



**SA Autism
Strategy**



Government
of South Australia

**South Australia's
First Autism Strategy
Discussion Paper**

Consultation Report 2023



Acknowledgement of Country

The Department of Human Services acknowledges and respects Aboriginal people as the state's first people and recognises Aboriginal people as traditional owners and occupants of lands and waters in South Australia. We acknowledge that the spiritual, social, cultural and economic practices of Aboriginal people come from their traditional lands and waters, and that the cultural and heritage beliefs, languages and laws are still of importance today. We are committed to ensuring that the needs and aspirations of Autistic Aboriginal people are incorporated in the design, development, and implementation of the State's first Autism Strategy.

Note: The Department of Human Services acknowledge that language is a personal preference, and that different language and terminology preferences exist within the Autistic and autism communities. Based on feedback from the Autistic and autism communities throughout the consultation process, and for the purposes of this consultation report, we will continue to use identity-first language.



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Executive Summary

Meaningful cultural change and greater inclusion in our community can only come about by consulting, listening, and creating open dialogue with the Autistic and autism communities.

The co-design process commenced with a workshop on 30 September 2022, facilitated by JFA Purple Orange, to develop South Australia's First Autism Strategy - Discussion Paper (the Discussion Paper). The workshop was attended by 19 Autistic people, as well as:

- the Hon Nat Cook MP, Minister for Human Services
- the Hon Blair Boyer MP, Minister for Education
- the Hon Emily Bourke MLC, Assistant Minister for Autism and Assistant Minister to the Premier
- representatives from the Department of Human Services (DHS).

The purpose of the Discussion Paper was to start a conversation and provide an opportunity for the Autistic and autism communities, along with the broader community, to respond and share their experiences, thoughts, and voices.

On 25 November 2022, the South Australian Government launched the Discussion Paper (including an Easy English version) to support the consultation process.

During the consultation process, the Autistic and autism communities, parents and carers, non-government organisations, public sector agencies, local councils and other interested parties were invited to participate and have their voices heard in a range of ways, including:

- YourSAy engagement
- attending community forums/ meetings
- providing a written, video, verbal and/or drawing submission
- contacting DHS directly via email and/or telephone.

The South Australian Autistic and autism communities responded to the call, submitting over 1,200 responses throughout the consultation period.

This is just the start of an ongoing process of active consultation and engagement with the Autistic and autism communities as we develop the State's first Autism Strategy and Autism Charter.

About this report

This report outlines the consultation process used, feedback received and summarises key findings from the consultation process held between 25 November 2022 – 20 February 2023.

The Autistic and autism communities shared some ideas about what we should include in the State Autism Strategy and Charter for South Australia.

In preparing this report, DHS have consolidated responses received throughout the consultation into key themes.



Key messages emerging from the consultation

Throughout the extended 12 week consultation period, a number of key messages emerged as being particularly important to the Autistic and autism communities:

Improved community attitudes, awareness, and education

The need for improved knowledge, understanding and acceptance of autism was noted as a key area of need across all areas of the community, including education, employment, health, and government services.

Improvements in support, attitudes, knowledge, and understanding in education settings

Knowledge and understanding of autism within preschool, primary, secondary and tertiary education environments was consistently called for, as well as additional support in schools. Negative, and at times traumatic, experiences of bullying and exclusion were shared and highlighted as key areas for change.

Improved employment opportunities and support

Meaningful and adequately paid employment opportunities for Autistic people is essential. Members of the Autistic and autism communities who provided feedback highlighted existing challenges related to current recruitment strategies, and the lack of support and understanding from employers regarding the needs of Autistic applicants and employees.

Improved access and affordability of diagnosis

Members of the Autistic and autism communities called for support and funding to reduce current wait lists and cost for an autism diagnosis. As a diagnostic assessment is required for access to NDIS supports, timely diagnosis is critical, with delays accessing support having a significant impact on the Autistic person and their family.

Support for parents, carers, and guardians for Autistic children and adults

Parents and carers of Autistic people highlighted the need for resources, information and services which support family members of Autistic children, young people, and adults. Parents and carers of Autistic people suggested that this should be provided via a centralised service which can assist families to navigate the NDIS and relevant government services.

Safe, sensory friendly spaces and an autism inclusive community

Feedback indicated the need for appropriate sensory spaces in the community, which enable Autistic people to regulate their sensory needs. Having appropriate spaces available is a significant factor to increasing the inclusion and participation of Autistic people within our community.

Listening to Autistic voices and ongoing collaboration and consultation with the Autistic and autism communities

Members of the Autistic and autism communities called for ongoing collaboration, consultation and engagement with Autistic people and their families throughout the development of the Strategy and Charter.

Recognising individual diversity and the range of Autistic experiences, as well as addressing the needs of Autistic people across the lifespan

The importance of considering and reflecting the diverse range of Autistic experiences in the development of the Strategy and Charter was highlighted. This included ensuring that the Strategy and Charter consider supports and needs of Autistic peoples across the whole lifespan and recognise the needs of non-speaking Autistic people and people with intellectual disability.



Engagement Summary

During the 12 week consultation period, the South Australian Government actively engaged with the state's diverse community of Autistic people, families, carers, guardians, service providers, the disability sector, peak bodies, the public sector, other interested parties, and the broader community.

Members of the Autistic and autism communities could provide feedback on the Discussion Paper by:

- completing a YourSAy survey
- participating in public forums
- posting or emailing a written, visual, video or audio submission.

It was clear the Autistic and autism communities wanted to contribute to the discussion regarding the State Autism Strategy. In all forums, discussions and interactions, participants and attendees were actively engaged.

Over 1,200 responses were received from various channels during the consultation period.



Social media interaction

The consultation was promoted by the Department of Human Services between 28 November 2022 and 17 February 2023 using a variety of media, including Facebook, Instagram, Twitter and LinkedIn.

Fifty-six advertisements on various DHS social media channels reached a combined total of 315,161 people and generated 563 clicks, 1,013 reactions and 2,902 shares.

				
Impressions:	15,208	2,824	1,943	9,019
Reach:	14,159	2,662	141,318	6,521
Clicks:	97	1	1	231
Reactions:	211	101	10	290
Shares:	92	12	20	67

YourSay responses

Total Responses Received	Total Autistic Responses	Total non-Autistic Responses
1,070	354¹ (33%)	716 (67%)

Aboriginal and Torres Strait Islander people	LGBTIQA+ people	Culturally and Linguistically Diverse people	Young people
17	185	62	90
Autistic person: 9 Non-Autistic person: 16	Autistic person: 153 Non-Autistic person: 32	Autistic person: 23 Non-Autistic person: 39	Autistic person: 75 Non-Autistic person: 19

1. We recognise that there may be people who are currently undiagnosed or do not feel comfortable disclosing their diagnosis and that this number may therefore not be representative of the total number of Autistic people who completed the YourSay survey.

Written submissions

During the consultation period, the Autistic and autism communities were also invited to provide written submissions to the Discussion Paper.

In total, 178 submissions to the Discussion Paper were received. Twenty responses to the Discussion Paper were received from non-government organisations (NGOs), seven submissions were received from public sector agencies and local councils, and 151 submissions were received from individual community members. It is noted that written submissions reflected similar themes to those arising from the YourSay responses.



	Community member submissions	151
	NGO submissions	20
	State Authority submissions	7

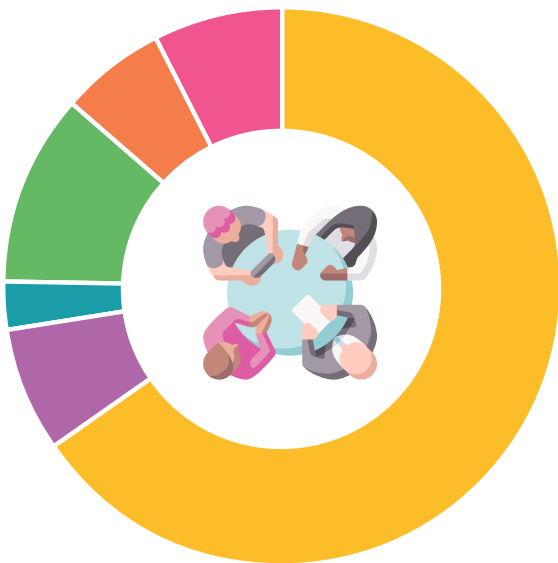
Forums and focus groups

DHS, partnering with JFA Purple Orange and Multicultural Youth South Australia (MYSA), undertook a range of targeted forums and focus groups throughout the consultation period, providing an opportunity for the Autistic and autism communities to share their experiences and support the development of both the Strategy and the Charter. We would like to thank both organisations for the valuable feedback and insight provided from this engagement.

