

**The Prevalence of Autism in Australia**  
**Can it be established from existing data?**

**A report prepared for**  
**Australian Advisory Board on Autism Spectrum Disorders**  
(formerly known as the Autism Council of Australia)

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## ABBREVIATIONS

<i>Abbreviation</i>	<i>Organisation, Department,</i>
AA	Autism Association
AACT	Autism ACT (Autism Association Australian Capital Territory)
AANT	Autism Association (Northern Territory)
AAWA	Autism Association of Western Australia
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AISWA	Association of Independent Schools of Western Australia
AQ	Autism Queensland (Autism Association)
ASA	Autism South Australia (Autism Association)
ASIQ	Association of Independent Schools of QLD
ASPECT	Autism Spectrum Australia (formerly Autism Association of NSW)
AT	Autism Tasmania (Autism Association)
AV	Autism Victoria (Autism Association)
Cath Ed	Catholic Education Office of WA
CDAC	Department of Aged Care (Commonwealth)
CDoH	Department of Health (Commonwealth)
Centrelink	a Department of Human Services agency
CSTDA NMDS	Commonwealth State/Territory Disability Agreement National Minimum Data Set
DADHC	Department of Ageing, Disability and Home Care (NSW)
DE	Department of Education (TAS)
DEA	Department of Education and the Arts (QLD)
DECS	Department of Education and Children's Services (SA)
DET	Department of Education and Training (WA, ACT, NSW, VIC)
DEET	Department of Employment, Education and Training (NT)
DEST	Department of Education, Science and Training (QLD)
DEWR	Department of Employment and Workplace Relations (Commonwealth)
DFC	Department for Families and Communities (SA)
DHCS ACT	Department of Disability, Housing and Community Services (ACT)
DHCS NT	Department of Health and Community Services (NT)
DHHS	Department of Health and Human Services (TAS)
DHS	Department of Human Services (Commonwealth)
DHS VIC	Department of Human Services (VIC)
DSC	Disability Services Commission (WA)
DSQ	Disability Services Queensland
FaCS	Department of Family and Community Services
FaCSIA	Commonwealth Department of Family, Community Services and Indigenous Affairs (formerly FaCS)
HACC	Home and Community Care (HACC) Program
HAAC MDS	Home and Community Care Minimum Data Set
IDSC	Intellectual Disability Services Council (SA)
NDA	National Disability Administrators
NSO	Australian Government Targeted Program: Non School Organizations

QH	Queensland Health
SDR	Severe Disabilities Register
TACT	Therapy ACT (a DHCS agency)
TEMHS	Top End Mental Health Service (NT)
	<b>Personnel</b>
Clin Psych	Clinical Psychologist
GO	Guidance Officer
MDT	Multi Disciplinary Team
OT	Occupational Therapist
Paed	Paediatrician
Psych	Psychologist
Psychtr	Psychiatrist
PT	Physiotherapist
SP	Speech Pathologist
SW	Social Worker
	<b>States and Territories</b>
ACT	Australian Capital Territory
NSW	New South Wales
NT	Northern Territory
QLD	Queensland
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

## TERMINOLOGY

<b>Terminology</b>	<b>Definition, explanation</b>
Incidence	A measure of the number of new cases of a condition occurring in the population over a defined period of time
Prevalence	A measure of the number of cases of a disorder in a defined population at a particular point in time
Denominator	Refers to individuals either at risk for a disease or condition (incidence) or in the population at the particular point in time (prevalence)
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders 4 <sup>th</sup> Edition (DSM-IV). Published by American Psychiatric Association 1994. DSM_IV-TR (Text Review edition) published 2000. Standard classification of mental disorders used by mental health professionals internationally
DSM-IV PDD	Pervasive Developmental Disorders category in the DSM-IV includes: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS).
ICD-10	International Classification of Diseases 10 <sup>th</sup> Revision (ICD-10).

	Published by World Health Organization 1994. The international standard diagnostic classification used for general epidemiological and many health management purposes.
ICD-10 PDD	Pervasive Developmental Disorders category in the ICD-10 includes: childhood Autism, Atypical Autism, Rett's Syndrome, Other Childhood Disintegrative Disorder, Over reactive disorder with mental retardation with stereotyped movements, Asperger's Syndrome, Other Pervasive Developmental Disorder and Pervasive Developmental Disorder, unspecified.
Autism Spectrum Disorder (ASD)	Autism Spectrum Disorder. Currently used interchangeably with Pervasive Developmental Disorder (PDD) in the literature and in common practice to refer to Autism, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). However there is no existing diagnostic classification system that uses this term.
Autism	Includes Autistic Disorder (DSM-IV) and Childhood Autism (ICD-10)
Asperger Syndrome (AS)	Used for Asperger Disorder (DSM IV) and Asperger Syndrome (ICD-10)
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified as described in DSM-IV; relates to ICD-10 classification of Atypical Autism, Other Pervasive Developmental Disorder and Pervasive Developmental Disorder, unspecified.
EI	Early Intervention: typically refers to the provision of therapeutic services provided to a child prior to entering Year 1 and/or who is aged less than 6 years
IEP	Individualized Education Program: the intervention plan that is devised, usually within an educational setting, to provide services to a child who has demonstrated special learning needs
ID / IH	Intellectual Disability / Intellectual Handicap: these terms are often used interchangeably to indicate an individual who has been assessed, using a standardized test of intellectual functioning and adaptive functioning, and subsequently diagnosed with a disability in this area.
ABA	Applied Behaviour Analysis: a behaviour-based intervention approach frequently used with children with ASD
HFA	High functioning autism: this is not a formal diagnostic category. It is a term in frequent use to describe people with a diagnosis of Autism who do not also have a diagnosed Intellectual Disability. It is not intended to describe any particular level of adaptive functioning.

## EXECUTIVE SUMMARY

This report is the first publication to estimate prevalence rates of children with ASD across Australia while taking into account information about diagnostic practices and intervention services for all Australian states and territories. The study arose from the continuing concern of increasing ASD prevalence in Australia and the lack of data about the number of affected children across the nation.

This study used a consistent method of case ascertainment to collect data across several data sources, including the health, disability and education sectors as well as the Autism Associations in each Australian state and territory. Information was sought on the number of cases registered with each agency, the diagnostic methods in place, pathways to diagnosis, as well as administrative and policy details in order to account for any differences seen between geographic regions.

The 2005 Centrelink data provides an estimated prevalence of autism spectrum disorders in Australia for 6-12 year olds of 62.5 per 10,000. At the current time, Centrelink provides the most comprehensive single source of National information about the number of individuals seeking funding with a diagnosis of Autism or Asperger Disorder in Australia. However, this data is incomplete in relation to individuals aged between 13 and 16 years with autism spectrum disorders and provides no information about individuals with PDD-NOS. Using national disability data provided by the Australian Institute of Health and Welfare (AIHW), and Centrelink data, this study found the prevalence of autism in Australia in 2003-2004 to range from 8.5 to 15.3/10,000 for 0-5 year olds, 12.1 to 35.7/10,000 for 6-12 year olds and 8.3 to 17.4/10,000 for 13 to 16 year olds, with a two-fold difference evident between the AIHW and the Centrelink data. According to available State and Territory data, the prevalence of autism in 2003-2004 ranged from 3.6 to 21.9/10,000 for 0-5 year olds, 9.6 to 40.8/10,000 for 6-12 year olds and 4.4 to 24.3/10,000 for 13-16 year olds.

The collected data, through their inconsistency, confirm that there are significant differences in the way children with ASDs are diagnosed, directed to services, and are offered different support schemes across Australia. Administrative services appear vastly different in the way their data is collected, stored and presented, according to their separate organisational objectives and client-focus. If good measures of Australian ASD prevalence are to be calculated and then re-calculated over time, streamlining of data collection methods is necessary across sectors and states/territories. Of particular concern is the current inability of agencies to provide good data on subgroups of children, in particular gender breakdowns, geographic locations, Indigenous status and presence of intellectual disability. These factors are important to the demography of ASD in Australia and are essential for the successful planning of services and support of affected children.

In response to the observed international trends in autism diagnoses and the findings of this current study, it is strongly recommended that for Australia to gather reliable information about the prevalence of ASD for national, State and Territory use, the development of additional data systems within both the private and government sectors is required.



Collection of valid and reliable prevalence data about autism will require a national consensus based on an understanding of the Australian context and best level evidence about diagnosis and assessment of children with autism, so that agreed approaches and standards are available and implemented. This type of diagnosis and assessment consensus is urgently needed, not only to ensure valid prevalence estimates, but to ensure appropriate provision of interventions to those in need.

Some possible pathways for ensuring comprehensive and valid national prevalence data in Australia would be to:

1. Explore ways of accessing Centrelink data at State/Territory level and possible ways in which identified information could be provided for validation and data-linkage to other data sources.
2. Explore ways of extending CTSDA-NMDS activity to other service providers for ASD and into the private sector.
3. Develop a virtual register of individuals with ASD (in line with a recently funded initiative in the US) that is linked to service information and best evidence dissemination.

Until a National approach to collection of prevalence data about autism is implemented, it is not possible to ensure that services are being provided to those who need them in a timely fashion and, as such, it is unlikely the potential of each individual with autism is being optimised. Opportunities to undertake useful research that has the potential to improve the lives of those affected and their families, are also being missed.

## INTRODUCTION

Australia has witnessed an increase in the number of individuals being diagnosed with an autism spectrum disorder. For example, in Western Australia over the past two decades, the number of new diagnoses per year has increased nearly 20-fold (Birnbrauer et al 1988; Glasson 2002), with more than 200 children newly diagnosed with an autism spectrum disorder in 2004 (Glasson et al 2006). This increase in identified children with autism spectrum disorders has been observed in other parts of the world (Chakrabarti & Fombonne 2001; Bertrand et al 2001; Croen et al 2002; Prior 2003; Williams et al 2005c; Chakrabarti & Fombonne 2005) and has led to (1) funding for development of ongoing data collection to monitor trends over time (Centers for Disease Control; MADDSP 2004 and ADDM Network 2006; Rice et al 2004), (2) development of national strategies and guidelines for diagnosis and assessment of autism spectrum disorders (Filipek et al 1999; Le Couteur et al 2003), (3) service support and development for the identification of ASD (Honda et al 2005; Chakrabarti & Fombonne 2001) and (4) early intervention service development and co-ordination (Le Couteur 2003; New York State Department of Health 1999; Shields 2001; Honda & Shimizu 2002). In Australia, this trend in diagnoses has raised concern amongst clinicians, service providers, administrators, and the general public. However, in the absence of any large scale study, the actual prevalence or incidence rates for autism spectrum disorders in Australia are unknown and little has been invested in development of approaches or systems to clarify local information. As a result non-Australian studies are commonly reviewed for estimates of population prevalence at a time when between country differences, as well as similarities are being reported (Williams et al 2005a).

Kanner first described what he called “early infantile autism” in 1943. While he never went on to suggest prevalence rates for this disorder, he assumed that it was rare (Wing 1993). The first epidemiologic study of autism was conducted by Lotter in England in 1966. The researchers applied Kanner’s criteria and used a large, population based methodological approach. This study yielded a prevalence rate of 4-5 per 10,000 children (Wing 1993; Howlin 2002; Yeargin-Allsopp & Rice 2004). Early studies using Rutter’s criteria (1978) yielded rates ranging from 1.9 to 5.6 per 10,000 (Yeargin-Allsopp & Rice 2004) and other studies published before 1985 that used similar diagnostic criteria also yielded prevalence rates of 4-6 per 10,000 (CDC 2001).

The publication of the *Diagnostic and Statistical Manual of Mental Disorders-3<sup>rd</sup> Edition* –DSM-III (American Psychiatric Association 1980) saw pervasive developmental disorder (of which infantile autism was a variant) become a diagnostic entity in its own right (Yeargin-Allsopp & Rice 2004; Wing 1993; Tidmarsh & Volkmar 2003). Subsequent studies, such as in Japan, US and Sweden, using DSM-III criteria reported rates ranging from 3.3 to 15.5 per 10,000 (Yeargin-Allsopp & Rice 2004; Wing 1993). The DSM-III-R was published in 1987 (American Psychiatric Association 1987) and included the introduction of the category of PDD-NOS. Studies using these criteria reported rates between 7.2 and 9.4 per 10,000 for people diagnosed with all three disorders described under the PDD diagnostic umbrella (Yeargin-Allsopp & Rice 2004).

In a review of 32 studies conducted between 1966 and 2001, Fombonne (2003a) summarized that a conservative global prevalence estimate for all PDDs is at least

27.5/10,000, including autism (10/10,000), PDDNOS (15/10,000) and Asperger syndrome (2.5/10,000). He also notes that three recent epidemiological surveys by Bertrand et al 2001, Baird et al 2000 and Chakrabarti and Fombonne 2001, yielded rates for PDD as high as 60/10,000. While his review found that studies conducted after 1987 reported consistently higher rates than those conducted prior to this period, this upward trend in prevalence rate cannot be directly attributed to an increase in incidence. Further studies including methodology which tightly controls for probable variability factors are required to investigate the question of increases in incidence. At this time, Fombonne suggests that these changes in prevalence rates reflect changes in case definition and improved recognition by both the lay and professional public. He suggests that future investigations should aim at setting up surveillance programs. This would allow improved estimates of incidence of PDDs (as opposed to autism only) and improved monitoring of changes over time. At the same time, it would be crucial to set up parallel investigations in different geographical areas allowing replication of findings across areas as a validating tool.

In 1994 the DSM-IV (American Psychiatric Association 1994) was published and, for the first time, the criteria for autism and related conditions were aligned with the 1992 edition of the *ICD 10- International Statistical Classification of Disease and Related Health Problems, 10<sup>th</sup> Revision* (World Health Organisation 1992). Both classification systems had also broadened the diagnostic criteria further to include Asperger Syndrome (Yeargin-Allsopp & Rice, Tidmarsh & Volkmar 2003). Studies using either DSM-IV or ICD-10 have yielded rates that range from 4.9 to 67 per 10,000, with several studies using population screening tools reporting consistent rates from 20 to 60/10,000 (Yeargin-Allsopp & Rice 2004, Tidmarsh & Volkmar 2003, Fombonne 1999, Chakrabarti & Fombonne 2001, Chakrabarti & Fombonne 2005, Bertrand et al 2001, Yeargin-Allsopp et al 2003, Williams et al 2005c, Croen et al 2002).

Chakrabarti and Fombonne conducted a population based study in the Staffordshire area of England in 1998-1999 (Chakrabarti & Fombonne 2001). The study employed intensive screening procedures and included 15,500 children aged between 2.5 and 6.5 years. They reported prevalence rates of 16.8/10,000 for autistic disorder and 62.6/10,000 for all PDDs. The researchers repeated their study, in the same area with a later birth cohort, in 2002. They reported a combined prevalence rate for all PDDs of 58.7/10,000. Comparison of the prevalence rates between the two studies found no statistical differences. As a result, they calculated a combined prevalence rate for the two studies, for all PDDs, excluding Rett's disorder, of 60.6/10,000 (Chakrabarti & Fombonne 2005). These findings are similar to those reported in other recent population studies (Bertrand et al 2001, Yeargin-Allsopp et al (2003).

Williams et al (2005a) conducted a meta-analysis review of 42 ASD prevalence studies published between 1966 and 2003. Meta-regression was used to explore the influence of various methodological factors and population characteristics on estimated prevalence. Their investigation identified a high degree of heterogeneity amongst the studies with an overall random-effects estimate of prevalence across all of the studies of 7.1/10,000 for typical autism and 20.0/10,000 for all ASDs. The factor found to be most significantly associated with prevalence rates for both typical autism and all ASDs was the diagnostic criteria used. Other significant factors included the age of the sampled children, geographical location and urban or rural location.

Prior (2003), an Australian ASD researcher, reviewed the possible factors which may be significant in the increase in clinical cases, both in Australia and internationally. These included changing diagnostic criteria, differing study methodologies, the coexistence of this disorder with a range of other conditions; heightened awareness of both professionals and the general public; an increase (though still inadequate) in services to meet the growing numbers of identified children which may then in turn also facilitate increased diagnosis; and the ongoing investigation of possible aetiological factors, as well as media publicity, both of which can affect public perceptions and result in increased case identification. In addition, reviews by Wing & Potter (2002), Williams Mellis & Peat (2005c) and Fombonne (1999 and 2003a) suggest that a range of factors including methodological differences between studies (such as ascertainment strategies, population sampling, sample size, method of analysis, age at diagnosis and diagnostic procedures and criteria used), referral patterns, diagnostic substitution, changes in the availability of services, the possible effects of migration into the area, and changes in public and professional awareness, make meaningful interpretation of prevalence rates and time trends across studies problematic.

Two reviews (Wing & Potter 2002; Fombonne 2003a) discuss the potential impact of changes in diagnostic classification systems on the reported prevalence of autism. Fourteen different diagnostic classification systems or instruments have been used in studies of the prevalence of autism. In two studies, cumulative incidence figures are reported for different diagnostic methods used (Arvidsson et al 1997; Kielinen 2000). In one study, the cumulative incidence when Kanner criteria were applied to cases was 5.6/10,000 (95%CI 4.4-6.8) and was statistically higher (12.2/10,000; 95% CI 10.5-14.0) when current DSM-IV and ICD-10 classification systems were used (Kielinen 2000). In the second study, the prevalence of ICD-10 childhood autism was three times higher than the prevalence of Kanner autism, but the difference was not significant (Arvidsson 1997).

The concept of autism as a spectrum of disorders has been useful to identify children with similar patterns of problems with social interaction, communication and behaviour (Wing & Gould 1979). In one state in Australia, Queensland, it has been reported to be widely and variably used (Skellern et al 2005a), with considerable variation regarding use of terminology and diagnostic constructs described (Skellern et al 2005b). In addition, in Queensland, specialist medical clinicians reported that, in the face of diagnostic uncertainty, they would provide an autism diagnosis on a service-providers form when their diagnostic specification had not been met (Skellern et al 2005b). The study findings indicated that when these clinicians 'upgraded' a child's symptoms to meet a service's eligibility criteria it was to enable the child to access limited funding resources that were tied to specific diagnoses. This practice occurred more frequently in regard to meeting Queensland's access requirements for special education services (which requires evidence of a DSM-IV category diagnosis of a PDD or some other qualifying disorder) than in the completion of Centrelink forms. The study authors conclude that these practices may at least partially explain the rapid increase in the number of students identified within the ASD category in the Queensland education system. They caution, therefore, that numbers resulting from educational ascertainment should not be considered a true reflection of the ASD prevalence rate in this state (Skellern et al 2005b). The prevalence of this practice in other states/territories of Australia is not known.

It is also important to consider the method of analysis used for studies reporting “prevalence” because cumulative incidence or birth prevalence estimates are likely to be higher than population prevalence (also called point prevalence) estimates. A statistically significant two fold increase in reported risk of autism is seen in the West Midlands study when cumulative incidence was calculated for children up to five years old born in 1990-1991 (16.2; 95%CI 10.6-23.8), compared to population prevalence (7.8; 95%CI 5.8-10.5) (Powell et al 2000).

Evidence from California (Croen et al 2002) suggests that diagnostic substitution may account for some of the observed increase, with a similar drop in the number of cases diagnosed with intellectual disability to those being diagnosed within the autism spectrum, however few geographic regions have been able to provide additional evidence for this phenomenon.

