AutismCRC

Community insights and unheard perspectives:

Recommendations for inclusive community engagement in the National Autism Strategy

Final Report

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> *"Our autistic community is our strength through the layers of support that we share in our peers, families and professionals. No two autistic people are the same shape or colour but with the right layers of support we celebrate neurodiversity."*

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Autism CRC

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

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

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

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or ‘person on the spectrum’. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity. Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being ‘diagnosed with Autism Spectrum Disorder’.

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Executive Summary

Why we did this work

The Australian Government aims to develop a National Autism Strategy that meets the needs of all autistic people. The development of the National Autism Strategy must involve a wide range of stakeholders from diverse backgrounds including the groups whose voices and perspectives often remain unheard. This work aimed to identify these groups and determine appropriate methods for engagement in the Strategy consultation.

What we did

A co-design process was implemented through five phases: Research, Problem definition, Solution ideation, Idea validation and testing, and Delivery. The phases of the co-design process, and methods employed, were:

- established an autistic advisory group and defined target groups (n=5) – research phase
- autistic-led literature and environmental scan on best practice community engagement and target group definitions and key considerations - research phase
- co-produced Community views national survey (n=645) - problem definition and solution ideation phases
- co-delivered workshops and interviews with autistic individuals (n=25), representatives from peak bodies, autism and/or disability organisations (n=13) and autistic representatives from autistic-led organisations (n=4) - problem definition, solution ideation and, idea validation and testing phases
- co-produced Community engagement plan – delivery phase.

What we found

Explored through the co-design process, the data showed significant overlap between the various methods employed to define and understand the groups that require a tailored or adapted approach to actively participate in the development of the National Autism Strategy.

These groups were determined as autistic people who are also: First Nations; from culturally and linguistically diverse backgrounds including migrants and refugees; LGBTIQA+; have an intellectual disability; live in cared or supported accommodation; live in rural and remote communities; have experienced incarceration; have experienced homeless; people whose primary method of communication is not spoken language; ageing and ageing carers of autistic people and; children and young people.

The literature, problem definition, solution ideation, idea validation and testing phases of the co-design process garnered clear recommendations for inclusive community engagement. These are:

- written information should be readily accessible and conveyed in easy-to-understand language, such as easy-read or plain English, accompanied by visual aids
- ensure communications about the National Autism Strategy and opportunities for engagement are not wholly reliant on access to technology
- work through and with organisations that have longstanding and trusted relationships with various community groups

- allow adequate time for people to prepare, process information and respond meaningfully
- consider the information and stories that have already been shared during other government consultations
- facilitate individuals' understanding of the direct impact of their contributions or how their input can lead to positive change
- ensure topics of distress and trauma are treated with the highest level of sensitivity and compassion, with options for follow-up support
- ensure meaningful involvement of autistic people with diverse cultural backgrounds and life experiences in decision-making processes, consultations and activities
- foster a culture of equity and transparency, recognising and valuing all contributions, and ensuring confidentiality is maintained
- facilitate engagement through diverse methods and platforms, allowing individuals to select an approach that aligns with their needs and preferences
- ensure that community engagement processes consider culturally appropriate questions about the intersectionality and attributes of various stakeholders
- ensure that community engagement processes consider the importance of capturing the diverse backgrounds and experiences of autistic people.

Next steps

The community insights and recommendations established through this body of work have informed the development of a Community engagement plan which outlines the process for involving all stakeholders in the development of the National Autism Strategy. These findings highlight that there is no 'one-size fits all' approach to the promotion of, and engagement in, co-design and consultation. Further, they emphasise the importance of an inclusive approach, enabling people to engage in ways that suit their individual needs and preferences – to ensure all voices and perspectives have equitable opportunity to be heard.

1. Introduction

The Australian Government aims to develop a National Autism Strategy that meets the needs of all autistic people. A comprehensive National Autism Strategy development process must incorporate the perspectives and ideas of a wide range of stakeholders from diverse backgrounds, and professional and life experiences. This inclusive approach encompasses autistic people, their families and carers, and those who work to support them.

However, there are several groups, some of which are identified in the Australian Government response to the Select Committee on Autism inquiry report: Services, support and life outcomes for autistic Australians, that may require a targeted focus. These include autistic people who are also: First Nations, from culturally and linguistically diverse backgrounds, LGBTIQA+, have complex needs, are women or girls, living in regional and remote locations as well as those from lower socio-economic backgrounds [1]. For these groups, an adapted or more tailored approach may be necessary to enable engagement in the development of the National Autism Strategy.

Every autistic person is unique, each having different backgrounds, identities and often other disabilities and co-occurring conditions. These different aspects of a person's identity are influenced by biological, social, or cultural factors that can have a significant impact on the way people experience the world. These aspects may include gender, sexuality, sex, race, ethnicity, disability, and age, as well as other characteristics such as socio-economic status and education. 'Intersectionality' refers to the ways in which aspects of a person's identity can overlap to create unique experiences of discrimination, disadvantage, and inequality. These experiences of intersectionality can significantly influence an individual's health and well-being, and access to and use of services, support systems and opportunities. Recognising the diversity of the autistic community means acknowledging the important role of intersectionality in understanding and responding to the needs of all autistic people.

Within the context of a national strategy, these factors can significantly impact a individuals' willingness and capacity to actively participate in public consultation processes. Without effectively reaching and engaging these groups, many of which face multiple challenges and disadvantage, their voices and important perspectives may remain unheard.

To gain a deeper understanding of intersectionality and its impact on community engagement, Autism CRC undertook a co-design process. This included a literature and environmental scan on best practice community engagement for the target groups listed on the following page, a series of workshops and interviews and input from the Community views national survey. This process took place from January 2023 to June 2023. A detailed breakdown of activities is described in section 2 of this report.

This report provides an overview of the significant considerations for the target population groups that may require a tailored or adapted approach to actively participate in the development of the National Autism Strategy. It highlights insights derived from the co-design process, incorporating direct quotes and recommendations from participants involved. The report concludes with a series of recommendations. These recommendations have informed the development of a Community engagement plan, which outlines the process for involving all stakeholders in the development of the National Autism Strategy. This plan was provided to the Department of Social Services on 7 July 2023, as a separate document accompanying this report.

2. Methods: Co-production and co-design

Co-production involves the inclusion of autistic individuals as equal partners, alongside families, carers and those who work to support them, throughout the entire project. In the context of co-design, this means that the team (which includes autistic people) collaboratively define the approach, identify relevant questions, and jointly design and facilitate engagement activities.

Co-production provided the framework for this body of work. Autistic collaborators and team members played instrumental roles in shaping the initial approach, co-developing survey questions, co-facilitating workshops and interviews, conducting analyses, and contributing to the development of this report. In addition, an autistic advisory group (n=5) was formed to identify those groups within the community that may require a more targeted or adapted approach to enable engagement in the development of the National Autism Strategy.

The autistic advisory group identified the following groups, including many already identified by the Australian Government, as those that may require a targeted or adapted approach. Throughout this report, they will be referred to as “target groups.”

The target groups were:

- First Nations people
- people from culturally and linguistically diverse backgrounds including migrants and refugees
- people with an intellectual disability
- people whose primary method of communication is not spoken language
- people living in cared or supported accommodation
- ageing autistic people and ageing carers of autistic people
- children and young people
- people who identify as LGBTIQA+
- people living in rural and remote communities
- homeless people and
- people who are incarcerated.

2.1 The co-design process

> *“It felt like a safe place to contribute to the discussion and [was] respectful of all viewpoints.”*
>
> *Autism CRC Co-design workshop participant (2022)*

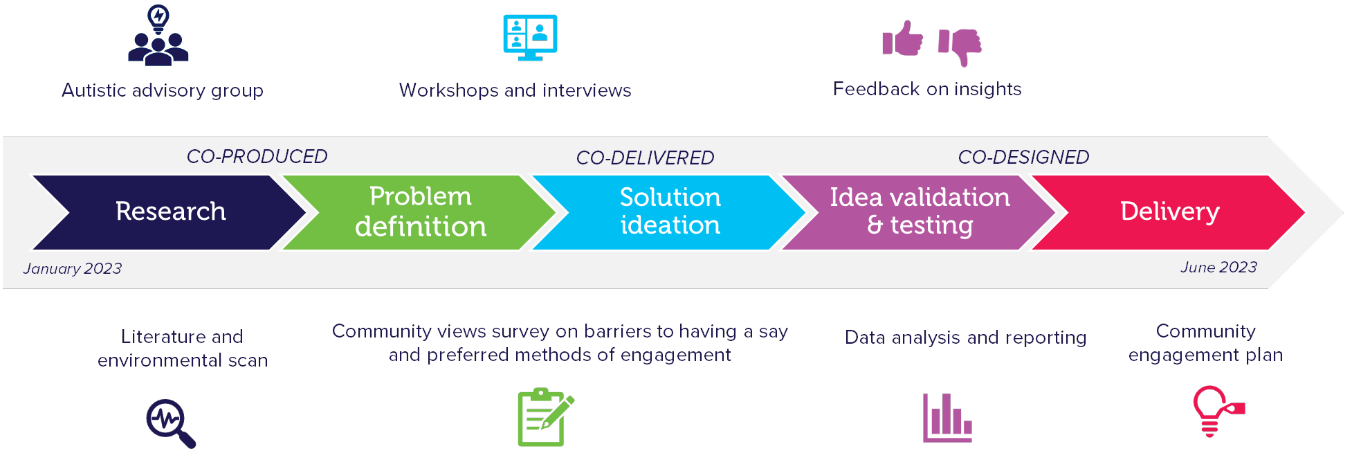
At its core, co-design is a collaborative problem-solving process. It is an investigative and creative process that brings together people impacted by a challenge or need and those with the knowledge and technical skills, to jointly create solutions. It aims to empower and put people with lived experience at the center, sharing the decision-making power to identify and understand existing needs, research and practice, and ideate and design possible solutions that address real-life challenges.

Co-design is an effective approach for exploring problems, uncovering unknown contexts, addressing unanswered questions, and ensuring that diverse opinions and experiences are heard. It serves as a powerful process to bring together stakeholders with varied skills, perspectives, and expertise, fostering collaboration to explore potential solutions that are valuable to all stakeholders.

In this project, the goal was to co-design a set of recommendations for inclusive community engagement – to inform the development of a Community engagement plan for the National Autism Strategy.

As shown in Figure 1, the co-design process encompassed five phases, each building on the previous phase: research, problem definition, solution ideation, validation and testing, and the delivery of a Community engagement plan. In this report, we will refer to this approach as ‘co-design’.

Figure 1: Co-design process overview



The specific activities undertaken within each of these stages are detailed in the table below.

Table 1: Co-design activities

Stage	Activities
1. Research	Established an autistic advisory group (n=5). Defined scope of the project and target groups. A literature and environmental scan on key considerations for best practice community engagement with target groups.
2. Problem definition	Workshops and interviews with autistic adults and peak body, disability or autistic-led organisation representatives to identify key challenges to reaching and engaging all autistic people, including the target groups. Co-produced Community views national survey questions on barriers to community engagement.
3. Solution ideation	Workshops and interviews with autistic adults and peak body, disability or autistic-led organisation representatives (n=42) to explore possible solutions and inclusive engagement methods. Co-produced Community views national survey questions on preferred engagement methods and potential solutions to support all autistic people to have their say. Data analysis and preliminary insights provided to workshop and interview participants with invitation to provide recommendations, ideas, and examples of good practice.
4. Idea validation and testing	Workshop and interview participant group validation of insights and ideas. Community views national survey data analysis (n=645). Presentation of preliminary insights to the Oversight Council. Review and refinement of the draft report and recommendations by members of the autistic advisory group.
5. Delivery	Community insights and unheard perspectives: Recommendations for inclusive community engagement in the National Autism Strategy (this report) and Community engagement plan finalised.

2.1.1 Research: Literature and environmental scan

The literature and environmental scan primarily focused on essential definitions related to the target groups, estimating the prevalence within the autistic population, and identifying significant factors concerning communication and engagement requirements. In the environmental scan, the emphasis was on uncovering instances of best practice in working with the identified target groups.

The literature and environmental scan was conducted from February 2023 to March 2023, using Google Scholar, Google, Australian government agency websites and journal articles. Keywords and key search terms relevant to the scope and focus of the literature scan were identified. These encompassed terms associated with autism and disability, such as autism, ASD, autistic, disability, disabled. Additionally, terms searched specifically included prevalence, definition, representative organisations, and consultation, co-design and engagement methods for working with autistic people, intersectional and the target community groups.

