

FOREWORD

The collation of the 2002 Report of the WA Register for Autism Spectrum Disorders represents four years of continuous comprehensive data collection. The data should now be examined for trends in incidence and prevalence and geographic variability. The data continues to be accessed by various organisations, government departments, researchers and individuals. The Register is grateful to the families and clinicians who contribute this information and to the government departments that offer financial support.

Dr John Wray
Spokesperson for the Advisory Committee.

INTRODUCTION

Background

Autism spectrum disorders include all autism-related conditions described medically as Pervasive Developmental Disorders. These are: Autism, Asperger syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Although Rett syndrome is also categorised as a Pervasive Developmental Disorder, people diagnosed with Rett syndrome are not included on this Register.

Autism spectrum disorders are characterised clinically by significant impairment in three areas of development: a) poor social interaction; b) deficits in communication; and c) restricted range of interests. Symptoms may be apparent before 30 months of age, but diagnosis is tentative before this time. Many children have difficulties integrating into society (eg in school, social gatherings and sporting activities), and each require varying degrees of supervision and support in daily living.

Current understanding of the aetiology and intervention strategies for autism spectrum disorders is limited. The WA Autism Register serves as a primary resource to researchers, clinicians and service providers to assist with our knowledge of these complex disorders. Western Australia (WA) has a variety of comprehensive state databases and its geographic isolation and centrally distributed population make it an ideal location to establish and manage a register. The WA Autism Register is prospective, collecting information on all people diagnosed in WA since January 1999.

Purpose and aims

The Register collects information that is useful in describing the pattern of autism diagnoses in WA, including;

- The number and ages of people diagnosed
- The severity of disability
- Shared biological, psychiatric and developmental features
- Individual or group changes over time

The Register has several applications;

- Research
 - Epidemiology
 - Biology and psychology
 - Longitudinal studies
- Planning for services
 - Health
 - Education
 - Disability

Types of information collected

The Register collects simple demographic and diagnostic information such as;

- Date of birth, sex, primary language at home
- Diagnostic criteria used
- Diagnostic methods
- IQ (verbal and non-verbal) and/or developmental abilities
- Cognitive assessments used
- Comorbidity (the presence of other conditions)
- Language assessments
- Adaptive abilities

The Advisory Committee

The Register is governed by an Advisory Committee. It currently comprises of one parent representative; two psychologists, one psychiatrist, and one speech pathologist in private practice; and three representatives from the major autism diagnosing centres (Disability Services Commission, the State Child Development Centre, and Princess Margaret Hospital). Each member was nominated by the institution they represent. The Advisory Committee meets on a regular basis. The issues discussed include the running and methodology of the Register, ethical issues, political concerns, diagnostic issues, and diagnostic training opportunities.

Confidentiality

The Register is bound by a confidentiality protocol (see Appendix). Information is stored on a non-networked computer that is kept in a locked room on secure premises at the Telethon Institute for Child Health Research, and is password protected. Requests for simple data are made to the Registrar, and the Advisory Committee considers requests for more complex data.

Ethical approval for the Register was received from the University of Western Australia, Princess Margaret Hospital, Disability Services Commission, State Child Development Centre, and the Royal Australian and New Zealand College of Psychiatrists.

Notifications to the Register

A data collection form for each newly diagnosed case is completed by a clinician at the time of diagnosis and sent to the Register. The clinician fills in the diagnostic and demographic details that are available to them. For the confidential information (name, date of birth, postcode) to be included with the entry, consent must be obtained from the parents or persons themselves. The confidential information helps to eliminate double entries of notifications to the Register, to recognise changes in diagnoses within the same person over time, and to assist with the manual checking of numbers received with numbers diagnosed at each centre. At the end of each year, the major diagnosing centres review their records for any cases that have been missed.

Register documents

The Register has several formal documents – a data collection form, consent form, information sheet, information pamphlet, and an interest form. It also has documentation of the terms of reference and its confidentiality guidelines.

