

Partnering with P&Cs to advance public education

WACSSO SUBMISSION National Autism Strategy: Response to Discussion Paper

October 2023

Acknowledgments

Acknowledgement of Country

The Western Australian Council of State School Organisations pays respect to First Nations and Traditional Custodians throughout Australia, recognising their connection to land, waters and sky.

We acknowledge parents, families, Elders and communities as sharers of culture and knowledge; and recognise the value this learning holds for children and young people.

The Voice of Parents

WACSSO acknowledges parents* as the first educators in their child's life. We celebrate and honour the diversity of families and recognise the vital role they play in supporting children and young people throughout their learning journeys.

This submission is informed by the experiences and feedback we receive from Western Australian Parents and Citizens Associations (P&Cs) and the parents of children attending WA public schools.

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^{*} WACSSO recognises the term "parent" to also include a child's primary carer.

Introduction

The Western Australian Council of State School Organisations (WACSSO) is the peak body representing parents of public school students in Western Australia. We provide services and representation at the State and National level to more than 650 Parents and Citizens Associations (P&Cs) across WA.

Together with the P&C community and all our stakeholders, WACSSO works tirelessly to advance public education in WA so that every student has the best chance to realise their potential and live the life they deserve. Our vision is for Western Australian schools to provide world-leading education to every student.

For over a century, we have worked passionately with school organisations across this State to improve the public education system, all the while never losing sight of a simple principle: that we are stronger together.

In preparing this paper, WACSSO surveyed parents of public school students in WA. We received over 20 first-hand accounts from parents whose children all require support at school. These children attend both mainstream and education support primary and high schools and live in metropolitan and urban regional areas around our State.

The testimony of these parents, along with the expert opinion of our network of State Councillors has been used to inform our response to this important Discussion Paper. We thank the Federal Department of Social Services for providing the opportunity to provide feedback on this topic. WACSSO has chosen to focus our response on the overarching key disucssion questions.

We acknowledge that individuals impacted by this Strategy will identify in a number of ways, including as autistic, as an autistic person, as a person living with autism, as neurodiverse and other related terms. We embrace all definitions that suit individuals. For the purposes of this submission, we have used terminology consistent with the Discussion Paper.

1. What does a National Autism Strategy need to achieve?

In preparation for our response to this paper, we surveyed and spoke with parents in Western Australian public schools. Their voices inform our response.

The overwhelming feedback received is that up-to-date training and a clearer understanding of Autism by teachers and school staff is essential; staff need to be equipped with the knowledge and skills needed to support Autistic children, and significant gaps in knowledge and training persist in the public education sector. The training provided should be continually built on as the understanding of Autism grows, informed by research. It should be acknowledged that just as no two neurotypical children are alike, so too are no two Autistic children alike. Parents also assert that open communication between themselves and the school, prioritising a partnership approach, will achieve the best outcomes for Autistic children in public schools.

Our parents voiced a wish that schools and the community understand and recognise Autism as a disability, not only a behavioural condition. Many referred to Autism as an 'invisible disability.' A clearer, better-understood definition of Autism and how to respond to its presentation in all the varying forms is critical for those affected to thrive. Parents also called for a rights-based framework approach. One example of this in practice would be that the right of a child to attend their local school should never be contested.

WACSSO asserts that EQUITY in all aspects of life, from the view of each individual person, is needed. For the Strategy to be impactful, it is important that those working in schools are trained on how to set expectations that fit with the neurodiverse perspectives found in classrooms.

Parents also assert that the National Autism Strategy needs to be consistent with the findings of the Disability Services Commission Report. These two pieces of work undertaken by the federal government should be reviewed in unison, with the learnings from each process informing this National Strategy. Our research also led us to review the "National strategy for autistic children, young people and adults: 2021 to 2026" (UK)[i]. WACSSO encourages the Australian government to use this strategy as reference material if it is not already doing so. This UK strategy contains a wealth of well-considered, important information relevant to the Australian context.

[i] National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk)

2. How do you think the Strategy can support the rights, autonomy, and diversity of the Autistic community?

Our parents call for the Strategy to enable key outcomes: equity, safety and access. Combined with education and training, these three outcomes would improve the situation for those living with Autism and their families while also fulfilling the articulated need for a human rights approach to care and treatment.

The Strategy should consider how to encourage a 'benefits model' of contribution to society. This will require understanding and education across all public services. WACSSO also encourages the Strategy to consider how to enable parents and children to undertake life planning at an earlier stage, with this planning and the resources used to be informed by the voice of individuals, families and carers living with Autism. The government is also encouraged to investigate how to simplify, streamline and facilitate continued access to support services for parents once their Autistic child is over 18 years of age.

