Autism/ASD
diagnosis rates in Australia

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Abstract

Reports show the number of people with an autism spectrum disorder (ASD) diagnosis in various parts of Australia. The reports provide prevalence and incidence data. The different types of data cannot be compared directly.

The detailed age distribution of diagnoses provides the means to calculate a ratio of the number of ASD diagnoses relative to the number of births for a region. This metric estimates the number of people in the population who have ASD. The current diagnosis rates in all regions of the country suggest that around 1% of Australians will be diagnosed with an ASD. ASD is life-long and can be severely disabling so this level of ASD imposes a substantial burden on the community.

The age distribution of diagnoses can be further used to estimate for planning purposes the number of people with an ASD diagnosis (including Asperger's syndrome) at important transitions, such as the how many students diagnosed with ASD enter primary or secondary school.

Introduction

Recently, the Minister for Health in Australia stated:

> "There is no national data on the diagnostic profiles of people with autistic disorder and/or Asperger's syndrome and/or pervasive developmental disorders." (Campbell 2003, page 16680)

and

> "the Government does not plan to establish central registers for autism, Asperger's syndrome, or pervasive developmental disorders. The provision of health and disability services for people with these disorders lies with State and Territory jurisdictions as is the responsibility for ensuring sufficient attention is made available from treating clinicians." (Campbell 2004, page 19851)

In the absence of official data, this paper collects the data available in Australia and considers how it can be interpreted to help in planning services for people with an autism spectrum disorder (ASD). In view of the varying classification criteria used by different agencies, the term ASD will be used to cover autism, Asperger's syndrome and pervasive developmental disorders.

Prevalence data

In recent times, a number of surveys have collected data that includes people who report having an r ASD diagnosis at a particular time.

Data of this type is called *prevalence* data. The prevalence of ASD is the number of people in a population who have ASD at a specified time. In practice, we count the number of people who *report* having an ASD diagnosis at a specified time. Typically, the prevalence of autism/ASD is reported as the *rate per 10 000 population*; that is, the number of people with an ASD among every 10 000 people if the people with ASD are distributed evenly throughout the population.

Recent prevalence reports from parts of Victoria are summarised in Table 1 below, which reveals a range of estimates from 27 per 10 000 to 54 per 10 000. Such a variation in reported prevalence can make it difficult to interpret this type of information.

> "The prevalence of children with ASD in the region is at least 38 per 10 000 children aged 2–5 years (inclusive). This is higher than the state-wide estimate of 27 per 10 000 children aged 0–6 in the *Autism in Victoria Report* (*AIV Report*)*." (Burke, 2003).

Ms Burke observes:

> "*The AIV Report calculation is not necessarily incorrect for the Eastern region when applied to the 0-6 population. However, when the AIV Report's calculation of 27 per 10 000 is applied to the 2–5 age group in the region, the number estimated would be less than the actual number of children with ASD aged 2–5." (Burke, 2003)

The Chief Executive Officer of Gateway Support Services Geelong has remarked "Gateways have identified 69 children between the ages of 2–6 years out of a total regional population of 12,800 (2–6 years) children in 2000." so ASD "may be as high as 1:200" (The Melbourne Age, 27 October 2002; "A riddle wrapped in an enigma", The Melbourne Age, 16 November 2002) The author subsequently confirmed this data with the CEO. The 2003 ratio of 1:200 is equivalent to 50 per 10 000, and this is approximately the same as 54 per 10 000 reported in 2000 (see Table 1) so it appears that the prevalence of autism in this region is relatively stable, at least according to Gateway.

In addition to being reported as *rate per 10 000*, prevalence can also be expressed as *numbers.* For example Table 2 reveals in 1998 there were 10 500 children identified with "autism and related disorders" in a total population of 2 627 500 children between the ages of 5-14 years. Prevalence data of this type was obtained by the author from The Australian Bureau of Statistics (ABS), derived from its Survey of Disability, Ageing and Carers (SDAC). The SDAC is conducted every five years, most recently in 1998 and 2003. Selected survey information, which is not part of the usual ABS publications, is shown in Table 2 and Table 3 below respectively. These data show the number of Australians who report having an ASD diagnosis to the ABS has more than doubled in the 5 years from 1998 to 2003. Numbers rose from 13,200 to 30,400 over the period. In addition, two of every three people reported as having an ASD diagnosis in 2003 were under 15 years of age, a point to be elaborated later.

