Australian Autism Research Council

Research report on focus groups to identify research questions for community informed priority areas

FINAL REPORT

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ORIMA RESEARCH

Contents

1 Acknowledgments

Focus group participants dedicated significant time and efforts contributing to the project. The following participants gave permission to be acknowledged by name:

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We also acknowledge the significant contributions of all other focus group participants who chose not to be acknowledged by name.

The findings in this report are a result of the aggregation of views expressed by focus group participants and do not represent the individual views of specific persons.

2 Introduction

2.1 Background

The Autism Cooperative Research Centre (CRC) is a national cooperative research effort focused on autism. The Autism CRC collaborates with autistic people and autism communities, research organisations, industry, and government to develop and deliver evidence-based outcomes (https://www.autismcrc.com.au/about-us). Under the auspices of Autism CRC, the Australian Autism Research Council (AARC) was established to review and define research priorities, based on the needs of the autism community.

Members of the AARC include:

- representatives of the autistic and broader autism communities;
- service providers;
- health and education professionals;
- government program managers and policy makers; and
- researchers.

In October 2019, the AARC released its 2019 Research Priorities Report which outlined 10 broad areas for research priority in Australia. This included Built Environment; Choice in Living and Housing; Communication; Education; Employment; Family and Carer Support; Gender, Diversity and Inclusion; Health and Disability Services Delivery; Health and Wellbeing; and Justice. These were identified through a community consultation process which included an online survey (completed by 1,102 respondents) and the opportunity to provide written submissions (21 were received) (Australian Autism Research Council, 2019).

The Research Priorities Report recommended that further research be undertaken to identify more specific areas of research interest within each of the Priority Areas. As such, the AARC commissioned ORIMA Research to conduct focus groups to define research questions and topics within five of the research Priority Areas. These five areas are Communication; Education; Employment; Health and Wellbeing; and Justice (depicted in Figure 1 below).

Figure 1: Five Priority Areas

The key objective of the research was to identify approximately **10 of the most important topics and questions for autism research in each of the five Priority Areas**. In addition, the research aimed to understand the intended impact of the proposed research questions.

2.2 Project governance

Acting under the auspices of Autism CRC, the AARC outlined the following three guiding principles, which informed the conduct of this research:

1. **Autistic people at the centre** – assist autistic people to discover what they want for their own lives and support them to achieve their goals;

2. **Inclusive of all autistic people** – be inclusive of the full diversity of the autism spectrum, as well as age, gender, LGBTIQA+, geography, ethnicity, co-occurring disability, socio-economic disadvantage, and Aboriginal and Torres Strait Islander individuals and families; and

3. **Impact** – target areas that will create the most meaningful impact.

To ensure these principles were reflected in the final priorities identified, as well as in our research processes, our research approach was informed by Autism CRC's *Inclusive Research Practice Guides* and *Checklists for Autism Research*. These guidelines outline best practice in conducting research with autistic people and their families throughout all stages of research, including commissioning research, undertaking research and disseminating, evaluating and utilising findings. Co-production is central to these guidelines.

Upon project commissioning, ORIMA Research engaged autistic researcher Gabrielle Hall, a member of the Victorian Disability Advisory Council, alumnus of the Autism CRC's Sylvia Rodger Academy Research Program, to work alongside ORIMA staff for the duration of this project. Gabrielle was a core member of the project team with responsibilities including development of research guides and tools, conduct of the fieldwork, analysis and reporting. In addition, Gabrielle provided guidance and expertise based on her life experiences and professional knowledge.

ORIMA Research also engaged Amaze, the peak body for autistic people and their supporters in Victoria, as a research partner to inform the delivery of this project. Specifically, Amaze provided additional guidance during the following key stages of the research process:

- Informing the project methodology and establishment by providing insight into best practice in research with the autistic community;
- Ensuring that the specific research questions are appropriate for informing practical and actionable priorities; and
- Providing context and advice for framing the analysis of findings to ensure that they create the most impact.

2.3 Research methodology

A total of 55 members of the autistic and autism communities participated in the research, conducted between 17 September and 23 October 2020.

Research participants included:

- autistic people;
- parents, carers and family members of autistic children or adults; and
- people who work with autistic people or in the autism sector, including in research.

All participants were recruited by AARC through an expression of interest process and consideration was given the relevant professional experience of participants. For example, the priority area of Communication included participants with professional qualifications in speech pathology, experience in communication research, and working with communication providers. This approach was adopted for all Priority Areas i.e. Education included teachers, Justice included a police officer, Employment included employers and employees, Health and Wellbeing included community health and social activity providers. For each Priority Area up to 13 people were invited to participate, however a small amount did not accept or respond.

For each of the five Priority Areas, focus groups were conducted via a 10-day online discussion board with up to 12 participants in each group. This was offered as the primary methodology for participation in the research. Additionally, there was an option available for participants to take part in an individual interview (through a mode of their choice) to support participation. All participants, however, chose to take part in the online discussion board.

During the discussion boards, some broad questions about the challenges and strengths for autistic and autism communities in the Priority Area were discussed to obtain a strong contextual understanding and assist with the generation of ideas for research topics. Participants were also asked directly which topics and questions they would like to see researched in the future. This information was used to create a poll of potential research topics taken at a mid-point in that discussion group. Topics included in this poll were derived directly from participants' suggestions with some edits to wording or phrasing for clarity, consistency, brevity and / or to combine suggested topics that were similar. Where a theme had been raised by multiple participants in the initial broad discussion but not explicitly raised as a research topic, the researchers developed a research topic to reflect this theme for testing in the mid-point poll. Participants were asked to select up to five topics in the mid-point poll that they felt were most important.

The results of the mid-point poll were shared with participants in the discussion board for further comment and feedback, and to suggest further topics they felt were missing from the list. Additional contextual information was obtained to understand why participants felt the topic was important and the potential impact of research.

Participants' feedback was used to inform the list of topics included in the final prioritisation poll. This included removing a few topics that received limited interest in the midpoint poll (lowest percentage rating), adding topics that were further suggested by participants, wording amendments and merging or separating topics.

At the conclusion of all discussion boards, the prioritisation poll with topics and questions generated across the five Priority Areas was sent to participants across all groups. The total number of participants for the final prioritisation poll was 45 (82%).

The results of the prioritisation poll were used to determine the top 4 research questions by participants in that discussion group and the overall top 10 research questions for each Priority Area, based on the number of participants who selected each topic. For Communication, there were two topics at equal tenth position, however one of these topics was left off the final list as it had overlapping content with a higher-ranking topic. For Justice there were four topics at equal ninth position, two topics were eliminated from the final list due to its content being reflected in a higher-ranked topic. These decisions were made to maximise fidelity to the poll results and keep the final list of topics as focused and concise as possible. Where relevant, topics were rephrased to a research question wherever this could be done without changing the meaning, sentiment or key words. This was undertaken in consultation with Amaze in order to present the topics in an actionable and impactful manner.

An overview of the research methodology and number of participants is shown in Table 1 below.

Table 1: Focus group participation

	Discussion board	Prioritisation poll[1]
Communication	12	11
Education	10	7
Employment	12[2]	9
Health and wellbeing	10	9
Justice	10[3]	9
TOTAL	55	45

Appendix A shows further demographic information about research participants collected during the expression of interest process presented at an overall level. Appendix B includes further information about participants' engagement with the discussion board.

Prior to commencing the fieldwork, an initial light-touch literature scan was conducted to develop a broad understanding of currently available autism research in each of the five Priority Areas to help guide the discussions groups.

This literature scan process was split into two phases:

- **Phase one**: prior to fieldwork commencement; and
- **Phase two**: during and post-fieldwork.

This process involved:

- Identifying key search terms and/or key databases – this process was done in consultation with AARC members, who provided key initial insights.
- Conducting the search though online databases – the primary focus was on meta-analyses conducted within the last 5 years, due to the recent increase in research in this field. However,

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[1] The figures reflect inclusion of one 'Education' focus group participant that completed both the midpoint and prioritisation poll but did not participate in the discussion boards.

[2] One additional participant was set up on the discussion board but did not provide feedback on the questions.

[3] One additional participant introduced themselves on the discussion board but did not provide feedback on the questions.

given the limited research in the Priority Area of Justice, this timeframe was extended to include research conducted within the last 10 years.

- Reviewing the titles of journal articles and reports returned from these searches, and where necessary the abstracts; and
- Compiling a list of studies under key headings within each of the five Priority Areas.

Phase two of the literature scan was conducted during and after the fieldwork process with the aim of conducting more tailored searches to match the topics identified by participants. In some instances, specific resources were highlighted by participants or Amaze. These additional findings were then added to, and used to complement, the literature scan findings from phase one. This literature scan provided additional context to the research.

2.4 . Limitations to the research

One limitation to the research was the relatively small sample size (n=55). In addition, certain demographics were either over- or under-represented in the sample (see Appendix A for a demographic profile of participants). For example, only 11% of participants spoke a language other than English at home. However, while the research was largely qualitative in nature and participants were selected based on their personal experience and expertise, some caution should be extended when extrapolating results.

A second limitation to the research was that time and budget constraints did not allow for an extensive literature review to provide detailed findings about the current gaps in the literature. The literature scan was limited in scope and primarily used to provide additional context to the researchers.

An additional consideration was that the research was conducted during the COVID-19 pandemic. This may have influenced the issues were top of mind for participants, and how effectively people were able to participate.

While the research design was supported through partnership with Amaze and refined with the AARC, which includes members from the autistic and autism communities, it would have also been beneficial to conduct a preliminary co-design workshop with autistic people and family members as part of the methodology.

2.5 Presentation of findings

Overall report structure

The results presented in this report are structured into three primary areas to aid interpretation. Our structured approach comprises:

- An executive summary (see separate document) that draws together and summarises key results and presents key research outcomes;

- Specific findings for each of the research Priority Areas. This structure also adopts a multi-layered approach to reporting for each Priority Area. Initially there is a summary of the broad issues from the research, then a list of the top 4 research topics chosen by participants in that discussion board (in each instance this represents at least 50% agreement), the top 10 research topics, and lastly detailed findings on research topics including policy and practice insights for the Priority Area; and
- A high-level overview of identified core themes and issues raised in the research across the Priority Areas, and considerations of the policy context.

The qualitative findings from the discussion group and quantitative findings from the final prioritisation poll have been integrated throughout the report.

Qualitative findings

The following terms used in the report provide a qualitative indication and approximation of the size of the target audience who held particular views:

- Most – refers to findings that relate to more than three quarters of the research participants;
- Many – refers to findings that relate to more than half of the research participants;
- Some – refers to findings that relate to around a third of the research participants; and
- A few – refers to findings that relate to less than a quarter of research participants.

The most common qualitative findings are reported except in certain situations where only a minority has raised particular issues, but these are nevertheless considered to be important and to have potentially wide-ranging implications / applications.

Participant quotes have been provided throughout the report to support the main results or findings under discussion. These quotes have not been attributed to preserve anonymity.

Quantitative findings

How results were calculated and displayed

About percentage results shown in this report:

- Results are based on the total number of valid answers collected for any given question. In most cases, results reflect those respondents who had a view, and for whom the questions were applicable. ‘Don’t know / not sure’ responses have only been shown where doing so helps interpretation of the results.
- Results for questions where respondents gave only one answer may not sum to 100% due to rounding. Results for questions where respondents could provide multiple answers do not sum to 100%.
- In some of the charts presented, results below 3% have not been shown, in the interest of making charts clearer, and easier to read.

Findings have only been reported where results were found to be meaningful.

The polling data used in this research have not been weighted. The results have been reported on a ‘one response, one vote’ basis.

Statistical precision

The online survey employed a census sampling approach – where all participants who participated in the five discussion boards were offered the chance to complete the survey. This means the results of this survey were not subject to sampling error (in contrast to sample surveys, where only a fraction of the total population is invited to participate). Therefore, the concept of Margin of Error is not applicable.

The census approach remains subject to non-sampling measurement error, with non-response bias the main risk (i.e., the situation where the people who choose to answer the survey differ systematically from those who choose not to do so in ways that are important to the items covered in the survey). To minimise non-response bias, considerable efforts were made to maximise the response rates to the surveys. The high response rate achieved to the final prioritisation poll implies that non-response bias is unlikely to be material.

Breakdown of findings for autistic and non-autistic participants

For each Priority Area the top five research topics identified autistic and non-autistic research participants in the final prioritisation poll are shown. Overall, 60% of all respondents indicated they were autistic (n=28). For each Priority Area, the proportion of autistic people who answered each prioritisation question ranged from 64% - 62%. The comparison group of those who were non-autistic is relatively small (n=16), and so comparison results should be interpreted with caution. That is, some differences are likely to be a factor of chance and variation (i.e., noise), and may not signify real differences in opinion.

Key terms

The definition of key terms used throughout this report are outlined in the box below. Further definitions can be found in the glossary at Appendix D and are highlighted in grey the first time they appear in the report.

- **Autistic community**: this term is used to refer to the collective community of autistic people.
- **Autism community:** this term is used refer to autistic individuals, their friends, families, allies and professionals who provide services and/or support.
- **Neurodiversity:** the natural differences in the way that human brains function. The neurodiversity perspective is that all neurological differences are valuable and should be respected as natural ways of being (den Houting, 2019; Walker, 2020)
- **Relational social model:** a concept that proposes that disability is created through unequal social relationships and restrictions placed on individuals through social barriers (Cologon, 2016).
- **Medical model:** a view of disability as impairments within an individual, that may need to change or be 'fixed' to reduce or eliminate disability or more easily fit in with society (Cologon, 2016).
- **Co-production:** involves researchers and end-users working together as peers to ensure that the purpose of the research, the research methodology and the application of research outputs are relevant to, and appropriate for the end-users. In the case of autism research this would involve autistic individuals and their communities (Autism CRC, 2021)
- **Self-advocacy:** an individual having their voice heard and understood in relation to their needs, wants and things that are important to them (Autism Launchpad, 2021).
- **Diverse communication:** this term is used to refer to the wide range of methods and styles of communication that a person may use, including non-speaking communication methods.

2.6 Quality assurance

The project was conducted in accordance with international quality standard ISO 20252 and the Australian Privacy Principles contained in the Privacy Act 1988. The project was approved by the ORIMA Human Research Ethics Committee (HREC), Reference Number 0062020.

