

The prevalence of autism in Australia. Can it be established from existing data?

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Aim: To assess whether existing data collection mechanisms can provide accurate and sufficient information about the prevalence of autism in Australia.

Methods: Summary data about the number of children aged 0–16 years known to have an autism spectrum disorder (ASD) were gathered from State and Territory health, disability, education sources and autism associations. Summary data were also provided by national sources. Initial contact was made by letter, and follow-up was undertaken by telephone or email.

Results: For the years 2003–2004, the estimated prevalence of autism for 6- to 12-year-olds ranged from 9.6 to 40.8/10 000 for the State and Territory data, and from 12.1 to 35.7/10 000 for the national data. There was a similar variation in prevalence estimates for children aged 0–5 and 13–16 years. There was also a variation in prevalence estimates between age groups.

Conclusion: Inconsistencies in autism prevalence estimates calculated from existing data sources suggest that further efforts are needed to ensure the collection of reliable information about the prevalence of ASD for national, State and Territory use. Existing data systems need to be improved or additional data systems need to be developed to ensure the collection of reliable information. Reliable and consistent ASD prevalence data would ensure that services are being provided to those who need them and would enhance the opportunities to undertake meaningful population-based research.

Key words: Autism spectrum disorders; Autism; Asperger disorder; Pervasive developmental disorder – not otherwise specified; prevalence; data collection.

Autism spectrum disorders (ASDs) include autism, Asperger disorder and pervasive developmental disorder – not otherwise specified (PDD-NOS) and are characterised by severe impairment in communication, behaviour and social interaction. Globally, the number of individuals being diagnosed with an ASD has increased substantially over recent years.^{1–3} Internationally, the increases have led to (i) funding for development of ongoing data collection to monitor trends over time;^{4–6} (ii) development of national strategies and guidelines for diagnosis and assessment of ASD;^{7,8} (iii) service support and development for the

identification of ASD;^{9–11} and (iv) early intervention service development and co-ordination.^{8,12–14} These initiatives have not been matched in Australia.

A recent systematic review and meta-analysis of 42 ASD prevalence studies published between 1966 and 2003² found an overall random-effect prevalence estimate across all studies of 7.1/10 000 for typical autism and 20.0/10 000 for all ASD. Five of the 11 studies published in 2000 or later reporting prevalence for all ASD, estimated prevalence greater than 50/10 000.² It is well described that differences and changes in methodology, referral patterns, diagnostic substitution, availability of services, migration and public and professional awareness of ASD make meaningful interpretation of prevalence rates and time trends across studies problematic.^{1,15–18}

In Western Australia (WA), over the past two decades, new diagnoses have increased nearly 20-fold,^{19,20} with more than 200 children now newly diagnosed each year with an ASD in 2004.²¹ To date, there have been three peer-reviewed publications about the prevalence or incidence of autism in Australia^{22–24} reporting data from New South Wales (NSW), WA, Barwon region of Victoria (VIC) and the Australian Capital Territory (ACT). From these studies, the maximum reported incidence of ASD in Australia is 8.0/10 000 (WA) for children diagnosed in 1999–2000, and the maximum reported

Key Points

- 1 Summary data were collected on the number of children 0–16 years known to have an autism spectrum disorder in Australia.
- 2 Inconsistencies in available data prevented reliable estimates from being calculated.
- 3 Existing data systems need to be improved or developed to ensure the collection and management of reliable information.

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prevalence is 39.2/10 000 for those diagnosed in 1986–2002 (VIC). In addition, in 2003, the Victorian Government Department of Human Services reported an estimated prevalence of 27/10 000 for children aged 0–6 years with diagnosed or suspected ASD as of June to July 2002.²⁵

In Australia, differences in how children with ASD receive diagnoses and services exist for each State and Territory. For example, it has been reported that in Queensland (QLD), the term ASD is used variably,²⁶ and in the face of diagnostic uncertainty, many specialist medical clinicians claim that they would affirm an autism diagnosis to service providers for the purpose of the children receiving specialist education when their diagnostic specification had not been met.²⁷ In WA, unique undertakings to help streamline and clarify diagnostic pathways have been initiated, including recommendations of a team assessment for all diagnoses to be considered for the eligibility of government-funded services.^{21,28}

The aim of this study was to estimate the current prevalence rates for children with ASDs in Australia from existing data. It used multiple sources from each of the States/Territories and includes national data, primarily from government sources. The challenges inherent in estimating a national Australian ASD prevalence rate using administrative data are discussed, and recommendations are made for future developments in this area.

