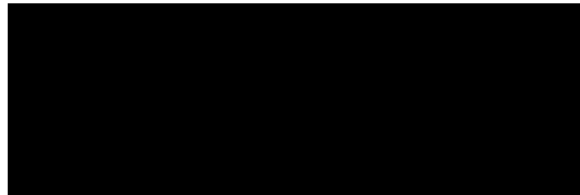


**AEIOU Submission: National Autism Strategy
consultation, October 2023**



Introduction

AEIOU Foundation welcomes the opportunity to provide a submission to this round of consultation for the National Autism Strategy. We strongly support the strategy's aim of providing a coordinated national approach to services and supports for Autistic Australians and their families.

AEIOU appreciates the efforts made to engage directly with those who have lived experience of autism, with consultation activities specifically designed for Autistic Australians and their families and carers. We also welcome the establishment of the National Autism Strategy Oversight Council, which includes people from the autistic community and sector members. However, there is a substantial gap in representatives advocating for the lived experience and needs of autistic children experiencing isolation and exclusion prior to school-age. Our submission draws on AEIOU Foundation's vast expertise and experience in the field of autism-specific early intervention for children with high support needs.

AEIOU appreciates any future opportunities for collaboration and consultation and looks forward to sharing relevant research and data on young children and families to support effective practices and policies for this group.

About AEIOU Foundation

AEIOU Foundation is Australia's leading provider of autism-specific early intervention for children under six years of age. Operating 11 centres across regional and southeast Queensland, South Australia, and the ACT, AEIOU supports around 300 children each year. For more than 18 years, AEIOU has supported and equipped thousands of children to develop the foundational life skills required to independently increase their social, educational, and economic participation in the community.

An expert transdisciplinary team of clinicians and educators work together to support the children. Working with the family, they share the responsibility of assessing, planning, delivering, and evaluating each child's individual plan. Teams are comprised of speech pathologists, occupational therapists, behaviour analysts, teachers, early childhood educators, early intervention specialists and allied health assistants.

The service integrates therapy, an education curriculum that meets the Early Years Learning Framework (EYLF), an approved kindergarten program, and care in a holistic, naturalistic setting. Children who typically experience exclusion and isolation from mainstream settings in an inclusive and supportive manner are engaged to actively participate in both therapy and EYLF and are supported to achieve their individual goals at AEIOU.

Our mission is to enhance the lives of children with autism and their families, through evidence-based, successful early intervention programs and practical support.

We believe children:

- Have a right to early intervention
- Benefit from therapy based on individual needs
- Learn using different learning styles and at different rates
- Are individuals, with differing personalities, needs, wants, interests, and levels of ability
- Require flexible routines in their daily program to cater for their individual needs
- Should receive evidence-based early intervention and access to appropriate assessment

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- Are entitled to a balanced program that bridges the gap between the home, AEIOU Foundation and the community
- And can benefit from families and staff working together

Families also have a right to support other members of the family unit and to work and participate in the community.

Key recommendations

This submission emphasises the importance of choice and control for autistic people and their families. This means that autistic people should have the right to choose the services and supports that work best for them, including those that are behavior science based.

Specific recommendations made in the submission include:

- To establish a smart self-assessment tool to support employers and businesses to build inclusive workplaces.
- Link a public awareness campaign to diversity/neurodiversity learning curriculum into the national curriculum for primary and secondary schools.
- Build in autism knowledge requirements to core subjects for degrees in allied health professions, teaching, social work, and health. Require teachers to rotate in an inclusive or specialist setting.
- Provide more funding for autism-specific programs and services and increase access to early intervention services.
- Promote quality inclusion in mainstream schools while also supporting the choices of autistic people and their families by ensuring access to a range of educational settings, including specialist education settings.
- Ensure open access to fairly represented and easily digestible information in multiple modes to enable individuals to make informed decisions for themselves.
- Regulate and require ongoing professional development for related professions, especially in the behaviour support sector.
- Ensure appropriate service availability and ensure service providers are trained in supporting autistic individuals.
- Creating a cyclical roadmap to collect data to measure an individual's difficulties, provide individualised targeted treatments, and measuring the outcomes of the intervention to ensure it is effective. Regular monitoring of outcomes in this manner would identify ineffective treatments sooner, allowing them to be adjusted in a timely way.

