

Submission on South Australia's Autism Strategy

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Introduction

As South Australia's Commissioner for Children and Young People, I welcome the opportunity to respond to South Australia's first Autism Strategy (the Strategy) Discussion Paper.

As you are aware, my mandate is to advocate at a systemic level for the rights, interests and wellbeing of all children and young people in South Australia. My advocacy is directly informed and guided by the experiences and voices of children and young people.

As a signatory to the United Nations Convention on the Rights of the Child (the UNCRC) and the United Nations Convention on the Rights of Persons with Disability (the UNCRPD), Australia commits to give effect to the full range of rights of children and young people with disability.

These rights are embedded in South Australia's *Disability Inclusion Act 2018* (the Act), which sets out a child's right 'to a full life in conditions that ensure the child's dignity, promote self-reliance and facilitate the child's active and full participation in family, cultural and social life' (s9(3)(a)).

Despite these legislative protections, the following concerns indicate a systemic failure to promote the rights, wellbeing and participation of children and young people with autism:

- A failure to recognise and resource opportunities for children and young people's participation in decision-making processes and in the community.
- 'Gatekeeping' practices that restrict the enrolment of children with autism in schools and exclusionary 'behaviour management' practices that disproportionately impact children with autism.
- A culture of low expectations, which leads to a failure to take the educational needs or future aspirations of children and young people living with autism seriously.
- A concerning use of restrictive practices, including restraint and seclusion.
- A lack of training and support for professionals across key services to provide autism-friendly, child-friendly and youth-friendly information and environments.
- Inaccessible complaints processes that place the onus on children and families to highlight discrimination rather than on the system to show non-discrimination.

The recent Senate Select Committee on Autism Inquiry (the Senate Inquiry) emphasised that the 'ongoing failure of the system to improve outcomes for autistic people means that there is little value in continuing to do more of the same'.¹ Where systems and services are not upholding the rights of all children and young people, it is the system that needs to change.

Background and summary of recommendations

The state-wide Autism Strategy (the Strategy) is an opportunity to guide whole-of-government and whole-of-community efforts to ensure that children and young people with autism are valued, safe and respected across all aspects of society and at all stages of life.

It is promising that the Discussion Paper refers to many of the following ‘features of a successful autism strategy’, as identified in the Senate Inquiry:

- A commitment to advancing human rights and inclusion.
- ‘Whole-of-life’ and ‘whole-of-spectrum coverage’.
- High quality information and training.
- Genuine co-production with the autistic community.
- Links to broader policy context.²

This submission makes recommendations for how the Strategy can adopt these features in ways that make a real difference to children and young people’s lives across the five dimensions of South Australia’s legislated Outcomes Framework for Children and Young People: health, safety, education, wellbeing and citizenship.³

Drawing on my direct engagement with children and young people, this submission highlights where the Strategy and Charter can amplify children and young people’s voices and experiences. Specifically, I recommend that South Australia’s first Autism Strategy:

- 1. Sets clear, tangible and achievable objectives, actions, targets and timeframes.**
- 2. Promotes the rights of children and young people with autism and is responsive to the diversity and breadth of children and young people’s experiences.**
- 3. Recognises children and young people as a priority group for engagement across all priority areas and at all stages of the Strategy’s development, implementation and evaluation.**
- 4. Supports the meaningful participation of children and young people with autism across the community, with a focus on:**
 - a. Education environments.
 - b. Physical and recreational activities.
 - c. Improving support at key transition points.
 - d. Training, education and employment pathways.
- 5. Builds the capacity of systems and services to provide child-friendly, autism-responsive and rights-respecting environments, including health, mental health, child protection and youth justice.**

The quotes throughout this submission are from children and young people who participated in my school exclusions project in 2019 or my targeted listening project with children and young people with disability during 2020 and 2021. The following reports present the findings of these projects in more detail:

- [*The Blame Game*](#): *The perspectives of South Australian children and young people on the causes and impacts of education exclusion.*
- [*From Checkbox to Commitment*](#): *What children and young people with disability said about identity, inclusion and independence.*

These reports highlight that children and young people with autism have diverse needs, capacities, resources, personalities, and experiences that we can only seek to understand and include by supporting them. If you would like to discuss anything further, please do not hesitate to contact me.