3 Overview

To assist in organising the key research questions identified for each Priority Area. Five broad thematic **research categories** were identified which were common across the Priority Areas. These have been used to assist in organising and discussing the findings throughout the report. They include:

Experiences, preferences and needs – improving understanding of the diverse life experiences and perspectives of autistic people. All five Priority Areas had topics falling into this category;

Policy, practices, supports and accommodations – developing knowledge, understanding and approaches that result in informed policies and practices to create changes that are broadly and consistently implemented. All five Priority Areas had topics falling into this category;

Information, training and professional development – improving knowledge about autism and best practice, often in the professional context. Four of five Priority Areas had topics falling into this category;

Awareness, understanding and attitudes – informing opportunities to increase awareness and understanding about the autistic community, and changing attitudes in the general population. While raised in most Priority Areas, Communication topics tended to focus on widespread community changes to community attitudes and awareness; and

People, community and prevalence – identifying the prevalent factors, characteristics and trends amongst the autistic community in the different Priority Areas. Two Priority Areas had topics falling into this category – these were Health and Wellbeing and Justice.

Throughout the report, the research topics identified as important by participants have been grouped according to these categories where relevant. While each topic has been discussed under a single category, some topics could fit in to more than one theme and these have been assigned based on the intention of the research.

For each Priority Area, the suggested research topics have been provided alongside contextual information from the discussion boards to enable insight into the perspective of participants reasoning and intended impact of the research topic.

The top five topics areas for each Priority Area have been shown broken down for autistic and non-autistic participants. Overall, there was a high level of alignment between priority topics for autistic and non-autistic participants, with the greatest alignment for Employment and Justice. The most divergent views were for Health and Wellbeing. Where there were differences, this appeared to reflect a high representation of parents that do not identify as being autistic (approximately 70%) with a greater preference for research into how autistic people can be supported at different stages of their lives by parents and by key systems. This appeared reflective of the experience and insights parents offer in navigating policy and administration within education, health and justice systems.

For each Priority Area, the full list of topics in the prioritisation poll is included in Appendix C.

In addition to the primary findings relating to the key research questions for each Priority Area, some broad themes which articulate the larger societal shift that participants hoped that research would contribute to are included in Section 9. In this section, the importance of autistic voice and co-produced research is also emphasised.

4 Communication

This chapter provides an overview of the findings from the research in relation to communication. A total of 12 members of the autistic and autism communities participated in the discussion group. Of these 12, four were autistic, seven were family members and three were relevant professionals[4]. Participants included: autistic people who communicate through non-speaking methods, autistic people (or their family members) who have experienced challenges due to a lack of communication supports or misunderstandings, autistic people or family members from non-English speaking backgrounds, and professionals working with members of the autistic community in relevant fields.

A total of 43 participants completed the final prioritisation poll in this Priority Area (11 who took part in the Communication discussion board, and 32 who took part in discussion boards on other topics).

4.1 Overview

This section summarises the broad issues and desired outcomes from research in the area of Communication.

Participants reported that there are a range of communication methods used and preferred amongst the autistic and autism communities, including written communication, use of assistive technology and communication displayed through behaviours. Participants also described differing preferences in relation to communication styles, such as direct/straightforward communication or informative/sharing based communication.

Most participants felt that **diverse communication methods and styles were undervalued** and not catered for in society. They reported that spoken language was perceived as the “gold standard” for communication and that throughout an autistic person’s life, there was continued pressure and expectation to use spoken language, even when this is not a person’s preferred or strongest communication method. They reported that this impacted people’s ability to participate or for their views to be regarded across different life areas including in relationships, education and employment.

The research identified that there is a desire for a research agenda that that contributes **to increased awareness, understanding and widespread acceptance of diverse forms of communication**.

> *“Communication plays an integral part of every part of life. When there are challenges or differences in communication it can create pressure, frustration, assumptions, distance, and all sorts of other problems for the person experiencing the challenges and sometimes the recipient/s”*

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[4] Participants could represent more than one category and as such these numbers do not sum to 12.

4.2 List of priority topics

This section provides a list of the topics identified as most important for future research in Communication. The list is in order of priority based on the overall results from the final poll.

The top 4 research questions for participants on the Communication discussion board were:

1. How can the acceptance and use of diverse forms of communication (including non-verbal) in education settings be improved, to support all autistic students to participate in the educational and social curriculum? (70%)

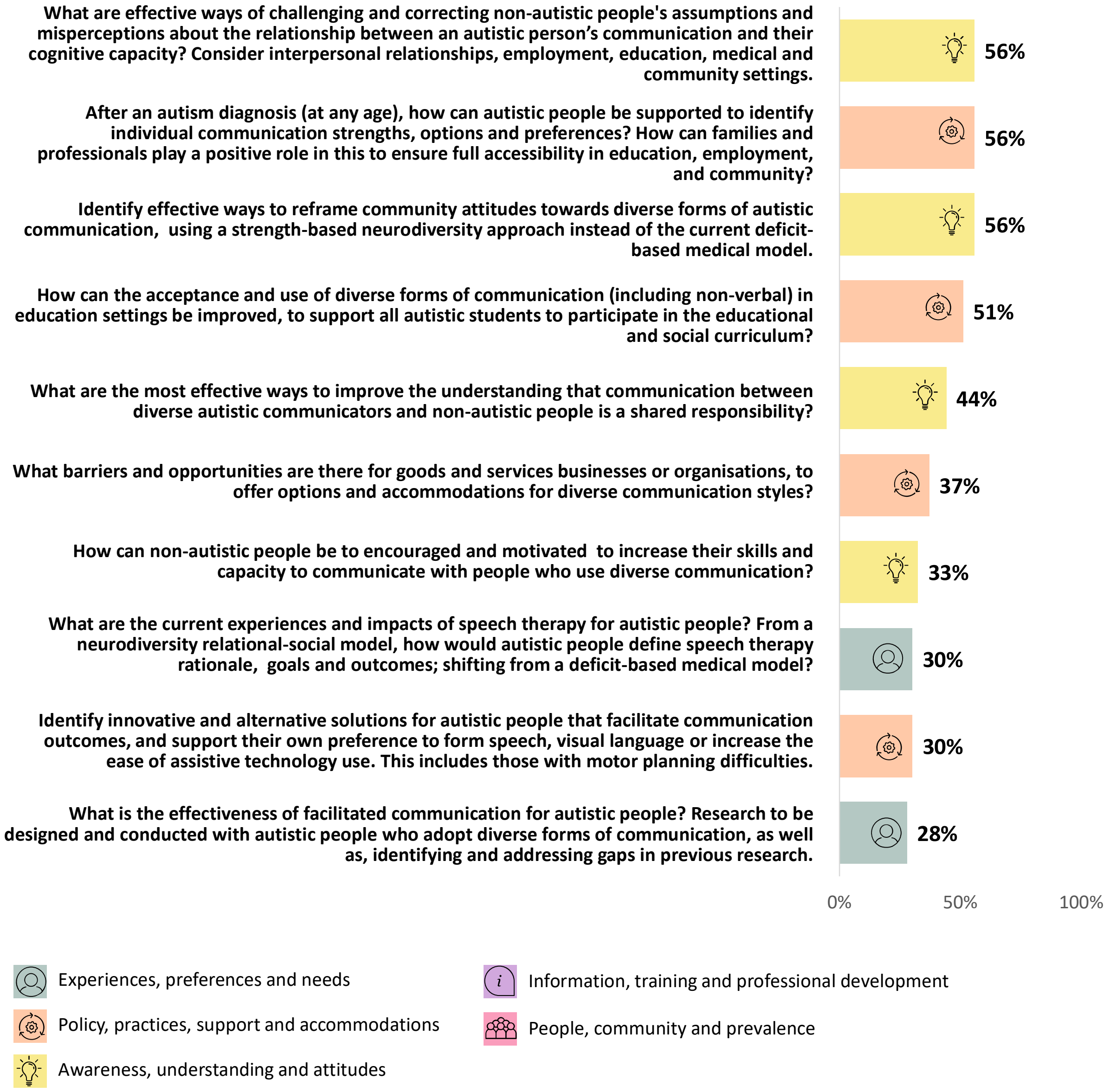
2. Identify effective ways to reframe community attitudes towards diverse forms of autistic communication, using a strength-based neurodiversity approach instead of the current deficit-based medical model. (60%)

3. After an autism diagnosis (at any age), how can autistic people be supported to identify individual communication strengths, options and preferences? How can families and professionals play a positive role in this to ensure full accessibility in education, employment, and community? (50%)

4. What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility? (50%)

Figure 2 on the next page, outlines the top 10 research topics by all discussion board participants in the area of Communication. These are discussed in more detail in the next section.

Figure 2: List of priority topics in Communication (n=43)



Relevant question: Q9. Which of the following topics related to Communication do you think are the five most important to research further? Which five areas, if better understood / researched, do you think would have the greatest positive impact on your life / the lives of autistic people? [please select up to 5 responses]

Breakdown of findings by autistic and non-autistic participants

Overall, there was great overlap between the top five topics for autistic and non-autistic participants. Topics which were in the top five for both groups are highlighted in blue in Table 2 below. There appeared to be a greater emphasis on topics related to changing community attitudes to diverse communication amongst autistic participants. While topics related to this theme were also evident in the non-autistic group, non-autistic participants tended to prioritise topics related to supporting autistic people to identify and use their preferred communication methods.

Table 2: Top five topics by autistic and non-autistic participants for Communication
(equal rating is possible)

Autistic participants (n=27)	
Identify effective ways to reframe community attitudes towards diverse forms of autistic communication, using a strength-based neurodiversity approach instead of the current deficit-based medical model.	67%
What are effective ways of challenging and correcting non-autistic people's assumptions and misperceptions about the relationship between an autistic person's communication and their cognitive capacity? Consider interpersonal relationships, employment, education, medical and community settings.	63%
After an autism diagnosis (at any age), how can autistic people be supported to identify individual communication strengths, options and preferences? How can families and professionals play a positive role in this to ensure full accessibility in education, employment, and community?	56%
How can the acceptance and use of diverse forms of communication (including non-verbal) in education settings be improved, to support all autistic students to participate in the educational and social curriculum?	48%
What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility?	41%
Non-autistic participants (n=16)	
How can the acceptance and use of diverse forms of communication (including non-verbal) in education settings be improved, to support all autistic students to participate in the educational and social curriculum?	56%
After an autism diagnosis (at any age), how can autistic people be supported to identify individual communication strengths, options and preferences? How can families and professionals play a positive role in this to ensure full accessibility in education, employment, and community?	56%
What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility?	50%
What are effective ways of challenging and correcting non-autistic people's assumptions and misperceptions about the relationship between an autistic person's communication and their cognitive capacity? Consider interpersonal relationships, employment, education, medical and community settings.	44%
What barriers and opportunities are there for goods and services businesses or organisations, to offer options and accommodations for diverse communication styles?	44%
Identify innovative and alternative solutions for autistic people that facilitate communication outcomes, and support their own preference to form speech, visual language or increase the ease of assistive technology use. This includes those with motor planning difficulties.	44%

4.3 Detailed findings on research topics

This section provides:

- *Additional context to the topics identified as important for future research;*
- *Insight into the desired impact from this research; and*
- *An overview of how the topics identified as important by participants align with the currently available research*

It is structured according to thematic research categories based on the highest rated topics.

Awareness, understanding and attitudes

Four research topics related to raising awareness and understanding, as well as changing attitudes in relation to communication. These were:

- *What are effective ways of challenging and correcting non-autistic people's assumptions and misperceptions about the relationship between an autistic person's communication and their cognitive capacity? Consider interpersonal relationships, employment, education, medical and community settings. (Selected by* ***56%*** *of participants)*
- *Identify effective ways to reframe community attitudes towards diverse forms of autistic communication, using a strength-based neurodiversity approach instead of the current deficit-based medical model. (Selected by* ***56%*** *of participants)*
- *What are the most effective ways to improve the understanding that communication between diverse autistic communicators and non-autistic people is a shared responsibility? (Selected by* ***44%*** *of participants)*
- *How can non-autistic people be to encouraged and motivated to increase their skills and capacity to communicate with people who use diverse communication? (Selected by* ***33%*** *of participants)*

Autistic, family member and professional participants reported that there was a common **misperception that if someone does not speak, they lack intelligence or the capacity to learn.** Family member participants reported that in the education setting, their children were often excluded from lessons and not expected to learn or progress. Autistic participants identified that this misperception persisted into adulthood where they were underestimated or patronised in employment and other social contexts. Participants identified a need for research that assists in identifying effective strategies and approaches to change assumptions about communication and capacity.

> *"…not speaking is in no way a reflection of intellectual ability and it just means we need to try harder to understand someone's perspective rather than ignoring them or giving them less choice and control in their life"*

Most participants reported that as **speech is so widely seen as the norm**, choosing or needing to use other forms of communication was seen as a deficit and something to be "fixed". A few autistic participants felt that this attitude begins with professionals supporting families when a child or young person is diagnosed with autism (e.g., doctor, speech pathologists and psychologist), and the use of deficit-based language. As such, they felt there was a need for change in the education and training of professionals. A few participants also felt broad community awareness campaigns could also assist in changing attitudes. The proposed research offers an opportunity to identify the most effective approaches to change attitudes and reframe community perceptions about autism and communication.

> *"I think having new research out there that challenges the narrative around autism from the medical/deficit model towards acceptance and understanding of neurodivergence is key. This type of research that changes the narrative will likely lead to more fulfilling lives, positive self-esteem, acceptance and understanding for autistic people and those around them"*

In addition to increasing awareness and changing attitudes, many autistic, family member and professional participants reported that there was a need for **non-autistic people to take on a greater responsibility** for **understanding the perspectives and communication methods and preferences of autistic people.** Most autistic participants reported that it was commonly expected that they needed to adapt and adjust to conform to non-autistic communication norms and when they did not, they were judged or excluded. As such, participants identified a need for research which shifts the focus from strategies that autistic people can use to adapt their communication, to understanding how to increase responsibility and skills amongst non-autistic people to participate in diverse communication.

> *"The lives of autistic people would be greatly improved if they weren't required to be verbal in order to be equally included, and if the [non-autistic] world accommodated alternative forms of communication"*

Policy, practices, supports and accommodations

There were four topics on the list which most strongly related to improving policy, practices, support and accommodations for communication. These were:

- *After an autism diagnosis (at any age), how can autistic people be supported to identify individual communication strengths, options and preferences? How can families and professionals play a positive role in this to ensure full accessibility in education, employment, and community? (Selected by **56%** of participants)*
- *How can the acceptance and use of diverse forms of communication (including non-verbal) in education settings be improved, to support all autistic students to participate in the educational and social curriculum? (Selected by **51%** of participants)*
- *What barriers and opportunities are there for goods and services businesses or organisations, to offer options and accommodations for diverse communication styles? (Selected by **37%** of participants)*
- *Identify innovative and alternative solutions for autistic people that facilitate communication outcomes and support their own preference to form speech, visual language or increase the ease of assistive technology use. This includes those with motor planning difficulties. (Selected by **30%** of participants)*

Most autistic family and professional participants reported that it was important that all autistic people were **supported to identify and use the communication approach which works best for them**. They felt that guiding autistic people to use speech should not be the default. Upon identifying unique communication needs and preferences, most participants reported that autistic people needed others to respect and support the use of these, including families and professionals.

