

SUBMISSION TO THE SENATE SELECT COMMITTEE ON AUTISM

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Introduction

The South Australian Commissioner for Children and Young People is an independent statutory position, established under the *Children and Young People (Oversight and Advocacy Bodies) Act 2016* (the Act). The Commissioner advocates at a systemic level for the rights, interests and wellbeing of all children and young people in South Australia, giving particular consideration to children and young people whose voices are not usually heard.

The Commissioner's functions include:

- Promoting the participation of children and young people in decision-making that affects them;
- Placing the rights, interests, development and wellbeing of children and young people front and centre in public policy and community life; and
- Advocating to decision-makers to create laws, policies, systems and services that support children and young people.

The Commissioner's advocacy is directly informed and guided by the issues, experiences and voices of children and young people themselves.

Under the Act, the Commissioner must also ensure that the State, at all levels of government, meets its international obligations as outlined in the United Nations Convention on the Rights of the Child (UNCRC). The UNCRC sets fundamental standards in relation to children and young people's rights and their access to justice, education, health care and social services. Further, it states that all children have the right to have a say on all matters that affect them and for their views to be taken seriously. All children have the right to be safe, to be free from discrimination, and to have their best interests a primary consideration in all actions that concern them.

The principles of the UNCRC are enshrined in international law and in key pieces of Commonwealth legislation that guide Australia's child protection legislation, including the *Australian Human Rights Commission Act 1986 (Cth)* and the *Family Law Act 1975 (Cth)*. While legislation varies across states and territories, it is guided by three similar principles: the best interests of the child, early intervention and the participation of children and young people in decision-making processes.

Section 4 of the *Children and Young People (Safety) Act 2017* (Safety Act) in South Australia recognises and commits to promoting the following outcomes for every child and young person, which reflect key articles of the UNCRC: to be safe from harm; to do well at all levels of learning and to have skills for life; to enjoy a healthy lifestyle; and to be active citizens who have a voice and influence.

Just as the *National Framework for Protecting Australia's Children 2009-2020* acknowledges that protecting children is "everyone's business", the Safety Act declares that the duty to safeguard and promote these outcomes lies with "every person in the State". Furthermore, where children and young people may be at risk, the priority must be early intervention.

Background and summary of recommendations

Since becoming Commissioner in 2017, I have spoken to thousands of children and young people across South Australia about issues that are important to them. Children and young people have consistently told me that they are concerned about students being excluded from school and the support these students receive to remain engaged with their education. As a result, doing something to “help everyone get an education” is one of the top five priorities that children and young people have identified for my work.

Under Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), state authorities must take all necessary measures to ensure that children living with a disability enjoy fundamental freedoms and human rights on an equal basis with other children, including the rights to be heard and to access education and justice. These rights have been codified in the *Disability Discrimination Act 1992 (Cth)* and protected in the subsequent *Disability Standards for Education*.

Despite these legislative protections, my investigation into school suspensions, exclusions and expulsions has highlighted a concerning connection between exclusions and students with a disability. Although school exclusions are considered to be a behaviour management strategy, this practice systematically discriminates against children with disability or with complex social, emotional and behavioural needs.

The prevalence of autism among the children whose stories of exclusion my office has reviewed, indicates a systemic issue in the ability of schools to understand, support and meet the diverse needs of this group of children. The support and services available to these children, not only at school but across all aspects of their lives, can set the trajectory for the rest of their lives.

Where systems and services are not meeting the needs of all children and young people, it is not the child who needs to change but rather the system. This submission makes five recommendations to the Senate Select Committee on Autism to guide where governments, decision makers, service providers, organisations, employers and employees can collaborate and take action to amplify the voices and improve the lives of children and young people with autism.

A summary of our recommendations is as follows:

- 1. The development of a National Autism Strategy that recognises the particular and diverse needs of children and young people with autism and promotes the participation of children and young people with autism through a child-friendly and autism-friendly consultation process.**
- 2. The regular collection of nationally consistent, gender-and age-disaggregated data that is publicly available to monitor the prevalence of autism and examine and better inform service provision.**
- 3. Increased and consistent standards for education and training for all workers who have contact with children and young people to understand autism and provide appropriate responses that facilitate the social inclusion and**



participation of children and young people with autism in the economy and community, particularly in relation to education, healthcare and justice.