Methods

Ethical approval for the study was granted by the Children's Hospital at Westmead Research Ethics Committee in NSW, and the Women's and Children's Health Service Ethics Committee in Perth, WA.

Inclusion criteria

The study sought information about all children aged 0–16 years residing in each Australian State and Territory who were identified as having a diagnosis of ASD at the time of sampling.

Data collection

The primary Commonwealth, State and Territory agencies that collected the data about and/or provided services to people with ASD were identified. These included the major disability and education agencies and autism associations in each State and Territory, as well as the Australian Institute of Health and Welfare (AIHW) and Centrelink. The AIHW is Australia's national agency for health and welfare statistics and information. Information about disability is collected through the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA-NMDS) and provided to the AIHW for collation and publication. Centrelink is an Australian Government Statutory Agency that provides a range of funded programs designed to meet individual and community needs. One such program, the Carer Allowance, funds the parents/carers of individuals with autism.

Questionnaires were sent to nominated officers within each agency requesting summary data about the numbers of children

with ASD that they provided services to, including information about their diagnostic and demographic subgroups. When necessary, additional clarification, discussion and follow-up were provided to questionnaire recipients by telephone and/or email. Questionnaire mail-out began in July 2005, and information was received until the end of May 2006. As only summary data was available, it was not possible to link data from different sources.

Data analysis

Information from the State and Territory agencies and Commonwealth agencies about the number of children known to have autism, Asperger disorder and/or PDD-NOS, along with the information about their age, gender, geographic location (rural/remote), aboriginality and intellectual disability, was requested. Large within-State variations in numbers of children reported precluded analysis of prevalence for State and Territory agency data. These differences are likely related to the variations in the date of reports being made to this study, the time periods for which data was reported and service-related variations. However, prevalence estimates were calculated for Commonwealth data, which represented the most consistent data held on a national level. Approximate 95% confidence intervals (CIs) were calculated using a formula recommended for the analysis of proportions.²⁹

Results

Questionnaire response

Eighty-five per cent of the State or Territory-based agencies returned the questionnaires. Of these, 75% provided the numbers of children known to them with ASDs. Reasons given by non-responding agencies included the small size of the agency; the agency's focus on immediate service provision with limited resources for data collection; data were already provided through an alternate source (e.g. CSTDA-NMDS collection); and concern about variable national and State/Territory ASD terminology and the implications for data collection and service delivery. National data about children with autism, Asperger disorder and/or PDD-NOS were provided by AIHW and Centrelink.

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

States and Territories information

There was considerable inter-agency variation for each State and Territory (Table 1). There was also considerable variance between states in regard to both the number of affected children and the range of years for which agencies provided information. Data provided by QLD and VIC disability services were not included in Table 1 as children with ASD were not identified separately from all children with disabilities and the proportion of children with autism was not available. 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, equivalent to 150 children.

Table 1 Numbers of children with ASD (autism disorder, Asperger disorder, PDD-NOS) provided by the State and Territory agencies, by age group and agency type

	Disability				Education				Autism association			
	0–5	6–12	13–16	Total	0–5	13–16	6–12	Total	0–5	6–12	13–16	Total
ACT	43	64	3	110	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	NA	NA	NA	NA†	419‡	3243‡	NA	3662‡	97	988	625	1710
SA	77	394	262	733§	129	402	235	759¶	276	644	620	1540
	155	253	132	540††								
TAS	NA	NA	NA	NA	120	59	28	207	NA	NA	NA	NA
VIC	NA	NA	NA	NA†	NA	757	195	1490‡‡	NA	NA	NA	NA
WA	249	943	327	1519	235	736	280	1331‡‡	113	324	164	601

Numbers were provided for the time period of 2004–2005 except for the ACT disability data (2002–2005) and QLD.³⁰ Education data (2000–2003). †Data provided were for all of the agency's clients not ASD specific. ‡Data sourced from the Report of the Queensland Paediatric Quality Council 2003.³⁰ §Data for IDSC. ¶Data for these age groups were provided as a percentage of the total. ††Data for DFC. ‡‡Total includes data that were not available in separate age groupings. ACT, Australian Capital Territory; ASD, autism spectrum disorder; IDSC, Intellectual Disability Services Council; DFC, Department for Families and Communities; NA, not available; NSW, New South Wales; NT, Northern Territory; PDD-NOS, pervasive developmental disorder – not otherwise specified; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

Many agencies were not able to provide information about diagnostic subgroups, gender, geographic location, aboriginality or intellectual disability (Table 2). For agencies that were able to provide such information, the percentage of males with ASD was over 80% and the majority had a diagnosis of autistic disorder (52–92%). At least one agency from each State or Territory (not including the ACT) provided information about families living in rural or remote locations, but information about intellectual disability and aboriginality was only available from some States and Territories.