Yours sincerely



Helen Connolly

Commissioner for Children and Young People, South Australia

1. The Strategy sets clear, tangible and achievable objectives, actions, targets and timeframes.

The following accountability mechanisms are critical to ensure that the Strategy's ambitions and aspirations translate into practice and real systemic change:

- Specific, measurable and achievable objectives, actions and targets.
- A plan for implementation with clearly defined responsibilities and timeframes.
- Timelines for review and renewal of the Strategy, which require public reporting of progress against Strategy's targets.
- Sustainable and coordinated funding to deliver on the Strategy's promises.
- Ongoing monitoring and reporting requirements.

South Australia can learn from the successes and challenges of autism strategies developed internationally.⁴ The recent review of the *Scottish Strategy for Autism* noted some areas of genuine progress, but highlighted a lack of accountability, a lack of training for professionals and minimal funding for valued services.⁵

2. The Strategy promotes the rights of children and young people with autism and is responsive to the diversity and breadth of children and young people's experiences.

In order to adopt a whole-of-government and whole-of-community approach to promoting the rights of people with autism, the Strategy should explicitly refer to the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Strategy and Charter should be underpinned by the Guiding Principles of the UNCRPD Articles of the UNCRC, including a child's right to be heard in all matters affecting them (Article 12), to education that develops their personality and talents to the full (Articles 28 and 29), to play and recreational activities (Article 31), and to the highest attainable standard of health (Article 24).

A rights-based Strategy is well-placed to respond to the diversity of children and young people with autism and the breadth of their experiences, views and support needs. Specifically, it is recommended that the Strategy:

- **Adopt a 'lifespan perspective'**, which recognises that 'early supports lay the foundation for a positive future', consistent with the *National Guideline for Supporting the Learning, Participation and Wellbeing of Autistic Children and their Families*.⁶
- **Acknowledge that identity develops over time and is influenced by relationships with family and peers, connection to community, access to supports and experiences in home, school and social environments.**
While some children and young people living with disability prefer identity-first language, many of the children and young people I have engaged with want to be seen as children and young people first. They want to be valued for their

relationships, interests and achievements as well as their hopes, dreams and wishes for the future, rather than defined by their disability. It can be difficult for children and young people to develop a positive identity in social and school environments that tend to highlight the things that make them different.⁷

- **Be responsive to the significant variation of children and young people's support needs, and recognise that people with autism may also be living with an intellectual disability, mental health conditions and/or other neurodevelopmental conditions, including ADHD and dyslexia.**

Particular consideration should be given to children with complex needs who require coordinated support from multiple service sectors. The Senate Inquiry highlighted that generic disability approaches are inadequate for people with autism, and those with more complex needs are least likely to benefit.⁸ My recent submission to a parliamentary inquiry in South Australia identifies systemic gaps in support for children with complex needs who are at risk of being unable to live safely in their family home, most of whom are living with autism and many who are also living with intellectual disability.⁹ These 'voluntary out of home care' arrangements are often crisis-driven, generally occurring due to a lack of appropriate services.

- **Recognise some recent research suggesting autism may be more common among trans and gender diverse people than cisgender people.¹⁰**

Whether this is the case or not, it is important to consider ways in which the Strategy can promote the rights of trans and gender diverse young people with autism. A recent study using data from the Trans Pathways study examines the mental health outcomes of trans young people with autism and highlights the need to improve access to gender-affirming care.¹¹ The *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* recommends that clinicians have 'a good understanding of gender diversity'.¹²

- **Address the intersecting factors that may exacerbate poor outcomes for children with autism,** including poverty, unsafe home or school environments, discrimination and exclusion, delays in diagnosis and early intervention, and a lack of understanding of autism.

