

**WA REGISTER  
FOR  
AUTISM SPECTRUM DISORDERS**

2003 Report

# FOREWORD

*The collation of the 2003 Report of the WA Register for Autism Spectrum Disorders represents five years of continuous comprehensive data collection. In this report, the 2003 data are compared to data from the preceding four years. The data continue 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 makes 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
- Other cognitive assessments
- 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 representatives from the two major diagnostic centres (Disability Services Commission and the State Child Development Centre). Each member was nominated by the institution they represent. The Advisory Committee meets on a regular basis. Issues that are discussed at meetings 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 to collect data 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 at the Register 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, and a research 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 from local, interstate and international sources for data, information, and research participants. Requests have been made from government departments, autism service providers, researchers, students, and the media.

## 2003 data

This report summarises the data for people who were diagnosed in Western Australia during the 2003 calendar year. While finalising the data for this report, a small number of cases diagnosed prior to 2003 who were not previously accounted for in earlier reports, filtered through the pathways of collection. Numbers have been adjusted accordingly. Brief comparisons between the 2003 year of data collection and the total five 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. Since 2002, funds have been received from both the WA Department of Education and the WA Department of Health 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 made the time during 2003 to fill in the information for each case and forward it to the Register:

*Aasta Abbott, Wendy Bajgerytsch, Helen Bolton, Linda Bradley, Ritu Campbell, Lynda Chadwick, Tania Dawson, Sabrina de Beer, Martin Exell, Annkathrin Franzmann, Manda Hollins, Sandy Jackson, Jane Klinken, Jane Lesslie, Alana Maley, Karen Mason, Sue Midford, Kathryn Oostroyck, Trevor Parry, Anoushka Rassau, Andrew Savery, Lelle Taffyn, Jura Tender, Amanda Wilkins, John Wray.*

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

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*Citation:*

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*Other references available for the WA Register for Autism Spectrum Disorders:*

Glasson EJ. The Western Australian Register for Autism Spectrum Disorders. *Journal of Paediatrics & Child Health*, 2002, **38**: 321.

Glasson EJ & Wray J. Obtaining consent affects the value of the Western Australian autism register. *Medical Journal of Australia*, 2004, **181**: 514-515.

Williams K, Glasson EJ, Wray J, Tuck M, Helmer M, Bower CI, Mellis CM. Incidence of autism spectrum disorders in children in two Australian states. *Medical Journal of Australia*, 2005, **182**: 108-111.

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Mr Derek Cohen  
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Mrs Bobbi McMullin  
Ms Jura Tender

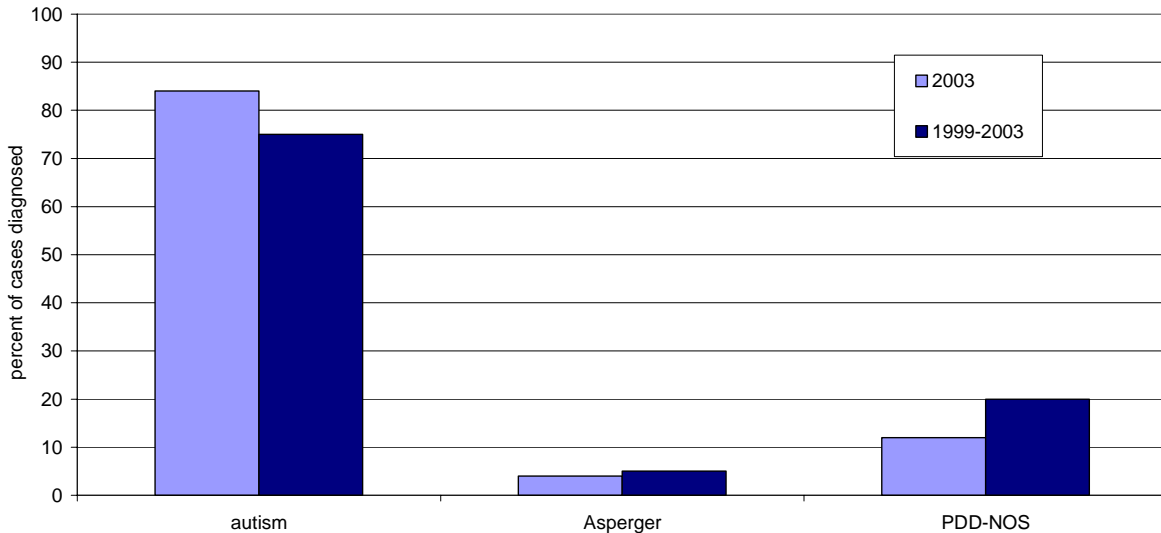
## STATISTICS

During the period January 1<sup>st</sup> 2003 to December 31<sup>st</sup> 2003, **218** people were diagnosed with an autism spectrum disorder in WA. The (revised) totals for the 1999-2002 years were 159, 174, 213 and 216 cases respectively.

