

## **Submission from**

Action for Autism Inc (ACT)  
Autism Behavioural Intervention Tasmania  
Autism Behavioural Intervention Queensland  
Autism Behavioural Intervention Association (Vic)

**to the**

**Senate Employment, Workplace Relations and Education  
Reference Committee**

**Inquiry into the**

# **Education of Students with Disabilities**

## **Introduction**

Autism and other disorders on the autism spectrum result from atypical neurological functioning. These conditions can be extremely disabling. By definition, autism:

- is present by age 3 years;
- impairs social interaction;
- impairs communication to the extent where many children with autism have little or no functional language;
- has unusual behaviour and restricted interests as a diagnostic criteria.

The prognosis for a child with untreated autism is particularly poor. Overseas studies suggest only a small percentage of individuals with the disorder go on as adults to live and work independently. Children with other autism-related disorders may need assistance with education, employment and community participation but their outcomes are generally better.

Between 0.6% and 1% of Australian children are affected by autism or a related disorder. The diagnosis rate for autism has increased around four- or fivefold in the last decade from around 4 children in every 10,000 to 16-20 per 10,000. Children with autism are between 20% and 25% of people being diagnosed with autism spectrum disorders (ASD). The increase can be partly attributed to improved awareness but there is no evidence (and it seems unlikely) that this is the sole cause of the alarming increase.

Children with autism often present with intellectual and severe learning difficulties. The appearance of intellectual disability can be an artefact of impaired communication, social and functional skills. Successful treatment of autism significantly improves a child's education prospects and overall performance.

The strongest evidence is that intensive and autism-specific early intervention programs that treat and rehabilitate children with autism are effective and have lasting results. The treatment

and support they require to meet their special needs is distinct from that provided for children with intellectual disability.

Few Australian children with autism gain access to effective early intervention. The required intensive treatment is not provided by the health, disability or education sectors. In particular, treatment in the mental health sector is unavailable until adolescence at the earliest.

By the time developmental delays and behavioural challenges in a child with autism reach crisis level it is too late. Intervention for older children with autism is extremely difficult and may be prohibitively expensive. Research shows most Australian children with autism have significant levels of psychopathology (anxiety, depression and psychosis) that often remains undiagnosed and untreated. Children with autism are among the worst affected by mental illness.

## **Terms of Reference**

### ***i. Criteria***

The level of handicap experienced in educational settings by people with a disability is highly variable. Most disabilities have both positive and negative consequences across a wide range of factors affecting development and learning. The support provided to meet the special needs of people with a disability is most effective when it addresses the full diversity of needs.

Typically, the criteria used to define disability effectively draw lines in the sand to impose barriers to service access. This method is particularly inappropriate for children with autism spectrum disorders.

Some education systems use IQ as the sole basis for any form of mental or intellectual disability. This criterion denies many children with a disability an effective education. All students with special needs that affect their education have a right to have those needs met free of charge (since Australia has signed the UN Convention on the Rights of the Child).

In education, any student who is not learning effectively has special needs. Failure to learn at close to their ability should be the primary criteria for the recognition of that individual's special needs in education.

### ***ii. Needs Assessment***

It is our observation that "needs assessment" usually means "resource distribution" processes. For convenience of administration, the arbitrary and limited services and resources allocation is divided annually into chunks over the school year. The process leaves significant levels of unmet need. The processes used avoid the possibility of reporting the level of unmet need.

Should the Inquiry be interested in specific data on unmet need, it could ask the ABS for an analysis of the extent to which need for assistance is met in relation to schooling (or by age) from its *1998 Survey of Disability, Ageing and Carers*.

As a result of the pervasive nature of autism, skilled professionals are required to assess needs. A student with autism requires skilled professionals to determine their level of functioning, design an appropriate program and identify relevant resources prior to "needs assessment".

Students with autism do not have access to the skilled professionals they require so their needs assessment is rarely appropriate. Among the most disabled, needs include intensive autism-specific treatment and rehabilitation to develop the most basic communication, social and behaviour skills that are a necessary prerequisite for learning. Autism-specific treatment and services are not part of the education repertoire so the needs are not recognised, hence the

essential needs will not be met.