A final source of prevalence data is the Department of Family and Community Services (FaCS), whose minister reported (Patterson, pages 25845–6) that

(1) At 2 July 2004, there were 11 694 children under 16 years of age with their first medical condition identified as autism whose carer received Carer Allowance. …
(2) At 2 July 2004, there were 2522 children under 16 years of age with their first medical condition identified as Asperger's syndrome/disorder whose carer received Carer Allowance. …
(3) Information on the number of families receiving Carer Allowance because they have a child with Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS) identified as F84.9 is not available.
(4) Information on the number of families receiving Carer Allowance because they have a child with another autism spectrum disorder identified as F84.1–F84.8 and not F84.5, is not available.

This shows there are at least 14,216 parents of children aged 0–15 years who report that their child has autism or Asperger's disorder to qualify for Carer's Allowance. As there are around 4.18 million children aged 0–15 years in Australia, prevalence would be calculated as 34 per 10 000 for this cohort.

Incidence data

Data describing the number of *new ASD diagnoses* is called *incidence* data.

Recent publications (Baker, 2002; Glasson et. al., 2002; Glasson et. al., 2003; and Williams et. al., 2002) report the number of people diagnosed with autism/ASD in three different states / territories over a 12 month period. The South Australian Autism Association provided its data for the years 2000 to 2002. Information from all these sources is summarised in Table 4 below.

FaCS also supply incidence data. The minister reported (Patterson, page 25846) that

(5) For the period 2000 to 2003 there were 5125 claims for Carer Allowance in respect of a child whose medical condition was listed as autism. …
(6) (a) For the period 2000 to 2003 there were 1944 claims for Carer Allowance in respect of a child whose medical condition was listed as Asperger's syndrome/disorder. …
(b) For the period 2000 to 2003 there were 1841 claims granted for Carer Allowance in respect of a child whose medical condition was listed as Asperger's syndrome/disorder. …

To summarise the FaCS information, there were at least 6966 Carer's Allowances granted in the four years 2000 to 2003, with a possible 7069 new diagnoses resulting in applications for Carer's Allowance over the period. The number of diagnoses may well be higher, because uptake of Carer's Allowance is not 100%, and this incidence report is just for the two main diagnoses in the autism spectrum.

A source of confusion for many people is that the different reports of the prevalence and incidence of ASD appear to show varying levels of autism in the community. This report provides illustrative data to demonstrate why the results cannot be

compared directly as they are currently presented, and it suggests a method for comparing prevalence data with incidence data and with other prevalence data. As discussed below, an advantage of this approach is that the available data can then be used to estimate the number of people who are likely to need services in any age group or at the various life-stage transitions.

Method

The effects of autism are said to last a lifetime and are expected (or required as part of the diagnostic criteria for Autistic Disorder) to have been present from an early age. If so, a person needs only one accurate diagnosis of ASD in their lifetime.

Because ASD is a lifelong condition, incidence and prevalence data can be compared using some simple models of its occurrence in the population.

While much of the data above shows rising diagnosis rates, the Gateways and WA data may be showing early signs that diagnosis rates may be levelling off. The assumption that diagnosis rates are about to plateau simplifies modelling ASD prevalence. The results may be conservative but they should still indicate the minimum prevalence of ASD in the community.

Assuming that most people with ASD will be diagnosed at some time and the pattern of diagnosis in recent times is close to stable, then the number of people in the population with ASD is the number of diagnoses divided by the size of the population from which they are drawn.

The results section below shows the estimates of ASD prevalence in the population based on the incidence figures reported above. In practice, the prevalence would only be measured in a population once all the diagnoses were made. The data suggests these levels would only be observed once the children diagnosed recently reach an age around twenty years.

Incidence data published by the Western Australian Autism Registry illustrates this point. These data, shown in Table 5 and Figure 1, provide an age breakdown for those diagnosed, and it is evident that some individuals are not detected until they reach their teenage years. These people are not included in prevalence studies based on young children. Thus, measured prevalence in young children will show the number of children in an *age range* who have a diagnosis, but it will not show the prevalence of ASD in the *entire population.*

The relationship between incidence and prevalence in young children up to six years is illustrated graphically in Figure 2. For this cohort, about 35% of autism diagnoses have yet to be made. A correction to this and other underreporting is presented below.