2.1.2 Problem definition and solution ideation: Community views survey

An online Community views national survey was used to capture the thoughts and perspectives of the autistic community and other relevant stakeholders (e.g., families/carers, teachers, health professionals) in relation to the National Autism Strategy. The survey included co-produced questions, developed with autistic team members and members of an autistic advisory group, to garner insight into the main issues that may make it challenging for autistic people to have their say, and the preferred methods for providing input and feedback in the development of the National Autism Strategy. In the survey, three questions were asked:

- How would you like to have your say?
- What do you think are the main issues that make it hard for autistic people to have their say?
- Is there anything else you would like us to know about how to give autistic people the opportunity to have their say?

For the first question, participants responded by indicating their support/preference for six pre-determined methods (e.g., online/paper based, interview). For the remaining questions, participants provided written responses indicating their thoughts. These three questions were added as the final section of a larger Community views survey informing the National Autism Strategy (Landscape Mapping of the National Autism Strategy domains) conducted by Griffith University and Curtin

University, commissioned by Autism CRC. The Community views survey received full ethical approval from Griffith University and was live from 13 March 2023 until 5 May 2023.

A total, of 1,018 people responded to the larger Community views survey, and 645 people chose to answer the questions relating to methods to support autistic people having their say in the development of the National Autism Strategy.

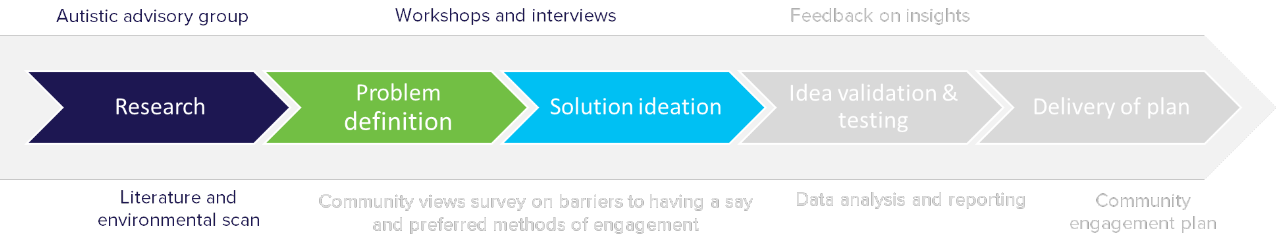
Data analysis and synthesis

Two methods were used to analyse the data. For the first question ("how would you like to have your say?"), the percentage of participants selecting each option was calculated. For the two open-ended questions, inductive content analysis was used. This technique means that categories and codes were developed from the responses provided by the respondents, thus ensuring that their specific ideas and perspectives were reflected. As such, each response provided by the respondents was read and coded, with similar responses grouped together into codes. Given the number of respondents, initially many codes were developed. Similar codes were then combined into categories.

The number of respondents who provided a response that reflected a category was then calculated. This provided an indication of how many people considered this category to be important to consider when asking the autistic community for input into the National Autism Strategy.

To ensure that the categories discussed in this report represent the perspectives of the community rather than an individual, only those categories mentioned by 5% or more of respondents were included.

2.1.3 Problem definition and solution ideation: Workshops and interviews



Workshops and interviews provided a forum to delve into the factors that may hinder autistic people from having a say when participating in public consultation. Workshop and interview participants were encouraged to reflect upon these barriers, either focusing on a specific target group or more broadly. After discussing challenges, participants were prompted with questions to stimulate discussion of potential solutions. Here the participants explored inclusive methods and processes to enable all autistic people to participate in public consultation related to the National Autism Strategy.

The workshops were 2 hours in duration, and interviews were up to 1.5 hours. All interviews and workshops were co-facilitated by an autistic collaborator/team member. Workshops and interviews were video recorded, with the consent of participants, and transcribed for ease of data analysis. Autism CRC's inclusive meeting protocol was used to promote a safe and accessible workshop environment. This included inviting people to participate in a way they felt comfortable, with the camera on or off, using the chat function instead of speaking, and enabling follow-up input from all participants. Autism CRC's inclusive and accessible meeting strategies protocol is provided in Appendix A.

These practices also supported a trauma-informed approach which was underpinned by the following principles of safety, trust, choice, collaboration, empowerment, and respect for diversity. These principles, which align with Blue Knot's (2023) foundational elements of a trauma informed service[2], are described in more detail in section 3 of this report.

To cater to the diverse needs and preferences of the participants, autistic participants were given the option to engage in a mixed stakeholders workshop, 'autistic people only' workshop or contribute their insights through interviews. This ensured that they had opportunities to engage in a manner that best suited their needs and preferences.

Seven workshops and eight interviews were held between March 2023 and June 2023, engaging 42 stakeholders including autistic people (71%), families/carers of autistic people (45%), representatives from organisations that work with autistic individuals (47%) and representatives from autistic-led organisations (11%).

Note: The total percentages add to greater than 100% as some respondents identified as being in multiple groups (e.g., autistic and/or organisation representative and family member).

Data analysis and synthesis

Data were analysed through thematic analysis to inform recommendations for inclusive community engagement in public consultations. Data was first organised by target group (First Nations, culturally and linguistically diverse, LGBTIQA+ etc) and then classified into barriers or solutions. From there, thematic analysis was conducted to identify common themes for each target group. These target group-specific themes were then consolidated to create overarching themes. Acknowledging that many in the autistic community, identify with multiple groups and belong to multiple communities, this approach ensured the recommendations were inclusive of all target groups, and all other stakeholders.

2.1.4 Idea validation and testing: Summary insights ideation

A summary of the information and ideas shared in the workshops and interviews was provided to the participants for validation and further input. Participants were also invited to comment on the ideas and provide examples of how this might work in practice.

Providing additional feedback on the workshop summary was optional. Twenty-three participants (54%) provided further input in the validation process including 18 (78%) autistic people representing themselves and 5 (21%) representatives of organisations.

This step enabled participants to offer additional ideas and insights, which were then analysed and synthesised along with the survey data and inputs from the workshops and interviews.

2.1.5 Delivery: Developing the recommendations for the Community engagement plan

The insights from the literature and environmental scan, Community views national survey, workshops, interviews and feedback from the validation process, have been synthesised into a series of recommendations for inclusive engagement. This includes clear direction on how these recommendations might be put into action in the context of the National Autism Strategy consultation process. These recommendations have informed the development of a Community engagement plan, which was provided to the Department of Social Services on 7 July 2023.

3. Findings from the research phase: Literature and environmental scan

The literature and environmental scan was the key activity of the research phase. It sought to provide an understanding of the diversity of autism and intersectionality that can impact community engagement in national consultation processes. Further, this assisted in clarifying the problem to be investigated in greater depth through subsequent surveys, workshops, and interviews.

3.1 Diversity of autism

Every person on the autism spectrum is unique, with individual strengths, interests, and challenges. Autism is a neurodevelopmental condition characterised by differences in social interaction, communication, behaviours, and interests. The presentation and impact of autistic traits can vary widely in nature and intensity between individuals; and in the same individual over time, as can their needs and nature of engagement with service sectors.

Life outcomes for people on the autism spectrum and their families have been and continue to be far from optimal on many dimensions including school completion, education, and employment outcomes. Today, we better understand that it is often an individual's co-occurring conditions, circumstances and non-inclusive environment that are disabling. As a result, the significant strengths and interests of autistic individuals have often not been recognised and engaged for their and the community's benefit.

3.2 Intersectionality

> *Autistic people are in every community, and always have been. Autistic people are people of colour. Autistic people are immigrants. Autistic people are a part of every religion, every income level, and every age group. Autistic people are women. Autistic people are queer, and autistic people are trans[gender]. Autistic people are often many of these things at once. The communities we are a part of and the ways we are treated shape what autism is like for us.*
>
> *Autistic Self Advocacy Network (2023).*[3]

Intersectionality is a framework for understanding how the different aspects of a person’s identity intersect to create unique experiences of discrimination, disadvantage, and inequality. This includes experiences of health, and wellbeing, and access to use of services, supports and opportunities.

Different aspects of a person’s identity are influenced by biological, social or cultural factors. This may include, but is not limited to gender, sexuality, sex, race, ethnicity, disability, and age, as well as other characteristics such as class and education. Recognising the diversity of the autistic community, means acknowledging the important role of intersectionality in understanding and responding to the needs of all autistic people.

3.3 Co-occurring conditions and disabilities

In addition to varied experiences associated with intersectionality, autistic people also experience other disabilities and/or conditions at a much higher rate than non-autistic people. Known as co-occurring conditions, these include: intellectual disability, , attention deficit hyperactivity disorder (ADHD), anxiety disorders, depression, , sleep disorders, epilepsy, and sight and hearing loss/impairment and gastrointestinal syndromes. .[4]

A US study on the prevalence of co-occurring medical and behavioural conditions found that more than 95% of children had at least one co-occurring condition or symptom. Results suggested that co-occurring conditions are more prevalent as autistic children get older.[5] Further, it is estimated that up to 79% of autistic people experience mental health difficulties.[6]

Autistic people often have co-occurring conditions and other disabilities. For people with a co-occurring health and mental health condition and/or disability, their engagement in co-design and consultation may be influenced by several factors:

- Attitudinal – Stigma, prejudice, discrimination, and stereotypes
- Environmental – venues, room layout, facilities, seating, lighting, technology
- Demographic – location and transportation
- Communication – hearing, speaking, reading, writing, and or understanding information.
- Condition or disability specific – type, nature of the condition and/or disability and impact on daily living.

3.4 Target groups

Table 2 presents a summary of each target group, including estimates of the autistic population and key considerations for fostering inclusive engagement. Through analysis of the literature, close links between barriers to service and key considerations in inclusive engagement were identified. As a result, barriers to service were noted in the findings, whenever it applied.

Table 2: Target group definitions and estimates

Group	Key definitions and statistics	Key considerations for services and community engagement
First Nations autistic people	First Nations people are those of Aboriginal and/or Torres Strait Islander descent, or people who identify as being of Aboriginal and Torres Strait Islander origin[7] The most recent Australian Bureau of Statistics (ABS) data (2021) reports that in 2018 of the 581,400 Aboriginal and Torres Strait Islander people in Australia living in households, 24% identified as having a disability.[8] The NDIS (2023) reports that 6% (12,243) of participants with autism as a primary disability, identify as Aboriginal or Torres Strait Islander.[9] The percentage of First Nations autistic people is not known.	The submission made by the National Aboriginal Community Controlled Health Organisation (NACCHO) to the Senate Select Committee on Autism highlighted that First Nations people have a lower likelihood of accessing and participating in disability services. The reasons for this include lack of awareness about autism, insufficient availability of services, especially in regional and remote areas, as well as a lack of culturally appropriate information, support, and services.[10] Other factors that can deter First Nations people from accessing support or services include: poverty, limited access to transport, cultural and language barriers, shame and stigmatisation around disability, a lack of trust in government, and experiences of racism in mainstream services.[11] Consequently, autistic First Nations people may be less likely to engage in public consultation without a specific and targeted approach through First Nations organisations. These organisations employ culturally appropriate practices and possess existing relationships and trust within the community.

Group	Key definitions and statistics	Key considerations for services and community engagement
Autistic people from culturally and linguistically diverse backgrounds	People who identify as culturally and linguistically diverse may do so for several reasons including country of birth, ancestry, where their parents were born, what language/s they speak, and their religious affiliation. The culturally and linguistically diverse community includes migrants and refugees.[12] Migrants are individuals and families who have chosen to move to another country, mostly to improve their lives, but can return home safely. Refugees are individuals and families who must leave their country or state because they are fleeing conflict or persecution and cannot return home safely.[13] According to the AIHW (2023) 28% of the Australian population were born overseas, including 23% (6 million) of all Australians reporting using a language other than English at home.[14] In 2022, there were 191, 251 NDIS participants with primary diagnosis of autism with 11,875 of those participants identifying as culturally and linguistically diverse.[15]	People from culturally and linguistically diverse backgrounds, migrants and refugees may be less likely to access services and supports due to factors such as accessibility of information, communication and cultural differences, cultural sensitivities, and experiences of discrimination and stigma.[16] These factors may also reduce engagement in public consultation without accessible, culturally appropriate information, methods and approaches.