3. Recognises children and young people as a priority group for engagement across all priority areas and at all stages of the Strategy's development, implementation and evaluation.

Children and young people should be recognised as key stakeholders throughout all stages of the Strategy's development, implementation and evaluation. I welcome the focus groups facilitated by JFA Purple Orange that have provided children and young people with autism the opportunity to contribute to the development of the Strategy.

Building on this, the Strategy should outline how children and young people will be supported to actively participate and contribute across all priority areas on an ongoing basis. Child-friendly and autism-friendly engagement processes should:

- Provide young people opportunities to participate in a range of formats, including through support from communication devices or through activities like drawing, colouring or plasticine.
- Use child-friendly language and information.
- Not only ask children and young people about barriers or issues they face, but also include children and young people in designing projects and solutions to meet the strategy's goals and be part of reviewing the Strategy.
- Report back to children and young people about the outcomes of the engagement to 'close the feedback loop'.
- Collaborate with youth-focused organisations or autism-specific programs, services and advocacy groups.

While many children and young people with autism have contact with many services and systems, they have very little say in how the majority operate. There is often a tendency to capture the voices of adults (either adults with autism or parents and carers of children with autism) or older young people (aged 18 to 30) as representative of the views of children and young people.

"They don't take younger people as seriously as they take adults. Adults don't understand what we are saying. Our thoughts and ideas are not respected."

– 11 year old, female

"make sure you capture what young people are actually saying, not twisting it cos it may be too hard"

– 18 year old

The *Disability Inclusion Act 2018* provides that 'the views of a child with disability will be listened to, and they should be given developmentally appropriate opportunities to participate in decisions that affect them'.¹³ Engagement will not only improve the design and delivery of systems and services, but also increase children's confidence and skills, sense of belonging and physical and emotional safety.

4. The Strategy supports the meaningful participation of children and young people with autism across the community, with a focus on improving support at key transition points.

The Strategy should promote the participation of children and young people with autism as active citizens in all aspects of society, across every stage of education and during key transitions, including from education into employment or further education opportunities.

Meaningful participation in everyday activities across home, community and educational environments drives healthy development, reduces social and physical isolation and is a key safeguard for children with complex support needs.¹⁴

a. Education environments.

Building on the State government's appointment of Autism Lead Teachers in government primary schools, the Strategy should facilitate broader changes to physical environments, practices and policies that will ensure safe, inclusive and rights-respecting education environments for all children and young people with autism.

This includes:

- Widespread adoption of peer buddy systems, school mentoring programs and lunchtime clubs that promote inclusion and positive relationships.¹⁵
- Initial and pre-service teacher education and ongoing professional development for all staff to understand autism and support student's wellbeing, learning, communication and sensory needs.
- Reducing the incidence and impact of exclusionary and restrictive "behaviour management" practices in schools, and reframing understanding of 'behaviours of concern' as valid responses to unmet needs or difficult environments or situations.¹⁶
- Improving transition planning and support at key transition points (see recommendation 4c and 4d).

Some children and young people describe positive experiences in school settings where they are supported to regulate their emotions, are listened to rather than 'always being ignored', have positive relationships and engaging learning experiences, and where they feel a greater sense of belonging and self-worth.

"Your less defined by a certain trait and more by yourself and who you are. I can talk to teachers like an adult. Students collaborate."

– **15 year old**

"One on one teaching. Receive support from teachers. Teachers know your learning and how each child learns best. Teachers modify learning for children who struggle with their learning. Mental health support, academic support."

– **16 year old**

However, positive experiences at school appear to be the exception rather than the norm. Many children and young people with autism report being bullied, excluded and having poor relationships with teachers and peers in school and social environments. Children with autism are disproportionately suspended and excluded from education from a young age, indicating a systemic inability of schools to understand, support and meet their diverse needs.¹⁷ The Strategy must seek to address this.

