Incidence of autism spectrum disorders in children in two Australian states

Katrina Williams, Emma J Glasson, John Wray, Marshall Tuck, Megan Helmer, Carol I Bower and Craig M Mellis

ABSTRACT

Aim: To ascertain the incidence of autism spectrum disorders in Australian children.

Setting: New South Wales (NSW) and Western Australia (WA), July 1999 to December 2000.

Design: Data were obtained for WA from a prospective register and for NSW by active surveillance.

Main outcome measures: Newly recognised cases of autism spectrum disorders (defined as autistic disorder, Asperger disorder and pervasive developmental disorder not otherwise specified [PDD-NOS]) in children aged 0–14 years; incidence was estimated in 5-year age bands (0–4 years, 5–9 years, 10–14 years).

Results: In WA, 252 children aged 0–14 years were identified with autism spectrum disorder (169 with autistic disorder and 83 with Asperger disorder or PDD-NOS). Comparable figures in NSW were 532, 400 and 132, respectively. Most children were recognised with autistic disorder before school age (median age, 4 years in WA and 3 years in NSW). Incidence of autistic disorder in the 0–4-years age group was 5.5 per 10 000 in WA (95% CI, 4.5–6.7) and 4.3 per 10 000 in NSW (95% CI, 3.8–4.8). Incidence was lower in older age groups. The ratio of all autism spectrum disorders to autistic disorder alone was 1.5:1 in WA and 1.3:1 in NSW, and rose with age (1.8:1 and 2.9:1 in 10–14-year-olds in WA and NSW, respectively).

Conclusions: These are the first reported incidence rates for autism for a large Australian population and are similar to rates reported from the United Kingdom. Ongoing information gathering in WA and repeat active surveillance in NSW will help to monitor any future changes.

MJA 2005; 182: 108–111

Recently, there has been controversy about the incidence of autism and whether it is increasing. Two reasons commonly suggested for a perceived increase are the lack of consistency of diagnoses and changes in diagnostic classification.[1-3] The diagnosis of autism has broadened since it was first described in 1943,[4] and there is evidence of poor agreement among clinicians about what constitutes autism for less severely affected children,[5] and whether subgroups of autism are distinct.[6] Variation in study methods has also been implicated as a cause of differences in reported prevalence.[1,7]

The concept of a continuum of autism was first discussed in 1979,[8] and the terms "autistic spectrum disorder" and "autistic continuum" were introduced in 1988.[9] To illustrate the complexity, the *ICD-10 International classification of mental and behavioural disorders*[10] and the *Diagnostic and statistical manual of mental disorders, 4th edition* (*DSM-IV*)[11] include "childhood autism" (ICD-10) and "autistic disorder" (DSM-IV) in a broad category of "pervasive developmental disorders" (PDDs). This also includes, when intelligence and language development are normal but there are social interaction and behavioural problems, the classification "Asperger disorder", and, when symptoms are insufficient for the above diagnoses, the classifications "atypical autism", "other PDD" and "PDD unspecified" (ICD-10), and "PDD not otherwise specified" (PDD-NOS) (DSM-IV). Contributing to the debate is the fact that the criteria for these diagnoses were derived through consensus, and that cut-offs have been hard to define.[12,13]

To assess whether autism is increasing, we need epidemiological studies in which incidence can be measured accurately.[7,14,15] This study describes the incidence of newly recognised autism spectrum disorders (defined as autistic disorder, Asperger disorder and PDD-NOS) in children in two Australian states.

Children's Hospital at Westmead, Sydney, NSW.
Katrina Williams, PhD, FRACP, FAFPHM, Paediatric Epidemiologist, and Clinical Lecturer, University of Sydney, NSW; Megan Helmer, MHlthSc(CDM), Research Officer, Clinical Epidemiology; Craig M Mellis, MPH, MD, FRACP, Head of Clinical Epidemiology, and Professor of Paediatrics and Child Health, University of Sydney, NSW; Marshall Tuck, MPH, Research Officer, Psychological Medicine.
School of Population Health, University of Western Australia, Perth, WA.
Emma J Glasson, PhD, Research Fellow; also Telethon Institute for Child Health Research, Perth, WA.
Centre for Child Health Research, Telethon Institute for Child Health Research, Perth, WA.
Carol I Bower, MSc, PhD, FAFPHM, Head of Division, Epidemiology.
State Child Development Centre, Perth, WA.
John Wray, FRACP, Paediatrician.
Reprints will not be available from the authors. Correspondence: Dr Katrina Williams, Clinical Epidemiology, Children's Hospital at Westmead, Locked Bag 4001, Westmead, Sydney, NSW 2145. katrinaw@chw.edu.au

METHODS

Setting

The study was conducted in Western Australia (WA) and New South Wales (NSW) between July 1999 and December 2000.