Changes in documents over time

Several of the documents have been modified since the Register began data collection. Minor changes to the information sheet and consent form and several changes to the data collection form have been made. All changes were approved by the relevant ethics committees.

Requests for information

Since its inception, the Register has received a large number of requests for information from local, interstate and international sources. They were made from government departments, autism service providers, researchers, students, and the media.

2002 data

This report summarises the data for people who were diagnosed in WA during the 2002 calendar period. While finalising the data for the 2002 report, a small number of cases diagnosed between 1999 and 2001, but not previously accounted for, filtered through the pathways of collection. Brief comparisons between the 2002 year of data collection and the complete four years of collection are made throughout this report using the adjusted figures.

Funding

Initial funding for the Register was received from two sources; the Disability Services Commission, and the Australian Rotary Health Research Fund. During 2002, funds were received from the WA Department of Education to maintain its activities. The financial support of these Departments is greatly appreciated.

ACKNOWLEDGEMENTS

The notifiers

The success of the Register is dependent upon the ascertainment of all new cases. Many thanks to the people who have made the time during 2002 to fill in the information for each case and forward it to the Register:

Aasta Abbott, Wendy Bajgerytsch, Linda Bradley, Ritu Campbell, Lynda Chadwick, Justine Doust, Annkathrin Franzmann, Adriana Heuzo, Sandy Jackson, Jane Klinken, Jane Lesslie, Rowena Mackiewicz, Karen Mason, Mary Oates, Grania O'Connor, Kathryn Oostryck, Carolyn Price, Jura Tender, Trish Webb, Helen Wolfenden, John Wray.

Thanks also to others not named here who have helped in various aspects of administration.

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Register correspondence:

The Registrar
WA Register for Autism Spectrum Disorders
Telethon Institute for Child Health Research
PO Box 855
West Perth WA 6872
Australia

Phone + (61 8) 9489 7777
Fax + (61 8) 9489 7700

autismreg@ichr.uwa.edu.au

Registrar:

Dr Emma Glasson

Advisory Committee:

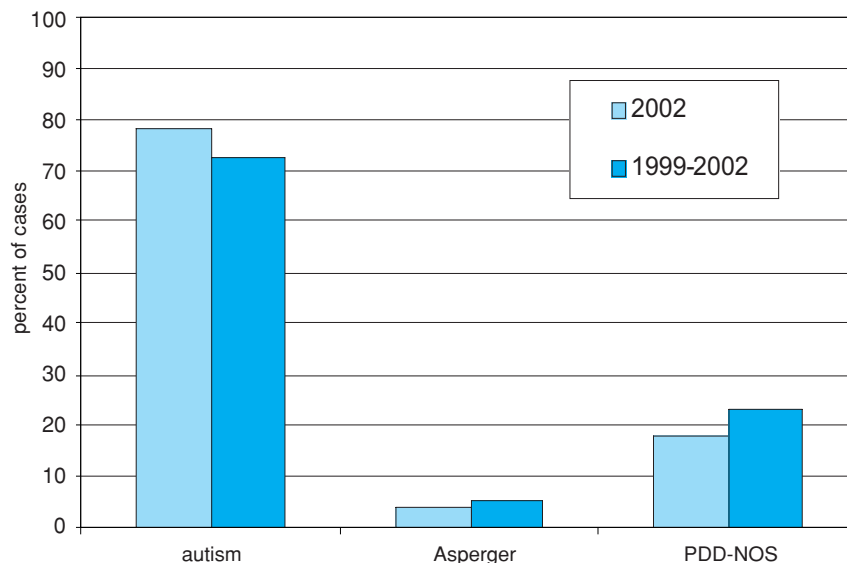
Dr John Wray (Spokesperson)
Dr Ritu Campbell
Dr Peter Chauvel
Mr Derek Cohen
Dr Hugh Cook
Mrs Bobbi McMullin
Ms Jura Tender
Mrs Helen Wolfenden

STATISTICS

During the period January 1st 2002 to December 31st 2002, **211** people were diagnosed with an autism spectrum disorder in WA. This exceeded the 1999 and 2000 (revised) totals of 161 and 174 cases respectively, and equalled the 2001 (revised) total of 211 cases.