### ***iii. particular needs***

There is a lot of talk about “squeaky wheels” in the disability sector. People feel that children with a disability depend on effective advocacy to get access to services. Children from any kind of disadvantaged background have reduced access to effective advocates or proximity (geographic or social) to the services they need.

### ***iv. early intervention***

Children with autism, in order to maximise their potential, need effective early intervention in the form of intensive behavioural intervention. Research reviews consistently report that this is the only treatment supported by a significant body of credible research.

Children with autism need early and intensive autism-specific behavioural intervention to prepare them for school. This form of treatment teaches them the basics of communication: for many, it teaches them to hear language and to speak. It teaches them to observe other children and learn through imitating their behaviour. It gives them basic social skills and prepares them for school. Without effective early and autism-specific intervention, they are less likely to benefit significantly from the years they spend attending special school at great cost to the community.

Outcomes the government expects from existing services are shown in documents such as the extract at Annex A that predicts a person who is disabled by autism will spend their entire adult life in palliative care in a nursing home. The cost of supporting a person with autism in a group home is significantly higher. The savings available through effective early intervention are considerable and deserve proper investigation by government.

Few students in Australia have access to effective early intervention for their autism. At best, children may have access to generic programs intended for children with an intellectual disability. Early intervention programs lack the required intensity and are chronically under-resourced. The outcomes and effectiveness of early intervention are not monitored or reported.

Australia would benefit substantially from providing effective early intervention for children with autism. The cost to people with autism, their families and the community of not providing this essential service is substantial.

### ***v. funding***

The cost of autism in Australia is unknown. The US Senate estimated that autism costs \$US13.3 billion per year. If we assume people with autism in Australia receive similar services and that one Australian dollar buys pretty much the same as a US dollar in the respective countries, then we can conclude that around \$1 billion is spent in Australia each year supporting people with autism. We could provide better services for people with autism if we knew how this money was being used.

Funding for special education varies considerably between settings. Budgeting for special education in some jurisdictions is conducted in the absence of adequate data. We do not know whether funds provided for special education are used effectively for children with autism. We do know that ineffective services are the most expensive services of all.

We do not know how funding is used for children with autism in the education system. For example, in the ACT each special school has a hydrotherapy pool. We are not aware of any research showing hydrotherapy is effective for students with autism. Some students with autism are provided with regular access to the hydrotherapy pool and some children with autism, those

who are not toilet trained or who have challenging behaviours, have their access to the hydrotherapy service limited. The cost of the hydrotherapy service is distributed across the whole student population.

Substantially improved data collection is required to inform funding policy for people with a disability. Whole of life outcomes need to be monitored. The impact of unmet need for early intervention, treatment/rehabilitation and education on whole of life support needs, on families, carers and the community need to be included in policy and planning.

## ***vi. mainstreaming***

Our hope is that children with autism will be educated in the least restrictive setting. However, in the ACT, most children with autism remain in special schools.

At parents request, an increasing proportion of children with ASD are being placed in mainstream classes or in special units in mainstream schools rather than special schools. Many parents prefer that their children be placed in the least restrictive educational setting that can be achieved. But there are concerns that, as with deinstitutionalisation of people with mental illness, mainstreaming or *inclusive practice* is becoming notorious for cost saving rather than for improved outcomes.

Parents and schools find it difficult to explain that children with ASD have significant needs and justify meeting a child's resource needs when others cannot see anything physically wrong with the child with ASD. Typically, community members regard them as problem children that just need good discipline.

Children with ASD could be better accepted in mainstream settings if they were better understood. The public has little understanding of or sympathy with the condition. Parents of students with ASD do not have the resources required to increase public awareness and understanding.

Children with ASD in mainstream settings need support that allows them to function in those settings without impacting on the learning of fellow students.

## ***vii. staff training***

Staff in special schools and units need autism-specific training for the autism-specific programs they need to deliver.