Statement on language

AEIOU acknowledges that people use different words to talk about autism, and that each person will have a way of talking about autism and about themselves that they like best. Some people like to say 'autistic person' (identity-first language), some like to say 'person with autism' (person-first language), and some are fine with using either.

For consistency, we will use identity-first language in this submission.

Key Discussion questions

The need for a National Autism Strategy is evident; there are a growing number of Australians on the autism spectrum, and for many autistic people, life outcomes in education, vocation, health, and family functioning are worse than they should be. To better support Autistic Australians and their families, we need a national plan that coordinates the services and supports they require. This is an urgent and important goal to enhance these life outcomes.

When devising a national strategy, it is important to recognise the diversity of experiences of autistic people. There is a great deal of debate about what constitutes the "right" approach to autistic supports and inclusions. These views are not consistent across the autistic community, and therefore any strategy must ensure that individuals have a choice and control over how they are supported. At the same time, we must hold expectations for change in standard community settings that will benefit all people, such as by improving autism awareness and education in community and health services.

To ensure autistic people are better supported for their whole life, it is essential that the strategy improves accessibility to:

- early diagnosis and intervention supports
- inclusive education and employment
- accessible mental health services
- support for autistic people to self-advocate and be decision-makers in their own lives

Improvements could be made in the education sector to lift the level of autism knowledge, understanding, and support for autistic students. Similarly, more training and resources are needed to help employers understand autism and the physical and flexible workplace considerations they could make to support autistic staff. This ties into the need for increased pathways into employment.

We know autism affects a broad range of the community, however more research is required to better understand how autistic individuals from different population groups:

- are diagnosed
- access and respond to early intervention
- define their diagnosis
- navigate their life and wellbeing

Further, more collaboration with Indigenous and CALD (Culturally and Linguistically Diverse) communities is required to inform and develop culturally appropriate autism interventions and supports. Given First Nations represent 8% and CALD 34% of AEIOU families, we believe it is essential that Indigenous and CALD communities participate in forums or when seeking feedback or undertaking consultation regarding autism issues and policy.

Social inclusion

In pursuit of a more inclusive society, it is imperative that we champion the rights of autistic and neurodivergent individuals, affording them the respect and understanding they rightfully deserve to enable their full participation in the broader community.

The discussion paper's recommended avenues for fostering social inclusion align with AEIOU's endorsement, underscoring their efficacy in enhancing services and support for autistic individuals.

However, the strategy must consider the financial implications to community groups, service providers and systems to make these proposed changes. It should factor in an alleviation of financial pressures as a result of these changes and incentivise larger organisations to share expertise externally for smaller businesses (e.g., models for sustainable change in practice to be more neuro-affirming or building plans for environments that are better at meeting the needs of all).

Establishing a smart self-assessment tool may support employers and businesses to build inclusive workplaces, with recommended steps to build towards. This could be linked to accreditation.

The discussion paper's suggested action for a public awareness and acceptance campaign is also supported by AEIOU to improve community attitudes towards autistic people. Such a campaign should run concurrently with or following diversity/neurodiversity learning curriculum into the national curriculum for primary and secondary schools.

Implementing a comprehensive public awareness campaign holds the potential to foster a more inclusive and accepting society. By promoting positive perceptions of individuals with disabilities, this initiative can cultivate meaningful shifts in societal attitudes and behaviors. As a result, it will serve to enhance the safeguarding of individuals with disabilities, reducing their vulnerability to violence, abuse, neglect, and exploitation.

Economic inclusion

Many families that attend a specialist service like AEIOU's have experienced trauma within mainstream childcare settings, relating to excessive use of restraint (which is often unreported) and lack of understanding of reasonable supports. This is just one example where children with high needs can be prevented from participating meaningfully in education, which could lead to future impacts through school, employment, and access to transport.

