

Submission to Senate Inquiry into the Education of Students with Disabilities by the Autism Association of NSW

Although the focus of this inquiry is on the education of students with disabilities this submission specifically focuses on the issues for students with autism, which is the focus of the work of this Association.

Are current policies and programs for students with Autism Spectrum Disorders adequate to meet their education needs?

Educational services for children with autism in NSW

The Autism Association of NSW (AANSW) is currently the primary non-government specialist service provider for children and adults with an Autism Spectrum Disorder in NSW.

The AANSW provides *early intervention services* in the Sydney region. Number of children and their families receiving home based and centre based early intervention programs in 2001 was 295.

The AANSW operates six *schools* for children with autism in the Sydney region and in regional NSW with 321 children currently enrolled in either the 6 base schools or in 30 support classes operated by the AANSW in mainstream government and non government schools.

The AANSW also provides *itinerant support services for students in mainstream schools* in the Sydney region with 839 students and their families receiving outreach services in 2001.

Demand for all services is very high across all AANSW children's services with more students waiting for services than there are currently receiving them.

The AANSW also provides a range of indirect services such as training and information and a help desk, in addition to consistently working to raise public awareness of autism.

Autism is a complex **developmental disability** in which there is dysfunction of some parts of the brain and central nervous system. Autism affects the way a child learns to understand and use communication, to interact with other people and make sense of the environment.

The term "Autism Spectrum Disorders" is used to describe a range of disorders, the most significant of which are Autistic Disorder and Aspergers Disorder. The term "autism" is used in this paper to mean "Autism Spectrum Disorders". For a diagnosis of Autistic Disorder or Aspergers Disorder to be made there must be evidence of significant deficits in three areas of functioning: communication, social relating and imagination, (evident by observation of repetitive ritualistic behaviour, restricted interests) DSM-IV R (1994). Aspergers Disorder is frequently diagnosed if there is

no associated intellectual disability associated with the characteristics of autism. In addition to characteristics included in the formal diagnostic framework we know that autism is usually, if not invariably, associated with significant sensory problems resulting from extreme sensitivity or insensitivity to sensory input, (e.g. sound, sight, touch). Motor problems are often associated with Aspergers Disorder, (Wing, 1981)

How many children have autism?

Historically the reported incidence of autism was 4:10,000 internationally. This has been revised over the past decade and is now conservatively 27 per 10,000 (Fombonne, 2001) with some studies putting the figure as high as 93:10,000 (Ehlers & Gillberg, 1993). As a result the estimated number of children with autism in NSW ranges from 5,000 to 15,000.

While there is agreement that there has been an increase in the incidence of Autism Spectrum Disorders, there is a great deal of debate about the possible cause(s) of this rise with no clear conclusions to date. However, it is clear that assessment services are identifying more children at a younger age especially those with High Functioning Autism (HFA) and Aspergers Disorder with service providers universally reporting a significant increase in the demand for services.

At the Autism Association of NSW, we believe that we are in an excellent position to draw the attention of the committee to the particular issues faced by children with autism and their families in NSW in accessing all levels and sectors of education. The issues of concern can be summarised as follows:

- Failure of those developing policy, funding and providing services to understand the strengths and needs of children with autism and their families.
- Failure to understand and address the implications of this rising demand for services (which may or may not be entirely attributable to better identification.)
- Failure of the government sector provide appropriate educational services or to provide adequate funding for non-government services to provide these services.
- Failure to understand the difficulties for people with autism and their families with self-advocacy due to the fundamental characteristics of autism.

The criteria used to define disability and to differentiate between levels of handicap.

Since July 2000 the NSW Department of Education and Training has recognised autism (DSM-IV, 1994) as a developmental disability and the Commonwealth (DETYA) accepts the state criteria for disability. However this is not consistent across government departments in NSW, for example DoCS provides services only to those children with a diagnosis of autism and a significant intellectual disability, effectively denying services to 80% of children with autism, regardless of their level of support needs. Australian and international research indicates that children with HFA and Aspergers Disorder have very high support needs as a result of high incidence of behavioural and emotional disturbance such as anxiety and mood disorders, (Tonge, Brereton, Gray and Einfeld, 1999, Kim, Szatmari, Bryson, Streiner, Wilson, 2000).

