

Inquiry into support for Autistic children and young people in schools

ENQUIRIES
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Introduction

La Trobe University's Olga Tennison Autism Research Centre (OTARC) welcomes the invitation from the Education and Health Standing Committee to provide a submission to the inquiry into support for Autistic¹ children and young people in schools in Western Australia (WA). Established in 2008, OTARC was the first dedicated Autism research centre in Australia. Its internationally recognised Autism research is making an impact not just in Australia but also globally.

At OTARC, our research aligns with United Nations Sustainable Development Goals², to optimise impact for the Autistic and Autism community through industry collaborations, public accountability, community engagement and using local paths to global change. Our research encompasses four research program areas; educational and vocational engagement, identification and diagnosis, supports and practices for daily living, and health and wellbeing. Our vision is for a world where Autistic people, their families and their carers thrive.

OTARC research aims to support Autistic people to realise their full potential, actively participate in the community, education, and employment, find enjoyment in life, and make meaningful contributions throughout their lives based on their goals.

The focus of this submission is to provide evidence-based, community informed recommendations that will benefit young Autistic Australians attending school in Western Australia. In making these recommendations we will be drawing on evidence from our research in the following areas:

- **Autism Prevalence**
OTARC has conducted four studies relevant to the prevalence of Autism in Australia demonstrating variation in prevalence over time and across states, highlighting a likely lack of diagnostic services and expertise, particularly in rural, regional, and remote areas.
- **Transition pathways of Autistic students**
We research supports and services required by Autistic youth for transitioning to and succeeding in tertiary education and/or employment. The evidence cited in this submission draws on the results of the SASLA study (Study of Australian School Leavers with Autism, 2014-2021) funded by the Autism Cooperative Research Centre.
- **Development of effective and valid strategies and tools to facilitate identification and diagnosis of Autism in children under 3 years**
Studies in this area led to the successful development of an early identification tool (SACS-R), the creation of a free early identification app (ASDetect) for parents and an ambitious Department of Health and Human Services project to train all Victorian Maternal and Child Health nurses (1750) to monitor the early signs of Autism.
- **Supports for improving school-age outcomes for Autistic students**
The impacts of early identification and supports on school age outcomes are significant, including in-school supports for self-regulation and strategies to accommodate sensory difference in classrooms.

¹ Our research shows that many people with lived experience of Autism prefer the use of identity-first rather than person-first language (Bury et al., 2020; Kenny et al., 2016). We acknowledge that some people with a diagnosis of Autism prefer person-first language. Where it is practical, we use an individual's preferred language.

² <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>; Goals relevant to this submission - 3. Good health and wellbeing, 4. Quality education and 10. Reduced inequalities

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Summary of Recommendations

1. Develop a State Autism Plan and accompanying implementation strategy within the next 12 months to drive state-coordinated action to improve services and supports for Autistic Western Australians. The plan should include a section on education that:
 - 1.1. is both student- and family-centred;
 - 1.2. addresses the needs of Autistic students from early childhood education through to tertiary education and vocational engagement;
 - 1.3. addresses the rights of Autistic students to enrol and participate in mainstream schools on the same basis as other students;
 - 1.4. aligns with other national strategies, including the National Disability Strategy and the National Autism Strategy (currently under development);
 - 1.5. is informed by the recommendations of this inquiry, the inquiry into the Services, support and life outcomes for Autistic Australians and the Disability Royal Commission;
 - 1.6. has a process by which the implementation of the plan is monitored and reported on annually;
 - 1.7. identifies actions to drive better integration between federal and state education service systems, including a roadmap to better integrate the National Disability Insurance Scheme (NDIS) and mainstream services;
 - 1.8. provides funded reasonable and adequate supports in schools in the state budget that complement reasonable and justified supports funded under the National Disability Insurance Scheme (NDIS).

**Please note: the recommendations in the body of the submission begin at number 2, as the above text comprises the totality of content for recommendation 1.*

TOR 1 - THE PREVALENCE OF AUTISM IN WA AND PROJECTED DEMAND FOR SUPPORT IN SCHOOLS

2. Provide funding for a comprehensive epidemiological study into the prevalence of Autism or Autism likelihood in children under 6 years of age in Western Australia to enable equitable provision of appropriate diagnosis and support services for Autistic people and their families before and during schooling. There is potential for OTARC to contribute expertise to this project, subject to supplementary funding becoming available.