The JFA Purple Orange consultation involved five focus groups held across a two-week period in January 2023 and involved 35 participants. All participants were Autistic. Participant groups included children (7), teenagers (6), young people (9), adults (6) and parents and carers of Autistic children (7).

In January and February of 2023, MYSA interviewed 22 Autistic young people and adults (9 formally diagnosed and 13 undergoing assessment), and 19 parents and carers of Autistic young people. Interviewees represented a wide range of cultural groups and were aged between 9 and 34.

DHS held a NGO forum on 2 February 2023 which was opened by the Minister for Human Services and Assistant Minister for Autism and attended by 36 organisations.



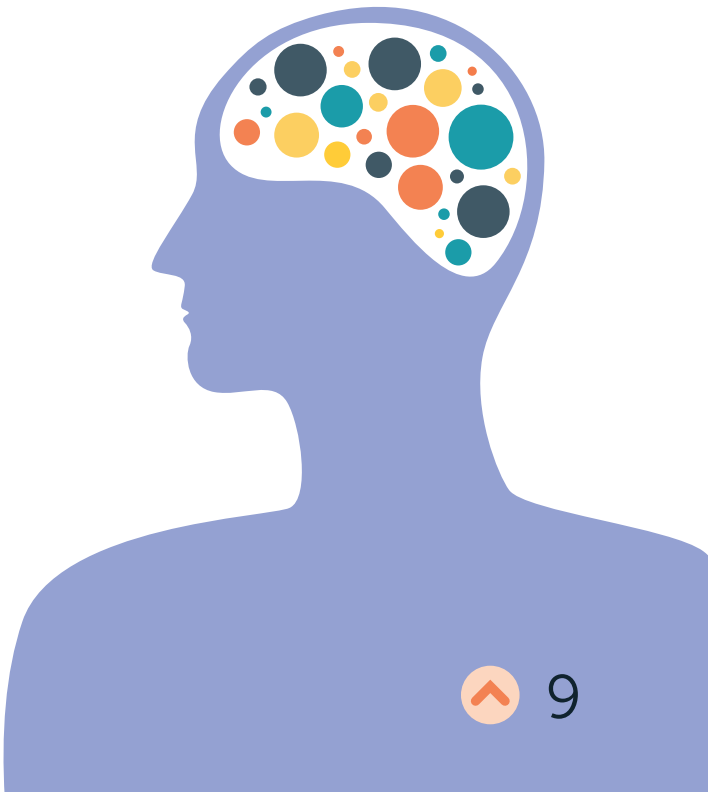
	MYSA Interviews	41
	JFA Focus Groups	35
	Public sector forum attendance	63
	Parents and Carers forum attendance	16
	NGO forum attendance	41
	Community forum attendance	371

On 14 February 2023, Autism SA facilitated a public sector forum on behalf of DHS to gather feedback on the creation of the Strategy and Charter. The forum was attended by both the Minister for Human Services and the Assistant Minister for Autism, along with 63 representatives from 36 State Government agencies.

Facilitated by the Gold Foundation on behalf of DHS, parents and carers were also invited to attend an in-person forum held on 17 February 2023. The forum was attended by 16 participants.

An additional 10 participants attended an online forum facilitated by the Gold Foundation on 13 February 2023.

The Assistant Minister for Autism also hosted a range of public community forums across the State to hear from the Autistic and autism communities and support the DHS consultation throughout January and February 2023.



Consultation feedback

Theme 1: Community attitudes, awareness, and education

Defining autism

Defining autism for the purposes of the Strategy is complex, but is fundamental to supporting community knowledge, understanding, appreciation, and attitudes over time.

Five definitions of autism were presented in the Discussion Paper. Of the total YourSAy responses received (1,070), 999 people responded to this question (673 non-Autistic, 326 Autistic). 525 (53%) of total responses to this question and 158 (48%) of the Autistic responses to this question indicated that they preferred the Autism SA definition, as follows:

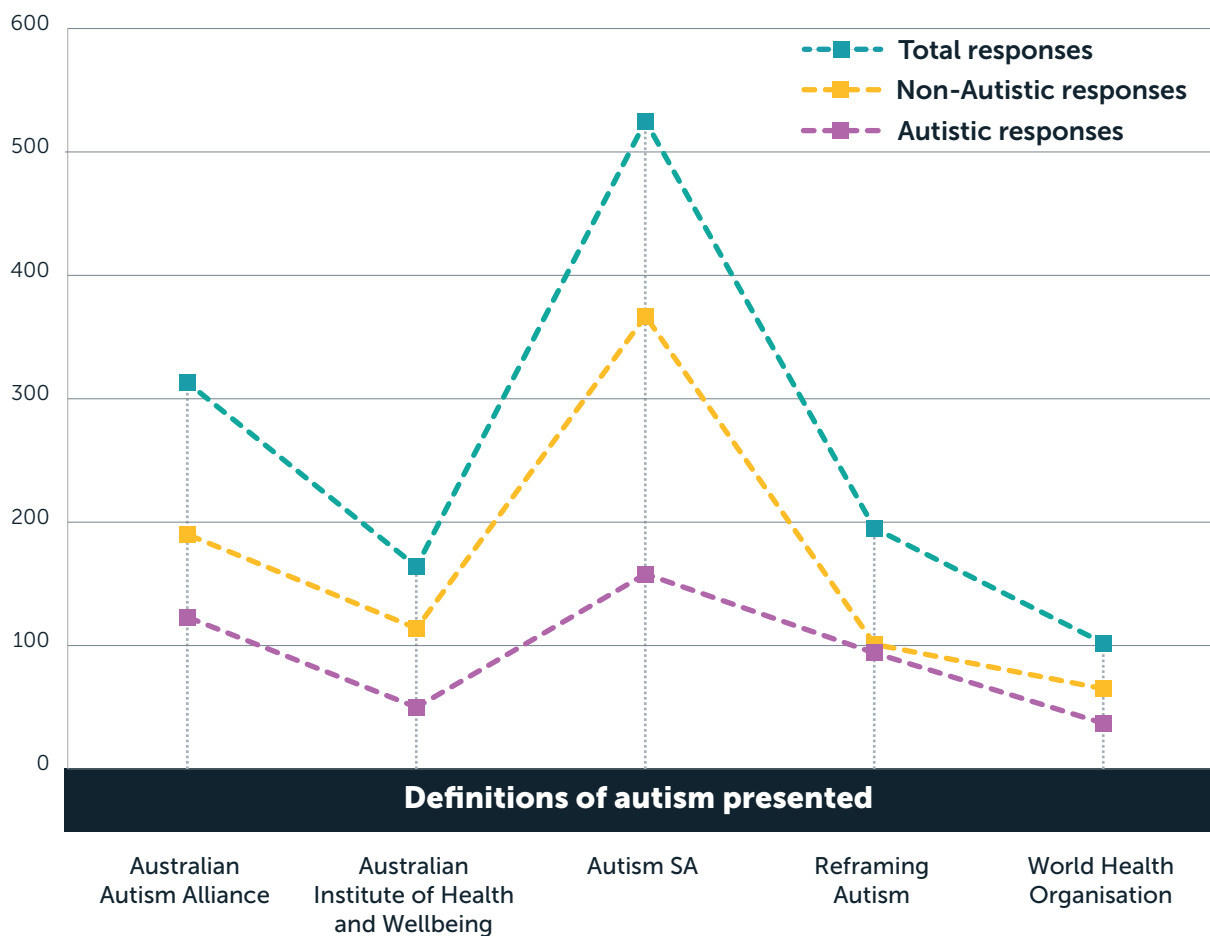


Autism is a neurological developmental difference that changes the way an individual relates to the environment and people in it.

Autism changes the way that an individual sees, experiences and understands the world.

There is not one way that an Autistic individual experiences the world, this is why the term 'spectrum' is used- this is to reflect the fact that every individual's lived experience of autism is different.

Individuals on the spectrum may have skills in particular areas, while finding other aspects of life particularly challenging. How skills develop across a life span varies as much as autism itself and can vary significantly from person to person.



*Respondents could select more than one option

Written submissions received also indicated a preference towards the Autism SA definition, which recognises autism as an individual difference and recognises the diversity of Autistic experiences.

Only half of the parents/carers interviewed during the MYSA consultation were able to articulate the diagnosis of autism. Only one young person was aware of the term "autism" and associated it with themselves, but did not necessarily identify as an Autistic person.

This reflects MYSA's case management experience that many multicultural young people do not identify themselves as having a "disability" and less understand autism. Some young people were able to talk about how they are different to their peers, how they struggle to make friends and sometimes struggle at school, however none used the word autism or Autistic. The participant who was aware of their diagnosis perceived that people attributed their differences to their culture, not to autism.