### Diagnosis

In 2003, autism accounted for 84% of the diagnoses, PDD-NOS for 12%, and Asperger syndrome 4%. No cases of Childhood Disintegrative Disorder were reported. Overall, between 1999 and 2003, 75% of cases were diagnosed with autism, 20% with PDD-NOS, and 5% with Asperger syndrome.

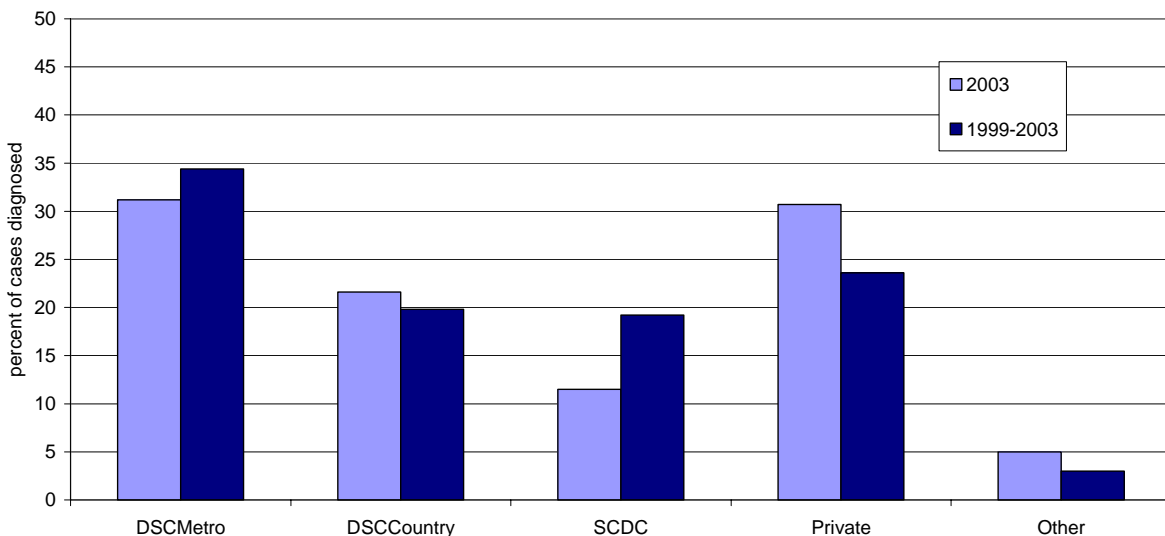
Percent of cases diagnosed with each autism spectrum disorder, by calendar period



### Place of diagnosis

In 2003, the metropolitan division of the Disability Services Commission (DSC) made 31% of the diagnoses, the DSC country division 22%, State Child Development Centre (SCDC) 12%, private practitioners 31% and other centres 5.0%. Since January 1999, 34% of people have been diagnosed at the metropolitan division of DSC, 20% at the DSC country division, 19% at SCDC, 24% in private practice, and 3% in other centres.