TOR 2 - CURRENT SUPPORT AVAILABLE FOR AUTISTIC STUDENTS IN WA SCHOOLS

3. Strengthen timely transition supports for Autistic students into secondary school through comprehensive consultation with Autistic students, their families and education, health and care professionals targeting:
 - 3.1. accessibility and equitable access to transition supports for Autistic students;
 - 3.2. acceptability and suitability of supports for Autistic students with an intellectual disability.

TOR 3 - STRATEGIES IN OTHER JURISDICTIONS THAT SUPPORT SCHOOL SYSTEMS TO RESPOND TO THE NEEDS OF AUTISTIC STUDENTS, AND THE APPLICABILITY OF THOSE STRATEGIES TO WA

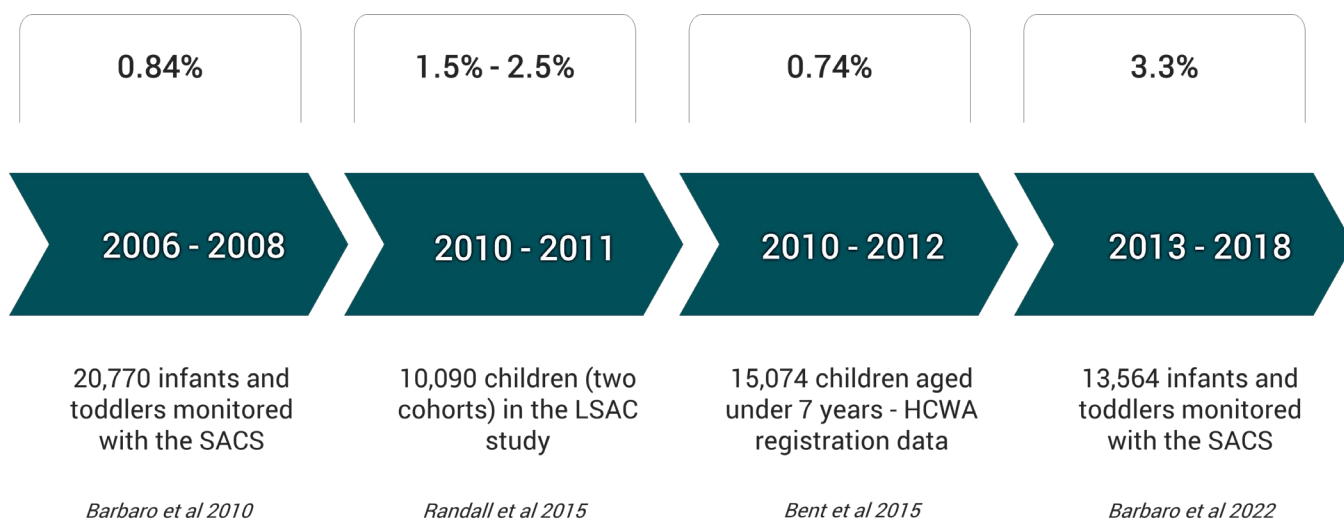
4. Ensure the State Government provides:
 - 4.1. improved access to evidence-based, inclusive and supportive early education for Autistic children in both specialist and inclusive settings; for example a state rollout of the Alert Program®;
 - 4.2. funds and resources to train early childhood education, health, and care professionals in the developmental monitoring of all children for Autism.
 - 4.3. Support for children and families requiring further assistance to obtain a referral for diagnosis using the Social Attention and Communications Surveillance (SACS) screening method.

These are universally applicable to varied early care and education settings and easily adaptable to local context (through co-development and thorough evaluation).

1. The prevalence of Autism in WA and projected demand for support in schools

OTARC has conducted four studies relevant to the prevalence of Autism in Australia (See Figure 1). Two studies used the Social Attention and Communication Surveillance (SACS) method to identify Autism prospectively in infants, toddlers, and pre-schoolers^{3,4}, the third used data from the Longitudinal Study of Australian Children (LSAC)⁵, and the fourth used HCWA (Helping Children with Autism) registration data⁶. The HCWA registration data (2010-2012) showed that prevalence varies dramatically across states and territories, ranging from 0.97% in Victoria to 0.46% and 0.34% in Western Australia (WA) and the Northern Territory, respectively. The low percentages in WA and NT may indicate the need for more identification services in their relatively large rural and regional areas. In addition, a Western Australia-specific study⁷ drawing data from the WA Birth Register and Intellectual Disability Exploring Answers (IDEA) database through the Disability Services Commission and the Education Department of WA found a prevalence of Autism with a co-occurring intellectual disability of 0.38% from 1980-1997. This rose to 0.51% from 1997-2010. The variation in prevalence estimates across studies highlights the likely lack of diagnostic services and expertise, particularly in rural, regional, and remote areas, and the need for a more comprehensive epidemiological study into Autism prevalence across Western Australia, preferably in partnership with other Australian jurisdictions.