Language and Terminology

For the purposes of the Strategy, it is important to define how best to refer to autism, and to those who have lived experience of autism. Feedback provided during the development of the Discussion Paper indicated that many Autistic people prefer identity-first language. Additionally, it was suggested that the following terminology be considered within the Discussion Paper consultation:

- **Autistic community:** the community of Autistic people themselves. You must be Autistic to be a member of the Autistic community
- **Autism community:** includes people who are not Autistic themselves, who provide support to Autistic people
- **Autistic and autism communities:** members of both the Autistic and autism communities, who share a common interest.

More than 60% of responses to the YourSAy survey received from Autistic people indicated that they felt it was appropriate to use the term "Autistic and autism communities" when referring to Autistic people, their families, carers and professionals who support Autistic people. More than half of the non-Autistic responses also indicated that these terms were appropriate.

"Yes, I'm so glad that you are starting to use autistic rather than just autism. It shows that you are listening!"

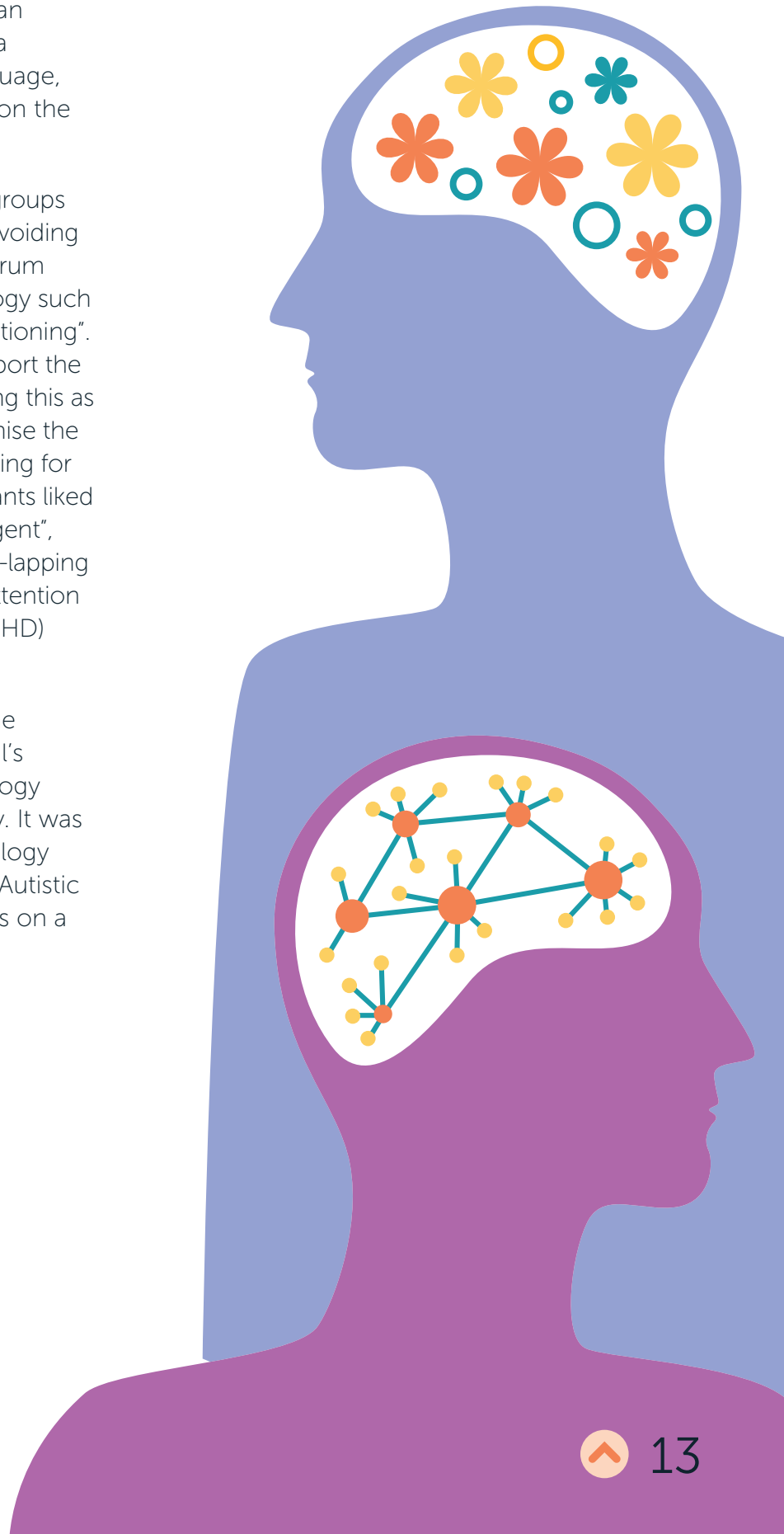
Respondents highlighted the importance of ensuring language is used respectfully and with the intention of helping others to understand and support Autistic people and their families. Some responses demonstrated a concern that, due to a lack of community understanding and acceptance, the term "autism" or "Autistic" may lead to stigma or discrimination towards the Autistic person.

"I don't find it [autism] defines me but allows others in the community to quickly understanding in a way who I am."

While most responses from Autistic people indicated a preference for identity-first language, non-Autistic respondents were more likely than Autistic respondents to indicate a preference for "person-first" language, or alternative language such as "on the autism spectrum".

Participants attending the focus groups identified a clear preference for avoiding the use of the term "autism spectrum disorder" or referring to terminology such as "low functioning" or "high functioning". Similarly, participants did not support the use of "levels" of autism, identifying this as problematic as it does not recognise the nuance and variability of functioning for an Autistic person. Many participants liked terminology such as "neurodivergent", which they felt captured the over-lapping diversity of neurotypes such as Attention Deficit Hyperactivity Disorder (ADHD) and autism.

Overall, responses highlighted the importance of using an individual's preferred language and terminology when working with them directly. It was also recommended that terminology be reviewed and discussed with Autistic and autism community members on a regular basis.



Community attitudes

Community attitudes and understanding of autism was a strong theme throughout the feedback in addition to the need for further public awareness and education campaigns to address misconceptions and stereotypes of autism that currently exist. Community attitudes were reported to have a significant impact on Autistic individuals, as well as their family members.

Respondents highlighted a range of misconceptions about autism that they had heard or seen in the community, including "everyone is a little bit autistic", "children 'grow out of' autism" and "Autistic people are anti-social, don't have emotions and lack empathy". In addition, many respondents indicated that misconceptions, perceptions and beliefs about autism were often based on stereotypes from movies, television shows and the media.

"there seems to be the misconception that we are all Rainman or Sheldon from big bang theory who are great with math, I am not great at math."

Furthermore, respondents noted that stereotypes of what members of the broader community think autism looks like resulted in assumptions that:

- Autistic people are all the same
- autism only occurs in boys/men
- Autistic people are all savants/have special skills, abilities, or talents
- all Autistic people have intellectual disability, are non-speaking, don't make eye contact
- Autistic people are unable to make a meaningful contribution or participate in education, employment, community or family life.

Respondents also noted the challenges that arise from the use of functioning levels and how this can impact on community attitudes and understanding of autism, leading to assumptions of the person's capacity. For example, that someone who is labelled as 'high-functioning' does not require support, and someone labelled as 'low-functioning' is less likely to make a positive contribution to society. Respondents also noted that functioning labels do not recognise the fluctuations in functioning and needs that can occur for Autistic people across their lives.