Percent of cases diagnosed at each centre, by calendar period



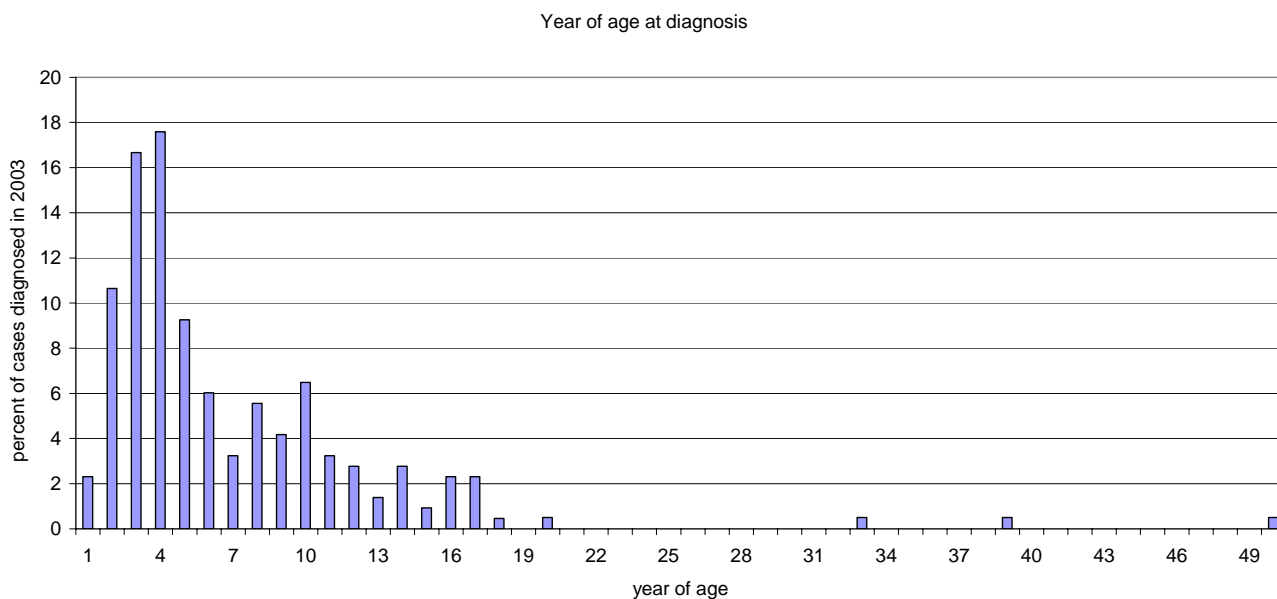
## Comorbid conditions

In 2003, 57 people (26%) were reported to have at least one comorbid medical condition, and 97 (44%) were reported as not having any other condition. The remaining 64 (29%) 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 57 people with a reported comorbid condition, several presented with more than one condition. Twenty one cases had Attention Deficit (Hyperactivity) Disorder, 11 had epilepsy, one had cerebral palsy, and five had a known chromosomal disorder (three with Down syndrome).

Comorbid condition	number of people diagnosed in 2003 with condition	% of 2003 cases with a comorbidity response (n=154)	% of 1999-2003 cases with a response (n=651)
ADHD/ADD	21	14%	20%
Epilepsy	11	7%	10%
Cerebral palsy	1	1%	2%
Tuberous sclerosis	0	0%	0.2%
Chromosomal	5	3%	3%

## Age at diagnosis

In 2003 the age at diagnosis ranged from 18 months to 50 years with a median age of 5 years. Approximately 50% of cases were diagnosed by 5 years of age, 75% by 9 years, and 90% by 13 years of age. Of the 23 people who were aged 14 years or over at the time of diagnosis, 20 (87%) were given a diagnosis of autism, 2 (9%) were diagnosed with Asperger syndrome, and 1 person (4%) was diagnosed with PDD-NOS. Overall, between 1999 and 2003, the median age at diagnosis was 4 years of age (range 15 months to 50 years).



## Gender

As expected, considerably more males than females were diagnosed during 2003 (183 males, 33 females, 2 cases unspecified), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:5.5. Overall, the female to male ratio for the cases diagnosed since 1999 is 1:4.5 (179 females, 799 males, 2 unspecified).

## Ethnicity

Information on ethnicity was stated for 153 (70%) of the 2003 cases, of whom 88% were recorded as having both parents of Caucasian origin. Three persons diagnosed during 2003 were known to be of Indigenous Australian heritage. Since 1999, 10 cases on the Register have been recorded as being of Indigenous Australian heritage (1.6% of cases where ethnicity is known).

## Country of birth

Details of country of birth were available for 204 (94%) people diagnosed in 2003. Of these, 95% were born in Australia. Four people were born in South-East Asia, five were born in the British Isles, and one in South Africa. Since 1999, of people who had information known about their country of birth, 7% were born outside of Australia.