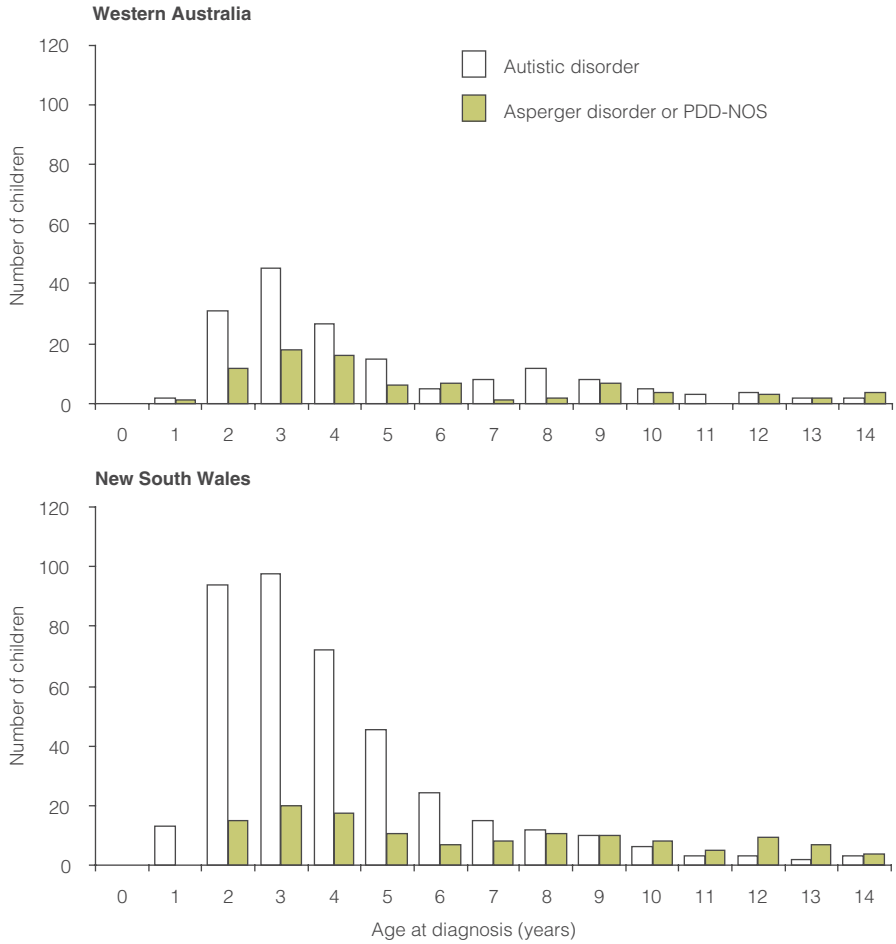
Case ascertainment

Western Australia: Since January 1999, the WA Register for Autism Spectrum Disorders has collected details of all newly diagnosed cases in WA of autistic disorder, Asperger disorder and PDD-NOS.[16] Cases of childhood disintegrative disorder are also recorded but were excluded from this study.