Group	Key definitions and statistics	Key considerations for services and community engagement
Autistic people with an intellectual disability	The term intellectual disability is used to describe a reduced ability to understand and process new or complex information, and to learn and apply new skills. It is a lifelong condition that typically originates before the age of 18 and can involve difficulties with communication, memory, understanding, problem-solving, fine and gross motor skills, and self-care.[17] The Department of Health and Aged Care reports that approximately 450,000 people in Australia have an intellectual disability.[18] With an estimated 33% of autistic Australians also having an intellectual disability.[19]	The experience of intellectual disability varies from person to person and may include difficulty with communication including talking, listening, and understanding. Consequently, engagement in public consultation may require adapted approaches that are responsive to the understanding and communication needs and preferences of individuals. Accessible information – communications, documents and surveys in Easy Read format, using pictures where possible is widely recognised as best practice communication. It is important to provide flexible methods of engagement and consultation that enable individuals to choose to respond in ways that suit their needs and preferences.[20]
Autistic people whose primary method of communication is not spoken language	Many autistic people identify as having multiple and complex support and communication needs. The ABS (2018) data reported that almost half (44.1%) of autistic people had a 'profound or severe' communication restriction.[21] There may be a requirement for assistance at least some of the time to understand or be understood by others and that many communicate more effectively using sign language or other forms of non-verbal communication. The number of autistic Australians whose primary method of communication is not spoken language is not known.	A variety of communication methods, including the use of technology, communication boards, visual aids and facial expressions and gestures, may be used by people with complex communication needs.[22] In the context of community engagement and public consultation, it is most important to enable and support people to communicate through their preferred, or necessary means of self-expression.

Group	Key definitions and statistics	Key considerations for services and community engagement
Autistic people living in cared or supported accommodation	The ABS defines cared or supported accommodation as encompassing: - hospitals, - residential aged care, - cared components of retirement villages, - aged care hostels, - psychiatric institutions, and - other homes - such as group homes for people with disability. Cared accommodation includes all meals and provides 24-hr access to assistance for personal and/or medical needs. A person is considered to be living in cared accommodation when they have resided in these settings for three months or longer. [23] There is little information about autistic Australians living in cared accommodation homes. However, it has been estimated that 17,000 people live in specialist disability accommodation.[24] It is likely that many of these individuals have multiple and complex needs and/or intellectual disability.	Engagement with individuals living in cared or supported accommodation in public consultation may require adapted approaches that are responsive to the understanding and communication needs and preferences of individuals. Some people in this cohort may have a supported decision-maker. It is important to develop appropriate mechanisms to ensure the autistic person is heard from directly, with the opportunity to talk about their experiences, needs and ideas. People living in cared or supported accommodation may further require a targeted effort to ensure awareness of the opportunity and access to appropriate engagement activities.

Group	Key definitions and statistics	Key considerations for services and community engagement
Ageing autistic people and ageing carers of autistic people	In 2018, 15.9% of the population, or 3.9 million people were aged 65 years and over.[25] The number of older autistic people is not known. There are 2.65 million carers in Australia, with 37.4% of carers having a disability and 34% of carers being aged 65 or over. The number of ageing carers of autistic people is not known.	Research from the UK suggests that older autistic people may experience increased isolation as they age[26]. As such, this cohort is identified as a marginalised group who are often disconnected from the community and require a targeted approach to ensure awareness of the opportunity for engagement in public consultation.
Autistic children and young people	Children and young people include those under the age of 25. Autism is most often diagnosed in children and young people. Accordingly, autistic people are more likely to be younger, with 83% aged under 25.[27] This cohort includes children and young people living in alternative accommodation and in out-of-home care settings, many of whom will have a care and protection order or are in juvenile detention.[28] In 2022, approximately 29% of children in out-of-home care across Australia had a disability.[29] The number of Australian autistic children and young people living in alternative accommodation and in out-of-home care settings is not known.	Children and young people under the age of 18 years require consent from their parent or guardian to participate in research and related activities, with informed assent being provided by the child or young person. Children and young people may acquiesce, may feel pressured to make the right decision, or tell you what you want to hear. The inherent power imbalance can be lessened through choosing environments that are familiar or selected by the group. The methods for engagement and public consultation should reflect generational interests, cognitive development stages and power imbalance.[30]

Group	Key definitions and statistics	Key considerations for services and community engagement
Autistic LGBTIQA+ people	LGBTIQA+ stands for Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual and other sexual orientations and gender identities that are not straight and/or cisgender.[31] The Australian Department of Health estimates up to 11% of the population identify as LGBTIQA+, exclusive of those questioning their sexual orientation or gender.[32] US research suggests that up to 70% of the autistic community identifies as non-heterosexual[33]. According to the most extensive study conducted in the UK to date, there is evidence suggesting that transgender and gender diverse adults have a 3.03 to 6.36 times higher likelihood of being autistic.[34] The number of Australian autistic people who also identify as LGBTIQA+ is not known.	Many autistic LBGTIQA+ people have experienced multiple forms of discrimination, exclusion and social injustice. Australia's largest survey on Australian LGBTIQA+ youth showed that over 90% of neurodivergent, or autistic young people, had experienced high to very high psychological distress - with one in eight (12.6%) reporting a suicide attempt in the past year, and over one in three (35.6%) reporting a suicide attempt in their lifetime.[35] This group is not identified as requiring a specific strategy for promotion of opportunities to engage in public consultation However, it is important to approach engagement and topics of discussion with sensitivity and responsiveness to the vulnerability of this group as evidenced by reported high levels of psychological distress.
Autistic people living in rural and remote communities	28% of the Australian population live in rural and remote areas, 18% in inner regional areas, 8.20% in outer regional areas and 2% live in remote or very remote areas.[36] According to the NDIS, autism and intellectual disability are the largest disability groups across all areas of remoteness including regional, remote, and very remote.[37]	Autistic people living in rural and remote communities typically have reduced access to services and supports. Further, one of the defining features of geographic remoteness is reduced access to infrastructure such as the internet. While 99% of Australians have mobile access, only one-third of the total land area has mobile connectivity. [38] Accordingly, a targeted approach for promotion of opportunities to participate in public consultation and methods to engage offline is required.

Group	Key definitions and statistics	Key considerations for services and community engagement
Autistic people who are incarcerated	This group refers to adults (aged 18 and over) who are in the custody of a correctional services agency, including those who are sentenced and those on remand awaiting sentencing or trial.[39] In 2018, there were 43,000 people aged 18+ incarcerated in Australia's prisons. 1 in 3 people (29%) had a chronic condition or disability.[40] It is speculated that there is an overrepresentation of autistic people in the Australian prison system, with a 2009 study estimating 1.5% of the prison population to be autistic at that time, based on epidemiological studies and the prison population in NSW in early 2008.[41] The number of Australian autistic people who are or have been incarcerated is unknown.	According to Australians for Disability Justice (2017), when considering cognitive disability, which includes autism, there are several challenges faced by individuals who are incarcerated. These challenges encompass challenges in establishing trust and forming relationships, reluctance to acknowledge their own disability, trauma and negative experiences with various systems.[42] Engagement in public consultation will need to consider the role of justice system authorities in ensuring access for people who are incarcerated.
Autistic people who are homeless	The Specialist Homelessness Services Collection defines a person as homeless if they are living in either in non-conventional accommodation or sleeping rough - such as living on the street - or in short-term or emergency accommodation due to a lack of other options. This may include living temporarily with friends and relatives.[43] In 2019-20 Specialist Homeless Services assisted 290,500 people, with 8.6% reported as having a disability.[44] The number of Australian autistic people who are homeless, or at risk of homelessness is not known.	People who are homeless often experience unmanaged health and mental health conditions due to disengagement from services, which makes it difficult to provide informed consent. Trust issues and difficulties with transportation, literacy, and providing identification or necessary personal information, suggest this is a group that will require targeted effort to engage in public consultation.[45]

3.5 Limitations of national data

During the literature scan, it became evident that there are significant limitations to the amount of available information and data on these target population groups within the autistic community in Australia. This reflects the current national data sets, which are fragmented and inconsistent, resulting in an inadequate understanding of the true representation of these target groups.

Examples in the national data include:

- The lack of or limited available data of different population groups
- Inconsistent data collection standards
- Inconsistent definitions for sampling of population groups.

Examples in the literature include:

- Small sample sizes for different population groups, meaning the data may not be representative of all members of the population group
- Samples limited to children, therefore lacking insight from autistic adults
- Reliance on inferences drawn from studies in the UK & US
- Suggestions or inferences made, but no reliable primary source cited.

3.6 Community engagement with target groups

The key considerations for services and community engagement with the target groups have emphasised the highly recommended approach put forth by the autistic advisory group. This approach advocates for the implementation of a trauma-informed perspective in all engagements involving autistic individuals, their families, and the professionals who support them.

It is important to acknowledge and (seek to) understand the impact of trauma and negative experiences in people's lives. This may include experiences of social exclusion and isolation, discrimination, intersectional marginalisation, and socio-economic disadvantage.

The evidence affirmed that autistic people often have co-occurring mental health conditions, including post-traumatic stress disorder (PTSD) and complex PTSD. They may also experience daily stressors and demands, associated with limited or absence of support and navigating systems, and barriers to education, healthcare and disability support. For autistic people who are homeless, incarcerated or low-income, additional stressors may arise as they may struggle to meet basic needs. These experiences of trauma and adversity can lead to feelings of mistrust, vulnerability, disbelief that change will occur, and a reluctance to trust institutions (including government), or actively participate in engagement and consultation processes.

Our trauma informed approach was underpinned by the following principles, aligned with Blue Knot's (2023) foundational elements of a trauma informed service:

- **Safety:** Promote an environment that encourages emotional as well as physical safety. The facilitators were welcoming and used strength-based language. Options were provided for contact before and after the workshops and interviews.
- **Trust:** Honesty and transparency about purpose of engagement and how input will be used. Clear and direct communication was provided in advance of workshops and interviews with ways to opt-out or contribute anonymously.

- **Choice:** Clear and direct communication about what to expect prior to engagement, so people could make informed choices. Information was provided in advance of workshops and interviews, including ways to contact the organisers to ask any questions, or discuss concerns.
- **Collaboration:** Working together to jointly solve problems. Clear communication of the values and purpose of the co-design process was made available in pre-workshop or interview preparation guide.
- **Empowerment:** Respecting individual communication needs and preferences. People were invited to participate in a way that works for them and that they would feel most comfortable with, (e.g. using chat, turn camera on or off, moving around or stimming).
- **Respect for diversity:** Acknowledging that people have multiple identities that influence who they are and their life experiences. Recruitment sought to engage a wide range of stakeholders including autistic people with diverse intersectional experiences[2].

3.7 Moving into the problem definition phase

The literature and environmental scan in the research phase provided valuable insights and understanding of the key issues facing the target groups. This provided an opportunity to garner even greater insight into the diversity of the autistic community, and key challenges to address in community engagement related to the National Autism Strategy.

4. Insights from the problem definition phase

An overview of the diversity of the autistic community, intersectionality and target groups derived from the literature and environmental scan was provided in the workshop and interview preparation guide. Additionally, a summary of these key points was presented at the outset of each workshop. This approach effectively framed the problem space, establishing a shared understanding among participants regarding the specific target groups under discussion.

Throughout the survey, workshops, and interviews, participants were prompted to consider both the challenges and potential solutions. This approach fostered ideation and exploration of inclusive methods, processes that could significantly enhance engagement in public consultation processes.

A total of 695 stakeholders across workshops (n=34), interviews (n=8) and the national Community views survey (n=645) were engaged. A breakdown of participants in each activity is detailed, followed by results for the problem definition and solution idea phases separately.

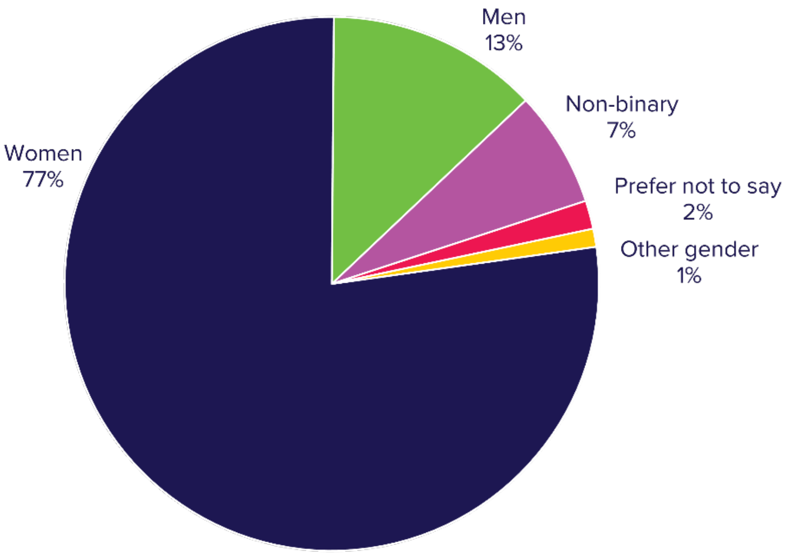
4.1 Community views survey participants

A total of 1,018 people responded to the larger Community views survey, and 645 people chose to answer the questions relating to methods to support autistic people having their say in the National Autism Strategy. Some people identified as being in multiple categories (e.g., autistic person and researcher) meaning that the percentages add up to more than 100%. Nearly half (n = 282; 44%) of the respondents were autistic and 59% (n = 378) were parents, family members, or caregivers of autistic people. Respondents also identified as educational professionals (n = 151; 23%), allied health professionals (n = 110; 17%), mental health professionals (n = 69; 11%), medical professionals (n = 35; 5%) and researchers (n = 68; 11%).

