



WACSSO

Partnering with P&Cs to
advance public education

WACSSO SUBMISSION

Inquiry into support for autistic children and young people in schools

July 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 40 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, regional and remote 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 Inquiry. We thank the WA Education and Health Standing Committee for providing the opportunity to provide feedback on this topic. WACSSO has chosen to focus our response on item 2 of the Inquiry Terms of Reference.

We acknowledge that individuals impacted by this Inquiry 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 Inquiry and its Terms of Reference.

Item 2: Current support available for autistic students in WA schools

Our survey found that while all parents who responded had a child that needed support at school, only one-third reported that the support provided was adequate to meet the needs of their child. The overwhelming majority of respondents (nearly 90%) were not in an Autism specialist learning program at school, but 76% of respondents had an individual education plan (IEP) in place for their child. Of those with an IEP, this was consistently implemented in only 41% of cases. Further analysis of the responses from parents whose children were on an IEP showed that in many cases, the IEP was developed by the school initially (without parent consultation), and parents were asked to review and sign. Some parents also report never being given access to their child's IEP, despite asking multiple times to view it. WACSSO's position is that when an IEP is needed for a child with Autism, standardising the process of developing this document and including parents in the conversation is essential and would be of greatest benefit to the student's school experience and learning outcomes.

Along with more transparency regarding the IEPs in place for children, parents are calling for more transparency on how funding linked to their child is allocated. A number of parents reported that they were unsure how the funding allocated to the school to support their child was being distributed and that there were barriers in place for them to access this information. "There needs to be more accountability for the way the funding is used. Being told the school uses it how they feel is suitable but not able to explain how or on exactly what, or how many hours of support a child receives." (Parent voice, WACSSO survey 2023)

Uncertainty on the distribution of allocations for children with additional education support needs is a common concern raised with WACSSO. While it is understood that schools would need to keep certain information, such as salaries, confidential, WACSSO supports parents' requests to better understand how funding is allocated in their individual cases (for example, how many EA hours will be allocated to support their child). Transparency nurtures open and trusted partnerships, which ultimately allows for a better relationship between the school and parents, in turn meaning better outcomes for the child.

Regarding support services in place for these children, nearly 80% of respondents do not (or, more importantly, cannot) access them at school. In most cases, the only support available is that of an Educational Assistant (EA), and this resource is frequently stretched over multiple children. We acknowledge the availability of The School of Special Educational Needs: Disability (SSEND) resource; however, the issue is that this is accessible to schools, not parents, and many parents do not know it exists. Most parents have private arrangements in place for OT, psychologist, and speech therapy support. This in itself is a difficult situation, as many children experience extensive waiting periods to see private therapists. Regarding the connection between these external services and the school, the experiences are varied. Some parents report that the relationship is positive, with therapists permitted on school grounds, reports shared, and treatment plans consistently applied. Other parents report that schools are unwilling to adopt strategies recommended by therapists, and some do not allow external therapists on site. Given the percentage of students accessing external services provided, because of the limited services available in schools, WACSSO recommends that the Committee investigates schools adopting a streamlined and standardised connection between schools and providers.

Pleasingly, most parents report there is a high level of general communication in place between home and the school, which mostly takes the form of in-person meetings, phone and email conversations and connections achieved through technology and apps. Parents also report that schools are typically accommodating of the needs of individual children, and while they are limited with regard to resources, teachers will do their best to support each child. Many parents also spoke highly of the EAs in place for their children but, at the same time, articulated that there were not enough EAs at the school, pointing to the value of a qualified EA in the classroom.

WACSSO highlights the vital importance of EAs being trained to attend to the specific needs of children living with autism, especially where the EA allocation is directly related to the child. Lack of expert training, knowledge and skills can hinder learning and development and negatively impact that student's school experience. Some parents report a willingness for schools to change strategies when certain interventions are not working; adaptability which is essential as students grow and mature. In many cases, however, parents rely on teachers and principals with lived experience or significant experience working in this area to show a deeper understanding of the challenges children living with autism face.

"Teachers and, in general, people forget so easily that my autistic child has special needs because he does not look disabled. So, they assume that he is just a normal child. The second my child does something "out of the ordinary/autistic," people look at my child in a weird way, make comments or pull a face that tells me I am not raising my child properly (as in he is misbehaving in their eyes). I'm finding it very difficult, and I don't want to tell every single person about his condition but by not openly justifying his behaviour, most people don't "get it". (Parent voice, WACSSO survey 2023)

Clearly, whole-of-staff training is essential to create inclusive learning environments where best practice and continual improvement are embedded in professional development. Including training for students with special needs within the compulsory first aid training all teachers undertake could be an effective first step.