4. Increased funding for consistent and early intervention support and services across an autistic child's lifespan and clearer promotion of available supports so that families know what support is available.
5. The development of and funding for autism-specific and child-friendly advocacy and self-advocacy services to support children and young people with autism to navigate complex systems and services.

If you have any questions or if you would like to discuss anything further, please do not hesitate to contact me.

Helen Connolly

Commissioner for Children and Young People, South Australia

Submission

- 1. The development of a National Autism Strategy that recognises the particular and diverse needs of children and young people with autism and promotes the participation of autistic children and young people through a child-friendly and autism-friendly consultation process.**

South Australia's Commissioner for Children and Young People (CCYP) supports the development of a National Autism Strategy to guide coordinated and targeted action and investment across local, state and Commonwealth governments and services.

A National Autism Strategy should recognise children and young people as key stakeholders throughout all stages of the Strategy's planning, design, implementation and governance. Particular consideration should be given to vulnerable groups of children and young people, including those who are in contact with the youth justice or child protection systems, those from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander children and young people.

Centring the voices and lived experiences of autistic children and young people is the best way to identify their particular and diverse needs so that systems, services and policies are effective, efficient, sustainable and responsive to these needs.

The consultation process should be child-friendly, autism-friendly and engage directly with children and young people about what they want from services and how they want to participate in an ongoing way. This requires collaborating and partnering with the disability sector, with education, health, child protection and youth justice services and with autism-specific programs, services and advocacy groups.

The strategy itself should be designed to promote the participation of people with autism as active citizens in all aspects of society, across every stage of schooling and during the transition from education into meaningful employment or further education opportunities. A National Autism Strategy should also:

- Provide clear and nationally consistent guidelines for timely and consistent diagnosis, transparent age- and gender-disaggregated data collection and monitoring to inform better service provision (see Recommendation 2);
- Increase public awareness and set national standards for education and training for all who work with children and young people (see Recommendation 3);
- Create consistent service standards across states, territories and the Commonwealth and match services, funding and resources to need for all autistic people, regardless of whether or not they are an eligible NDIS participant;
- Ensure the interests of people with autism, particularly children and young people, are represented across all services and areas of policy development, including in education, health and mental health, employment, justice and social inclusion;
- Guide future autism research, prioritising research that focuses on improving outcomes for autistic people;

- Inform governments, policymakers, decision-makers and urban planners to design public spaces, buildings, workplaces and events to be child-friendly, youth-friendly and autism-friendly; and
- Apply an autism lens to policy proposals, legislation and regulations beyond those that specifically target people with autism, potentially through the development of an Autism Advisory Panel comprising self-advocates, family and carers and experts.

A National Autism Strategy will also complement the next phase of the National Disability Strategy. Given the challenges that arise from differences within states and between commonwealth, state and local government systems, a nationally-coordinated approach to improving and increasing opportunities and life outcomes for people with autism is important.

CCYP recommends that Australia's Strategy take a whole-of-government and rights-based approach. It could follow best practice examples internationally, such as the strategic outcomes of the Scottish Strategy for Autism:

1. **A healthy life:** Autistic people enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.
2. **Choice and control:** Autistic people are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs.
3. **Independence:** Autistic people are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.
4. **Active citizenship:** Autistic people are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.ⁱ

The development of the Strategy must be detailed and outline concrete objectives and actions that will improve the lives of all people with autism. To track the Strategy's progress and ensure its success, a National Autism Strategy must be accompanied by consistent and long-term funding and informed by the latest research and improved data collection and monitoring.

2. **The regular collection of nationally consistent, gender-and age-disaggregated data that is publicly available to monitor the prevalence of autism and examine and better inform service provision.**

Meaningful, regular and nationally consistent data collection is fundamental to the planning and timely provision of services that identify and appropriately respond to individual and community needs. This data should be made publicly available to improve service planning, reporting and accountability.

Overwhelmingly, current practice does not reflect this. There is limited data on the prevalence of autism and on the nature and impact of funded services or interventions, including their performance, outcomes and participation rates. There are also no standard definitions for autism and its relationship to disability across and within community and government departments, agencies, systems and services.

Australian studies into the prevalence of autism currently rely on datasets that are collected for specific purposes that capture only part of the population, or for broader purposes such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) survey.

