental health support for their autistic family member and were unsure about where to go to access services. Having an autism diagnosis served as a barrier for many autistic people trying to access mental health support as there was a lack of clarity across services regarding whose responsibility it was to provide mental health support to autistic individuals. According to participants, the complexities of navigating the health, disability and education systems, and the lack of accommodations or supports within them often negatively impacted autistic people's mental health. They also described how mental health services were often not equipped to support autistic people with mental health difficulties or distress. This was of particular concern due to the common co-occurrence of mental health conditions and autism.

4.5.1 Research focus

There is a need for research that explores the mental health needs of autistic people, particularly autistic women, and people from diverse cultural backgrounds. There is also a need for research that seeks to ascertain factors that may improve the mental health and well-being of autistic individuals and their family that is inclusive of factors in the built environment.

4.6 The NDIS

The role of the NDIS was discussed across all priority areas. Participants expressed mixed views about its effectiveness in meeting the needs of the autistic community. The NDIS was acknowledged as a source of support for families and carers, but participants discussed that the NDIS processes were confusing, tedious, overwhelming and difficult to navigate. While participants felt that the funding and supports offered through the NDIS was a major help to allowing autistic people to have some choice in their living arrangements. Other participants believed that the funding and supports provided through the NDIS were limited and inflexible and did not consider the diversity of individual needs of autistic people.

Moreover, there was a lack of clarity for families around the types of supports that could be funded by the NDIS, as well as lack of communication between services and government departments. Within the health, disability and education topic, several challenges with the NDIS were raised. These included the complexity of the system, inconsistent decision making and changing requirements, lack of available supports and inappropriate use of goals in relation to funding supports. It was clear that the NDIS was providing many people with a range of supports, but these difficulties often led to high levels of stress and burnout in order to access them.

4.6.1 Research focus

There were varying views and expectations across participants as it related to the role of the NDIS. There is a need for research that explores the level of awareness and understanding of the NDIS processes, mission and scope within the autistic and autism community. This can aid the NDIS in developing strategies for building public awareness of its role and function as well as strategies for simplifying its processes and making the service more accessible to those who need it.

4.7 Conclusion

In conclusion, the findings of this report indicate that the autistic and autism community considered research that would help build awareness and understanding of autism within the wider society would be most beneficial to improving the experiences and outcomes of autistic people. Participants stressed the need for the inclusion of the autistic voice in the co-creation of all future research to ensure that it is relevant and impactful to their community. Although research may be based in any of the five priority areas outlined in this report, the overarching themes of awareness and understanding of autism, finances, the role of family, support need, mental health and the NDIS should be included as key aspects of future research.

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Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



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Independent national source of evidence for best practice



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