

**WA REGISTER  
FOR  
AUTISM SPECTRUM DISORDERS**

2005 Report

## FOREWORD

*The collation of the 2005 Report of the WA Register for Autism Spectrum Disorders represents seven years of continuous comprehensive data collection. In this report, the 2005 data are compared to data from the preceding six 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 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 (e.g. 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 the availability of empirically validated 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 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
- 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, gender, 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 behaviour

## **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 to discuss methodology, ethical issues, political concerns, diagnostic issues, and diagnostic training opportunities.

## **Confidentiality**

The Register is bound by a confidentiality protocol (see Appendix). Information is stored securely at the Telethon Institute for Child Health Research. 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, including a data collection form, consent form, information sheets, and a research interest form. It also has documentation of the terms of reference and confidentiality guidelines.

## **Changes in documents over time**

Several of the documents have been modified since the Register began data collection. 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.

## **Funding**

Initial funding was received from two sources; the Disability Services Commission, and the Australian Rotary Health Research Fund. Subsequent funds were received from both the WA Department of Education and the WA Department of Health.

## 2005 data

This report summarises data for people who were diagnosed in WA during the 2005 calendar year. While finalising the data for this report, a small number of cases diagnosed prior to 2005 who were not previously accounted for in earlier reports, filtered through the pathways of collection. Numbers have been adjusted accordingly. Brief comparisons between the 2005 year of data collection and the total seven years of collection are made throughout this report using the adjusted figures.

## 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 2005 to fill in the information for each case and forward it to the Register:

*Aasta Abbott, Jessica Adderley, Zia Ardeshir, Jo Bristow, Wendy Britten, Ritu Campbell, Lynda Chadwick, Bronwynn Comerford, Hugh Cook, Riva Curtis, Teresa Davidson, Sabrina de Beer, Malini De Silva, Robyn Della Franca, Annkathrin Franzmann, Sandy Jackson, Michelle James, Jane Klinken, Helen Knott, Jane Lesslie, Debbie Lobb, Alana Maley-Berg, Sue Midford, Ashanthi Munasinghe, Ti-Wan Ng, Amber Price, Anoushka Rassau, Lynne Scrimgeour, Lelle Taffyn, Jura Tender, Amanda Wilkins, Fawzia Wilson, Natasha Woodhouse, John Wray.*

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

Williams K, MacDermott S, Ridley G, Glasson EJ & Wray JA (2008). The Prevalence of Autism in Australia. Can it be established from existing data? *Journal of Paediatrics and Child Health*, 44, 504-510.

Glasson EJ, MacDermott S, Dixon G, Cook H, Chauvel P, Maley-Berg A and Wray J (2008). Management of assessments and diagnoses for children with autism spectrum disorders: The Western Australian model. *Medical Journal of Australia*, 188, 288-291.

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.

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

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

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### Registrar:

Dr Emma Glasson

### Project Officer:

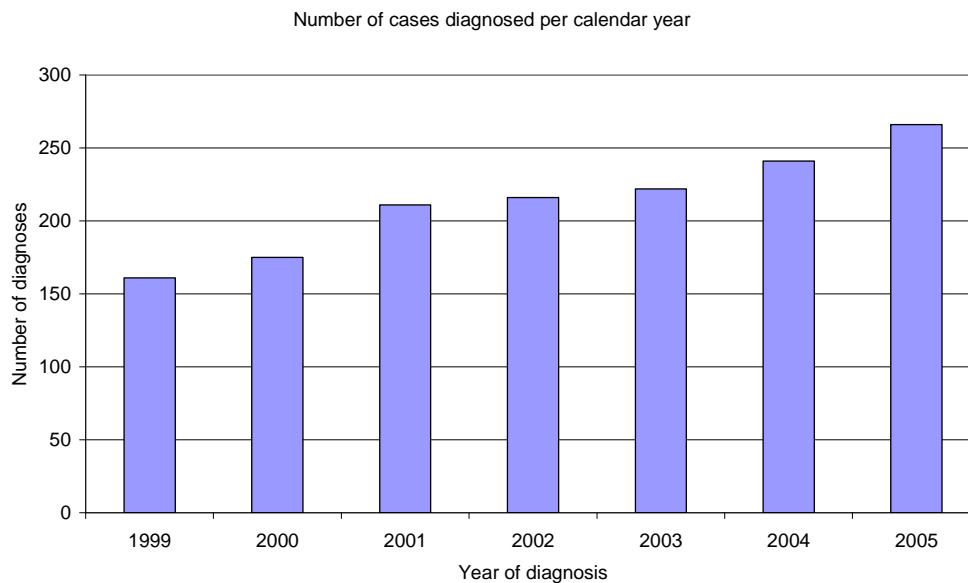
Ms Sarah MacDermott

### Advisory Committee:

Dr John Wray (Spokesperson)  
Ms Helen Bolton  
Dr Peter Chauvel  
Mr Derek Cohen  
Dr Hugh Cook  
Mrs Jane Klinken  
Mrs Bobbi McMullin  
Ms Jura Tender

## STATISTICS

During the period January 1<sup>st</sup> 2005 to December 31<sup>st</sup> 2005, **266** people were diagnosed with an autism spectrum disorder in WA. The (revised) totals for the 1999-2004 years were 161, 175, 211, 216, 222 and 241 cases respectively.

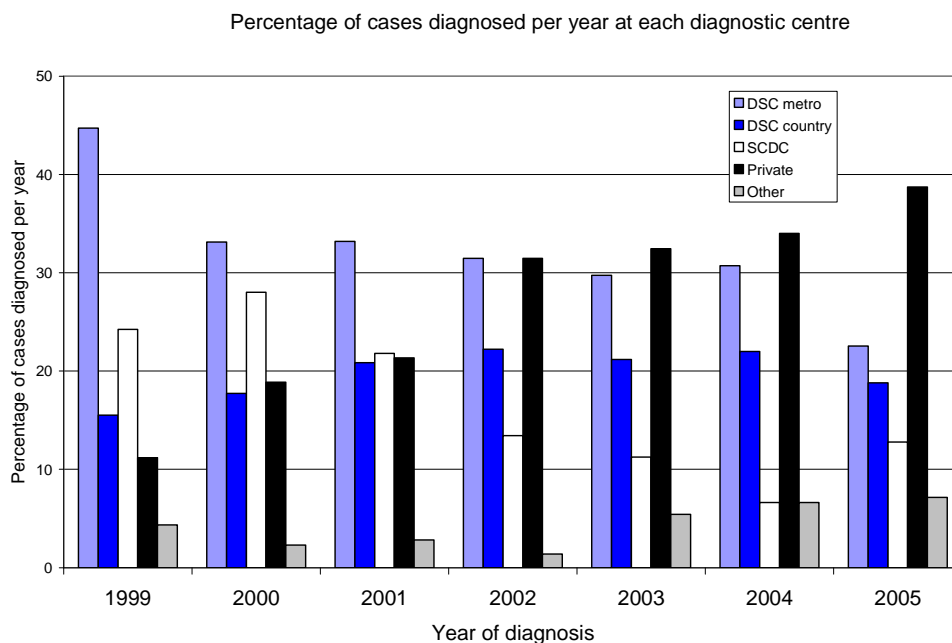


### Diagnosis

In 2005, 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 2005, 76% of cases were diagnosed with autism, 19% with PDD-NOS, and 5% with Asperger syndrome.

### Place of diagnosis

In 2005, the metropolitan division of the Disability Services Commission (DSC) made 23% of the diagnoses, the DSC country division 19%, State Child Development Centre (SCDC) 13%, private practitioners 39% and other centres 7%. Since January 1999, 31% of people have been diagnosed at the metropolitan division of DSC, 20% at the DSC country division, 16% at SCDC, 28% in private practice, and 4% in other centres.