"I have autism and I get really stressed at school. How will sending me away and taking me from the few friends I have make me calm and be able to do flexible thinking and expected behaviour? I hate my principal and my teacher because they hate me. If they liked me it would be easier for me to like them. But even though I hate them I don't want to be taken away from my friends. I'll never be able to make new friends."

– 9 year old

"the way school wants kids to learn doesn't work for the kids. It's lonely and means my bedroom is my safe place. School is too noisy and too confusing. just because I have autism shouldn't mean school should be a too hard place. teachers just tell me i'm difficult or lazy. It's too hard to be around the other kids. I don't know what they're thinking about me. then school tells my mum she's a bad mum and the boss comes to my house. that makes me want to stay at home more"

– 17 year old, female

b. Physical and recreational activities.

The Strategy should seek to give effect to children's right 'to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts' (Article 31 of the UNCRC).

Participation in sport and other recreational activities helps children and young people feel valued in their schools and communities, build confidence, independence and social and practical skills. Yet the following systemic barriers limit and prevent the participation of children and young people with autism, particularly those with complex support needs:

- Logistical barriers, including infrastructure, transport and cost barriers.
- Attitudinal barriers, including low expectations and ableist assumptions made about children's capacity.
- A focus on immediate safety and a tendency to prioritise individual and medicalised therapy at the expense of other social and community-based supports.
- A dependence on adults to support their participation in 'fun things' that many other children and young people take for granted.
- An inability of services to safely include and accommodate children and young people with more complex support needs.

The Strategy must acknowledge and address these barriers and support schools and community services to be proactive and innovative in fostering the inclusion and participation of all children and young people with autism.

“Sometimes people might think I struggle with things I don’t. And they talk to me differently.”

– 11 year old, female

“having a differently wired brain gives me and others similar to me a different perspective ... Although my ideas may be blunt, it is important to remember we do have a population of people who think this way and are important to the South Australian population.”

– 17 year old, female

c. Improving support at key transition points.

The Strategy should prioritise improving support for children and families to navigate key transition points across early childhood and through adolescence to adulthood. This includes school and post-school transitions, transitions between living and care arrangements, and transitions between services, with particular regard to:

- The transition from the Department of Child Protection to adult services, particularly for children and young people who are transitioning to guardianship of the Public Advocate.¹⁸
- The transition between child and adult health and mental health services.
- School transitions, including starting school and moving from primary to high school.¹⁹

Transition planning should start early across key systems and services, and the widespread adoption of peer mentoring programs should be explored as a mechanism to improve transitions.²⁰

Improving transitions is key to improving wellbeing, reducing social isolation and preventing children and families from falling through the cracks between systems or reaching crisis point. For example, key issues remain at the interface between the NDIS and other key service systems, which too often become evident during crisis situations. There is a need for greater clarity regarding the roles and responsibilities of different sectors to deliver supports, and families need information and support to be connected with right services, whether or not they are funded by the NDIS.

The Senate Inquiry highlighted the ‘compounding effect’ of a failure to provide adequate supports and services at key transition points on life outcomes.²¹

"I do need to get help sometimes cos I do have autism and it gets in the way. I can get a bit confused and my brain gets fogged up and I can't think of anything. It's basically how my brain works. I want to be able to work independently but I can't. I'm a bit nervous about year 12. I think the teachers have high expectations and that's kinda scary 'cos I don't know how I'm gonna meet that."

– 16 year old, male

d. Training, education and employment pathways.