Data provided by the AIHW from the CSTDA-NMDS

Data provided by the AIHW from the CSTDA-NMDS data collection for the period July 2003–June 2004 included data about diagnosis (autism and Asperger disorder), gender, age, aboriginality and country of birth for each State. In total, 5459 services users were identified. However, age, country of birth, indigenous status and gender information were not provided for all users. Where data were available, males represented 81–86% of children, 1–5% were indigenous and 84–98% were Australian-born.

Table 3 shows State prevalence estimates for each age group based on CSTDA-NMDS data using denominators from the Australian Bureau of Statistics for resident population of children for the year 2003.³¹ Within each State there were significant differences between age groups for all States except South Australia (SA). In SA, Tasmania, VIC and WA, the prevalence was highest in the 6- to 12-year age group. In QLD, the prevalence was highest in the 13- to 16-year age group, but not significantly different to the prevalence in the 6- to 12-year-olds. In NSW, the prevalence was significantly higher in the 0- to 5-year age group. Between States, there were significant differences in reported prevalence within and between age

groups. The minimum reported prevalence was in 0–5 year olds in Queensland (3.6/10,000). The maximum reported prevalence was in 6–12 year olds in WA (40.8/10,000).

Centrelink data

National data were provided by Centrelink for gender, age groups and ASD subgroups (autistic disorder and Asperger disorder) for the calendar years of 2004–2006. Prevalence was estimated for autism and Asperger disorder combined by age group and compared with CSTDA overall prevalence by age group (Table 4). Using the available data, there was a twofold difference between overall prevalence estimates for autism using Centrelink and CSTDA data.

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 autism and Asperger disorder in 2005 for 6- to 12-year-olds was 47.2/10 000 (95% CI 46.2–48.1) and 15.3/10 000 (95% CI 14.8–15.9), respectively. Consistent with the CSTDA, the prevalence rate for autism and Asperger disorder was highest in the 6- to 12-year age group. Furthermore, this pattern carried across each year of data collection. The prevalence rate for autism was much greater than Asperger disorder for the 0- to 5- and 6- to 12-year age group.

Discussion

This study is the first attempt to present prevalence statistics for ASD in each Australian State and Territory using a consistent method of data gathering for all jurisdictions.

The number of children identified, and hence, estimated prevalence of ASD among Australian children, varied considerably depending on the data source. As such, the prevalence of

Table 2 Summary of questionnaire data received from each sector, by State or Territory

		Male (%)	Autistic disorder (%)	Intellectual handicap (%)	Remote/rural (%)	ATSI/aboriginal (%)
ACT	Education	86	NA	NA	0	0.83
	Disability	90	82	NA	0	NA
NSW	AA	NA	NA	NA	NA	NA
	Education	NA	NA	NA	NA	NA
	Disability	80	NA	NA	25	2
NT	AA	NA	NA	NA	NA	NA
	Education	87	80	NA	39	NA
	Disability	87	92	12	29	1
QLD	AA	NA	NA	NA	NA	NA
	Education	NA	NA	NA	NA	NA
	Disability†	NA	NA	NA	NA	NA
SA	AA	84†	52‡	NA	36‡	NA
	Education	86	57	NA	NA	NA
	Disability – IDSC	84	59	NA	24	2
TAS	AA‡	85	53	NA	16	NA
	Education	88	92	NA	37	NA
	Disability	NA	NA	NA	NA	NA
VIC	AA	NA	NA	NA	NA	NA
	Education	85	NA	NA	18	NA
	Disability	NA	NA	NA	NA	NA
WA	AA	NA	NA	NA	NA	NA
	Education§	83	69	NA	12	NA
	Disability	84	77	16	31†	4‡
	AA	NA	NA	NA	14	NA

