



**Department  
of Ageing,  
Disability &  
Home Care**

**Office of  
the Director-  
General**

Mr Bob Buckley  
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D06/9632

Dear Mr Buckley

I refer to your email message regarding my response to your correspondence of 30 March 2006 relating to services for children with Autism Spectrum Disorder in New South Wales.

Thank you for the time you have taken to consider my response and for the opportunity for me to review your subsequent commentary.

As you will see in the attached report the Department is able to provide more extensive comments.

I trust this information is of assistance.

Yours sincerely

**Brendan O'Reilly  
Director-General**

Encl: Response to Questions

**Question 3:**

*Does the New South Wales Government recognise that an autism spectrum disorder is usually severely or profoundly disabling?*

**Response:**

There is a significant range across the autism spectrum, covering mild, moderate, severe and profound levels of disability. It cannot therefore be speculated that a child with an autism spectrum disorder is usually at the severe or profound level of disability. The level of disability varies greatly across the spectrum.

Autism is recognised as a life long disorder of unknown aetiology that presents as quantitative impairments in social skills, verbal and non-verbal communication and restricted or repetitive interests or behaviours (Perry & Condilac, 2003).

Autistic Disorder is considered to be the more severe as it is accompanied by significant cognitive impairment. Children with Aspergers Syndrome however, are reported to have average to above average intellectual functioning and as such may lack the early indicators of developmental delay that typically alert early referral and diagnosis. (Perry & Condilac, 2003)

**Question 4:**

*Does the New South Wales Government recognise ASD as a separate disability type that is distinct from intellectual disability, for example?*

*What reporting of outcomes measures for people with ASD does the New South Wales government use to ensure outcomes for people with ASD are equitable?*

*What are the measured results achieved in New South Wales, and where are they published?*

**Response:**

The Government does not confer different status upon particular types of disability and there is no obligation on the Minister to provide or fund services to all persons with Autism Spectrum Disorder, or in fact all persons with any type of disability.

Rather, the Government aims to deliver services in a way that recognise people with a disability as having diverse physical, social, psychological and cultural needs that can be met in different ways.

The Department does not report measures for specific disability groups. However key service provision data are reported annually in the Department's Annual Report that is presented to Parliament under the provision of the Annual Reports (Departments) Act 1985 and the Annual Reports (Statutory Bodies) Act 1984.

**Question 5:**

*What measures does the New South Wales Government have to show that the treatment and early intervention it provides for children with an autism spectrum disorder is effective in improving outcomes for those children?*

**Response:**

Services funded by the Department of Ageing, Disability and Home Care are required to report against performance indicators. The Department is committed to clearly describing the services that it wants to buy, and in monitoring them to make sure that they meet quality standards.

Performance indicators include but are not limited to:

- A decrease in the average age of entry to early childhood intervention services.
- An increase in the number of children supported by the early childhood intervention service in mainstream settings.
- An increase in the percentage of individual family service plans that involve the family and the full range of agencies that are providing support to the child with a disability and their family.
- Families report being supported by formal and informal networks.
- The early childhood intervention service participates in the Early Childhood Intervention Coordination Program.
- A progressive reduction in the numbers of families seeking crisis and/or low risk support.
- Awareness of continued improvement in and innovation in service delivery.
- Evidence of strategies identified for research and implementation of best practice.
- Continuity of overarching service support to families as the child transitions from early childhood intervention into school age services and transitions to adult services where required.
- Families and clients are assisted to access and participate fully in preferred service option and community activities.
- Families and extended family members are assisted to access a range of formal and informal structured supports.
- Provision of information and resources to families.

**Question 6:**

*Does the New South Wales Government accept that children with autism who do not receive effective treatment for their autism will impose substantial long-term burdens on the affected families, reduce the productivity of family members and diminish the capacity of the whole community to provide the growing level of support required for an ageing population?*

**Response:**

The NSW Government has a strong commitment to the well-being of families, especially those with special needs. We recognise that the pressures on carers grow as they age and as families in Australia become smaller. Families and careers are central to our disability support system.

It has been reported that families with a child with autism may experience a range of needs including autism specific information, contact with other families, support for critical transitions, support at the point of identification, parent education strategies and community education. It is also been acknowledged that parents of a child with autism may experience greater stress, depression and mental health difficulties than parents of children with other types of disabilities.

In 2006/2007 the Department will trial new models of respite for children with challenging behaviours at three different sites and provide 200 additional therapy places at a cost of \$1.1 million per year. The Department will also develop and introduce new parenting programs costing \$300,000 in 2006/2007 and trial programs to promote parent, sibling and peer support networks and development of information kits for families with a child with a disability.