For the Register, autistic disorder and Asperger disorder are defined according to DSM-IV criteria.[11] As the DSM-IV does not specifically define PDD-NOS, the Register defines it as cases satisfying four DSM-IV criteria for autistic disorder, including at least one social criterion and at least one communication or behavioural criterion.[17]

In WA, diagnosis of autism spectrum disorders usually incorporates assessments

1 Age distribution of children newly recognised with autism spectrum disorders in two Australian states, July 1999 to December 2000



PDD-NOS = pervasive developmental disorders not otherwise specified.

by a team of health professionals familiar with autism, including a paediatrician or psychiatrist, clinical psychologist and speech pathologist, as this is a requirement for eligibility for government assistance for early intervention services. Autism diagnostic and intervention services are centralised in the WA capital, Perth, with most diagnoses made at four government centres. However, as up to 30% of cases per year are diagnosed in private practice, informal networks have been established to encourage clinicians to forward demographic and diagnostic information to the Register. The number of cases reported to the Register is compared with the number of cases diagnosed at each centre annually, and any missed cases are added.

New South Wales: As NSW lacks centralised diagnostic and intervention services for autism spectrum disorders, we established a system of active surveillance, modelled on the Australian Paediatric Surveillance Unit.[18,19]

Contact details of medical, educational and community services professionals who might have contact with children with autism were obtained from the Royal Australasian College of Physicians, the Faculty of Child and Adolescent Psychiatry of the Royal Australian and New Zealand College of Psychiatrists, the Department of Community Services (DOCS), the Department of Education and Training (DET) and the Autism Association of NSW. They included general and developmental paediatricians, community child health doctors, paediatric geneticists and neurologists, adolescent medicine physicians, psychologists, speech and language pathologists, school placement professionals with the Autism Association of NSW, and DET district guidance officers.

These professionals were asked whether they had had contact with children aged 0–14 years with autism, and those who had were invited to participate in the study; 77% agreed. Agreement rate varied between groups (district guidance officers, 56%; Autism Association professionals, 67%; psychiatrists, 71%; paediatricians, 85%; and DOCS psychologists, 89%). A further 146 professionals who heard of the study through advertisements and presentations volunteered to participate. These included early intervention workers, psychologists, speech and language pathologists, teachers and school counsellors.

A total of 466 professionals agreed to participate. They were sent monthly postcards or emails asking if they had had contact with any child aged 0–14 years who was newly recognised in the previous month with at least one DSM-IV criterion for autistic disorder. They were also asked to complete a detailed questionnaire about any cases, including a checklist of DSM-IV criteria. Overall response rate to mail-outs was 82%.

We classified cases as autistic disorder, Asperger disorder or PDD-NOS using the DSM-IV checklist and the definitions of the WA Register. Cases that fulfilled criteria for both autistic and Asperger disorder were classified as the former.[6] If DSM-IV criteria were incomplete, but a diagnosis was available from a psychiatrist, paediatrician or multidisciplinary team, we used that diagnosis (10% of cases). Children who were known to have been diagnosed with autism or had been recognised to have any autistic features before July 1999 were excluded.

Analysis

All children aged 0–14 years who were reported in the two states as newly recognised between July 1999 and the end of December 2000 with autistic disorder, Asperger disorder or PDD-NOS were considered incident cases. Incidence in 5-year age bands was estimated using data from the Australian Bureau of Statistics for children resident in WA and NSW in the various age groups in 1999 and 2000.[20] The denominator used was the total number of children of the same age in 2000 plus half the number of children in these age groups in 1999. Annual incidence rates and 95% confidence intervals were calculated using exact methods with Epi Info version 6.[21]

Ethical approval

In WA, ethical approval for the establishment of the Register was received from the

2 Annual incidence of autism spectrum disorders in two Australian states, July 1999 to December 2000

Age (years)	Annual incidence per 10 000 children in age group (95% CI)					
	Autistic disorder		Asperger disorder and PDD-NOS		All three disorders combined	
	NSW	WA	NSW	WA	NSW	WA
0–4	4.3 (3.8–4.8)	5.5 (4.5–6.7)	0.8 (0.0–1.1)	2.5 (1.8–3.3)	5.1 (4.6–5.7)	8.0 (6.8–9.3)
5–9	1.6 (1.3–1.9)	2.4 (1.8–3.2)	0.7 (0.0–0.9)	1.1 (0.0–1.7)	2.3 (1.9–2.7)	3.5 (2.8–4.4)
10–14	0.3 (0.0–0.4)	0.8 (0.0–1.3)	0.5 (0.0–0.7)	0.6 (0.0–1.1)	0.8 (0.0–1.0)	1.4 (0.0–2.0)

PDD-NOS = pervasive developmental disorders not otherwise specified.