## Cognitive abilities

Due to young ages or non-compliance during testing, only 81 (37%) of the 218 cases diagnosed during 2003 had an estimated level of intellectual ability represented by a full scale test score or completion of both the verbal and performance components of an administered test. For five cases (2%), only a verbal or a performance score was obtained, and for a further 38 cases (17%), a developmental assessment tool was used to estimate mental age. In the absence of a formal test score, clinicians gave an estimate of intellectual ability for another 25 cases (12%), and no information on either intellectual or developmental ability was available for 69 cases (32%). By convention in Western Australia, young children assessed for autism spectrum disorders who are non-compliant during cognitive testing are considered to be at risk or vulnerable for having intellectual disability.

For at least 88 cases (40%) in 2003, intellectual disability was not present, as determined by either a full-scale test scores above 70 points or informal clinician estimates. Since 1999, 64% of the 980 cases included on the Register have had an estimate of cognitive functioning from either a full-scale score on a standardised assessment or a clinician estimate, showing that at least 37% of all diagnosed cases do not have intellectual disability.

## Adaptive behaviour

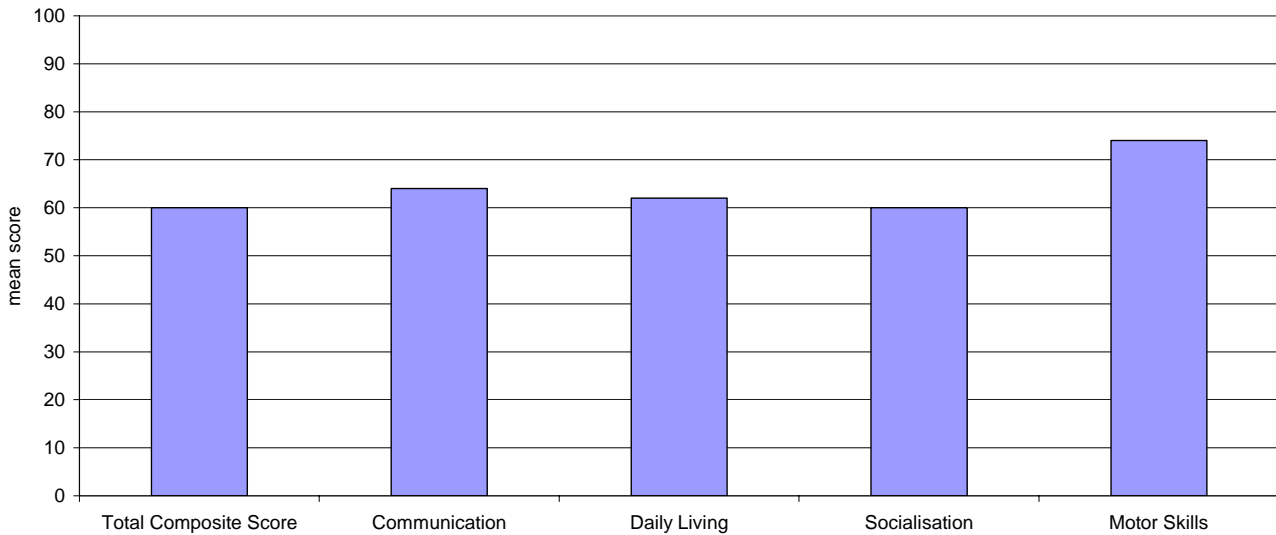
Adaptive behaviour is a person's ability to adapt to and manage their surroundings. An adaptive behaviour assessment measures areas of independence, physical skills, and interpersonal relationships; and makes a comparison to other persons of the same age. For most children diagnosed with autism since 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 during 2003:

Domain	Number of cases with a score	Mean score	Range of scores	Standard deviation
Total Composite Score	612	58	20-119	12
Communication domain	619	62	20-130	15
Daily Living domain	618	61	19-106	14
Socialisation domain	617	58	20-108	11
Motor Skills domain	500	71	20-152	17

Mean ABA domain scores for cases diagnosed during 2003



### Primary language at home

Ten people (5%) diagnosed during 2003 were reported to have a language other than English at home. Over the 1999-2003 period, 6% of people spoke a language second to, or other than, English at home.