Figure 2: Community views survey respondents by stakeholder group

Most of the respondents identified as a woman (n = 495; 77%), followed by men (n = 82; 13%) and non-binary (n = 45; 7%). Seven people identified as a different gender, eleven selected that they would prefer not to answer the question, and five did not provide a response.

Figure 3: Community views survey respondents by stakeholder group



The most common age range of the respondents was 50-64 years old (*n* = 217; 34%), with 18- to 29-year-olds (*n* = 54; 8%) and 65+ year olds (*n* = 36; 6%) being the least represented.

Over half of the respondents identified as neurodivergent (*n* = 339; 53%), and 17% identified as LGBTIQA+ (*n* = 112). When asked, 12% of respondents identified as having a physical disability (*n* = 80) and 2% reported having an intellectual disability (*n* = 15). Only 0.2% (*n* = 1) identified as non-speaking, with 2 respondents using AAC (Augmentative and Alternative Communication) full-time (0.3%) and 16 respondents using AAC part-time (3%). Two percent (*n* = 13) identified as Aboriginal and/or Torres Strait Islander, and 9% identified as being culturally and linguistically diverse (*n* = 55).

4.2 Workshop and interview participants

In total, 42 stakeholders were engaged- including autistic people, families/carers of autistic people and representatives from organisations that work with them.

Out of 42 participants, 25 were autistic and representing themselves (not an organisation), 4 were representatives from autistic-led organisations, all autistic themselves, and 13 were representatives from peak bodies, autism and/or disability organisations.

All participants were aged over 18, with the most common age group being 30 to 39 years.

Figure 4:
Co-design participants by age representation

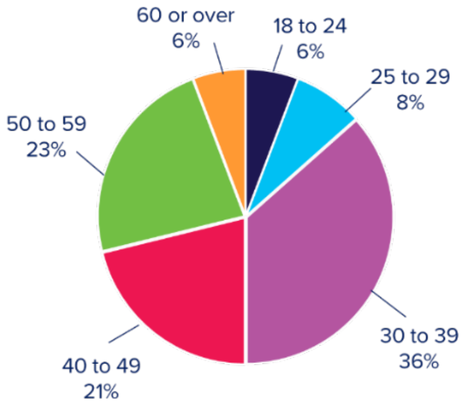
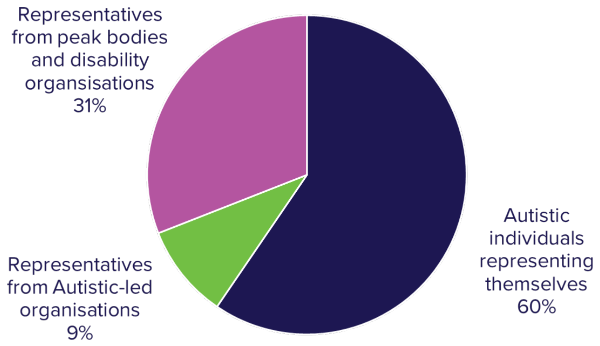
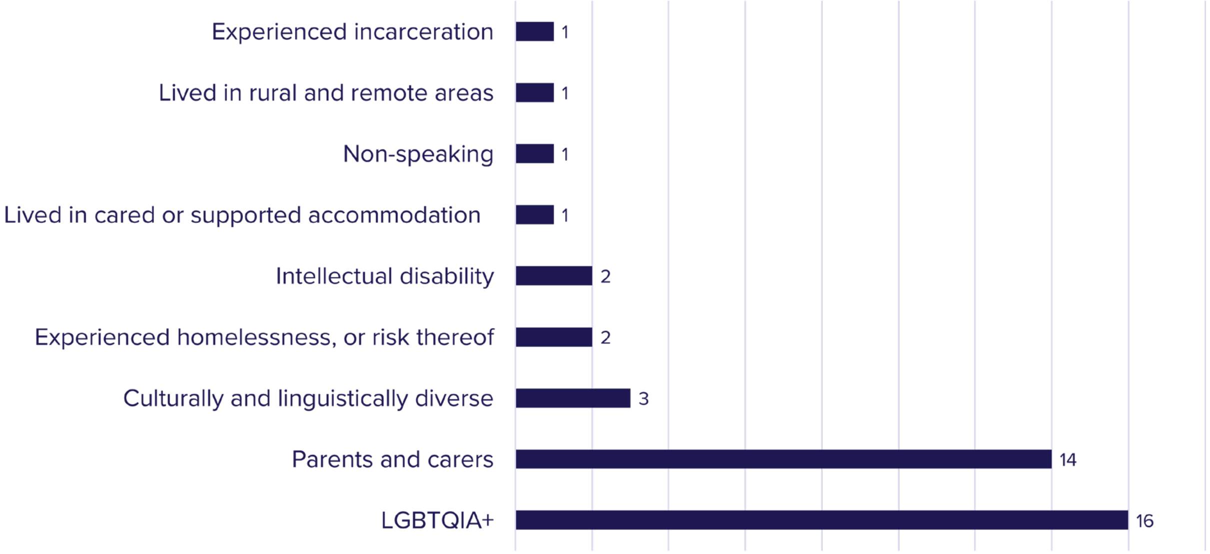


Figure 5:
Co-design participant



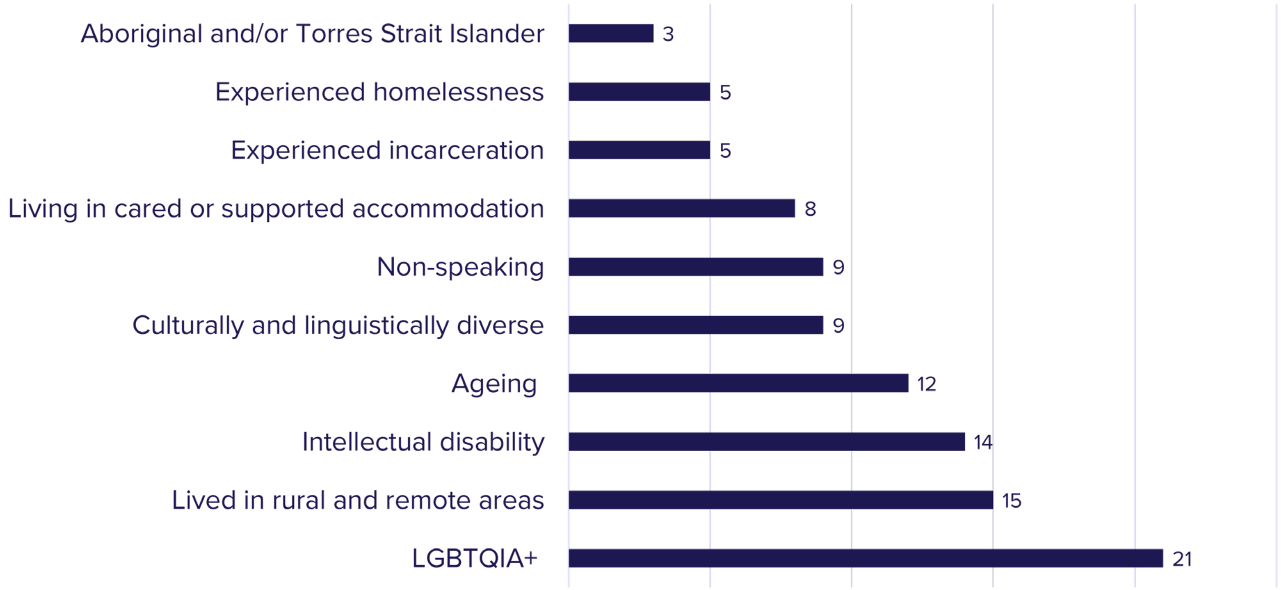
All 30 autistic people in the workshops and interviews identified with at least one form of intersectionality, as shown in Figure 6.

Figure 6: Autistic participants and identified intersectionality



Individuals with significant expertise and firsthand experience in engaging with the target groups were involved in the workshops and interviews. The greatest level of experience was focused on working with LGBTIQA+ individuals, those residing in rural and remote communities, and individuals with intellectual disabilities.

Figure 7: Participants knowledge and experience with target groups



4.3 Insights from participants: barriers and challenges to reaching and engaging autistic people in public consultation

Well understood problems are the key to finding solutions. In the co-design process, survey, workshops and interviews were used to explore the problem space and gather ideas about potential solutions.

The following section reports on the Community views survey responses, workshops and interviews.

4.3.1 Community views survey results: barriers to autistic people having their say

The Community views national survey data showed that approximately:

- 1 in 5 respondents highlight challenges to accessibility as a barrier to autistic people having their say.
- 1 in 5 respondents highlight that methods often do not take into consideration the communication differences or challenges experienced by autistic people.

Ranking of issues identified by all respondents, and by respondent group is shown in Table 3.

Table 3: Fifteen most frequently identified barriers to autistic people having their say

Rank	Issue	Direct insights	All respondents N = 544	Autistic people n = 232	Family / carer of autistic person n = 322	Other respondent groups n = 326
1	**Lack of consideration of accessibility** (e.g., autism-friendly communication methods; format of surveys)	*"Accessibility for autistic people with intellectual disability or who are non-verbal - they are usually the group left out of conversations on autism." (ID 91)*	23%	25%	21%	26%
2	**Lack of consideration of communication differences or challenges**	*"Autistic communication styles and preferences are sometimes not aligned to neuronormative expectations. Sometimes autistic people need longer to work out what they want to say. It's also important that the listener checks for meaning instead of making assumptions." (ID 194)*	21%	15%	22%	21%
3	**Limited opportunity or options to have a say**	*"Nobody usually asks for our say. And where are we meant to proactively ask to have our say?" (ID 288)*	15%	13%	15%	14%
4	**Not feeling safe or listened to**	*"The need to know they have a voice and people will listen to them and value their input." (ID 409)*	13%	17%	13%	11%
5	**Doubt in the process** (e.g., feeling powerless to cause change; not knowing what needs to be changed; lack of trust in the person or organisation asking the questions)	*"They don't know the person/person who will read the Community views survey." (ID 334)*	13%	10%	13%	12%

Rank	Issue	Direct insights	All respondents N = 544	Autistic people n = 232	Family / carer of autistic person n = 322	Other respondent groups n = 326
6	**Society's negative attitudes and preconceptions about autism**	*"Autistic people are a minority, and the minority are assumed by the majority to be in the wrong." (ID 484)*	11%	14%	13%	11%
7	**Fear or shame experienced by the autistic respondent(s)**	*"Fear of persecution." (ID 532)*	8%	9%	9%	8%
8	**Lack of knowledge, understanding, or awareness**	*"Lack of awareness by Communities, Government agencies, and school districts." (ID 590)*	7%	8%	7%	5%
9=	**Autistic people may not know where to have their say, or that there are opportunities to have their say** (e.g., not aware of opportunities; lack of publicity of opportunities)	*"Not knowing where organisations are facilitating the process to create opportunities for autistic people to give an opinion on the National Autism Strategy." (ID 61)*	6%	7%	6%	6%
9=	**Most vocal autistic people are heard, while non-speaking, higher support needs, and/or co-occurring intellectual disability are not represented**	*"Communication accessibility! How many non-verbal Autistic people who use AAC to communicate will you interview for this project?" (ID 767)*	6%	4%	5%	7%
11	**Other people think they know better than autistic people themselves**	*"Our voices are not deemed as important as "professionals." (ID 816)*	6%	10%	5%	6%
12	**Lack of support to provide their say** (e.g., additional guidance or advocacy from a trusted support person)	*"The autistic person may be able to have their say through their caregiver with preparation and time." (ID 452)*	6%	5%	6%	8%

Rank	Issue	Direct insights	All respondents N = 544	Autistic people n = 232	Family / carer of autistic person n = 322	Other respondent groups n = 326
13	**Impact of other co-occurring conditions and experiences** (e.g., executive function; burnout)	*"Being too burned out from this hostile world to engage in research." (ID 572)*	6%	4%	7%	6%
14	**Time and/or energy required**	*"Many autistic people are exhausted at the end of their day, often seeking solace or down time of their choosing. They might find it difficult to allocate time and energy to a project like this- despite probable motivation." (ID 808)*	5%	8%	6%	4%
15	**Anxiety or stress experienced by the autistic person**	*"Often the difficulty with anxiety and stress." (ID 458)* *"Anxiety in group situations and on the phone." (ID 837)*	5%	4%	6%	6%

Note: The total percentages add to greater than 100% as some respondents identified as being in multiple groups (e.g., autistic and family member).

