

**WA REGISTER
FOR
AUTISM SPECTRUM DISORDERS**

2004 Report

FOREWORD

The collation of the 2004 Report of the WA Register for Autism Spectrum Disorders represents six years of continuous comprehensive data collection. In this report, the 2004 data are compared to data from the preceding five 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 (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 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. 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 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.

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.

2004 data

This report summarises the data for people who were diagnosed in Western Australia during the 2004 calendar year. While finalising the data for this report, a small number of cases diagnosed prior to 2004 who were not previously accounted for in earlier reports, filtered through the pathways of collection. Numbers have been adjusted accordingly. Brief comparisons between the 2004 year of data collection and the total six 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 2004 to fill in the information for each case and forward it to the Register:

Aasta Abbott, Simone Benson, Carla Bormolini, Linda Bradley, Wendy Britten, Ritu Campbell, Debbie Lobb, Bronwynn Comerford, Sabrina de Beer, Justine Doust, Annkathrin Franzmann, Sandy Jackson, Michelle James, Jodie Junk-Gibson, Jane Klinken, Jane Lesslie, Alana Maley, Wendy Marshall, Sharyn Mascall, Karen Mason, Sue Midford, Ti-Wan Ng, Mary Oates, Kathryn Oostroyck, Pauline Pannell, Anoushka Rassau, Lynne Scrimgeour, Mia Sutton, Lelle Taffyn, Jura Tender, Tony Vlachou, Trish Webb, Amanda Wilkins, Fawzia Wilson, Natasha Woodhouse, John Wray.

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

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

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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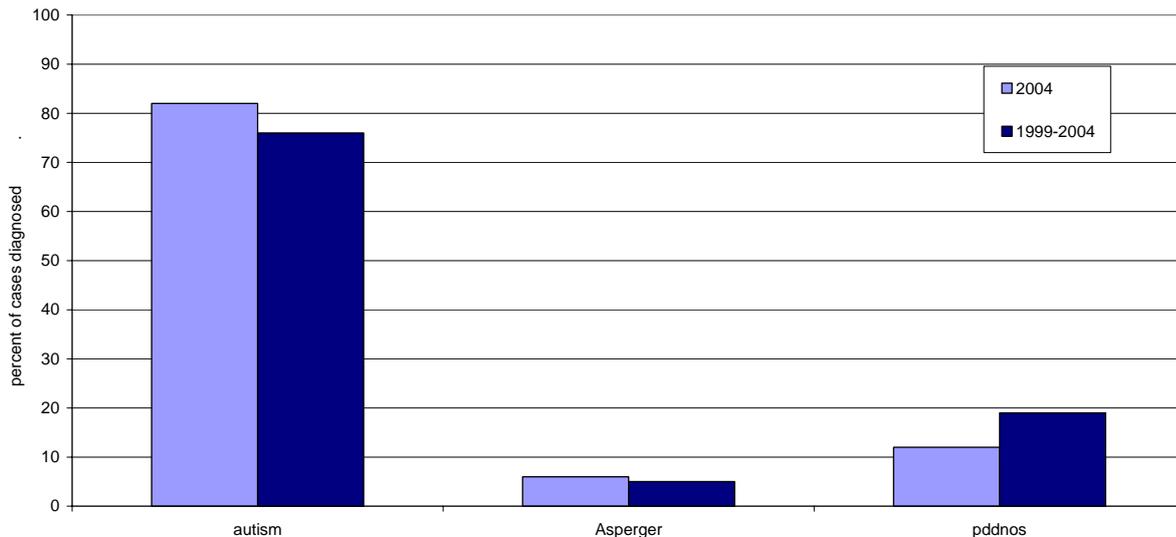
STATISTICS

During the period January 1st 2004 to December 31st 2004, **237** people were diagnosed with an autism spectrum disorder in WA. The (revised) totals for the 1999-2003 years were 160, 174, 212, 216 and 224 cases respectively.

Diagnosis

In 2004, autism accounted for 82% of the diagnoses, PDD-NOS for 12%, and Asperger syndrome 6%. No cases of Childhood Disintegrative Disorder were reported. Overall, between 1999 and 2004, 76% of cases were diagnosed with autism, 19% with PDD-NOS, and 5% with Asperger syndrome.

