

Australian Advisory Board on Autism Spectrum Disorders

formerly the Autism Council of Australia

National Call To Action

The Australian Advisory Board on Autism Spectrum Disorders represents the views of its corporate members in identifying and addressing the needs of people with an autism spectrum disorder (ASD) in the Australian community.

The ***National Call to Action*** is the result of a collaborative approach that identified the imperatives for the autism community. We appeal to both national and state policy makers for a whole of government approach to ensure effective resourcing and structuring of future service delivery.

1. Access To Diagnosis

We call for access to timely and affordable diagnosis for both regional and rural Australia that is governed by the following principles:

- A national experience of no more than 3 months waiting time for a diagnosis;
- A national benchmark for a multi-disciplinary diagnostic team responsible for the process of diagnosis; and
- Medicare rebates are available for diagnosis.

This will be achieved by:

- A national benchmark for the funding of the diagnostic process; and
- Medical courses incorporating information on ASD.

This is a critical priority for the following reasons:

- Currently there is up to 24 months waiting list across the states and territories of Australia;
- A time delay creates additional frustration and stress on family members who are living with the pressures of raising a child with ASD;
- Diagnosis is the critical starting point for families to access intervention support services which maximise positive outcomes for both the child and his/her family;
- Diagnosis is often at the family's expense; and
- Diagnosis can be difficult to obtain in rural and remote areas.

2. Official Reporting of Autism Spectrum Disorders

We call for *autism spectrum disorder* to be reported as a distinct disability governed by the following principle:

- That autism spectrum disorder be included on state and national data registers such as the Australian Bureau of Statistics (ABS), Centrelink and the Australian Institute of Health and Welfare (AIHW).

This will be achieved by:

- The development of a national Register of Autism Spectrum Disorders, that includes autism or autistic disorder, atypical autism and Asperger's disorder; and
- Government action to include autism spectrum disorders on registers such as the ABS and AIHW.

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This is a critical priority for the following reasons:

- There is an increase in the number of individuals diagnosed with ASD; and
- State and national data is essential for planning purposes.

2. **Early Intervention For Young Children (aged 0 – 6 years)**

We call for early intervention services that are governed by the following principles:

- Every child has access to a minimum 20 hours of support per week;
- There is a waiting period of no more than 3 months between diagnosis and service provision; and
- Equitable access is provided for all children with special consideration given to families in rural and remote regions.

This will be achieved by:

- An increase in resources allocated specifically for early intervention services to children with an autism spectrum disorder (ASD); and
- The establishment of clear service standards and codes of conduct for the delivery of early intervention services based on sound evidence and quality indicators.

This is a critical priority for the following reasons:

- All research to date demonstrates that early intervention leads to better outcomes for children with an autism spectrum disorder;
- There are a number of significant stressors that impact on both the family and individual that are exacerbated by an unresponsive service system; and
- Sustainable positive outcomes are achieved by providing effective support in the early years.

3. **Education**

We call for educational services for school age children with an ASD that are governed by the following principles:

- That 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);
- That educational services are based on sound evidence and quality indicators;
- That all government and non-government educational sectors provide educational services appropriate to the needs of children with an ASD;
- That educational services be responsive to all children across the autism spectrum, including children with Asperger's disorder who are frequently not diagnosed until they are at school;
- That there should be a range of educational services for children with an ASD from specialised autism-specific programs to mainstream programs with appropriate adjustments;
- That there be a waiting period of no more than six months between application for an educational service and enrolment; and
- That 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; and

- 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; and
- There are high rates of exclusions, suspensions and part time schooling for children with ASD.

4. **Family Support, Assistance And Respite**

We call for the development of a comprehensive and integrated system of providing support to families that are governed by the following principles:

- That families have access to a range of models for support and respite;
- That the models of support are flexible and responsive to the needs of families;
- That specific services be targeted at meeting the needs of siblings of a person with ASD;
- That specialised services be available for people with exceptional needs;
- That generic services be adequately informed and educated to provide appropriate support; and
- That ageing carers of adults with ASD have access to flexible and affordable short term respite support for their son or daughter as required.

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; and
- Ongoing collaboration between the public, private and voluntary sectors.

This is a critical priority for the following reasons:

- This a proactive strategy that decreases the likelihood of family breakdown, preventing progression to more expensive crisis responses;
- It improves quality of life outcomes for both families and individuals; and
- Community awareness, knowledge and understanding is improved.

5. **Services to Adults with an Autism Spectrum Disorder**

We call for an improved range of services for all adults with ASD governed by the following principles:

- That adults with ASD receive services and support from professionals with appropriate training in autism and related needs;
- That adults with ASD be given every opportunity to have a full and rewarding life by being as much part of the community as they possibly can be;
- That adults with ASD be given every opportunity to be part of the work force;
- That specialised models for long and short term accommodation services be designed to meet the specific needs of adults with ASD; and
- That 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 Commonwealth and State funding for adults with autism to establish specialised services in metropolitan and regional areas;
- Targeted Commonwealth and State funding for adults with Asperger's Syndrome to establish services in metropolitan and regional areas;
- Targeted funding to support specialised training of staff working with adults with ASD; and
- Replicating services and supports for adults with ASD that are based on sound evidence and have 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 issues;
- The human and financial costs associated with family breakdown and dysfunction increases significantly if the needs of adults with ASD are ignored; and
- 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.

6. Research

We call for Australian research program into the treatment/intervention and aetiology of autism spectrum disorders

This will be achieved by:

- An increase in resources allocated to 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;
- The establishment of a national research network linked with an established research organisation in this country; and
- Establishing a chair in autism spectrum disorder in a major Australian university.

This is a critical priority for the following reasons:

- There is an increase in the numbers of people being diagnosed with an autism spectrum disorder;
- The findings from the recent Australian prevalence study showing a prevalence rate of 1 in 160 in children aged 6 – 12 years; and
- 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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