Within Australia, there have been few formal ASD prevalence studies. Icasiano et al (2004) conducted a study in the Barwon region of Victoria. The authors describe the area as a well defined geographical region, representative of regional Victoria, and with a stable population that included approximately 54,000 children at the time of the study (2002). The professional group providing diagnostic and intervention services to children in the area was well known and collaborative. The study collected data for preschool and school aged children who had been previously diagnosed with an ASD. A prevalence rate of 39.2/10,000 for all ASDs was established which represented a 10 fold increase in the rate of ASD diagnosis in the area over the past 16 years. Male/female ratio was 8.3:1. and age at diagnosis ranged from 2.3 years to 16.3 years. One of two specialist psychologists made 76% of the diagnoses (preschoolers), a multidisciplinary diagnostic team for school aged children made a further 11%, and another psychologist made the remaining 13% of the diagnoses. Diagnostic criteria for preschoolers were based on parental interview, child observation and the Psycho-Educational Profile – Revised (PEP-R) instrument while the school aged assessments were based on DSM-IV criteria. Of the 243 children included in the study, 50.8% had been formally diagnosed with Autism, 26.6% Asperger’s syndrome, 5.6% PDD-NOS and 16.9% with Autism Spectrum Disorder. The majority of diagnoses (74.1%) were made during 1997-2002 while 25.9% were made during 1986-1996. IQ classification was available for 131 children of whom 46.6% were intellectually disabled. As described above, the incidence and prevalence figures were reliant on individual clinician or team diagnoses without standardised diagnostic assessment or the use of validated diagnostic tools. Also incidence of autistic disorder was not reported separately. The authors state that while the increase in prevalence during the study period was relatively even across all levels of intellectual functioning there was an increase in the number of children in the normal IQ range diagnosed in 2002. They conclude that their identified increase in prevalence is consistent with international findings and attribute this increase to changes in diagnostic criteria, increasing community awareness and the need for support at all levels of intellectual functioning.

A comparison review of ASD diagnoses was made in the Australian Capital Territory (ACT) between the years 1997 and 1989 (Baker 2002). The 1989 study included a total of 17 children who were referred for ASD assessment and whose ages “ranged from younger than 3 years to 10 years of age”. The 1997 study included 45 children whose ages “ranged from younger than 3 years to over 14 years”. The author’s table includes groupings for both 0-3 years and children over 14 years. The author reports that, in spite

of population stability in the area, there was a significant increase in both referrals and positive ASD diagnoses between these years. The author also notes a reduction in male/female ratio from 8:1 to 3.5:1 between 1989 and 1997. The referral sources and procedures were similar during each of the data collection periods. However, it was not possible to ascertain the effect of varying assessment methodologies between the two time periods. In 1989, assessments were conducted by the study's author, who used the Childhood Autism Rating Scale (CARS) (Schopler et al 1986), the Abnormalities of Behaviour Profile of the Handicaps, Behaviours and Skills Schedule (Wing 1982), observations in various settings and discussions with significant others. Diagnoses were made on the basis of the assessment information and according to the DSM-III-R criteria. In 1997, assessments were conducted by the author as well as other psychologists who used an assessment protocol developed by the author. The author also acted in a supervisory role. A wider range of assessment tools were used including the CARS (Schopler et al 1986), the Developmental Behaviour Checklist (Einfeld & Tonge 1991), the Child Behaviour Checklist (Achenbach 1991), the Wing Autistic Disorder Interview Checklist (Rapin 1996), observations in various settings and discussions with significant others. Additional assessments used, depending on the child's age and presentation, included the Australian Scale for Asperger Syndrome (A.M.S. Garnett & Attwood 1995), the First Order Theory of Mind (S. Baron-Cohen et al 1985; for children  $\geq 4$  years) and Second Order Theory of Mind (S. Baron-Cohen 1989, for children  $\geq 7$  years). Diagnoses were made on the basis of the assessment results and according to DSM-IV criteria.

Buckley (2004) reported estimated Australian autism spectrum disorder incidence and prevalence rates based on both state and national data sources. The author reported that while diagnostic rates in Australia had risen significantly over the past 10-15 years, in line with international trends, his findings suggested that Australian rates had been 'reasonably consistent in recent years'. However, the gathered data does show wide variations in calculated rates at both state and national levels. Victorian prevalence rates are reported from data gathered from a specific service provision agency in 2000, a 2003 regional area report and a 2003 state wide study sponsored by DHS Victoria, and range from 27 to 54 per 10,000 for children aged 0-6 years. Nationally, the author indicated that data derived from the Australian Bureau of Statistics's (ABS) 1998 and 2003 Survey of Disability, Ageing and Carers (SDAC) showed a two fold increase in the number of Australians under 15 years of age with an identified ASD, and that the 2004 Department of Family and Community Services data, for children under 16 years of age and in receipt of the Carer's Allowance, provided a prevalence estimate of 34 per 10,000 for Autism Disorder and Asperger's syndrome combined. The author highlights the need for accurate incidence and prevalence estimates in order to adequately plan for the current and future needs of people with an ASD thereby enabling them to maximize their potential to participate in their communities.

In 2003 the Victorian Government Department of Human Services (DHS) published an investigation of prevalence and service delivery for children aged 0-6 years in that state. The research team contacted all public and some Applied Behavioural Analysis program providers delivering intervention services for children with either diagnosed or probable ASD. Data was collated on the basis of DHS geographic regions and estimations of prevalence were then made for areas in which all service providers responded and for whom all data were included. The study reported an estimated prevalence rate of 27 per 10,000 for children aged 0-6 years with diagnosed or

suspected ASD as of June-July 2002. Only 5 percent of these children were considered to be either high functioning or to have Asperger's Syndrome, while 56 percent of the children were reported to have a formal or informal diagnosis of ASD rather than autism or Asperger's Syndrome. In line with other studies, the reported male to female ratio was approximately 4:1.

Other attempts at gathering Australian data were reported by Williams et al (2005b) and include an ongoing ASD Register in Western Australia and a system of active surveillance for 18 months in New South Wales. The WA Register for Autism Spectrum Disorders was established in 1999. The Register collects details of all newly diagnosed cases of autistic disorder, Asperger disorder and PDD-NOS in WA. All diagnoses are based on DSM-IV criteria. Informal networks are in place to encourage reporting of all diagnoses to the register by both public and private practitioners. Missing cases are identified and followed up at the end of each calendar year. A system of active surveillance was established in NSW between July 1999 and December 2000. Medical, educational and community professionals who might have contact with children with autism were recruited for the study. These professionals were contacted on a monthly basis and asked to provide detailed information for all new cases, up to 14 years, who met at least one DSM-IV criterion for autistic disorder. Comparative incidence rates for Western Australia and New South Wales were estimated based on the number of children from the two States, aged 0-14 years, who were identified with autistic disorder, Asperger disorder or PDD-NOS, between July 1999 and 2000. Incidence in the 0-4 age group in WA was 5.5/10,000 and 8.0/10,000 for all ASDs. Comparable figures for NSW were 4.3 and 5.1/10,000. The incidence was found to be lower in older age groups. It was concluded that the differences between the States were most likely a result of differing ascertainment procedures.

It is apparent from the available local and international data that large regional differences exist in diagnostic methods and case ascertainment, which are both influenced by changes in local policies over time. It is therefore important to base prevalence estimates on the specific region under investigation, and this includes specific rates for Australian children using current Australian data. These data must be collected in a way that provides sufficient similarity between diagnostic ascertainment and analysis methods across the nation in order to produce information that is relevant locally.

This current study attempts to calculate estimates of current national prevalence for Autism Spectrum Disorders for children in the Australian population from existing data sources. It uses multiple sources from each of the States/Territories and national data, primarily from government sources. It describes data collection and use, diagnostic practices, intervention services and funding arrangements currently occurring in Australia. The challenges inherent in estimating a national Australian ASD prevalence rate using administrative data are discussed and recommendations made for future developments in this area.

## **METHODS**

This study was funded by a grant provided by the Department of Family, Community Services and Indigenous Affairs (FaCSIA), formerly known as the Department of Family and Community Services (FaCS), to The Autism Council of Australia Ltd (ACA). A research proposal and design by the research team was approved by the ACA prior to commencement. Ethical approval for the study was granted by the Children's Hospital At Westmead Research Ethics Committee, and the Women's and Children's Health Service Ethics Committee in Perth Western Australia.

### **Autism Council of Australia (Ltd)**

At the time of funding this proposal the ACA described itself as "...the national peak body representing people who have an autism spectrum disorder, their families, carers and helpers." The autism associations in each of the States and Territories comprise the corporate members of the Council. Through these member organizations, the ACA represents over 12,000 people who live with an autism spectrum disorder. The ACA also works "...with governments to develop appropriate policies for people who have an autism spectrum condition, their families and carers, disseminating information about ASDs and working with the Australian ASD community to build skills."

### **Commonwealth of Australia**

Australia consists of six States, New South Wales (NSW), Queensland (QLD), South Australia (SA), Tasmania (TAS), Victoria (VIC) and Western Australia (WA), and two Territories, the Australian Capital Territory (ACT) and the Northern Territory (NT). In July 2005, the beginning of the data collection period for this study, the Australian population was 20,328,600 of which 4,533,355 were children aged between 0-16 years of age. The gender ratio for this age group was 1.05 males to every 1.0 females. The distribution of the population for the States and Territories is as follows; NSW (33.1%), VIC (24.1%), QLD (20.3%), WA (10.1%), SA (7.2%), TAS (2.4%), ACT (1.6%) and the NT (1.2%). (Australian Bureau of Statistics, 2005).

### **Inclusion criteria**

The study sought information from targeted respondents for children aged 0-16 years of age who were identified as having a diagnosis of ASD (Autistic Disorder or Childhood Autism, Asperger syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)). Information was not sought on children with a diagnosis of Rett Disorder or Childhood Disintegrative Disorder. Where possible, respondents were asked to provide information on any known co-morbid conditions for the targeted group.

### **Case Ascertainment**

This study relied on the reporting of summary administrative data by the targeted respondents. Respondents included the major disability agencies, education agencies and autism associations in each of the States and Territories, as well as the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and



Centrelink. To respect individual privacy and confidentiality protocols of organizations, information about individuals or identified data was not requested. As a result it was not possible to compile data from different sources in a way that would take account of duplicate reports of the same individual from more than one source.

## **Agency Descriptions**

Appendix 1 provides detailed information about each agency and contact information. Below is a summary of information about each agency that is relevant to this study.

### **Centrelink**

Centrelink is an agency of the Australian Government's Department of Human Services and answers directly to its Federal Minister. This agency is charged with delivering a wide range of services to the community on behalf of ten different government policy departments. One of the government funded services administered by Centrelink is the Carer Allowance (Child). This allowance is payable to the carer who has a child under the age of 16 living in their home with a disability or severe medical condition which requires a lot of additional care or attention within their own home. Both carer and child must meet specific residency requirements. The Child Disability Assessment Tool (CDAT) is used by Centrelink to assess medical eligibility for the Carer Allowance (Child). However, certain diagnoses permit "fast-track entry" to the allowance without the need to meet any additional eligibility requirements, of which Autistic Disorder is one condition.

### **Commonwealth State/Territory Disability Agreement**

The Commonwealth State/Territory Disability Agreement (CSTDA) is a publicly funded agreement, which in 2003/04 had a value of \$AU3.3Billion. The CSTDA-National Minimum Data Set (NMDS) is a set of nationally significant data items that are collected in all Australian jurisdictions (States and Territories) in an agreed manner and timeline. This process is a way of fulfilling the administrative and public reporting responsibilities of this disability agreement.

### **Australian Institute of Health and Welfare**

The Australian Institute of Health and Welfare (AIHW) is Australia's national agency for health and welfare statistics and information. This agency is an Australian Government statutory authority within the Health and Ageing portfolio and reports directly to the portfolio Minister. One of the roles of the AIHW is the collection and analysis of data related to the CSTDA of 2002-2007. Under this agreement, the National Disability Administrators (NDA) in all jurisdictions (one administrator per State or Territory) are responsible for ensuring the quality implementation of all aspects of the CSTDA-NMDS, in collaboration with AIHW. An important role of the NDAs is to ensure that the data collection process is implemented consistently within and between States and Territories.

Prior to 1994, no national data were available about disability support services. After a test period, a national 'snapshot day' data collection began in 1995 through the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS). Ongoing modifications and improvements continued, including the introduction of a statistical linkage key in 1999. The redeveloped Commonwealth/State Territory Disability Agreement National Minimum Data Set (CSTDA-NMDS) was implemented

nationally in 2002 with continued use of a 'snapshot day' data collection up to June 30, 2003. The first full financial year collection took place between July 1, 2003 and June 30, 2004. The data collected during this process has been used by Commonwealth and State disability agencies to inform planning, fiscal/budgetary requirements and submissions, payment subsidy levels for service users, national program evaluation and the monitoring of the agreement's program objectives and priorities. The data also allow national comparisons of various service uses, and an awareness of under-utilisation of funded services by particular groups such as people of Aboriginal and Torres Strait Islander origin. The data collection has included a specific data point for Autism since at least 1999. This disability category includes both Autistic disorder and Asperger Syndrome, however in AIHW reports they are included together in the single category of 'Autism'.

### **Disability Agencies**

Each State and Territory has a primary agency responsible for the development and implementation of policy relating to the needs of people with disabilities. These agencies act as the primary dispersers of both State/Territory and Commonwealth funds dedicated to disability. Some of these agencies also act in a dual role of service-funder and service-provider. All of these agencies are party to the CSTDA and contribute to the collection of CSTDA-NMDA which is then sent to the AIHW for analysis and review.

### **State/Territory Government Education Departments**

Publicly funded Education departments in each State and Territory have responsibility for providing educational services to all students from school entry to age 18 years. Names of departments and models for service provision for students with disabilities vary across States and Territories. A single administrative body in each State or Territory services all government education department students whether they are receiving regular and/or special education services.

### **Private Education Agencies**

In Western Australia the Catholic Education Office and the Association of Independent Schools are known to provide a range of support services to their enrolled students with disabilities, however private educational organizations in the other States or Territories were not identified by the study due to a lack of resources. Further investigation of this sector would be beneficial to any future study.

### **Autism Associations**

Autism Associations exist in each of the States and Territories, however their roles vary considerably. Associations in the smaller States and Territories (eg: TAS, NT, ACT) are focused primarily on providing family support and information. They may also act in both an advocacy and broader community education role when the need arises. Larger associations in the more populous States provide a range of services that may include assessment and diagnosis, centre-based programs, school-based support, outreach services and a range of services for post-school members. The primary focus of these groups is service provision. The operational guidelines for some associations limit the range of data that can be collected in regard to their client base.

## Data Collection

The primary Commonwealth, State and Territory agencies that collected data about and/or provided services to people with ASDs, were identified (**Table 1**). All of these agencies were asked to provide information.

QLD Ed Dept declined to provide data to the study due to concerns that “.....*the use of the term autism is not based on a nationally agreed definition so will lead to inappropriate data comparisons across jurisdictions. In addition, there is some contextual information that would be useful to accompany the data to ensure any interpretations and elaborations are based on qualitative as well as quantitative findings*”. Data provided elsewhere in this report for Education Queensland was sourced from the *Report of the Queensland Paediatric Quality Council, 2003: Morbidity and Mortality Sub-Committee*.

Two data collection questionnaires, designed to gather information about services provided and the numbers of children aged 0-16 years with autism, Asperger disorder or PDD-NOS, were developed by the study team and distributed to each agency. One questionnaire targeted agencies that provided direct intervention services to individuals with ASD (**Appendix 2**). The other questionnaire targeted agencies that acted in a broader administrative/funding role within each State and Territory but did not provide direct intervention services (**Appendix 3**). Some agencies within each of the States and Territories provided only one of these types of services, however, others provided both. Agencies were asked to select and complete one or both of the questionnaires depending on the services they provided. The Commonwealth agencies (AIHW and Centrelink) were approached to identify the types of information they were able to provide to the study. A formal questionnaire was not used with these agencies.

Questionnaires were sent, by both mail and e-mail, to nominated officers within each of the 27 identified agencies, along with a Letter of Endorsement from the ACA and a cover letter from the study team explaining the goals of the study and requesting the respondents' participation. Additional clarification, discussion and follow-up by both telephone and email, was provided when necessary. Questionnaire mail-out began in July 2005. The majority of responses were received by the end of March 2006 and final outstanding responses were collected by the end of May 2006.

Data about numbers of children known to have autism, Asperger disorder or PDD-NOS was provided by State and Territory agencies for the 2004-2005 period. Commonwealth agencies provided similar data for the periods 2003-2004 (AIHW) and 2004-2006 (Centrelink). State and Territory agencies also provided qualitative data, mostly relating to descriptions of changes in referral patterns and their agency's service provision for the period 1999-2005.

**Table 1 All identified Commonwealth, State and Territory agencies that collected data about and/or provided services to people with ASDs**

<i>Jurisdiction</i>	<i>Agency name</i>	<i>Supplied information</i>	<i>Information supplied or reason for not supplying information</i>
Commonwealth	ABS	YES	National population data accessed from website
	AIHW	YES	Prevalence data
	Centrelink	YES	Prevalence data
ACT	AACT	NO	Does not collect data. Volunteer run group; provides parent support and information service.
ACT	TACT	YES	Prevalence data for assessments completed between 2002 -2005. Limited descriptive data related to assessment process.
ACT	DET	YES	Prevalence data, brief descriptive data
NSW	DADHC	YES	Prevalence data same as CSTDA NMDS data provided to AIHW; limited descriptive data
NSW	DET	YES	No prevalence data; brief description of service provision changes
NSW	ASPECT	YES	Brief prevalence and descriptive data
NT	DEET	YES	Prevalence and descriptive data
NT	DHCS -TEMHS	YES	Prevalence and descriptive data
NT	AA	NO	Does not collect data. Provides parent support and information service.
QLD	DSQ	YES	Prevalence (not ASD specific) and descriptive data
QLD	DEST	NO	See explanation below
QLD	AQ	YES	Prevalence and descriptive data
SA	ASA	YES	Prevalence and descriptive data
SA	IDSC (DFC)	YES	Prevalence and descriptive data
TAS	DHS	NO	Referred study to AIHW for CSTDA NMDS data
TAS	DE	YES	Prevalence and descriptive data
TAS	AT	NO	Does not collect data. Provides parent support and information services.
VIC	DET	YES	Prevalence and descriptive data
VIC	DHS	YES	Prevalence and descriptive data but not ASD specific
VIC	AV	YES	Does not collect prevalence data; some descriptive data
WA	DET	YES	Prevalence and descriptive data
WA	Cath Ed	YES	Prevalence and descriptive data
WA	AISWA	YES	Prevalence and descriptive data
WA	DSC	YES	Prevalence and descriptive data
WA	AAWA	YES	Prevalence and descriptive data
WA	WA Register for ASD	YES	Prevalence and descriptive data

Prevalence data refers to the information collected on the questionnaire seeking information about numbers of children with autism spectrum disorders. This includes numbers of children from important subgroups such as age range, gender, indigenous status, intellectual disability, location (metro, rural/remote) and diagnosis (autism, Asperger disorder, PDD NOS).