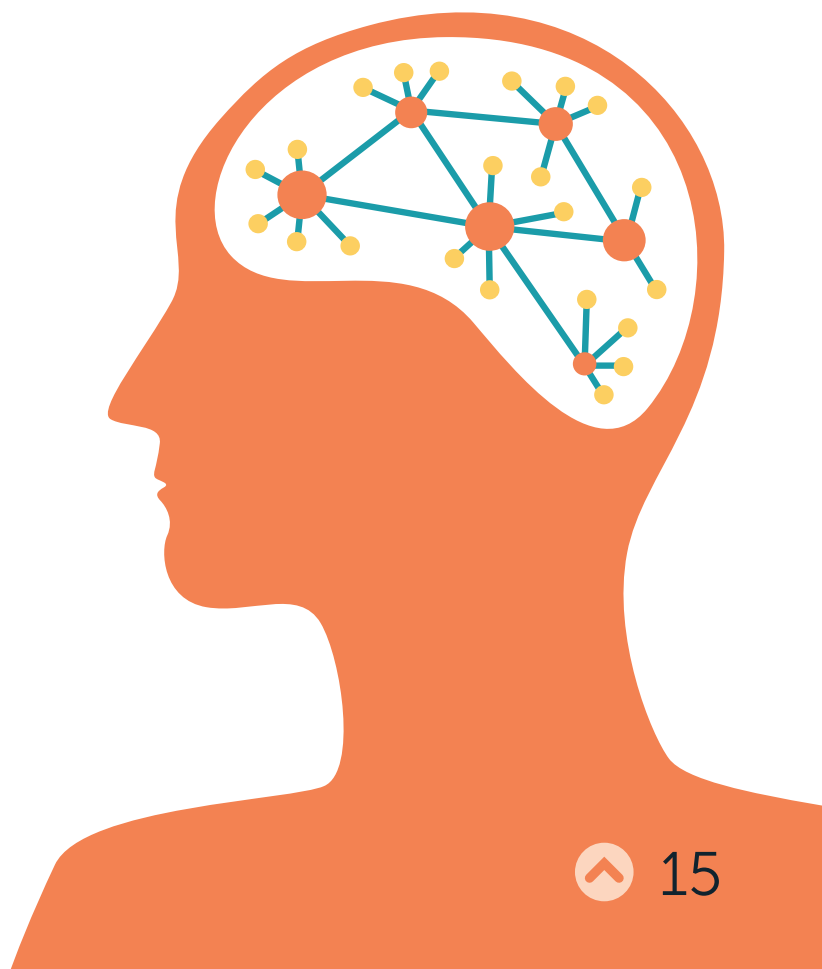


Misperceptions around Autistic behaviours were also noted by participants as barriers in the community. For example, parents reported their child's behaviour as being seen as "naughty", "badly behaved", "violent" or "they just need more discipline". Autistic parents further raised concerns about the understanding of autism within child protective services. They raised grave fears about their right to be parents being questioned by social workers or other professionals and feared their children being removed and placed in care. Both adults and children raised concerns about disclosure, highlighting the fact that not everyone feels safe to disclose that they are Autistic.

Autistic people also described the challenges associated with having a disability that is not always visible, such as having their Autistic identity questioned due to not "looking" Autistic enough, or not behaving in a way that others expected an Autistic person to behave.

To improve community understanding and acceptance of Autistic people, participants felt that there was a need for Autistic representation in media and social media. In addition, developing and distributing language guides to change language on forms and in the media and day to day conversations was noted as particularly important by young Autistic adults.

Additionally, one NGO submission highlighted concerns associated with the reporting of criminal court matters involving Autistic people within the media. The submission highlighted the importance of language guidelines within the Criminal Justice System and the media more broadly to ensure that messages portrayed do not promote myths and misconceptions of autism already prevalent within the community.



Theme 2: Support, attitudes, knowledge and understanding in education settings

Education settings

Respondents described a range of challenges experienced within education settings including trauma, exclusion and bullying experienced by Autistic students. There was a call for additional funding and support to meet the needs of Autistic students and increased knowledge, understanding and awareness of autism throughout the school community.

Respondents identified a range of strategies that would be needed to address the existing challenges, including:

- registered mental health supports in schools
- autism specific training for all preschool, primary, secondary and tertiary staff
- more structured supports for Autistic children in high school, including the expansion of existing strategies such as the new Autism Inclusion Teacher currently rolled out to public primary schools
- support for other children and families within the school community to develop an understanding and acceptance of autism, to combat bullying and exclusion
- mechanisms for the early recognition of autism within schools such as early screening
- strategies to ensure allied health professionals such as Occupational Therapists and Developmental Educators can attend and support the child within the school setting
- strategies to address the high number of Autistic students who are expelled or excluded from school
- strategies to support social skill development for Autistic children
- quiet/low sensory spaces available in schools which can be accessed by the Autistic child when they most need it
- expansion of Autism Inclusion Teacher initiative to include private and independent schools
- increased flexibility available for all Autistic students which include individualised support plans
- a focus on employment outcomes and skills throughout schooling.

Education was highlighted as a key issue in all focus group discussions. Both Autistic children and teenagers stated that opportunities for sensory regulation was important for their successful participation within the classroom. Some participants highlighted the need for additional support for home-schooling families. It was clear across all focus groups that Autistic people valued flexibility in education and saw value in open access learning options.

Children and teenagers resoundingly said that other students, teachers and school support staff lacked an understanding of neurodivergence or autism which led to discriminatory and inaccessible educational practices that disadvantaged neurodivergent students in the classroom.

Adult participants also talked about further education opportunities post-high school and noted several barriers, including:

- long days and inflexible times for breaks
- the issue of not fitting in well with the lesson structure
- issues of negotiating support needs with educators
- negative assumptions and attitudes from educators.

Despite the challenges raised within the forums, one attendee shared that “not every school is failing kids” and that there are some good examples of inclusive education throughout the state.

Transition periods

Transition was identified by forum attendees as particularly challenging, noting that transitions day to day, from one year to the next, and the transitions from preschool to primary school and primary school to high school were often challenging for Autistic children and students. Attendees also noted the importance of support for the transition from school to post-school options (including tertiary studies and employment). Flexible learning options and alternative ways for students to gain their SACE certificate were also highlighted.



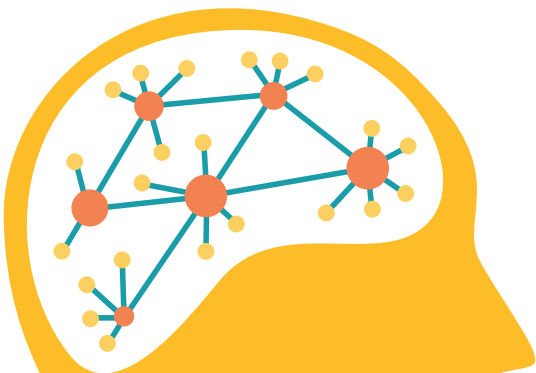
Experience of young CALD people

In the wider society, young CALD people spoke about respect, wanting to feel a sense of belonging and not wanting to be judged for being different. School and youth groups were seen as sources of support and belonging. Carers suggested it might be useful to speak with other carers about their parenting challenges in a new country but did not want to do this within their own community.

Most young people were positive about school and enjoyed the social aspect, however some felt that teachers did not like them and treated them differently and unfairly. They expressed frustration at receiving lower grades and not being supported to improve. Two participants mentioned discrimination but felt this was due to their cultural background, rather than their autism diagnosis.

Suggestions for supporting multicultural Autistic young people and their families included:

- cultural awareness and competency training to support staff to understand the differences between cultural practice, limited English, and cognitive challenges and to help staff to better understand autism within multicultural communities
- improved affordability and access to diagnostic services to enable access to support
- upskilling of practitioners to be able to undertake autism diagnosis
- create more opportunities for dialogue between school staff and parents/carers of CALD students to help identify issues for those who may be Autistic
- upskilling community liaison officers to have a sound understanding of autism and how to support CALD families to navigate assessments and diagnosis
- review of visa and residency limitations for those with a diagnosis of autism.



Theme 3: Employment and workplace culture

Recruitment

Respondents noted a range of difficulties experienced by Autistic people during the recruitment process which created barriers to gaining employment. Respondents called for adjustments to job application and recruitment processes, for example:

- providing questions and relevant information prior to the interview
- enabling a carer or support person to attend the interview with the person
- providing opportunities for Autistic people to demonstrate their skills and abilities outside of traditional interview processes (e.g. paid trial periods)
- providing work experience, traineeships, or opportunities to gain professional experience such as being on boards, committees, and sub-committees.

Barriers associated with recruitment processes, which were seen as related to stigma, discrimination, and a lack of general understanding of autism, were also raised throughout the community forums.

It was agreed that recruitment processes often disadvantage many common characteristics of autism and there is a clear disconnect between the processes for panel selection and the Autistic community which includes identifiers such as non-verbal cues and eye contact.

Attendees who were in employment noted the impact of masking and the resulting fatigue that impacted on their work and wellbeing. They also noted experiences with the lack of understanding and awareness in workplaces and noted that this often resulted in Autistic employees choosing not to disclose their autism to their current or prospective employer or colleagues.

"Only when autistic people are in senior positions can accepted practices be challenged to become more inclusive."

Employment

In addition to inaccessible recruitment processes, respondents described a variety of challenges related to employment including a lack of meaningful employment opportunities, and a lack of support and understanding from employers.

Respondents highlighted the importance of Autistic people having meaningful, ongoing employment opportunities in line with their skills, passions and values. This included opportunities in mainstream employment as well as supported employment, and "not just IT". In addition, some respondents noted the importance of ensuring that wages are adequate and support the person to live independently.

"Leading by example – making the SA public sector truly a model employer for autistic people."

"I want jobs and opportunities for autistic people so they have financial independence."