Figure 1
OTARC studies of Autism prevalence in Australia



³ Barbaro et al (2010)
⁴ Barbaro et al (2022)
⁵ Randall et al (2016)
⁶ Bent et al (2015)
⁷ Abdullahi et al (2019)

Recommendation 2: Provide funding for a comprehensive epidemiological study into the prevalence of Autism or Autism likelihood in children under 6 years of age in Western Australia to enable equitable provision of appropriate diagnosis and support services for Autistic people and their families before and during schooling. There is potential for OTARC to contribute expertise to this project, subject to supplementary funding becoming available.

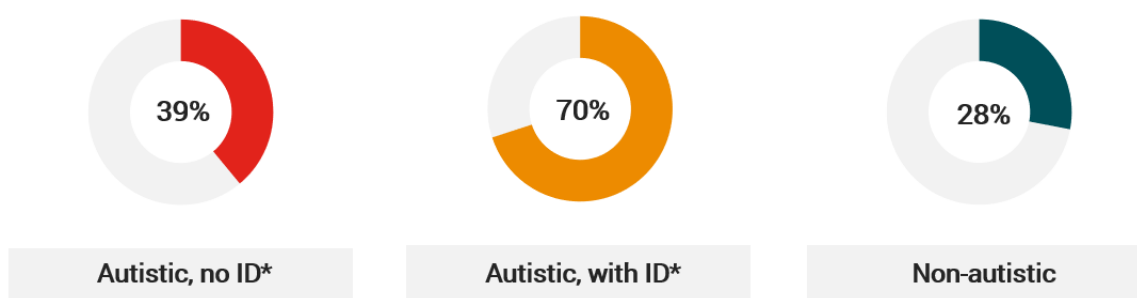
2. Current support available for Autistic students in WA schools

ADEQUACY OF CURRENT SUPPORTS FOR TRANSITIONING FROM SECONDARY SCHOOLING

Transition supports and services are vital in empowering students as they prepare to leave school and embark on their next phase of life. These supports and services should provide essential guidance, resources, and skills development to ensure a smooth and successful transition into higher education, vocational training, employment, and independent living, setting a strong foundation for future endeavours. We surveyed Australian Autistic youth (aged 15-25 years) with and without a co-occurring intellectual disability (ID) and non-Autistic youth about the supports they had received (Figure 2) and their satisfaction with these supports⁸.

Figure 2

Transition supports received by group



We found that:

- Autistic students with ID are the most likely to receive transition support but are the least satisfied with these supports (43%).

⁸ Richdale et al. (2021); * intellectual disability

- Autistic students without ID and non-autistic students received similar amounts of transition support but less than Autistic students with ID. Autistic youth were relatively satisfied with the support received (71-77%).
- Most participants from all groups (> 60%) would have liked to have more supports available.

These figures suggest a shortfall in the provision or availability of transition supports, especially for Autistic students without an ID. Additionally, the supports available to Autistic students with ID appear unsuitable, emphasising the importance of promptly addressing this issue and providing tailored assistance to meet their unique requirements.