A few participants highlighted that unique needs of those in bilingual and multilingual households should be given explicit consideration. The proposed research offers an opportunity to inform best practice in helping to identify communication strengths and preferences, and effective approaches for supporting this.

> *"Speech is not the best way to communicate for everyone. Speech isn't the most effective mode of communication for everyone"*

Education settings were identified by most family member participants as important environments to build acceptance and use of diverse communication to ensure all students are given the opportunity to learn, socialise and reach their potential. Family member participants reported experiences where their children were not supported to use their communication devices or preferred method by teachers, teachers' aides or speech therapists in mainstream and special schools. It was noted that their child's expression through "challenging behaviours" resulted in being punished or excluded. The proposed research offers the opportunity to understand what the barriers are to supporting all forms of communication and inform how these can be overcome to ensure equal access to education.

> *"To me the worst thing is that some of these schools do not even provide a child with a way to communicate. Communication devices aren't encouraged or are barely used"*

More broadly in the community, many autistic participants identified opportunities to improve the **diverse communication offerings of organisations providing goods and services**. For example, having multiple channels to engage with the businesses (such as, in-person, telephone and online), making it straightforward for people to identify and use their preferred communication method, and offering documentation in plain, but not oversimplified, language. The proposed research offers an opportunity to identify what would encourage greater use of inclusive communication practices in these setting.

> *"There are a lot of non-verbal approaches to communication that could be implemented to support both autistic and non-autistic people. Often businesses and services don't know what they are, or how easy they are to implement"*

Some autistic, family member and professional participants identified the importance of the **continued development and effective use of alternative communication methods**, including for those with motor planning difficulties. A few participants identified that some communication methods only allow people to react or respond, not generate spontaneous communication. Participants identified a need for research which continues to develop innovative communications approaches, ensuring that the needs and goals of autistic people are used to determine the success or failure of solutions.

Experiences, preferences and needs

There were two topics on the list which related to developing insight into the experiences, preferences and needs of autistic people. These were:

- *What are the current experiences and impacts of speech therapy for autistic people? From a neurodiversity relational-social model, how would autistic people define speech therapy rationale, goals and outcomes? (Selected by **30%** of participants)*

- *What is the effectiveness of facilitated communication for autistic people? Research to be designed and conducted with autistic people who adopt diverse forms of communication, as well as identifying and addressing gaps in previous research. (Selected by **28%** of participants)*

Some autistic participants reported that they had had negative **experiences with speech therapy** in the past as the goal of this therapy had been to make them speak and make their speech sound "normal", even when this was not their preferred communication method. Participants were interested in future research to understand the experiences of autistic people accessing speech therapy with a view to understanding how autistic people can play a bigger role in defining the goals and success of speech therapy.

> *"In regard to the speech therapy question, I believe improvements as a result of asking these questions would ensure that speech therapists are focussed on improving the quality of life for Autistic people rather than simply focussing on making us 'fit-in' to the so-called 'norm'"*

Some autistic and family member participants identified that **facilitated communication techniques** were important for giving some autistic people a voice. They raised that there has been mixed evidence about the effectiveness of these techniques, which has impacted their endorsement and use. They reported that it was important for future research to review and identify the gaps in this research and ensure that future research on these communication techniques is co-produced by autistic people using diverse forms of communication.

> *"It is important to sift through the evidence supporting or refuting these positions to clarify the issues. Personally, (facilitated communication) has given me a voice which is life changing"*

5 Education

This chapter provides a brief overview of the findings from the research in relation to Education. A total of 10 members of the autistic and autism communities participated in the discussion group. Amongst these 10, four were autistic, eight were family members and three were relevant professionals[5]. This included autistic people, their family members and those with professional connections with perspective relevant to different models of education (e.g., public, private, autism specific and home schooling). It also included family members of those who had experienced school refusal.

A total of 43 completed the final prioritisation survey in this Priority Area (7 who took part in the Education discussion board, and 36 who took part in discussion boards on other topics).

5.1 Overview

This section summarises the broad issues and desired outcomes from research in the area of Education.

Most participants in the Education research discussion were primarily focused on the issues for autistic students in primary and secondary school years, despite prompting on early learning and post-secondary education. A few participants highlighted that many of the issues are also relevant for autistic students in tertiary education.

Many participants reported that there was **systemic failure to support autistic children** in the current education system. This was most pronounced in mainstream schools of all types (i.e., government, independent and catholic), but was also an issue in special schools. Participants reported that in mainstream schools, as well as special schools, students were often socially segregated and not academically extended. Combined with reported lack of accommodations to ensure student safety and engagement, students were often not prepared academically, socially or emotionally for adulthood. They reported that there is a lack of strengths-based, personalised and flexible learning and teaching which considers autistic students' learning and social styles, needs and preferences.

Many participants reported that in addition to having a negative impact on autistic students' learning, development and wellbeing, the current system also creates strain for families more broadly. Most family member participants reported continually advocating for their child within schools or to take their children out of school to home school instead. They reported that this took a considerable emotional and financial toll on families.

The research identified the need for a research agenda that contributes to the **systematic inclusion of autistic students in all Australian schools**.

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[5] Participants could represent more than one category and as such these numbers do not sum to 10.

> *"Addressing these challenges [in education] and improving understanding would firstly address the often awful experience of autistic individuals in the education system... It would lessen the tremendous stress and strain on families as they try to deal with the inadequacies of the system but more importantly it would enable people with autism to access the education they have a right to, to fulfill their potential and to live their best lives. At the moment we are failing a large majority of these kids."*

5.2 List of priority topics

This section provides a list of the topics identified as most important for future research in Education. The list is in order of priority based on the overall results from the final prioritisation poll.

The top 4 research topics and questions for participants on the Education discussion board were:

1. How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom? (88%)

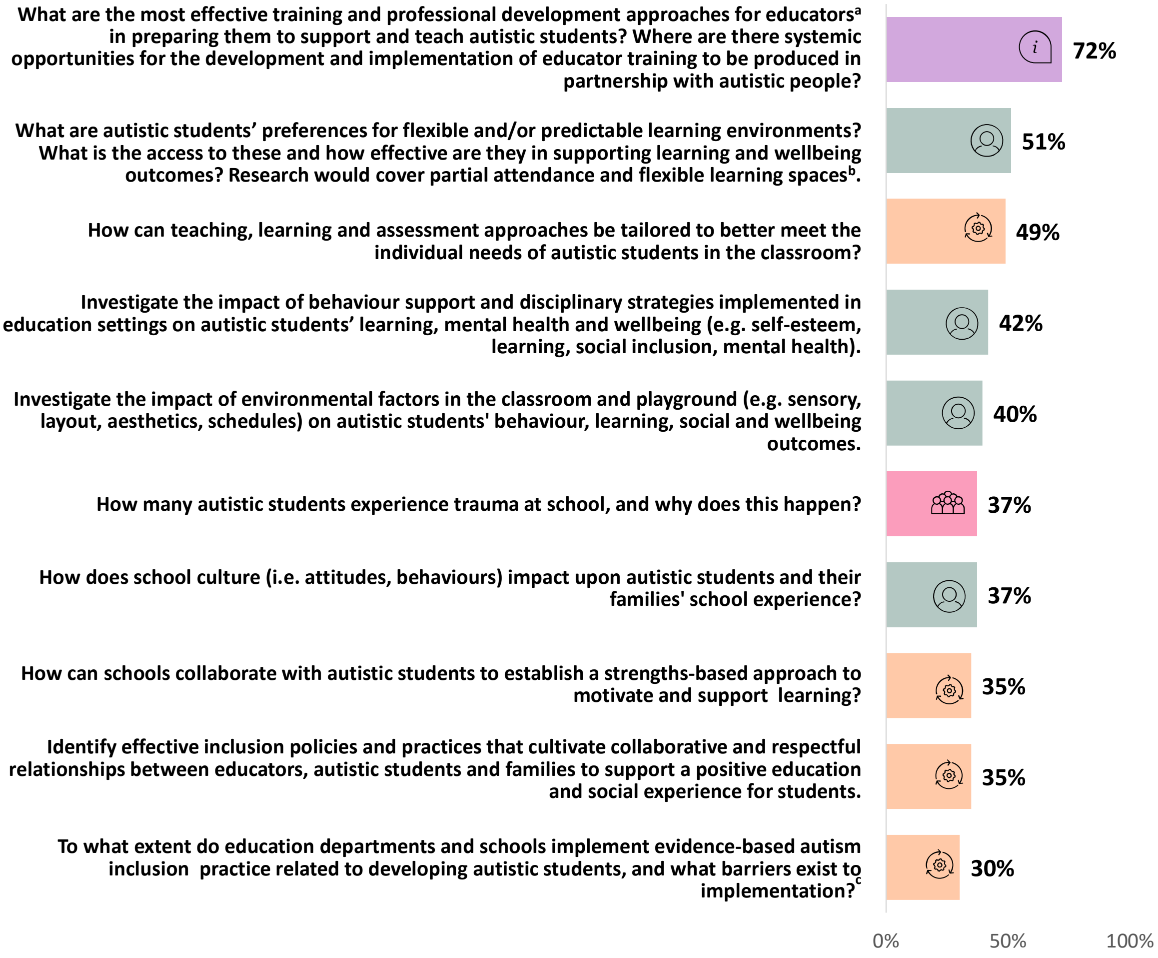
2. What are the most effective training and professional development approaches for educators in preparing them to support and teach autistic students? Where are there systemic opportunities for the development and implementation of educator training to be produced in partnership with autistic people? (88%)

3. Investigate the impact of environmental factors in the classroom and playground (e.g. sensory, layout, aesthetics, schedules) on autistic students' behaviour, learning, social and wellbeing outcomes. (63%)

4. What are autistic students' preferences for flexible and/or predictable learning environments? What is the access to these and how effective are they in supporting learning and wellbeing outcomes? Research would cover partial attendance and flexible learning spaces. (50%)

Figure 3 on the next page, outlines the top 10 research topics by all discussion board participants in the area of Education. These are discussed in more detail in the following section.

Figure 3: List of priority topics in Education (n=43).



[a] Educators means the following people or positions: teachers, teacher aides, wellbeing coordinators and school leaders.
[b] i.e. mixed attendance and distance education, micro-schools - small neighbourhood schools, quiet study spaces.
[c] This includes, exploring the perspectives of autistic students, their families, educators and policy makers at all education stages.

Experiences, preferences and needs
Policy, practices, support and accommodations
Awareness, understanding and attitudes
Information, training and professional development
People, community and prevalence

Relevant question: Q3. Which of the following topics related to Education do you think are the five most important to research further? Which five areas, if better understood / researched, do you think would have the greatest positive impact on your life / the lives of autistic people? [please select up to 5 responses]

Breakdown of findings by autistic and non-autistic participants

Overall, there was some overlap between the top five topics for autistic and non-autistic participants. Topics which were in the top five for both groups are highlighted in blue in the Table 3 below. The top three topics for each group were the same. In addition, the topic given fourth priority in the autistic group was given sixth priority for the non-autistic group (38%) and the topic given fourth priority for the non-autistic group was given sixth priority for the autistic group (37%). However, autistic participants showed greater interest in the specific topic of individuals' experiences of trauma at school, while non-autistic participants were interested in the broader topic of school culture on students as well as families. Further down the list of topics, the non-autistic groups placed greater emphasis on topics related to understanding governance arrangements in relation to support for and funding of supports for autistic people in the education system.

Table 3: Top five topics by autistic and non-autistic participants for Education

Autistic participants (n=27)	
What are the most effective training and professional development approaches for educators in preparing them to support and teach autistic students? Where are there systemic opportunities for the development and implementation of educator training to be produced in partnership with autistic people?	74%
How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom?	52%
What are autistic students' preferences for flexible and/or predictable learning environments? What is the access to these and how effective are they in supporting learning and wellbeing outcomes? Research would cover partial attendance and flexible learning spaces.	52%
Investigate the impact of behaviour support and disciplinary strategies implemented in education settings on autistic students' learning, mental health and wellbeing (e.g. self-esteem, learning, social inclusion, mental health).	44%
How many autistic students experience trauma at school, and why does this happen?	44%
Non-autistic participants (n=16)	
What are the most effective training and professional development approaches for educators in preparing them to support and teach autistic students? Where are there systemic opportunities for the development and implementation of educator training to be produced in partnership with autistic people?	69%
What are autistic students' preferences for flexible and/or predictable learning environments? What is the access to these and how effective are they in supporting learning and wellbeing outcomes? Research would cover partial attendance and flexible learning spaces.	50%
How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom?	44%
Investigate the impact of environmental factors in the classroom and playground (e.g. sensory, layout, aesthetics, schedules) on autistic students' behaviour, learning, social and wellbeing outcomes.	44%
How does school culture (i.e. attitudes, behaviours) impact upon autistic students and their families' school experience?	44%

5.3 Detailed findings on research topics

This section provides:

- *Additional context to the topics identified as important for future research;*
- *Insight into the desired impact from this research; and*
- *An overview of how the topics identified as important by participants align with the currently available research*

It is structured according to thematic research categories based on the highest rated topics.

Information, training and professional development

The number one topic for Education related to the training and professional development of teachers. This was:

> *What are the most effective training and professional development approaches for educators in preparing them to support and teach autistic students? Where are there systemic opportunities for the development and implementation of educator training to be produced in partnership with autistic people? Educators means the following people or positions: teachers, teacher aides, wellbeing coordinators and school leaders. (Selected by* ***72%*** *of participants)*

Many participants identified that **often teaching practices and policies are not aligned with the learning, social and emotional needs of autistic students**. They identified a range of awareness, understanding and attitudinal barriers to educators implementing best practices, to ensure that autistic students can engage with education and their peers. A few participants identified that some educators are well informed, but this is not widespread. Many participants felt that there was a need for universal training of teachers about autism and neurodiversity to ensure that all educators are equipped to meet the need of all their students. A few participants highlighted that this would not only benefit autistic students and their families, but also educators themselves by increasing their self-efficacy and reducing the stress cause by ineffective practices. Many participants reported that it was essential the any research, training and professional development be informed by autistic people, including students.