The transition from education settings to work is one of the most critical yet also one of the most poorly supported transitions for young people with autism. The Strategy should seek to:

- Improve early planning and collaboration between services, schools, universities, training providers and employers.
- Increase children and young people's opportunities for skill development, work experience and work-based training, including through peer mentoring programs.
- Ensure support for adjustments and sensory regulation for young people in workplaces.²²

As they finish school, many young people with disability reported feeling excluded from decision-making about their own future. They said sometimes teachers or parents would make decisions about their subject choices and future pathways without any consideration of their passions, interests, and personal goals, and that this approach leaves them feeling ill-prepared, disinterested and more likely to withdraw from study and work options altogether.

"When I finish school I want to be a paleontologist. I just hope that the fact I'm on the autism spectrum doesn't impact me"

– 11 year old, female

"'Here is an area we think you'd be good in' and completely ignore what the person is actually good at."

– 21 year old, male

Supporting post-school transitions is critical and aligns with the Senate Inquiry's key recommendations and with Policy Priority 2 of Australia's Disability Strategy 2021-2031.

5. The Strategy builds the capacity of systems and services to provide child-friendly, autism-responsive and rights-respecting environments, including health, mental health, child protection and youth justice.

Beyond improving access to services for children and young people with autism, the Strategy must also build the capacity of service systems and staff to provide environments that are autism-responsive, child- and youth-friendly. This includes:

- Providing training and resources for all professionals and staff working across education, health, mental health, child protection and youth justice systems, and the NDIS.
- Monitoring with a view to eliminate the use of restrictive practices, including the use of physical or chemical restraint, seclusion or coercion, which violate children and young people's rights, cause harm and exacerbate trauma and may also involve a lack of communication and empathy.²³
- Improving support for families to navigate complex systems, including access to advocacy services, and feedback and complaints mechanisms.

This will help to ensure services are meeting their obligations under the *Children and Young People (Safety) Act 2017*, the National Principles for Child Safe Organisations, and the UNCRC. The Strategy should be based on a review of existing approaches, build on promising pilots to ensure long-term systemic rather than siloed and short-term change.

There is currently an over-reliance on the hospital or youth justice system to bridge the gap in appropriate support for children and young people with autism with complex care needs.²⁴ As such, the Strategy should improve service integration and address gaps in crisis prevention and intervention support in order to prevent hospital admissions and reduce exposure to the youth justice system.

“kids with autism. no-one understands”

– **17 year old, female**

“School councilors and how school handles mental health and neurodiverse students, I think schools could do a lot better then they do.”