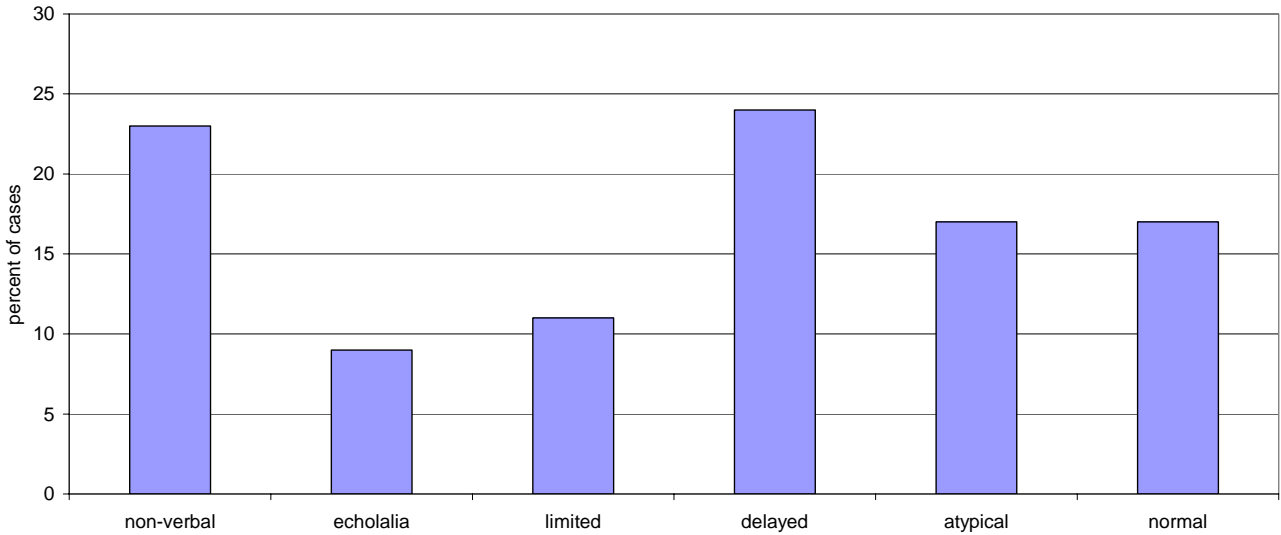
### Language skills

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

<b>1</b>	Non verbal	<ul style="list-style-type: none"> <li>• Fewer than 5 words</li> <li>• Speech not used on a daily basis</li> </ul>
<b>2</b>	Echolalia and/or jargon	<ul style="list-style-type: none"> <li>• Speech, but not used for primary communication</li> </ul>
<b>3</b>	Limited functional	<ul style="list-style-type: none"> <li>• Speech, up to 3 word phrases used on a daily basis for communication</li> </ul>
<b>4</b>	Delayed language	<ul style="list-style-type: none"> <li>• Language development normal but delayed</li> </ul>
<b>5</b>	Atypical	<ul style="list-style-type: none"> <li>• Structure appropriate for mental age, but use is inappropriate</li> </ul>
<b>6</b>	Normally developing	<ul style="list-style-type: none"> <li>• Speech is appropriate for age and general level of ability</li> </ul>