One way to improve services and supports is to build in autism knowledge requirements to core subjects for degrees in allied health professions, teaching, social work, and health. This would ensure that all graduates have a foundational knowledge regarding autism to better support autistic people in their work.

Particularly for teachers, rotation in an inclusive or specialist setting should be a requirement. This would give teachers firsthand experience of teaching autistic students in a diverse classroom setting. Additionally, services and supports could be improved by providing more funding for autism-specific programs and services and increasing access to early intervention services.

We need to respect the individual needs and preferences of autistic people to better support them in education, employment, and the workforce. This may mean providing specialist settings for those who need them, as well as opportunities for autistic people to participate in mainstream education and employment with the necessary supports in place.

Currently, mainstream educational settings are inadequate, underfunded, and under-supported to accommodate autistic children with complex needs. Significant long-term investment would be required to bring mainstream schools up to an adequate level to meet the required standards for these children.

While promoting quality inclusion in mainstream schools can work in some instances, we should also support the choices of autistic people and their families with complex needs by ensuring access to a range of educational settings, including specialist education settings.

Choice and control are cornerstones of the NDIS, which recognises the unique needs, values, and learning styles of all autistic learners. Mainstream schools are not equally equipped to support additional needs. Autistic people should also have the choice to receive education in a service with more specialist skills if they prefer.

Services like AEIOU play a key role in developing the skills of complex needs autistic children aged 2-6 years old so that they can more easily transition to and participate in mainstream settings. It is important to acknowledge and fund services that facilitate the transition between specialist and mainstream education.

Diagnosis, services and supports

Long waitlists for diagnostic and intervention services, and a shortage of psychologists and diagnostic clinicians, are the two significant barriers that prevent autistic people from getting a diagnosis and accessing the services or supports they need. Waitlists for autism diagnoses can extend to two years despite evidence linking timely early intervention to improved developmental outcomes for autistic children, making these delays genuinely concerning.

Additionally, fewer psychologists are entering service, and more are leaving. Many psychologists are no longer accepting new clients, which further limits access to support. Before COVID-19, 1 in 100 Australian psychologists had their books closed for new clients. Now it is 1 in 3. These barriers are particularly harmful to autistic people, who have a relatively high rate of service utilisation compared to other conditions listed on the DSM-V.

Better access to diagnosis, services, and supports for autistic people involves ensuring open access to fairly represented and easily digestible information in multiple modes, enabling individuals to make informed decisions for themselves.

Even after receiving a diagnosis, families must endure months of additional assessments, reports, and duplication, which is burdensome and delays critical early intervention. The NDIS should better respect diagnoses from medical professionals. For example, if a child receives a level 3 autism diagnosis from a pediatrician, the NDIS should issue a plan without delay. The finer details can be worked out later, but if someone has a diagnosis and chooses early intervention, NDIS bureaucracy should not impede progress.

One way to ensure that diagnosis, services and supports for autistic people are strengths-based, culturally responsive and trauma-informed, is to regulate and require ongoing professional development for related professions, especially in the behaviour support sector. There is a wide range of skill levels and evidence-based practice among behavior support practitioners, which can lead to autistic people receiving inappropriate or ineffective services.

The strategy must also make clear that autistic individuals require flexible support systems that can meet their changing needs throughout their lives. At different times, an autistic individual may require intensive supports, while at other times they may need less. Autistic individuals will always require some level of support, and the system needs to be able to provide that support as and when it is needed. The system must have the flexibility to "dial up" or "dial down" support for individuals as needed.

Under the diagnosis, services and supports section of the discussion paper, the following point is included: *The role of behaviour science in services and supports for Autistic people is the most challenging and contentious.* Choice and control are key for autistic people and their families. Individuals and families should have the right to choose the best fit evidence-based practice for them, including those that are behaviour science based. Diversity in supports is essential, as it is a diverse autistic community who seek different things from their supports. Committing to the regulation of the sector can only help to weed out those who are continuing to use unethical and non-evidence-based supports.