4.3.2 Workshop and interview insights: barriers to reaching and engaging all people to have their say

Data gathered in response to the key barriers and challenges in reaching and engaging target groups, are presented in table 4 below. It is worth noting that these key barriers and challenges were largely consistent with those identified in the national Community views survey responses, however, the workshops and interviews provided the opportunity to develop a deeper understanding of the challenges.

Table 4: Insights from workshops and interviews: barriers and challenges to people having their say

Key challenge	Issues raised	Direct insights
Lack of accessible information	- Lack of culturally appropriate and translated information. - Information may not be easy to understand. - Language barriers, including translated information, non-consideration of different dialects and cultures within cultures. - Children may be required to translate for other family members. First Nations people often have high rates of low literacy skills. - Information may be outdated or inappropriate.	*"...with the big words, I don't really understand what they are."* *Autistic participant with an intellectual disability* *"... when we genuinely use language really well, it is easy to understand.... A lot of those things, I think they're not actually making language more effective or clearer, they're sometimes making it more convoluted."* *Autistic participant*

Key challenge	Issues raised	Direct insights
Lack of access to information	• There are barriers to sharing information with people who are incarcerated. • People living in supported and cared accommodation often have limited or dependent access to the broader community. • Older autistic people and ageing carers of autistic people sometimes feel that they are left “out of the loop”. • There are autistic people who are disconnected or isolated from communities. • Low awareness of the National Autism Strategy. • Communications regarding public consultations are often only delivered online via websites, social media and email. • No, or low internet access, particularly in rural and remote areas. • Poor digital literacy in some groups. • Low-income people may have restricted access to the internet.	*“it's really important to try and get to these people in their, where they're living in their environments.”* *Autistic participant* *“Social isolation and loneliness in the autistic community also means that some people are hard to reach or may be disconnected from the community.”* *Autistic participant*

Key challenge	Issues raised	Direct insights
Differences in experiences, perspectives and understanding of autism	• Diversity of communication support needs. • Misunderstandings in communication of ideas. • Assuming intelligence by the way people may communicate. – Consideration of cultural perspectives of disability and autism including: the way autism is understood and spoken about, including the absence of language or words for disability and autism for First Nations people and people from culturally and linguistically diverse backgrounds. – autism is a western and foreign concept often with no culturally diverse representation – the feelings of stigma and shame attached to disability for people from culturally and linguistically diverse backgrounds – for First Nations people there may be feelings of shame and stigma, due to the similarities between autism and Foetal Alcohol Syndrome. • Differing views of autism within the community, alongside different sectors differing in their understanding and language • Lack of awareness and understanding of the diversity of autistic people and of co-occurring conditions. • For people in rural and remote areas, less exposure to disability and low levels of health literacy, resulting in less awareness and understanding of autism.	*“I don’t always know if people are genuinely listening to me or if they are doubting my intelligence because I’m using multi modal communication techniques.”* *Autistic participant* *“I think it's important to make sure that there's not one perspective that's dominating the entire conversation.”* *Autistic participant*

Key challenge	Issues raised	Direct insights
Consultation fatigue	- The emotional toll of telling the same story repeatedly with no outcome. - Autistic people may be burnt out, exhausted and over-researched. - Large number of recent or in progress consultations requesting significant input from autistic people, their families, carers and the people who work to support them. This includes: The Select Committee Review on Autism, National Disability Insurance Scheme review, Australia's Disability Strategy, and Early Years Strategy. - For some people it can be difficult to see the bigger picture vs attending to immediate needs.	*"People get tired of telling their story, explaining their situation, repeatedly … especially when they see no outcome or result of their effort."* *Autistic participant* *"… it is about having to give them spoons in order to be able to do it…"* *Autistic participant*

Key challenge	Issues raised	Direct insights
Trauma, discrimination and past negative experiences	• Many autistic people have experienced discrimination, mistreatment and trauma. • Many autistic people have had experiences of feeling that they were being dismissed, not taken seriously or misunderstood, leading to lack of confidence and self-doubt about contributing. • People may be limited by their own previous experiences of marginalisation and potential trauma with authority. • Sharing experiences of trauma can leave people feeling vulnerable, or re-traumatised. • Spaces for sharing experiences can be intimidating, triggering, and lead to experiences of rejection sensitivity dysphoria. • Culturally and linguistically diverse people may experience shame and stigma.	*"It can be difficult to believe that you have a right for your voice to be heard…"* *Autistic participant* *"Safety to share your experiences starts well before anyone gets into the room and adding hurdles just means people won't have the energy to try."* *Autistic participant*

Key challenge	Issues raised	Direct insights
Lack of time	• Consultations often have short timelines that do not provide adequate time for people to prepare and respond. • When people ask for more time, it is because they need it. • Families and carers may be time-poor and focused on day-to-day support. • There is sometimes an assumption of availability - autistic people may have work and other commitments that mean they cannot just "drop everything" to attend a forum or meeting. • People who are quiet, or who need processing time sometimes miss out on having a say. • For some people, contributing can create pressure as it feels like it is adding another thing to do.	*"It can be incredibly frustrating when meetings describe themselves as accessible and provide questions and discussions points beforehand, but then go off on other tangents where I cannot contribute in the moment..."* *Autistic participant* *"You know, these big picture issues like National Strategy might not seem to families like they have an actual everyday impact on their life. And therefore, I guess why prioritise engagement and involvement, if there aren't any immediate benefits to a family."* *Organisation representative*

Key challenge	Issues raised	Direct insights
Tokenism, power dynamics and not feeling valued	• Sometimes consultation feels like people are just ticking a box. • Dynamics of consultation sometimes leave people feeling like they have no power to improve things. • Need to acknowledge institutional trauma, and mistrust of government, particularly in First Nations, culturally and linguistically diverse and refugee communities, homeless people and people in, or who have experienced incarceration. • Negative experiences with some organisations may lead to people not feeling safe to contribute. • Need to acknowledge neurotypical culture, privilege, and the inherent power imbalance with autistic people. • Trust takes time to build. For many communities, particularly First Nations people, building trust and forming relationships and connection with community is important. • Within the autistic community, there is a power imbalance, and the presence of a hierarchy of who people want to consult with and who is “not acceptable”. This means that there is often an over-representation of some autistic voices, with other autistic voices not being heard and prioritised.	*“Acknowledge people's institutional trauma and the power dynamics at play when engaging in these forums with organisations and government bodies.”* *Autistic participant* *“…it takes a lot of time, energy, investment for somebody to come along and participate, that they really actually want to know what happens with their information afterwards. So let's make sure that we're giving people the report that's produced or what that leads to, etc.”* *Organisation representative*

Key challenge	Issues raised	Direct insights
Concern about privacy	• Concern that personal information (contact details) may be shared with the government. • Perceived repercussions of speaking honestly about experiences using services or systems (schools, healthcare, disability, employment). • Concern that participation in a public process may inadvertently result in broader disclosure of autism. • Identifying as autistic may lead to perceived repercussions including social, financial, connection, stigma and support. • For First Nations people, there may be experiences of intergenerational trauma and mistrust of institutions, government and authority, including a fear of children being removed from care or not being believed. • Elderly autistic people may self-identify, experience generational stigma and not disclose or engage in consultation. • Disclosing that you are autistic, can be a risk for people who are incarcerated.	*"...there's a great fear by people putting that they have a disability that because of that they will be black noted for the rest of their life."* *Autistic participant* *"confidentiality, the importance of knowing that it's safe and that nothing you say here will be used against you."* *Autistic participant*
Lack of accessible methods to provide input	• Written submissions are not accessible to everyone. • Surveys formats are often inaccessible. • Consideration of people who need assistance, by way of communication partners, or aides to participate.	*"working with people in the way that they need to be worked with, and that can mean, thinking about things in ways that you might not."* *Autistic participant*

Key challenge	Issues raised	Direct insights
Role of carers, providers and institutional gatekeepers	• Not everyone can independently seek out opportunities to be involved. • People who have carers are often spoken about and not to. *Children and young people* • Access to children and young people is through parents and carers. • Children and young people may not be aware of their diagnosis. • Conversations often centre around children, but they may not be part of them. • The perspectives of the young people differ from their parents/carers. *Institutional gatekeepers* • Access to people living in cared or supported accommodation is through the providers, which the participant may wish to make comment on. • Access to people who are incarcerated may be through the prison system, which the person may wish to make comment on. • There is limited or dependent access to people who are in closed environments, including those who are incarcerated or in cared or supported accommodation. • There is often a difference in the agenda and experience of the person and that of gatekeepers.	*"A lot of people are making decisions on behalf of those students with assumptions about their experiences and their needs which are not true."* *Autistic participant* *"Honestly, the people who we need to hear from the most are the ones who are stuck in institutionalised group homes / settings where their voices have been stifled."* *Autistic participant whose primary method of communication is not spoken language*

5. Insights from the solution ideation phase

In the survey, workshops and interviews, participants were invited to consider the challenges and solutions in the same session. This allowed for ideation on inclusive methods, processes, and potential solutions that could facilitate meaningful participation.

5.1 Participants

For information regarding participants in the Community views survey, and workshop and interviews, please refer to sections 4.1 and 4.2 respectively.

5.2 Community views survey results: potential solutions

The Community views survey included an open question regarding how to give autistic people the opportunity to have their say.

- Approximately 1 in 3 respondents drew attention to the importance of ensuring flexibility to support the diversity of autistic people’s communication and response preferences.

Ranking of the additional information provided, relevant to supporting autistic people to have their say, is shown in Table 5.

Table 5: Ten most frequently reported methods or considerations to support autistic people having their say

Rank	Issue	Direct insights	All respondents N = 153	Autistic people n = 83	Family / carer of autistic person n = 99	Other respondent groups n = 83
1	**Flexibility in approach is needed to support variety of preferences and communication methods** (e.g., multiple choice; alternative communication such as Picture Exchange Communication System)	*"Provide multiple modes that include individual, social and non-face to face options." (ID 144)*	31%	36%	32%	34%
2	**Listen to and prioritise the views of autistic people**	*"Prioritise the views of people that are autistic themselves. Being autistic adjacent may give carers/parents/ educators good insights but it doesn't mean they know better than autistic people the experience of being autistic." (ID 159)*	18%	21%	19%	15%

Rank	Issue	Direct insights	All respondents N = 153	Autistic people n = 83	Family / carer of autistic person n = 99	Other respondent groups n = 83
3	**Gather perspectives from across the lifespan and different cultures and/or marginalised communities**	*"I find that a lot of autistic Community Views surveys, etc, are focussed on children and males. The voices of the increasing group of older women are really lost in it all. Please notice us and listen to us. Some of us have had our autism missed or misdiagnosed for decades and those experiences alone are worth digging into and looking at." (ID 330)*	17%	18%	16%	16%
4	**Promote the opportunity to engage using a range of media channels** (e.g., mainstream media; social media; autistic influencers)	*"Please advertise things like this on social media so that younger autistic people can contribute." (ID 81)*	16%	11%	15%	17%
5	**Ensure the perspectives of autistic people who are non-speaking, have higher-support needs, or have co-occurring conditions such as intellectual disability are included**	*"Make sure autistic people with intellectual disability are not excluded." (ID 707)*	16%	15%	18%	18%

Rank	Issue	Direct insights	All respondents N = 153	Autistic people n = 83	Family / carer of autistic person n = 99	Other respondent groups n = 83
6	**Recruit respondents from a range of places in order to gain a broad representation of perspectives** (e.g., special schools, workplaces)	*"Maybe visiting a range of sites could help so that people with current and lived experience can give direct feedback." (ID 1060)*	11%	6%	12%	12%
7	**A variety of options are needed**	*"Not requiring me to give answers in the form of numbers and/or 'more likely-less likely' responses. Those questionnaires do my head in!" (ID 1538)*	10%	12%	7%	7%
8	**Include the perspectives of other stakeholders** (e.g., parents/family; neurotypical classmates; teachers; clinicians)	*"Speaking with teachers, school communities and students that have students in their class with autism. Need to build a picture how these individuals are impacted and what they need to enable students with autism to access educational experiences same as their peers." (ID 666)*	8%	5%	9%	8%

Rank	Issue	Direct insights	All respondents N = 153	Autistic people n = 83	Family / carer of autistic person n = 99	Other respondent groups n = 83
9	**Allow a longer time to provide responses to support those who require more time processing information**	*“Not have too tight deadlines. I have tried to write things for many "enquiries" but have only once met the short deadlines. As a carer and autistic (with comorbidities - as 100% of us do) it takes me a lot longer to put things/ideas into words.” (ID 1118)*	7%	7%	8%	6%
10	**Co-design (or autistic-led) methods/strategies to gain the perspectives of autistic people**	*“Questions need to be explicit, clear and direct, ideally written by autistic people.” (ID 976)*	5%	6%	5%	6%

Note: The total percentages add to greater than 100% as some respondents identified as being in multiple groups (e.g., autistic and family member). The two categories ranked 4= were endorsed by the same number of respondents overall.