University of Western Australia, The Princess Margaret Hospital, the Disability Services Commission, the State Child Development Centre, and the Royal Australian and New Zealand College of Psychiatrists. Confidential information (child's name, date of birth and postcode) were included with the written permission of parents at the time of diagnosis. If permission was not provided, children were included on the register without identifiers.

In NSW, ethical approval was obtained from two area health services, the Department of Community Services, the Autism Association of NSW and the University of Sydney for clinicians to provide information with limited identifiers (first two initials of first name and surname, date of birth, postcode and sex) to the study without parents' consent. The Department of Education and Training gave permission for children to be reported to the study with either consent from parents/carers or after one month of not hearing from the parents. Education professionals could report children but not provide further information.

RESULTS

The WA Register included 252 children aged 0–14 years who were newly diagnosed with autism spectrum disorders between July 1999 and December 2000: 169 with autistic disorder and 83 with Asperger disorder or PDD-NOS. They comprised 105 children with identifying information and 147 without this information.

In NSW, in the same period, we received 1395 reports of children with at least one DSM-IV criterion of autistic disorder, and classified 532 of these with autism spectrum disorders: 400 with autistic disorder and 132 with Asperger disorder or PDD-NOS. The remaining reports were excluded because they were duplicates (201); the child did not fit the study criteria (eg, not a NSW resident, older than 14 years, previously recognised with autistic features) (437); the report provided insufficient information for classification (135); the child did not satisfy the criteria for autistic disorder, Asperger disorder or PDD-NOS (72); or the child was reported to satisfy the criteria, but parents/carers had refused consent to reveal more details (18).

The age distribution of children with autism spectrum disorders at the time of reporting is shown in Box 1. In both states, most children were newly recognised with autistic disorder before school entry, with a median age of diagnosis of 4 years in WA and 3 years in NSW. Asperger disorder and PDD-NOS were recognised at median ages of 4 years in WA and 6 years in NSW.

The annual incidence of newly recognised autism spectrum disorders is shown by 5-year age group in Box 2. The incidence of both autistic disorder and Asperger disorder and PDD-NOS was higher in WA than in NSW in all age groups, with the difference most marked for 0–4-year-olds with Asperger disorder or PDD-NOS. The highest incidence was for autistic disorder in the 0–4-years age group: 5.5 per 10 000 in WA and 4.3 per 10 000 in NSW.

The ratio of all autism spectrum disorders to autistic disorder alone was 1.3:1 in NSW and 1.5:1 in WA. This ratio increased with increasing age, from 1.2:1 for 0–4-year-olds to 2.9:1 for 10–14-year-olds in NSW, and from 1.4:1 for 0–4-year-olds to 1.8:1 for 10–14-year-olds in WA.

DISCUSSION

This study shows that a large number of Australian children were newly recognised with autistic spectrum disorders, particularly autistic disorder, in NSW and WA in 1999 and 2000. The annual incidence in the 0–4-years age group in WA was 5.5 per 10 000 for autistic disorder and 8.0 per 10 000 for all autism spectrum disorders. Comparable figures for NSW were 4.3 and 5.1 per 10 000. Incidence was lower in older age groups. These results are the first reported figures for incidence of autistic disorder and other autism spectrum disorders in a large Australian population. The differences between the states are likely to be due to differences in ascertainment.

The incidence figures for both states are likely to be underestimates of the true incidence, particularly for Asperger disorder and PDD-NOS. However, the potential underascertainment can not be quantified, as no other information is available about the incidence of autism in NSW or WA. In both states, case ascertainment relied on reporting by professionals. In NSW, participation of relevant professionals was incomplete, and a substantial number of reports included insufficient information for diagnosis. In addition, many children were excluded from the study because of previous identification with autistic behaviour. Case ascertainment may have been greater in WA, which has a smaller population than NSW and more centralised autism diagnostic services, which are directly linked to the Register for Autism Spectrum Disorders.

However, in both states, factors associated with service contact may also have led to underascertainment, including variation in symptom onset, delay in seeking help from services, and waiting periods for assessment (which can be up to 12 months for school-aged children in WA).