## Comorbid conditions

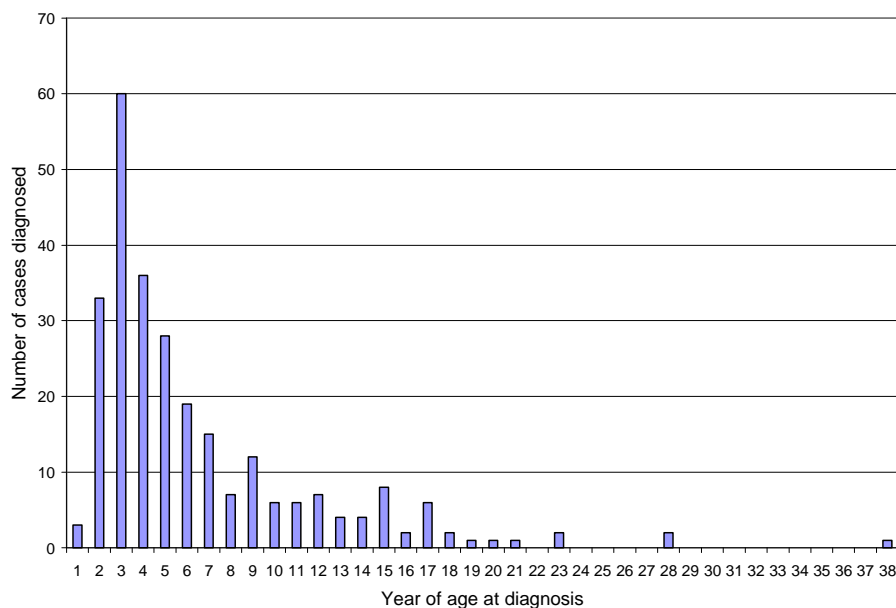
In 2005, 102 people (38%) were reported to have at least one comorbid medical condition, and 92 (35%) were reported as not having any other condition. The remaining 72 people (27%) did not have this item completed. Of the 102 people with a reported comorbidity, several presented with more than one condition. Thirty cases had Attention Deficit (Hyperactivity) Disorder, five had epilepsy, and two had a known chromosomal disorder. Since 1999, 49% of cases with a response on the data collection form (n=1187) were reported to have a comorbid condition.

Commonly reported comorbid conditions	number of people diagnosed in 2005 with condition	% of 2005 cases with a comorbidity response (n=194)	% of 1999-2005 cases with a response (n=1187)
ADHD/ADD	30	15%	18%
Epilepsy	5	3%	7%
Cerebral palsy	2	1%	1%
Tuberous sclerosis	0	0%	<1%
Chromosomal	2	1%	2%

## Age at diagnosis

In 2005 the age at diagnosis ranged from less than two years of age to 38 years with a median age of 4 years. Approximately 50% of cases were diagnosed by 4 years of age, 75% by 8 years, and 90% by 14 years of age. Of the 26 people who were aged 15 years or older at the time of assessment, 22 were given a diagnosis of autism, two were diagnosed with Asperger syndrome and two with PDD-NOS. Overall, between 1999 and 2005, the median age at diagnosis was 4 years of age (range 15 months to 50 years).

Number of cases diagnosed per year of age at diagnosis, 2005



## Gender

As expected, more males than females were diagnosed during 2005 (222 males, 40 females, four cases with missing information), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:5.6. Overall, the female to male ratio for the cases diagnosed since 1999 is 1:4.7 (259 females, 1226 males, seven unspecified).

## Ethnicity

Information on ethnicity was recorded for 253 (95%) of the 2005 cases. Four persons diagnosed during 2005 were known to be of Indigenous Australian heritage. Since 1999, 16 cases on the Register have been recorded as being of Indigenous Australian heritage (1.4% of cases where ethnicity is known).

## Country of birth

Details of country of birth were available for 253 people (95%) diagnosed in 2005. Of these, 93% were born in Australia. Ten people were born in South-East Asia, four in the British Isles, one in New Zealand, one in The Netherlands, and one in the USA. Since 1999, 6% of people who had information known about their country of birth were born outside of Australia.

## Cognitive abilities

During 2005, 112 (42%) of the 266 cases had a level of intellectual ability represented by a test score or completion of both the verbal and performance components of a standardised test. In the absence of a formal test score, clinicians gave an estimate of intellectual ability for a further 46 cases (17%). No information on cognitive ability was available for the remaining 41% of cases, including those with only some subtests completed, those assessed by developmental tests only, and those for whom assessments were attempted but not completed. Incomplete results were often received for younger children or those with limited compliance at the time of assessment. By convention in Western Australia, young children assessed for autism spectrum disorders who are non-compliant are considered to be at risk or vulnerable for having intellectual disability.