Descriptive data refers to the descriptions of intervention services provided, data management, funding sources, assessment and diagnostic practices, referral patterns and agency related changes

## **Data analysis**

Information provided by State and Territory agencies about the number of children known to have autism, Asperger disorder and PDD-NOS, along with information about their age, gender, geographic location (rural/remote), Aboriginal or Torres Strait Islander identification and intellectual disability, was collated to highlight similarities and differences within and between reporting areas regarding availability of important subgroup information. Summaries of data from Commonwealth agencies were also developed. Within-state variations in numbers of children reported by different agencies precluded analysis of prevalence for information provided by State and Territory agencies. However, prevalence estimates were calculated for Commonwealth data. Approximate 95% confidence intervals were calculated using a formulae recommended for the analysis of proportions (Agresti et al 1998).

Qualitative data from the questionnaires was summarized according to State and Territories and divided into the areas of assessment and diagnostic practices, data uses, intervention services and funding, referral patterns and agency changes. Trends, similarities and differences across State and Territories as well as Sectors are identified and discussed.

## **RESULTS**

### **Questionnaire Response Rate**

As shown in **Table 1** a response rate of 85% was achieved across all respondents. Of the 15% of agencies that did not respond to the request for information. The reasons given for non-participation included the size of the agency (eg: smaller autism associations); the agency's primary focus being on immediate service provision with limited resources for data collection (eg: some autism associations); data available from the agency was already seen as being provided through an alternate source (eg: CSTDA-NMDS collection); and concern about variable national and State/Territory usage of terminology such as ASD and its implications for data collection and service delivery.

In addition, while the majority of targeted agencies provided a response, the complexity and completeness of these responses varied widely, across both states/territories and sectors (ie: education, disability, autism association). For example, while some agencies provided detailed information for both the prevalence and qualitative questions, others only provided data relating primarily to age and gender for their client populations leaving many questions unanswered.

Considerable time and effort was made to identify the appropriate recipient within each agency. The organizational structures of many of the larger government agencies did not always make either the appropriate department or individual contact readily available to outside requests. In addition, initial enquiries frequently resulted in multiple redirections within the agency, lengthy response times, and the need for multiple communication attempts, before an appropriate contact was made. Similarly, many agencies required extended response times and several prompts in order to return their completed questionnaires. One of the reported challenges for many agencies in completing the questionnaires was the decentralized and departmentalized nature of much of their data. This often limited the specificity of their responses due to a lack of resources to access and collate the requested data. Many of the autism associations indicated that they were attempting to improve their data collection strategies but that historically their focus had been on service provision and meeting the immediate needs of clients and families.

It is important to note that, in spite of these difficulties, there was considerable interest and support expressed by many of the individuals who responded on behalf of their organizations, regarding the nature of the study, its timeliness, and its potential findings.

### **Numbers of children with autism, Asperger disorder or PDD-NOS**

#### **States and Territories information**

As shown in **Table 2** not all State and Territory agencies approached could provide information about the numbers of children diagnosed with autism, Asperger disorder or PDD-NOS.

Of the agencies providing information about the number of children known to their organization with ASD the years from which they provided information varied. It

ranged from numbers of children from 2000-2003 (Education Queensland), 2002-2005 (ACT Disability services) to all data from NSW, NT, SA, TAS, VIC, WA for 2004 – 2005. Of the agencies who responded to the questionnaire, four (*NSW DET, DSQ, AV, VIC DHS*) were not able to provide information about numbers of children provided services by their agency for the purpose of this study.

Although data were provided by Queensland and Victorian disability services they were not included in **Table 2** as it included all children with disabilities and did not identify children with ASD separately. Subgroup information from QLD disability services suggested that 8% of the children they reported to this study (N= 1745) had autism as a primary diagnosis, which would be equivalent to 150 children . VIC disability services stated that the Aged Care Branch of DHS manages the Home and Community Care (HACC) Program. These funds are distributed to service providers to deliver a suite of home care services to frail aged people and those with disabilities. Victoria disability does not collect differential diagnostic information in the HACC MDS.

**Table 2 Numbers of children with ASD (Autism Disorder, Asperger Syndrome, PDD-NOS) provided by State and Territory agencies, by age group, and agency type**

	Disability				Education				Autism Association			
	0-5	6-12	13-16	Total	0-5	6-12	13-16	Total	0-5	6-12	13-16	Total
ACT*	43	64	3	110 <sup>7</sup>	NA	261	101	362	NA	NA	NA	NA
NSW	833	850	286	1969	NA	NA	NA	NA	600	430	NA	1030
NT	9	36	10	55	18	99	63	180	NA	NA	NA	NA
QLD <sup>^</sup>	NA	NA	NA	NA <sup>8</sup>	419 <sup>2</sup>	3243 <sup>2</sup>	NA	3662 <sup>2</sup>	97	988	625	1710
SA	77	394	262	733 <sup>3</sup>	129	402	235	759 <sup>5</sup>	276	644	620	1540
	155	253	132	540 <sup>4</sup>								
TAS	NA	NA	NA	NA	120	59	28	207	NA	NA	NA	NA
VIC	NA	NA	NA	NA <sup>8</sup>	NA	757	195	1490 <sup>6</sup>	NA	NA	NA	NA
WA	249	943	327	1519	235	736	280	1331 <sup>1</sup>	113	324	164	601

Numbers were provided for the time period 2004-2005 except for the ACT<sup>7</sup> Disability data (2002-2005) and QLD<sup>2</sup> Education data (2000-2003)

<sup>1</sup> Includes total AISWA data that was not available in separate age groupings

<sup>2</sup> Data sourced from Report of the Queensland Paediatric Quality Council 2003, which included data, for the years 2000 – 2003, for preschoolers and school aged children with an identified ASD. Data was reportedly obtained from Education Queensland. Data shows totals for ASD and for the state's educational regions (Central Southern, Metropolitan and North-Western). No other variable breakdowns were available.

<sup>3</sup> Data for IDSC

<sup>4</sup> DFC provided some direct data for 2003-2004 however IDSC provides most Autism services on their behalf

<sup>5</sup> Data for these age groups were provided as a percentage (total=101%) of the denominator of 759

<sup>6</sup> Totals included students in Preprimary and Special education who were not reported within separate age groups

<sup>7</sup> Data is for assessments completed between 2002 / 2005; not a complete listing of current clients with an ASD diagnosis

<sup>8</sup> Data provided was for all of the agency's clients not ASD specific



As shown in **Table 2** there is considerable variation between agencies within one State or Territory in data provided about the number of affected children in each sector. In addition there is considerable variation between states as to which agencies were able to provide the information requested.

**Table 3 Summary of Questionnaire Data received from each sector, by State or Territory**

		Male %	Autistic Disorder%	Intellectual Handicap%	Remote/Rural%	ATSI/Aboriginal%
WA	Education	83 <sup>1,2</sup>	69 <sup>2,3</sup>	NA	12 <sup>2</sup>	NA
	Disability	84	77	16	31 <sup>4</sup>	4 <sup>5</sup>
	AA	NA	NA	NA	14	NA
NSW	Education	NA	NA	NA	NA	NA
	Disability	80	NA	NA	25	2
	AA	NA	NA	NA	NA	NA
SA	Education	86	57	NA	NA	NA
	Disability -IDSC	84	59	NA	24	2
	AA <sup>4</sup>	85	53	NA	16	NA
QLD	Education	NA	NA	NA	NA	NA
	Disability <sup>6</sup>	NA	NA	NA	NA	NA
	AA <sup>5</sup>	84 <sup>4</sup>	52 <sup>5</sup>	NA	36 <sup>4</sup>	NA
VIC	Education	85	NA	NA	18	NA
	Disability	NA	NA	NA	NA	NA
	AA	NA	NA	NA	NA	NA
TAS	Education <sup>5</sup>	88	92	NA	37	NA
	Disability	NA	NA	NA	NA	NA
	AA	NA	NA	NA	NA	NA
NT	Education <sup>5</sup>	87	80	NA	39	NA
	Disability	87	92	12	29	1
	AA	NA	NA	NA	NA	NA
ACT	Education	86	NA	NA	0	0.83
	Disability	90	82	NA	0	NA
	AA	NA	NA	NA	NA	NA

<sup>1</sup>Data from DET

<sup>2</sup>Data from Catholic Education

<sup>3</sup>Data from AISWA

<sup>4</sup>Percentage based on information for all ages as not available for 0-16 year old subset

<sup>5</sup>Information not available for all children reported. Percent calculated with number with available information as the denominator

<sup>6</sup>Data provided was for all of the agency's clients not ASD specific

**Table 3** shows that many services were not able to provide information about diagnostic subgroups, including gender, geographic location, aboriginal or Torres Strait Islander identification or intellectual disability. For all agencies that were able to provide such information, the percentage of males with ASD was over 80% of the total numbers. Agencies providing information about diagnosis reported that the majority of children (range 52-92%) had a diagnosis of Autistic Disorder, and as such the minority had other

types of ASD. Only two agencies from two different States provided information about intellectual disability of children known to them with ASD, with percentages of children with intellectual disability ranging from 12% to 16%. At least one agency from each State or Territory (not including the ACT) provided information about families living in rural or remote locations with children with ASD, with percentages ranging from 12% to 39%. At least one agency from each of the States and Territories except QLD, VIC and TAS provided information about Aboriginal or Torres Strait Islander identification for children with ASD. Percentages reported ranged from 1 to 4%.

#### **Data provided by AIHW from the CSTDA-NMDS**

Data were provided by AIHW from the CSTDA-NMDS data collection. July 2003-June 2004 was the first year that CSTDA-NMDS data collection had been undertaken for all service recipients in that period, rather than as a designated single day “snap-shot” which was used as a representative for the whole year. In 1999 a statistical linkage key was introduced to prevent duplicate counting of individuals who received services from more than one service during a 12-month period. Table 4 shows the number of children nationally aged 0-14 identified by CTSDA-NMDS data collection from 1999, which was the year that the statistical linkage key was introduced to the collection. There was an increase in numbers during the years 1999-2002, and an increase over 4-fold between the last “snap-shot” year data collection and the first full data collection year (July 2003-June 2004).

**Table 4 CSTDA-NMDS Historical Data for Primary Disability of Autism, for children aged 0-14 years**

	Snapshot Data Years				Full Year Data July 2003- June 2004
	1999	2000	2001	2002	
Males	776	883	859	922	4114
Females	165	182	180	198	864

Further information was also provided for the period July 2003-June 2004, including data for each State about diagnosis, gender, age (0-16 years), Indigenous identification and country of birth (**Table 5**). Prior to presentation of this data, services that provided information to the CSTDA-NMDS were asked for permission to present data from their state in this report.

NSW and ACT requested that data about the number of children for Indigenous and Country of Birth subgroups (as below) not be published due to low cell counts. In addition, data about the numbers of children in ACT and NT, including subgroups, was suppressed by AIHW because of low cell counts. However the suppressed data are included in national totals for age groups. In addition, Disability ACT noted *"The number of service users reported in the primary disability group of autism is likely to be unreliable, particularly for younger age groups. The proportion of not stated for primary diagnosis is high. In younger age groups diagnosis may not have been made formally or may be inconclusive - leading to non-response for the disability group variable or a change in reported disability group over time."*

Service user data shown are estimates after use of a statistical linkage key to account for individuals who received services from more than one service during the 12-month period. In total 5459 services users were identified. However, age, country of birth, Indigenous status and gender information was not provided for all users. Service users with missing age who responded 'child aged 5 years (not applicable)' to the communication method data item were included in the 0-5 years age group. Other service users for whom age was not available were excluded.

The numbers of children provided by the CSTDA-NMDS from AIHW are not the same as those provided by disability services for each state, except for the DFC (SA), which provided data for the same years (2003-2004) (see **Table 2**). Most of the numbers from services provided by age group by the State disability agencies were higher than the numbers reported by AIHW. These differences may be due to a number of factors including, but not limited to the following; the years of reporting were different and numbers of individuals had changed; individuals may be registered with a disability agency but not receiving CSTDA funded services due to diagnosis based eligibility restrictions; CSTDA NMDS data collection includes individuals with an autistic disorder or Asperger's Syndrome diagnosis only (reported together under the primary disability group of Autism) however disability agencies may also include data for individuals with PDD-NOS within their agencies' ASD reporting; available CSTDA funded services may not meet the individual's needs however the individual may still be registered with a disability agency but accessing necessary services through the educational and/or private sector; or differences between CSTDA NMDS and internal agencies' guidelines for recording and reporting primary and secondary diagnoses may influence reported numbers.

**Table 5 Numbers of users aged 0-16 years of CSTDA-funded services who reported a primary disability group of Autism, and age, indigenous identification and country of birth distribution for each state, July 2003-June 2004**

	Age group (N)				Male (%)	Indigenous (%)	Country of birth (%)			Total (N)
	0-5	6-12	13-16	Sub totals			Australia	Other English Speaking	Non English Speaking	
WA	327	780	274	1381	81	3	84	1	1	1381
NSW	683	605	167	1455	84	*	*	*	*	1455
SA	155	253	133	541	86	1	98	0.4	1	541
QLD	106	399	258	763	81	5	96	2	0.8	763
^VIC	206	673	248	1127	82	2	90	1	6	1127
TAS	51	65	10	126	85	1	98	2	0	126
NT	*	*	*	*		*	*	*	*	
ACT	*	*	*	*		*	*	*	*	
<b>Subtotals</b>	<b>1551</b>	<b>2810</b>	<b>1098</b>			<b>*168</b>	<b>4979</b>	<b>*72</b>	<b>*129</b>	

\* Data suppressed due to low cell counts

^Victorian data are reported by DHS VIC to be “*significantly understated; errors in the 'date of last service received' as well as lower than expected response rates have led to an undercounting of service users in the current year. Figures in this table relate to primary disability, however many clients are registered as primarily having an intellectual disability with autism being listed as a secondary disability*” .

**Table 6** shows prevalence estimates for each state based on CTSDA-NMDS numbers of children for age groups in each state using ABS data for resident population of children in each state for the year 2003 as the denominator, with 95% confidence intervals. As shown there is wide variation in prevalence of autism by state and age group. Within each state there are significant between age group differences for all States except SA. The trend in most States (SA, TAS,WA) is for prevalence to be highest in the 6-12 year old age group. In QLD prevalence was highest in the 13-16 year old age group, but not significantly different to the prevalence in the 6-12 year olds. In NSW prevalence was significantly higher in the 0-5 age group. Between States, there are significant differences in reported prevalence, with the minimum reported prevalence for any State ranging from 3.6 to 21.9/10,000 children and the maximum reported prevalence ranging from 12.1 to 40.8/10,000 children. Prevalence estimates for Victoria were not included at the request of DHS VIC.

**Table 6 Prevalence estimates per 10,000 for children with Autism resident in that State or Territory of that age (95% CI) for each State based on CSTDA-NMDS and ABS data (June 2003)\***

State	Age group		
	0-5	6-12	13-16
NSW	13.3 (12.3, 14.3)	9.6 (8.8, 10.3)	4.7 (4.0, 5.4)
QLD	3.6 (2.9, 4.3)	10.5 (9.5, 11.5)	12.1 (10.6, 13.6)
SA	14.5 (12.2, 16.7)	18.3 (16.1, 20.6)	16.7 (13.9, 19.5)
TAS	14.5 (10.6, 18.4)	14.3 (10.8, 17.7)	4.4 (1.9, 6.9)
VIC	n/a	n/a	n/a
WA	21.9 (19.6, 24.3)	40.8 (37.9, 43.7)	24.3 (21.5, 27.1)

\*Australian Bureau of Statistics, 2005

### Centrelink Data

National data was provided by Centrelink for gender, age groups and ASD subgroups (Autism Disorder and Asperger Syndrome) for the calendar years 2004-2006. (**Table 7**). From this data, prevalence was estimated for autism and Asperger disorder by age group and compared to CTSDA overall prevalence by age group (**Table 8**). As shown, using available data there is a two-fold difference between overall prevalence estimates for autism using different data sources, Centrelink and CTSDA.

Between 2003 and 2005 there was an increase in the prevalence of children known to Centrelink with a diagnosis of Autism and Asperger Disorder. Maximum prevalence for Autistic Disorder and Asperger Disorder in 2005 for 6 to12 year olds and was 47.2/10,000 (95%CI 46.2-48.1) and 15.3/10,000 (95%CI14.8-15.9) respectively. Consistent with CSTDA, the prevalence rate for Autism Disorder and Asperger Disorder was highest in the 6-12 year age group compared with the 0-5year and 13-16year age groups. Furthermore this pattern carried across each year of data collection and for both diagnostic subgroups. Within the diagnostic subgroups, the prevalence rate for Autism versus Asperger disorder was much greater for the 0-5year and 6-12yr age group than for the 13-16year age group. The differences between prevalence for 6 to 12 year olds compared to 13 to16 years olds were greater for Autism than Asperger Disorder for all years Centrelink data was provided.

**Table 7 Numbers of children known to Centrelink with a diagnosis of Autism or Asperger disorder by age groups for the years 2003-2005**

			2003			2004			2005		
			0-5	6-12	13-16	0-5	6-12	13-16	0-5	6-12	13-16
Centrelink	Autism	Males	1937	5632	1572	2220	6517	1880	2560	7489	2205
		Females	390	1173	318	470	1334	363	539	1430	492
		Total	2327	6805	1890	2690	7851	2243	3099	8919	2697
	Asperger	Males	100	1676	780	170	1952	967	215	2510	1228
		Females	29	265	137	30	311	153	41	385	187
		Total	129	1941	917	200	2263	1120	256	2895	1415
	ASD*	Males	2037	7308	2352	2390	8469	2847	2775	9999	3433
		Females	419	1438	455	500	1645	516	580	1815	679
		Total	2456	8746	2807	2890	10114	3363	3355	11814	4112

\*combination of Autism and Asperger disorder

**Table 8 Estimated national prevalence, with 95% confidence intervals (CI), from CTSDA and Centrelink data and ABS population data\***

			2003			2004			2005		
			0-5	6-12	13-16	0-5	6-12	13-16	0-5	6-12	13-16
CTSDA <sup>1</sup>	Autism	Total	1289	2314	904						
		Prevalence	8.5	12.1	8.3						
		95%CI	8.0-8.9	11.6-12.6	7.8-8.9						
Centrelink	Autism	Males	1937	5632	1572	2220	6517	1880	2560	7489	2205
		Females	390	1173	318	470	1334	363	539	1430	492
		Total	2327	6805	1890	2690	7851	2243	3099	8919	2697
		Prevalence/ 10,000	15.3	35.7	17.4	17.7	41.3	20.3	20.3	47.2	24.2
		95%CI	14.7-15.9	34.8-36.5	16.6-18.2	17.0-18.4	40.4-42.3	19.5-21.2	19.6-21.1	46.2-48.1	23.2-25.1
	Asperger	Males	100	1676	780	170	1952	967	215	2510	1228
		Females	29	265	137	30	311	153	41	385	187
		Total	129	1941	917	200	2263	1120	256	2895	1415
		Prevalence	0.9	10.2	8.4	1.3	11.9	10.2	1.7	15.3	12.7
		95%CI	0.7-1.0	9.7-10.6	7.9-9.0	1.1-1.5	11.4-12.4	9.6-10.7	1.5-1.9	14.8-15.9	12.0-13.4
ABS*	Population	Males	781027	979790	557758	780516	974827	564659	782303	971097	572031
		Females	742485	929465	531229	741024	925007	537822	742903	920551	544470
		Total	1523512	1909255	1088987	1521540	1899834	1102481	1525206	1891648	1116501

\*Australian Bureau of Statistics, 2005. Population estimate for each year in June. <sup>1</sup> July 2003-June 2004 data

## Sensitivity analysis comparing different data sources

**Table 9** shows the numbers of children with an ASD: a) according to the service in each state which reported the maximum number of children, b) as reported by the CTSDA-NMDS, and c) the estimated number of children with an ASD, for each State and Territory, based on both Centrelink national data and ABS data about the population distribution for each State and Territory. This table illustrates that in each State or Territory the information about numbers of children with ASD varies for different sources. This is not surprising as the years for data collection and the diagnostic groups included in different data collection sources vary. However, what is shown is that in some States (NSW, TAS, VIC) there is a greater discrepancy between data provided by one State-based source and Centrelink data than for other States and Territories.