†Data provided was for all of the agency's clients not ASD specific. ‡Percentage based on information for all ages as not available for 0–16 years old subset. §Data from DET, Catholic Ed and/or AISWA. AA, Autism Association; ACT, Australian Capital Territory; AISWA, Association of Independent Schools of Western Australia; ASD, autism spectrum disorder; ATSI, Aboriginal or Torres Strait Islander; DET, Department of Education and Training; NA, not available; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

Table 3 Prevalence estimates per 10 000 for children with autism resident in that State of that age (95% CI) for each State based on CSTDA-NMDS and ABS data (June 2003)³¹

State	Age group					
	0–5		6–12		13–16	
	<i>n</i>	Prevalence/10 000 (95% CI)	<i>n</i>	Prevalence/10 000 (95% CI)	<i>n</i>	Prevalence/10 000 (95% CI)
NSW	683	13.3 (12.3, 14.3)	605	9.6 (8.8, 10.3)	167	4.7 (4.0, 5.4)
QLD	106	3.6 (2.9, 4.3)	399	10.5 (9.5, 11.5)	258	12.1 (10.6, 13.6)
SA	155	14.5 (12.2, 16.7)	253	18.3 (16.1, 20.6)	133	16.7 (13.9, 19.5)
TAS	51	14.5 (10.6, 18.4)	65	14.3 (10.8, 17.7)	10	4.4 (1.9, 6.9)
VIC	206	5.7 (4.9, 6.4)	673	14.7 (13.6, 15.8)	248	9.6 (4.9, 6.4)
WA	327	21.9 (19.6, 24.3)	780	40.8 (37.9, 43.7)	274	24.3 (21.5, 27.1)

ABS, Australian Bureau of Statistics; CI, confidence interval; CSTDA-NMDS, Commonwealth State/Territory Disability Agreement National Minimum Data Set; NSW, New South Wales; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

autism in 2003–2004, according to State or Territory data, ranged from 3.6 to 21.9/10 000 for 0- to 5-year-olds, 9.6–40.8/10 000 for 6- to 12-year-olds and 4.4–24.3/10 000 for 13- to 16-year-olds. Using nationally collated data, the prevalence of

autism in Australia in 2003–2004 ranged from 8.5 to 15.3/10 000 for 0- to 5-year-olds, 12.1–35.7/10 000 for 6- to 12-year-olds and 8.3–17.4/10 000 for 13- to 16-year-olds with significant differences between a national funding agency

Table 4 Estimated national prevalence/10 000 of autism and Asperger disorder, with 95% confidence intervals (CIs), from CSTDA and Centrelink data and ABS population data³¹ for three age groups

Age (year)	Centrelink			CSTDA†		
	0–5	6–12	13–16	0–5	6–12	13–16
2003	16.1 (15.5–16.8)	45.8 (44.9–46.8)	25.8 (24.8–26.8)	8.5 (8.0–8.9)	12.1 (11.6–12.6)	8.3 (7.8–8.9)
2004	19.0 (18.3–19.7)	53.3 (52.2–54.3)	30.5 (29.5–31.6)	NA	NA	NA
2005	22.0 (21.3–22.8)	62.5 (61.3–63.6)	36.0 (35.7–38.0)	NA	NA	NA

†July 2003–June 2004 data. ABS, Australian Bureau of Statistics; CSTDA, Commonwealth State/Territory Disability Agreement; NA, not available.

source (Centrelink) and a nationally collated source (CSTDA-NMDS) from State disability services. The prevalence of children accessing Centrelink funding with a diagnosis of autism increased significantly between 2003 and 2005 in 6- to 12-year-olds from 35.7/10 000–47.2/10 000 (95% CI 46.2, 48.1). In addition, a significant increase in children accessing Centrelink funding with a diagnosis of Asperger disorder in 6- to 12-year-olds occurred between 2003 and 2005, increasing from 10.2/10 000 (95% CI 9.7, 10.6) to 15.3/10 000 (95% CI 14.8, 15.9).

Prevalence estimates

Since 2000, seven studies have reported the prevalence estimates from other countries for children under 6 years old.^{3,9–11,32–34} Estimated prevalence for Australian children aged 0–5 years in 2003–2004 are similar to the prevalence estimates reported in other countries for children less than 6 years of age, which range from 7.8 to 55.0/10 000.^{32,33} Recently published prevalence estimates for Asperger disorder have been 9–10/10 000,^{35,36} similar to prevalence estimates calculated using the Australian Centrelink data for 2003.