For at least 100 cases (38%) in 2005, intellectual disability was not present, as determined by either a full-scale test score above 70 points or an informal clinician estimate. Intellectual disability was confirmed in 25% of cases. A level of intellectual functioning was not available for the remaining 38% of cases. Since 1999, 38% of all diagnosed cases were reported not to have an intellectual disability, 22% were confirmed to have an intellectual disability and level of functioning was unknown for the remaining 40% of cases.

## Adaptive behaviour

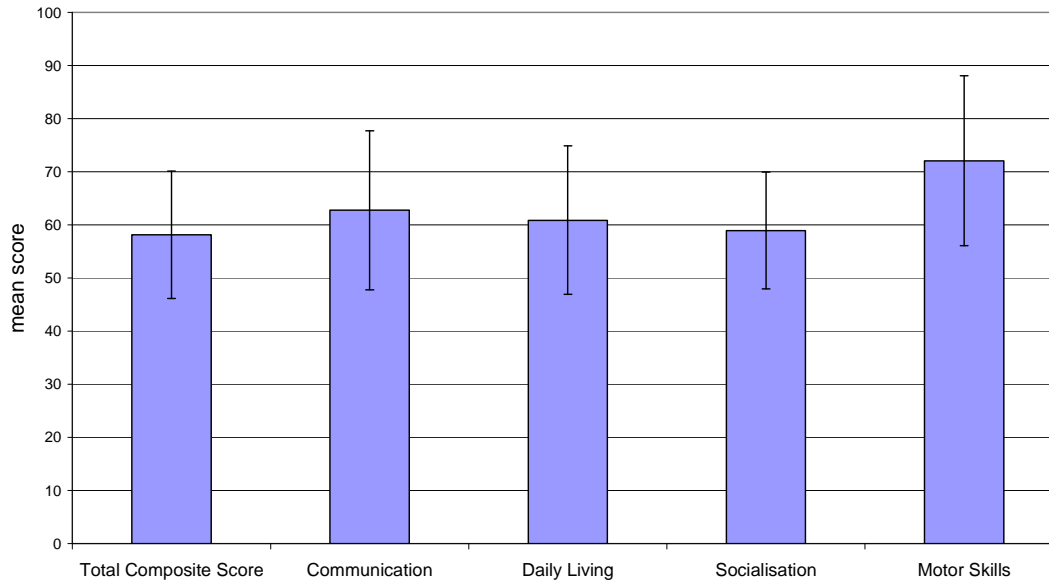
Adaptive behaviour is a person's ability to adapt to and manage their surroundings. An adaptive behaviour assessment measures areas of independence, physical skills, and interpersonal relationships; and makes a comparison to other persons of the same age. Since 1999, most children diagnosed with an autism spectrum disorder in WA have been assessed using 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 during 2005 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 since 1999:

Domain	Number of cases with a score	Mean score	Range of scores	Standard deviation
<i>Total Composite Score</i>	195	59	20-97	11
Communication domain	194	64	20-122	15
Daily Living domain	194	62	20-116	16
Socialisation domain	194	60	20-100	11
Motor Skills domain	132	74	44-104	13

Mean ABA domain scores for cases diagnosed 1999-2005



### Primary language at home

Twelve people (4%) diagnosed during 2005 were reported to have a language other than English at home. Over the 1999-2005 period, 5% of diagnosed cases spoke a language second to, or other than, English at home.