> *"When [teachers] understand what drives behaviour and have practical ways to build better relationships, they go away and practice this. You don't know what you don't know"*

> *"I would also hope that research would uncover meaningful ways for teachers to be better equipped, confident and supported to teach ALL kids, not just kids who fit in the box"*

Experiences, preferences and needs

Four topics were about increasing the understanding of the education experiences, needs and preferences of autistic students. There is overlap with the theme of policy, practices, supports and systematic accommodations with many of these topics. These topics were:

> *What are autistic students' preferences for flexible and/or predictable learning environments? What is the access to these and how effective are they in supporting learning*

*and wellbeing outcomes? Research would cover partial attendance and flexible learning spaces (i.e. mixed attendance and distance education, micro-schools - small neighbourhood schools, quiet study spaces). (Selected by **51%** of participants)*

- *Investigate the impact of behaviour support and disciplinary strategies implemented in education settings on autistic students' learning, mental health and wellbeing (e.g. self-esteem, learning, social inclusion, mental health). (Selected by **42%** of participants)*
- *Investigate the impact of environmental factors in the classroom and playground (e.g. sensory, layout, aesthetics, schedules) on autistic students' behaviour, learning, social and wellbeing outcomes. (Selected by **40%** of participants)*
- *How does school culture (i.e. attitudes, behaviours) impact upon autistic students and their families' school experience? (Selected by **37%** of participants)*

The research found that to inform policies, practices and training there was a need to increase the understanding of the experiences, needs and preferences of autistic students. Most autistic, family member and professional participants reported that autistic students may have **unique needs and preferences in their learning processes and physical environment**, however these are often not supported. They reported that unique preferences may be in areas such as the sensory environment in the classroom, how their day is structured and how tasks are set. There may also be additional needs based on co-occurring learning difficulties. Participants reported that these factors have significant impacts on a students' ability to engage with the learning and the social curriculum and can cause anxiousness and distress. They reported that when a student struggles, the student is often blamed and there is little consideration of the external factors that contributed. Research offers an opportunity to define the current state of play and identify clear, evidence-based opportunities for improvement in flexible approaches and accommodations in the education setting.

> *"There's a focus on behaviour instead of a focus on looking at how the environment, social interactions, internal stresses and delivery of learning impacts behaviour"*

> *"Many, many facets of the current school environment present hurdles to autistic kids' learning. These hurdles are comprised of an extremely complex intersection of factors which can result in high levels of constant anxiety in autistic kids, and no one, no matter their neurotype, can process new info and learn in that high anxiety state"*

Many autistic and family member participants reported that the commonly applied **disciplinary and behavioural management strategies** used in education settings are generally ineffective and damaging for autistic students. This included strategies such as escalating punishment and excluding students from the classroom. Participants reported that these often did not modify student's behaviour, particularly when external environmental factors which may have contributed to the need for behaviour support or disciplinary action remined unchanged. Furthermore, some participants reported that behaviour support or disciplinary strategies which singled out autistic students also had the impact of signalling to their peers that they were different and contributed to exclusion of autistic students. Participants felt that there was a need for more understanding to support identification of ineffective strategies and support the development and use of more effective strategies.

In addition to specific practices and accommodation in the learning environment, some participants felt that **broader cultural issues within education settings** also needed to be investigated. They reported other families in the school community and student peers demonstrated a lack of understanding, empathy or support for diversity. Participants reported that this added to the challenges experienced by autistic students, who may be struggling to navigate the school environment and develop a positive sense of identity. They also identified that it increased the difficulty for parents trying to be heard and understood while advocating for their child. The proposed research in this area offers an opportunity to understand the factors that could help to create a safe and supportive culture for autistic students and their families.

> *"I would like to think effective research would lead to autistic kids being properly accepted, understood and included in their local school communities rather than segregated and isolated. A feeling of acceptance and belonging with their peers"*

A few participants highlighted the COVID-19 pandemic had been a trigger for adapting the learning environment and structure with new strategies and opportunities being identified. They felt that this experience could be used to consider different ways of engaging with education.

Policy, practices, supports and accommodations

There were four topics most closely linked to informing policies, practices and accommodation in the education sector. There were:

- *How can teaching, learning and assessment approaches be tailored to better meet the individual needs of autistic students in the classroom? (Selected by **49%** of participants)*
- *How can schools collaborate with autistic students to establish a strengths-based approach to motivate and support learning? (Selected by **35%** of participants)*
- *Identify effective inclusion policies and practices that cultivate collaborative and respectful relationships between educators, autistic students and families to support a positive education and social experience for students. (Selected by **35%** of participants)*
- *To what extent do education departments and schools implement evidence-based autism inclusion practice related to developing autistic students, and what barriers exist to implementation? This includes exploring the perspectives of autistic students, their families, educators and policy makers at all education stages. (Selected by **30%** of participants)*

Many autistic and family member participants reported that there is often a **lack of adaptation to learning and assessment approaches** to make the curriculum accessible to autistic students. They identified that often autistic students have understood the lesson or have the capacity to learn the content, but assessment and teaching approaches act as a barrier to demonstrating this. Many participants reported that autistic students have individual strengths that can be used in teaching strategies to ensure that all students are engaged and can meet their potential. While some participants reported experiences of individual teachers or schools tailoring learning and assessment approaches effectively, these were generally exceptions based on the actions of specific individuals.

> *"Addressing this would hopefully improve the daily lives of autistic students by allowing them to show their potential at school more consistently and equip schools with evidence around what practices may be holding their students back"*

To cater for the great diversity within the autistic student population, autistic and family member participants highlighted a need for educators to **work with students, as well as their families**, to understand their unique strengths, challenges and preferences. They also felt that processes to support the collaboration between students, families and educators could be improved more broadly so that there is safe and open communication. This includes from the very beginning before a child starts school, where families can be given the information they need to decide on a school for their child, and to know their rights and responsibilities in this process. Research offers an opportunity to provide insights into factors that support effective relationships and how these can be fostered.

Many autistic and family member participants felt there was a need to identify **autistic-informed, evidence-based teaching and learning practices**, as well as how they can be implemented more widely and consistently. Some felt many useful practices had been identified but were not being consistently translated into practice. Research offers an opportunity to understand what barriers may exist for schools and other educational institutions using inclusive, supportive and tailored strategies, and how these can be overcome to positively impact the educational experiences of autistic students and their families.

People, community and prevalence

There was one topic which was linked to understanding occurrences within the population of autistic students, this was:

> *How many autistic students experience trauma at school, and why does this happen? (Selected by **37%** of participants)*

Many participants reported that the **school environment could be traumatic for students** for the range of reasons previously discussed in this chapter; as well as the flow on effects from these, such as being excluded by peers, being asked to leave schools and not being able to reach their learning potential. Participants felt it was important for research to identify how many students experience trauma, and to build an understanding of the pathways that lead to this, in order to highlight targets for changes in systemic policies and the practices that enact these.

> *"So many of these kids are lost. They are passed from setting to setting like hot potatoes and the child makes no progress and their self-esteem just dwindles to [zero]. They learn nothing and are left traumatised, feeling worthless. Change from a departmental level down is a critical part of the solution"*

6 Employment

This chapter provides a brief overview of the findings from the research in relation to Employment. A total of 12 members of the autistic and autism communities participated in the discussion group. Amongst these 12, nine were autistic, seven were family members and five were relevant professionals[6]. The group included autistic people or their family members employed in different kinds of employment, autistic people or their family members who have experienced under-employment or unemployment, and people who have autistic employees.

A total of 44 participants completed the final prioritisation poll in this Priority Area (9 who took part in the Employment discussion board, and 35 who took part in discussion boards on other topics).

6.1 Overview

This section summarises the broad issues and desired outcomes from research in the area of Employment.

Most participants reported that **under-employment and unemployment are major concerns** for the autistic community. Participants reported that under-employment and unemployment have a broad range of negative impacts for autistic people, including on mental health, financial security, range of choice and opportunity, and finding fulfilment and purpose in life. Participants reported that there are also impacts for workplaces, which miss out on the opportunity to employ autistic people who have value to add through their unique perspectives, skills and strengths.

> *"…being under-employed (especially) and also experiencing periods of unemployment, after doing all of that studying and earning two degrees, is soul destroying and heart breaking"*

> *"Work allows for friendships, feelings of being appreciated, pride and also let's not forget productivity. Workplaces can benefit from hiring more autistic staff"*

The research identified the need for a research agenda that contributes to the **removal of barriers and creation of opportunities for autistic people to participate in employment that aligns with their individual interests and skill sets across all industries and sectors**.

> *"The knowledge on both sides (employers and autistic people) can get autistic people into work that is meaningful and satisfying, and also work which is in the fields of their skill sets and knowledge. This can drive down the high rates of unemployment and under-employment of autistic people. Having meaningful and satisfying work, can also increase the social and economic participation of autistic people and increase their wellbeing and happiness."*

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[6] Most participants represented more than one category and as such these numbers do not sum to 12.

6.2 List of priority topics

This section provides a list of the topics identified as most important for future research in Employment. The list is in order of priority based on the overall results from the final prioritisation poll.

The top 4 research questions for participants on the Employment discussion board were:

1. What are the flexibility and predictability needs and preferences of autistic people in the workplace and how these can be supported? This includes working hours, environment, workplace practices and processes, setting spoken and unspoken social expectations, diverse communication preferences, etc. (78%)

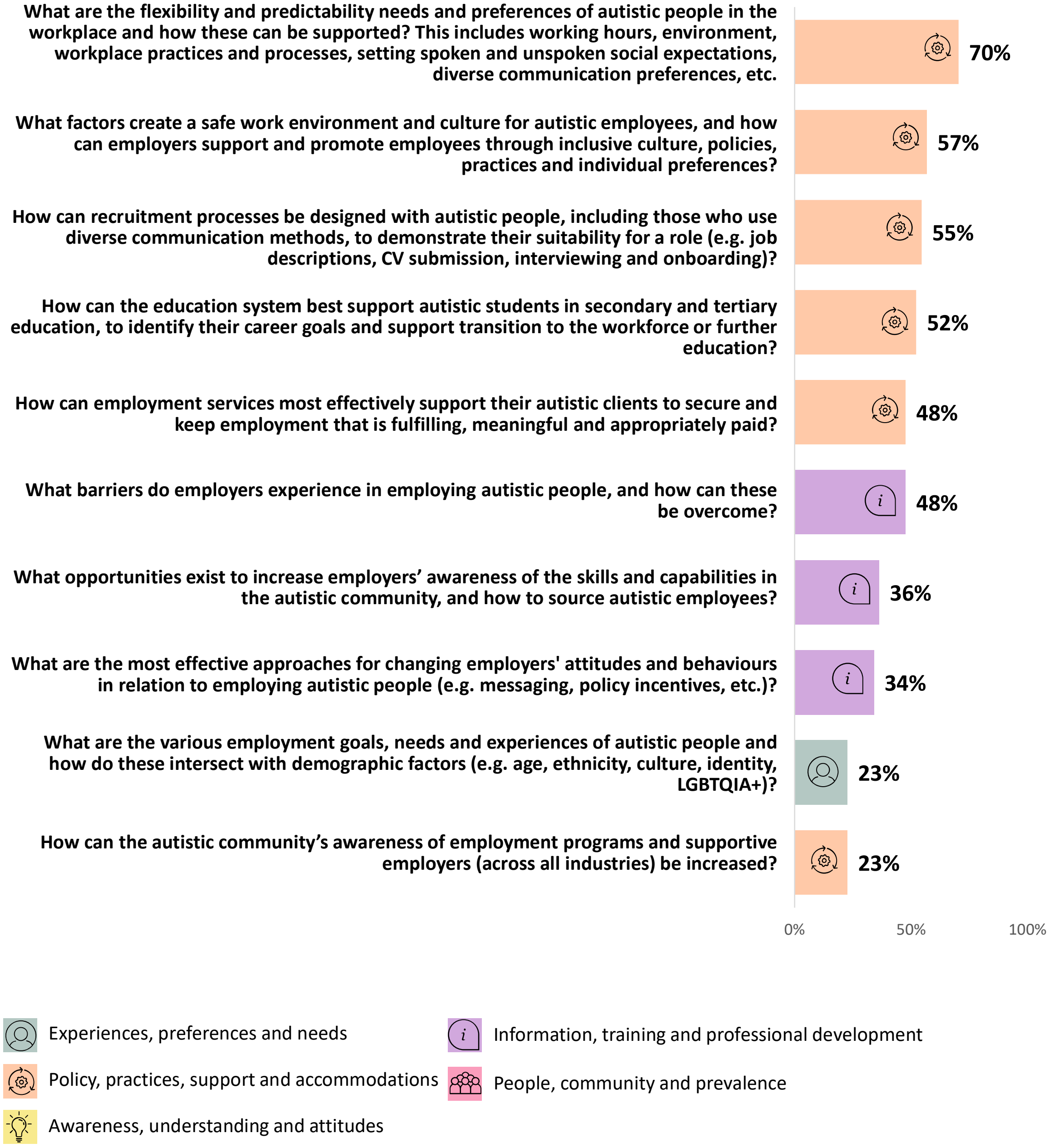
2. What barriers do employers experience in employing autistic people, and how can these be overcome? (78%)

3. How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid? (67%)

4. What factors create a safe work environment and culture for autistic employees, and how can employers support and promote employees through inclusive culture, policies, practices and individual preferences? (56%)

Figure 4 on the next page, outlines the top 10 research topics by all discussion board participants in the area of Employment. These are discussed in more detail in the following section.

Figure 4: List of priority topics in Employment (n=44)



Relevant question: Q1. Which of the following topics related to Employment do you think are the five most important to research further? Which five areas, if better understood / researched, do you think would have the greatest positive impact on your life / the lives of autistic people? [please select up to 5 responses]

Breakdown of findings by autistic and non-autistic participants

Overall, there was great overlap between the top five topics for autistic and non-autistic participants. Topics which were in the top five for both groups are highlighted in blue in the Table 4 below. Autistic participants showed greater interest in the recruitment process, potentially reflecting salient negative experience autistic participants reported having in this process. Non-autistic participants placed greater emphasis on the topic related to how the education system can support future employment, potentially reflecting that they have autistic children are or have been in the education system.