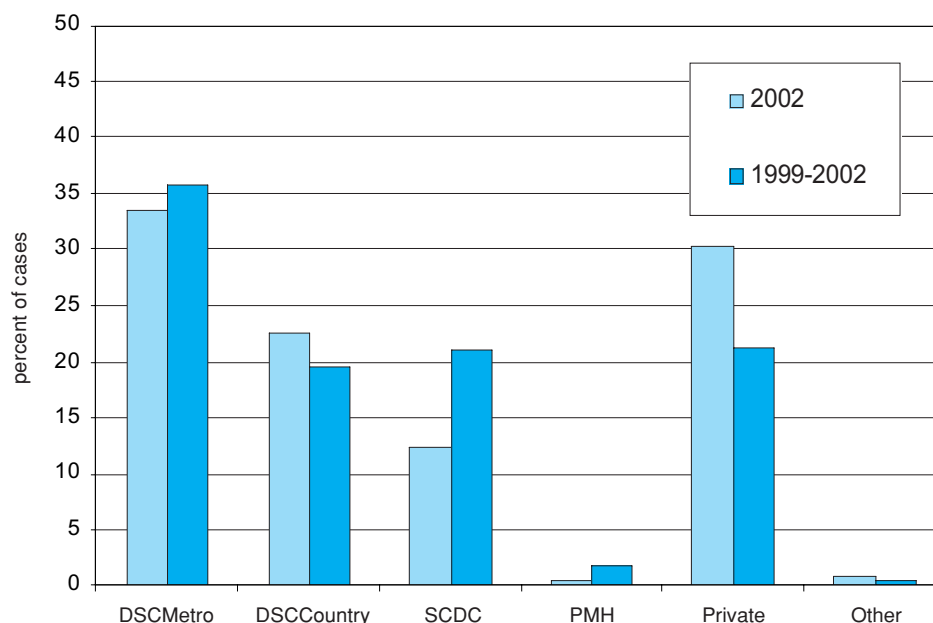
Diagnosis

In 2002, autism accounted for 78% of the diagnoses, PDD-NOS for 18%, and Asperger syndrome 4%. No cases of Childhood Disintegrative Disorder were reported. Overall, between 1999 and 2002, 72% of cases were diagnosed with autism, 23% with PDD-NOS, and 5% with Asperger syndrome.



Place of diagnosis

In 2002, the metropolitan division of the Disability Services Commission (DSC) made 33% of the diagnoses, the DSC country division 23%, State Child Development Centre (SCDC) 12%, Princess Margaret Hospital (PMH) 0.5%, and private practitioners 30%. Since January 1999, 36% of people have been diagnosed at the metropolitan division of DSC, 19% at the DSC country division, 21% at SCDC, 2% at PMH, and 21% in private practice.