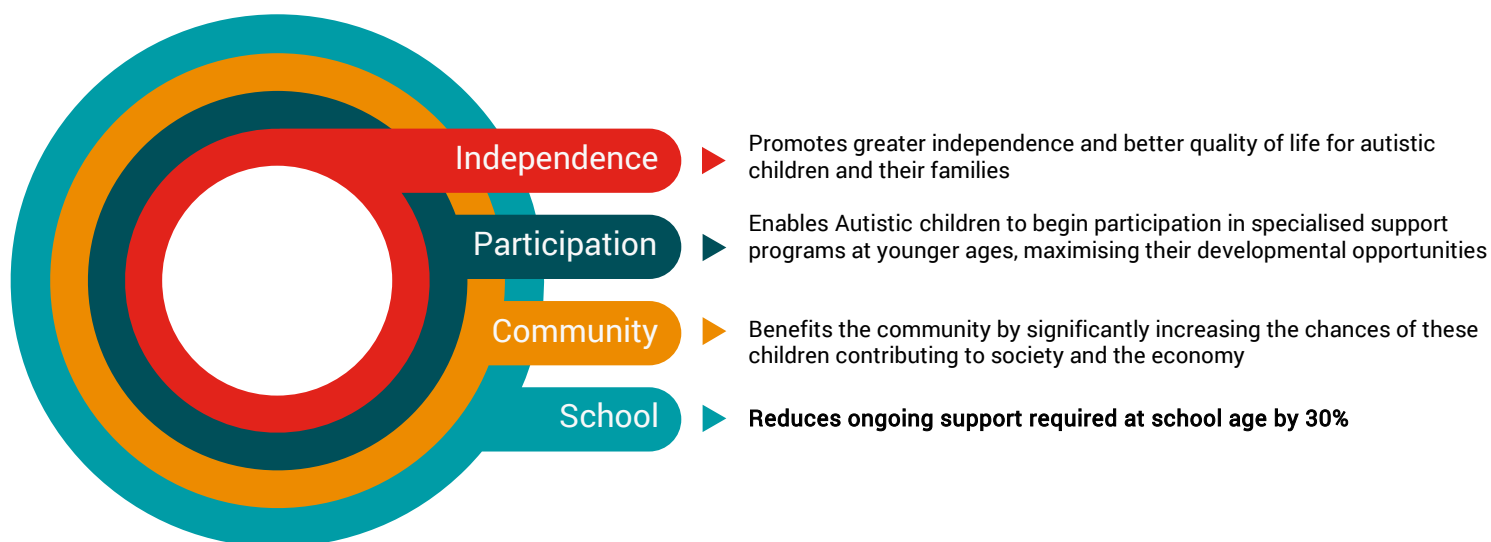
Recommendation 3: Strengthen timely transition supports for Autistic students into secondary school through comprehensive consultation with Autistic students, their families and education, health and care professionals targeting:

- 3.1. accessibility and equitable access to transition supports for Autistic students;
- 3.2. acceptability and suitability of supports for Autistic students with an intellectual disability.

3. Strategies in other jurisdictions that support school systems to respond to the needs of Autistic students, and the applicability of those strategies to WA

Autism can have significant impacts on learning, communication, and behaviour. Many children will meet criteria for multiple diagnoses and be susceptible to poor mental health during their school years and beyond, reducing their own and their family’s wellbeing across the lifespan. Therefore, an early diagnosis, not only of Autism but of co-occurring conditions such as intellectual disability, attention-deficit/hyperactivity disorder, sleep difficulties, and mental health conditions, must be a priority for any government aiming to enable Autistic students to realise their full potential at school by facilitating active participation in education.

What can an early Autism diagnosis mean for the child, family and community? ⁹



⁹ Buescher et al (2014), Clark et al (2017), Clark et al (2018)



Improving the developmental outcomes of Autistic children in Australia and across the world through access to evidence-based, supportive early education and care

OTARC has an embedded research-in-practice program at the La Trobe University Community Children's Centre on its Melbourne campus¹⁰. Approximately 50 children participate daily in an evidence-based early support program called the Early Start Denver Model (ESDM).

More than 300 Autistic children have attended the Centre since it opened in 2010. The findings from research undertaken within the Centre are incorporated into a cycle of continuous evidence-based improvement and were pivotal in the development and implementation of the Early Start Denver Model (ESDM) in inclusive (mainstream early education) and specialised (Autistic children only) settings. A group version of the EDSM (G-EDSM) was developed within the Centre and has been adopted worldwide, including programs in the following services:

Gowrie Early Learning Centre



Every Child-US



Our research shows that Autistic children who receive ESDM supports embedded in childcare for one year make significant developmental gains across a variety of early learning and care settings, increasing their chances of participation¹¹, with an earlier age of access bolstering their outcomes¹². Importantly, our research shows these children continue to make significant cognitive gains into their school years,¹³ a finding we have recently replicated in new (as yet unpublished) research.