The criteria used to define autism and assess support needs are set out in the major classification systems DSM-IV, 1994 and ICD-10. Both of these systems fail to adequately describe several important characteristics of autism, which consequently may be overlooked. These are:

- ❑ The sensory aspects of the disability and problems processing the sensory information that is received
- ❑ The social aspects of the disability are poorly defined with no adequate diagnostic criteria for social deficits or deficits of empathy
- ❑ The communication problems associated with HFA and Aspergers Disorder (Primarily problems with pragmatics/conversational skills and understanding of overall meaning)

There are no adequate standardised approaches to the diagnosis of all the characteristics of autism resulting in lack of accuracy and sensitivity in the diagnosis of the disability and most particularly in the assessment of level of support need. As a result referrals may be inappropriate or children with autism are excluded from appropriate services.

Although the NSW Dept of Education & Training (DET) has criteria for the identification of autism the experience of many families is that these are applied inconsistently and sometimes too late for the child, in that, typically, autism is not recognised until the child's behaviour breaks down as a result of the failure to recognise and address support needs. Behaviour problems result when autism and the child's related needs are not understood and met. Therefore, in effect, what is being assessed is not the child's autism but the failure of existing services to meet the needs of the child with autism. This is particularly common for children with HFA and Aspergers.

The accuracy with which students disability related needs are being assessed

Difficulties with the assessment and diagnosis of autism are compounded when strengths and needs are assessed. The expression of the characteristics of autism, which result in the need for support, is likely to be variable between individuals and within any one individual. For example the three clusters of characteristics necessary for a formal diagnosis to be made, may vary. For example a child with autism may have a very pronounced communication and social deficit with mild expression of obsessive repetitive behaviour and restricted interests. In addition characteristics of autism which are not directly observable and are not included in the major diagnostic classification systems (DSM-IV and ICD-10) are frequently overlooked completely. Support needs related to sensory over or under sensitivities, and distortions, perceptual, processing, attentional deficits, differences in thinking and learning styles, and deficits in empathy, are often not identified let alone described in terms of the resulting needs.

To compound the challenge of assessing support needs the manifestation of characteristics may also vary across settings. For example a child with autism in an autism specific unit may appear to be functioning within the normal range however if the same child is in a crowded community setting such as a supermarket or in the school playground their autism will be very evident. Too often disability needs particular to autism are not identified in the first instance. The child responds to this

with escalating levels of inappropriate behaviour driven largely by fear and frustration and is then assessed as having high behaviour support needs. Strategies employed to meet behaviour support needs may or may not address the autism-related needs. If they do not they will be unsuccessful and challenging behaviour will escalate further frequently resulting in exclusion from school.

Unfortunately there is no universal instrument to assess the support needs of children with autism spectrum disorders.

The particular needs of students with disabilities from low socio-economic, non-English speaking and indigenous backgrounds and from rural and remote areas.

Students from low socioeconomic backgrounds in NSW are doubly disadvantaged in that their families may not have the resources to access non-government services for which fees are charged. There is a consequent restriction of choice and in some cases inability to access any appropriate services at all.

For families of NESB there are all the difficulties associated with dealing with a complex and at times baffling disability for which there may not even be a name in their first language.

Children from rural and regional NSW are particularly disadvantaged as services are very limited and almost always generic, ie not disability specific. Families in country areas tend to be very resourceful but levels of frustration and distress are high because the service providers they are dealing with, may not even have the most fundamental understanding of the disability and appropriate services are not available. For example there are almost no experienced diagnostic and assessment services outside the Sydney metropolitan area and as a result families must travel to Sydney for assessment and diagnosis.