Linked with the feedback received on the need for education and professional development for school staff, many parents urged the Committee to ensure that they listen to the voices of those with lived experience when making decisions. Ideally, the Committee will include individuals who are themselves autistic or who have trodden the path of a parent/carer of an autistic child. It is very difficult to make recommendations and decisions on funding and support for these young people without inside knowledge of what it is like to live with or raise a child with autism. "You need to consult with and listen to autistic adults when making any decisions on the education of autistic children. Ensure any changes are neuro-affirming and are not intended in any way to turn a neurodivergent child into a neurotypical one." (Parent voice, WACSSO survey 2023).

Respondents to the WACSSO survey also expressed gratitude and positive feedback that this Inquiry was in progress, demonstrating that families are highly invested in finding solutions and improving practice so that all children and young people can thrive in our public schools "We have moved from school to school to find a place where our child feels comfortable and supported. I often worry about my child's self-esteem in the mainstream school environment due to some of the limitations and challenges related to his disability. It makes a big difference when a teacher is ASD-educated and is providing an inclusive environment for the child." (Parent voice, WACSSO survey 2023)

In summary, the support currently available for students living with autism in WA schools is not meeting the needs of those students or their parents. There is a lack of clarity and transparency around essential issues such as the allocation of funding and the content of IEPs, and much more training and development are needed for teachers and education assistants in schools to respond to the needs of these students. The types of services on-site at government schools (eg psychologists, speech therapists, OTs and so on) are very limited, meaning parents must engage private therapists. The waiting times for these therapists are excessive, and even when they are engaged, the relationship between the school and external providers is not always smooth. Lack of access to services and wait times is further exacerbated in regional, rural and remote areas.

“Children who are awaiting formal diagnosis need support too, especially when waitlists are 2+ years. More awareness about autism and ADHD with a focus on promoting an understanding of how the child's cognitive abilities differ from a neurotypical (NT) child. If they can understand the disorders, they'll be able to look beyond the "issues" and adapt the classrooms to cater for neurodiverse (ND) learners. Providing a curriculum and classroom that support kinaesthetic education and looks at the child holistically would enable both NT and ND children the same learning opportunities and would reduce the behavioural disruptions in the classroom and school environment.” (Parent voice, WACSSO survey 2023)

Many parents spoke of their experiences as being lonely, hard and incredibly frustrating. Parents want only the best for their children, echoing WACSSO's position that Western Australian schools should provide world-leading education to every student. This Inquiry is an important step to achieving much-needed improved outcomes for the autistic children enrolled in WA's public schools.

Other Relevant Information

WACSSO considers it vital that the voices of WA public school parents are heard. As such, the below series of comments summarises the responses we received to the question 'What do you think the Committee needs to know about the lived experience of a parent raising an autistic child who attends a WA government school?' It is our hope that the Committee will take the time to review these comments and use them to inform decisions flowing from this Inquiry.

“How hard it is and lonely. There is no inclusivity and if you don't have an autistic child then the other parents just don't get it.”

“Teachers need more training. My experience is that most teachers have a very limited understanding of autism and got most of their understanding from me.”

“It is a very rigid system. Generally, staff are not well trained or have enough knowledge of what is the best way.”

“Government schools need to be supported in having the resources to provide smaller classes, training in mental health first aid and full-time child psychologist onsite and that person being an active presence to support teachers, children and their families.”

"I am very lucky. The current teacher is very understanding and accepting of my child's differences. I wish all teachers were better educated on Neurodiversity. Kids don't need to sit still and make eye contact. Some kids need to fidget, and it is actually painful for them to make eye contact."

"Schools need to listen parents and external providers. EAs need to be trained better on how to deal with Autistic children. There needs to be a better understanding of "masking". Use the resources available to the school when required and not wait until the situation becomes extreme; be proactive, not reactive."

"Parents need support as well as kids need support."

"I think the Committee needs to be made up of parents who have children with autism not just professionals. I think they know what it is and have no idea about living with children with it."
"There is absolutely no school that provides the smaller class sizes and teacher-student ratio and the educational needs of my child. My child does not have an intellectual disability, so Ed Support does not support him academically, and mainstream does not support his environment. Speech-Language Pathologists (SLPs) are a waste of time because they are still in a mainstream environment. The student still has the same sensory overload from the environment that leaves them too overwhelmed to participate in the required work."

"More assistance and observation are required for high-masking autistic individuals to make sure they get the level of help required."

"There needs to be more training for teachers to understand autism and ADHD. If there was more understanding, there would be more support, and from there, our kids wouldn't get pushed to the back and forgotten about."

"Fighting for services. Would highly recommend school-provided OT/Speechie services that can work closely with the school."

"More allowances and ease of having external providers provide services during school hours. We are paying for the services, but I feel it's limited in what we can do at school. The risk of not doing it at school is the teacher and therapist can't work together and where services can't be found outside of school hours the child loses more time away from school in the commute."