Parents of Autistic children shared their sense of loneliness and detachment from the community when they are navigating the school system. Parenting an Autistic child can be an isolating experience, and more needs to be done to facilitate networks for the parents and carers of Autistic children and the children themselves. For the children, establishing buddy systems that partner younger Autistic children with older ones might be productive. We also asked parents what their children would like from this Strategy. Some responses echoed the need for connection; the children want to be understood, feel cared for at school and often need support making and maintaining friendships. Much of this could be achieved with a broader community awareness campaign to boost understanding of this disability in the general population.

3. What needs to improve so Autistic people are better supported across their whole life?

In sharing their experiences with WACSSO, parents highlighted a need for integrated approaches to schooling, but with families having the option to choose a specialised school if appropriate. It is evident from the parents' testimony that integration is the goal for many. For this to occur, a better understanding of the disability is needed, as are particular resources (such as quiet spaces, engagement strategies, the ability to take breaks, sufficient Educational Assistants etc) as standard across the public school sector. Parents understand that good inclusive practice that supports students will require the upskilling of many teachers (for example, understanding of quality inclusive strategies). The mindset and culture of the school must also be one of inclusion, which in many cases will require a culture change. WACSSO asserts that an inclusive culture and approach will benefit both children with Autism as well as children more broadly across the diverse groups found in the community.

Parents also expressed a need for flexibility and adaptability in the education system. This approach is not only needed for teaching time but also for assessments and tracking students' progress. Adding emotional regulation to the curriculum for students was also suggested. This addition would benefit all students and could include content that allows students to understand how to build their own regulation, as well as understand the ability and capacity of others regarding self-regulation.

Parents have also emphasised that early intervention is essential. Clearer pathways for parents to access diagnosis, treatment and funding are also required. Support and collaboration are also key factors that will improve conditions for children and families. Parents also express that there is an incredible wealth of knowledge in the community and that speaking with those who have lived experience (as this submission process is doing) is essential to properly inform the Strategy.

WACSSO encourages co-designed, person-centred inclusive plans with services that reach across the lifespan. The current NDIS program is not inclusive of all life stages. One example is the education system – when children change providers or move from primary to high school, the process is unstable. A goal of this Strategy should be to remove barriers families and individuals face, thus facilitating success. Success could mean, for example, a smooth transition between schools and minimising harm and or setbacks for students.

4. What can be done to better support Autistic people from different population groups, including:

- First Nations Autistic people?
- Autistic people from culturally and linguistically diverse communities including those from multicultural, immigrant, and refugee backgrounds?
- · Autistic women and girls?
- Autistic people who identify as LGBTQIA+?
- Autistic infants, children, and young adults?
- Older Autistic people?
- Autistic people who also have an intellectual disability?

WACSSO encourages the government to create culturally appropriate resources and provide relevant, applicable education. The only path to supporting Autistic people from diverse populations is to collaborate with them directly and listen and respond to their needs and outcomes. It is vital to respect individuals' identity and beliefs to succeed in diverse populations. Additionally, taking the time to learn, accept and integrate cultural practices, embedding them into the Strategy, is essential.

5. What might help to improve people's understanding of Autism?

WACSSO believes advocacy programs, community education, inclusivity in schools and community programs, provision of support networks, and education for families will all boost understanding of Autism. We also suggest the focus be on sharing achievements (not deficits) and providing explicit education to those in public service positions would be beneficial. Communications that celebrate Autism should be favoured.

As mentioned above, training school staff is essential. Understanding and teaching neurodiverse students should be part of the curriculum in teacher education, with practical teaching experiences in this context offered. Professional development in the area of teaching neurodiverse children should be on-going and routine for all school staff.

6. Are there any areas missing from this discussion paper that should be a priority in the Strategy?

WACSSO understands that there is an Autism aware card (<u>Autism Alert Card</u>), provided by the Autism Association of Western Australia, which has a huge potential. Currently, however, it is not well known in the Autism community, plus it is often not recognised by public service personnel. A national card that is promoted, well understood and is supported by an education and awareness campaign would solve many communication issues and promote inclusion.

As a part of our research, we reviewed the UK Department of Health "Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy" and found this sentence from the Ministerial Forward to be particularly compelling: "Crucially, at its core, people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care support criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families."[ii] That the UK government has a specific Autism Act (the only condition-specific legislation in the UK) demonstrates the importance placed on ensuring the needs of the Autism community are appropriately met by government and its agencies. We applaud the UK government for taking this approach and encourage similar action in Australia.

[ii] Adult autism strategy: supporting its use - GOV.UK (www.gov.uk)

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