The AANSW conducts regular training in regional centres across the state and as a result staff are very familiar with the thirst for information about autism and for strategies for its management.

The effectiveness and availability of early intervention programs

There is a great deal of regional variation in the availability of effective early intervention programs for children with autism. Specialist services, such as the home based and centre based programs operated by the AANSW, cannot meet the demand. Government services tend to be very poorly resourced. Those who can afford it, tend to seek out non-government services where these are available. Those who cannot afford it or who do not have access to non-government services tend to miss out. Some generic early intervention service providers do understand autism and are able to meet the child's needs but this is not usual, with few early intervention providers having any training in autism.

Autism is characterised by problems with generalisation of knowledge, what is learned in one setting will not automatically be generalised to others. As a result

taking a child out of their normal environment and teaching them skills in a clinical setting will not result in those skills being transferred to their daily environments. The AANSW has found that teaching children with autism is most effective if it is done in their normal environment involving those with whom they usually interact.

The HFA/Aspergers group is particularly disadvantaged in early childhood because of the difficulties of assessment and diagnosis. Most services require a diagnosis as part of their accountability requirements. Unless children with HFA/Aspergers behave badly they tend to be overlooked, and miss critical learning opportunities.

Access to and adequacy of funding and support in both the public and private sectors

Resources are not adequate to support children with Autism Spectrum Disorders in educational settings in NSW. Access to service provision varies from autism specific school placements (currently 320 in AANSW schools and approximately 30 places in DET autism classes) to 1-2 hours of aide support per week in a mainstream setting. It is not uncommon for students with autism to be either excluded from school or offered part placement because the state education system is unable to meet their needs. Funding is required to boost professional skill development, to support families, to provide more specialist classes and specialist (trained) aide support.

The nature, extent and funding of programs that provide for full or partial learning opportunities with mainstream students

There is a particular need in this area as manifest by the high level of demand for the Association's school outreach service in NSW. There are particular stresses on children, their families and their teachers at points of transition, particularly school entry and the transition from primary to high school and from high school to TAFE or other post school options. There is a major issue of continuity of service and restricted and/or inadequate models of service provision. Survival at high school is a particular challenge with many adults with autism reporting that this time was the worst of their lives. Students with HFA and Aspergers rarely achieve their learning potential with many capable students leaving school prior to the HSC despite exceptional abilities in some subject areas.

Some TAFEs are meeting the needs of students with autism but this is not consistent across the state and the support needs of students with autism are frequently overlooked. The AANSW has developed autism specific study skills workshops for students with autism, which are structured and visually based, (visual perception and processing in autism is typically superior to auditory processing). There is a need for programs such as these to be available to all students with autism in the secondary and tertiary system.

Ideally service delivery would be seamless, flexible and focused on transition points in the education process. Services provided should address the characteristics of autism and most importantly be based on assessment of individual strengths and needs.

Teacher training and professional development

There is a very marked need for specialised training for all those working with students with autism. Training needs to be incorporated into the pre-service training of all teachers and therapists likely to work with children with autism in the education system. The current provision of pre-service training in special needs for teachers in NSW is woefully inadequate and may at best only touch on autism in passing. There is a need for long-term ongoing provision of skill development for those working in the field and there is a need for highly trained specialist support staff/consultants who can provide school staff with the specialised assessment and program support students with autism are likely to require.

The legal implications and resource demands of current Commonwealth and state territory legislation

The state has a legal and moral responsibility to ensure that students with disabilities have access to education. The provision of appropriate educational programs for children with autism in our schools, based on their strengths and needs, must be a right and not a privilege or stroke of luck.

Children and young people with Autism Spectrum Disorders now represent one of the largest groups of people with a particular range of disabilities that must be specifically addressed. Autism is not as visible as some other disabilities but the educational needs of these students are challenging and require specific training by the professionals involved in their schooling. The Association calls on this inquiry to review all aspects of policy and resourcing as it affects children and young people with autism across Australia.

Representatives of the Association would be prepared to address the inquiry in person if this was required.

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