One such kit will be specifically targeted to supporting families with a child with autism. This kit will include information to assist services and families to access intervention options, support services and management techniques immediately following diagnosis. It will also provide an overview of autism spectrum disorders, early indicators, the diagnostic process and responses to questions typically asked by parents.

**Question 7:**

*Professor Margot Prior told the National Forum "applied behaviour analysis can achieve very good outcomes" for children with ASD but that "it is not the only approach". Ms Roberts, in A Review of the Research to Identify the Most Effective Models of Best Practice in the Management of Children with Autism Spectrum Disorders prepared for DADHC, refers repeatedly to universal agreement on approaches that produce positive outcomes for children with autism. What approaches to treating autism known to produce the positive outcomes does the New South Wales Government provide (or fund)? What are the measured outcomes for children with ASD in New South Wales? How do the outcomes achieved through New South Wales Government services for children with autism compare to the positive outcomes reported in autism research literature?*

**Response:**

The Department funds Autism Spectrum Australia (ASPECT) to provide a range of accommodation support, community support and community access services for individuals with autism.

The Department has recently informed Autism Behavioural Intervention NSW of funding to provide Behaviour Support Programs to families.

The Department provides services to individuals with an intellectual disability through Community Support Teams and Behaviour Intervention Services.

Behavioural interventions include positive behaviour support, functional assessment and functional communication training. These strategies are incorporated within the Department's Behaviour Intervention Services.

The University of Newcastle has been funded to provide professional training to the non-government early childhood intervention services in NSW. This professional training project will focus on capacity building in non-government early childhood services funded by DADHC in positive behaviour supports and development of functional communication skills.

Each service funded by DADHC is required to report against performance indicators. The indicators are negotiated at the time of establishing the funding agreement.

**Question 8:**

*What services does the New South Wales Government fund that are best practice as described by experts in autism or ASD?*

- a) *Which of these services provide "between 15 and 25 hours [per week] of specific intervention"?*
- b) *Which of these services provide 20+ hours per week of ASD-specific intervention?*
- c) *Apart from service mentioned in a) and b) above, which services funded by the New South Wales Government meet any description of best practice for children with autism or ASD, whose description of best practice is it and what is their description of best practice for treating ASD in young children?*
- d) *Does the New South Wales Government have specific plans to provide best practice early intervention and treatment for children with ASD in the foreseeable future? If so, what are the plans?*

**Response:**

As indicated above, the Department is providing funding to Autism Behavioural Intervention NSW to provide non-intensive service for young children with autism and their families, to prevent and reduce challenging behaviours and to develop socially accepted alternatives in the home, school and community. This service is to be made available for longitudinal research and analysis to be conducted by the Department.

**Question 9:**

*Does the New South Wales Government accept that few families of children with ASD in New South Wales can access the evidence-based intensive ASD-specific early intervention recognised national and international experts in treating ASD say their children need for their development?*

*The Hon Sherryl Garbutt MP, Minister for Children and Community Services in Victoria, recently wrote:*

*"International research supports services delivered in non-categorical settings (universal services, ECIS or a mix of both) in the child's natural environment. "*

*My audience is keenly interested in research showing universal services and/or generic ECIS (based on non-categorical settings) are effective in improving outcomes for children with autism. Notice this view differs significantly from expert opinion on treatment and rehabilitation for autism.*

**Response:**

The evidence base reports a range of treatment models for individuals with autism and supports for their families. Most interventions utilise elements of behavioural strategies to some degree and that no one approach is recommended. Instead there are a number of key elements that need to be incorporated into programs for people with Autism. Interventions need to be early, intensive and family based, appropriately adapted to the child's pattern of strengths and weaknesses, take account of family circumstance, incorporate a functional approach to problem behaviour and support transitions.

**Question 10:**

*What "international research" relating to outcomes for people with autism "supports" generic disability services "based on non-categorical settings"? How does the research "support" these services as they relate to children with autism?*

**Response:**

There has been much debate in recent years about the appropriateness of the traditional discrete-trial behavioural interventions and the more normalised intervention approaches, particularly in relation to the areas of social communication and language development. It has been reported that the normalised approach is more effective than discrete trial training for the child's language development particularly in relation to consistent application and generalisation, and that this approach has a positive effect on the parent's interaction and communication styles with their child. It has also been reported that discrete-trial interventions may be more effective in teaching the acquisition of language structure, indicating a greater match for some individuals with autism, depending on individual strengths and cognitive abilities.

**Question 11:**

*What conclusions has the New South Wales Government reached about the effectiveness of "non-categorical", "generic" or "specialist" disability services for people with autism? How do these conclusions affect the Government's policy on and service provision for people with autism in New South Wales? What evidence is there that outcomes like those described in the research are realized in services provided or funded by the New South Wales Government?*

**Response:**

The evidence reports reinforce the need to match the particular intervention with the pattern of strengths of the child with autism and their family.

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