National Roadmap to Improve the Health and Mental Health of Autistic People

Improvement is needed in health and mental health services and supports, with challenges such as a decrease in the number of psychologists entering the field, higher attrition rates due to burnout, and limited availability of services affecting various populations, including autistic individuals who experience the impact of these issues.

Supporting better health and mental health outcomes for Autistic people involves ensuring appropriate service availability and ensuring service providers are trained in supporting autistic individuals.

To improve the health and mental health of autistic people, a cyclical roadmap is required. This would involve collecting data to measure an individual's difficulties, providing individualised targeted treatments, and measuring the outcomes of the intervention to ensure it is effective.

Regular monitoring of outcomes in this manner would identify ineffective treatments sooner, allowing them to be adjusted in a timely way.

A holistic approach that considers the individual's unique macrosystem is an essential consideration for such a cyclical roadmap.

Appendix

AEIOU Foundation's feedback to National Autism Strategy survey, May 2023

Note: this appendix contains survey responses that were originally submitted to the National Autism Strategy consultation in May 2023. However, these responses have been updated to provide more detail and context to our initial responses.

Education

Question 1

What are three problems that autistic people experience with education?

- While awaiting a formal diagnosis of autism and a NDIS plan to access appropriate supports, autistic children are often forced into unsuitable mainstream childcare or education settings that don't cater for the developmental age in the curriculum design or classroom supports.
- When a child presents with complex needs, delays to diagnosis, funding and appropriate supports can present serious harm to the child and family
- The availability of specialist early intervention services designed to support early learners with accessing education can be restricted depending on a person's location (for example those in rural and remote areas) or enrolment availability.
- Mainstream educational settings in both public and independent schools require teachers with more training to support those with diverse learning needs such as autistic children.

Question 2

What do you think is causing these problems?

- A major hurdle to accessing appropriate, funded supports is securing a diagnosis due to delays to both private and public paediatricians. Allied health assessments are also expensive and delayed. Further feedback regarding diagnostic issues is covered later in the survey.
- Specialist early intervention services are in high demand, and particularly hard to access for those in regional and remote areas.
- Teachers, as well as Heads of Departments/Curriculum, lack the required training to deal with autistic students, with complex needs, particularly given the increased prevalence of autism in the population.
- Mainstream education services lack the funding, planning time and staff to adequately diversify their teaching strategies to meet the needs of autistic children in their classroom. There remains an unfortunate expectation that the child needs to adjust to the environment and teaching style rather than consider how to adjust lessons and environments to support the child to be successful. This ultimately leads to placement breakdown.

Question 3

What do you think could prevent or reduce these problems?

- The NDIS could consider a scheme that helps fund assessments for earlier diagnosis, removing a major financial barrier for the families of participants and addressing delays in accessing essential supports.
- Further funding for services like AEIOU Foundation to establish centres areas outside of metro regions e.g., AEIOU received \$2m in funding from Federal Budget in October 2022-23 to construct an expanded Townsville centre.

- It should be a requirement that all teaching degrees and diplomas include practical modules on supporting those with diverse learning needs, such as those with learning difficulties, developmental disorders, and mental health diagnoses.
- Consideration of how to increase teacher's planning time so that they can better prepare classroom materials for diverse learning needs.

Question 4.

What is working well, or has worked well, for autistic people in education?

- AEIOU research unequivocally demonstrates that evidence informed early intervention, combining therapy and specialist education not only facilitates notable developmental progress for autistic children, but also yields impressive returns on investment. The research substantiates the life-changing impact early intervention services can have on autistic children. It shows us children at AEIOU, even when presenting with elevated levels of difficulty, make significant gains, catching up from their developmental delays at rates over and above what would be expected for a typically developing child
- In some instances, in mainstream schooling:
 - Increased collaboration with parents and caregivers to ensure consistent support, and the development of individualised learning plans to cater to each student's needs. Schools are also better at recognising neurodiversity and promoting inclusive learning environments.
 - Increased peer acceptance and understanding through awareness campaigns and peer mentoring.
 - Reduced sensory overload and enhance academic outcomes with smaller class sizes or skilled teaching aids.
- Transition supports (i.e., short term intensive supports between educational settings), when funded and schools feel confident in allowing therapists in to support students, are extremely effective.