At present, teaching staff may be expected to deliver a comprehensive range of therapies after a short consultation. Therapy services in schools are provided using a "consultative model". This means teachers, like parents, are expected to deliver complex behavioural interventions, speech pathology, physiotherapy and occupational therapy with only the most minimal training. The training comes in the form of brief in-service courses and short consultancies from therapist with little knowledge, interest or skill in training adults.

Significantly better training for staff who teach and support children with autism is urgently required to avoid situations such as those mentioned in *WorkCover Authority of New South Wales v The Crown in the Right of the State of New South Wales (known as New South Wales Department of Education and Training) [2000] NSWIRComm 181*, wherein the defendant pleaded guilty to the charge that:

"the State of New South Wales, the defendant, being an employer, DID FAIL to ensure the health safety and welfare at work of all its employees"

Teachers in special schools and units need their training to be coupled with their career

planning and professional development.

Teachers in mainstream settings need improved recognition for their role in supporting children with special needs. The current culture is that they should all do it as part of their job. Particular skills in teaching students with special needs must be recognised and respected.

### ***viii. legislation***

The legal implications and resource demands of current legislation are indiscernible. The legislation is largely untested.

The recent attempt to develop a national education standard failed.

Australia needs a national legislative instrument like the *Individuals with Disabilities Education Act* (IDEA) in the USA to ensure children with autism have equitable access to effective early intervention and education.

## Organisation Contacts

Action for Autism Inc PO Box 201 Ainslie ACT 2602	Bob Buckley, Vice-President Phone: +61 2 6248 7711
Autism Behavioural Intervention Tasmania 48 Drysdale Ave Kingston TAS 7050	Lisa Minchin, President Phone: 6223 2317
Autism Behavioural Intervention Queensland 30 Kneale St Holland Park West Queensland 4121	Karen Burnham, President Ph 07 3892 2347
Autism Behavioural Intervention Association PO Box 443 Ashburton VIC 3147	Ms Julia Seedsman, Coordinator Phone: 03 9685 7463

## Annex A. IMMIGRATION REVIEW TRIBUNAL

IRT REFERENCE: ..... Q97/00823 10584.doc

...

[SU] has Autism with significant intellectual delays and attentional problems.

He is in full time residence with a special educational institution. This is intended to get the best possible teaching to enable him to get the most from his limited potential. It is expected that he will not reach a level of education and functioning considered normal for an adult.

It is expected that he will have difficulty performing the full range of activities of daily living necessary for independent functioning in the community. He would be unlikely to be able to perform any employment at award conditions and is medically eligible for social security benefits.

Permanent or intermittent residential care, or respite care, will be required if family support is not to be available and may be needed as he gets older.

...

3. He would require supervision in the long term, and possibly for the duration of his life.

**Likely cost the Australian community for health care and community services.**

**\*These costs do not include the cost of specialized education/programs he is currently undertaking.**

1. Eligibility for **Child Disability Allowance** : \$1887 per year till aged 16 years.

Total cost =  $1887 \times 11 \text{ years} = \underline{\$20,757}$

2. Carer's eligibility for Carer's Pension: \$9000 per year for the next 15 years and assuming he will be institutionalised after that.

Total cost =  $9000 \times 15 \text{ yrs} = \underline{\$135,000}$

3. Eligibility for **Disability Support Pension**, at \$11,000 per year: From age 16 to 66 years (assume death at 66 years old).

Total cost =  $11,000 \times 50 \text{ years} = \underline{\$550,000}$

4. Medical/pharmaceutical costs: Assume \$1000 a year for life, from age 5 till 66 years old.

Total cost =  $1000 \times 61 = \underline{\$61,000}$

5. Institutional care cost : Assume he requires institutional care from age 20 onwards till death at age 66. \*Current estimate of cost of subsidy of a place in a nursing home per year is \$26,793.

Total cost =  $26,793 \times 46 \text{ years} = \underline{\$1,232,478}$

6. **Total welfare cost (estimate only) = 1 + 2 + 3 + 4 + 5 =**

**$\$135,000 + \$550,000 + \$61,000 + \$1,232,478 = \$1999,235$**