Some respondents felt this could be achieved through the introduction of subsidies and incentives, including government funded traineeships and apprenticeships, for business and organisations to employ Autistic people. Some respondents also suggested the implementation of quotas for employing Autistic employees and improved employment pathways for Autistic people and easily accessible information on how to access these. Respondents also wanted to see improved career progression opportunities for Autistic people, including opportunities in leadership and senior positions.

Forum participants recommended the following strategies to improve employment outcomes for Autistic people:

- design and layout of workspaces to better suit the sensory and social needs of neurodivergent people
- neurodivergent trainers delivering workplace training to educate employers about providing a safe and supporting workplace
- autism-specific employment entry programs and support services.

Workplace environment

Respondents called for greater inclusion and acceptance in the workforce and highlighted concerns regarding workplace culture and understanding of Autistic people. To address this, respondents called for greater understanding of the strengths and attributes of Autistic employees and autism specific training for staff.

"Business/work place could register their commitment to being inclusive and increase their knowledge and understanding of people living with a disability. Their commitment could be publicly identified for individuals to recognise and feel safe and comfortable to approach that organisation for employment/support."

Respondents also suggested that employment support could include:

- flexible working hours
- accommodations to support sensory needs
- additional leave entitlements or options
- providing safe, quiet, sensory break spaces for Autistic employees.

"To allow a role (job/positions) which allows time and space for those on the spectrum to understand the fundamentals and terminology without prejudice, so they can learn how they can be productive in their work environment and assist government agencies positively."



Theme 4: Diagnosis and access to services

Diagnosis

Respondents identified significant barriers which prevent or delay people from accessing an autism diagnosis. Costs to access a diagnosis and the length of current waitlists for an assessment were two key barriers. In highlighting the long wait times to access a diagnosis, participants also noted the impact this delay can have on access to services and support.

The importance of early diagnosis in supporting Autistic people, and the benefit that this provided in enabling them to find a sense of belonging and identity by connecting with other neurodivergent people was echoed by participants attending the forums.

Existing barriers to diagnosis, especially for girls and adults, was noted in several written submissions by community members. In addition, submissions highlighted the need for further understanding of autism and co-occurring eating disorders, with some submissions noting the lack of understanding of autism within health settings, including GPs and hospitals.

Regional Health

Community forum attendees from regional areas highlighted a range of challenges they experienced in accessing diagnostic assessments and support services. One attendee noted that autism assessments in regional areas were sometimes being done by telehealth appointments which they felt may not be accessible to Autistic people who do not like talking on the phone. They reported limited workforce in their local region, and difficulties in accessing paediatricians and therapists locally. NGOs also highlighted the need to build capacity of local service providers to understand and support the needs of Autistic people and their families in regional and rural areas.



Health and Mental Health Services

Overall, respondents highlighted a lack of understanding of autism and strategies for supporting Autistic patients as a barrier across health and mental health services. Respondents noted the need for further training in autism for all health services staff which includes understanding of Autistic communication and behaviour, sensory needs (e.g., lighting, noise), and experiences of trauma. Increased awareness of the frequent occurrence of co-existing medical conditions for Autistic people is also required for medical practitioners. Eating disorders such as Avoidant/Restrictive Food Intake Disorder (ARFID) were noted by some participants as specific areas where further research and expertise is needed. It was also noted that health services need training, education and experience in supporting Autistic people who are non-speaking or have complex communication needs.

Participants in the forums identified challenges they had experienced in accessing health and mental health services and reported that access difficulties were the result of:

- inflexible ways to contact service providers making it difficult to book appointments
- copious amounts of paperwork (too overwhelming and difficult)
- paperwork and forms that assume gender-binary standards making it difficult for people to identify by their preferred pronouns and names
- the lack of understanding of Autistic communication methods and presentation
- stress associated with sensory experiences within health services, where there was a lack of safe, sensory-friendly spaces.

It was also highlighted that health and mental health services need to ensure they are addressing the needs of Autistic people across the lifespan.



Hospital and Emergency Departments

Some respondents described issues specific to hospital emergency departments such as a lack of understanding of autism and Autistic communication needs, and a lack of safe/sensory spaces within hospital emergency departments and waiting areas. One respondent also highlighted the current lack of training provided to staff in hospital emergency departments for recognising and working with Autistic patients.

"I am an emergency nurse and there have been many times where a person with ASD has presented to an emergency department and no one knows how to speak / communicate, how to approach and how to assess...the people with ASD are lumped in with mental health patients, and the nurses don't have the skill set or training to manage them while they are unwell or distressed."

To address the lack of awareness and understanding of autism, one respondent suggested reviewing the training provided in universities, and ensuring it includes informed input from those with lived experience of autism. Several respondents also indicated that it was important for them that health and medical services were trauma informed and responsive to Autistic needs.

According to respondents, medical support was difficult to find for Autistic people experiencing a meltdown, and this lack of support can result in the Autistic person being referred to mental health services or emergency mental health support. Respondents noted that this support did not always meet the needs of Autistic people and suggested that a dedicated support service or department for supporting Autistic people in meltdown or burnout would be beneficial.

DHS also received a significant number of responses from individuals recommending the expansion of existing Animal-Assisted Therapy programs to school environments to support Autistic children. Benefits of Animal-Assisted Therapy were highlighted, including reduced anxiety, improved emotional regulation and communication, and supporting Autistic students to feel more comfortable in new spaces and situations. Submissions noted the benefits of music therapy, as well as the importance of oral health and hygiene.

First Responders and Emergency Services

Some respondents noted the need for autism specific training for emergency services personnel such as ambulance staff and police. In addition, one respondent recommended implementing Autistic liaisons for police to support the understanding of Autistic presentations. In suggesting the provision of further training for police and emergency services staff, several respondents reflected on their concerns about potential consequences of a lack of understanding.

Attendees at one of the community forums highlighted concerns about the level of knowledge and understanding of autism in South Australia Police (SAPOL), which can lead to misinterpretation of communication styles and behaviours of Autistic people. However, one attendee at another forum highlighted that SAPOL are working to increase their awareness and understanding of autism and indicated that autism awareness training is now being provided in the Police Academy.

"[the Strategy] needs to address emergency services; to ensure that all services have adequate training to understand and assist Autistic people, in both the creation of emergency plans and their implementation. Police and ambulance services need specific training to enable them to support Autistic people in distress and reduce the potential for compounded trauma due to unnecessary restraint etc. The training should include a focus on assuming competence and facilitating communication."



Access to other services (including government)

Respondents indicated that navigating supports, and services could be challenging. The barriers noted by participants in accessing government services included:

- staff lack of understanding and knowledge of autism
- a lack of communication options and alternative communication modes for those who are non-speaking or have complex communication needs
- difficulty finding and accessing relevant information; complex systems and websites that are not user friendly
- a lack of consideration for sensory needs for Autistic people accessing the service.

"In many cases, I have found myself forced to my limits whilst waiting in a sensorily hostile location, only to eventually be forced to meet the needs of the person I am asking for help from, under fear of losing essential supports."

Access to services and support was often reliant on diagnostic confirmation of autism, therefore delays in access to diagnostic assessments often resulted in delays in accessing relevant government services. In addition, some respondents noted that services required review and confirmation of their autism diagnosis on a regular basis.

Respondents recommended better service collaboration to address this issue, as well as ensuring appropriate supports and services are in place to address co-occurring conditions experienced by Autistic people (e.g., Intellectual Disability, Mental Health, Eating Disorders). Respondents suggested the need for improved access to information which is clear and accurate and available in a variety of modes to support all aspects of engagement.

"Like most people, they're not great places to go or phone. Autistic people need different ways to access and more concrete information."

"Very difficult - as someone who is non verbal my parents have to advocate on my behalf (which they don't mind doing) but I find then I become invisible in the room with those people, I see the stress it puts on my parents filling in paperwork constantly."

Some Autistic respondents noted that they required family or parental advocacy and support to access government services, noting the complexity of support access as a significant challenge.

These sentiments were supported by forum attendees who found that accessing government services was often difficult and mentally taxing. For some this resulted in them being unable to seek support from government services altogether.

Participants called for further education of staff within government services which is led by neurodivergent people, including training which addresses the needs of Autistic members of the LGBTIQ+ community. This was also highlighted in submissions related to experiences of the criminal justice system. In addition, another submission highlighted the importance of highly skilled and trained communication partners to support Autistic people when navigating the criminal justice system. The importance of written information which uses Easy English principles and Communication Access accreditation for police stations were also noted as improvement strategies that could be implemented.

At the public sector forum, many of the above sentiments were reiterated with suggestions regarding the introduction of 'helplines' or 'social narrative videos', that give an overview of the service and what to expect when attending the service, were raised as useful tools.