**Table 9** Numbers of children by State/Territory for different data sources

	Maximum number from one service for each state	CTSDA-NMDS	Estimated numbers per state based on Centrelink data and national population distribution
ACT	362 <sup>1</sup>		307
NSW	1969 <sup>2</sup>	1455	6349
NT	180 <sup>1</sup>		230
QLD	3662 <sup>1</sup>	763	3894
SA	1540 <sup>3</sup>	541	1381
TAS	207 <sup>1</sup>	126	460
VIC	1490 <sup>1</sup>	1127	4623
WA	1519 <sup>2</sup>	1381	1937

<sup>1</sup> education, <sup>2</sup> disability, <sup>3</sup> autism association

### Descriptive Data

For this section, absence of data in any one area does not necessarily mean that individual agency does not collect that data, or provide a particular service, just that this information was not available to the study. **This applies to Tables 10 to 14 inclusive and all discussions related to these tables.**

### *Diagnosis and diagnostic process*

Information about referral for diagnosis and the diagnostic process was provided by eight agencies in seven States/Territories (**Table 10**). As shown, waiting times for assessment ranged from one to 24 months. In WA where information about preschool and school-aged children and children living in metropolitan and rural settings was provided separately, waiting times were longer for school-aged children and in rural settings. Most services are based in metropolitan settings. Diagnostic assessment was provided by a range of agencies, including disability, health and autism associations and in the private sector. In the majority of cases a Multi-disciplinary team (MDT) performed the assessments and provided further case management. Although most services reported using or requiring a team assessment, some services used or accepted assessments from paediatricians or psychiatrists working in public or private settings.



All services that reported diagnostic assessment criteria reported using DSM-IV-TR, and some also reported using ICD-10 classification in addition to other diagnostic tools. In the NT, between 2000-2004, an interdepartmental (DEET & DHCS) MDT provided screening, assessment and diagnosis. This is the only Education Department assessment service reported to this study. Focus was on children aged 3-6 years. Priority was given to the older children in this group to ensure access to assessment and diagnostic services prior to entering full time school, at which time they were no longer eligible for early intervention services. Paediatricians referred directly to this team. Families' responses to this approach were 'overwhelmingly favourable'. Prior to the establishment of the MDT, paediatricians provided assessment services or families travelled interstate. However, the MDT was disbanded due to lack of funding. At the time of reporting to this study DEET staff were developing a range of practices aimed at supporting families and facilitating the assessment and diagnostic process. This included a case coordination/management approach, the provision of background information to the Top End Mental Health Services' assessing psychiatrist, and family and community consulting and collaboration strategies.

**Table-10: Assessment and Diagnostic Practices**

State	Agency	Referral	Receipt of Referrals	Diagnostic assessment	Criteria used	Waiting times (months)	Case management
WA	DSC	Medical and Allied health practitioners, School Psych and/or other educators in both Govt and Private sectors	DSC, Health Dept, Private practitioners	MDT: SP, Psych or Clin Psych, & Paed. When needed: Psychtr, SW, OT Private assessments also available in community	DSM-IV-TR	Preschool age Metro~2-3 Rural~3-4 School age Metro~18-24 Rural~12	MDT makes intervention referrals and recommendations Client is referred to DSC for eligibility for level and type of services determination
NT	DHCS Top End Health Service	Psychs, Advisory Teachers, ECI, Special Education	Child & Adolescent Team	Clin psych Child psychtr	DSM-IV-TR ICD-10 ADI-R	~1-2	Psychiatrist provides case management
SA	IDSC		Central Intake Team	ASA Registered practitioners			Central intake team identify functional needs then transfer to region where patient resides
SA	ASA		Coordinator Diagnostic Services	MDT: Psych, Psychtr, SP	DSM-IV-TR ICD-10, CARS	~ 3-6	
QLD	DSQ	Medical specialist & Allied Health practitioners	Family & Early Childhood Services Team	MDT: Psych, SP, OT, PT, SW, Resource Officers	DSM-IV-TR	~ 6	Family & Early Childhood Services Team
NSW	ASPECT	Psych Paed	ASPECT	Psych, Paed ASPECT staff			ASPECT for ASPECT services
TAS	DET	Support teachers, Branch Autism Consultant, Class teachers, GO, SP, Educational Psych, SW	DET	Individual clinicians (private Paed or HD) MDT	DSM-IV-TR Gillberg's Criteria ICD-10 PEPR, CARS		-SW are employed directly by DET to work with families and schools - OT & PT provide assessment & consultative support
ACT	TACT			Since 2005 MDT: Psych, SP, OT. Hearing test, Paed assessment, cognitive/developmental assessment and observation at school	DSM-IV ADI-R ADOS		

MDT Multi Disciplinary Team, SP Speech Pathologist, Psych Psychologist, Clin Psych Clinical Psychologist, Paed Paediatrician, Psychtr Psychrist, SW Social Worker, GO Guidance Officer, HD Health Department

### ***Data collection and use***

Information about data collection and uses was provided by twenty agencies in eight States/Territories (**Table 11**). All agencies reported gathering data on an ongoing basis. All of the agencies who provided information collate their data for internal use in budget/resource allocation and planning for service delivery and development. Agencies that distribute or use CSTDA funds have a commitment to coordinate the collection and submission of CSTDA NMDS to the AIHW. NSW DADHC indicates that CSTDA data is gathered quarterly and sent to the AIHW annually. Staff in these agencies also participate in AIHW developed data collection training programs. Many CSTDA supported agencies also provide data to ABS on request. As a participant in the Home and Community Care (HACC) Program, DHS VIC provides information to the HACC MDS. No other agencies reported providing information to National data collection systems. Agencies providing assessment services indicated that data is gathered as assessments are completed, and the DET WA uses a bi-annual central census. DECS SA indicate that they generate most of their own data though they also have access to data from agencies with which they have a Memorandum of Understanding plus data from Government agencies.

Most agencies report that they share their data with other State/Territory agencies and colleagues as appropriate. However both DE TAS and DET ACT indicated that they do not share data with outside agencies, organizations or colleagues. Several agencies also indicated that they will collaborate with research projects which meet their research criteria. DSQ and DEST (QLD) are two agencies that require the submission of detailed research proposals prior to participation in research.

Data collection by Autism Associations varied considerably depending on the services offered and their funding sources. Education department data collection occurs at various levels, reflecting the different internal organisation of the individual education departments. In general, data is collected at the school or education unit level and collated centrally. Detailed case information is held at the school level, rather than centrally. Some Education Departments use specific systems, such as disability registers, specialised committees and intervention teams to evaluate students' special needs, allocate resources and deliver specialist intervention services

**Table 11 – What happens to collected data**

State	Agency	Data collection and follow-up						
		Data collected by	Frequency of Data collection	Data collated / summarized within agency/department	Internal data use		Data shared externally	
					Budget allocation	Service development	Federal agencies	State agencies
WA	Cath Ed WA		Annual	✓	✓	✓		On request: Government agencies; approved research
WA	DET	Electronically at school level; collated centrally	Bi-annual central census; At schools as assessments completed	✓		✓		-DSC -internal Schools Plus resource allocation database -via computer based internal edstats website
WA	DET Autism Intervention Team	Autism intervention team	On regular basis -as assessments are completed	✓		✓		-DSC -other education & autism service providers
WA	AISWA		-annual	✓	✓	✓	ABS, AIHW, Centrelink NSO	-on request
WA	DSC	Agency staff in all Depts	-ongoing -annual reports	✓	✓	✓	ABS, AIHW, Centrelink	-other appropriate State and Government agencies -on request: eg: research
NT	DHCS		-as assessments completed	✓				-intrastate with colleagues & agencies
NT	DEET	Student Services Division: -Discipline Coordinators -Cluster Managers -General Manager	-as assessments completed -ongoing basis and formal schedule	✓	✓	✓		-other relevant agencies within the Territory - other appropriate agencies & colleagues in predetermined process
SA	DECS	Collated centrally -districts and schools keep more detailed case info		✓				Autism SA who provide support to DET sites
SA	IDSC			✓	✓	✓		-on request by groups such

State	Agency	Data collection and follow-up						
		Data collected by	Frequency of Data collection	Data collated / summarized within agency/department	Internal data use		Data shared externally	
					Budget allocation	Service development	Federal agencies	State agencies
								as DCS (SA Govt)
SA	ASA	Diagnostic Service, Client Records Officer	-as assessments completed	✓	✓	✓	AIHW, FaCS DEWR	-shared with other State agencies & colleagues
QLD	DSQ			✓			AIHW	-shared with other State agencies and colleagues
QLD	AQ		As clients registered	✓	✓	✓	AIHW NSO	ASIQ DSQ DEST
NSW	DADHC	Service providers of CSTDA funded services	Data gathered quarterly and sent to AIHW annually	✓	✓	✓	AIHW	-as requested by other state/territory and Federal agencies and the Cabinet Office
NSW	ASPECT	Combination of Unit and Divisional level		✓	✓	✓	AIHW	NSW Board of Studies DADHC
TAS	DE	Moderation Committee for inclusion of students on the SDR -at school: assessment and IEP planning as required		✓	✓	✓		No agency data is shared with outside agencies or organizations
TAS	DHHS			✓			AIHW	
VIC	DET			✓	✓	✓		
VIC	DHS			✓	✓	✓	AIHW CDH CDAC	Productivity Commission
VIC	AV	Agency staff	Ongoing data collection	✓	✓	✓		AV Board and DHS
ACT	DET	-Special Education -Early Intervention	As assessments completed	✓	✓	✓		Not routinely shared with other agencies or colleagues

SDR Severe Disabilities Register

### ***Intervention services***

Information about intervention service provision across the states and territories was provided by twenty four agencies in eight States/Territories (**Table 12**).

### ***Education Agencies***

Public education departments in all Australian States and Territories have a responsibility to meet the learning needs of all school aged children within each of their jurisdictions. This responsibility extends to the children with special learning needs who are enrolled in any of their publicly funded facilities. The specific details of how these needs are met may vary across states and territories, as well as from school to school.

Different educational settings are available for children with ASD. Two states (NSW and SA) indicated that, depending on individual need, a child with an ASD might attend a regular class, a special class within a regular school, a special unit (SA) or a special school. In WA parents can choose to place their school aged children in a mainstream classroom, an Education Support Centre (provides limited inclusion in a typical school setting) or an Education Support School (some integration with local regular schools when appropriate).

Additional support is provided to children in school using various allocation strategies. VIC, TAS and WA described a general policy of providing additional support and resources to schools to enable them to support students with disabilities (including but not limited to ASD) rather than tying the additional supports to specific students. In NSW special classes received additional personnel and resources based on identified needs. In four states (TAS, SA, NSW, WA) resources were described as being provided in response to identified student needs rather than based on a diagnosis per se. These four states also described the development of a negotiated IEP as the fundamental basis for needs determination and subsequent resource allocation. In WA, district based specialist inclusion support teachers provide initial consultations and strategies, however further intensive support can be requested from the Autism Intervention Team whose members are available to provide support to teachers in both metropolitan and rural schools.

A variety of forms of support are available including the provision of teacher aide, or educational assistant, time especially to support students in regular classrooms and their teachers. In TAS the majority of students who have an IEP are reported to also receive teacher aide time and additional support to their classroom teacher. Other frequently mentioned strategies for supporting schools, trainee and qualified teachers and families include the provision of professional development courses, consulting specialists from a variety of professional backgrounds, and the use of itinerant specialist support teachers. The majority of services were reported to be delivered in students' primary educational placement. However, in the NT interventions are also delivered in the home, centre based and childcare placements. In SA, the education department has service agreements with other agencies and organizations, including ASA, to provide some in-school & preschool consultancy support, intervention programming, and professional development courses to DECS staff.

WA DET also provides a range of EI options including four Autism Units for 4-5 year olds who parents are intending to seek mainstream school settings; a transition program which commences the term prior to kindergarten to prepare up to 6-8 children to enter

mainstream kindy; and small (4-5 children) structured classes, which follow ABA principles, at several of the Education Support Schools. TAS also provides Music Therapy for Early Intervention students and speech therapy aide programs in rural areas as required.

In WA, the Association of Independent Schools of WA, provides a limited support service for students with disabilities through a consultancy model with its member schools at their request. The Catholic Education Office of WA is able to provide regular support to its schools and teachers through a range of mechanisms administered through its 'Students with Disabilities K-12 Team'. Private educational organizations in the other states or territories were not identified by the study.

### *Disability Agencies*

Government agencies within each of the States and Territories are responsible for providing a range of services to all of the people in their communities who have disabilities, and they play important roles in ensuring the effective provision of quality services to people in need in their communities. They also participate in supporting developments within their sector, and in working with the appropriate state/territory and federal departments and agencies to develop and implement governmental initiatives and policies. As recipients of both state/territory and federal funds they are also required to report on key accountabilities. In WA and QLD these agencies focus specifically on people with disabilities. In NSW, NT, SA, TAS, ACT and VIC these agencies also provide services to the aged and other vulnerable members of the community. All of the agencies discharge their responsibilities directly and/or through additional funded agencies.

In the NT, NSW, TAS and WA, services to people with disabilities and their families/caregivers are provided both directly through these agencies and via funded providers. In SA, DFC funds a specific agency (IDSC) to provide services and support to people with ID and ASD. In QLD direct services are provided by DSQ to children aged 0-6 years and adults aged 18-65 years, while school aged children receive services through funded providers.

A wide range of service provision types are reported by the various agencies. These services are provided to clients via individual, group and/or consultative models and in a range of settings including home, centre-based, and child care settings. In QLD, WA and SA, services for young children include EI programs as well as a range of allied health services which may include SP, Psych, behaviour management, OT, PT, and SW. In WA, DSC provides some school aged services while SA (IDSC) and QLD (DSQ) both provide a range of allied health services to this age group. The Child and Adolescent Team in the NT provide clinical consultation, Psych, behaviour managements and educational interventions. Therapy ACT provides a range of multidisciplinary therapy and support services for people with disabilities and developmental delay ([www.dhcs.act.gov.au/TherapyACT](http://www.dhcs.act.gov.au/TherapyACT)) and VIC DHS reports the provision of a wide range of state-wide nursing and allied health services for its clients however neither agency identified ASD specific services. The majority of DSC's services are provided in the metropolitan area however rural and remote area services are provided where possible and often in collaboration with other local agencies. IDSC also reports that while their metropolitan area services to children are interdisciplinary,

their country services are not, which minimizes individuals' access to a wider range of services.

Additional services reported by one or more agencies (**Table 12**), which are aimed at providing broader family and community support, included family support, counseling, information and education; crisis intervention services; support groups and sessions and skills workshops for clients; local area coordination; respite; recreation and holiday programs; independent living; community access; and community support and education services.

#### *Autism Associations*

Direct service provision is the focus of all of the Autism Associations, however the nature and complexity of the services offered by each of the associations depends on their size, available resources and general disability support context. The three smaller associations in TAS, NT and ACT report that they provide family information and support services only. The VIC association provides information and resource services for families, limited family counseling and consultancy services to members and member agencies. In addition, they are the peak body for ASD in Victoria, representing 12 specialist autism service providers covering all age groups. The remaining four (WA, NSW, QLD, SA) associations report a wide range of service provision. EI services are provided by all of these agencies, with variations in EI service type and delivery (**Table 12**). In WA an EI centre has been established. NSW, SA and QLD all provide services to school aged clients and outreach services are provided in NSW and QLD. QLD and WA also provide a range of family support, accommodation, respite care and training services to clients, their families/carers and the staff supporting them.

A variety of innovative services are provided by the Autism Associations. In WA this includes the provision of four respite homes for stay-aways for clients up to 18 years of age, as well as group homes and individual residential options and an intensive family support program for families in critical circumstances. Other innovative programs provided by one or more agency include; siblings workshops; a school holidays program; resource kits, books and information packs for families; seminars and workshops; video conferencing to families and professionals living in rural areas; an employment agency which includes job matching and on-the-job training; a Clin Psych service to assist families with adults with autism who are living at home; web based information service; telephone information line; services for adults and services to promote post-school community access and employment opportunities. In some States there are User Pay programs available.



**Table 12 Intervention Service Provision**

State	Agency	Intervention							Who refers to your agency? ✓ Who provides data to your agency? X			
		Type	Via agency	Via consultants	Age group (yrs)	Setting			Family	Health provider	Educator	Other
						School	Home	Centre or Outreach				
WA	Cath Ed WA	Support to school and teachers	✓		5-17	✓					✓ X	
WA	DET Schools Plus	Supplementary resources IEP development	✓		✓	✓					X	X
WA	DET Autism Intervention Team	ASD intervention team Support to teachers	✓		4-17	✓					✓	
WA	AISWA	Support and range of services		✓	4-17	✓	✓				✓	
WA	Autism Association.	EI Clinical teams (SP, Clin psych, OT, therapy aides) Respite / family support Information/training	✓	✓	3-adult		✓	✓	✓	✓	✓	
WA	DSC	Direct and centre-based EI Respite, behaviour, counseling, education, community, family support	✓	✓	3-adult	✓	✓	✓	✓ X	✓ X	✓ X	✓ X
NT	DHCS Top End Health Service	Child & adolescent team provide: Clinical consultation Psych, behaviour, education interventions		✓	3-17	✓	✓	✓	✓ X	✓ X	✓ X	✓ X
NT	DEET	Assessment Psych, behavioural, educational services Information/ training	✓	✓	3-17	✓	✓	✓	✓	✓	✓	✓
SA	DECS	Support -information and teacher aides EI services Behaviour, Psych, SP, OT Negotiated IEP placement Special class, school, unit placements	✓	✓	3-17	✓						

State	Agency	Intervention							Who refers to your agency? ✓ Who provides data to your agency? X			
		Type	Via agency	Via consultants	Age group (yrs)	Setting			Family	Health provider	Educator	Other
						School	Home	Centre or Outreach				
		Information/ training										
SA	IDSC	MDT for Children & Youth and Early Childhood Services Accommodation and community support Case management Ranges of services SP, OT, Psych, PT, counseling, SW	✓	✓	3-adult		✓	✓	✓	✓	✓	✓
SA	AA	Social & behavioural support: group sessions Clinical family support: referrals Information Psych, Behavioural, SP, OT, education, EI	✓	✓	3-adult		✓	✓	✓	✓	✓	✓
QLD	DSQ	EI Psych, Behavioural, SP, OT, PT Information and support	✓	✓	3-adult	✓	✓	✓	X	X	X	X Funded disability orgs
QLD	AA	Education Psych, Behavioural, SP, OT, PT Family and home support Accommodation, respite	✓	✓	3-adult		✓	✓	✓	✓	✓	✓
QLD	DET	Not available										
NSW	DADHC	Family support Education Accommodation Range of services	✓	✓	3-adult		✓	✓				X Service providers
NSW	AA	Information and support EI Special schools and satellite classes Psych, Behavioural, SP, OT	✓	✓	3-adult	✓	✓	✓	✓	✓	✓	✓

State	Agency	Intervention							Who refers to your agency? ✓ Who provides data to your agency? X			
		Type	Via agency	Via consultants	Age group (yrs)	Setting			Family	Health provider	Educator	Other
						School	Home	Centre or Outreach				
NSW	DET	Teacher aides Special classes, special schools Psych, behavioural	✓	✓	4-17	✓			✓	✓		
TAS	DET	EI Teacher aides Special schools Psych, Behavioural, SP, OT	✓	✓	3-17 0 ~ 6 disab	✓		✓				
TAS	DHS	No information provided								X		
VIC	DET	Teacher support Psych, Behavioural, SP, OT	✓	✓	4-17	✓					✓	
VIC	DHS	Family support, respite Psych, SP, OT, SW, PT, dietetics	✓	✓	3-adult		✓	✓		✓		✓
VIC	AA	Information Family support Range of services	✓	✓	3-adult		✓	✓	✓			
ACT	AA	Family support Information Range of services	✓	✓	3-adult		✓	✓	✓			
ACT	DET	Teacher support	✓		4-17	✓					X	

EI Early Intervention, IEP Individual Education Program, SP Speech Pathologist, Psych Psychologist, SW Social Worker, OT Occupational Therapist, PT Physical Therapist, Outreach may be home or educational setting, Centre based services are at agency designated sites

### ***Funding sources, referral patterns and changes within agencies***

Information about referral patterns (**Table 13**) and data on funding sources, and changes within agencies (**Table 14**) was provided by twenty-three agencies in eight States/Territories.