Problems in ascertainment are magnified for children who fulfil the diagnostic criteria for Asperger disorder or PDD-NOS but not autistic disorder. In WA, these children may have been underascertained because they were less likely to access healthcare services, while in NSW they may have been underascertained because of the low participation rate of education professionals (56%), clinician unwillingness to report children with less certain diagnostic labels, and clinician concern about the workload of reporting. In addition, overlap between autistic disorder and Asperger disorder is an international problem for estimating the incidence of autistic subgroups.[6] The most complete information about PDD is likely to come from population screening[6] or population-based surveillance.[22]

Internationally, few data have been published on the incidence of autism and other PDDs, and comparisons are difficult because of differences in definitions, age groups assessed and methods. The ratio of other PDD to autism has ranged from 0.7:1 to 3.3:1 in prevalence studies.[22-24] Our inci-

dence data are similar to those reported for children aged 1–4 years in the United Kingdom in 1995–1996, where an incidence of 4.3 per 10 000 was found for autism and 8.9 per 10 000 for all autism spectrum disorders, based on records of child development centres.[24] A 1999 UK study reported an incidence of 2.1 per 10 000 for autism for children aged up to 12 years, based on a general practice research database.[25] In Australia, a recently reported study from the Barwon region of Victoria reported an incidence of autism spectrum disorders of 4.26 per 10 000 person-years in children aged 2–17 years during the period 1998–2002.[26] Total population of children in this age group was about 50 000. Incidence of autistic disorder was not reported separately. To date, incidence figures have not been available from the United States.

A limitation of the WA Register as a research tool is the need for parental consent to include identifying information. Consent was received for only about a third of cases collected since 1999,[27] possibly because consent is requested from parents at a sensitive time, and because the task of obtaining consent is a workload burden for clinicians. This affects the ability to collect detailed information and to link data to other health research databases. This limitation might be overcome if protocols were implemented for using named patient data in population-based registries that provide a large benefit to the community at relatively low risk to participants.[28,29]

In NSW, gaining ethics approval for active surveillance was a lengthy process, as described by others.[30] We agree with suggestions that consideration be given to either a single institutional ethics committee acting as the sole reviewer for large population-based epidemiological studies[30] or to the development of state or national ethics bodies.[28,30,31] However, neither approach would completely resolve the burden of applications for surveillance systems such as ours, which involve government and non-government organisations outside the healthcare sector.

Despite the limitations of this study, it shows that a large number of children were newly recognised with autism spectrum disorders, particularly autistic disorder, in the study period. These children require sufficient and appropriate health, community and education services to cater for their ongoing needs.

In addition, the study has provided a baseline for assessing whether the incidence of autism spectrum disorders is increasing in NSW and WA. Ongoing information gathering in WA and repeat active surveillance in NSW will help monitor any future changes. Ideally, national, ongoing data collection should be established for autism and other developmental disabilities in Australia.

ACKNOWLEDGEMENTS

Funding for the NSW project was provided by the Children's Hospital Fund of the Children's Hospital at Westmead and the Apex Foundation Grant for Intellectual Disability. The authors are grateful to the project's steering committee, Andrew Hayen for statistical advice, and all professionals who reported cases.

This research was undertaken with assistance from the Australian Department of Community Services and the NSW Department of Ageing, Disability and Home Care. However, the information and views contained in this study do not necessarily, or at all, reflect the views or information held by the NSW Government, the Minister for Ageing, Disability and Home Care, or the Department.

Initial funding for the Western Australian Register for Autism Spectrum Disorders was received from the Disability Services Commission of WA, and an Australian Rotary Research Grant. Further funding has been received from the WA Department of Education and Training and the WA Department of Health.