Those interviewed by MYSA noted particular challenges in accessing government services, including:

- long wait times for appointments
- lack of interpreters
- miscommunication and confusion after appointments
- challenges with being 'heard' by staff
 - attributed to their English skills
 - government staff seen as 'rude' and treating them 'differently' – due to their CALD background rather than autism.



Navigating services

Accessing information and support services was identified as a potentially overwhelming experience. The need for support to navigate these services was noted, and it was suggested that a central website for autism information would be beneficial.

Submissions identified a range of potential solutions, including:

- support for parents and siblings of Autistic children and young people
- safe, quiet spaces in government buildings and community areas
- inclusive sports and leisure opportunities for Autistic children and young people
- autism training for staff in all government services
- consideration of sensory needs in the built environment
- improving accessibility of arts, culture, and local events through the inclusion of quiet, sensory break areas
- expanding the Autism Inclusion Teacher role into high schools, Catholic schools and Independent schools
- providing opportunities for development of communication skills and life skills in schools
- employment supports which address sensory needs, and provide flexibility, and an understanding of individual needs
- training to support the understanding of Autistic and autism communities' needs for emergency services and first responders, including police
- one submission highlighted the need for safety considerations when designing local playgrounds, including fencing
- improving accessibility of community spaces through the implementation of quiet, safe, sensory spaces.

Continuous research

Submissions were also received from organisations with a focus on research relating to autism and Autistic experiences. These submissions highlighted the importance of research funding to explore early support programs and interventions, programs to support the quality of life of Autistic people, as well as ensuring research can be effectively and efficiently translated into practice.

Theme 5: Support for parents, carers and guardians

Assuming the role of advocate

Parents and carers noted concerns for the future of their Autistic children and highlighted the importance of supporting independence which includes the need for secure housing and employment.

Parents, carers and guardians spoke of their need to take on advocate roles for their children in many situations, especially in relation to education support. In addition, parents reported their need to frequently attend to their child's school needs or attend allied health appointments for their child. Attendees at several forums highlighted the impact this can have on their own working lives and careers, and noted the long-term financial implications this can have on the family.

Parents also noted a lack of support for carer support groups and services. These concerns were also highlighted throughout the focus groups and YourSAy responses, with particular focus on the need for allied health support and respite for families.



Access to Services

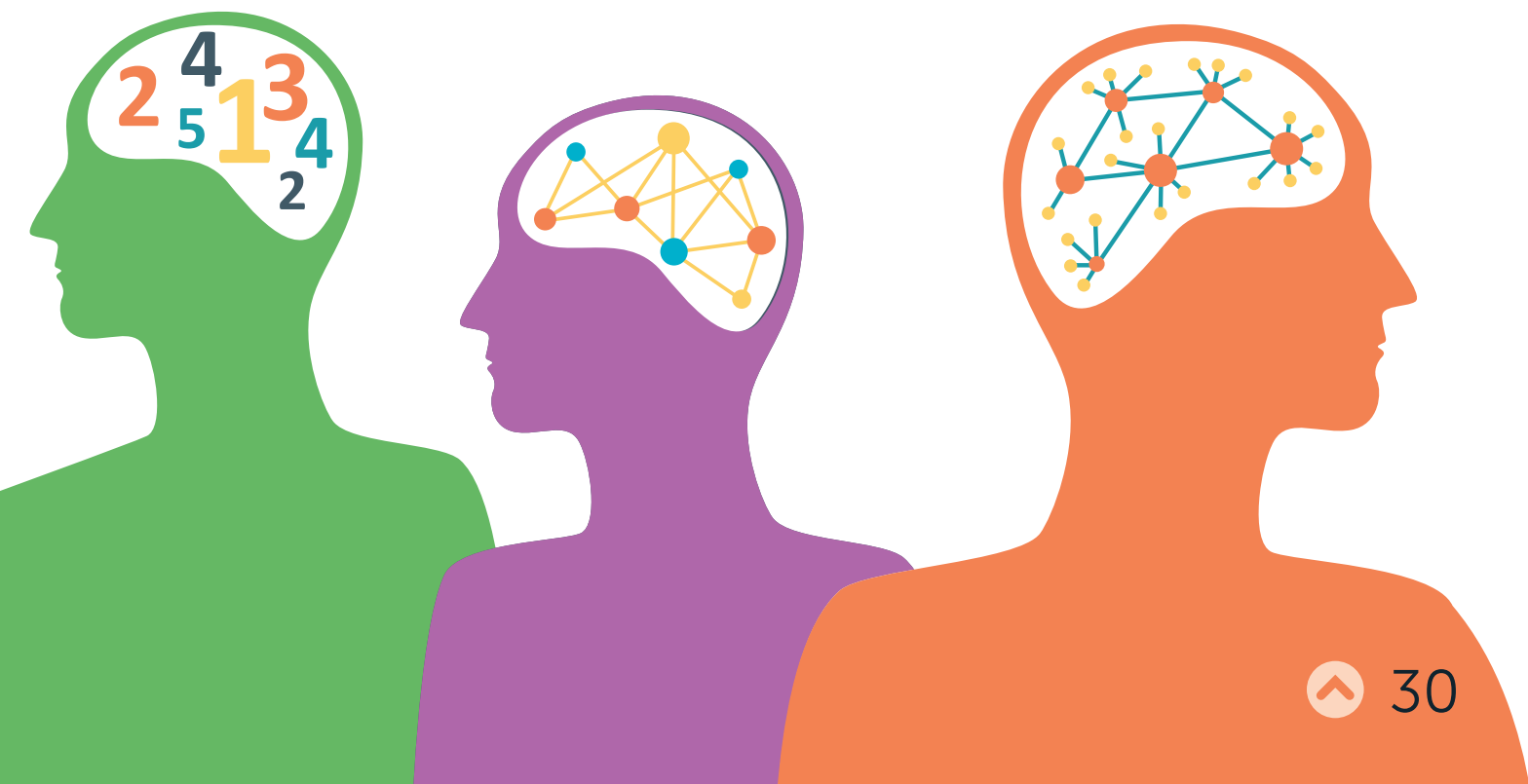
Some attendees called for a centralised information point about services and resources that can be easily accessed. This could include a list of preferred allied health professionals and GPs that have an understanding of autism. Attendees also suggested there was a need for more post-university training for health care workers to increase knowledge and understanding of autism.

Access to a formal autism diagnosis was highlighted as a significant issue due to long wait lists, the cost of assessments, and a lack of awareness and experience diagnosing autism. Some attendees also noted their experiences of medical professionals who expressed fears of using labels such as autism for their children.

Educating the community

Community education was identified as a foundational pillar to inclusion by community forum attendees. Attendees called for community awareness and education strategies which worked to “demystify” autism and address myths and misconceptions associated with autism. Attendees at one community forum felt that community acceptance of autism is currently interpreted as pity, which can feel disempowering.

One attendee also highlighted the fact that further community understanding is needed of the fact that autism does not end in childhood, and that Autistic adults also require understanding, acceptance and support. Attendees also noted the resulting social isolation that can be experienced by Autistic people and their families due to the lack of inclusive community spaces and activities.



Theme 6: Safe, sensory-friendly spaces and an autism inclusive community

Rights, safety, and equality

The need for improved public awareness, acceptance and understanding of autism was a consistent message from both Autistic and non-Autistic respondents, in addition to the need for safe, autism-inclusive spaces in schools and the community.

"Having businesses and governments create more Autistic friendly environments. Having a way for these businesses and governments to be able to communicate to the community that it is a safe place for Autistic people to exist and accommodations will be made for them."

Respondents highlighted the importance of recognising the diversity of Autistic experiences, including strengths and support needs. For example, respondents noted the importance of considering Alternative and Augmentative Communication (AAC) and complex communication needs as well as the experiences of non-speaking Autistic people. To ensure access for people with complex communication needs, respondents highlighted the need for alternative communication modes and the acceptance and understanding of people who require them.

Access to supports and services, such as housing and financial support, was raised by several participants in addition to the importance of supporting independence for Autistic adults across the lifespan. This was particularly noted by parents of adult Autistic people, who were concerned about their future independence and support as they age.

Other areas identified to support and promote the fundamental rights of Autistic people included:

- the need for timely and affordable access to diagnostic assessments
- the need for appropriate training and education for teachers, practitioners and professionals to better understanding autism
- the need for support for family members and carers for Autistic children and adults.

NGOs indicated that, above all else, State Government and NGOs need to work together to develop an understanding of what 'safety' means to the Autistic and autism communities, including consulting with the communities and focusing on priority groups.

The built environment

The need for safe, sensory-friendly spaces within the community was a significant issue highlighted by the Autistic and autism communities throughout the consultation.