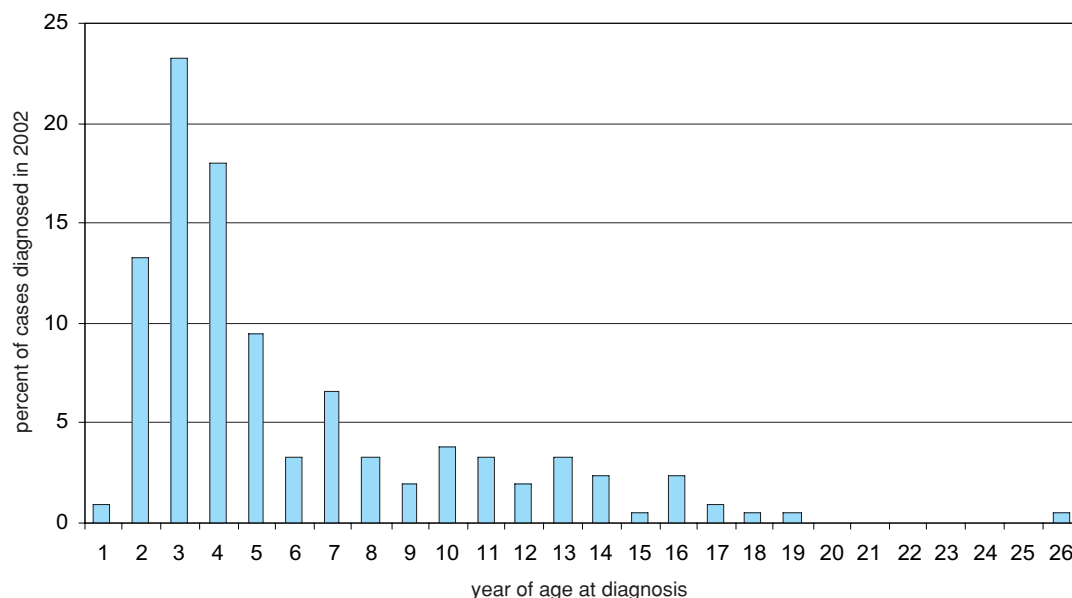
Comorbid conditions

In 2002, 71 people (34%) were reported to have at least one comorbid condition, and 103 (49%) were reported as not having any other condition. The remaining 37 people did not have this item completed but it is likely that many of these did not present with another condition if the clinician did not report a positive finding. Of the 71 people with a reported comorbid condition, several presented with more than one condition. Thirty cases had Attention Deficit (Hyperactivity) Disorder, 37 had intellectual disability, 12 had epilepsy, 1 had cerebral palsy, 7 had a known chromosomal disorder, 1 had tuberous sclerosis, and 10 had another less common comorbid condition. The numbers of people reported to have intellectual disability may be underestimated, and partly reflects the impact of 92 people for whom a formal level could not be ascertained at the time of assessment.

Comorbid condition	number of people diagnosed in 2002 with condition	% of 2002 cases with a comorbidity response (n=174)	% of 1999-2002 cases with a response (n=579)
ADHD/ADD	30	17%	18%
Intellectual disability	37	21%	29%
Epilepsy	12	7%	9%
Cerebral palsy	1	1%	2%
Tuberous sclerosis	1	1%	0.2%
Chromosomal	7	4%	3%
Other	10	6%	10%

Age at diagnosis

In 2002 the age at diagnosis ranged from 19 months to 26 years with a median age of 4 years. Approximately 50% of cases were diagnosed by 4 years of age, 75% by 7 years, and 90% by 12 years of age. Of the 23 people who were aged 13 years or over at the time of diagnosis, 18 (78%) were given a diagnosis of autism, 2 were diagnosed with PDD-NOS, and 3 people were diagnosed with Asperger syndrome. Overall, between 1999 and 2002, the median age at diagnosis was 4 years of age (range 15 months to 43 years).



Gender

As expected, considerably more males than females were diagnosed during 2002 (169 males, 42 females), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:4. Overall, the female to male ratio for the cases diagnosed since 1999 is 1:4.2 (146 females, 611 males).

Ethnicity

Information on ethnicity was stated for 123 (58%) of the 2002 cases, of whom 82% were recorded as having both parents of Caucasian origin. One person diagnosed during 2002 was known to be of Indigenous Australian heritage. Since 1999, seven cases on the Register have been recorded as being of Indigenous Australian heritage (1.5% of cases where ethnicity is known).

Country of birth

Details of country of birth were available for 198 people diagnosed in 2002. Of these, 95% were born in Australia. Four people (2%) were born in South-East Asia, two people (1%) were born in the British Isles, two people (1%) in North America, and one person from the Middle East region. Since 1999, 7% of people who had information about their country of birth were born outside of Australia.