Diagnostic

Question 1

What are three problems that autistic people, and their families/carers, experience with autism diagnostic services?

- The long waiting lists for specialists that can give autism diagnoses is well documented. Obtaining a formal diagnosis under the public health system is often drawn out by delays, with waiting times of up to 18 months in some areas, while private psychologists have extensive waitlists, are expensive, and are not always available in rural/remote locations. This delay results in delay to early intervention which remains the most evidence-based support resulting in positive outcomes for children and their future levels of support.
- High costs in addition to long waits
- Lack of consistent support and guidance post diagnosis

Question 2

What do you think is causing these problems?

- The long waiting lists for specialists that can give autism diagnoses can have multiple causes, including:
 - A shortage of specialists in the public health system to meet the demand for autism diagnoses.
 - The diagnostic process is complex and requires multiple assessments and evaluations from different specialists. This can lead to longer waiting times and delays.

- There are geographical barriers where some areas may have a limited number of specialists who are qualified to diagnose autism. This can be especially true in rural or remote areas, where there may be fewer healthcare providers in general.
- There is a growing awareness of autism with more people are seeking diagnoses than ever before. This increased demand can put a strain on the already limited resources available for diagnosing autism.
- The NDIS does not cover clinical diagnostic assessments under the current model; however, NDIS plan holders can use their funding to cover the cost of progress tracking assessments.
- People are told that without a diagnosis they will get no access to funded supports.
- Age related challenges - i.e.: very young children may have behaviours that change over time.

Question 3

What do you think could prevent or reduce these problems?

- The NDIS could consider a scheme that helps fund assessments for earlier diagnosis, removing a major financial barrier for the families of participants and addressing delays in accessing essential supports.
- More broadly, there needs to be a more open and transparent objective assessment process to obtaining a diagnosis and entering NDIS, to ensure the system is fair and equitable and ensures kids with higher needs receive the NDIS support they need.
- Increase pathways and attractions into the relevant university courses to increase the work force.
- Increase cultural competency: Healthcare professionals and educators need to be trained on how to identify and assess autism in children from diverse cultural backgrounds.
- Improve feedback mechanisms: develop systems to collect feedback from families and communities on their experiences of the autism diagnostic process. This feedback can be used to improve the quality and cultural responsiveness of services.
- Create a standardised information gateway: a central repository of reliable and up-to-date information on autism diagnosis and support services. This information should be available in multiple languages and accessible to families and communities across Australia.
- Implement an autism advisor program: Autism advisors, similar to the advisors that were employed under Helping Children with Autism (HCWA) initiative, to provide support to families and healthcare professionals throughout the diagnostic process. They can also help to coordinate services and ensure that families have access to the support they need.
- Develop an education program for healthcare professionals and educators: This program should teach participants about the signs and symptoms of autism, as well as the best practices for assessment and diagnosis.
- Reduce wait times: This can be done through partnerships with other organisations and training professionals to manage the diagnostic process more efficiently. Funding is also needed to support these initiatives.
- Make services available via telehealth: This is especially important for families living in rural and remote areas. Telehealth can provide access to specialists and other resources that may not be available locally.

Early intervention

Question 1.

What are three problems that autistic people, and their families/carers, experience when accessing, or trying to access, early intervention or support services?