Respondents called for the implementation of sensory rooms or quiet spaces in shopping centres and other community spaces where Autistic people could go to reduce sensory overload, de-escalate when in meltdown and regulate sensory input. The benefits of existing strategies were noted, including sensory-friendly shopping hours in supermarkets, however there were calls to extend these hours, and provide these opportunities outside of the 9am – 5pm workday.

"sensory spaces for effective self regulation and to ensure there is no stigma attached to accessing such facilities when in the general public domain."

Respondents also noted the need for sensory rooms or quiet spaces to be implemented in education settings, hospitals, and workplaces.

"I want to have somewhere to cry at school that's not germey toilets I want a safe spot to go when the world is to loud to noisy to colourful to moving around. I want a spot to go at school where I can calm down and I want a spot at the shops and at the footy and at church where I can be safe and quiet and calm down but I don't want it to be locked and only be used when a teacher is on Judy... I just want to be aloud to calm down and have a break from the noise and colour and moving rushing world."

In addition, community forum attendees noted the challenges Autistic children and adults experience in accessing community venues, for example swimming centres, due to sensory overload. Attendees raised concerns related to the lack of inclusive community spaces that accommodate sensory regulation needs, and suggested that it is important to ensure that these are normalised and accepted in the community.



Participants also felt that there needed to be better consideration of how the sensory environment can significantly impact accessibility. Participants called for the inclusion of sensory rooms and spaces at major events and venues across South Australia and reflected that the implementation of these at recent events was seen as positive.

The public sector made several suggestions during the forum, particularly to consider altering physical spaces to make them more accessible for Autistic people. Making public building waiting rooms bigger, reducing ambient noise, and softer lighting were three common strategies highlighted. Clear signage and wayfinding tools were recommended, especially in larger public facing spaces in which people are expected to walk distances across multiple services.

Discussion also highlighted how the public sector can better manage physical queueing for services, such as Service SA. Reducing time spent standing in a line was often advised, with people being given a virtual queue experience and access to sensory or quiet rooms until it was their turn.

Accessible transport options were also raised as an important consideration for community access. Participants also highlighted public transport as being too overwhelming due to sensory aspects such as noise or light. Participants wanted to see the introduction of quiet carriages or quiet, spacious zones allocated to public transport.



Theme 7: Collaboration and consultation with the Autistic and autism communities

There was a strong call from YourSAy respondents for ongoing collaboration, consultation and engagement with the Autistic and autism communities throughout the development of the Strategy and Charter. **Respondents highlighted the importance of ensuring that Autistic voices are central to the decision-making process.**

Forum attendees passionately advised that they are supportive of, and want to be involved in, reframing the narrative and creating an inclusive community for Autistic people in South Australia. While several organisations that attended the forum were 'Autistic led', the majority of organisations advocated for, and supported, an 'Autistic led' approach to the development of the Strategy. Organisations indicated that it was paramount that Autistic people were at the front and centre of all stages of the development, implementation and review of the Strategy.

NGOs felt they could contribute to the development of this approach by being strong advocates for change, sharing their experience and expertise on Autistic led advocacy, neuro-affirming practices, workplace culture and education, employment, and mental health. In addition, NGOs indicated that they would support government to engage with Autistic people that may be in priority cohorts and/or have complex support needs.

NGOs attending the forums recommended that State Government partner with Autistic people and the NGO sector to increase understanding and awareness in mainstream society and reframing community understanding of autism through a strengths-based approach. Representatives emphasised that changing community attitudes is about more than inclusion; it involves creating a society where everyone belongs.



NGOs acknowledged that community attitudes towards autism need to change and indicated that they want to work together, with State Government, to change these attitudes and the narrative surrounding autism.

Improving understanding and awareness of autism could be achieved by working together to:

- provide education to children and young people to improve the language used by future generations
- provide education and training to employees, who will take this advice home and into their communities
- engage appropriately with a variety of communities. This includes recognising that in Culturally and Linguistically Diverse and Aboriginal and Torres Strait Islander communities, kinship and community structures need to be respected and acknowledged to develop trust and distribute information.

NGOs would like to be involved in changing community attitudes about autism by role modelling good approaches within NGOs and government.

Awareness and culture

The public sector indicated that their workplaces need to perform intentional work to identify and remove barriers for Autistic people. Many participants reasoned that if Autistic people are to be engaged and supported effectively in the workplace, then a common understanding about autism needs to occur. This can be somewhat supported by training public sector employees and most importantly, engaging with Autistic people and organisations to deliver specialist autism awareness programs.

There was broad acceptance that the announcement of an Autism Inclusion Teacher within the public education system is an initiative that could be extended across all public sector settings. Alternatively, having an 'Autism Ally' or 'Autism Mentor' present within public sector settings to help identify opportunities for autism inclusion could be considered.

Forum attendees reiterated that consulting with Autistic people is required before actioning any of their recommendations.

Theme 8: Intersectionality and Diversity

Rights, autonomy, and diversity

The experience of intersectionality is present for many in the Autistic community and important to recognise and address as part of the Strategy to ensure the diversity of experiences within the Autistic community are effectively captured.

LGBTIQA+ people

Responses from the Autistic LGBTIQA+ community highlighted the need for inclusive communities, and improvement in community attitudes, understanding and awareness of both Autistic needs and the needs of LGBTIQA+ people. Respondents called for the breaking down of stereotypes and provision of educational strategies.

"More education and public awareness of the additional complexities faced by people with intersecting identities. Greater focus on accessibility in terms of inclusion and diversity."

The importance of representation of Autistic and LGBTIQA+ people in government, policy, media and leadership were also highlighted by Autistic LGBTIQA+ people.

Some respondents also noted the need for sex education programs and resources to help Autistic people learn more about sexuality and sex. Educational programs within schools which support learning about diversity and inclusion was also mentioned by one forum participant.



Respondents noted that there is a need for strategies and supports for Autistic LGBTIQ+ people to be developed in collaboration with those who identify as Autistic and LGBTIQ+ and the need for genuine consultation and listening to lived experience in developing strategies to support members of these communities. Strategies and supports identified by Autistic LGBTIQ+ respondents included:

- safe, drop-in spaces
- peer-support
- support groups (and ensuring these are well promoted in the community).

"As a queer Autistic person, I believe that increased awareness and education about Autistic people experiencing the whole range of the human experience would begin to shift community mind sets. When it comes to the LGBTQIA+ community, we know our own minds, and should not be treated like children who are "experimenting with gender or sexuality".

Aboriginal and Torres Strait Islander people

Some Autistic Aboriginal and Torres Strait Islander respondents noted stigmatisation as an issue and highlighted the need for cultural awareness and inclusion.

"Understand we are people too, we love Australia and our land and we Are connected to out land and all the animals and the trees and the sun and the sky."

Trust, consistency and locally available access to support in regional areas was also noted by Autistic Aboriginal and Torres Strait Islander respondents.

"...the biggest issue is trust amd consistency. It takes a long time to build trust and then having to change practitioners feels like starting all over again and even going backwards. No more fifo, we need permanant regular staff in rural communities."

The need for increased support for Autistic Aboriginal and Torres Strait Islander children in state care, and the need for review of the systems and supports for Autistic Aboriginal and Torres Strait Islander mothers was also highlighted throughout the community forums.

Culturally and Linguistically Diverse people

Autistic members of Cultural and Linguistically Diverse communities indicated that there is a need for resources and information on autism to be made available in languages other than English.

"My CALD background is that I am from a Deaf family and my first language is Auslan. More information about autism in this language would be great."

Some respondents also called for developing awareness of Autistic needs with Culturally and Linguistically Diverse communities to enable Autistic people to participate in cultural activities.

"I would suggest finding ways for us to participate in cultural practices that aren't overwhelming sensory-wise."

Community understanding and acceptance of autism was also noted by some respondents, who raised the need for representation of intersectionality in media and promotional material.

"Explicitly showing diversity in autistic people in pamphlets, speakers at events etc, can help show autistic people that they are not alone."

Respondents also highlighted the need for:

- strategies and supports for Autistic people which acknowledge, respect, and recognise their cultural background or identity
- strategies and resources to be developed by members of the community
- improved training for professional staff working in the autism community to develop their cultural identity.



Regional and remote people

Responses from Autistic people and their families/carers in regional areas called for increased access to services and supports locally including diagnostic assessments, mental health care, and Allied Health services.

"...I have to drive an hour to get supports for my children. I live 45 minutes down the freeway from Adelaide South Australia. This means an appointment during school time adds travel time. So my child misses more school unnecessarily. Not to mention past mount barker we may as well not exist. If you want someone to come and visit your child during school hours most therapist won't because of the distance. Or they charge ungodly amounts of money which is taken away from their NDIS funding effectively reducing more therapy opportunities."