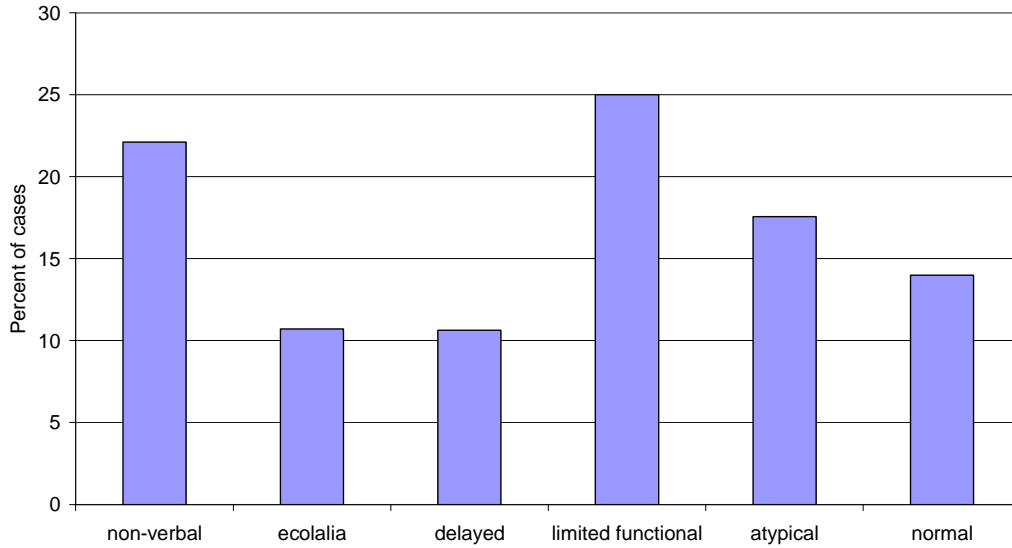
### Language skills

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>

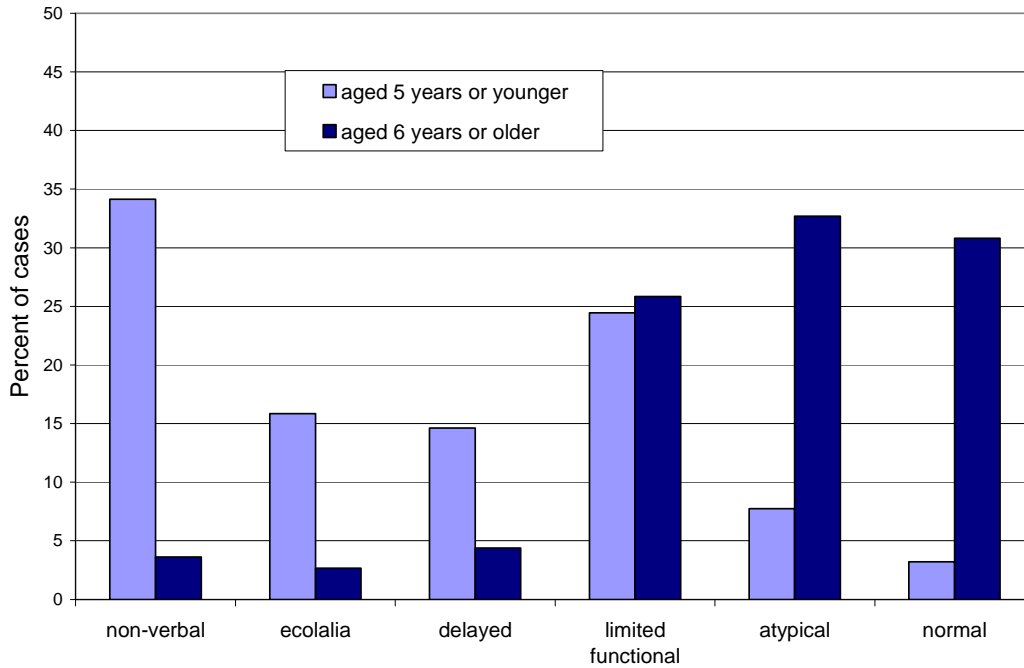
Of the people diagnosed in 2005 who had a language level recorded (221 cases), 21% were described as non-verbal, 8% as having echolalia or jargon, 10% as limited functional, 27% as having delayed language, 20% with atypical language, and 14% were developing age-appropriate language at the time of diagnosis.

Language ability for cases diagnosed 1999-2005



The level of language skills typically varied with age at diagnosis. Children aged 5 years or younger at the time of diagnosis are more likely to be described as non-verbal or having delayed skills, and people aged 6 years and older at the time of diagnosis are 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 1999-2005



## 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.
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 and approved by the Advisory Committee. The Committee will consider each request on its merits and provide direction regarding any additional information that may be required. Final written approval is given by the Spokesperson of the Advisory Committee.
8. 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.
9. Any costs incurred in fulfilling these guidelines are to be borne by the requesting body.
10. Final reports or papers for publication are to be vetted by the Advisory Committee before publication.

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