Table 4: Top five topics by autistic and non-autistic participants for Employment

Autistic participants (n=28)	
What are the flexibility and predictability needs and preferences of autistic people in the workplace and how these can be supported? This includes working hours, environment, workplace practices and processes, setting spoken and unspoken social expectations, diverse communication preferences, etc.	71%
How can recruitment processes be designed with autistic people, including those who use diverse communication methods, to demonstrate their suitability for a role (e.g. job descriptions, CV submission, interviewing and onboarding)?	64%
What factors create a safe work environment and culture for autistic employees, and how can employers support and promote employees through inclusive culture, policies, practices and individual preferences?	61%
How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid?	50%
What barriers do employers experience in employing autistic people, and how can these be overcome?	46%
Non-autistic participants (n=16)	
How can the education system best support autistic students in secondary and tertiary education, to identify their career goals and support transition to the workforce or further education?	88%
What are the flexibility and predictability needs and preferences of autistic people in the workplace and how these can be supported? This includes working hours, environment, workplace practices and processes, setting spoken and unspoken social expectations, diverse communication preferences, etc.	69%
What barriers do employers experience in employing autistic people, and how can these be overcome?	50%
What factors create a safe work environment and culture for autistic employees, and how can employers support and promote employees through inclusive culture, policies, practices and individual preferences?	50%
How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid?	44%

6.3 Detailed findings on research topics

This section provides:

- *Additional context to the topics identified as important for future research;*
- *Insight into the desired impact from this research; and*
- *An overview of how the topics identified as important by participants align with the currently available research*

It is structured according to thematic research categories based on the highest rated topics.

Policy, practices, supports and accommodations

Six of the topics identified in the area of Employment related to building understanding to directly inform policy, practices, support and accommodations in relation to:

- Creating more inclusive and accessible workplaces; and
- Improving recruitment and job matching processes.

These topics were:

> *What are the flexibility and predictability needs and preferences of autistic people in the workplace and how these can be supported? This includes working hours, environment, workplace practices and processes, setting spoken and unspoken social expectations, diverse communication preferences, etc. (Selected by **70%** of participants)*

> *What factors create a safe work environment and culture for autistic employees, and how can employers support and promote employees through inclusive culture, policies, practices and individual preferences? (Selected by **57%** of participants)*

> *How can recruitment processes be designed with autistic people, including those who use diverse communication methods, to demonstrate their suitability for a role (e.g. job descriptions, CV submission, interviewing and onboarding)? (Selected by **55%** of participants)*

> *How can the education system best support autistic students in secondary and tertiary education, to identify their career goals and support transition to the workforce or further education? (Selected by **52%** of participants)*

> *How can employment services most effectively support their autistic clients to secure and keep employment that is fulfilling, meaningful and appropriately paid? (Selected by **48%** of participants)*

> *How can the autistic community's awareness of employment programs and supportive employers (across all industries) be increased? (Selected by **23%** of participants)*

Many autistic participants reported that they often have **unique needs and preferences for their work environment and structure** requiring accommodation to ensure that they can work independently, productively and safely in their roles. This included aspects such as:

- Opportunities to work part-time and use flexible hours;
- Flexibility in the physical environment to suit sensory needs and preferences (e.g. lighting, noise, temperature);

- Clarity around the, often unspoken, rules and expectations of the workplace; and
- Opportunities to use diverse communication styles and methods.

> *"…many places of work are too loud, too bright, expect you to be good at your job within the first week or two"*

The lack of flexibility in workplaces also speaks to broader issues raised by participants about **workplace culture and attitudes to diversity**. They reported that while there was growing awareness, understanding and practice relating to creating safe and inclusive cultures for different forms of diversity, neurodiversity was not as commonly considered. Furthermore, a few participants felt that diversity policies could often be "tokenistic" and fail to have meaningful impact. Participants reported that autistic employees want to be accepted for who they are, have equal opportunity to progress and be treated fairly. They identified a need for research that contributes to increased knowledge of the issues, upskilling of the workforce and greater accountability to inclusivity processes and practices.

> *"If we have supportive, aware workplaces, I see successful employment outcomes for autistic people in any sector"*

In the recruitment process, many autistic participants reported that they had found it **challenging "selling themselves" in job applications and in job interviews,** as these processes were often unclear, provoked anxiousness and did not align with their strengths, despite being well suited to the role. They also reported that accommodations were generally not made for diverse communication needs and preferences. A few participants reported that they had often had previous experiences throughout their lives that had knocked their confidence and self-esteem which further contributed to the challenges of this process. Many participants reported that there were opportunities to improve recruitment processes to ensure that all candidates have equal opportunity to demonstrate their capability to perform the job role successfully. There was a desire for future research to support the widespread development and use of more inclusive and innovative recruitment processes.

> *"Almost everyone uses the same recruitment practices - I would like to see employers become aware that their selection processes have a bias that favours [non-autistic] people. I would like to see some original thinking by companies in the way they recruit"*

For those autistic participants who had used employment services, particularly **Disability Employment Services**, many reported issues or concerns with these services including:

- Being encouraged to take roles below their skill level, qualification or capability;
- A tendency for employment programs in specific sectors or industries which did not align with their interests; and,
- A lack of assistance once a candidate is placed in a role to support ongoing employment.

Participants reported a desire for research to contribute understanding of people's experiences with these services and improvements in service policies and processes to support fulfilling and sustainable employment for autistic individuals.

> *"… putting people into jobs that they are ill suited to or below their capabilities is a short-term solution - being miserable at work leads to greater mental health issues"*

Some autistic participants provided examples of positive experiences of finding work and securing work, including through specialist autism services. However, they reported that there was often **limited awareness of these programs and services**, and how to find employers who were knowledgeable and supportive in relation to hiring and working with autistic employees. Participants were interested in how research could assist maximising access to employment opportunities amongst autistic people, including those diagnosed, undiagnosed and self-diagnosed.

Some autistic and family member participants reported that autistic students, particularly **near the end of secondary school**, need to be equipped with the knowledge and skills that will assist them to enter the workforce and navigate a career pathway. This may include exploring career and training options, getting "hands on" work experience, understanding their rights and how to self-advocate, and understanding how to access services and supports to find employment if these are desired. Participants reported that this is not consistently offered in schools, and often parents are driving much of the support for their child. Participants felt that research could assist in understanding what is needed in the education setting to best support autistic students.

> *"I've had many students who simply can't find anywhere for work experience, so they work in the school's library… Unless there is someone championing the student such as a mum or exceptional careers teacher, or integration aide, then these students are not catered for at all"*

Participants felt that insights were also needed in the **tertiary setting**, as often autistic people were highly successful in their university studies, but then experienced difficulties finding work after graduating.

Information, training and professional development

There were three topics in the top 10 that related to understanding the perspective of employers and identifying development opportunities to overcome barriers:

> *What barriers do employers experience in employing autistic people, and how can these be overcome? (Selected by **48%** of participants)*

> *What opportunities exist to increase employers' awareness of the skills and capabilities in the autistic community, and how to source autistic employees? (Selected by **36%** of participants)*

> *What are the most effective approaches for changing employers' attitudes and behaviours in relation to employing autistic people (e.g. messaging, policy incentives, etc.)? (Selected by **34%** of participants)*

Many participants felt the changes needed to improve autistic employment outcomes often needed to **start with employers**. However, they reported that amongst many employers there was:

- A lack of understanding about autism with employers often holding misperceptions and low expectations of the skills and capabilities of autistic individuals;
- A lack of appreciation of the diversity of the autistic population, the range of interests and skill sets, and consideration of autistic individuals as potential candidates for job roles; and
- Concern that the cost of hiring and autistic employees and making adjustments to support their needs and preferences would outweigh the benefit.

Participants identified a need for research that improves understanding of the perspective of employers across industries, including their knowledge, attitudes and behaviours that create barriers to employing autistic individuals.

> *"Employment success or failure largely rests in… the behaviours, attitude and capacity of the employer… i.e. the "fixes" need to be made to the workplace, not to autistic employees"*

> *"There is no point in just asking what we autistics need without knowing the issues and hesitations of employers. If we want to truly understand the barriers of employment, we need to know all stakeholders' views to get a complete picture of what is happening"*

Experiences, preferences and needs

The ninth topic on the list was:

> *What are the various of employment goals, needs and experiences of autistic people and how do these intersect with demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)? (Selected by* ***23%*** *of participants)*

Most participants highlighted that the autistic community is **diverse, having a range of differing interests, strengths and aspirations**. They highlighted that often assumptions are made that autistic individuals are interested certain industries (e.g., information technology) and types or roles (e.g., repetitive tasks). As a result, employment programs, services and opportunities can be focused in narrow areas and fail to cater the range of interests and skills in the populations.

> *"…there is still such a dominant singular narrative about the employment needs of Autistic people. We're all different, and not all of us are interested in computer programming and mathematics…"*

Participants identified a need to challenge these assumptions, with consideration of specific subsets of the population (e.g., across gender and cultural identities). Future research in this area offers an opportunity to improve understanding, correct misperceptions to better appreciate the diversity of the autistic population and open broader employment opportunities.

> *"It's also really important to consider intersectional employment barriers such as for LGBTIQA+ and CALD Autistics, as well as more generally expanding the narrative of Autistic employment to incorporate how different we all are"*

7 Health and wellbeing

This chapter provides a brief overview of the findings from the research in relation to Health and Wellbeing. A total of 10 members of the autistic and autism communities participated in the discussion group. Amongst these 10, nine were autistic, nine were family members and four were relevant professionals[7]. This included autistic people (or their family members) with one or more co-occurring health conditions, including mental health conditions, and professionals who have worked with members of the autistic community in relevant fields.

A total of 44 participants completed the final prioritisation poll in this Priority Area (9 who took part in the Health and Wellbeing discussion board, and 35 who took part in discussion boards on other topics).

7.1 Overview

This section summarises the broad issues and desired outcomes from research in the area of Health and Wellbeing.

The discussion about Health and Wellbeing was broad and considered holistic health and wellbeing of autistic people across genders and across the lifespan; from childhood to puberty, then through young, middle and late adulthood. Many participants reported that they had complex mental and physical health and wellbeing needs, which were often not well understood or catered to by health professionals and services. They also discussed a range of systemic and structural factors more broadly which can impact health and wellbeing.

The research found that there was a desire for a research agenda that builds **understanding of autistic health** and informs improvements in understanding of autism and unique considerations for providing health care amongst **health professionals and services.**

> *"Researchers need to keep in mind that the medical community (in general) believes that autism is a childhood disorder that mostly occurs in boys and that can be fixed during childhood. They need to be mindful of how these beliefs have shaped healthcare and the wide-ranging negative impacts of this on the health and wellbeing of the autistic community"*

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[7] Participants could represent more than one category and as such these numbers do not sum to 10.

7.2 List of priority topics

This section provides a list of the topics identified as most important for future research in Health and Wellbeing. The list is in order of priority based on the overall results from the final prioritisation poll.

The top 4 research questions for participants on the Health and Wellbeing discussion board were:

1. What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)? (60%)

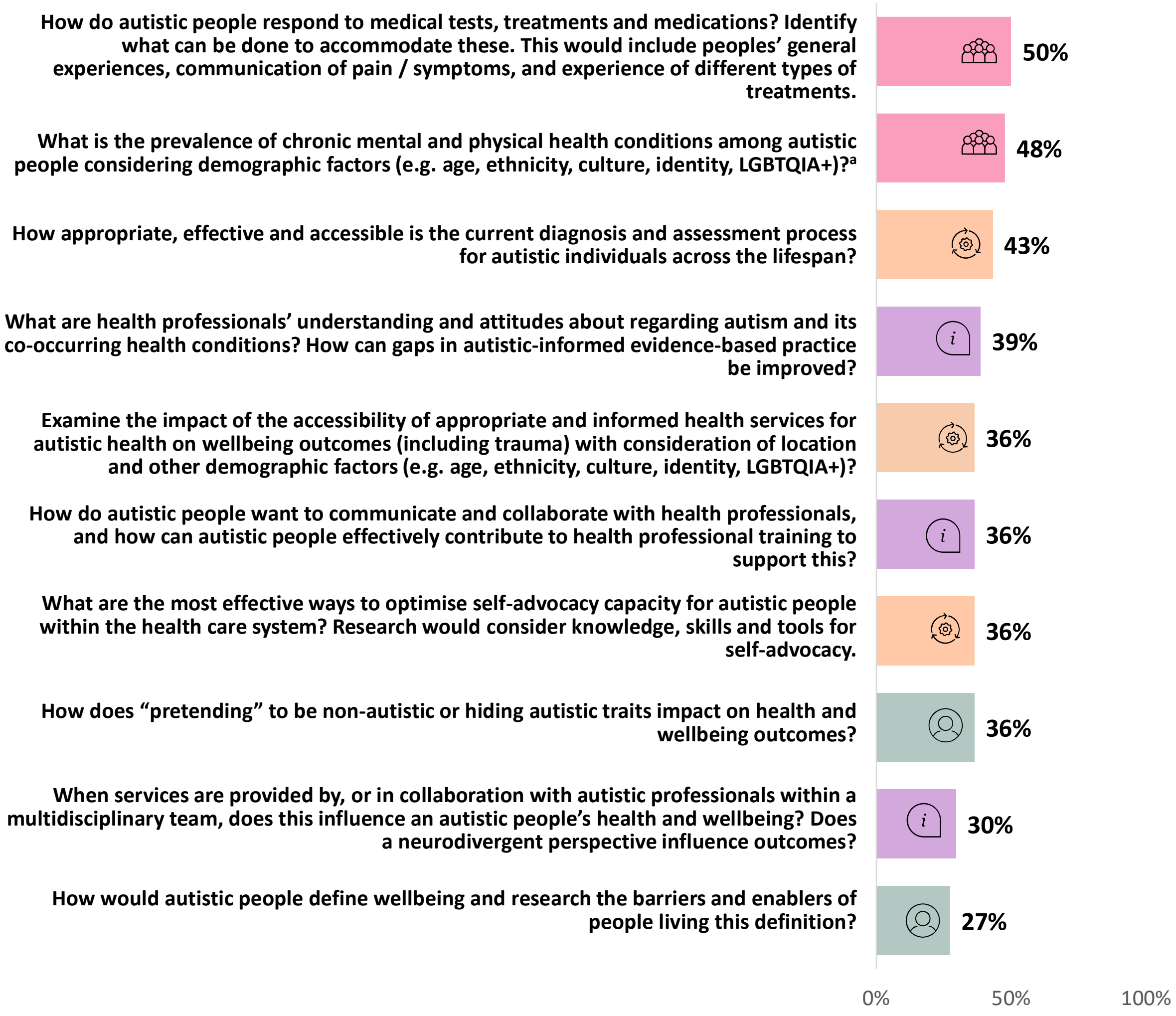
2. How do autistic people respond to medical tests, treatments and medications? Identify what can be done to accommodate these. This would include peoples' general experiences, communication of pain / symptoms, and experience of different types of treatments. (60%)

3. How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan? (50%)

4. How does "pretending" to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes? (50%)

Figure 5 on the next page, outlines the top 10 research topics by all discussion board participants in the area of Health and Wellbeing. These are discussed in more detail in the following section.