5.3 Workshops and interview insights: potential solutions

In the co-design workshops and interviews, participants were asked to identify potential solutions regarding reach and engagement. The solutions are mapped against key challenges and are summarised in Table 6.

Table 6: Insights from workshops and interviews: key challenges and potential solutions

Key challenge	Potential solutions	Key insights
Accessible information	• Public awareness campaigns in: Plain English and Easy Read including visuals, and multi-language including Auslan. • Work through trusted organisations and community groups. • Information should be: – provided in multi-media formats: videos, websites, social media posts, and paper-based flyers – inclusive of LGBTIQA+ people utilising gender inclusive language – inclusive and respectful of cultural differences and include the embedment of culture and representation of disability. – targeted to different age groups.	*“When reaching out into community I think it's important that any message comes directly from the community leaders rather than people doing the reaching out.”* *Autistic participant* *"...means that it's NOT like writing a job application.”* *Autistic participant* *“providing accessibility options as a default....then people can opt in without having to specifically ask for something.”* *Autistic participant*

Key challenge	Potential solutions	Key insights
Access to information	• Public awareness campaigns should be promoted in community, education, and healthcare settings, in addition to the internet and social media. • Information and public awareness campaigns should be promoted through the following channels: – local community groups, leaders, and service providers – local councils – government services – educational institutions, – advocacy and peak body organisations – disability, justice, health and aged care services. • Information should include the following information: – what the National Autism Strategy is – how people can be involved – the importance of having a say – point of contact details – FAQ's – visual maps for in-person activities.	*"if you can't find the people, you can't have those conversations."* *Autistic participant* *"You need to go into those environments, because they'll never be heard otherwise."* *Organisation representative*

Key challenge	Potential solutions	Key insights
Consultation fatigue	• Consider what has already been shared during other government consultations. • Provide clear communication about: – time commitment – expectations of involvement and levels of input – consultation spaces and accessibility – how input will be used and the outcomes of consultation. • Provide clear information and a visual representation about how the National Autism Strategy sits with past, current, and future government consultations. • Provide an acknowledgement of past failings of consultations and examples of positive influences on policy. • Throughout the process, provide reminders or check-ins with people to see if they would like to contribute or if they have anything further to add. • Provide a point of contact for questions.	*"It's a given that everyone is fatigued."* *Organisation representative* *"I think expectation about how much their voice can shift the needle from the onset is really important."* *Autistic participant*

Key challenge	Potential solutions	Key insights
Trauma, discrimination and past negative experiences	• Approach all communications and interactions with sensitivity and transparency. • Provide people with support from peers, mental health professionals and social workers. • Offer people the opportunity to have a support or safe person with them or other necessary adjustments and supports. • Offer people the opportunity to opt out of specific topics that may be triggering. • Provide people with information about how they can access support and how they can support themselves before, during and after their involvement. • Ensure a trauma-informed approach (safety, trustworthiness, choice, collaboration, and empowerment as well as respect for diversity) throughout the process. • Work through and with specialist, peak body and community organisations, groups and leaders that have experience, knowledge and existing trusted relationships with community and marginalised groups.	*"Provide trigger warnings in respect to sensitive topics. Ensure you give people explicit instruction at the beginning of any conversations that they can choose not to discuss any topics they do not want to discuss....and they can end the conversation at any time.* *Provide something more than a link to Lifeline. Check in with anyone interviewed 24-48 hours later to ensure they are ok and offer a discussion with a psych if they aren't."* *Autistic participant*

Key challenge	Potential solutions	Key insights
Lack of time	• Provide information about what to expect and what will be required of people, in advance of meetings and events. In addition, provide reminders. • Work through and with organisations that have existing longstanding, and trusted relationships. • Provide opportunities for families and carers to access (free) respite or support to attend meetings and consultation events. • Provide people with appropriate payment for their time and contributions. • Provide clear and adequate timeframes and deadlines for promotion and engagement. • Provide adequate time for engagement, keep to structure and embed time for preparation, processing of information, and questions, • Provided extended time for responses (particularly for non-speaking autistic people), decompression, and the opportunity for feedback, or provide more input afterwards.	*"providing information ahead of time is very important and makes it easier for everyone to know what to expect and reduce anxiety."* *Autistic participant*

Key challenge	Potential solutions	Key insights
Tokenism, power dynamics and not feeling valued	• Involve autistic people and autistic-led organisations as co-leaders, collaborators, co-decision makers and in every stage throughout the process. • Ensure that people are made to feel their opinions are important. • Provide options for engagement that allows for translators, communication partners, families, and support people. • Highlight benefits of involvement and be clear about how people's input will influence the National Autism Strategy. • Remunerate appropriately. • Acknowledge that the community experiences discrimination and disadvantage. • Provide clear information about the scope, goals and parameters. • Take a personal approach – introduce the National Austism Strategy, provide information about who the team are, their motivation for why they are doing this work etc. • Working through and with autistic-led, and community-specific organisations, including autistic leaders.	*"I think, for really meaningful change to happen in, to provide an environment where we can actually say in the most detail, candidly as we can, what is going to help us, we need to actually be told that we're like leading that conversation."* *Autistic participant* *"How can disadvantaged groups be heard if they are not given a seat at the table."* *Autistic participant*

Key challenge	Potential solutions	Key insights
Concern about privacy	• Provide direct and clear communication in accessible formats, about what will happen with the information people provide, including anonymity, sharing and level of detail. • Provide reassurance and value individual contributions, recognising that individuals are giving personal information and sometimes sharing deeply traumatic experiences that may leave them feeling vulnerable. • Acknowledge that some people may not identify or be connected to any community group. It may also be unsafe for people to publicly identify as autistic.	*"…you're asking people to be vulnerable and share their experiences, it often could be very sensitive, so putting in things like a privacy disclaimer, or making it really easy for people to opt out of that particular story being shared widely, or anything like that. Privacy is definitely a huge concern"* *Autistic participant* *"Some people are very concerned about confidentiality … or even just saying negative things to anyone else."* *Organisation representative*

Lack of accessible methods to provide input	• Adopt a human rights approach - affirming and accepting that everyone can engage in the development of the National Autism Strategy, and that all input is valuable. • Provide explicit information about the ways people can give their input. • Embed opportunities in consultations for discussion, processing, asking questions and follow up. • Pilot testing of participation methods with autistic people. • Provide options for engagement and consultation that enables direct engagement and participation in all activities. • Provide options for communication engagement that are flexible and support all communication methods including verbal, choice boards, body, facial expressions or eye movements, written, text, choice board, PECS, AAC device, sign language interpreter and communication partner. • Support the use of translators, interpreters, communication partners, families, support people, technology and assistive technology. • Provide multiple options for participation, including: – online and offline – individual and group – culturally appropriate – forums, meetings and social events – community and individual visits.	*“Provide the means of communication that works for the autistic person and listen to them without judgement. Record what the autistic person says without changing their words.”* *Autistic participant* *(Ask) “is there anything we can do for you to make this process work?”* *Autistic participant*

Key challenge	Potential solutions	Key insights
Differences in experiences, perspectives and understanding of autism	• Representation of autistic people from different backgrounds and community groups. • Information and education about concepts such as privilege, discrimination, diversity, and intersectionality. • Information needs to be co-designed and written in a culturally appropriate and sensitive way, including representation of disability. • Information needs to be non-judgemental and sensitive to parent/carers and the decisions they have made.	*"Ensure that representation from autistic people is well spread from very young children to older adults and those that are non-speaking to ensure accurate representation."* *Organisation representative* *"...what they think they might need, might be different than what you think they might need."* *Autistic participant*
Role of carers, service providers and gatekeepers	• Provide options for engagement, that include visiting people directly who live in closed environments. • Work through and with specialist, peak body and community organisations, groups and leaders that have experience, knowledge and existing trusted relationships with gatekeepers and those living in closed environments. • Acknowledge the role of families and people who work with autistic people, and additionally provide ways that autistic people can provide their input directly.	*"How do we get past the gatekeepers? And how do we know if people are being stopped from participating? Or we don't."* *Autistic participant* *"...sometimes with my support workers they talk to my support worker and not me."* *Autistic participant with an intellectual disability*

5.4 Community views survey: preferred participation methods

The Community views survey asked participants to indicate which of the listed methods supported autistic people to have their say. Data analysis showed that approximately:

- 4 in 5 indicated online or paper-based surveys as a way that autistic people can have their say.
- 1 in 2 indicated interviews over the phone or online were an effective method for autistic people to have their say
- 2 in 5 respondents indicated that group discussions (or focus groups) were an effective method for autistic people to have their say.

Table 7: Percentage of respondents who identified pre-determined methods as effective for autistic people to have their say

Rank	Method	All respondents N = 645	Autistic people n = 282	Family / carer of autistic person n = 378	Other respondent groups n = 387
1	Online or paper-based surveys	83%	83%	84%	84%
2	Interview (over the phone or online)	51%	51%	57%	53%
3	Focus group (discussing the topic in a group)	44%	42%	49%	45%
4	Ideas wall (online space to write or draw ideas and vote on the ideas of others)	39%	42%	37%	42%
5	Written submission in a document	38%	41%	39%	34%
6	Video or audio submission(s)	19%	16%	19%	19%
7	Other	4%	5%	4%	5%
8	I would not share my views or provide feedback on the National Autism Strategy	2%	3%	2%	2%

Note: The total percentages add to greater than 100% as some respondents identified as being in multiple groups (e.g., autistic and family member).

Respondents were also provided with the opportunity to suggest additional methods to support autistic people having their say (listed as “other” in Table 6).

Additional suggestions included:

- online discussion boards that are available for longer time periods to allow for processing time;
- expressive art (e.g., digital, painting, drawing, music);
- clinician facilitated or supported interviews.

It is important to note that multiple respondents indicated autistic people should be able to contribute in any way they find possible, with numerous options offered so the autistic person can choose the method most appropriate for them.

5.4.1 Idea validation and testing: Summary insights ideation

A summary of the information and ideas shared in the workshops and interviews was provided to the participants for validation and further input. Participants were also invited to comment on the ideas and provide examples of how this might work in practice.

Participation in this was optional. 23 participants (54%) provided further input in the validation process including 18 (78%) autistic people representing themselves and 5 (21%) representatives of organisations.

This step enabled participants to offer additional ideas and insights, which were then analysed and synthesised along with the survey data and inputs from the workshops and interviews to inform the recommendations.

6. Recommendations for inclusive community engagement

In addition to conducting a literature and environmental scan, valuable insights were derived from the Community views survey and the workshops and interviews. There was significant overlap and taken together, this information provides clear recommendations for inclusive community engagement.

Recommendation 1

Ensure that community engagement processes consider culturally appropriate questions about the intersectionality and attributes of various stakeholders.

Recommendation 2

Written information should be readily accessible and conveyed in easy-to-understand language, such as easy-read or plain English, accompanied by visual aids.

Recommendation 3

Ensure communications about the National Autism Strategy and opportunities for engagement are not wholly reliant on access to the internet or technology.

Recommendation 4

Work through and with organisations that have longstanding and trusted relationships with various community groups.

Recommendation 5

Allow adequate time for people to prepare, process information and respond meaningfully.

Recommendation 6

Consider the information and stories that have already been shared during other government consultations and facilitate individuals understanding of the direct impact of their contributions or how their input can lead to positive change.

Recommendation 7

Ensure topics of distress and trauma are treated with the highest level of sensitivity and compassion, with options for follow-up support.

Recommendation 8

Ensure meaningful involvement of autistic people with diverse cultural backgrounds and life experiences in decision-making processes, consultations, and activities.

Recommendation 9

Foster a culture of equity and transparency, recognising and valuing all contributions, and ensuring confidentiality is maintained.

Recommendation 10

Facilitate engagement through diverse methods and platforms, allowing individuals to select the approach that aligns with their needs and preferences.