– **Year 11 student, male**

- ¹ Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022). https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services.supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf p.65.
- ² Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022). https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services.supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf p. 59.
- ³ Child Development Council South Australia. *South Australia's Outcomes Framework for Children and Young People*. (2019). <https://childrensa.sa.gov.au/wp-content/uploads/2019/11/Outcomes-Framework-Final-2019-10-11.pdf>.
- ⁴ AMAZE. *Towards a National Autism Strategy: International lessons for Australia Background Paper* (2021). <https://www.amaze.org.au/wp-content/uploads/2021/10/Towards-a-national-autism-strategy-international-lessons-Oct-2021-Amaze.pdf>.
- ⁵ Cross-Party Group on Autism. *The Accountability Gap: A review of the Scottish Strategy for Autism*. (2021). <https://s3.chorus-mk.thirdlight.com/file/1573224908/63654983914/width=-1/height=-1/format=-1/fit=scale/t=445041/e=never/k=2910a506/CPG%20on%20Autism%20report%20-%20The%20Accountability%20Gap%2006.10.2020.pdf>.
- ⁶ AutismCRC. *National Guideline for supporting the learning, participation and wellbeing of autistic children and their families in Australia*. (2023). <https://www.autismcrc.com.au/access/supporting-children/guideline>.
- ⁷ Commissioner for Children and Young People South Australia. *From Checkbox to Commitment: What children and young people with disability said about identity, inclusion and independence*. (2022). <https://www.ccyp.com.au/wp-content/uploads/2022/05/Screen-From-Checkbox-to-Commitment-Report.pdf>.
- ⁸ Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022). https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024412/toc_pdf/Services.supportandlifeoutcomesforautisticAustralians.pdf;fileType=application%2Fpdf.
- ⁹ Commissioner for Children and Young People South Australia. *Submission to the Social Development Committee Inquiry into NDIS participants with complex needs living in appropriate accommodation*. (2022). <https://www.ccyp.com.au/wp-content/uploads/2022/09/2022-08-31-Submission-to-SDC-Inquiry-re-NDIS-participants-with-complex-needs-in-inappropriate-accommodation.pdf>.
- ¹⁰ Varun Warriar, David M. Greenberg, Elizabeth Weir, Clara Buckingham, Paula Smith, Meng-Chuan Lai, Carrie Allison, and Simon Baron-Cohen. "Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals." *Nature Communications* 11 (2020): 1-12. <https://www.nature.com/articles/s41467-020-17794-1>. Warriar, Varun, and Simon Baron-Cohen. "Transgender and gender diverse people up to six times more likely to be autistic." *The Conversation* (2020). <https://theconversation.com/transgender-and-gender-diverse-people-up-to-six-times-more-likely-to-be-autistic-new-study-144085>.
- ¹¹ Strauss et al., "Mental health difficulties among trans and gender diverse young people with an autism spectrum disorder (ASD): Findings from Trans Pathways." *Journal of Psychiatric Research* volume 137, (May 2021): 360-367, <https://www.clinicalkey.com.au/#!/content/playContent/1-s2.0-S0022395621001497?returnurl=https%3F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS0022395621001497%3Fshowall%3Dtrue&referrer=https%3F%2Fresearch-repository.uwa.edu.au%2F>.
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- ¹³ *Disability Inclusion Act 2018* (SA), section 9(3)(a). https://www.legislation.sa.gov.au/_/legislation/lz/c/a/disability%20inclusion%20act%202018/current/2018.1.auth.pdf.

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¹⁵ I CAN Network. *A Safe Space: Social Impact Report*. (2022). <https://icannetwork.online/wp-content/uploads/2022/05/I-CAN-Network-2021-Social-Impact-Report.pdf>.

¹⁶ Jorgensen, Mikaela, Karen Nankervis, and Jeffrey Chan. "'Environments of concern': reframing challenging behaviour within a human rights approach." *International Journal of Developmental Disabilities* 69, no. 1 (2023): 95-100. <https://www.tandfonline.com/doi/full/10.1080/20473869.2022.2118513>.

¹⁷ Commissioner for Children and Young People South Australia. *The Blame Game: The perspectives of South Australian children and young people on the causes and impacts of education exclusion and why we need to stop blaming children for system failure*. <https://www.ccyp.com.au/wp-content/uploads/2022/03/The-Blame-Game-The-perspectives-of-South-Australian-children-and-young-people-on-the-causes-and-impacts-of-education-exclusion-and-why-we-need-to-stop-blaming-children-for-system-failure.pdf>.

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¹⁹ AutismCRC. *The Longitudinal Australian Study of Students with Autism (LASA) Final Report*. (June 2022). https://www.autismcrc.com.au/sites/default/files/reports/2.007RC_LASA_Final-report.pdf. p. 9.

²⁰ Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022). p. 252.

²¹ Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022).

²² AMAZE. *Opportunity Autism: Next Steps for Victorian Autism Policy*. (July 2022). <https://www.amaze.org.au/wp-content/uploads/2022/07/Opportunity-Autism-July-2022.pdf>. p. 5.

²³ United Nations Committee on the Rights of Persons with Disabilities. *Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities. The right to liberty and security of persons with disabilities*. (2015). <https://www.ohchr.org/Documents/HRBodies/CRPD/14thsession/GuidelinesOnArticle14.doc>. Para. 12.

²⁴ Senate Select Committee on Autism. *Services, support and life outcomes for autistic Australians*. (2022). p. 343.