Cognitive abilities

Clinicians reported that for 16% of cases diagnosed during 2002, non-compliance with testing meant that a level of IQ could not be determined, and many other cases had incomplete assessments. Due to young ages at diagnosis or non-compliance during testing, only 56% of cases had an estimated level of intellectual ability represented by a test score. For 87 people, at least one verbal IQ, performance IQ, or a full scale IQ was estimated. For a further 32 people, an estimate of intellectual functioning was given by the diagnosing clinician. For the 119 cases with an estimated level, 31% were in the range of intellectual disability and 69% were not.

For cases diagnosed during 2002, a verbal IQ score was available for 68 cases (32%), ranging between 46 and 160 (median score 90). A performance IQ score was available for 72 cases (34%), ranging between 46 and 145 (median score 98). A full-scale IQ score was calculated for 81 cases (38%), ranging between 40 and 147 (median score 92). Performance scores were higher than verbal scores by an average of 5 points.

Since 1999, 55% of cases have had an estimate of cognitive function as measured by a score on a standardised assessment or an estimate by a clinician, of whom 41% were recorded to have intellectual disability.

Primary language at home

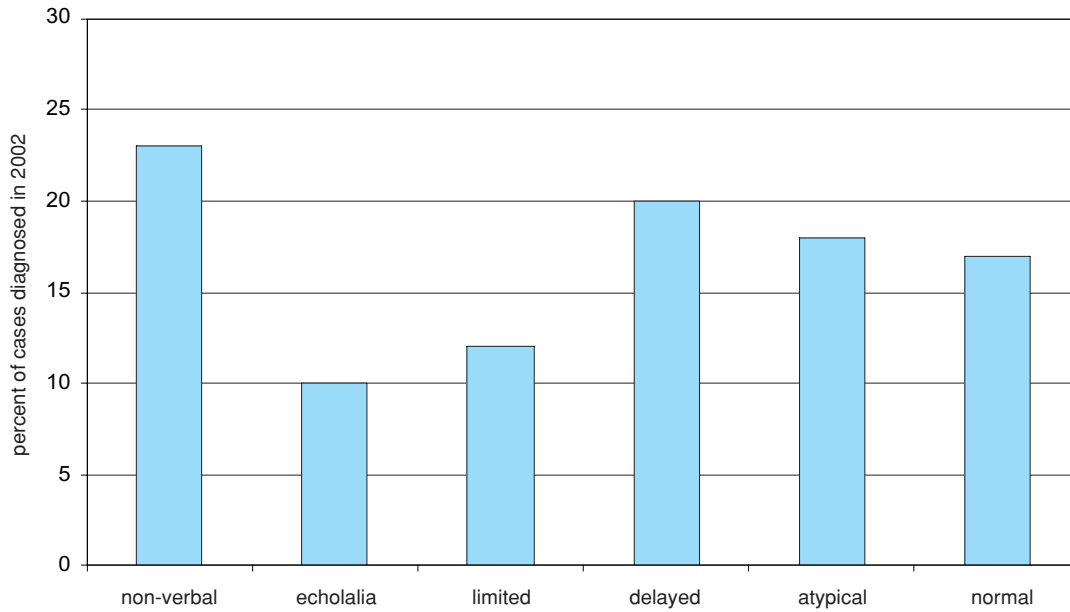
Sixteen people (8%) diagnosed during 2002 were reported to have a language other than English at home. Over the 1999-2002 period, 8% of people spoke a language second to, or other than, English at home.