6.1 Understanding who is, and is not in the conversation

The literature and environmental scan revealed noticeable gaps in data reporting on the prevalence of autistic people and their intersectional experiences. This gap was further explored through workshops and interviews, where participants demonstrated a keen awareness of the perspectives of those who were not present in the discussions. A fundamental challenge arises when we lack awareness of the intersectionality of individuals 'present in the room', making it difficult to identify who might be missing.

The survey responses from the community, or lack thereof in certain groups, reinforced the limited representation of certain groups, such as First Nations people, culturally and linguistically diverse people, older adults (including aging carers of autistic people), people with co-occurring intellectual disability, non-speaking people, homeless people, and those living in cared or supported accommodations. These groups possess valuable insights into their experiences, and it is crucial to ensure their perspectives are heard. Without addressing this underrepresentation, these groups will continue to be overlooked in policy and service provision.

During the workshops and interviews, the role of gatekeepers was highlighted. It was acknowledged that in certain situations, such as within accommodation providers, or the justice system, access to autistic people may need to be facilitated through these individuals and/or organisations.

Recommendation 1

Ensure that community engagement processes consider culturally appropriate questions about the intersectionality and attributes of various stakeholders.

How this works

- Throughout the process ask, who are we hearing from and who is being excluded?
- Balance the need to respect people's privacy with the need to gain necessary information, by only asking what is necessary.
- Communicate why this information is necessary to obtain.
- Include the option to opt out of answering questions about personal characteristics.
- Include stakeholders to identify questions and needs of the community in data collection.

6.2 Making information easy to understand for everyone

Communication plays a crucial role not only in obtaining information but also in making individuals feel included, valued, comfortable, and heard. Taking the necessary steps to ensure accessible communication enables opportunity for the community to participate fully in national consultation.

In the Community views survey, lack of consideration of accessibility was the most frequently identified barrier to autistic people having their say in a national consultation process. In the workshops and interviews, it was noted that information is not always easy to understand. One participant shared their difficulty in understanding information that did not use plain language or visual aids, stating "*with the big words, I don't really understand what they are*".

Easy Read is widely promoted as the best practice for accessible communication for individuals with an intellectual disability. This also aligns with the Migration Council Australia's (2022) recommendation that effective communication should involve presenting information in a language that is easily understood, at an appropriate comprehension level, and from a trusted source.[46]

Taking the time to ensure information is accessible is necessary to ensure individuals can meaningfully engage and contribute to the National Autism Strategy.

Recommendation 2

Written information should be readily accessible and conveyed in easy-to-understand language, such as easy-read or plain English, accompanied by visual aids.

How this works

- Write all communications in plain language, in words everyone can understand quickly and without using jargon.
- Information should be inclusive and respectful of cultural differences and include the embedded culture and representation of disability. It should cater to different age groups and be presented in multiple accessible formats such as plain English, multi-language, and Easy Read with visuals and Auslan sign language.
- Ensure budget provisions for translation of written communication into Easy Read and different languages.
- Information should include details about the National Autism Strategy, how to be involved, the importance of having a say, point of contact details, FAQs, and visual maps for in-person activities.
- Present information in multi-media formats including social media, audio, video for easy translation, and infographic or visual format.
- See the Australian Government's Style manual for guidance on accessible writing and communications particularly for Government communications .

6.3 Addressing barriers to accessing information

There are various factors that can impede people's access to online information and their ability to provide input through online platforms. A significant portion of autistic individuals in Australia reside in remote and very remote areas, where reliable internet access may be limited. Additionally, access to technology can be significantly restricted for individuals who are homeless, incarcerated, or living in supported and cared accommodations. This limitation is often due to their reliance on others for information and technology access, or in cases where access is provided, it is subject to strict regulations.

Further, even when access is available in some form, for some there is an additional barrier of digital literacy or familiarity. Internet-based channels like social media or media campaigns are less like to reach individuals facing this barrier, particularly those experiencing homelessness or living in rural and remote areas.

The limitations of internet-based communications were affirmed in the workshops and interviews, where participants suggested that many people may not be aware of the National Autism Strategy, or opportunities to become involved. This may be more significant for autistic people who are isolated, ageing autistic people and ageing carers of autistic people who are often left out of the loop, as well as children and young people.

A consistent message conveyed throughout the co-design process emphasised that access to technology and digital literacy should not serve as barriers to raising awareness about the National Autism Strategy or engaging in its development.

Recommendation 3

Ensure communications about the National Autism Strategy and opportunities for engagement are not wholly reliant on access to the internet or technology.

How this works

- Ensure an offline, paper-based version of all communications are available.
- Encourage active participation through traditional media and communication channels, such as newspapers, television, local councils, and community groups, whenever there are opportunities for involvement.
- Targeted recruitment and communication, through trusted organisations and community groups for people from different cultural backgrounds.
- Information and public awareness campaigns should be promoted through the following channels:
  - local community groups, leaders and service providers
  - local councils
  - community settings
  - government services
  - healthcare settings
  - educational institutions
  - advocacy and peak body organisations
  - disability, justice, health and aged care services.

6.4 Partnerships to address cultural barriers and sensitivities

The National Autism Strategy will be strengthened by input from a wide range of stakeholders including autistic people with a range of cultural backgrounds and life experiences.

A key recommendation throughout all co-design engagements was the importance of adopting a partnership approach and collaborating with trusted organisations who are deeply rooted within communities.

These organisations can support engagement in the National Autism Strategy in several ways. They can leverage their networks and audiences to foster broader awareness of the National Autism Strategy and encourage active engagement. Additionally, organisations can offer specific guidance on cultural appropriateness, effective engagement methods, and appropriate language use. Because of their existing relationships, they can also provide culturally sensitive support to individuals before, during, and after engagement events and activities.

The literature affirms the value of this approach, emphasising that cultural appropriateness encompasses more than just language translation and behavioural considerations. It extends to respecting cultural sensitivities and addressing topics that may be ‘triggering’ or distressing to certain groups.

It is important that individuals can input into the National Autism Strategy in a culturally sensitive and safe manner. This is especially important for First Nations people and culturally and linguistically diverse communities, including refugee groups. Throughout the co-design phases, the value of co-leadership and co-production, particularly with autistic people of similar cultural backgrounds and life experiences, was emphasised. This approach ensures cultural relevance and promotes psychological safety in any engagement.

Recommendation 4

Work through and with organisations that have longstanding and trusted relationships with various community groups.

How this works

- Engage a mix of peak bodies and “grassroots” community organisations, nominated by autistic people.
- Develop key messages and base communications that can be tailored by organisations to suit the needs of their specific population group.
- Partner with organisations that have the capacity for and commitment to co-leadership and co-production with autistic people who identify with specific intersectionalities.

6.5 Allowing time for meaningful engagement

During the workshops and interviews, participants shared their experiences of not being given adequate time to process information, prepare their responses, or contribute after consultation activities. Individuals with intellectual disabilities expressed that insufficient time for processing hindered their ability to express their ideas effectively. Similarly, insufficient time also posed a significant barrier for non-speaking autistic individuals who described the process of using multi modal communication as exhausting and time-consuming. They emphasised the need for substantial preparation, as exemplified by one participant who was non-speaking stating, "just to put this into context, it took me approximately 8-10 hours to type and produce these answers (for the one-hour co-design interview), over the period of 2-3 weeks."

This was consistent with the Community views survey findings which indicated sufficient time should be provided to support the processing of the questions and the construction and delivery of responses (whether written or verbal). This may be, for example, through providing a long lead-time for the submission of a survey or providing interview questions prior to the interview.

Furthermore, it was noted that families and carers, who are often responsible for day-to-day support, may have limited time available and may prioritise immediate needs over policy-related matters. Contributing to initiatives like the National Autism Strategy can create additional pressure for them. Given these considerations, it is crucial to provide individuals with adequate time to prepare, process information, and respond.

Recognising the role of preparation in alleviating anxiety, it is necessary to provide adequate information in advance. For workshops, interviews, meetings, and events this encompasses agendas and schedules as well as event and venue guides. By providing these resources ahead of time, individuals will have an enhanced opportunity to prepare themselves, enabling greater capacity for contribution and an increase in meaningful and productive engagement.

Recommendation 5

Allow adequate time for people to prepare, process information and respond meaningfully.

How this works

- Ensure an early communication plan that includes information about objectives, processes and a calendar of events that will allow people to plan ahead.
- Ensure sufficient time for preparation by sending event guides, meeting agendas and questions at least one week in advance. These guides should encompass the following components:
  - Detailed agenda including a comprehensive schedule with time stamps, clearly indicating when participants will have the opportunity to contribute. This helps individuals plan and allocate their time effectively.
  - Instructions for accessing or attending the meeting: Provide clear instructions on how to access the meeting, whether it is in person or virtual. Include any necessary login details, links, or visual directions to the physical location or venue layout.
  - Specify who will be attending the meeting. This information allows participants to familiarise themselves with the individuals they will be interacting with, promoting a sense of inclusion and preparedness.

- Provide opportunities for families and carers to access (free) respite or support to attend meetings and consultation events.
- Allocate sufficient time for consultations, ensuring a structured approach that allows for preparation, response preparation (especially for non-speaking autistic individuals), processing, decompression, and post-consultation feedback opportunities.
- Throughout the process, provide reminders or check ins with people to see if they would like to contribute or if they have anything further to add.

6.6 Addressing consultation fatigue

While not explicitly highlighted in the literature and environmental scan, or the Community views survey, a common sentiment of consultation fatigue experienced by the autistic community was indicated in the workshops and interviews. Many individuals expressed a sense of exhaustion from repeatedly recounting their personal experiences to the government and various other organisations. This included recent reviews and initiatives like the Senate Select Committee on Autism inquiry, National Disability Insurance Scheme review, Australia's Disability Strategy, Early Years Strategy, Senate Select Committee Inquiry into School Refusal, Senate Select Committee Inquiry into disruption in Australian classrooms, and state-based initiatives such as the development of South Australia's Autism Strategy.

In the workshops and interviews, it was expressed that families, especially those with young children on the autism spectrum, may experience a sense of being overwhelmed by the substantial amount of research and the numerous requests for engagement and consultation. Another significant challenge identified was the difficulty of engaging individuals when they are unable to see the direct impact of their contributions or how their input can lead to positive change. Participants emphasised the challenge of prioritising consultations amidst the immediate needs that require their attention.

One important suggestion was for the National Autism Strategy to consider the insights shared in previous government consultations. Additionally, emphasising that maintaining ongoing communication and providing follow-up on the utilisation of input are foundational to developing trust and providing transparency. This continuance of communication is a key element in conveying what actions will be taken based on the contributions. Thus, ensuring stakeholders are informed about the tangible outcomes resulting from their participation.

Recommendation 6

Consider the information and stories that have already been shared during other government consultations and facilitate individuals understanding of the direct impact of their contributions or how their input can lead to positive change.

How this works

- Consider the information (and data) that people have already shared in other government consultations, inquiries, and research activities.
- Provide clear communication up front about community engagement and consultation activities, what will be asked of them as well as information about how their input will be used in the development of the National Autism Strategy.
- Provide a consistent point of contact for questions, contactable via accessible multi-methods (webform, email, post, phone etc).
- Create a visual representation, such as an infographic or timeline, that illustrates the relationship between the National Autism Strategy, previous consultations/inquiries, and potential future developments. This visual aid can enhance comprehension and provide a clear overview of the policy landscape.

6.7 Navigating discrimination and trauma and acknowledging past experiences

During workshops and interviews, many participants spoke about instances of discrimination, mistreatment, and trauma faced by autistic individuals. Participants also expressed feeling disregarded, not being given due attention, or being misunderstood - resulting in diminished confidence and self-doubt when sharing their viewpoints. One participant stated, "It can be challenging to believe that your voice deserves to be heard…". Non-speaking autistic individuals conveyed similar sentiments, frequently unsure if their thoughts and intellect were genuinely recognised by others.

The literature and environmental scan highlighted the occurrence of institutional trauma, particularly among individuals who have experienced homelessness, First Nations communities, culturally and linguistically diverse (CALD) groups, and individuals who have had experiences involving the criminal justice system. Also, the increased occurrence of psychological distress and suicide rates within the LGBTIQA+ community emphasises the importance of conducting all engagement and consultation activities with sensitivity and compassion. This extends to all target groups, community engagement and consultation will be best facilitated by trusted organisations that understand the unique intersections of each target group and can support people before, during and after the engagement.

Facilitating a tolerant, sensitive, and secure environment for individuals to comfortably share their experiences and concerns is paramount to engagement with the National Autism Strategy. The government bears the responsibility to guarantee the safety and confidentiality of this environment, by the provision of suitable support before, during, and after these engagements.

Recommendation 7

Ensure topics of distress and trauma are treated with the highest level of sensitivity and compassion, with options for follow-up support.