¹⁰ <https://www.latrobe.edu.au/otarc/margot-prior-autism-intervention-centre>

¹¹ Clark et al (2017; 2018)

¹² Vivanti et al. (2016)

¹³ Vinen et al (2018; 2022); Clark et al. (2023)

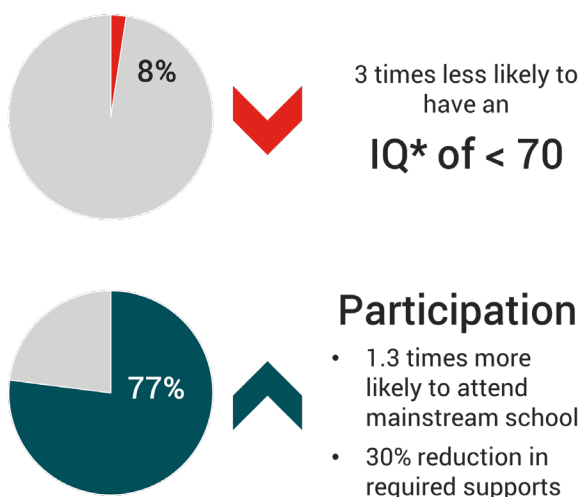
We have also charted the behavioural and cognitive profiles from toddlerhood to middle childhood in 48 Australian children who received an Autism diagnosis before they turned 2 years old¹⁴: We found that children diagnosed by 2 years of age, compare to those diagnosed between 3- to 5-years-old were:

- **3 times less likely** to have an IQ < 70 and,
- **1.3 times more likely** to be in a mainstream school (Figure 2).

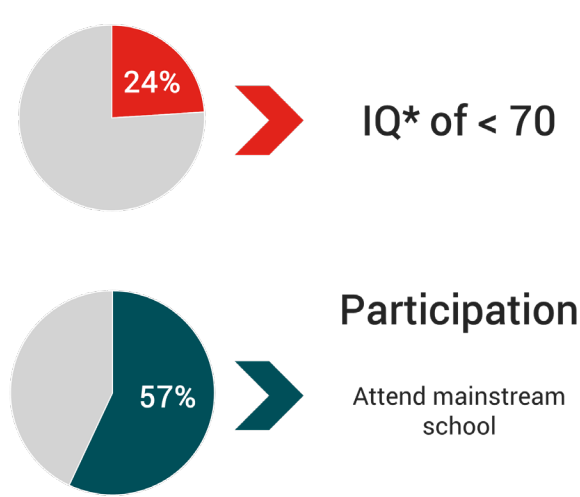
Figure 2

School age outcomes for Australian Autistic children

Autism Diagnosis received before 2 years



Autism Diagnosis received between 3-5 years



**Intelligence Quotient*

Australian children who receive an Autism diagnosis and subsequent supports in the early and critical years (18-36 months) have better school-age developmental outcomes. And yet, the average age of Autism diagnosis in children remains at about 4 years¹⁵ in Australia.

Access to evidence-based, supportive early childhood education is crucial to addressing inequalities experienced by Autistic children throughout their schooling.

¹⁴ Clark et al (2017), Clark et al (2018)

¹⁵ Bent et al (2015)

PROFESSIONAL TRAINING

Earlier diagnosis of Autism is possible by training professionals to identify the early signs of Autism as part of routine interactions families have with health, education, and care professionals through services such as the Child and Adolescent Health Service (CAHS) – Community Child Health and early childhood education and care.

OTARC research has revolutionised how professionals are trained to screen for Autism in very young children. The Social Attention and Communication Surveillance (SACS) studies are the foundation of the SACS-R (11 to 30 months old) and SACS-Preschool (3.5 to 5 years old) training programs. The SACS method identifies a set of behaviours or 'early markers' that are characteristic of children on the Autism spectrum, from as young as 12 months old. 82% of babies who show early behavioural signs of Autism at 12, 18 and 24 months using the SACS go on to be diagnosed with Autism¹⁶.

The SACS-R IS THE MOST ACCURATE TOOL FOR EARLY AUTISM DETECTION IN THE WORLD.



Transforming Autism Care in Victoria: Improving accessibility and early supports

In 2018, OTARC successfully tendered to train all maternal and child health (MCH) nurses in Victoria using the SACS to improve access to Autism assessment, diagnosis, and early supports. This training was a commitment in the Victorian Autism Plan¹⁷ funded by the (then) Department of Education and Training. OTARC has trained all (~1700) Victorian MCH nurses in identifying the early signs of Autism, with over 90% agreeing that the training was clear of high quality, and most would recommend it to a colleague¹⁸. Post training, MCH nurses effectively incorporated SACS-R assessments into their work practice, completing 82,581 assessments in the first 6 months.