Results

From the 1998 and 2003 SDAC data (see Table 2 below national prevalence *rates* were derived by dividing the prevalence *numbers* (total numbers of people with autism) by the numbers in the population from which they were drawn (both expressed as ‘000s). The results are shown in Table 6 below. The statewide prevalence rates were derived in a similar fashion from Table 4, and are presented in Table 8.

Table 8 reveals some discrepancies in the prevalence data reported by different organisations. There are several reasons for this. Sometimes, personal preferences and

diagnostic conditions skew the results. For example the Carer Allowance data from FaCS identifies 14,216 children as having autism or Asperger's syndrome out of 4.18 million children aged 0–15 years. This is fewer than 20,980 estimated from the ABS from the SDAC 2003 figures in Table 3. (This estimate was obtained by adding the numbers of identified children in the 0–4, 5–9, and 10–14 age ranges then taking one fifth of those in the 15–19 age range.) The different estimates arise because some families do not apply for Carer's Allowance. Some applications relating to Asperger's syndrome are not granted. Only some of the conditions regarded as ASD are included in this data.

The rate that Carer Allowance was granted from 2000 to 2003 indicates the prevalence of autism and Asperger's syndrome among children is around 67 per 10,000. The four-year incidence is divided evenly between the years and compared to the annual birth rate.

A second reason for different prevalence reports can be found by analysing the age distribution of diagnoses. The prevalence of people with a diagnosis of autism/ASD in an age range does not accurately reflect the number of people who have autism/ASD. The prevalence of ASD observed in young children significantly under-estimates the actual prevalence. This point is illustrated in Table 5, where the "cumulative %" columns allow us to determine the extent of the under-estimate in Western Australia for 2001 and 2002. This column indicates the weight that should be given to the prevalence figure, as it shows prevalence observed in each year of the 20 years age-range as a fraction of the expected total prevalence of autism/ASD in the population.

Furthermore, weights can be calculated for a range of ages, not only for each year. This is achieved by taking an average of the prevalence weights observed in the age range. For example, in the 0–5 years age range in Table 5, the average in 2002 is [(0 + .95 +14.22+37.44+55.92) divided by 5], or 29%. Thus, weightings can be applied to the various age ranges sampled by different organisations, and more meaningful comparisons can be made between them.

Applying this reasoning to the current data, Table 9 the displays the weightings for the age ranges sampled by the three Victorian surveys, and the ABS and FaCS Australian surveys. These weightings are reproduced in the second last column of Table 10. The "real" prevalence is obtained by dividing the observed prevalence by the weighted prevalence. This is represented as prevalence per 10 000 in the final column of Table 10. Implications of this correction to the data are discussed below.

Discussion

The corrected prevalence shown in Table 10 is higher than "traditional" estimates of prevalence of autism or ASD. Before discussing this discrepancy, there are some sources of variation – to both corrected and uncorrected prevalence figures – that should be acknowledged. In the first place, some irregularities in the data can be accountable to changed reporting requirements. People who were 10–14 years of age in the ABS data in 1998 are in the 15–19 year age range in the 2003 data. The number reporting a disability dropped slightly (from 29.7 to 28.6 per 10,000) in this group from 1998 to 2003. This effect is observed among people with other types of disabilities when the survey method changes from parent reporting to self-reporting.

A second cause of variance in the data, mentioned previously, is that some families do not apply for Carer's Allowance, or their applications are rejected. Finally, some of

the conditions regarded as ASD may not be completely included in this data. For example, supplementary Western Australian information indicates that only a small percentage of people with Asperger's syndrome were identified. This is not typical of the other data collected in Australia. This would also mean that even the corrected prevalence estimates in this paper are conservative.

The above caveat notwithstanding, the analysis in this paper shows there is good reason to suggest that some of the data used to plan service provision in the past may underestimate the prevalence of ASD. A crucial message from this analysis is that observed prevalence of ASD among young children varies enormously with the age range. Table 5 shows the observed prevalence in different age ranges varies enormously. For example, the rate that children have a diagnosis in the 2–5 year age range is much lower than the rate of children aged 5 or 6 years entering primary school. Put simply, the Western Australian data reveal most diagnoses of autism occur at an early age, and so the prevalence estimates calculated above are conservative for regions where diagnosis happens at a higher age.