How this works

- Embed a trauma-informed approach throughout the entire process, encompassing safety, trustworthiness, choice, collaboration, empowerment, and respect for diversity. This approach should be evident in all aspects, including the provision of information and conduct of consultations.
- Training should be extended to all individuals engaged in facilitating co-design and consultation activities for the National Autism Strategy, as well as those involved in developing communications. The training should cover the following areas:
  - Mental health first aid
  - Neurodiversity-affirming practice
  - Trauma-informed practice.
- Encourage people to engage with their personal and professional support networks. Provisions should be made for the inclusion of support people in co-design or consultation events and meetings, as required.

- Offer comprehensive guidance on self-support before, during, and after participation.
- Include trigger warnings for content that some people may find distressing.
- Provide information on necessary accommodations or supports, the option to have a support person present, the ability to opt out of certain topics, and access to mental health professionals experienced in working with autistic people.
- Use strength-based language that promotes understanding and acceptance of autism.

6.8 Co-production and co-facilitation with autistic people from diverse backgrounds and life experiences

The concept of collaboration, including through co-production, and shared facilitation was raised consistently by all stakeholder groups in the interviews and workshops and the Community views survey. The importance of involving diverse community representatives in communication development and co-facilitation of community engagement events was also reinforced in the literature and environmental scan.

Implementing visible co-production, including co-leadership and co-facilitation in; governance, workshops, interviews, working groups, forums, and meetings promotes increased and genuine collaboration. Developing a culture of inclusive collaboration is integral to meaningful engagement with marginalised groups and those who have faced discrimination.

Recommendation 8

Ensure meaningful involvement of autistic people with diverse cultural backgrounds and life experiences in decision-making processes, consultations, and activities.

How this works

- Co-production of the design of consultation events and activities including all written communications, agendas, schedules, and questions.
- Testing ideas and draft documents with autistic people including those from culturally diverse backgrounds (e.g. First Nations, culturally and linguistically diverse) as well as people with a range of co-occurring conditions including people with an intellectual disability.
- Collaborate with autistic-led and community-specific organisations, including autistic leaders that have experience working with the target group and existing trusted relationships and connections.

6.9 Tokenism, power dynamics and valuing contributions

Power sharing and transparency is important to help people understand how their contributions are utilised and fosters meaningful engagement. The Community views survey highlighted a barrier to contributing to the National Autism Strategy feeling as though they might not be listened to, doubting the effectiveness of the process, and feeling powerless to effect change.

During the workshops and interviews, participants expressed a common concern in public processes that their contributions may be undervalued, and perceived engagement as a superficial 'checkbox exercise', even if that was not the intention of the organisation or people asking for input. Concern was also raised regarding certain stakeholders not being represented accurately when people speak on behalf of others. It was also reported that people with an intellectual disability, children, or others were spoken about rather than directly engaged. This barrier highlights the presence of a power imbalance, and privilege within consultations, which further contributes to the sense of powerlessness in making improvements. Further, aging autistic individuals felt overshadowed by younger voices, and aging carers were not approached for their input.

The recommendations from the literature, survey, workshops and interviews highlighted the importance of establishing trust between respondents and the individuals/organisations seeking their perspectives. A crucial aspect of building this trust is through clear communication about the process, including information on data access, data usage, and the confidentiality of responses. It is also essential to provide feedback on how the responses have contributed to shaping outcomes, including those related to the National Autism Strategy.

Recommendation 9

Foster a culture of equity and transparency, recognising and valuing all contributions, and ensuring confidentiality is maintained.

How this works

- Support and accommodations addressing communication needs and preferences.
- In all communications, highlight the practical benefits and expected outcomes of 'having your say'.
- Provide personalised acknowledgement when contributions are received and clearly outline how people's input and ideas will be incorporated into the development of the National Autism Strategy and follow up with actual outcomes.
- Provide reassurance and value individual contributions, recognising that individuals are giving personal information and sometimes sharing deeply traumatic experiences that may leave them feeling vulnerable.
- Acknowledge that some people may not identify or be connected to any community group.
- Be aware that it may be unsafe for some people to disclose aspects of their intersectionality or that some may be uncomfortable with sharing certain aspects.
- Seek consent and explicitly inform people about the levels of privacy maintained.
- Provide people with appropriate payment for their time and contributions.
- Provide clear information about the scope, goals, and parameters of the consultation.
- Take a personal approach – introduce the National Autism Strategy and the people working on it, including government representatives. Provide relevant information for example their motivations for being involved, their personal goals or the outcomes they expect to achieve.

6.10 Diverse participation methods

The National Autism Strategy consultation should include perspectives from the multiple cohorts that it will impact- autistic people, their families and carers, and those who work with them. This will require a range of consultation methods that enable community engagement, in ways that suit individual needs and preferences, to facilitate an inclusive and comprehensive co-design and consultation process.

The autistic community is diverse. Embracing a human rights approach, everyone should have the opportunity to contribute to the development of the National Autism Strategy. Ensuring that individuals can contribute in a manner that suits their needs and preferences is essential to reaching and including a wide range of perspectives.

The Community views survey responses emphasised the importance of providing diverse engagement methods and formats to accommodate individual needs and preferences. A preference for online and paper-based surveys was expressed by different stakeholders, including autistic individuals, families, and professionals. However, it is important to acknowledge that this preference was indicated through an online survey, suggesting that people were already inclined and able to engage with a survey format. Phone or in-person interviews and focus group discussions were also indicated as preferred options. Additionally, an ideas wall, an online platform for sharing and voting on ideas, garnered positive feedback.

The importance of involving families and professionals working with autistic individuals was identified during the workshops and interviews, alongside the provision of direct avenues for autistic people to share their input. This includes the consideration of groups such as children and young people as well as individuals living in supported accommodations, those who require support or translation services for access or have gatekeepers to their access.

A key recommendation, therefore, is that a range of accessible methods should be used to support the diverse communication skills and preferences of the autistic community. While this can include online and paper-based surveys, other methods that are accessible to those with different communication skills and preferences should be available.

Recommendation 10

Facilitate engagement through diverse methods and platforms, allowing individuals to select the approach that aligns with their needs and preferences.

How this works

- Methods used to gain the perspectives of autistic people should be co-produced and/or co-designed with autistic people
- Conduct pilot-testing of participation methods, surveys, questions, and activities with several autistic people with different needs, preferences, and intersectionality
- Offer a variety of engagement and consultation options that facilitate direct involvement and active participation in all activities. These options should accommodate diverse communication methods such as:
  - verbal communication
  - choice boards

  - nonverbal cues (body language, facial expressions, eye movements)
  - written responses, text-based communication,
  - visual supports (PECS, AAC devices), and
  - sign language interpretation.
- Consider the involvement of translators, interpreters, communication partners, family members, support persons, and assistive technology.
- Provide multiple avenues for engagement, both online and offline, catering to individual and group preferences, age-specific considerations, cultural appropriateness, and a range of formats including surveys, forums, meetings, social events, community gatherings, and individual visits. These options should allow for flexible contributions and customisation to meet the unique needs of each person involved.

7. Next steps

The Australian Government has made a commitment to the co-design and development of the National Autism Strategy that is firmly based on evidence and shaped by the experiences of autistic people, their families and carers and the people who work to support them. The goal of the National Autism Strategy is to establish a comprehensive approach that spans the entire lifespan. It seeks to enhance access to assessments and diagnosis, promote better integration and coordination of services, provide improved support for parents and caregivers of autistic individuals, foster social inclusion, and enhance educational, employment, and health outcomes for autistic Australians. The development of the National Autism Strategy must involve a diverse range of perspectives so it can truly meet the needs of the autistic and autism communities.

The community insights and recommendations established through this body of work have informed the development of a Community engagement plan which outlines the process for involving all stakeholders in the development of the National Autism Strategy. These findings highlight that there is no ‘one-size fits all’ approach to the promotion of, and engagement in, co-design and consultation. Further, they emphasise the importance of an inclusive approach, enabling people to engage in ways that suit their individual needs and preferences – to ensure all voices and perspectives have equitable opportunity to be heard.

Appendix A:
Inclusive & accessible meeting strategies

1 May 2023

Document purpose

The aim of this document is to set out strategies and protocols for chairing meetings that promote equity in accessibility, engagement, and contribution.

Prior to the first meeting

- Provide information about what to expect during the meetings, including:
  - names and photos of members, chair and co-chairs
  - protocols (please see below section)
  - location of the meeting, if in person, directions on how to get there.
- Attendees and members surveyed about any requirements, including that of interpreters. This should reflect collaboration and power-sharing, rather than ‘offering accommodations’.
- Provide an optional session dedicated to checking technology and familiarisation with the platform. This should be scheduled at the time of day consistent with when meetings will typically be held. Alternatively, the beginning of the first meeting should allow dedicated time for technology problem-solving.

Prior to each meeting

- Send agendas and any pre-reading in advance, ideally 1-2 weeks.
- Agendas should clearly identify items for group discussion, as well as at what point motions will be voted on. The agenda should have background information to enable members to decide in advance whether they wish to contribute to the discussion and/or how they may vote on motions.

During the meeting

- Closed captions should be turned on
- Protocols (see below) to be affirmed by the Chair
- Breaks should be proportional to meeting length e.g. a 10-15 minute break every hour for meetings greater than 60 minutes.

Protocols

- Participation
  - members to participate in any way they feel comfortable. Specifically, have cameras off; use the chat function instead of speaking; and move around, stim and use sensory tools during the meeting.
- Accessibility
  - members to mute themselves when not speaking
  - regularly take 20-second pauses to allow people to process information
  - comments in the chat should be read out by the Chair or a designated person
  - ‘space’ to contribute may need to be created so every person may input.

- Contributions
  - all members to:
    - respect that everyone has different experiences, perspectives, and opinions
    - allow everyone to talk and provide their input
    - avoid acronyms and jargon, and if repeatedly used, definitions to be provided in the chat
    - respect people's pronouns and language preferences e.g. person on the autism spectrum, an autistic person
    - use strengths-based language that promotes understanding and acceptance of autism.
  - members afforded an opportunity to process the meeting information and contribute via email or phone within a period of time to be determined by the Chair (typically 7-days). Ideally notes from the meeting distributed immediately to facilitate this.
  - Chair to enable ‘space’ to allow all members to contribute. Members encouraged to use the virtual raise-hand function or raise their hand on camera to enable the Chair to create ‘space’. After ‘pauses’ (see accessibility), the Chair can invite contributions from “those who have not yet had an opportunity to contribute”.
  - if a member is speaking for more than 3 mins, the Chair may need to interrupt. Members should be advised at the beginning of the meeting that if they are interrupted, they can continue to type in the chat or email the additional contribution to the chair (via written, video or audio formats). These may be made available for other members, at the discretion of the Chair.

Physical environment

Structuring the physical environment appropriately can make people feel comfortable and lead to increased engagement and participation. Information about the physical environment should be sent out prior to the meeting.

Consideration needs to be given to all aspects of the environment:

- Lighting
  - avoid bright, fluorescent, or flickering lights
  - use adjustable lighting, including blinds
  - if there is no option, let people know in advance if there is fluorescent lighting. You can suggest they might like to bring a cap, sunglasses, or tinted glasses.
- Odours
  - ask people to avoid wearing perfume or strongly scented deodorants
  - have catering away from seated/work areas
  - check the cleaning schedule and products to be used because the smell of cleaning products can be overwhelming.
- Décor
  - visual ‘clutter’ can be distracting for some people, and for others, it can lead to sensory overload. Where possible choose rooms that:
    - do not have brightly coloured or highly patterned: carpets; curtains/blinds; furniture; ceilings; walls; or artwork;

  - avoid using ceiling fans, if possible. These can be visually distracting as well as noisy.
- Sound
  - small group activities can be noisy. Break-out rooms are ideal. However, if this is not an option, ensure the groups are as far away from each other as possible.
  - bathroom hand dryers are very noisy, particularly in a small area. If there are hand dryers:
    - unplug the hand dryer or put an ‘out of order’ sign on them; and/or
    - provide paper towels and a waste bin.
- Temperature
  - individual experience of what is a comfortable temperature varies. If possible, ask participants whether they would like it cooler or warmer
  - room temperatures are not always adjustable, therefore, in advance of the event, encourage individuals to bring layers of clothes so they can make themselves comfortable.
- Chill out room
  - a quiet, low sensory space for people to use if they need a break from the environment.
  - ideally, a chill out room will have a variety of comfortable seating, water, low lighting, device charge points, sensory tools and instructions for use of the room displayed.

For more information, see Autism CRC Sylvia Rodger Academy Guidelines for creating inclusive environments

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