



## **National Call To Action November 2011**

The Australian Advisory Board on Autism Spectrum Disorders is the national peak body representing the autism spectrum community. 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.

[Click here to view the Advisory Board's Position Paper on ASD Diagnosis.](#)

**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 in accordance with best practice guidelines (Roberts and Prior, 2006)
- A delay of no more than 3 months for getting a child with ASD into an early intervention service
- Equitable access for all children with ASD, with particular attention to equity for 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.

[Click here to view the Advisory Board's Position Paper on Early Intervention Services.](#)

**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)
- Students with ASD are protected from bullying in and around schools
- Students with ASD who are bullied get an appropriate, immediate and effective response
- 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



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- Educational services are responsive to all children across the autism spectrum, including children with Asperger disorder many of whom are 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 that address 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.

[Click here to view the Advisory Board's Position Paper on Education.](#)

### **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 that can be accessed from all areas (metropolitan, regional and remote)
- 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 and with ongoing measures of quality and effectiveness.

**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.



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- The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.0>) shows poor outcomes for Australians with ASD in tertiary education, labour force participation, need for and receipt of assistance.

### **Call to Action 7: Research**

We call for a comprehensive Australian research program into Autism Spectrum Disorders including the aetiology, diagnosis, intervention and prognosis of ASDs and whether the incidence is increasing.

#### **This will be achieved by:**

- An increase in resources allocated to ASD research
- Evaluation of current diagnostic pathways and processes
  - Evaluation and assessment of existing and new programs, practices and services for children and adults with ASD
  - Establishing population based data about 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:**

- The number of Australians being diagnosed with an ASD is increasing.
  - The Australian prevalence study (2007) indicates a national prevalence rate of 1 in 160 for children aged 6 – 12 years. Further analysis (Buckley, 2009 and Wray, 2011) of additional FaHCSIA/Centrelink data shows
    - Steady annual growth in ASD diagnoses from 2004 to 2009
    - National ASD prevalence exceeded 1 in 100 (or 1%) in 2009
- The lack of consistency in diagnostic pathways and processes within and between states and territories
- The lack of interventions and services based on sound evidence and quality indicators
- The lack of evidence about causes of ASD.

**For more information on the Advisory Board's National Call to Action, please contact Jon Martin, Chairperson (08) 8379 6976.**