An essential component of the program's success was the creation and distribution of the parent resource booklet "Promoting Social Attention, Communication, and Interaction Skills"¹⁹. Over 40,000 copies have been distributed to all MCH centres across Victoria since September 2019, ensuring every family visiting their MCH centres receives a copy. This has contributed to capacity-building in parents, opened dialogue between parents, MCH nurses, and medical practitioners, and empowered families to actively participate in their child's developmental journey.

The ongoing impact of these initiatives has been significant. As a result of the training program, all Victorian children now receive comprehensive monitoring for early behavioural signs of Autism during their routine universal child health visits. This proactive approach identifies developmental concerns early, leading to quicker diagnoses and targeted, timely supports. The Victorian rollout has drawn attention to the importance of developmental monitoring at a national level. The Federal Standing Select Committee on Autism recommended that this training be rolled out nationally in 2022²⁰.

¹⁶ Barbaro et al (2022)

¹⁷ Victorian State Government (2019)

¹⁸ Gilbert et al (2023)

¹⁹ Department of Health (2019)

²⁰ Commonwealth of Australia (2022)





ASDetect

Following the success of SACS, we worked to enable parents to identify potential signs of Autism in their children with the touch of a button. With over 100,000 downloads since its launch in February 2016, ASDetect is empowering parents and caregivers around the world. ASDetect is now available in English, Mandarin Chinese, Slovak and Spanish.

ASDetect is a free mobile app based on the SACS method. The app guides parents through age-appropriate assessments, using videos of Autistic and non-Autistic children to illustrate questions about social communication milestones. Parents receive an on-screen result of either a 'low' or 'high' likelihood of Autism, and a detailed results email, which they can take to their family doctor. This integration between the app and healthcare professionals ensures that caregivers receive the support and guidance necessary to make informed decisions about their child's care.



The Federal Select Committee on Autism recommended the promotion of the use of ASDetect by parents/ caregivers, health professionals and educators in 2022²¹.

²¹ Commonwealth of Australia (2022)

INITIATIVES IMPROVING EDUCATION EXPERIENCE FOR AUTISTIC STUDENTS

It is important to develop and evaluate evidence-based practices and supports that facilitate inclusive and accessible education for Autistic students and to support learning in their natural environments. Two programs are described below that we use to address; (1) self-regulation, and (2) sensory challenges experienced by Autistic children.

1. Fostering self-regulation in children

Self-regulation²² is a foundational contributor to learning, being linked to long- and short-term outcomes for behaviour and academic achievement in children, relating to²³:

- levels of achievement (literacy, numeracy, vocabulary)
- interpersonal behaviours (aggressiveness, peer victimisation)
- mental health (internalising and externalising behaviours)
- overall healthy living in childhood

For some children, difficulties with self-regulation may contribute to absenteeism and school refusal in primary school, a key issue which has been found to predict educational and socio-emotional outcomes throughout adolescence and early adulthood²⁴.

The Alert Program[®] teaches children to identify their own 'alert' states using the analogy of a car engine - too fast, just right or too slow - and to modify those 'alert' states using sensory and movement tools depending on what is needed to support their learning at school. We have trained OTs, teachers, and OT students to co-teach the Alert Program[®] over one school term via a single weekly 45-minute session in the classroom.

²² Refers to the broader concept of managing one's thoughts, behaviors, and emotions in order to achieve personal goals and adapt to different situations e.g. impulse control, self-discipline, and managing one's attention and motivation

²³ E.g. Allan et al. (2014); McClelland & Cameron, (2011); McClelland et al. (2007); McClelland & Wanless, (2012); Rimm-Kaufman et al. (2009); Robson et al. (2020); Smithers et al. (2018)

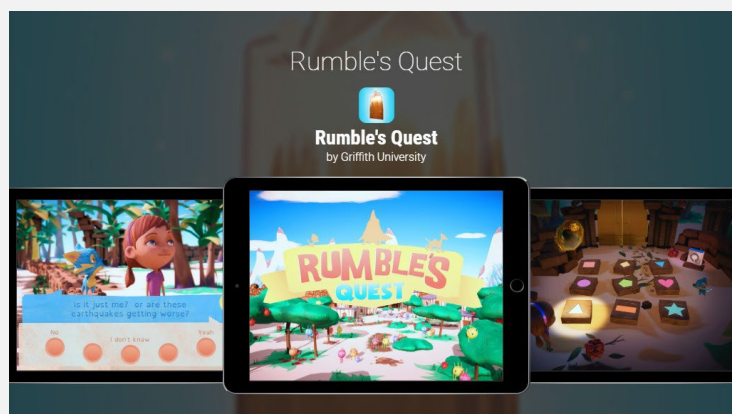
²⁴ Ansari & Pianta, (2019); Smerillo et al. (2018).