The differences between prevalence estimates based on CSTDA data and Centrelink data most likely reflect different patterns of access to services and data collection mechanisms. Similar differences have been reported internationally in one country at one point in time from different data sources.³⁷ There are many possible reasons for these differences in Australia including service utilisation variations and diagnostic practice in relation to primary and secondary diagnoses such as intellectual disability versus autism specific labels. Reported differences in prevalence from different data sources have been cited internationally as a reason for requiring diagnostic validation for autism data sources.³⁸ 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.

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 elsewhere^{3,32,39,40} and has been said to indicate that lower prevalence in older age

groups reflects the increase in the true prevalence of autism over time with rates in the older cohorts, reflecting previous prevalence estimates. Children in this study aged 13–16 years in 2005 were born in 1989–1992. Other possible explanations for a decrease in prevalence in older age cohorts include improvements in function made by 10–20% of children over time^{41–43} 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.^{44,45} However, neither of these losses of older children with autism would be sufficient to explain a halving of the rate as calculated using Centrelink data. Lower prevalence in older age groups could also be because of the 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 and could be related to changes in funding needs or access to funding as individuals with autism age.

Subgroup data

At the State and Territory levels, as well as the national level, information about diagnostic subtypes, age groups, gender, intellectual handicap, aboriginality or place of residence was not consistently available to make reliable conclusions about these factors. Of the services that did provide information, the ratio of approximately four males to every one female with autism was consistently found. This is in line with the gender ratio reported by other studies.^{1,11,20,33} All services saw a majority (52–92%) of individuals with autism, rather than other ASD diagnoses. This does not reflect the accepted distribution of ASD, based on population studies.¹¹ 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. It is uncertain where or whether children with other ASD are actively receiving services.

There was limited information available about the proportion of individuals with ASD using services who also have intellectual disability, possibly reflecting the practice in some States to allocate services based on intellectual functioning or that many children are too young to have assessments of intellectual functioning at the time of diagnosis. There was incomplete information about the number of individuals with ASD living in remote or rural locations, which has direct implications for models of service delivery.

Limited information was also available from service providers about aboriginality, reflecting the finding that in many Australian administrative data sets, there is a failure to accurately identify individuals of indigenous origin.⁴⁶

The proportion of individuals with ASD who were identified as Aboriginals (CSTDA data) compares poorly with the proportion of individuals aged 0–14 who were identified as Aboriginals in each State,^{47,48} with substantial between-State variation. It is improbable that real differences in ASD prevalence exist in Aboriginal children by state, and the variation is more likely because of the differences in coding, reporting or the use and availability of current diagnostic pathways available to Aboriginal people.

Private sector information

Funding and timeline restrictions for this study did not allow the exploration of services provided in the private sector. Data from the WA Register for Autism Spectrum Disorders indicate that the number of ASD diagnoses in the private sector has increased over time, from 14% in 1999 to 41% in 2005.²¹

Conclusion and Recommendations

At the current time, the prevalence of ASD in Australian children cannot be estimated accurately from existing data. This study has shown that Centrelink is the most comprehensive single source of national information about the number of individuals seeking funding with a diagnosis of autistic disorder or Asperger disorder. However, these data are limited to only autism or Asperger disorder diagnoses, are more complete for younger children, are not readily available for each State and Territory, and are not designed for research and therefore, may not be appropriate for the identification of individuals for the purpose of diagnostic validation or data linkage.

CSTDA-NMDS has been a substantial initiative towards 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 CSTDA-NMDS data compared with the Centrelink data and the substantial between State/Territory variability of these data suggest that it has considerable limitations for use for service planning or research. This is echoed by the variation and difference between other individual State or Territory-based service provider sources of data.

In response to the international trends in autism diagnoses and the findings of this current study, it is highly recommended that in order for Australia to gather reliable information about the prevalence of ASD for national, State and Territory use, additional data systems are required. These systems need to be equipped to gather information across all of the states and territories and from both the private and public sectors. Recently announced funding initiatives for autism, in particular specific Medicare billing items for autism consultations, provide a new opportunity for this type of national data collection, especially if linked with existing data sources. 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 CSTDA-NMDS data collection and could be extended to turn this new opportunity into action.

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