



National Call To Action

The Australian Advisory Board on Autism Spectrum Disorders is the national peak body representing people who have an autism spectrum disorder (ASD), their families, carers and helpers. Through its members, the Advisory Board represents a significant number of Australian citizens who live with an ASD and who are members of, or who obtain services from, the Advisory Board's member organisations.

The **National Call to Action** is the result of a collaborative approach between all autism associations in all States and Territories and has identified a number of critical imperatives for the Autism Spectrum community. We appeal to policy makers in the Australian community to ensure effective resourcing and structuring of future service delivery.

Call to Action 1: Access To Diagnosis

We call for access to timely and affordable diagnosis for both metropolitan and regional Australia that ensures:

- A national experience of no more than 3 months wait time for a diagnosis
- A national benchmark for a multi-disciplinary approach to diagnosis
- Extended Medicare rebates are available for diagnosis.

This will be achieved by:

- A national benchmark for the funding of the diagnostic process
- Comprehensive workforce capacity development strategies.

This is a critical priority for the following reasons:

- Families and individuals can wait up to 24 months for a diagnosis
- A time delay creates additional frustration and stress on family members
- Diagnosis is the critical starting point for families to access services
- Diagnosis is often a significant financial expense for the family
- Diagnosis can be difficult to obtain in rural and remote areas.

Call to Action 2: Official Reporting of Autism Spectrum Disorders

We call for the establishment of a National ASD Register to ensure the collection of quality data across Australia that ensures:

- Accurate profiling of ASDs in Australia at any one point in time and to describe trends over time
- Informed decision-making regarding policy, services, clinical practice and workforce development
- Detailed data for clinical research and population based analysis.

This will be achieved by:

- The establishment of a National ASD Register as proposed by the Australian Advisory Board in 2009
- Government action to include ASD on registers such as the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW).

This is a critical priority for the following reasons:

- There is an increase in the number of individuals diagnosed with an ASD
- State, Territory and National data is essential for planning purposes
- There are existing deficiencies in the comprehensiveness of information available and inconsistencies in data collection between states/territories.

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Call to Action 3: Early Intervention For Young Children (aged 0-7 years)

We call for early intervention services that ensure:

- Every child has access to a minimum 20 hours of ASD-specific intervention per week
- A wait period of no more than 3 months between diagnosis and service provision
- Equitable access for all children with special consideration given to families in rural and remote regions.

This will be achieved by:

- An increase in resources allocated that ensures the benchmark for intervention intensity is achieved
- The establishment of national service standards and codes of conduct for the delivery of early intervention services.

This is a critical priority for the following reasons:

- Research demonstrates that early intervention leads to better outcomes
- There are a number of significant stressors that impact on both the family and individual that are exacerbated by an unresponsive service system
- Sustainable positive outcomes are achieved by providing effective support in the early years.

The Advisory Board's Position Paper on Early Intervention Services may be found at www.autismadvisoryboard.org.au .

Call to Action 4: Education

We call for educational services for school age children with an ASD that ensure:

- Every child has access to an appropriate educational service appropriate to his/her needs in compliance with the federal Disability Discrimination Act (Education Standards, 2005)
- Educational services are based on sound evidence and quality indicators
- All government and non-government educational sectors provide educational services appropriate to the needs of children with an ASD
- Educational services are responsive to all children across the autism spectrum, including children with Asperger disorder who are frequently not diagnosed until they are at school
- There are a range of educational services for children with an ASD from specialised autism-specific programs to mainstream programs with appropriate adjustments
- There is a wait period of no more than six months between application for an educational service and enrolment
- Educational programs and services address the needs of speech, social skills, behaviour and sensory issues and family support.

This will be achieved by:

- An increase in resources allocated specifically for appropriate needs-based educational services across government and non-government educational sectors
- Improving the capacity of generic and specialised educational services to respond through the increased provision of training, education and consultancy support
- Increased collaboration between government and non-government educational sectors and across agencies.



This is a critical priority for the following reasons:

- Research indicates that positive outcomes are achieved by the provision of appropriate educational services related to the needs of children with ASD
- There is an increase in the number of children diagnosed with ASD that require specialised educational support
- There is a lack of educational programs and services that support the needs of children with ASD
- There are high rates of exclusions, suspensions and part time schooling for children with ASD.

The Advisory Board's Position Paper on Education may be found at www.autismadvisoryboard.org.au .

Call to Action 5: Family Support, Assistance And Respite

We call for the development of a comprehensive and integrated system of providing support to families that ensures:

- Families have access to a range of models for support and respite
- Models of support are flexible and responsive to the needs of families
- Specific services are targeted at meeting the needs of siblings of a person with ASD
- Specialised services are available for people with exceptional needs
- Generic services have capacity and capability to provide appropriate support
- Ageing carers of adults with ASD have access to flexible and affordable respite.

This will be achieved by:

- Gathering accurate data on the nature and extent of the need for family support to assist with future planning and effective resource allocation
- Improving the capacity of generic services to respond through the provision of training, education and consultancy
- Ongoing collaboration between the public, private and voluntary sectors.

This is a critical priority for the following reasons:

- Proactive strategies decrease the likelihood of family breakdown, preventing progression to more expensive crisis response
- It improves quality of life outcomes for both families and individuals
- Community awareness, knowledge and understanding is improved.

Call to Action 6: Services to Adults with an Autism Spectrum Disorder

We call for an improved range of services for all adults with ASD that ensures:

- Adults with ASD receive services and support from professionals with appropriate training in autism and related needs
- Adults with ASD are given every opportunity to have a full and rewarding life
- Adults with ASD are given every opportunity to be part of the work force
- Specialised models for long and short term accommodation services are designed to meet the specific needs of adults with ASD
- Adults with ASD who have a dual diagnosis have access to community, health, mental health and related services and support as required.



This will be achieved by:

- Effective planning and support for transition to post school options
- Targeted funding for adults with ASD to establish specialised services in metropolitan and regional areas
- Targeted funding to support specialised training of staff working with adults with ASD
- Developing services and supports for adults with ASD that are based on sound evidence with quality indicators.

This is a critical priority for the following reasons:

- People with ASD are adults for much longer than they are children and require services and supports that will maintain the progress made during their childhood years
- Without appropriate supports, adults with ASD are at high risk of developing co-morbid mental and physical health conditions
- The human and financial costs associated with family breakdown and dysfunction increases significantly if the needs of adults with ASD are not met
- Employment and post-school experiences valued by the wider community are of enormous benefit to adults with ASD when provided with appropriate opportunities to participate
- Such support increases the social and economic participation of adults with ASD in the Australian community.

Call to Action 7: Research

We call for an Australian research program into the treatment, intervention and aetiology of ASDs.

This will be achieved by:

- An increase in resources allocated to ASD research
- Evaluation and assessment of existing and new programs, practices and services for children and adults with ASD
- Collaboration and partnerships with governments, universities and service providers
- Links with international research in the field
- Establishing a chair in ASD in a major Australian university.

This is a critical priority for the following reasons:

- There is an increase in the number of people being diagnosed with an ASD
- The Australian prevalence study (2007) indicates a prevalence rate of 1 in 160 for children aged 6 – 12 years
- The lack of interventions and services based on sound evidence and quality indicators.

**For more information on the Advisory Board's National Call to Action, please contact
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