- For those seeking access to early intervention services like AEIOU, the process to enter the NDIS is complex and overwhelming for families, particularly those who are new to the disability sector and managing the confronting challenges of raising a child with autism. As previously mentioned, access to appropriate supports can be restricted depending on a person's location (for example those in rural and remote areas) or enrolment availability. Even with a diagnosis, many paediatricians and medical staff are unaware of all the supports available to families and how to direct them through the next steps.
- Recruitment and retention of allied health professionals, particularly those with autism experience, is also challenging for providers like AEIOU. Using speech pathologists as an example, while the number of qualified professionals in Australia has doubled in less than a decade, the primary workplace or choice of employed is most often private practice. We are now experiencing reductions in the number of job applicants and extreme competition for speech pathologists in the job market.
- There are significant funding barriers preventing many eligible individuals from accessing the clinically recommended early intervention support they need.
- Unregistered NDIS providers that price gouge, and provide inconsistent, non-evidence-based services. This results in a market that has significant inconsistencies and results in poor perceptions around early intervention services. Access partners providing early intervention services is a conflict of interest.
- The lack of a standardised gateway and pathway to supports with streamlined, unbiased and evidence-informed information
- Limited service options and long wait times: the number of services like AEIOU is growing, but service options are still limited and many people must move home or separate families to access quality supports. Even with funding or diagnosis, it is difficult to start services at AEIOU immediately, and wait times are even longer for plan reviews.

Question 2.

What do you think is causing these problems?

- Plans consistently do not match the clinical recommendation, leaving a service / funding gap.
- Once participants are established on a NDIS initial plan, there are delays in the plan review process and funding continuity for families. The process for plan progression needs to be faster and less complicated for families that have well-documented evidence of early intervention requirements. Lengthy gaps in plan renewals are compromising access to essential early intervention services in a stable, consistent, and continuous manner. Delegates reviewing plans should be well-appraised of the needs and clinical recommendations for children with level 2 or 3 ASD (autism spectrum disorder) diagnoses, and their life potential should they access evidence-based supports. This is particularly important for the early cohort AEIOU delivers to (2–6-year-olds), where plans are often 12 months maximum and non-recurrent.
- Geographical barriers: The high cost to provide targeted / specialist services makes it challenging to deliver supports in regional and remote areas.
- NDIS participants and their families face inconsistent funding decisions, with ongoing assessments and clinical recommendations (for early intervention services) provided by specialists disregarded. We have seen firsthand the difficulties families face when trying to secure the funded plans required for intensive early intervention services, including inconsistent funding decisions that do not align with clinical recommendations, no clear explanation or funding decisions, and confusion as to what exactly is required to justify funding/supports.

- The lack of transparency and the bureaucratic delays results in children missing therapy during a critical developmental window, triggering the likelihood of their future increased reliance on the NDIS.
- High burnout rates of allied health professionals, often due to pressure to meet billables which forgoes key learning and professional development for those early in the carer seeing them exit to less challenging disciplines within the profession than early intervention and autism.
- Typically, as they are female dominated professions, the overall therapist population looks significant however many are working part time which reduces overall availability of therapeutic support.

Question 3.

What do you think could prevent or reduce these problems?

- For NDIS participants, ensure best practice planning and assessment with supporting evidence from a registered clinician that has ASD experience.
- Provide consistency and transparency around funding decisions.
- Ensuring that detailed information about early intervention options is provided alongside diagnosis. (e.g., private therapy, group-based programs etc).
- Ensure funding available to pay staff to access quality clinical supervision so that it is not dropped in favour of a billable hour.
- Provide consistent and evidence-based information about autism early intervention for health professionals
- Such specific information for health professionals, as well as information targeted at families navigating early diagnosis for the first time, should be available in a variety of formats, including online, digital, and printed materials. The same resources should also be tailored for CALD communities to eradicate barriers to early intervention

Question 4.

What is working well, or has worked well, for autistic people when using or trying to access early interventions and supports?

- AEIOU research unequivocally demonstrating that early intervention not only facilitates notable developmental progress for autistic children, but also yields impressive returns on investment. The research substantiates the life-changing impact early intervention services can have on autistic children.
- When families are empowered to make their own choice about services and there is choice in those service types available (i.e., not forced into one option because it is all that's available)