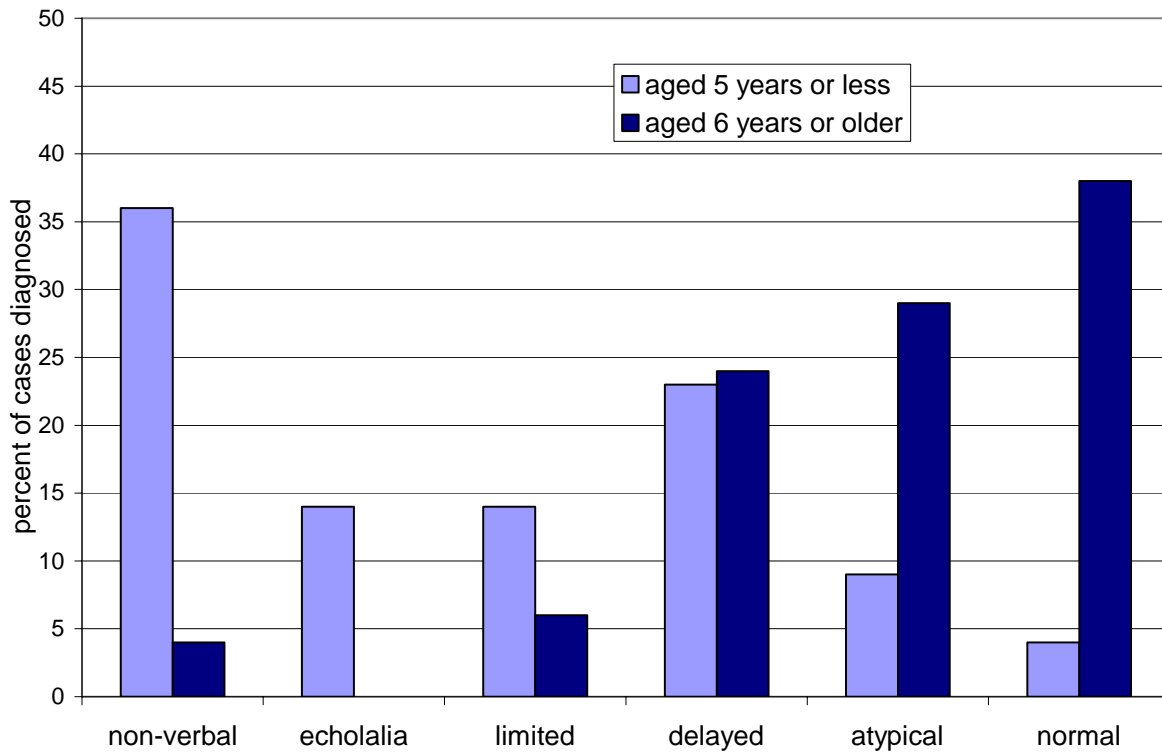
Of the people diagnosed in 2003 who had a language level recorded (195 cases), 23% were described as non-verbal, 9% as having echolalia or jargon, 11% as limited functional, 24% as having delayed language, 17% with atypical language, and 17% were developing age-appropriate language at the time of diagnosis.

Language ability for cases diagnosed in 2003



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

Language ability by age at diagnosis for cases diagnosed in 2003



APPENDIX

**WA REGISTER FOR AUTISM SPECTRUM DISORDERS**

Guidelines for confidentiality and release of data

1. Responsibility for the confidentiality of the WA Register for Autism Spectrum Disorders data lies ultimately with the Advisory Committee.
2. All Register staff are instructed regarding the need for and maintenance of confidentiality. The staff are responsible to the Advisory Committee for ensuring that confidentiality is maintained.
3. All persons who have access to name-identified data for routine maintenance of the Register or for research purposes shall complete a signed declaration binding them to respect the confidentiality of the information obtained therein, and to follow this code of practice.
4. All routine reports from the collection are in statistical form without identification of individual patients, doctors, clinicians, diagnosing institutions or service providers.
5. Non-routine release of tabulated, non personally-identified data from the Register is the responsibility of and at the discretion of the Registrar.
6. All requests for access to Register information must be approved by the ethics committee of the institution requesting it prior to Advisory Committee consideration.
7. All requests for information from the Register must be received in writing by the Registrar. Each Committee member must receive a copy of the proposal. A proposal is approved if a two-third majority of the Committee members present are in support. Final written approval is given by the Spokesperson of the Advisory Committee.
8. All requests for access to data that include information held on the Register that has been collected from a source other than the Register itself must be approved by the respective source(s) in addition to the Advisory Committee.
9. Access to patient identifiers by other than the Register staff or Register research personnel will be given only by the express permission of the Advisory Committee.
  - (i) Such permission will be granted only if:
    - (a) It is considered that such use of the data would positively advance the knowledge of Autism Spectrum Disorders;
    - (b) It is considered unlikely to harm the patients or families concerned in any way.
  - (ii) Should permission be granted for the release of personal identifiers, the following requirements will be made:
    - (a) That only minimum identification necessary to the proposed use be given.
    - (b) That the use of the data be under the supervision of a bona fide researcher who is responsible for instructing his or her staff regarding the need for and maintenance of confidentiality;
    - (c) That the data be handled according to the code of confidentiality set down by the National Health & Medical Research Council, particularly that no confidential data be released to any third party.
10. Any costs incurred in fulfilling these guidelines are to be borne by the requesting body.
11. Final reports or papers for publication are to be vetted by the Advisory Committee before publication.

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