"Need routines to feel secure, particularly when out and change is difficult to work through, but my chdn are facing change constantly with supporting services as country positions are hard to fill and have people transferring to metro or appointments are cancelled."

Respondents suggested that this could be achieved by having places locally for visiting professionals to stay while in regional areas and by implementing strategies to attract and retain qualified and experienced practitioners to the regions.

Some respondents also highlighted the benefits of telehealth services and the need for these to be more readily available and accessible for people in regional areas.

Diverse communication types

Submissions from NGOs highlighted the importance of recognising the diversity and intersectionality of Autistic experiences, including intellectual disability and co-occurring conditions, with complex communication needs.

Submissions also raised the importance of information and communication access which can be achieved by providing resources and information through multiple formats and modes to meet the varied communication styles and needs of Autistic people. These submissions also highlight the benefits of enabling inclusion of Autistic people in the community, including improving community understanding, recognition and acceptance.

Theme 9: The Autism Charter

The State Government is developing a Charter that all State Government agencies will be required to adopt. The Charter will provide State Government agencies with a set of principles and commitments to ensure they are responsive to the needs of Autistic people and are accountable for how their agency and the services provided by the agency engage with, and respond to, the Autistic and autism communities.

Feedback was sought on the suitability of 16 Principles identified for potential inclusion in the Autism Charter.

1,050 people responded to this question, by selecting up to five of the principles as most important to them. The responses received indicated the following were considered most important.



Increased workplace knowledge, understanding and appreciation of autism through informed training provided or endorsed by Autistic people, including, but not limited to, best practice communication.

54% of total responses to this question included this principle in their top five (54% of Autistic responses and 54% of non-Autistic responses).



The right to education and employment opportunities that are accessible for Autistic people

54% of total responses included this principle in their top five (49% of Autistic responses and 56% of non-Autistic responses).



Increased workforce capacity to support Autistic students, employees and customers

39% of total responses included this principle in their top five (28% of Autistic responses and 45% of non-Autistic responses).



Maintaining collaboration, consultation and conversation with the Autistic and autism communities

40% of total responses included this principle in their top five (48% of Autistic responses and 36% of non-Autistic responses).



Increased access to, and information about, support and diagnostic services

34% of total responses included this principle in their top five (38% of Autistic responses and 32% of non-Autistic responses).



Acknowledge that many Autistic people also have co-occurring diagnoses and complex needs.

34% of total responses included this principle in their top five (38% of Autistic responses and 32% of non-Autistic responses).



A whole coordinated Government approach towards autism inclusion

36% of total responses included this principle in their top five (32% of Autistic responses and 38% of non-Autistic responses).



Acknowledge and respect the diverse abilities, strengths, goals and needs of Autistic people

33% of total responses included this principle in their top five (38% of Autistic responses and 30% of non-Autistic responses).

Commitment from the government

Community forum attendees highlighted the need for commitment to autism inclusion across all government agencies and ensuring that the Autistic and autism communities are engaged in ongoing consultation and feedback. Government agencies were also called upon to set the standard in including and promoting neurodivergent employees, and partnering with private organisations to achieve this in the private sector.

Attendees expressed hope that South Australia can become an "autism friendly state" and highlighted the importance of ensuring the Autism Strategy addresses the needs of the Autistic and autism communities in metropolitan, regional and rural South Australia. Recognition of diversity and the intersectional experiences of those who also identify as LGBTIQ+, or experience co-occurring mental health conditions, was noted as important.

Displaying a clear sign that services were a part of the Autism Charter, once established, was viewed as desirable by public sector forum attendees and a key component of this would be the way in which front line personnel communicated.

Clear and measurable outcomes

A very clear vision statement should be communicated and the changes that the Charter makes must be visible, relevant, noticed, and valued by the Autistic community. Although it was agreed that outcome data must be collected, a 'checkbox' audit style approach was not a preference when it comes to humanistic endeavours. Given the Charter is a long-term strategy, it was identified that annual reporting will be important.

"We need tangible outcomes, not fluffy KPIs."

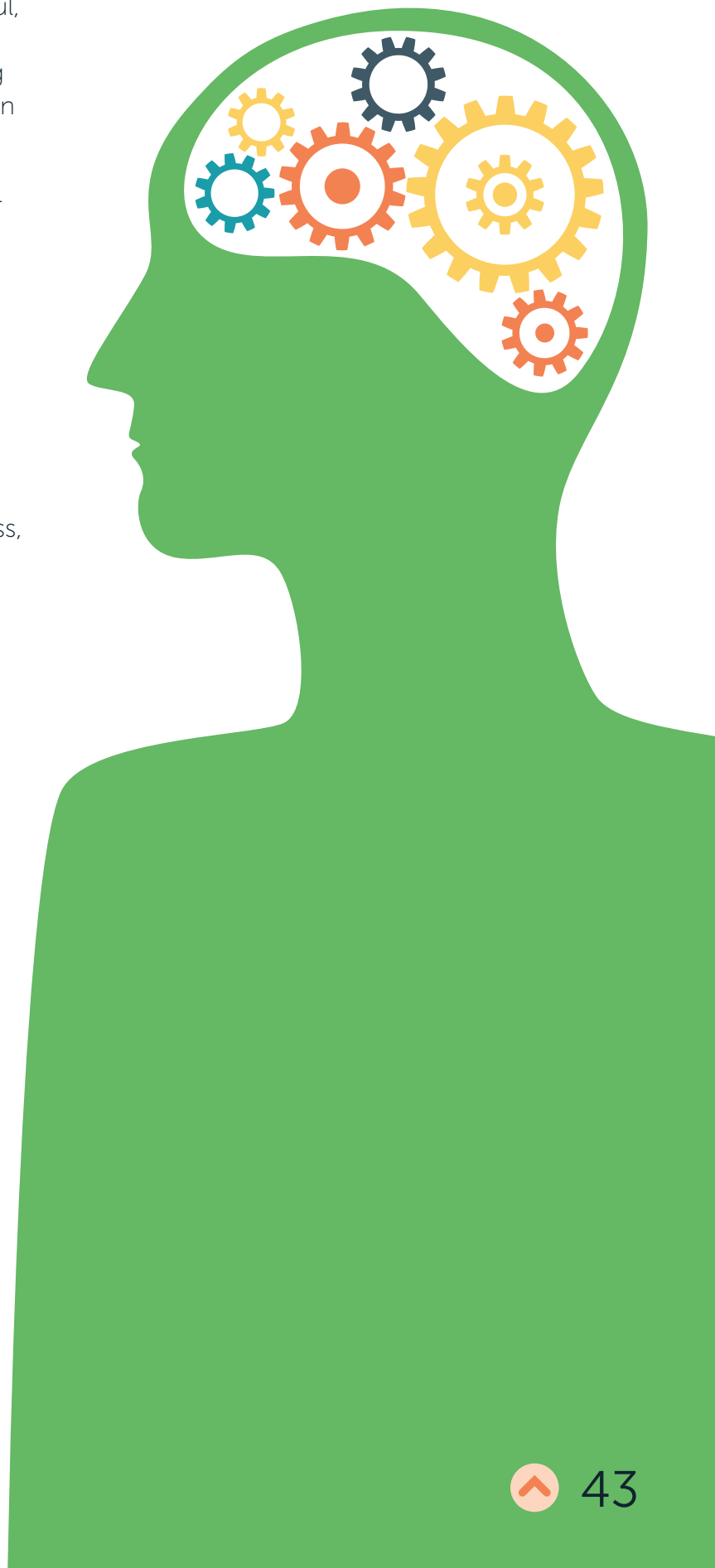


Prioritisation and resourcing

In order for the Charter to be successful, it must be supported with a 'top down' approach, with Chief Executives setting the tone and driving its realisation within departments. Resourcing was also a significant discussion topic by the public sector, ensuring that the Charter had adequate and dedicated financial expenditure, policy development and human resources.

Communication is acknowledged as a key aspect, and the Charter will need to be both simple in design, and wide ranging in its effect. Starting with small changes and building up gradually will ensure the Charter can build on success, as opposed to trying to implement all the changes at once.

"It is important that the Charter's position is clearly understood through a coordinated, whole of government approach."



Conclusion

This consultation report reflects the voices and submissions of the initial public consultation and co-design process in developing the State's first Autism Strategy and Charter.

Consultation on the Discussion Paper was just the beginning of the co-design process.

Feedback from the consultation has been reviewed and used to inform this consultation report. It will also be used to support the State Government developing the draft Autism Strategy and Charter.

The draft Strategy and Charter will be presented for further public consultation throughout 2023 to ensure it accurately reflects the feedback provided, responds to the aspirations of the Autistic and autism communities and that it makes a positive difference to the lives of Autistic people in South Australia.