Figure 5: List of priority topics in Health and Wellbeing (n=44)



How do autistic people respond to medical tests, treatments and medications? Identify what can be done to accommodate these. This would include peoples' general experiences, communication of pain / symptoms, and experience of different types of treatments.

What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?[a]

How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan?

What are health professionals' understanding and attitudes about regarding autism and its co-occurring health conditions? How can gaps in autistic-informed evidence-based practice be improved?

Examine the impact of the accessibility of appropriate and informed health services for autistic health on wellbeing outcomes (including trauma) with consideration of location and other demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?

How do autistic people want to communicate and collaborate with health professionals, and how can autistic people effectively contribute to health professional training to support this?

What are the most effective ways to optimise self-advocacy capacity for autistic people within the health care system? Research would consider knowledge, skills and tools for self-advocacy.

How does "pretending" to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes?

When services are provided by, or in collaboration with autistic professionals within a multidisciplinary team, does this influence an autistic people's health and wellbeing? Does a neurodivergent perspective influence outcomes?

How would autistic people define wellbeing and research the barriers and enablers of people living this definition?

[a] Examine contributing factors to these conditions (e.g. lifestyle, socio economic status, social, physiology, stress, access to health services, culture, location, trauma).

Experiences, preferences and needs

Information, training and professional development

Policy, practices, support and accommodations

People, community and prevalence

Awareness, understanding and attitudes

Relevant question: Q7. Which of the following topics related to Health and Wellbeing do you think are the five most important to research further? Which five areas, if better understood / researched, do you think would have the greatest positive impact on your life / the lives of autistic people? [please select up to 5 responses]

Breakdown of findings by autistic and non-autistic participants

Overall, there was limited overlap between the top five topics for autistic and non-autistic participants. Topics which were in the top five for both groups are highlighted in blue in the Table 5 below. Autistic participants placed greater emphasis on topics that increased knowledge about their own health and health experiences, as well as health service-related topics. Non-autistic participants were more likely to place greater priority on research into effective diagnosis and supports at different stages of life.

Table 5: Top five topics by autistic and non-autistic participants for Health and Wellbeing

Autistic participants (n=28)	
How do autistic people respond to medical tests, treatments and medications. Identify what can be done to accommodate these. This would include peoples' general experiences, communication of pain / symptoms, and experience of different types of treatments.	57%
What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?	50%
Examine the impact of the accessibility of appropriate and informed health services for autistic health on wellbeing outcomes (including trauma) with consideration of location and other demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?	46%
How does "pretending" to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes?	43%
How do autistic people want to communicate and collaborate with health professionals, and how can autistic people effectively contribute to health professional training to support this?	39%
Non-autistic participants (n=16)	
How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan?	56%
What are the most effective ways to optimise self-advocacy capacity for autistic people within the health care system? Research would consider knowledge, skills and tools for self-advocacy.	50%
What are health professionals' understanding and attitudes about regarding autism and its co-occurring health conditions? How can gaps in autistic-informed evidence-based practice be improved?	44%
What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)?	44%
Examine how developmental stages may differ across the lifespan for autistic people. Developmental stages include physical, cognitive/thought, language and social and emotional growth.	44%

7.3 Detailed findings on research topics

This section provides:

- *Additional context to the topics identified as important for future research;*
- *Insight into the desired impact from this research; and*
- *An overview of how the topics identified as important by participants align with the currently available research*

It is structured according to thematic research categories based on the highest rated topics.

Population, people and prevalence

The highest rated research topics related to understanding the autistic population's experience of medical treatments and co-occurring conditions. These were:

- *How do autistic people respond to medical tests, treatments and medications? Identify what can be done to accommodate these. This would include peoples' general experiences, communication of pain / symptoms, and experience of different types of treatments. (Selected by* ***50%*** *of participants)*
- *What is the prevalence of chronic mental and physical health conditions among autistic people considering demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+)? Examine contributing factors to these conditions (e.g. lifestyle, socioeconomic status, social, physiology, stress, access to health services, culture, location, trauma, intimate relationships). (Selected by* ***48%*** *of participants)*

Many autistic and family member participants reported that they **respond differently to medical tests, treatments and medication** compared to the general population. Some noted that differences in sensory perceptions and needs may contribute to this including differences in experience of pain and symptoms, severe discomfort from some medical tests and procedures, and differences in responses medications and treatments. Many participants reported that there was a lack of understanding about why this may occur and how medical professionals should account for this issue. Participants reported this lack of understanding resulted in feeling disbelieved, undermined and fatigued by explaining themselves to health professionals when they experienced challenges that many others may not. Research in this area offers the opportunity to measure and explain potential differences experienced by autistic individuals and build on understanding about how this can be accommodated in the health care system.

> *"…sensory issues common in autism affects every domain of health, from dental, to physical, to pharmacological to nutrition to neurological to cognitive and mental well-being. It can change how you respond to treatment or how you even interact in a certain environment and even the aetiology of some issues are related to the sensory issues arising from autism"*

Many participants identified that they and others in the autistic community often have **more complex health needs and co-occurring conditions** compared to the general population, such as gut health and food intolerances. Some participants suggested that there may be underlying differences in physiology for autistic people, but also identified that systemic structural inequities as a stressor could contribute to downstream impacts on mental and physical health. A few participants cautioned that research in this area should not incorrectly attribute the presence of symptoms and conditions to autism itself. There was, however, a desire to know more about commonly co-occurring conditions and building and evidence base for autistic people to better understand their own health. Participants hoped this would improve appreciation of the complexity of autistic health amongst health professionals and inform care.

> *"Identifying common autistic co-conditions would validate our experiences. People might finally start to believe us"*

Policy, practices, supports and accommodations

There were three topics that seek to directly inform the provision of accessible support for autistic people. These were:

- *How appropriate, effective and accessible is the current diagnosis and assessment process for autistic individuals across the lifespan? (Selected by **43%** of participants)*
- *Examine the impact of the accessibility of appropriate and informed health services for autistic health on wellbeing outcomes (including trauma) with consideration of location and other demographic factors (e.g. age, ethnicity, culture, identity, LGBTQIA+) (Selected by **36%** of participants)*
- *What are the most effective ways to optimise self-advocacy capacity for autistic people within the health care system? Research would consider knowledge, skills and tools for self-advocacy. (Selected by **36%** of participants)*

Many autistic and family member participants reported that there were **challenges to obtaining an autism diagnosis**. These included:

- Lack of expertise and knowledge – this was particularly felt to be the case for diagnosing women with autism; participants reported that the common understanding of the autistic presentation was based on the male experience and this informed diagnostic criteria;
- Physical access barriers – participants living in regional and remote areas reported that local medical professionals often had generalist skillsets and therefore to access a professional qualified to give an autism diagnosis often meant traveling long distances; and
    - Some participants noted that they had had positive experiences with telehealth services, although not for diagnosis;
- Cost barriers – participants reported diagnosis could be prohibitively expensive and there were often long waitlists for public services. Costs were raised further for those who needed to travel great distances for an appointment.

Some autistic participants reported that obtaining diagnosis was often an important step in helping them to understand themselves better, connect with the autistic community, and was a requirement to access supports. Therefore, participants felt that improving access to timely diagnosis was essential. Research offers an opportunity to better understand where the gaps may be in accessing timely diagnosis and inform policy to address these.

> *"In my experience, diagnosis is an essential step towards self-understanding, accessing support, and lifestyle adjustments... I don't believe that it's possible to get diagnosed in my (regional) area unless you travel quite some distance. If you're female, you may need to travel further"*

Many autistic, family member and professional participants reported that **health care accessibility challenges extended beyond diagnosis**. They identified challenges in obtaining continuity of care due to the physical environment of services (e.g., bright lights and waiting rooms); the autism knowledge of health care professional (discussed in the next section) or short appointment times. This is complicated by also needing to communicate with someone who may not be skilled in diverse modes of communication, or know how to manage the diverse presentations an autistic person may display if they are unwell, tired or stressed. Participants identified that location, as well as cultural and gender identity may also impact the accessibility of services. Participants were interested in understanding what the impacts were for autistic people when they had access to informed and accessible health care services, with consideration of how this may inform future service delivery. Further exploration may also cover cost/benefit of access.

Many autistic and family member participants reported needing to **commonly advocate for themselves and / or their family member** in the health care system, as they do in many other areas of life. A few participants reported that often others will have the control over the services that an autistic person can access. They reported that there was a need for more tools and support to ease the burden of self-advocacy in this setting. Research offers an opportunity to understand what autistic people want and need to support self-advocacy and identify effective tools and approaches to ensure they receive the health care that is needed or wanted.

> *"By identifying the barriers to self-advocacy, tools and resources can be implemented to remove the barriers. This would increase self-advocacy, self-determination, empowerment and by extension, improve health and wellbeing outcomes"*

Information, training and professional development

Three topics directly related to the training and professional development of health professionals. These were:

- *What are health professionals understanding and attitudes regarding autism and its co-occurring health conditions. How can gaps in autistic-informed evidence-based practice be improved? (Selected by **39%** of participants)*
- *How do autistic people want to communicate and collaborate with health professionals, and how can autistic people effectively contribute to health professional training to support this? (Selected by **36%** of participants)*
- *When services are provided by, or in collaboration with autistic professionals within a multidisciplinary team, does this influence an autistic people's health and wellbeing? Does a neurodivergent perspective influence outcomes? (Selected by **30%** of participants)*

Most autistic and family member participants reported a **lack of knowledge about autism amongst health professionals**. They reported that there was a considerable difference in quality of care when seeing a health professional who understood autism, and what this may mean for an individual's health, compared to one who did not. Some participants felt that their complex range of health needs were often dismissed or not supported holistically. Some participants reported being patronised or spoken down to by health professionals, while a few reported needing more support than they we given. Participants felt the was a need for more research to identify gaps and misperception about autism amongst health professionals, as well as informing opportunities for improving knowledge and understanding where this is needed.

> *"The more health professionals and the community in general know and understand autism the more supports will evolve and become inclusive"*

Many autistic participants also identified a need for greater skills amongst health professionals in taking a **collaborative approach to health care**. Autistic participants reported that they were interested in and knowledgeable in their own health and wanted this to be respected by health professionals. They also wanted to be given information about their health and the opportunity to understand their options and be involved in decision making. They identified that part of the challenge was that professionals were not always knowledgeable in accommodating diverse communications need and preferences. Participants were interested in future research to inform effective training and professional development approaches.

> *"Using a strengths-based approach should improve self-efficacy and self-determination. If autistic people feel more involved and empowered in their healthcare decisions, then hopefully that has a direct improvement on health and wellbeing outcomes"*

Some autistic participants felt that having health **professionals who were autistic** could improve the experience of health and wellbeing services. This could include having a direct consult with an autistic health professional or receiving care from a multidisciplinary health team which includes an autistic person. Participants highlighted the need to be considerate of the power dynamics within that team and ensuring that autistic voice is heard. Research in this area could assist in understanding what the impacts are when health care provided by those with lived experience. This may inform future service delivery and possibly strengthen the case for developing the autistic health professional workforce.

> *"I would also like to see if there are better outcomes for autistic clients when there are autistic professionals who have a significant role and are heard in their teams"*

Experiences, preferences and needs

There were two topics related to improving understanding of the experiences and perceptions of autistic people in relation to the provision of health services, and wellbeing. These were:

- *How does "pretending" to be non-autistic or hiding autistic traits impact on health and wellbeing outcomes? (Selected by **36%** of participants)*
- *How would autistic people define wellbeing and what are the barriers and enablers of people living this definition across the lifespan? (Selected by **27%** of participants)*

Many autistic participants in the health and wellbeing discussion, as well as discussion in other Priority Areas, highlighted the **challenges and impacts of "masking"**, that is, covering up their autistic traits to fit in or try to belong. Participants reported that the effort of masking had impacts on their health and wellbeing as it often left them exhausted and impacted their sense of identity. A few participants reported that it also impacted their experience of receiving health care as it contributed to professionals questioning their diagnosis or making assumption about their ability. Participants were interested in understanding more about masking and its impacts in autistic people's lives, including to improve awareness and understanding of this issue amongst the general community.

Many autistic and family member participants reported a range of **unique challenges to experiencing wellbeing** for autistic people many of which stem from needing to navigate a world which is generally not sensitive to their needs and preferences. Some specific factors contributing to wellbeing mentioned in the discussion included the impact on self-worth of interventions aimed at encouraging autistic people act “more normal”, social exclusion, forming safe and respectful intimate relationships and opportunities to access creative experiences (e.g. art and music) in a suitable way. Research offers an avenue for bringing the wellbeing of autistic people into to focus and providing insight into how it can be optimised in line with unique aspirations and goals throughout different areas of life.

> *“…developing a positive sense of identity and good self-esteem are important for the wellbeing of autistic people. We need to be able to be who we are and not what others expect of us”*

8 Justice

This chapter provides a brief overview of the findings from the research in relation to Justice. A total of 10 members of the autistic and autism communities participated in the discussion group. Amongst these 10, seven were autistic, eight were family members and six were relevant professionals[8]. This included autistic people (or their family member) who have had previous contact with police and/or the justice system and professionals with experience working in the justice field.

A total of 42 participants completed the final prioritisation poll in this Priority Area (9 who took part in the Justice discussion board, and 33 who took part in discussion boards on other topics).

8.1 Overview

This section summarises the broad issues and desired outcomes from research in the area of Justice.

Most participants in the discussion highlighted a need for increased consideration, awareness and understanding of autistic people in the criminal justice system. They reported a lack of autism education, which results in poor identification, recognition and support of autistic people at each stage of their justice engagement. It was emphasised that this was particularly an issue amongst police and resulted in a lack of appropriate insights and accommodations to ensure the fair and respectful treatment of autistic people as victims or perpetrators. Participants reported that this impacted the risk of being charged for an offence, the likelihood of reporting crime and appropriateness of rehabilitation programs.

Some participants also emphasised a need to support the prevention of criminal offending and re-offending. They suggested supporting this by ensuring that autistic people knew what behaviours could lead to being charged; and being able to discern if they are manipulated by other people to partake in criminal activity.

The research identified a desire for a research agenda that contributes **ensuring the fair treatment of autistic people in the criminal justice system,** supporting prevention of contact with the justice system where possible.