#### ***Referral patterns***

Respondents from at least one service in each of the State/Territories that provided this information indicated a pattern of increases in referrals for both diagnosis and intervention across the autism spectrum in the period 1999-2004. Some agencies highlighted a particular increase in older children with Asperger Disorder or High functioning autism during this period. NT DEET staff participated in a multidisciplinary assessment team which saw a steady increase in referrals during its period of operation from 2000-2004. NT disability services reported very few referrals prior to 2004 with increased referrals since then which they attributed to the arrival of a child psychiatrist in 2004. Agencies from different states/territories also report a rise in the number of people seeking both private diagnostic assessments and intervention services. Several states reported a rise in the number of people in the community with increased awareness and skills in the ASD area. QLD DSQ reported a level of 'sophisticated' knowledge of ASD by Paediatricians but a 'limited' understanding by educators. They also indicated a clearer diagnostic process for children with a 'classical presentation' but significant disagreement regarding the diagnosis of Asperger Disorder and significant confusion recognizing the difference between high functioning autism and Asperger Disorder. They also noted differences in the application of diagnostic criteria by the Health Department and DSQ leading to differences in referral patterns. NT DEET reports earlier identification of children with a more overt autism presentation but less understanding by referral sources of the wider range of presentations within the autism spectrum. Since their multidisciplinary assessment team ceased operations at the end of 2004, DEET reports interdepartmental collaboration and coordination has also been affected, that there is currently limited consultation or collaboration with the primary assessment agency, and that parents are experiencing limited follow-up or intervention from the assessing agency following diagnosis.

**Table 13 Referral patterns to agencies**

State	Agency	Referral patterns		
		2004-2005	1999-2003 Past five years	Comments
WA	Cath Ed WA		-increase in students with ASD	
WA	DET Schools Plus	rate and pattern of referrals slowed in 2004*	significant increase in rate of diagnosis /referral for all ASDs	* except for a trend of re-diagnosis or co-morbid diagnosis of PDD-NOS with ADHD
WA	DET <sup>1</sup>		- pattern of increasing numbers of referrals	
WA	AAWA		Stable pattern of referrals	
WA	DSC		-Significant increase in ASD diagnosis and intervention	-increase in people accessing private services - increase in ASD expertise and knowledge in community
NT	DHCS <sup>2</sup>	-increased since 2004	-very few referrals during 1999-2004	
NT	DEET	-stable since 2004 - families referred to DHCS	2000-2004 -steady increase in referrals	2000-2004: -MDT provided ASD assessment and diagnosis for EI services only -older children referred to local Paeds or traveled interstate for assessment -MDT ceased operation end of 2004 – due to funding
SA	DECS		-increased students with Autism and Asperger diagnosis - increased students verified with Communication and Language Disability	
SA	IDSC	-referrals increasingly complex. small % with very complex needs	-increased Asp Synd especially 10-15 yr s	-random referral patterns in country, focused more around services -High referrals from schools in 10-15yr age group
SA	ASA	235 in 2003, 251 in 2004, 299 in 2005	-steady increase from 1999-2003, marked increase from this point on	-Autism referrals have improved in accuracy -significant increase in referrals for Asp but not as accurate -referral sources knowledge of ASD is good when effective links exist between referrers and Autism SA
QLD	DSQ	2004: increased referrals for younger children (under 2 yrs) with definitive diagnosis, reduction in PDD-NOS	-increasing referrals from 1999 to present for mostly older children (3+ yrs)	- significant disagreement regarding diagnosis of children with Asp across the sector -reduction in children labeled as PDD-NOS -application of different diagnostic criteria in different settings eg Health vs disability led to differences in referral patterns -increasing trend by medical professionals to label children to enable access to funded programs -confusion between children with HFA and Asp Synd -limited awareness in educators of ASD criteria
QLD	AQ	-2004: increase in PDD-NOS as a category; increase in children under 4	-significant increase in referrals overall - greater number Asperger & HFA -mostly Autism and Asp but PDD-NOS on rise	-more PDD-NOS diagnoses made due to difficulty making diagnosis but need for support/services from schools/ agencies -improved ASD knowledge in education sector - more recent increase in awareness of HFA and Asp -no specific group under-referred compared to others
NSW	ASPECT	-2005:increased referrals, more in mid to upper end of spectrum		
TAS	DE	-2004: greater referrals at EI age particularly in the south of the State	steady increase in all age groups	-more referrals at both EI and secondary levels -increased referrals due to greater awareness around ASD generally - expertise and knowledge of referrers is growing
VIC	AV		-older teenagers & adults with Asperger increasing -younger children steady or slight increase	pro-active in promoting our services in recent years
ACT	DET	2004: Stable pattern of referrals		

<sup>1</sup>Autism Intervention Team <sup>2</sup>Top End Health Service

### *Funding sources*

The majority of agencies who reported funding information indicated that they received both State and Federal funding. By nature of the agreement, all disability agencies that are party to the CSTDA receive both Commonwealth and State/Territory funding. State/Territory and Federal funding varied for education agencies, with either State funding or a combination of State and Federal funding reported. The Autism Associations which provide direct assessment and/or diagnostic services receive both State and Federal funding. SA IDC pursue some additional small grant funding. In addition the QLD and VIC Autism Association reported that they generate additional funding through private donations, fund raising, and commercial enterprise income (fees for service). The QLD association also receives funds from philanthropic trusts. The smaller Autism Associations which provide volunteer based services rely on volunteers and/or private funding sources.

### *Agency changes*

#### Staff and Program Changes

The increasing demands for services reported across all sectors are being responded to by a variety of actions. Respondents frequently reported the need for agencies within states and territories to work in a broad collaborative manner in order to maximize their services and meet increasing consumer needs. Agencies are employing a range of approaches to meet identified need, including the use of increased specialist consultative/support positions especially within school systems, workshops, media based resources, and in states such as WA, the use of technology such as video conferencing to rural areas. In addition, Education Departments are reporting increased provision of services that are directed to the school rather than the individual student, such as the use of specialist consultant teachers to support regular education teachers who have children with ASD in their classrooms. Use of private diagnostic and intervention services is increasing as is the provision of 'user pay' services within agencies that also receive public funding. Service expansion has also occurred to meet the needs of the families of children with autism. Autism Associations in particular are attempting to provide services such as sibling workshops, family crisis support and increased respite and holiday programs.

#### Data Management

Changes to data management were reported by several agencies. Public education departments in SA and WA, as well as the Catholic education system in WA, have increased their diagnostic subgroups of ASD related information. In SA this also means that the more specific data held at district and site levels will become more centralised. In TAS the DET reported recent inclusion of ASD as a category in their Severe Disabilities Register which will allow access to central funding mechanisms. In Victoria, the Autism Association is automating its data base, but for service usage rather than as a method of data collection. The disability agencies also reported changes in their CSTDA NMDS data collection with the introduction of a statistical linkage key and the move from single day snapshot data collection to a continuous annual collection, as described above.

#### Funding Changes

Funding arrangements were reported to be having an impact on services offered across sectors. In 1995, DSC (WA) changed from a model of individualised funding for

intervention services to block funding to accredited service providers. This resulted in a change from \$10,000 per year per child if receiving services for a full financial year to \$6,000 per year per funded place. With block funding it was expected that the money spent would be better allocated to needs rather than allocating the same amount of money to each individual child regardless of severity of need in each case. DSC's funding growth since 1995 has been allocated to therapy services and Early Intervention in order to decrease waiting lists. In the NT, the DEET is reviewing their Inclusion Support Funding guidelines to allow students with an ASD, but without an intellectual disability, greater access to these funds, with implementation of these changes planned for 2006-2007. These changes are based on the recognition of the impact of ASD on these students' ability to access both the academic and social curriculum in their school settings. Since 1995, the NSW DET has established support classes for autism across the state and itinerant support teacher positions to enhance integration of students with autism into regular classes. Their Integration Funding Support Program also provides support funding to schools with children with identified disabilities who are enrolled full time in their regular education program. ASPECT (NSW) report less money per student this year for their intervention support program. Also, changes to funding models reduced funding to special independent schools in NSW, however effective lobbying resulted in a reinstatement of these funds. QLD DSQ provides both individualized funded programs that are accessed through an application process and block funded services accessed through funded providers. They began developing their funded programs in 1998, and saw an increase in families served from 950 in 2004-2005 to 1350 in 2005-2006. AQ has reduced its EI placements in Brisbane from full time to part time due to a lack of funding however, the agency has recently (2006) received EI funding for an additional site that will allow either full or part time placements depending on the child's need. This new funding will also allow some individual short term programming specific to issues of need for families, as well as EI outreach. AQ's school age placements continue to be part time in order to support students' continued placement in both mainstream school and their specialist programs. In SA, DECS has increased its cooperation with ASA in order to provide services to DECS sites.

**Table 14 – Funding and Agency Changes**

State	Agency	Funding source/s		Agency changes		
				Staff and program changes	Data management	Funding changes
WA	Cath Ed WA			-increased skill development of staff	-introduced diagnostic category breakdown -increased requests for data	
WA	DET Schools Plus	✓	✓		-2005 introduced diagnostic categories to school census -increased data sharing with other agencies	
WA	DET Autism Intervention Team	✓	✓	-increase in number of team members (3 to 7) - improved understanding and management of ASD by teachers	-improved transmission of information across years and classrooms as child moves	
WA	AISWA	✓	✓	-increase in FTE from 1-2 -increase use of private providers for assessments and PD		
WA	AAWA	✓	✓	-expansion of centre based EI services -expansion of clinical teams for case management -additional respite stay homes for all ages -intensive family support program for families in critical circumstances -sibshops and school holiday programs	-production media resources for families -expansion community training services -established video conference service to rural areas	
WA	DSC	✓	✓			-change from individualized funding to block funding to accredited agencies -changed from \$10k per child per yr to \$6k/yr per funded place -growth in therapy funding especially EI to decrease waiting lists
NT	DHCS <sup>1</sup>	✓	✓			
NT	DEET	✓	✓	-change in focus from individual to school as client - Early Childhood Intervention (ECI) and Transition from school program remain family centred as best practice for service delivery -target group for ECI was expanded to year 3 but reverted to 0-6 yrs (end of first full year at school) -increasing service requests -increased case management & collaboration in service delivery, screening, assessment, reporting, intervention, PD, family support, schools, community agencies and services	- “Intervention First” concept has enabled closer collaboration and consultation with schools in identification of students at risk and appropriate intervention prior to “formal Request for Service”	-Inclusion Support Funding available to schools on application -students with ASD but no IH had limited access to support funding -support funding model is being reviewed to allow access based on need not diagnosis (2006-07)
SA	DECS	✓	✓	-move to management at site level and to District Support Services structures	-more specific case data held at site and district levels -central data being modified to include more diagnostic categories -increased focus on gathering data in conjunction	-increased cooperation with Autism SA which is funded to provide support to DECS sites



State	Agency	Funding source/s		Agency changes		
				Staff and program changes	Data management	Funding changes
					with Autism SA	
SA	IDSC	✓	✓	-focus on providing services earlier, groups, support sessions, communication workshops -targeted training for workers re ASD - work with Autism SA who provide ASD diagnosis services -inclusion of clients with Asp Disorder		
SA	ASA	✓	✓	-units at 3 major hospitals do diagnosis now -private practitioners trained in diagnosis -majority diagnoses now done privately in SA		
QLD	DSQ	✓	✓	-changes in eligibility for services - services through public health services (eg Child Development Unit) in greater demand – especially Paeds -increased role of private Paeds	-changes to data gathered re CSTDA NMDS	-implementation and expansion of funded programs from 1998 (eg: 950 families receiving funding in 2004-05, 1350 in 2005-06)
QLD	AQ	✓	✓	-increased provision of outreach -training and user pays services introduced -all AQ Therapy and Education Centres placements now part time not full time -increase in respite and holiday program options -AQ ended Diagnostic service approx 10 yrs ago, now primarily by Paeds in Health Dept or private practice. -increase in private agencies providing intervention eg: ABA		
NSW	DADHC	✓	✓		CSTDA NMDS has changed from snap shot data to continuous data collection in 2002-03	
NSW	ASPECT	✓	✓	-expanding existing services & adding new services and programs -use public and private services for diagnostic services and not for intervention services		-some increases and decreases in funding - Intervention support program has less money/student this year -cut in special independent school funding was reversed through lobbying
NSW	DET	✓	✓	- support classes established across state for Autism since 1995 -teacher & aide special support in these classes has increased - enhanced support to students in regular classes		-Integration Funding Support program provides additional funding to regular schools with fulltime students with disabilities
TAS	DE	✓	✓	-implementation of specific EI Autism program -increase from 1 to 4.5fte branch Autism consultants -intro of the cluster support model directly to schools -ABA is accessed by some families privately -development of statewide Autism Plan (2005) -intro of the Grad Cert of ASD through the Institute of	-inclusion of ASD as a category within the Severe Disabilities Register to access central funding mechanisms	

State	Agency	Funding source/s	Agency changes		
			Staff and program changes	Data management	Funding changes
				Inclusive Learning Communities	
TAS	DHHS	✓			-CSTDA NMDS change from snapshot to continuous data -HACC MDS Collection agencies submit data on 1/4ly basis
VIC	DET	✓			-specific funding for students with Autism was introduced in approx 1998
VIC	DHS	✓	✓		-data collection commenced in 2001 –HACC MDS Version 2 (July 2006) will collect data on functional dependency
VIC	AV	✓		-users of counseling service now grouped into the 0-5, 6-17 and 18+	-have automated data capture for service usage -limited demographic data collection
ACT	AACT			NA	
ACT	DET	✓		No historical data collected	

<sup>1</sup>Top End Health Service

## DISCUSSION

There is considerable evidence that the diagnosis of ASDs has increased globally over the last two decades. The reasons for the increase are still largely unexplained, but it is most likely the product of several factors, and in particular include differences in case ascertainment, changes in diagnostic methods and improved pathways to diagnosis. This study was the first attempt to present statistics for ASD diagnoses among Australian children using data from every state and territory. The aims of the project were to provide Australian prevalence rates with which to describe the burden of the disorder throughout the country, to provide baseline statistics from which to measure patterns in prevalence over time, and to ultimately help policy planners to adequately manage the provision of services required for these children living in our community.

This study used a consistent method of case ascertainment to collect data across all jurisdictions in each Australian state and territory. For each source of data, information was sought on the diagnostic methods and pathways to diagnosis as well as administrative and policy details in order to account for any differences seen between geographic regions. The results of the study clearly indicate that the rate of ASD diagnoses, and therefore observed prevalence of ASD, among Australian children at this point in time varies considerably across states, largely affected by the use of different diagnostic pathways and administration procedures. As such the prevalence of autism in 2003-2004, according to State or Territory data, ranged from 3.6 to 21.9/10,000 for 0-5 year olds, 9.6 to 40.8/10,000 for 6-12 year olds and 4.4 to 24.3/10,000 for 13-16 year olds (**Table 6**). Using nationally-derived data, the prevalence of autism in Australia in 2003-2004 could have ranged from 8.5 to 15.3/10,000 for 0-5 year olds, 12.1 to 35.7/10,000 for 6-12 year olds and 8.3 to 17.4/10,000 for 13 to 16 year olds with a two-fold difference between a national funding agency source(Centrelink) and a nationally collated source from state disability services. (**Table 8**)

The descriptive information collected from the various services and agencies for children with ASD provided a detailed “snap-shot view” of diagnosis and assessment and intervention services as well as information about funding sources and models, changing referral patterns and organisational changes for each state and territory. This provided previously unavailable information about the similarities and difference of services throughout Australia. Potential important differences, such as variations in requirements and processes for diagnosis and assessment activities, differences in record-keeping protocols, and types and availability of intervention services, could contribute to inconsistencies and inequity both within and between states in allocation of services to children and their families, eligibility for funding and numbers of children diagnosed.

### **Data collection**

Considerable time and effort was needed to collect and collate the information provided in this report, with many of the obstacles to data collection and information gathering described previously. However the challenges experienced during this process were also very useful in elucidating some of the issues which restrict this type of data collection.

More than one agency in each of the disability and education sectors reported that their most detailed data were maintained at their service delivery sites rather than in a

centralized data base and therefore the resource allocation (primarily in terms of staff time) necessary to retroactively gather the requested data was prohibitive. In addition even within-sector data was not always consistent. For example, the provision of data from more than one data base within an agency, or data from an agency as well as its funded service provider, frequently resulted in different total values for the target variables. One national data source (Centrelink) was unable to provide more extensive data due to the limitations of its most readily accessible data base; the high volume of informational requests encountered by frontline staff; and the time and resources limitations and privacy considerations which may impact on the agency's ability to respond to a request for a higher level data search. The autism associations' focus on service delivery as well as privacy legislation limitations (as reported specifically by one of these agencies) have also limited their development of data collection processes. The limited representation of private service providers also highlights a whole sector that was outside the scope of this study but which increasingly provides services to people with ASD and merits further investigation.

Regional as well as sectorial differences in terminology use and data collection strategies also make data ascertainment, collation and interpretation more challenging and open to a higher degree of error. It is interesting to note that more than one responding agency reported planned action to redefine their data field more narrowly (for example, increased use of ASD subgroups) as well as a move towards centralization of data in addition to their currently more extensive site records. Collaboration between agencies and regions regarding a more standardized approach to these issues could enhance opportunities for information sharing and facilitate a smoother national dialogue in this area.

There was also considerable variability in the amount of data provided by agencies across all sectors. Some respondents provided extensive and detailed descriptions of their agency's role in regard to people with ASD, including both current and historical information. Other agencies were only able to provide minimal prevalence data. In addition, on more than one occasion follow-up contacts for the purpose of clarifying a response yielded considerable information even beyond that originally sought. This variability suggests that there are significant amounts of data held within agencies which, if accessible, would help provide a clearer and more comprehensive picture of ASD in Australia.