Currently, data is presented in age brackets that are inconsistent, too broad and therefore unable to adequately inform service provision. For example, the NDIS groups 7 to 14 year olds together, whilst the Productivity Commission's 2020 Report on Government Services under the National Disability Agreement (NDA) groups 0 to 14 year olds together and 15 to 24 year olds together.ⁱⁱ Other state authorities, including the Australian Institute of Health and Welfare, have grouped 15 to 64 year olds together as “working-age people”.ⁱⁱⁱ

Given the evidence that the developmental, social and emotional needs of a 7-year-old differ greatly compared to the needs of a 14-year-old, whose needs also differ greatly from those of a 24 year old, let alone a 64 year old, it is crucial that age-disaggregated data is collected and presented in a consistent and meaningful way.

Breaking data down into meaningful categories and by state and territories will improve the quality of data, allow for more flexible analysis and better establishment of base line and measures of progress. It will also comply with legislation, the National Disability Strategy and best practice internationally and lead to a greater understanding of the true prevalence of autism in Australia.

The Cooperative Research Centre for Living with Autism (Autism CRC) developed a National Guideline for Assessment and Diagnosis of Autism (2018 Guideline), which was released in 2018. However, this is not being used and autism diagnosis varies between states and territories in terms of which professionals and what level of experience is required. This inconsistency leads to confusion and uneven and delayed support and service provision. A 2014 review of Australia’s autism diagnostic practices recommended the adoption of a national standard for autism diagnosis and this office recommends that the 2018 Guideline be adopted.

A National Autism Strategy could provide a funding mechanism for the implementation of such a national and consistent guideline across Australia. The Select Committee could also consider the development of a national register that monitors the prevalence of autism diagnoses, based on the only existing State-based registry in Western Australia.

Whether established as part of a National Autism Strategy or not, nationally consistent guidelines for data collection, diagnosis and monitoring must be prioritised. This will allow for an understanding in trends over time and promote consistency, best practice and equal access in diagnosis and service planning and provision.

- 3. Increased and consistent standards for education and training for all workers who have contact with children and young people to understand autism and provide appropriate responses that facilitate the social inclusion and participation of children and young people with autism in the economy and community, particularly in relation to education, healthcare and justice.**

Recent research by AMAZE, the peak body for autistic people and their supporters in Victoria, shows that an overwhelming majority of the population knows what autism is and knows someone with autism. However, despite this knowledge and personal contact, there is a significant lack of understanding about what individuals and the community can do to support autistic people. Only 4% of autistic people believed people in the community knew how to support them.^{iv}

This office has heard from children and young people and from parents, carers and other stakeholders that many workers who work with children and young people across systems and services do not adequately understand autism. A failure to understand and provide appropriate support has a significant impact on the health, wellbeing and education outcomes, engagement, social inclusion and participation of people with autism.

The Scottish Strategy for Autism supported an Autism Training Framework for those working in health and social care. As part of the National Autism Strategy, Australia could develop a similar national framework for autism-specific training for all workers. This could be based on a review of the education and training provided to all professionals and service delivery staff that encounter or work with children and young people with autism across education, health, child protection and youth justice systems, including teachers and other school staff, police, court and other youth justice employees, health professionals, and agencies contracted to provide services.

Education and training must equip all workers with resources and skills to support the varied and complex communication, social interaction, sensory regulation and cognitive needs of autistic people, to understand children's rights and to create autism-friendly environments, to minimise anxiety and understand and appropriately respond to the commonly co-occurring mental health needs of people with autism.

Given that one third of NDIS participants are people with autism, autism-specific training should be prioritised and provided for NDIS planners and all individuals and services that interface with the NDIS. It is concerning that this office has heard from stakeholders that there is a very limited understanding of autism at the planning level within the NDIS. The Australian Autism Alliance recently reported that the majority (65%) of autistic NDIS participants or their carers rated their planner's knowledge and understanding of autism as "None" to "Moderate".^v A lack of understanding and training has significant implications for the adequacy and efficacy of a participant's plan.

My investigation into suspensions, exclusions and expulsions in South Australian schools has also highlighted that students with autism are disproportionately excluded from education. A lack of understanding and a lack of capacity or resources to listen to students and their families or carers, to understand the student's needs and to provide appropriate support means that responses are punitive and exclusionary.