> *"My experience has very much been that there are gaps in knowledge ranging from preventing offending, to engagement with police, engaging with courts, responding to treatment/rehabilitation needs in prison, making accommodations for autistic individuals within prison, establishing appropriate release plans, supporting individuals on orders/parole/supervision within the community and addressing reoffending once released - also understanding the relationship to neurodiversity and offending…"*

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[8] Participants could represent more than one category and as such these numbers do not sum to 10.

8.2 List of priority topics

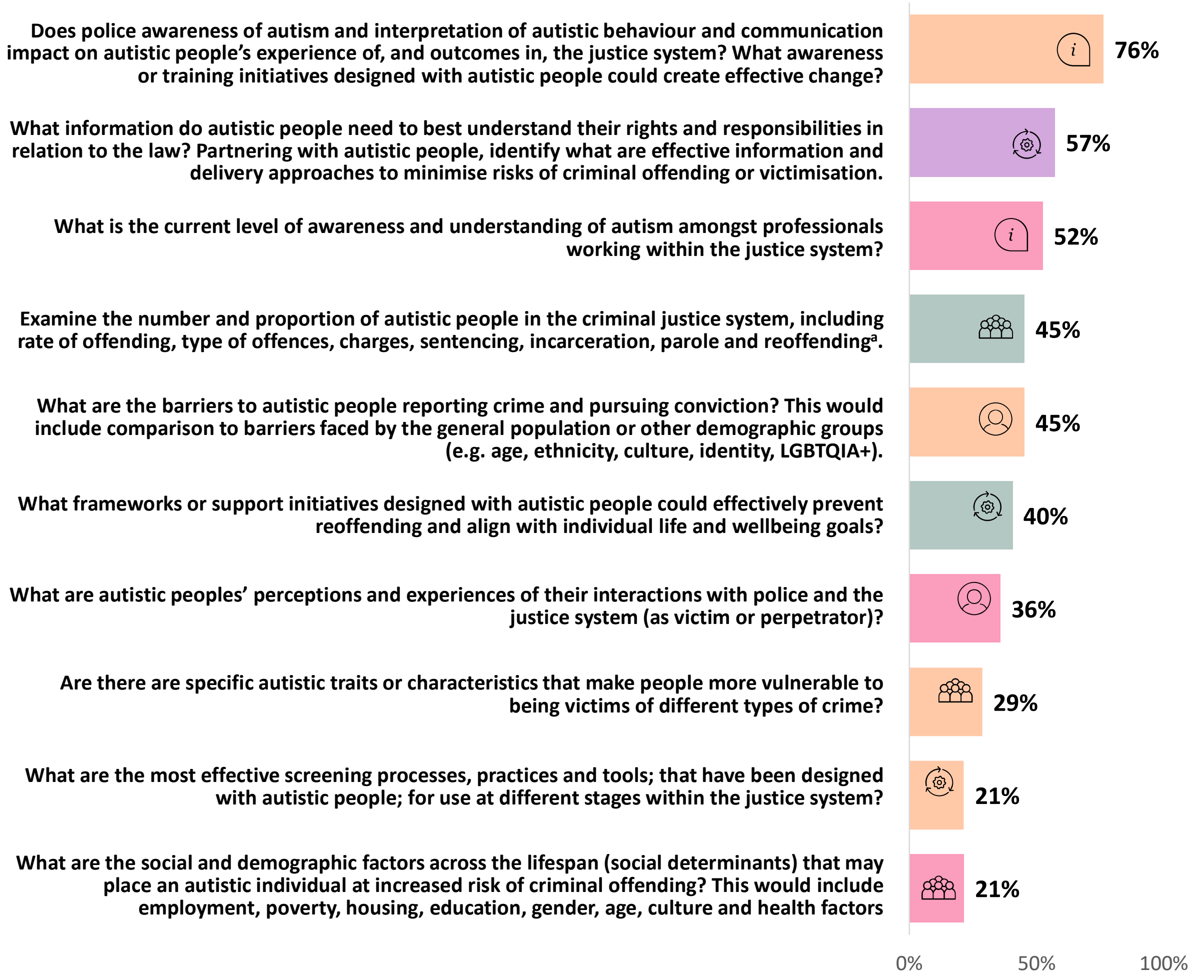
This section provides a list of the topics identified as most important for future research in Justice. The list is in order of priority based on the overall results from the final prioritisation poll.

The top 4 research questions for participants on the Justice discussion board were:

1. Does police awareness of autism and interpretation of autistic behaviour and communication impact on autistic people's experience of, and outcomes in, the justice system? What awareness or training initiatives designed with autistic people could create effective change? (75%)
2. What is the current level of awareness and understanding of autism amongst professionals working within the justice system? (50%)
3. What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and wellbeing goals? (50%)
4. Examine the number and proportion of autistic people in the criminal justice system, including rate of offending, type of offences, charges, sentencing, incarceration, parole and reoffending. (50%)

Figure 6 on the next page, outlines the top 10 research topics by all discussion board participants in the area of Justice. These are discussed in more detail in the following section.

Figure 6: List of priority topics in Justice (n=42)



[a] Identify demographics (e.g. age, ethnicity, culture, identity, LGBTQIA+) and diversity factors (e.g. co-occurring disabilities, mental health).

Experiences, preferences and needs	Information, training and professional development
Policy, practices, support and accommodations	People, community and prevalence
Awareness, understanding and attitudes	

Relevant question: Q5. Which of the following topics related to Justice do you think are the five most important to research further? Which five areas, if better understood / researched, do you think would have the greatest positive impact on your life / the lives of autistic people? [please select up to 5 responses]

Breakdown of findings by autistic and non-autistic participants

Overall, there was great overlap between the top five topics for autistic and non-autistic participants. Topics which were in the top five for both groups are highlighted in blue in the Table 6 below. Autistic participants placed a higher priority on awareness of autism amongst professionals the justice system as well as barriers to reporting crime. Non-autistic participants gave priority to understanding the prevalence of autistic individuals in the justice system.

Table 6: Top five topics by autistic and non-autistic participants for Justice
(equal ratings are possible)

Autistic participants (n=26)	
Does police awareness of autism and interpretation of autistic behaviour and communication impact on autistic people's experience of, and outcomes in, the justice system? What awareness or training initiatives designed with autistic people could create effective change?	77%
What is the current level of awareness and understanding of autism amongst professionals working within the justice system?	58%
What information do autistic people need to best understand their rights and responsibilities in relation to the law? Partnering with autistic people, identify what are effective information and delivery approaches to minimise risks of criminal offending or victimisation.	50%
What are the barriers to autistic people reporting crime and pursuing conviction? This would include comparison to barriers faced by the general population or other demographic groups (e.g. age, ethnicity, culture, identity, LGBTQIA+).	50%
What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and wellbeing goals?	39%
Examine the number and proportion of autistic people in the criminal justice system, including rate of offending, type of offences, charges, sentencing, incarceration, parole and reoffending.	39%
Non-autistic participants (n=16)	
Does police awareness of autism and interpretation of autistic behaviour and communication impact on autistic people's experience of, and outcomes in, the justice system? What awareness or training initiatives designed with autistic people could create effective change?	75%
What information do autistic people need to best understand their rights and responsibilities in relation to the law? Partnering with autistic people, identify what are effective information and delivery approaches to minimise risks of criminal offending or victimisation.	69%
Examine the number and proportion of autistic people in the criminal justice system, including rate of offending, type of offences, charges, sentencing, incarceration, parole and reoffending.	56%
What is the current level of awareness and understanding of autism amongst professionals working within the justice system?	44%
What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and wellbeing goals?	44%

8.3 Detailed findings on research topics

This section provides:

- *Additional context to the topics identified as important for future research;*
- *Insight into the desired impact from this research; and*
- *An overview of how the topics identified as important by participants align with the currently available research*

It is structured according to thematic research categories based on the highest rated topics.

Information, training and professional development

There were two topics related to information and training for professionals. These were:

- *Does police awareness of autism and interpretation of autistic behaviour and communication impact on autistic people's experience of, and outcomes in, the justice system? What awareness or training initiatives designed with autistic people could create effective change? (Selected by **76%** of participants)*
- *What is the current level of awareness and understanding of autism amongst professionals working within the justice system? (Selected by **52%** of participants)*

Almost all participants identified a need for **more training and education about autism** across police, prison staff, court staff and community corrections staff. Participants felt this was particularly important for police as they are generally the first professionals that individuals come into contact within the criminal justice system, and therefore the earliest opportunity to divert people away from further engagement. Furthermore, autistic and family member participants reported that trusting and informed relationships with police were important, as poor experiences, either directly or reported in the media, could make autistic people reluctant to report crime, press charges and create a fear of being approached by police.

Participants reported that a **lack of understanding and stereotypes about autism amongst police,** meant that the communication and behaviour of autistic individuals could be misinterpreted. For example, participants reported that being quiet and avoiding eye contact could create suspicion; asking direct questions could be seen as disrespectful; or slowness in response may be perceived as being substance effected. Participants highlighted that traditional policing approaches could increase stress or discomfort for autistic people (e.g., approaching with flashing lights and sirens and being asked multiple questions at once).

> *"Non-autistic people need to know that we can have behaviours which might appear disruptive when we are distressed and that we cannot always communicate verbally, or clearly when we are anxious or distressed"*

> *"Broader understanding within the justice system would lead to more equitable treatment for autistic people"*

Research offers an opportunity to measure the current levels of awareness and understanding amongst different professionals within the criminal justice system and to address gaps. It also provides an opportunity to understand and address the impact lack of awareness may have on outcomes for autistic people.

Policy, practices, supports and accommodations

Four topics related to informing policy, practices, support and accommodations. These were:

> *What information do autistic people need to best understand their rights and responsibilities in relation to the law? Partnering with autistic people, identify what are effective information and delivery approaches to minimise risks of criminal offending or victimisation. (Selected by* ***57%*** *of participants)*

> *What frameworks or support initiatives designed with autistic people could effectively prevent reoffending and align with individual life and well-being goals? (Selected by* ***40%*** *of participants)*

> *What are the most effective screening processes, practices and tools; that have been designed with autistic people; for use at different stages within the justice system? (Selected by* ***21%*** *of participants)*

> *Which professionals and services are best placed to design and deliver strategies in partnership with autistic people for prevention of criminal behaviour? (Selected by* ***21%*** *of participants)*

Some autistic, family member and professional participants identified a need to **empower autistic people with information** to assist with the prevention of offending, understanding rights and options as a victim, and how to navigate the system. Autistic participants highlighted that delivery of information should be informed by autistic people, to ensure that it is practical and can be drawn upon when facing real-life situations and to support information processing. A few family and professional participants were also interested in identifying the different professionals or services who may be well placed to assist people at risk of criminal behaviour. There is an opportunity for research to inform personalised information, learning and support needs for autistic individuals to help reduce contact with the criminal justice system and assist in navigating the system when required.

"… it would be great if the justice sector created training targeted for autistic people, so we can understand our rights, and also know who to contact when we need support"

Some autistic and professional participants identified that for those autistic people who are charged with an offence **rehabilitation programs can be ineffective** as conceptualisation of offending and rehabilitation have not been considered from a neurodiversity perspective. Furthermore, they highlighted the prison environment can be particularly challenging for autistic individuals due to sensory factors and the highly social environment which may contribute to extended imprisonment or further challenges on release. The proposed research may assist in understanding the support needs for autistic prisoners in prison and upon leaving, to give them the best chance of not reoffending and enabling them the lead a fulfilling life.

"…conceptualisations of offending, the underlying issues, treatment within the criminal justice system and rehabilitation often does not meet the needs of autistic individuals - in many instances makes things far worse"

Some participants highlighted that part of the challenge of making accommodations for autistic individuals in the justice system is that autism and neurodiversity is not something generally considered and screened for upon contact with the justice system. Research offers an opportunity to identify the best approached for identifying autism in a criminal justice setting.

Population, people and prevalence

Three topics were linked to understanding population, people and prevalence in the justice system. These were:

- *Examine the number and proportion of autistic people in the criminal justice system, including rate of offending, type of offences, charges, sentencing, incarceration, parole and reoffending. Identify demographics (e.g. age, ethnicity, culture, identity, LGBTQIA+) and diversity factors (e.g. co-occurring disabilities, mental health). (Selected by **45%** of participants)*
- *Are there are specific autistic traits or characteristics that make people more vulnerable to being victims of different types of crime? (Selected by **29%** of participants)*
- *What are the social and demographic factors across the lifespan (social determinants) that may place an autistic individual at increased risk of criminal offending? This would include employment, poverty, housing, education, gender, age, culture and health factors. (Selected by **21%** of participants)*

A few participants highlighted that **justice and autism is not a well understood area** and there was a need to obtain a clearer understanding of the intersection between autism and the criminal justice system as offenders or victims. There was an interest in understanding the factors that could reduce risk of victimisation or offending that may uniquely impact autistic individuals. Research offers an opportunity to better understand the extent of the issues the area of justice and look at the systems and structures that may be placing autistic people at greater risk, if risk factors are identified.

> *"We need to look at the bigger picture and look at the life cycle of an individual… then the solutions to provide the pathways for prevention which would have a massive impact on the overall outcomes"*

Experiences, preferences and needs

Two topics were linked to understanding autistic people's experiences, needs and preferences. These were:

- *What are the barriers to autistic people reporting crime and pursuing conviction? This would include comparison to barriers faced by the general population or other demographic groups (e.g. age, ethnicity, culture, identity, LGBTQIA+). (Selected by **45%** of participants)*
- *What are autistic peoples' perceptions and experiences of their interactions with police and the justice system (as victim or perpetrator)? (Selected by **36%** of participants)*

Some autistic and family member participants reported experiencing reluctance to report crime or pursuing a conviction, namely due to **negative experiences with police** including feeling intimidated, misunderstood, dismissed or unfairly treated. Research in this area offers an opportunity to identify unique barriers in the autistic community to reporting crime and pursuing convictions, as well as building understanding of autistic people's experiences of their interactions with the justice system. This may then inform initiatives that help create equal access and fair treatment of autistic people in the justice system if these are required.