Actively addressing these sorts of data collection issues could impact strongly on the ongoing exploration of prevalence rates, diagnostic practices, subcategory information, intervention needs, and current diagnostic and intervention services across the country. This expanded and aligned information would in turn facilitate improved planning at all levels for current and projected service needs.

### **National data**

Currently there are two sources of national data about autism, Centrelink and AIHW (CTSDA-NMDS data), that were able to provide information to this study. AIHW were able to provide information about individuals with a primary disability group of Autism (which includes Asperger's Syndrome but does not differentiate between Autistic Disorder and Asperger Syndrome) while Centrelink provided information about individuals seeking funding with a diagnostic label of Autistic Disorder or Asperger Disorder. As they do not provide funding to individuals with a diagnosis of PDD-NOS

no data about this diagnostic group were available. AIHW were able to provide information about important subgroups such as age group distribution, gender, Indigenous identification and country of birth. Centrelink was able to provide age group and gender distribution data.

### **State and Territory data**

Information from individual States and Territories was provided by CTSDA-NMDS for 2003-2004 and from some State/Territory service providers. Centrelink was not able to provide a breakdown of numbers of children by State or Territory because of insufficient resources necessary to “interrogate their mainframe”, as necessary to generate this subgroup presentation of data. It is uncertain if this could be done with further funding or in a recurrent fashion if sufficient demand could warrant this process. In addition to data provided to CTSDA-NMDS some agencies from the States or Territories were able to provide numbers of children known to them with ASD. Numbers of children with ASD were not able to be provided by all State/Territory based service providers and numbers that were provided varied considerably between service providers within each State/Territory. This study did not seek identified information about individuals known to services and as such could not make adjustments for individuals seeking more than one service, as is now done for the CTSDA-NMDS. Initial suggestions of provision of identified data to this study raised concerns about individual privacy that are not likely to diminish for future attempts to collate national data about ASD. As such, information provided by different services in each State or Territories could not be combined in a way that would have potentially provided a better indication of numbers of individuals with ASD known to services in each State or Territory.

From sensitivity analysis, there was a greater variation between expected numbers per State/Territory generated from Centrelink data for some States and Territories compared to others. The overall variation between reported numbers by single services, CTSDA-NMDS and Centrelink data State/Territory estimates suggests that reliability of data from any one State or Territory based source is likely to be an unreliable way to provide information about service needs for children with ASD.

### **Prevalence estimates**

Prevalence estimates, calculated from data provided by these sources using ABS population data, were significantly different for the year that data was available for both sources. Both data sources are closely linked to access to services and/or funding and neither have diagnostic validation mechanisms in place.

CTSDA-NMDS data is collated from State or Territory data providers. However, this data varied more between States and Territories than would be expected based on known population distribution and varied with data provided by individual State or Territory sources to this study, even when reported by agencies providing data to the CTSDA-NMDS collection. Possible explanations for this include; differing processes for data collection and sites of data storage, making access to data or collation of data difficult or data collection at the point of service (as undertaken for collection of CTSDA data), or different guidelines for individuals to be included in CTSDA data collection due to specific funding guidelines. The type of data collection undertaken through CTSDA requires many professionals and as such, standardized training has

been implemented. However, it is always difficult to guarantee standardization when so many people, working in a wide range of services are involved.

National prevalence estimates for autism from existing data sources in 2003-2004 could range from 12.1/10,000 (95%CI 11.6, 12.6) to 35.7/10,000 (95%CI 34.8, 36.5). From Centrelink data the prevalence of autism in 6-12 year olds has increased significantly between 2003 and 2005 from 35.7/10,000 to 47.2 (95%CI 46.2, 48.1). In addition, a significant increase in estimated prevalence of Asperger Disorder in 6-12 year olds has occurred between 2003 and 2005, with an increase from 10.2/10,000 (95%CI 9.7, 10.6) to 15.3/10,000 (95%CI 14.8, 15.9).

The differences between prevalence estimates based on CTSDA data and Centrelink data are most likely to reflect the differences in data collection mechanisms and service usage of children with ASD. Similar differences have been reported internationally in one country at one point in time from different data sources (Fombonne 2003b). There are many possible reasons for these reported differences including the possibility that the difference is secondary to utilisation of CTSDA funded services by only a proportion of children with a diagnosis of ASD who are seeking Centrelink funding, as all service providers are aware of children with ASD who are using private or other non CTSDA funded services and/or who are coping in the mainstream and accessing services that are not designated as Autism specific. Alternatively it could be that diagnostic practice in relation to primary and secondary diagnoses is different in disability services, with more emphasis being given to intellectual disability rather than an autism diagnosis. Importantly, reported differences in prevalence from different data sources have been cited internationally as a reason for requiring diagnostic validation for autism data sources. Without diagnostic validation it is not possible to make decisions about which data source is more likely to reflect the true prevalence of ASD or whether a data source is sufficiently reliable to monitor trends over time.

Since 2000, seven studies have reported prevalence estimates from other countries for children under six years old (Honda et al 2005; Chakrabarti & Fombonne 2001; Chakrabarti & Fombonne 2005; Bertrand et al 2001; Powell et al 2000; Croen et al 2002; Baird et al 2000). Estimated prevalence for children age 0-5 years in 2003-2004 ranged from 8.5/10,000 (95%CI 8.0-8.9) for CTSDA-NMDS data to 15.3/10,000 (95%CI 14.7-15.9) for Centrelink data. Between 2003 and 2005 estimated prevalence from Centrelink data increased from 15.3/10,000 to 20.3/10,000 (95%CI 19.6-21.1) for this age group. These prevalence estimates are similar to prevalence estimates reported in other countries for children less than six years of age, which range from 7.8 to 55.0/10,000 (Powell et al 2000; Bertrand et al 2001). Recently published estimated prevalence for Asperger Disorder have been 9 to 10/10,000 (Fombonne et al 2006; Gillberg et al 2006), similar to estimated prevalence calculated using Centrelink data for 2003.

Prevalence estimates were not calculated from State and Territory data, other than CTSDA-NMDS data, because of considerable variation within the States and Territories. CTSDA prevalence estimates were significantly different between States and Territories and showed between State/Territory differences for the age group distribution of autism. It is unlikely that these differences represent true between State/Territory differences, but rather reflect different patterns of access of services and service usage reporting overall and for different age groups between jurisdictions.

### **Age specific prevalence**

The reasons for the variation of prevalence by age, in particular the decrease in prevalence of autism and Asperger Disorder in the older age groups is not clear from available data. This same pattern of prevalence has been reported in other countries (Croen et al 2002; Bertrand et al 2001; Bohman et al 1983; Hoshino et al 1982) and a number of possible explanations have been suggested. For example it has been suggested that lower prevalence in older age groups reflects the increase in the true prevalence of autism over time with estimated prevalence in older age groups reflecting previous prevalence estimates. Children in this study age 13-16 years in 2005 would have been born between 1989 and 1992. The only published data about the prevalence of autism in Australia for individuals of similar birth years is from the ACT, where the prevalence of autism in 1989 was reported to be 8.6/10,000 (95%CI 0.0-17.3) and in 1997, 15.2 (95%CI 0.0-25.8). Internationally prevalence rates for autism for children born in the same birth years have been reported ranging from 7.8 and 40.5 (Powell et al 2000; Bertrand et al 2001). Other possible explanations for a decrease in prevalence in older age cohorts include improvements in function made by 10-20% of children over time (Howlin 2004; Gonzalez et al 1993; von Knorring & Hagglof) or death of children with autism, with the death rate known to be approximately double that of groups of the same age and gender in the general population (Isgar et al 1999, Shavelle et al 2001). However, neither of these losses of children with autism would be sufficient to explain a halving of the rate as seen across the Centrelink derived prevalence estimates for autism for all years. In addition, lower prevalence in older age groups could be due to changes in service usage, poorer identification of children as they leave school and child health services or the decreased need for autism-specific services later in life. This type of change in "service" usage seems the most likely explanation for lower rates of Autism in individuals age 13-16 from Centrelink data and could be due to changes in funding needs of families as individuals with autism age, or changes in requirements to access funding for older individuals. However, further exploration of the way individuals of different ages seek and receive Centrelink funding is needed to prove this hypothesis.

### **Subgroup data**

At the State and Territory level, as well as the National level, information about diagnostic subtypes, age groups, gender, intellectual handicap, aboriginal identification or place of residence was not consistently available for the study and therefore it is not possible to make reliable conclusions about these factors.

Few services were able to provide information about subgroups of interest in autism research or important to service delivery, such as gender, intellectual disability, indigenous status etc. Of the services that did provide information male to female ratios for autism ratios of approximately 4 males to every 1 female were consistently found. This is in line with the gender ratio reported by other studies (Fombonne 2003a, Powell et al 2000, Chakrabarti and Fombonne 2005, Glasson 2002). All services saw a majority of individuals (52-92%) with Autism, rather than other ASD diagnoses. This does not reflect accepted population distribution of ASD, based on population studies (Chakrabarti et al 2005). However it is not surprising that this is the distribution when data are provided by service-providers who are most likely to see children with the most severe problems. Within Australia it is not known whether this diagnostic group profile for the services we surveyed reflects the intake criteria of services, the referral practices of professionals or a model of care for providing services for those with most needs by the services surveyed. It is also uncertain where or whether children with other ASDs

are actively receiving services. A more detailed study in this area is needed to explore these issues.

There was limited information available about the proportion of individuals with ASD using services who also have intellectual disability. This suggests that limited information is kept about intellectual ability, possibly because it does not influence service access or utilization or that many children are too young to be properly assessed in cognitive assessments at the time of diagnosis. The proportions reported by some services were lower than would be expected from international literature. It is known that different services are available to individuals depending upon their intellectual functioning and it is also possible that numbers reported are influenced by diagnostic coding which would alter allocation to an ASD if an intellectual disability is also present.

The number of individuals with ASD living in remote or rural locations has direct implications for models of service delivery. Unfortunately there was limited information available from the services providing data to this study about area of residence of individuals.

Again, limited information was available from service providers about Aboriginal identification of individuals known to their services. In Australia many data sources have problems collecting reliable information about Aboriginal identification. For ASD, there is limited information available about whether the prevalence of ASD is the same in individuals who identify as Aboriginal and those who do not. When the proportion of individuals with ASD who identify as Aboriginals (CSTDA data) is compared with the proportion of individuals aged 0-14 who identify as Aboriginals and the proportion of individuals in each state who are Indigenous (Australian Bureau of Statistics 2002 and Australian Bureau of Statistics 2001) substantial between State variation is seen (**Table 15**). It is improbable that this reflects a real difference in the occurrence of ASD in Aboriginal individuals in each State, but is more likely that the differences reflect variations in coding and reporting, or the use and availability of current diagnostic pathways to Aboriginal people.

**Table 15 Proportions of individuals with ASD reported to identify as Aboriginals compared to population percentages of Indigenous people, for States with this information available**

<b>State</b>	<b>Proportion of the State population who are Indigenous (ABS data)</b>	<b>Proportion of state aged 0-14 who are Indigenous (ABS data)</b>	<b>Proportion who are Indigenous from CTSDA data</b>
WA	3.5%	6.4%	3%
SA	1.7%	3.3%	1%
QLD	3.5%	6.5%	5%
VIC	0.6%	1.1%	2%
TAS	3.7%	6.9%	1%

#### **Epidemiological data in Australia**

To date there have been two studies in Australia to investigate the incidence of ASD, in NSW and WA (MJA publication Williams et al 2005b). Both studies used



epidemiological methods which were only for one time period in NSW but have continued in WA.

#### NSW Surveillance project

NSW data collection was funded between July 1999 and December 2000 by a competitive hospital-based research fund and the Financial Markets Foundation for Children. No funding has been secured to support ongoing data collection in NSW using active surveillance methods despite applications to overseas, national and non-government funding organisations since 2003. Applications in the last two years have been in collaboration with VIC, providing the opportunity to collect information about children with autism from the two most populated states in Australia. As such no epidemiological data about autism is available after 2000 in NSW and no recent data is available for VIC.

#### Western Australian Register for Autism Spectrum Disorders

The WA Autism Register was initiated in 1999 and serves as a primary resource to researchers, clinicians and service providers to assist with knowledge about ASDs, specifically autism, Asperger syndrome, childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). Although Rett syndrome is also categorized as a Pervasive Developmental Disorder, people diagnosed with Rett syndrome are not included on the register. The WA Autism Register is prospective, collecting information on all people diagnosed in WA since January 1999. Initial funding for the register was received from two sources: DSC (WA) and the Australian Rotary Health Research Fund. Since 2002, funds have been received from both the WA DET and the WA DoH to maintain its activities. Since its inception, the Register has received a large number of requests from local, interstate and international sources for data, information, and research participants. These requests have been made from government departments, autism service providers, researchers, students and the media.

The WA Autism Register is the only ongoing population-based register in Australia, and its success lies in the collaborative nature of clinicians and departments across the state. The WA Autism Register has received funding from the Disability and Education Sectors and currently receives ongoing funding from the Health Sector. While this funding supports the Register in a mode of minimal data collection, greater funding is needed to allow the Register to increase its capacity to collect more detailed and rigorous information on all newly diagnosed cases in WA. The model could be modified to apply to data collections in other Australian states/territories if the necessary collaborations and pathways were established, thus providing more constant and comparable prevalence statistics.

### **Descriptive information**

#### *Data collection and use*

Data available to this study varied between agencies, as described above. In addition, in response to specific questions about data storage and use, agencies reported a variety of data collection mechanisms and willingness to share data with relevant other agencies. Data collection was most organised under the CTSDA, however this data varied between States and Territories, suggesting the agencies involved in the agreement may not be a comprehensive source of data for all States and Territories. Information from Autism Associations and Education agencies suggest that data about children with

autism is currently collected. This may be a useful source of data to improve the comprehensiveness of State or Territory based data collection where services participating in the CTSDA agreement are not seeing all children with autism. If this were to occur, privacy would have to be ensured and legislative differences, about data storage and sharing, between organisations overcome. However, changes toward improvements in data collection, storage and categorisation for many agencies surveyed suggests that collaboration towards multi-agency data collection could be an avenue for collection of comprehensive information about autism in the future.

### **Diagnosis and assessment**

Diagnosis and assessment services vary between and within States and Territories in regard to the personnel involved in the diagnosis and assessment process and the diagnostic classification systems and tools used. Although there was consistency in the use of DSM-IV between services reporting the classification system they used, not all services reported this information and no information was available from the private sector. There is also evidence for considerable between-clinician variation in allocation of autism diagnoses using DSM-IV (Buitelaar et al 1999; Volkmar et al 1994), which, if not addressed, will impact on prevalence estimates.

It was outside the scope of this study to gather detailed information about diagnostic processes or to gather information about diagnostic processes in the private sector. However, the types of variations reported to this study could create substantial differences in the way children are diagnosed. For example, it is currently not known whether a diagnosis from a multidisciplinary team is equivalent to that of a single clinician diagnosis of children. As a child's diagnosis is so closely linked with access to services and funding, between agency differences in the services they accept diagnoses from, and differences in practice of the agencies providing diagnosis and assessment services, could be creating inequities for children and their families seeking help. Differences in diagnosis and assessment practices will also compromise validity and accuracy of data collected from different agencies.

### **Intervention services**

Many agencies in Australia are providing innovative services in an attempt to meet the needs of children with autism and their families. Many of these interventions and services are in line with the current approaches internationally toward early intervention and whole of family services. There were, however, between-State and Territory differences in the services provided by different agencies and also in the types of services reported to be available. In addition, some States and Territories reported differences in the availability of services to children and families living in remote and rural locations compared to metropolitan areas. These differences are likely to lead to within and between state inequalities in services available to children and their families.

### **Changes in patterns of referrals**

Many services reported changes in referral numbers over the last seven years. With most reporting an increase in total referral numbers and changes in the diagnostic profile of children referred. Information about the diagnostic profile of children being seen by agencies in Australia, along with information about co-morbidity, such as intellectual disability or psychiatric disorder, is crucial for service development that will cater to the needs of children with autism and their families. It is also important in assessing whether there have been changes in diagnostic practice and patterns of service

use in recent years. Diagnostic practice change, professional, service provider and public awareness of social interaction problems and service use changes have all been reported as possible explanations of increases in referrals in the last seven years.

### **Changes in funding and organisational structure or process**

Agencies have reported expanding the types of services they provide and the ways they provide services, including increasing collaboration with other agencies, to try to meet the needs of the children and families referred to them.

Different funding models have been trialled by different agencies both within and between States and Territories. No information about the evaluation of these different models was available to this report, but information about the variation in models currently being used across Australia suggests that there is an opportunity for comparative analysis of their cost effectiveness to ensure best application of funding models in the future.

### **Private sector information**

Funding and timeline for this report did not allow exploration of services provided in the private sector. However, private services were mentioned as increasingly providing both diagnosis and intervention services. The best published source of data about diagnosis and assessment activities completed in the private sector comes from the WA Autism Register. **Table 16** shows the percentage of assessments conducted in the Private Sector between the years 1999 and 2004, inclusive (Glasson et al 2000, 2001, 2001, 2003, 2005, 2006). As shown, there has been a substantial increase in diagnostic assessments completed privately over that time.

**Table 16 Percentage of children for Location of diagnostic assessments as reported to the WA Register for Autism Spectrum Disorders between 1999 and 2004.**

Agency	1999	2000	2001	2002	2003	2004
DSC Metro	44	35	33	33	31	31
DSC Country	15	19	22	23	22	22
SCDC	24	27	22	12	12	7
Princess Margaret Hospital	3	1	2	0.5		
Private Practitioners	14	18	22	30	31	35
Other centres					5	6

## CONCLUSIONS

At the current time, the prevalence of ASDs in Australia is not certain from existing data. However, in 2005, Centrelink data provides an estimated prevalence of autism spectrum disorders in Australia for 6-12 year olds of 62.5 per 10,000. Centrelink can provide the most comprehensive single source of National information about the number of individuals seeking funding with a diagnosis of Autism or Asperger Disorder in Australia. It provides information about the minimum number of individuals living with these diagnoses each year. However, these data are best for younger children diagnosed with either Autism or Asperger Disorder. Centrelink data are incomplete in relation to individuals between 13-16 with Autism and Asperger Disorder and provides no information about individual with PDD-NOS who may also require services to maximize their potential abilities and to minimize the burden of care for themselves, their families and the community. In addition, there are difficulties accessing specific Centrelink data in a way that provides information needed by States and Territories, which are ultimately the sources of funding for many services for affected individuals and their families. Privacy legislation is also a potential barrier to further examining validity of Centrelink diagnoses that would be required to investigate whether the trends towards and increase in individuals seeking funding for Autism and Asperger Disorder reflect a true increase in the incidence of these disorders. Privacy legislation is also likely to prevent use of Centrelink data for identification of individuals for research initiatives into diagnosis, treatment and prognosis.

CTSDA-NMDS has been a substantial initiative toward documenting the number of individuals in all Australian States and Territories living with disability. The focus of this activity is not ASD, although it is one of the diagnostic groups about which information is collected. However, the significantly lower prevalence estimated from CTSDA-NMDS data compared to Centrelink data and the substantial between State/Territory variability of this data suggest it has considerable limitations for use for service planning or research. This is echoed by the variation and difference between other individual service provider sources of data.

The current study arose from the continuing concern of increasing ASD prevalence in Australia and the lack of data about the number of affected children across the nation. This report is the first publication to include information about diagnostic practices, intervention services and prevalence rates for all Australian states and territories. While the study achieved an 85% response rate from agencies that were approached for data, completeness of the data across both states/territories and sectors was variable. However, almost all respondents offered their personal support that the study was well-justified and of high importance.