Some reports suggest that some sectors may be gaining a finer appreciation of prevalence data in recent years. In its report on *Education of students with a disability* (December 2002), the Senate Employment, Workplace Relations and Education Reference Committee said:

> "*Over the whole of Australia between 0.6 per cent and 1 per cent of children are affected by autism or a related disorder*", p 54.

The results reported in Table 10 support the Committee's conclusion, particularly in light of their conservative nature mentioned above.

The data currently available does not help in understanding whether more people now have autism or whether there was chronic under-diagnosis in the past. Nor does the data tell us whether outcomes are improving. What we do know is that planning places for individuals with ASD using prevalence measures requires a clear understanding of the data.

Service providers and planners in WA can expect around 35 children aged 2–5 years (or 42 children aged 3–5 years) per 10,000 children in the age range will be diagnosed with ASD. WA schools can expect at least 64 children with an ASD diagnosis per 10,000 primary aged students and 79 per 10,000 high school students. Nationally, the ABS SDAC 2003 found 62.9 children aged 5–9 years and 80.2 children aged 10–14 years report having an ASD diagnosis (see Table 7).

The greatest increase shown in the nationwide data from the ABS is the increase in the number of adults reported as having a diagnosis of ASD. From 1998 to 2003, the number of people reported as having an ASD diagnosis rose from an estimated 1,700 (from Table 2 calculate 13,200 less 1,000+10,500) to 10,100 (from Table 3 calculate 3,900+6,200). This brings the rate of reported ASD diagnosis among Australian adults closer to the rate expected in the population 15 years ago (Wing 2002). Whether the diagnosis rate for ASD in adults will reach levels well over 10 per 10,000, significantly higher than levels previously expected, has yet to be seen.

Preliminary data from FaCS suggests that 3 of every 4 people with ASD now reaching age 16 years, the eligible age, are granted a Disability Support Pension. The large number of pensions granted shows existing services do not succeed in preparing children to participate economically in their community.

Conclusion

Counting young children with an ASD diagnosis does not measure the prevalence of ASD in the population. The number of children reported as having received an ASD diagnosis varies considerably with the age range being observed.

The diagnosis rates for autism and ASD have risen significantly in Australia, as they have elsewhere in the world over the last 10 to 15 years.

Nevertheless, the analysis in this paper suggests that the ASD diagnosis rate documented in recent years is reasonably consistent when the various observations are normalised.

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Source	*Age range (years)*	*ASD per 10,000*	*year*
Gateway Support Services	2–6	54	2000
Autism in Victoria (Crewther, 2003)	0–6	27	2003
Eastern Region (Burke, 2003)	2–5	38	2003

Table 1 ASD prevalence reports (per '000) in Victoria

Age range	*ASD '000s*	*Population '000s*
0–4	**1.0	1,284.8
5–14	10.5	2,627.5
Total	13.2	18,660.6

** this value has a high standard error.

Table 2 ASD national prevalence (numbers) from ABS 1998 SDAC

age range (years)	*Male '000s*	*Female '000s*	*Total ASD '000s*	*Population '000s*
0–4	1.2	0	1.2	1,243.5
5–9	6.5	1.8	8.2	1,309.9
10–14	8.2	2.6	10.8	1,347.3
15–19	3.3	0.7	3.9	1,363.1
20+	6.1	0.1	6.2	14,547.3
Total	25.3	5.1	30.4	19,811.1

Table 3 ASD national prevalence (numbers) from ABS 2003 SDAC

State	*Year*	*Number with ASD*
ACT (Baker, 2002)	1989	9
	1997	27
WA (Glasson et al., 2002)	1999	159
	2000	173
	2001	204
WA (Glasson et al., 2003)	2001	211
	2002	211
NSW (Williams et al.; 2002)	2000	758
SA	2000	115
	2001	206
	2002	270

Table 4 Statewide incidence data.