"Parents need to be strong advocates for their children and need a high level of education to navigate the system, as well as the financial means to get a diagnosis in the first place. None of my child's teachers suggested to us that he might be autistic - we had to actively push through an expensive and hard-to-enter system in order to get a diagnosis. Once we had a diagnosis, the school happily talked to us and put an IEP in place, but I've got no idea what's in it. They applied for EA funding, but again we don't know how much EA time he gets or what they do to help him. We're fortunate to attend a highly socio-economically advantaged school that has more resources available than many other public schools, but the school is still limited in what supports it can provide. It seems to me that the lack of a coordinated approach to link the school with my son's external support providers (speech therapist, psychologist) is a lost opportunity to make sure they're all working collaboratively to maximise the outcomes for my child."

"Specialised training in Autism and regular training."

"That autistic children can mask very well, and just because you are not witness to all sides of autism does not mean it is not there. When a family member explains to you, do not tell them it is parenting or that the child is "stubborn." Every child who is autistic is very different, and the family knows the child better than the rest. The family see the after-school meltdowns from a hard day that can be violent. Schools need professionals that are trained to work with autistic children and fully understand the ways in which they learn. Teachers are not trained for this."

"That it's hard, and the children with Autism need the support they need and are allocated, not what the school thinks they need."

"How frustrating it is to get help, to maintain help and to communicate with the school."
"More access to specialised learning programmes and awareness of ASD."

"We should be able to celebrate our children's wins without the fear of support through funding being pulled. Wins happen because of the support. More SLP' s are needed."

"Funding is appalling. Training is not adequate. Spaces designed for sensory processing issues are non-existent. Support designed for the parents and child should be more available and EARLY in the process, not brushed off by heads of school."

"Raising an ASD child is a difficult, lonely experience. We need support with our child entering Kindergarten in particular. Often there are no supports in place, eg no EA time, as it is not compulsory. The Early Intervention funding from WANSLEA does not transfer over into the Education Department, nor is it recognised. Also, there needs to be more support so that these students are not constantly going home or being suspended. Maybe some other way of tracking behaviours in order to get funding. Often parents are not able to remain employed when this is the case. For some students, it creates a learnt behaviour of if I do this behaviour, I leave school."

"It's very confusing at the start and you feel helpless. For some reason, once you have paid a few thousand dollars privately (the public waitlist is too long, my son would have been 13 before we could get an assessment! That's his entire primary education out the window, once he missed those building blocks for education, what hope did he have in high school) for a piece of paper, your world changes, and you can access the services you need to integrate your child into the world. But it's the early intervention that will not only change a child's entire life but also be the most cost and resource effective in the long run. It will also yield the best result for individuals, families, schools and the education system. In under a year of intensive PBS support, no one knows my son is autistic. He doesn't embarrass himself in a small community, and he finally has a solid group of friends for the first time in his life. I can contribute to society by working more instead of taking my son to multiple therapy appointments that span out over years, and these services can help other young kids who get added to the waitlist at a young age and will benefit from early intervention."

"Ask for advice from the parent and learn about the child's history and experiences. Look at the holes in the school system because there are a lot."

"The schools need to be aware of adolescents that are flailing in high school. In our experience - a high-achieving perfectionist who became lonelier and more anxious as each day she struggled to understand the social norms, her anxiety rising as her self-worth plummeted. Eating her lunch in the toilets. Sad. Lonely. Unable to speak. Tremulous (other kids noticed, didn't the teachers?). Suicidal. If only someone had noticed and cared enough to tell us how isolated and withdrawn she was. After the ASD diagnosis. She needed mentoring. She needed a safe place. Needed understanding and compassion. Needed staff who understood her neurodivergence, her rigidity, her social anxiety, her desire for friendship, her inability to process humour. Without a friend, she had no one to translate these things to her."

"That the funding the parents fight to get for their child really isn't utilised well and in the long run, these students are not gaining any education, emotional support, knowledge or life skills."
"As the ASD diagnosis grows in number, every teacher should have some basic training to deal with Autistic kids, especially non-verbal children."

"It is a nightmare, our children cannot help how they were born, they have a hard road to travel, find adulthood a struggle in many areas and, regardless of their academic ability, most often struggle with executive function."

"Funding and resources in regional government schools need to be increased to ensure children and teenagers in regional WA with ASD are given the necessary support in their educational programs. Would be fantastic to have more support programs and strategies for preparing year 12 students with ASD for the transition into adulthood in a regional setting. Working together with families to develop a meaningful plan."

"Need levels change depending on what is going on in the child's and family life."
"It's hard - the education system is too rigid & doesn't make accommodations for neurodiverse children or those who don't quite fit the mould."

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