The Alert Program[®]: A 2023 trial in Victorian primary schools²⁵

We trialled a new method of collaboration between occupational therapists (OT) and teachers - The Alert Program[®] - in two regional primary schools in Bendigo (St Peter's and Kallianna), to support the wellbeing of Victorian school children in regional and rural settings.

We measured its impact on students and wellbeing using an innovative game-based tool called Rumble's Quest²⁶. It allows students to answer questions about their wellbeing while playing a fun, quest-based video game.



This was the first time the classroom approach was formally evaluated. Our data show that at least 30% of students attending the two schools demonstrated wellbeing concerns before the commencement of the program. Preliminary findings suggest that the program improved students' executive function, which underpins their ability to self-regulate and optimises engagement with learning. Success at school is likely to improve the wellbeing of all students but particularly vulnerable learners, including Autistic students and those with trauma backgrounds. Future iterations will be evaluated for the acceptability and efficacy of the program from teachers' points of view.

2. Inclusive educational practice for students with sensory needs

Sensory differences are a core diagnostic criterion for Autism Spectrum Disorder²⁷. Autistic students may encounter challenges in interpreting and organising sensory input from their visual, gustatory, tactile, auditory, and olfactory senses, resulting in sensory perceptions that may be perceived as frightening or even painful, triggering heightened anxiety and distress behaviours.

These sensitivities can significantly impact daily life, contributing to difficulties with sensory processing and creating unique sensory preferences or aversions. It is crucial to have inclusive

²⁵ Lane, AE, et al. (unpublished data)

²⁶ <https://www.realwell.org.au/rumbles-quest/>

²⁷ American Psychiatric Association (2013)

learning environments, including reasonable adjustments and tailored teaching strategies to support Autistic students' full participation in their education.



Breaking barriers in education: The SENSIBLE approach for Accessible Learning

As a result of a 2022 project commissioned by the Queensland Department of Education, OTARC Director Professor Alison Lane and colleagues delivered a Rapid Evidence Assessment (REA) of the literature about sensory processing challenges in school settings²⁸. This review assessed the evidence for various interventions, including weighted vests, alternate seating, classroom amplification systems and multisensory environments and provided recommendations for their use.

The findings from this review were incorporated into developing training and resources for teachers and learning support staff, specialist advisors, occupational therapists, physiotherapists, principals and teacher's aides. The findings of focus groups with school staff indicated a need for more knowledge amongst teachers in mainstream schools about how sensory processing challenges may impact student behaviour and learning. Further, decisions regarding the strategies used by school staff to address these challenges were not always grounded in evidence²⁹.

The suite of resources includes a flow-chart-style poster to guide decision-making regarding sensory needs, two webpages explaining sensory issues, and explaining inclusive education principles, all linked to the Department resources, together with a manual setting out the overall approach.

These materials were developed using a practical framework comprising five decision-making phases, called "a **SENSIBLE** approach: **SENS**ory-Informed **B**est practices for **LE**arning". This framework assists school staff in implementing strategies that facilitate inclusive access, active participation, and academic success for all students, regardless of their sensory processing challenges. It also encourages integrating evidence-informed practices and inclusive education principles when creating learning opportunities that accommodate sensory variations.

This approach is unique because it is designed for education teams within schools rather than focusing solely on classroom teachers. The SENSIBLE approach is currently being rolled out in Queensland government schools, with evaluations of its impact planned.

²⁸ Unwin et al. (2022)

²⁹ Lane & Leonard (2023)

Recommendation 3: Ensure that the State Government provides:

4.1. improved access to evidence-based, inclusive and supportive early education for Autistic children in both specialist and inclusive settings; for example a state rollout of the Alert Program®;

4.2. funds and resources to train early childhood education, health, and care professionals in the developmental monitoring of all children for Autism.

4.3. Support for children and families requiring further assistance to obtain a referral for diagnosis using the Social Attention and Communications Surveillance (SACS) screening method.

These are universally applicable to varied early care and education settings and easily adaptable to local context (through co-development and thorough evaluation).

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