Age of diagnosis (years)	*2001*			*2002*		
	Count	*%*	*Cumulative %*	*Count*	*%*	*Cumulative %*
1	1	0.49	0.49	2	0.95	0.95
2	26	12.75	13.24	28	13.27	14.22
3	44	21.57	34.80	49	23.22	37.44
4	32	15.69	50.49	39	18.48	55.92
5	22	10.78	61.27	20	9.48	65.40
6	14	6.86	68.14	7	3.32	68.72
7	7	3.43	71.57	13	6.16	74.88
8	6	2.94	74.51	7	3.32	78.20
9	7	3.43	77.94	4	1.90	80.09
10	7	3.43	81.37	8	3.79	83.89
11	6	2.94	84.31	7	3.32	87.20
12	5	2.45	86.76	4	1.90	89.10
13	4	1.96	88.73	7	3.32	92.42
14	1	0.49	89.22	5	2.37	94.79
15	5	2.45	91.67	1	0.47	95.26
16	1	0.49	92.16	5	2.37	97.63
17	5	2.45	94.61	2	0.95	98.58
18	5	2.45	97.06	1	0.47	99.05
19	1	0.49	97.55	1	0.47	99.53

Table 5 WA incidence by age up to 20 years

age range (years)	*Male*	*Female*	*Total*	*M/F ratio*
0–4			**7.8	
5–9	82.2	19.8	51.0	4.15:1
10–14	48.7	10.7	29.7	4.55:1
15+			*1.2*	
Total			7.1	

Table 6 Prevalence rates per 10 000 (From ABS 1998 SDAC - Table 2)

age range (years)	*Male*	*Female*	*Total*	*M/F ratio*
0–4	19.3	0.0	9.7	
5–9	99.2	27.5	62.6	3.6:1
10–14	121.7	38.6	80.2	3.2:1
15–19	48.4	10.3	28.6	4.7:1
20+	8.4	0.1	4.3	
Total	*25.5*	*5.2*	*15.3*	*4.9:1*

Table 7 Prevalence rates per 10 000 (From ABS 2003 SDAC -Table 3)

Region	*Year*	*No. diagnosed*	*Birth Rate*	*ASD per 10,000*
ACT	1989	9		
	1997	27	4,582	58.9
WA	1999	159		59.8
	2000	173		65.0
	2001	211		79.3
	2002	211	26,602	79.3
NSW	2000	758	87,783	86.3
SA	2000	115		58.8
	2001	206		105.3
	2002	270	19,556	138.1
Australia–FaCS	2000–03	6966–7069	263,114	~67.2

Table 8 Prevalence estimates from incidence data

Age range (years)	*Part of prevalence %*
0–5	29.0
2–5	43.2
2–6	48.3
0–4	21.7
5–9	73.5
10–14	89.5
15–19	98.0
0–15	64.7

Table 9 Observed prevalence for age ranges

Location		*year*	*Observed prevalence*	*Age range (years)*	*Part of Prevalence %*	*Corrected Prevalence per 10,000*
Victoria	Gateway	2000	54	2–6	48.3	**112**
	Autism in Victoria	2003	27	0–5	34.8	**78**
	Eastern Region	2003	38	2–5	43.2	**88**
Australia	ABS	2003	9.7	0–4	27.1	**36**
			62.6	5–9	73.5	**85**
			80.2	10–14	89.5	**90**
			28.6	15–19	98.0	**29**
	FaCS	2003	34	0–15	64.7	**53**