The collected data, through their inconsistency, confirm that there are significant differences in the way children with ASDs are diagnosed, directed to services, and are offered different support schemes across Australia. Administrative services appear vastly different in the way their data is collected, stored and presented, according to their separate organisational objectives and client-focus. If good measures of Australian ASD prevalence are to be calculated and then re-calculated over time, streamlining of data collection methods is necessary across sectors and states/territories. Of particular concern is the current inability of agencies to provide good data on subgroups of children, in particular gender breakdowns, geographic locations, Indigenous status and

presence of intellectual disability. These factors are important to the demography of ASD in Australia and are essential for the successful planning of services and support of affected children.

Descriptive information suggests that services are being provided by multiple organisations with increasing activity in the private sector for diagnosis and assessment and intervention services. It shows interesting similarities and important differences in the way that children are diagnosed and assessed and provided with the services they and their families need. Resources for this report have not allowed assessment of whether existing need, based on prevalence and complexity of problems of children with ASD, are currently being met in Australia. However, the difference between reported rates from one funding agency and state-based services suggests that some children are not receiving services they need. In addition, the availability of some services in some States or Territories but not in others and the differences identified between services in metropolitan and rural services suggest that there is unmet need.

## RECOMMENDATIONS

In response to the international trends in autism diagnoses and the findings of this current study, it is strongly recommended that for Australia to gather reliable information about the prevalence of ASD for national, State and Territory use, the development of additional data systems is required. These systems will need to be equipped to gather information from both the private and public sector. Legitimate concerns about privacy raise barriers to sharing of information in a way that is needed to ensure that all individuals with ASD are identified and not counted more than once. This has been overcome for CTSDA-NMDS data collection, and needs to be extended to facilitate collection of similar information from other sources.

Collection of valid and reliable prevalence data about autism will require a national consensus based on an understanding of the Australian context and best level evidence, about diagnosis and assessment of children with autism, so that agreed approaches and standards are available and implemented. This type of diagnosis and assessment consensus is urgently needed, not only to ensure valid prevalence estimates, but to ensure appropriate provision of interventions to those in need. While it was outside the scope of this study to explore the prevalence or service provision needs of individuals with ASD who are older than 16 years of age, investigation of this group is essential to a complete understanding of the needs of all individuals in Australia with autism. This information would not only assist with meeting the needs of individuals currently in the over 16 year old age group but would also facilitate planning for the future of today's children as they age and their needs change.

Description of the range of intervention services currently available in Australia, and within and between State and Territory differences suggests that consensus in Australia is also needed about requirements for intervention for children of different ages, based on local knowledge and best level evidence. This approach would ensure the availability of effective interventions to all children and families in need.

Some possible pathways for ensuring comprehensive and valid national prevalence data in Australia would be to:

1. Explore ways of accessing Centrelink data at State/Territory level and possible ways in which identified information could be provided for validation and data-linkage to other data sources.
2. Explore ways of extending CTSDA-NMDS activity to other service providers for ASD and into the private sector
3. Develop a virtual register of individuals with ASD – in line with a recently funded US initiative (A national online interactive ASD data base funded by Autism Speaks [www.autismspeaks.org](http://www.autismspeaks.org) and to be developed by Kennedy Krieger Institute [www.kennedykrieger.org](http://www.kennedykrieger.org)) – that is linked to service information and best evidence dissemination.

If a mechanism for National collation of data from multiple sources, with opportunities for diagnostic validation could be established, then this would form the basis for future much needed research into the causes (including genetic and environmental interactions), effective treatments, diagnostic pathways and prognosis of individuals with autism, with the potential to further reduce the occurrence and long term adversity of ASD.

Increasing involvement of the private sector in diagnosis and intervention services for children and families with autism raises some specific issues that also need consideration and planning. Some of these issues include;

1. Data collection from the private sector will need to occur through separate mechanisms to agency based data collection and as such requires establishment of new and specific systems that are accessible and appropriate for professionals working in this sector.
2. If recommendations are made about diagnosis and assessment practices and minimum standards for intervention services, then they must be able to be implemented and evaluated in the private sector. This is likely to require a separate implementation process and evaluation mechanism.
3. It is possible that utilization of private sector services or “fee for service” services via agencies is creating further inequity in provision of care for children with autism.
4. If families of children with autism are spending money in the private sector to access diagnosis and assessment and intervention services then this cost needs to be known so that an accurate understanding of the cost of caring for a child with autism is available.

Collaboration between agencies and regions regarding a more standardized approach to these issues could enhance opportunities for information sharing and facilitate a smoother national dialogue in this area.

Until a National approach to collection of prevalence data about autism (reaching consensus about approaches to diagnosis and assessment and intervention services to be provided to all affected children and their families) is underway, it is not possible to ensure that services are being provided to those who need them in a timely fashion and, as such, it is unlikely the potential of each individual with autism is being optimised. Opportunities to undertake useful research that has the potential to improve the lives of those affected and their families are also being missed.

APPENDIX 1

National, State and Territory Agency Summaries and Contact Information

State	Agency	Primary Role	ASD Related Role	Contact Information
Federal Govt	<p><b>Australian Institute of Health and Welfare – AIHW</b></p> <p><b>Unit</b> Functioning and Disability Unit - FDU</p>	<p>The <b>Australian Institute of Health and Welfare (AIHW)</b> is Australia's national agency for health and welfare statistics and information.</p>	<p>The <b>FDU</b> employs "data development, collation and analysis. In line with AIHW legislation" in order to "provide information on the need for, provision and use of disability services in Australia; and increase the quantity and quality of policy relevant information in Australia, and ensure its availability to a diverse audience". Autism is one category of disability identified, analyzed and reported on in various AIHW reports.</p>	<p><b>AIHW</b> 26 Thynne Street, Fern Hill Park, Bruce ACT GPO Box 570, Canberra, ACT 2601 Ph: (02) 6244 1000 Fax: (02) 6244 1299 Web: <a href="http://www.aihw.gov.au">www.aihw.gov.au</a> Email: <a href="mailto:info@aihw.gov.au">info@aihw.gov.au</a></p> <p><b>Functioning and Disability Unit</b> GPO Box 570, Canberra ACT 2601 Ph: (02) 6244 1189 Fax: (02) 6244 1069 Web: <a href="http://www.aihw.gov.au/disability/index.cfm">www.aihw.gov.au/disability/index.cfm</a> Web: <a href="http://www.aihw.gov.au/orgchart/28.cfm">www.aihw.gov.au/orgchart/28.cfm</a></p>
Federal Govt	<b>Australian Bureau of Statistics - ABS</b>	<p>The ABS mission is to "assist and encourage informed decision making, research and discussion within governments and the community by leading a high quality, objective and responsive national statistical service".</p>		<p><b>National Information &amp; Referral Service</b> Ph within Aust: 1300 135 070 Fax: 1300 135 211 Email: <a href="mailto:client.services@abs.gov.au">client.services@abs.gov.au</a> Census info: <a href="mailto:census2001@abd.gov.au">census2001@abd.gov.au</a></p>
Federal Govt	<p><b>Department of Human Services</b></p> <p><b>Agency</b> Centrelink</p>	<p>DHS delivers social and health related services through its various agencies, one of which is Centrelink.</p> <p>Centrelink is an agency that delivers a wide range of Commonwealth services to the Australian Community.</p>	<p>One of the Centrelink services is the management of the Carer Allowance (Child). This is a supplementary payment for carers who provide daily care and attention for children with a disability or severe medical condition at home. Autism is one of the eligible diagnoses for this payment.</p>	<p><b>DHS</b> PO Box 3959, Manuka ACT 2603 Ph: 130055 44 79 General Enquiries Ph: (02) 6223 4000 General Switchboard Fax: (02) 6223 4999 Web: <a href="http://www.humanservices.gov.au">www.humanservices.gov.au</a></p> <p>General Centrelink Contact Web: <a href="http://www.centrelink.gov.au">www.centrelink.gov.au</a></p> <p><b>For research &amp; statistics related questions; BI Frontdoor</b> Performance &amp; Information Branch Business Integrity Division National Support Office DE4, Tuggeranong Office Park</p>



				Ph: (02) 6244 7270 Fax: (02) 6244 1819 Email: <a href="mailto:bi.frontdoor@ecntrelink.gov.au">bi.frontdoor@ecntrelink.gov.au</a>
WA	<b>Disability Services Commission (DSC)</b>	Responsible for policy and program development and service planning in all areas that affect the rights and needs of Western Australians with disabilities. Provides services for individuals aged 0-65 years.	Provides some direct assessment and intervention services. Provides funding and co-ordination support to assist with the delivery of intervention services within the Perth metropolitan as well as rural and remote areas of Western Australia.	<b>DSC</b> 146-160 Colin Street West Perth, 6005 WA PO Box 441, West Perth WA 6872 Gen Enquires: (08) 94269200Main Fax: (08) 9226 2306 TTY: (08) 9426 9315 Country callers: Freecall 1800 998 214  Email: <a href="mailto:dsc@dsc.wa.gov.au">dsc@dsc.wa.gov.au</a> Web: <a href="http://www.dsc.wa.gov.au">www.dsc.wa.gov.au</a>  <u>Who to Contact:</u> Senior Policy Officer Strategic Policy Branch
WA	<b>Disability Services Commission (DSC)</b>	Responsible for policy and program development and service planning in all areas that affect the rights and needs of Western Australians with disabilities.	Provides some direct assessment and intervention services. Provides funding and co-ordination support to assist with the delivery of intervention services within the Perth metropolitan as well as rural and remote areas of Western Australia.	<b>DSC</b> 146-160 Colin Street West Perth, 6005 WA PO Box 441, West Perth WA 6872 Gen Enquires: (08) 94269200Main Fax: (08) 9226 2306 TTY: (08) 9426 9315 Country callers: Freecall 1800 998 214  Email: <a href="mailto:dsc@dsc.wa.gov.au">dsc@dsc.wa.gov.au</a> Web: <a href="http://www.dsc.wa.gov.au">www.dsc.wa.gov.au</a>  <u>Who to Contact:</u> Senior Policy Officer Strategic Policy Branch
WA	<b>Department of Education and Training (DET)</b>	Aims to provide a quality lifelong learning environment in which everyone will have the opportunity to reach their learning and skills potential and contribute to society.	Provides services for students with disabilities, including those with Autism Spectrum Disorders, through their Schools Plus and Center for Inclusive Schooling programs.	<b>DET</b> Central Office 151 Royal Street, East Perth, WA 6004 General Enquiries Ph: (08)92644111 Fax: (08) 92645005 <a href="http://www.eddept.wa.edu.au">www.eddept.wa.edu.au</a> Email: <a href="mailto:websupport@det.wa.edu.au">websupport@det.wa.edu.au</a>
	Schools Plus (SP)	<u>Schools Plus</u> was developed by DET as a model of informed	Autism Spectrum Disorder is one of the 8 groups identified	<b>SP</b> General Enquiries

	<p><u>The Centre for Inclusive Schooling (CIS)</u></p> <p>▪</p>	<p>practice to match the educational needs of students to supplementary resourcing for schools. SP allows schools to plan, implement and review appropriate educational programs for students on the basis of educational need and provides direct supplementary resources to schools that have eligible students.</p> <p>The CIS is part of the Student Services Team within the Student Services and Community Support Directorate of the DET, Western Australia. It provides a statewide support service for students with disabilities and learning difficulties via school districts and through them to schools. This service is provided via dedicated teams, of which the Autism Intervention Team (AIT) is one. CIS also provides a Resource Library and a Production Unit which produces resources for teachers which are not available commercially.</p>	<p>by <u>SP</u> as an eligible condition. Student eligibility is determined on a case by case basis. The student must be identified as requiring significant levels of adjustments that are ongoing and beyond the school's current level of resourcing.</p> <p>The Autism Intervention Team (AIT) is comprised of a Team Coordinator and Visiting Teachers for Students with Autism. The AIT works across the State and allocates team members according to particular districts' needs. The team meets on a regular basis to discuss student, school and district based issues and needs.</p>	<p>Ph: (08)92644111  Fax: (08) 92645005  Web: <a href="http://www.schoolsplus.det.wa.edu.au/splus">www.schoolsplus.det.wa.edu.au/splus</a></p> <p><b>CIS</b>  Hale House, Parliament Place, West Perth WA 6005  Ph: (08) 94267111  Fax: (08) 94267117  <a href="http://www.eddept.wa.edu.au/CIS/index.html">www.eddept.wa.edu.au/CIS/index.html</a>  Email: <a href="mailto:cis@det.wa.edu.au">cis@det.wa.edu.au</a></p> <p><u>Who to Contact:</u>  Autism Intervention Team Leader</p>
WA	<p><b>Catholic Education Office of Western Australia (CEOWA)</b></p>	<p>The CEOWA, through its various metropolitan and regionally based schools, provides opportunities for Catholic education to be available to all children of Catholic parents who seek such an education for their children.</p>	<p>Special Learning Needs Team's role is to</p> <ul style="list-style-type: none"> <li>• help Catholic school communities to respond to the special needs and talents of students who experience significant difficulties with learning;</li> <li>• support the inclusion of students with disabilities in appropriate educational settings; and</li> <li>• promote exemplary pedagogical practices for students with special learning needs.</li> </ul> <p>Students with a diagnosis of Autism Spectrum Disorder are amongst those eligible to access these services.</p>	<p><b>CEOWA</b>  50 Ruslip Street, Leederville WA 6007,  PO Box 198, Leederville WA 6903  Ph: (08) 9212-9239  Fax: (08) 9212-9298</p> <p><u>Who to Contact:</u>  Co-Ordinator, Special Learning Needs Team</p>
WA	<p><b>Association of Independent Schools of Western Australia (AISWA)</b></p>	<p><b>AISWA</b> is the peak body representing independent schools in Western Australia. It's primary role is to develop, assist, strengthen and promotes the interests of independent schools in WA.</p>	<p><b>AISWA</b> employs two Inclusive Education Consultants. The consultants are available, at the invitation of member schools, to give advice aimed at supporting their students with learning difficulties or disabilities. The consultants provide a range of collaborative services for parents and teachers within and across member schools.</p>	<p><b>AISWA</b>  Suite 3, 41 Walters Drive, Osborne Park, WA 6017  Ph: (80) 9244-2788  Fax: (08) 9244-2786  Web: <a href="http://www.ais.wa.edu.au">www.ais.wa.edu.au</a></p> <p><u>Who to Contact:</u>  Special Needs Consultant</p>
WA	<p><b>Autism Association of Western Australia Inc</b></p>		<p><b>AAWA's</b> Aim is: To advance the personal development, equality of opportunity and community participation of people with autism.</p> <p>AAWA provides a range of services including;</p> <ul style="list-style-type: none"> <li>▪ Early Intervention services</li> <li>▪ School age services</li> <li>▪ Post school options/alternative to employment programs</li> <li>▪ Employment support services</li> </ul>	<p><b>AAWA</b>  37 Hay Street, Subiaco, WA 6008  Locked Bag 9, Post Office, West Perth, WA 6872  Ph: (08) 94898900  Fax: (08) 94898999  Email: <a href="mailto:autismwa@autism.org.au">autismwa@autism.org.au</a>  Web: <a href="http://www.autism.org.au">www.autism.org.au</a></p> <p><u>Who to contact</u></p>

			<ul style="list-style-type: none"> <li>▪ Group homes and individual accommodation support services</li> <li>▪ Family support services</li> <li>▪ Training services</li> </ul>	General enquiries: Receptionist at phone number above
NT	<b>Dept of Health and Community Services (DHCS)</b>  <b>Section:</b> <u>Aged &amp; Disability Program(ADP)</u>	DHCS provides a wide range of services across the Northern Territory aimed at maximizing the physical, mental, social and environmental well being of the whole population.	<p>The <u>ADP</u> develops and implements disability and ageing related policy. It also funds and/or directly provides a range of services that aim to enhance the opportunities for people with disabilities, children with developmental concerns, people who are ageing and their families and carers to contribute to and participate in the community.</p> <p><u>Top End Mental Health Service</u>  Child and Adolescent Service</p>	<b>(DHCS)</b> Health House, 87 Mitchell St, Darwin, NT PO Box 40596, Casuarina, NT 0811 Ph: (08) 89992831 Fax: (08) 89992488 <a href="http://www.health.nt.gov.au">www.health.nt.gov.au</a>  <u>Who To Contact:</u> Director, Aged and Disability Program  Ph: (08) 89994988
NT	<b>Dept of Employment, Education &amp; Training (DEET)</b>  <b>Section:</b> <u>People &amp; Learning</u>  <b>Division:</b> <u>Student Services Division (SSD)</u>	Responsible for education, employment , training and NT Worksafe. Focus is on building and protecting the Territory workforce, improving educational outcomes for all students and providing safe working and learning environments. DEET is committed to creating and improving pathways between school, training and employment.	<p><u>SSD</u> conducts assessment, provides an advisory service, intervention and educational support to all NT schools, parents and community based programs for students with special needs.</p>	<b>People &amp; Learning</b> GPO Box 4821, Darwin, NT 0801 Ph: (08) 89995618 Fax: (08) 89995843 <u>Who to Contact:</u> General Manager  <b>Student Services Division</b> Brolga St, Wulagi School GPO Box 4821, Darwin, NT 0801 Ph: (08) 8999 8750 <u>Who to contact:</u> General Manager
NT	<b>Autism Association</b>		Small volunteer resourced association that focuses on providing parent support, information and advocacy services.	<u>Who to Contact:</u> Alison Bird Executive Officer PO Box 36609 Winnellie, NT 0821 Ph: (08) 9322395 Email: <a href="mailto:autismnt@bigpond.net.au">autismnt@bigpond.net.au</a>
SA	<b>Department for Families and Communities - DFC</b>	Has a broad mandate to work with those in need, including those who may be poor, vulnerable, at risk of harm or isolated and disconnected. Overall mission is to improve the quality of family and community life in South Australia.		<b>DFC Central Office</b> Level 2, Riverside Centre North Terrace, Adelaide SA 5000 GPO Box 292, Adelaide SA 5001