In 2019, I heard from over 300 South Australian children and young people about their experiences, perceptions and the impacts of school exclusions. The following quotes from young people with autism who have been excluded from education highlight how a lack of support to deal with sensory or communication challenges led to their exclusion and impacted their relationships, learning and wellbeing:

“Teachers need to understand Autism more. My ASD is why I get suspended and I can’t help that.” – 13 year old

“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

This highlights the importance of teacher education and training that increases the confidence of teachers and education staff and the support available to them and ensures they have skills, knowledge and access to resources that are designed to support the communication and sensory needs of children with autism in autism-friendly environments that are inclusive and calm.

While there is often a lack of awareness and limits to adjustments made for some students with autism in “mainstream” classes, there can be strict eligibility criteria for students to access a “special” unit or school. As a result, some children and young people with autism are falling through the gap between these options or are being pushed out of the education system.

I have seen first-hand how inclusive approaches to education are not only possible, but also benefit all children, ensuring that they feel known, included, supported and valued. I recently visited Springbank Secondary College in Adelaide, where students reflected on the fact that their school is truly inclusive. Young people at this school spoke about the integrated nature of “mainstream” education and “the unit” – or disability unit – and how this was important to everyone’s wellbeing and learning. They described the students in the unit as “legends” and teachers as “kind” and they reported that a truly inclusive approach based on listening and understanding reduces bullying.

“The unit was never merged with mainstream and now they are merged and people treat them like normal and you won’t get that at a different school.”

– Year 10-12 group

“This school allows everybody to be themselves... A myriad of schools squeeze students into a tiny little box, they want every individual student to act the same, dress the same, and function the same and if you go against that you’re ridiculed for it. This school allows students to be individuals and take their own direction in life.”

– Year 10-12 group

“There is no bullying happening since I’ve been here like my old school, no one has name called me.”

– Year 8-9 group

A failure to provide adequate training to inform the right support and services is likely to bear greater social and economic costs in the longer term. Exclusion often creates the conditions for further behavioural issues and increases the likelihood of disengagement from education. This disengagement can have a “domino effect” that exacerbates problems elsewhere in a child’s life, impacting their wellbeing and relationships and increasing their vulnerability and the likelihood of coming into contact with the youth justice system, either as victims or perpetrators.

This is not inevitable. There was a real sense from my conversations with children, young people and their families and carers that exclusions could be avoided if students were better supported to regulate their emotions and understand the consequences of their behaviour. This was seen to depend on teachers and other school staff having a better understanding of autism and better communication between students and teachers, where students are asked what they needed and listened to rather than “always being ignored”.

One young person who was forced to move schools described how a greater level of understanding in schools and the community can make a positive difference to their life and educational outcomes but can also reverse the current trends of punitive and exclusionary responses.

“My Mum moved me to a better school that doesn’t do suspensions outside school. The new school listens. I get more help with my learning... My old school and teachers and head hated me and didn’t understand me.”

– 13 year old

Listening to children and young people is key to providing the right support and services, not only in education but across all services. This requires a significant cultural shift in how we value children and young people, where we engage children and young people directly and create opportunities for their voices to inform decisions, particularly about the individualised supports and services that they need in order to overcome barriers in education, employment and community participation.

The payoff of having well-trained, informed and dedicated professionals and service delivery staff will be profoundly positive and fulfil the promise and responsibility of all Australian Governments under the Alice Springs (Mparntwe) Education Declaration to ensure all children do well at all levels of learning, are confident and creative, are active and informed citizens and have skills for life.

Consistent and autism-specific education and training will improve how individuals, communities and systems understand autism in a way that values the strengths and individuality of every child, promotes their participation and ensures the protection of their rights under the UNCRC and UNCRPD to reach their full potential and to access education, healthcare and justice on an equal basis with others. The long term social and economic benefits of this education, training and understanding will significantly outweigh any initial costs.

4. Increased funding for consistent and early intervention support and services across sectors and across an autistic child's lifespan and clearer promotion of available supports so that families know what support is available.

Increased funding is necessary to ensure that services are adequate, affordable and timely, and that children and young people are not falling through the gaps between mainstream services, services funded through the NDIS and other specialist disability services, both not-for-profit and private. The earlier this is provided, the better.

While the National Disability Insurance Scheme (NDIS) is considered a significant achievement under the National Disability Strategy, not all people with autism access formal support services and many seek assistance through mainstream health and welfare services.