REFERENCES

1 Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord* 2003; 33: 365-382.
2 Wing L, Potter D. The epidemiology of autistic spectrum disorders: is the prevalence rising? *Ment Retard Dev Disabil Res Rev* 2002; 8: 151-161.
3 Prior M. Is there an increase in the prevalence of autism spectrum disorders? *J Paediatr Child Health* 2003; 39: 81-82.
4 Kanner L. Autistic disturbances of affective contact. *Nervous Child* 1943; 2: 217-250.
5 Mahoney WJ, Szatmari P, MacLean JE, et al. Reliability and accuracy of differentiating pervasive developmental disorder subtypes. *J Am Acad Child Adolesc Psychiatry* 1998; 37: 278-285.
6 Baird G, Charman T, Baron-Cohen S, et al. A screening instrument for autism at 18 months of age: a 6-year follow-up study. *J Am Acad Child Adolesc Psychiatry* 2000; 39: 694-702.
7 Fombonne E. Epidemiological trends in rates of autism. *Mol Psychiatr* 2002; 7: S4-S6.
8 Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *J Autism Dev Disord* 1979; 9: 11-29.
9 Filipek PA, Accardo PJ, Baranek GT, et al. The screening and diagnosis of autistic spectrum disorders. *J Autism Dev Disord* 1999; 29: 439-484.
10 World Health Organization. The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. Geneva: WHO, 1993.
11 American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4th ed (DSM-IV). Washington, DC: American Psychiatric Association, 1994.
12 Medical Research Council. Review of autism research: epidemiology and causes. London: Medical Research Council, 2001.
13 Bristol MM, Cohen DJ, Costello EJ, et al. State of the science in autism: report to the National Institutes of Health. *J Autism Dev Disord* 1996; 26: 121-154.
14 Fombonne E. Is there an epidemic of autism? *Pediatrics* 2001; 107: 411-412.
15 Howlin P. The importance and implications of early diagnosis. Biennial National Autism Conference. Positive steps forward. Sydney: Autism Council of Australia, 2001.
16 Glasson EJ. The Western Australian register for autism spectrum disorders. *J Paediatr Child Health* 2002; 38: 321.
17 Buitelaar JK, van der Gaag RJ. Diagnostic rules for children with PDD-NOS and multiple complex developmental disorder. *J Child Psychol Psychiatry* 1998; 39: 911-919.
18 Elliott EJ, Nicoll A, Lynn R, et al. Rare disease surveillance: an international perspective. *J Paediatr Child Health* 2001; 6: 251-260.
19 Gazarian M, Williams K, Elliott E, et al. Evaluation of a national surveillance unit. *Arch Dis Child* 1999; 80: 21-27.
20 Australian Bureau of Statistics. Australian demographic statistics. Canberra: ABS, 2000. (Cat. no. 3101.0.)
21 Epi Info, version 6: A word processing, database and statistics program for epidemiology on microcomputers. Atlanta, Ga: US Centers for Disease Control and Prevention, 1994.
22 Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. *JAMA* 2001; 285: 3093-3099.
23 Bertrand J, Audrey M, Boyle C, et al. Prevalence of autism in a United States population: the Brick Township New Jersey, investigation. *Pediatrics* 2001; 108: 1155-1161.
24 Powell JE, Edwards A, Edwards M, et al. Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas of the West Midlands, UK. *Dev Med Child Neurol* 2000; 42: 624-628.
25 Kaye JA, del Mar Melero-Montes M, Jick H. Mumps, measles and rubella vaccine and the incidence of autism recorded by general practitioners: a time trend analysis. *BMJ* 2001; 322: 460-463.
26 Icasiano F, Hewson P, Machet P, et al. Childhood autism spectrum disorder in the Barwon region: a community based study. *J Paediatr Child Health* 2004; 40: 696-701.
27 Glasson EJ, Wray J. Obtaining consent affects the value of the Western Australian autism register [letter]. *Med J Aust* 2004; 181: 514-515.
28 Williamson OD, Cameron PA, McNeil JJ. Medical registry governance and patient privacy. *Med J Aust* 2004; 181: 125-126.
29 Tu JV, Willison DJ, Silver FL, et al. Impracticability of informed consent in the Registry of the Canadian Stroke Network. *N Engl J Med* 2004; 350: 1414-1421.
30 Smith MA, Jalaludin B, Leeder SR, Smith WT. Isn't one institutional ethics committee's approval enough? *Med J Aust* 1994; 160: 662.
31 Beran RG. Should there be an accredited ethics committee system for centralised review of multicentre clinical research? *Med J Aust* 1998; 168: 174.

(Received 10 May 2004, accepted 10 Dec 2004) ❑