			<i>Application to Conduct Research</i>	PO Box 806, Brisbane QLD 4000 Ph: (07) 3224 8031 Toll free: 1 800 177 120 TTY Toll-free: 1 800 010 222 Calls from mobile phones are charged at applicable rates. Fax: (07) 3224 8037 <a href="http://www.disability.qld.gov.au">www.disability.qld.gov.au</a> Email: <a href="mailto:disabilityinfo@disability.qld.gov.au">disabilityinfo@disability.qld.gov.au</a> Who to Contact:
Qld	Dept of Education & The Arts - DEA		Note: All research requests require completion of a research application. Enquiries to: Principal Policy Officer Research & Education Futures Strategic Policy & Education Department of Education and the Arts Floor 21, Education House, 30 Mary St PO Box 15033, city East, QLD 4002 Ph: (07) 32371286 Fax: (07) 32371175	<b>DEA Central Office</b> Education House 30 Mary Street, Brisbane QLD 4000 PO Box 15033, City East, QLD 4002 Ph: (07) 3237 0111 <a href="http://www.education.qld.gov.au">www.education.qld.gov.au</a>  <b>Student Services</b> Floor 21, Education House Ph: (07) 32371063 Reception Fax: (07) 32354099 Who to Contact: Director of Student Services
Qld	Autism Queensland Inc (Autism Association)		Provides centre based and outreach educational support, centre based and outreach therapy services, family support, accommodation, respite care and training services to people with Autism Spectrum Disorders, their families and support staff.	<b>Autism QLD Head Office</b> 437 Hellowell Rd, Sunnybank, Qld 4109 PO Box 354, Sunnybank QLD 4109 Ph: (07) 3273 0000 Fax: (07) 3273 8306 Email: <a href="mailto:tonic@autismqld.com.au">tonic@autismqld.com.au</a> <a href="http://www.autismqld.asn.au">www.autismqld.asn.au</a> Who to Contact: Penny Beeston, Chief Executive Officer
NSW	Department of Ageing, Disability and Home Care - DADHC	Responsible developing and implementing policy, planning, resource allocation and performance measurements in order to improve service delivery and provide opportunities for older people and people with a disability, to assist them to participate fully in community life and to improve their quality of life.		
NSW	Department of Education and Training - DET	Meets the educational and learning needs of children, young people and adults, addresses training needs in industry and promotes life long learning.	Provides a range of services to support students with disabilities, and their teachers, including those with Autism or Asperger Syndrome. These include support for children in mainstream classes, specials classes, special schools and itinerant specialist support services.	NSW DET GPO Box 33, Sydney, NSW 2001 Ph: (02) 9561 8000 Web: <a href="http://www.det.nsw.edu.au">www.det.nsw.edu.au</a> Research enquiries: <a href="http://www.det.nsw.edu.au/research/index.htm">/www.det.nsw.edu.au/research/index.htm</a>

				<u>Who to contact</u>
<b>NSW</b>	<b>Autism Spectrum Australia - Aspect</b>		Aspect builds partnerships with people with Autism Spectrum Disorders, their families and the community to provide information, services, learning and research. Provides early intervention, school outreach, behavioral and social programs and limited diagnostic and assessment services. Adult focused services also include employment and community participation services.	<b>Autism Spectrum Australia (Aspect) Central Office</b> 41 Cook Street, Forestville, NSW 2087 PO Box 361, Forestville NSW Ph: (02) 8977 8300 Fax: (02) 8977 8399 Email: <a href="mailto:contact@aspect.org.au">contact@aspect.org.au</a> Web: <a href="http://www.autismnsw.com.au">www.autismnsw.com.au</a> <u>Who to Contact:</u> Director, Education and Research Centre for Western Sydney PO Box 770, Seven Hills NSW 1730 Ph: (02) 8868 8500 Fax (02) 9896 5266 Email: <a href="mailto:education_research@aspect.org.au">education_research@aspect.org.au</a>
<b>TAS</b>	<b>Department of Education - DE</b>	The Department is responsible for primary and secondary education, library and information services, vocational education and training services, children's services, assessment and certification services and youth affairs.	DE is responsible for providing early intervention services for children aged from birth to school entry for young children with disabilities. Support is also provided for students in mainstream, special class and special school placements.	Central Office 116 Bathurst Street, Hobart Tas GPO Box 169, Hobart Tas 7001 Telephone: 1300 135 513 Fax: (03) 6231 1576 Web: <a href="http://www.education.tas.gov.au">http://www.education.tas.gov.au</a>  State Support Service Inclusive Learning Support GPO Box 169 Hobart Tas 7001 Ph: (03) 6233 7743 Fax: (03) 6233 6780  Web: <a href="http://www.education.tas.gov.au/statesupport">www.education.tas.gov.au/statesupport</a> <a href="http://www.education.tas.gov.au/statesupport/early-special-ed">www.education.tas.gov.au/statesupport/early-special-ed</a>  <u>Who to Contact</u> E-mail: <a href="mailto:lynne.james@education.tas.gov.au">lynne.james@education.tas.gov.au</a>
<b>TAS</b>	<b>Department of Health and Human Services - DHHS</b>	The Department of Health and Human Services (DHHS) contributes funding to over 240 organisations to provide a range of services to the Tasmanian community.	DHHS is divided into service and support divisions. The service division is then divided into 4 main sections. The Children and Families section provides a range of complementary services for children, young people, families, individuals and the communities that support them.	<b>DHHS</b> 34 Davey Street, Hobart TAS 7000 GPO Box 125, Hobart TAS 7001 Reception and Enquiries Ph: 1 300 135 513

				(03) 6233 3185 <u>Who to Contact:</u>
<b>TAS</b>	<b>Autism Association of Tasmania</b>		Provides a point of contact, information and support for families of individuals with an Autism Spectrum Disorder.	<b>AAT</b> PO Box 1552, Launceston TAS 7250 Ph: (03) 6344 3261 Email: <a href="mailto:autism@autismtas.org.au">autism@autismtas.org.au</a> Web: <a href="http://www.autismtas.org.au">www.autismtas.org.au</a>
<b>VIC</b>	<b>Department of Human Services</b>  <b>Branch</b> Aged Care Branch	The mission of the Department of Human Services is 'To enhance and protect the health and well-being of all Victorians, emphasising vulnerable groups and those most in need'.  DHS consists of 8 service divisions. The Aged Care Branch, which is contained within the Rural and Regional Health and Aged Care Services, manages the Home and Community Care program (HACC)	The HACC program provides funding for services which support frail older people, younger people with disabilities and their carers. These services provide basic support and maintenance to people living at home and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long-term residential care	<b>DHS</b> 55 Collins Street, Melbourne VIC 3000 Ph: 1 300 650 172 Ph: (03) 9096 0000 Web: <a href="http://hnp.dhs.vic.gov.au/wps/portal">hnp.dhs.vic.gov.au/wps/portal</a> Web: <a href="http://www.dhs.vic.gov.au/contact.htm">www.dhs.vic.gov.au/contact.htm</a>  <b>Aged Care Branch</b> HACC Data Collection & Analysis Aged Care Branch Department of Human Services GPO Box 4057 <u>Who to Contact</u> Victorian HACC Data Help Desk Ph: (03) 9616 7255 Fax: (03) 9616 8680
<b>Vic</b>	<b>Department of Education and Training – DET</b>  <b>Branch:</b> Student Wellbeing - SWB  <b>Program</b> Program for Students with Disabilities -PSD	The DET's primary responsibilities include the provision of, and access to high quality primary and secondary education for all Victorian children in both government and non-government schools. It is also responsible for ensuring high quality post secondary training and education options.  <b>SWB</b> is responsible for the management and implementation of the Program for Students with Disabilities	<b>PSD</b> provides a framework to support the educational programs of eligible students within government schools. This program provides resources to schools in order to assist the students' education. Autism Spectrum Disorder is one of 6 eligible categories within the PSD framework.	Contact <b>DET</b> via <b>DE&amp;T</b> Information and Referral Service Department of Education and Training GPO Box 4367, Melbourne VIC 3001 Ph: 03 9637 2222 or Freecall: 1800 809 834 <b>Main</b> Switchboard: (03) 9637 2000 <b>Fax:</b> (03) 9637 2626 <b>Web:</b> <a href="http://www.det.vic.gov.au">www.det.vic.gov.au</a> Email: <a href="mailto:edline@educail.vic.gov.au">edline@educail.vic.gov.au</a>  <b>PSD Central Office</b> 33 St Andrews Place, East Melbourne VIC 3002 Ph: (03) 9637 2106 <b>Web:</b> <a href="http://www.sofweb.vic.edu.au/wellbeing/disability">www.sofweb.vic.edu.au/wellbeing/disability</a> Email: <a href="mailto:disability.services@edumail.vic.gov.au">disability.services@edumail.vic.gov.au</a>
<b>Vic</b>	<b>Autism Victoria – Autism Association</b>		Autism Victoria provides a range of services including policy analysis at State and national levels; lobbying for issues important to members; hosting a membership forum;	Autism Victoria 35 High Street, Glen Iris, VIC 3146 PO Box 235, Ashburton VIC 3147 Ph: (03)

			providing specialist advice and information to families and service providers and increasing public awareness and understanding of ASD.	9885 0533 Fax: (03) 9885 0508 E-mail: <a href="mailto:admin@autismvictoria.org.au">admin@autismvictoria.org.au</a> Web: <a href="http://www.autismvictoria.org.au">www.autismvictoria.org.au</a>  Who to Contact: Chief Executive Officer
ACT	<b>Department of Education and Training</b>  Section: Special Education - SES	Delivers high quality education services through government schools; registers non government schools; and administers vocational education and training in the ACT.	<b>SES</b> manages the provision of educational services to students with disabilities in ACT government schools. Pervasive Developmental Disorder (as defined in the DSM-IV & ICD-10) is one of 8 eligible disability categories.	<b>DE&amp;T</b> 186 Reed Street, Greenway, ACT 2900 PO Box 1584, Tuggeranong, ACT 2901 Ph: (02) 6207-5111 Fax: (02) 6205-9333 Web: <a href="http://www.det.act.gov.au">www.det.act.gov.au</a> Email: <a href="mailto:DETFEedback@act.gov.au">DETFEedback@act.gov.au</a>  <b>SES</b> Enquiries: Ph: (02) 6205 6925 Fax: (02) 6205 5447 Web: <a href="http://www.det.act.gov.au/services/Useful%20Informatio.htm">www.det.act.gov.au/services/Useful%20Informatio.htm</a>
ACT	<b>Department of Disability, Housing and Community Affairs DDHCA</b>	The ACT DDHCA has responsibility for a wide range of human services functions in the ACT, including multicultural and community affairs, public and community housing services and policy, children, youth and family support services and policy, disability policy and services, therapy services, Child and Family Centres, the ACT Government Concessions Program, homelessness and community services.	<b>Therapy ACT</b> is a division of the DDHCA. It provides a multidisciplinary therapy and support service for people with disabilities and delays in their development aged from birth to 65 years of age.  Therapy and support services are available for physiotherapy, occupational therapy, speech pathology, social work and psychology.	<b>Disability ACT</b> GPO Box 158, Canberra, ACT 2601 Level 2, Nortel Networking Building, 12 Moore St, Canberra City  Enquiries Ph: (02) 62071086 Fax: (02) 62050940 TTY: (02) 62050888 Email: <a href="mailto:DisabilityACT@act.gov.au">DisabilityACT@act.gov.au</a>  <b>Therapy ACT</b> General Enquiries: Ph: (02) 62051277 Email: <a href="mailto:TherapyACT@act.gov.au">TherapyACT@act.gov.au</a>



**APPENDIX 2**



**7 Key Questions  
Agencies collecting Prevalence Data**

<b>AgencyName</b>	
<b>Contact Person/ Department</b>	
<b>Phone</b>	
<b>Email</b>	
<b>Contact Date</b>	
<b>Follow-up Needed /Comments</b>	

**1. What is the general nature of your agency and the services it provides?**

**2. Who provides data to your agency?**

- Family self referral
- Health providers
- Educators
- Other

**3. What can you provide in terms of data for children that are referred to your agency?**

- **Numbers in age ranges** No/Yes

Age Ranges		Numbers
Preschool	0-5 yrs	
Primary	6-12yrs	
Secondary	13-16	

- **Gender breakdown** No/Yes

Gender	Numbers
Female	
Male	

**- Ancestry** No/Yes

The ancestry with which the respondents in your data base identified themselves

Ethnicity	# in caseload	OR % in caseload
Aboriginal/Torres Strait Islander		
Other – please identify		

**- Home Language** No/Yes

Home Language	# in caseload	OR % in caseload
English		
Chinese languages		
Vietnamese		
European languages		
African languages		
Middle Eastern languages		
Other – please identify		

**- Location** No/Yes

Location	Numbers
Metro	
Rural	
Remote	

**- Differential Diagnostic Information** No/Yes

Diagnostic Information	Description
Number of clients with these specific ASD diagnoses:  Autism No/Yes  Asperger’s Syndrome No/Yes  PDD-NOS No/Yes	
Degree of intellectual handicap	
Other comorbid condition/s	
Comments	

**- Intervention service/s that are provided to children and/or families** No/Yes

SERVICE TYPE	FREQUENCY daily, weekly etc	LENGTH ½ hr, hourly etc	LOCATION Centre based, home, school, other	DURATION Weeks, months, years etc
Medical				
Psychological/ Behavioural				
Psychiatric				
Speech Pathology				
Occupational Therapy				
Physiotherapy				
Educational				
Other				

**4. What happens to the data collected by your agency?** *Tick and complete the appropriate boxes*

<p>Data is not gathered in any systematic manner →Go to Q 5</p>
<p>Data is gathered by _____ but is not summarized or disseminated in any formal manner</p>
<p>Data is gathered _____ as assessments are completed _____ on a regular formal schedule ¼ ly, biannual, annual, other _____</p>
<p>Gathered data is _____ summarized within our agency _____ summarized by a separate/specific department within the agency _____ _____ available on request from _____ _____ disseminated on a regular formal schedule ¼ ly, biannual, annual, other _____ by _____ to _____</p>
<p>Data is for internal use _____ to plan budget allocations for services _____ to develop new services based on apparent/developing needs</p>
<p>Data is also shared with other agencies/colleagues _____ within the state/territory only _____ with other non-state/territory agencies eg ABS/AIHW/Centrelink _____ _____ with a centralized state/territory register _____ with another form of register OR inter-agency data collection group: please describe _____</p> <p>Data is shared with other agencies and/or colleagues _____ in a predetermined process – please describe _____ _____</p>

	AND/OR _____ on request to _____
--	----------------------------------

**5. Who provides the funding for your agency?**

Public	Private briefly describe	Public & Private briefly describe
<input type="checkbox"/> state <input type="checkbox"/> federal <input type="checkbox"/> state & federal		

**6. How would you describe the patterns of assessment referral data received by your agency over the past year (2004) and the past 5 years (1999 – 2004)?**

	Past Year 2004	Past 5 years 1999-2004
Stable pattern of referrals		
Changing pattern of referrals – describe		

**7. Have there been any broad changes in the ways in which your agency has operated since 1995?**

	Describe
No changes	
Changes in data collection <ul style="list-style-type: none"> <li>- type of data collected</li> <li>- data sources</li> <li>- data recipients</li> <li>- data requesters</li> <li>- frequency/intensity etc</li> </ul>	
Other?	

**APPENDIX 3**



**11 Key Questions  
Diagnostic and Intervention Service Providers**

<b>Agency/Practice Name</b>	
<b>Contact Person/ Department</b>	
<b>Phone</b>	
<b>Email</b>	
<b>Contact Date</b>	
<b>Follow-up Needed /Comments</b>	

**5. What is the general nature of your agency/practice and the services it provides?**

**6. Who refers children to your agency/practice?**

- Family self referral
- Health providers
- Educators
- Other

**7. What can you provide in terms of data for children that are referred to your agency/practice?**

- Numbers in age ranges No/Yes

Age Ranges		Numbers
Preschool	0-5 yrs	
Primary	6-12yrs	
Secondary	13-16	

- Gender breakdown No/Yes

Gender	Numbers
Female	
Male	

**- Ethnicity** No/Yes

The ancestry with which the respondents in your data base identified themselves

Ethnicity	# in caseload	OR % in caseload
Aboriginal/Torres Strait Islander		
Other – please identify		

**- Home Language** No/Yes

Home Language	# in caseload	OR % in caseload
English		
Chinese languages		
Vietnamese		
European languages		
African languages		
Middle Eastern languages		
Other – please identify		

**- Location** No/Yes

Location	Numbers
Metro	
Rural	
Remote	

**- Differential Diagnostic Information** No/Yes

Diagnostic Information	Description
Number of clients with these specific ASD diagnoses:  Autism No/Yes Asperger’s Syndrome No/Yes PDD-NOS No/Yes	
Degree of intellectual handicap	
Other comorbid condition/s	
Comments	

**- Intervention service/s that are provided by the agency/practice** No/Yes

SERVICE TYPE	FREQUENCY daily, weekly etc	LENGTH ½ hr, hourly etc	LOCATION Centre based, home, school, other	DURATION Weeks, months, years etc
Medical				
Psychological/ Behavioural				
Psychiatric				
Speech Pathology				
Occupational Therapy				
Physiotherapy				
Educational				
Other				

8. **What happens to the data collected by your agency/practice?** *Tick and complete the appropriate boxes*

<input type="checkbox"/>	Data is not gathered in any systematic manner →Go to Q 5
<input type="checkbox"/>	Data is gathered by _____ but is not summarized or disseminated in any formal manner
<input type="checkbox"/>	Data is gathered _____ as assessments are completed _____ on a regular formal schedule ¼ ly, biannual, annual, other _____
<input type="checkbox"/>	Gathered data is _____ summarized within our department/independent practice _____ summarized by a separate department within the agency _____ available on request from _____ _____ disseminated on a regular formal schedule ¼ ly, biannual, annual, other _____ by _____ to _____
<input type="checkbox"/>	Data is for internal use _____ to plan budget allocations for services _____ to develop new services based on apparent/developing needs
<input type="checkbox"/>	Data is also shared with other agencies/colleagues _____ within the state/territory only _____ with other <b>non</b> -state/territory agencies eg ABS/AIHW/Centrelink _____ _____ with a centralized state/territory register _____ _____ other form of register/inter agency data collection group: please describe _____
<input type="checkbox"/>	Data is shared with other agencies and/or colleagues _____ in a predetermined process – please describe _____ _____

	AND/OR _____ on request to _____
--	----------------------------------

**5. Who conducts the diagnostic assessments in your agency/practice?**

DISCIPLINE	INDIVIDUAL ONLY Which discipline/s?	TEAM MODEL Which disciplines?
Paediatrics		
Psychology		
Psychiatry		
Speech Pathology		
Occupational Therapy		
Physiotherapy		
Educational		
Social Work		
Other		

**8. What diagnostic criteria are used by the assessors?**

Diagnostic Criteria	Yes	No
DSM-IV-TR		
Gillberg's Criteria		
ICD-10		
Other – briefly describe		

**9. What is the process that families go through to receive a diagnosis and service/ intervention if required, and how long does it take?**

Process	Diagnosis	Service/Intervention
Who/where are they referred to within the agency/ practice?		
Who manages the case once a referral is made?		
How long are the wait times?		
Do any of these practices vary according to the child's age?		
What is the funding availability for families?		



**10. How accurate do you feel the referral patterns are for different diagnostic groups on the spectrum?**

Are there differences in patterns of referral for Autism, Asperger's Syndrome and/or PDD-NOS?	No    Yes
How would you describe these differences?	
Why do you think these differences are occurring?	
How would you describe the awareness/knowledge of ASDs of your referral sources?	
Do you feel any of these diagnostic groups are under referred?	

**11. How would you describe the assessment referral patterns received by your agency/practice over the past year (2004) and the past 5 years (1999 – 2004)?**

	Past Year 2004	Past 5 years 1999-2004
Stable pattern of referrals		
Changing pattern of referrals – describe		

**12. Who provides the funding for your agency/practice?**

Public	Private briefly describe	Public & Private briefly describe
<input type="checkbox"/> state <input type="checkbox"/> federal <input type="checkbox"/> state & federal		

**11. Have there been any broad changes in the ways in which your agency has provided its services since 1995?**

	Describe
No changes	
Changes to <b>services</b> provided – disciplines, service model, frequency/intensity etc	

Use of <b>public</b> agencies to deliver diagnostic and/or intervention services	
Use of <b>private</b> agencies to deliver diagnostic and/or intervention services	
Changes to <b>funding</b> model/s eg: to own funding or way they fund other agencies and/or practices	
Other	

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