It is critical that all people with autism and disability, whether or not they receive an NDIS package, are supported to live in inclusive communities with accessible infrastructure and services that are both broad and targeted, generic and specialist and consistent across all stages of life.

However, mainstream services are often under-resourced, uninformed and therefore do not often have the capacity to meet individual and community needs across the lifespan. Where services do exist, they are often costly, have long waiting times or are not supported by NDIS funding. Under the NDIS, children are currently facing up to 12 months delay in accessing early intervention services. Those who are not eligible for NDIS funding are waiting too long and paying out of their own pocket for costly support.

Perhaps most concerning is a shortage of services. Given that autism commonly co-occurs with mental health issues, more support services are needed in this area. A recent review of mental health services for children and young people found that services "did not match the level of need across the life span".^{vi} Other health and wider community services, such as housing, transport, sport and leisure, should also be matching the level of need across the lifespan.

Experiencing issues in one system impacts a child's ability to thrive in the community as a whole. This office therefore advocates for multi-agency responses and early, consistent and wraparound support services. The earlier these supports are provided, the better. A

failure to provide early and adequate diagnosis, support and intervention is more likely to bear increased economic and social burdens and costs in the longer-term, including in social services support and in the costly youth or adult justice systems.

A joined-up approach to service planning and delivery is central to promoting engagement, self-regulation and the full participation of people with autism and reducing exclusionary practices. Services also require funding in order to be consistent, targeted and effective across key environments – home and school, supported accommodation, hospitals, health facilities and youth justice environments – and across life time, particularly during key transitions from early childhood to adolescence to adulthood.

Where services do exist, there is a need for better promotion of what options are available, particularly to support key transitions, into school, between schools and out of school and into adulthood.

As part of the Scottish Strategy for Autism, a multi-agency group that included people with autism and their parents and carers created a “Menu of Interventions” to guide people to identify what support and advice was available.^{vii} The Scottish government also mapped out local autism services to improve their coordination. These mapping exercises coincided with significant funding for local authorities and local and national organisations to develop projects, local autism strategies and action plans.

5. The development of and funding for autism-specific and child-friendly advocacy and self-advocacy services to support children and young people with autism to navigate complex systems and services.

Article 7 of the United Nations Convention on the Rights of Persons with Disabilities obliges state parties to ensure that children with disabilities “have the right to express their views freely on all matters affecting them... on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”.^{viii}

In line with the UNCRPD and the UNCRC, this office recommends increased funding for autism-specific and child-friendly advocacy services to support children and young people with autism to navigate complex systems, and to ensure they have their voices heard in decisions and the design of services and supports that affects them.

Adult decision-makers often think that they know what is best for children and young people, while children and young people are often perceived as incapable of making their own decisions. These perceptions can be heightened in relation to neurodiverse children and young people because of their communication, social and sensory needs. In order to challenge these misconceptions and increase community education and acceptance, it is crucial to support these children to be heard, included and to advocate for their rights.

This office supports a nationally consistent approach to disability advocacy that defines clear responsibilities for state and territory governments and Commonwealth government, and involves communication and collaboration with existing services and advocacy groups. Advocacy should be child-focused and tailored to the individual needs of people, be informed by an evidence base and promote awareness of rights, social inclusion and community education.

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- ⁱ The Scottish Strategy for Autism: Outcomes and Priorities 2018-2021. Available at <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>
- ⁱⁱ NDIS, "Participant data", 31 March 2020. Available at <https://data.ndis.gov.au/explore-data/participant-data>. Australian Government, Productivity Commission, Report on Government Services 2020. Part F: Community Services. Available at <https://www.pc.gov.au/research/ongoing/report-on-government-services/2020/community-services/services-for-people-with-disability>.
- ⁱⁱⁱ Australian Institute of Health and Welfare. People with Disability in Australia 2019. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/summary>.
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- ^v Australian Autism Alliance, 2019. "Federal Election Manifest: How the next Commonwealth Government can make positive change for autistic people across Australia." Available at http://www.australianautismalliance.org.au/wp-content/uploads/2019/02/Australian-Autism-Alliance-Federal-Election-Manifesto_web.pdf.
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- ^{viii} United Nations Convention on the Rights of Persons with Disabilities, Article 7 - Children with disabilities. Available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-7-children-with-disabilities.html>.