Language skills

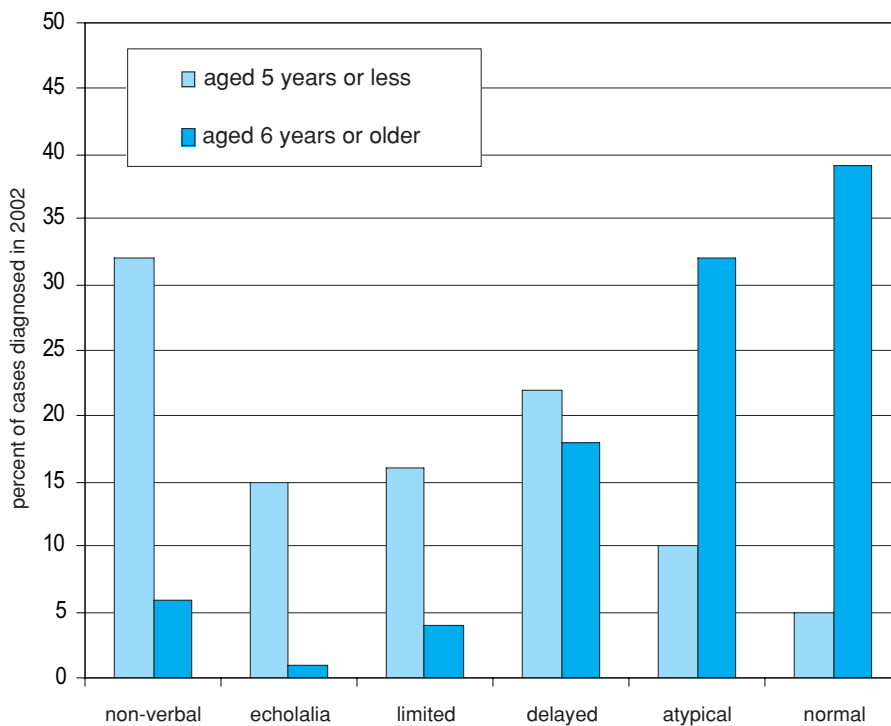
Clinicians were given 6 response categories to describe language skills at the time of diagnosis:

1	Non verbal	• Fewer than 5 words • Speech not used on a daily basis
2	Echolalia and/or jargon	• Speech, but not used for primary communication
3	Limited functional	• Speech, up to 3 word phrases used on a daily basis for communication
4	Delayed language	• Language development normal but delayed
5	Atypical	• Structure appropriate for mental age, but use is inappropriate
6	Normally developing	• Speech is appropriate for age and general level of ability

Of the people diagnosed in 2002 who had a language level recorded (206 cases), 23% were described as non-verbal, 10% as having echolalia or jargon, 12% as limited functional, 20% as having delayed language, 18% with atypical language, and 17% had normally-developing language at the time of diagnosis.



The level of language skills varied with year of age at diagnosis. Children aged 5 years or under were more likely to be described as non-verbal or having delayed skills, and people aged 6 and over were more likely to be described as having language present but with peculiar characteristics or approximating normal development.



Adaptive behaviour

Adaptive behaviour is a person's ability to adapt to and manage their surroundings. An adaptive behaviour assessment measures areas of independence, physical skills, and interpersonal relationships; and makes a comparison to other persons of the same age. For most children diagnosed with autism since 1999, adaptive behaviour has been measured by the Vineland Adaptive Behavior Scales (devised by Sparrow *et al.*, 1985). Similar to most IQ tests, the Vineland has a standardised mean of 100 points and a 15-point standard deviation. Therefore a score of 100 is considered to be average, and any score between 85 and 115 is also age-appropriate. Scores less than 85 indicate the person is functioning below what is expected for that person's age, and a score of less than 70 means that difference is very significant. The Vineland provides an overall adaptive behaviour score (composite), as well as individual scores in four subdomains:

1. Communication (receptive, expressive, written);
2. Daily Living Skills (personal, domestic, community);
3. Socialisation (interpersonal relationships, play and leisure time, coping skills);
4. Motor Skills (gross and fine).

A summary of the adaptive behaviour scores for all people diagnosed since 1999 who were assessed with the Vineland are presented in the table below, followed by a figure representing the mean scores for each domain for cases who were diagnosed in 2002:

Domain	Number of cases with a score	Mean score	Range of scores	Standard deviation
Total Composite Score	497	57	20-119	12
Communication domain	498	62	20-130	14
Daily Living domain	497	61	19-106	13
Socialisation domain	497	58	20-108	11
Motor Skills domain	406	71	20-152	17

Mean Adaptive Behaviour score for each Vineland domain - cases diagnosed in 2002 (n=146)