Table 10 Population prevalence based on observed prevalence

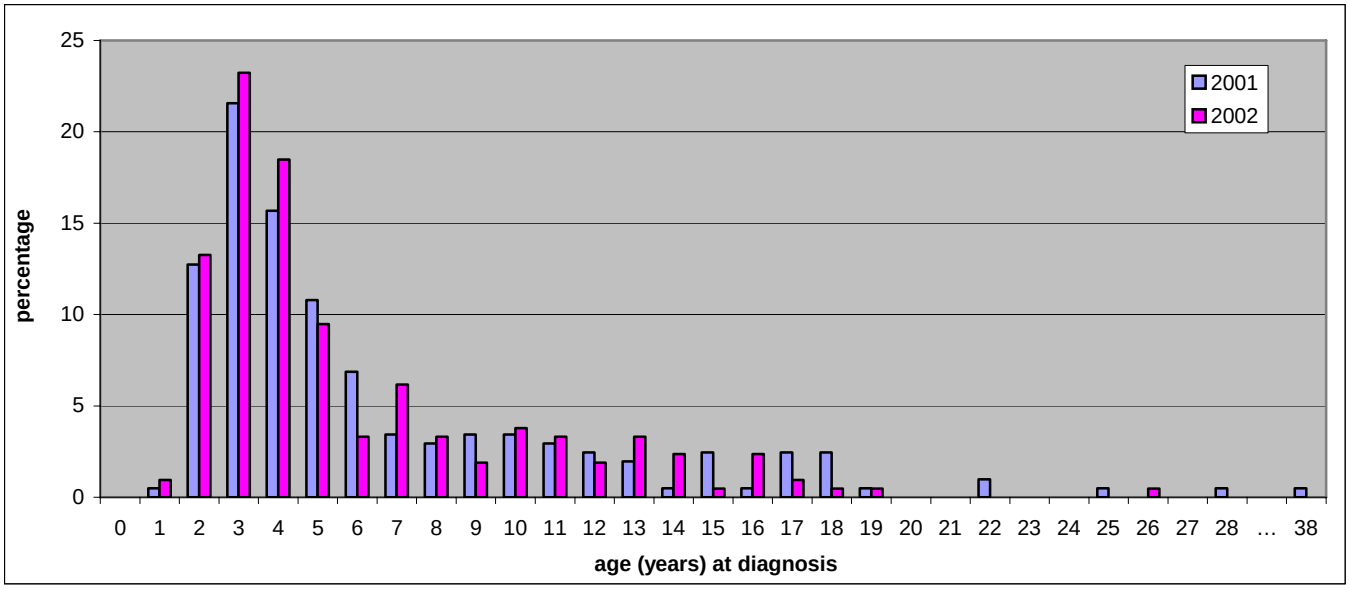

Figure 1 Age at diagnosis in Western Australia

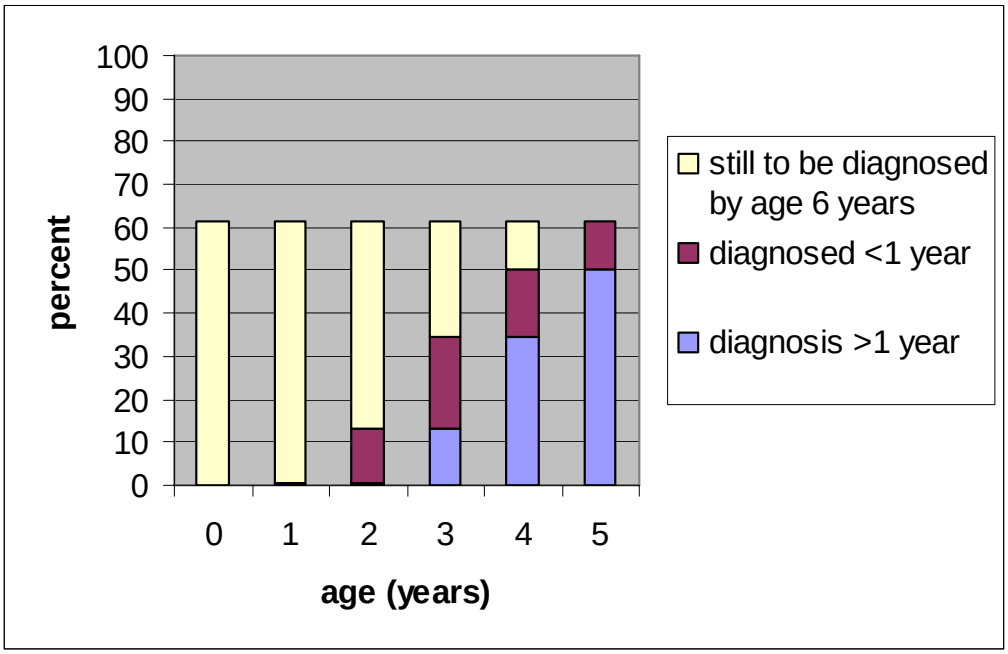

Figure 2 Relating incidence and prevalence