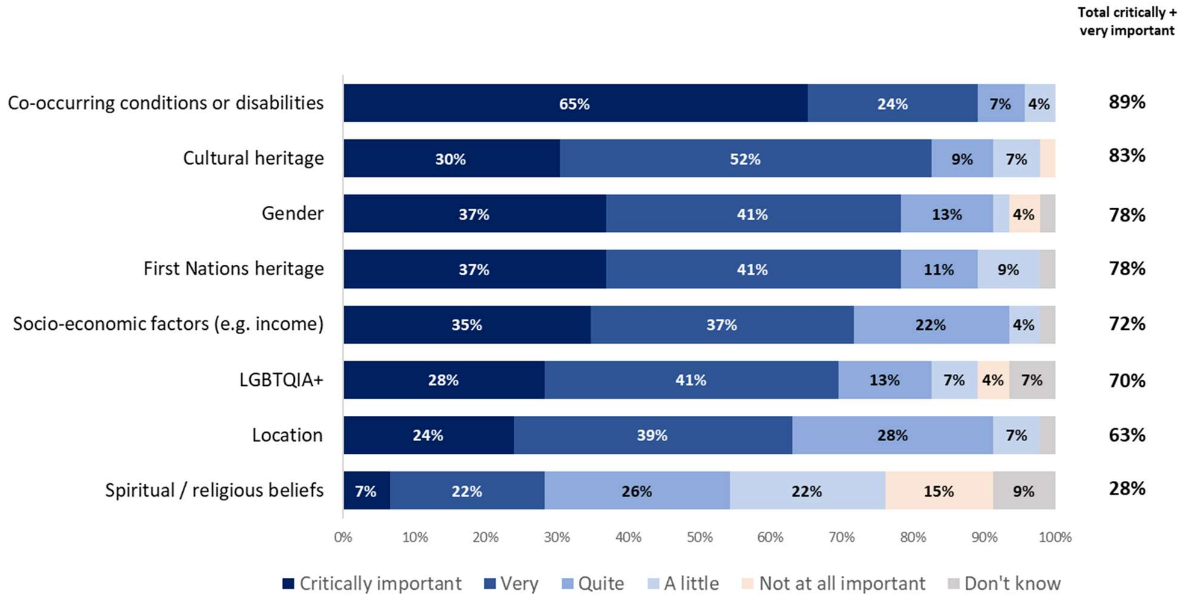
> *"When I have had to interact with Police,…they made intense eye contact and asked the same questions repeatedly which made me feel like I was not believed"*

9 Diversity of experience and impact

The research found that it is important that research is inclusive of a broad range of perspectives within the autistic and autism communities. This includes consideration of intersecting factors which may impact autistic people's experiences, such as co-occurring conditions or disability, cultural identity, gender identity and socioeconomic factors.

In the final prioritisation poll, respondents were asked how important it was to consider the experience or impact of a range of these factors in autism research. For almost all factors considered in the poll, a majority of respondents indicated that the factor was critically or very important (Figure 7). While many of the topics that participants identified as important for future research in the five Priority Areas do not explicitly reference these factors, these findings highlight the importance of inclusive research which is sensitive to the diversity of autistic and autism communities.

Figure 7: Factors to consider in conducting autism research (n=45).
Note: Percentages are rounded to whole number.



Relevant question: Q11. How important is it to explicitly consider the experience / impact of the following factors when conducting autism research?

10 Broader themes and findings

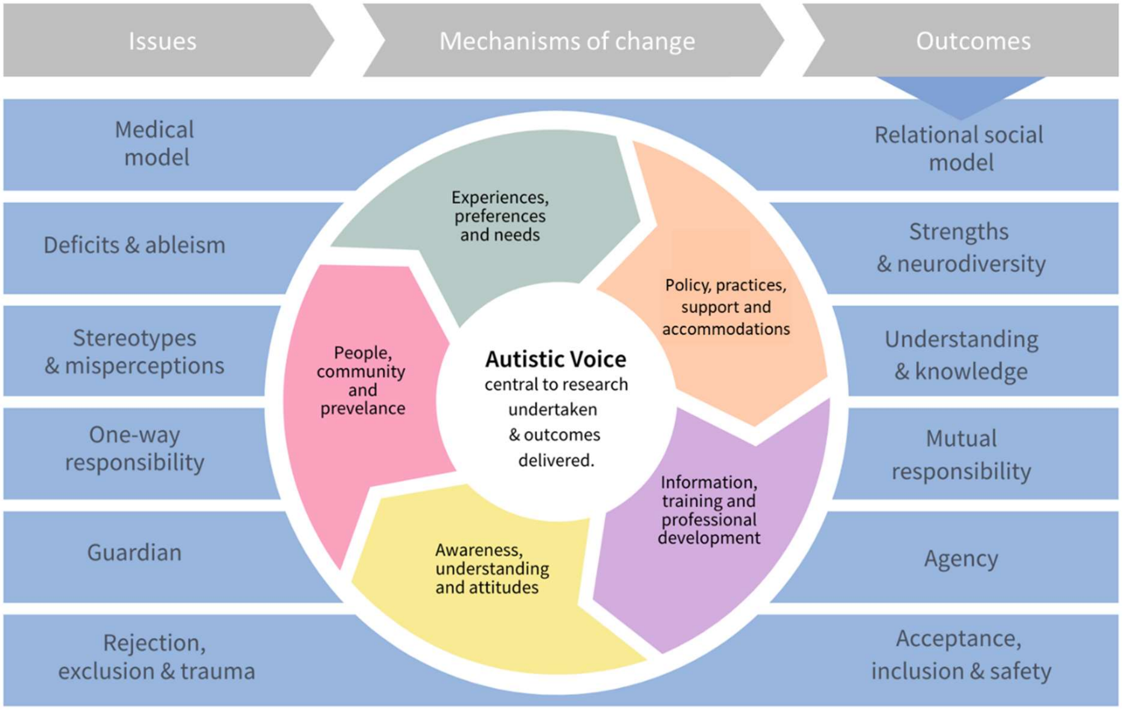
While not the key objective of the project, the research identified some broad overarching themes that summarised the changes that participants hoped that future research would contribute to. The purpose of including these findings is to give some broader context to the findings and highlight the similarities in areas of focus across the Priority Areas. These are ancillary findings to complement the main findings for each of the Priority Areas.

The research found that across all Priority Areas there was a strong desire for attitudinal and practical changes that would contribute to more autistic people having the best possible opportunity to lead meaningful and fulfilling lives. Participants identified that current societal systems and structures create barriers to this and negatively impact the lives of autistic people, as well as their families. Participants reported these negative impacts in areas such as social inclusion, mental health and wellbeing; identity formation and self-esteem; access to educational and employment opportunities; and financial wellbeing and economic security.

> *"The majority of the challenges are inherent to the system rather than autistic people ourselves. [People] need to understand how hard and soul destroying it is for us... it needs to be changed. It is possible, and it needs to be done"*

The research identified broad underlying changes that participants felt were needed across the general community, as well as avenues for creating these changes that could be targeted in research. These are summarised in Figure 8 and described in more detail below.

Figure 8: Overarching themes from the research



At the centre of the figure is the importance of **autistic voice**. Most participants identified that it was essential that autistic voices contribute to all aspects of research and its potential translation into updated policies, practices and processes. This is to ensure that autistic voices are telling the story about autistic people and help to shape policies that are fair, accurate and respectful. They reported that research and initiatives should be co-produced with autistic individuals. This includes with autistic people who use diverse, non-speaking communication methods. They also reported it may be important for family members /carers to be involved in coproducing research, where appropriate. Participants emphasised that co-production must be genuine, respectful and give equal value to the knowledge that autistic people and their families / carers can provide based on their life experiences. They highlighted the need to ensure autistic people are engaged at every stage of the research project including identifying the research questions, designing the methodology, understanding the findings and sharing the results.

> *"I think having research that is starting to be led and directed by autistic voices and our priorities will go a long way towards changing the current mindset that causes autistic people to be marginalised in society"*

The research found that there is a desire for six **key shifts** in the way that autism is understood, considered and behaved towards throughout society (shown in blue in Figure 8). These factors are useful to consider in the process of deciding on a research topic, framing research and informing the implications drawn from research. The shifts include moving towards:

1. **A relational social model of autism** – many participants reported that their experiences with various professionals, services and the broader community reflect a medical model of autism, which focuses on a person's impairments as the cause of challenges participating in society and personal discomfort. They reported a need to shift to a relational, social model that recognises 'disability' is created by unequal social structures and relationships that label people as impaired and creates barriers for people living as themselves. Therefore, supporting a shift to positive and equal personal and societal relationships, that affirm autistic capacity, difference and value.

   > *"Understanding that autism is not the thing that makes you broken but that society is the broken thing is world-changing for people who have lived lives thinking that they are intrinsically broken"*

2. **A strengths and neurodiversity framework** – many participants reported that throughout their lives they or their family members had experienced expectations that their autistic traits meant they were broken and that they had to be 'fixed.' Interventions were aimed to change them to make them 'right' - to appear 'normal'. They reported a need to celebrate diversity, and to express their genuine selves. Furthermore, participants reported a need for a greater focus on the strengths of autistic individuals and utilising these strengths so that the person can flourish.

   > *"There are so many strengths that are not always recognised, appreciated or expected"*

3. **A recognition of the diversity of the autistic community** – most participants reported that there is a stereotypical understanding about autism and autistic individuals, which does not recognise the diversity within the autistic community. They reported a need for broader and more nuanced understanding of autism, including an understanding the great diversity within the autistic community. A few participants identified that a common misperception is that autism is a childhood condition rather than a diverse neurotype persistent across the lifespan.

> *"Autistic people are not a monolith, we are incredibly diverse and have a wide range of strengths and weaknesses, different hobbies, interests, and talents"*

4. **Mutual responsibility** – a few participants highlighted that autistic and non-autistic individuals may have difficulty understanding each other's experiences, perceptions and intentions. They identified that current power imbalances privilege the non-autistic experience, requiring autistic people to adapt to meet non-autistic expectations and norms. They also highlighted that family members of autistic individuals can experience judgment and discrimination. Many participants reported the need for an increased openness and willingness amongst non-autistic individuals to understand and accommodate autistic perspectives and experiences.

> *"If there was more widespread acceptance of autistic communication and less assumptions that [non-autistic] communication was default, this would go a long way to breaking down these barriers"*

5. **Agency** – some participants reported that decisions are often made for autistic people about what is best for them by others. Participants reported a need to ensure that autistic people are asked about their needs and preferences, and given every opportunity to make informed choices in the decisions that affect their lives.

> *"Present us with information about conditions, our choices, consequences, possible outcomes. The information alone is empowering…. With some help to navigate our choices we will be really pragmatic and logical about it"*

6. **Acceptance and inclusion** – many participants reported that autistic people were often under-represented or excluded from different areas of the community for a range of reasons including a lack of awareness, understanding, patience, acceptance of diversity and practical resources. They reported a need for systematic accommodations in different areas of society to enable equal participation and engagement, and to create environments that are easier, safer and more comfortable for autistic people.

> *"…this group of kids is put in the 'too hard basket' in more and more contexts, not only are they being segregated and excluded from school, it also seems they're being excluded from conversations, strategies, research… approaches, programs"*

10.1 Policy context

In considering the proposed research topics, consideration may be given to the current policy landscape that might impact on the timing, prioritisation or sensitivities of research. The following were identified by Amaze:

- **COVID-19** has significantly impacted the public policy landscape and government priorities. Positioning research and policy to be COVID-relevant is required to mitigate the impact of the pandemic on autistic people and ensure they are included in the recovery efforts. Current stimulus measures may give way to budget austerity as the economy improves. In a competitive budget environment, the need to demonstrate strong Return on Investment for autism initiatives will be heightened.
- The **Senate Inquiry into Autism** is currently underway. Its reporting date its October 2021. As the first national parliamentary inquiry into autism, it represents a landmark opportunity. The broad terms of reference cover major policy domains, including research. A key outcome being

sought from the autistic community is bipartisan commitment to the development of a National Autism Strategy.

- The **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability** will be undertaking its work until the end of 2022. A recent interim report identified key areas for further inquiry including: Education and Learning – including the role and impact of specialist/segregated settings; Homes and living – including group homes; Health care – including treatment of those with cognitive impairment; Relationships – including family violence and child removal; Community participation; Economic participation; the National Disability Insurance Scheme (NDIS); and the justice system.
- The **National Disability Strategy** is being renewed. Identified outcome areas include: Economic security; Inclusive and accessible communities; Rights protection, Justice and legislation; Personal and community support; Learning and skills; and Health and wellbeing.
- A **National Disability Employment Strategy** is being developed by the Department of Social Services. Related policy developments include implementation of the NDIS Employment Strategy (which is set to include specific autism initiatives) and disability employment targets recently introduced into the Commonwealth (and some state) public sectors.
- As the **NDIS** is implemented, it will continue to be changed and reformed. Emerging concerns around financial sustainability may create pressure to tighten access and support. In 2021, the National Disability Insurance Agency plans to introduce mandatory functional assessments for prospective and current participants. The Early Childhood Early Intervention pathway is also under review. Participant improvements, identified by the Tune Review, are being rolled out. With the intent of the NDIS to deliver participant outcomes, it should be noted that that **targets, measures and accountability for outcomes** are relatively immature in autism related public policy and public investment.
- Major systemic reform in **mental health** is expected following the Productivity Commission's Inquiry into the Economic Impacts of Mental Ill-health and Victoria's Mental Health Royal Commission. Ensuring that these reforms work well for autistic people is a key challenge.
- The **Disability Standards for Education (DSE)** – covering early learning, schools, community, further and higher education environments – are being refreshed. It is anticipated the Disability Royal Commission will also make findings and recommendations about the DSE's.
- The value of **early learning** – both for child wellbeing and development and parental economic participation is in sharp focus. Some states are moving to introduce universal pre-school for three-year-old children. There is significant momentum for reforms in the childcare setting to expand access and reduce out of pocket costs.

11 Conclusion

Overall, across the Priority Areas, the autistic and autism community were interested in research that would assist in understanding autistic experiences and perspectives. There was a strong desire for the broader community and various professionals to understand more about autism. Participants prioritised research that proposes how systems, structures and the broader community could accommodate autistic people, over research investigating intervention or strategies that autistic people can use to try to adapt to these. It was recognised that some areas (e.g., Justice) require a foundational knowledge base to better understand the prevalence and experiences of autistic people.

The future research into these topics and questions should continue to be led by the voices of the autistic and autism communities and co-designed with autistic people and their families. In designing and conducting research, consideration should be made about how the research may contribute to progress towards:

1. The widespread acceptance of a relational social model of autism;
2. A strengths-based and neurodiversity framework of autism;
3. Improving recognition of the diversity of the autistic and autism communities;
4. Increased responsibility of the broader community to accommodate the autistic community;
5. Promoting the agency of autistic people to make decision about their own lives; and
6. Improve autistics' experiences of society, by widespread acceptance, inclusion and safety.