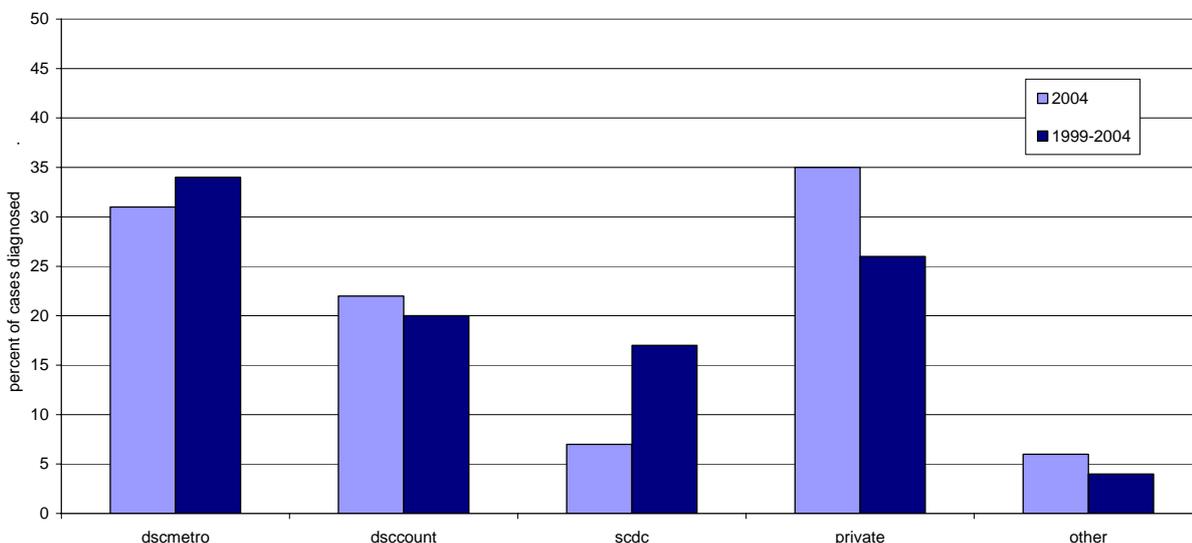
Percent of cases diagnosed with each autism spectrum disorder, by calendar period



Place of diagnosis

In 2004, the metropolitan division of the Disability Services Commission (DSC) made 31% of the diagnoses, the DSC country division 22%, State Child Development Centre (SCDC) 7%, private practitioners 35% and other centres 6%. Since January 1999, 34% of people have been diagnosed at the metropolitan division of DSC, 20% at the DSC country division, 17% at SCDC, 26% in private practice, and 4% in other centres.

Percent of cases diagnosed at each centre, by calendar period



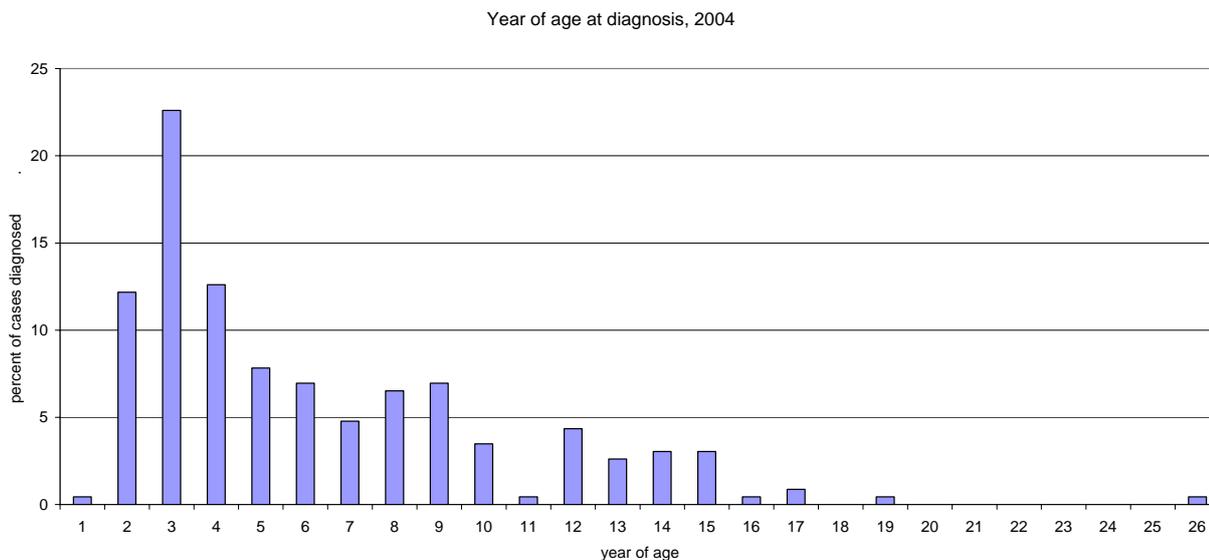
Comorbid conditions

In 2004, 105 people (44%) were reported to have at least one comorbid medical condition, and 96 (41%) were reported as not having any other condition. The remaining 36 people (15%) did not have this item completed. It is likely that these 36 individuals did not present with another condition since the clinician did not report a positive finding. Of the 105 people with a reported comorbidity, several presented with more than one condition. Forty-two cases had Attention Deficit (Hyperactivity) Disorder, 12 had epilepsy, and four had a known chromosomal disorder. Since 1999, 48% of cases with a response on the data collection form (n=973) were reported to have a comorbid condition.

Comorbid condition	number of people diagnosed in 2004 with condition	% of 2004 cases with a comorbidity with a response (n=201)	% of 1999-2004 cases with a response (n=973)
ADHD/ADD	42	21%	18%
Epilepsy	12	6%	8%
Cerebral palsy	0	0%	1%
Tuberous sclerosis	0	0%	<1%
Chromosomal	4	2%	3%

Age at diagnosis

In 2004 the age at diagnosis ranged from 21 months to 26 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 19 people who were aged 14 years or over at the time of assessment, all were given a diagnosis of autism. Overall, between 1999 and 2004, 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 2004 (195 males, 41 females, one case unspecified), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:4.8. Overall, the female to male ratio for the cases diagnosed since 1999 is 1:4.6 (219 females, 1001 males, three unspecified).

Ethnicity

Information on ethnicity was stated for 211 (89%) of the 2004 cases. Two persons diagnosed during 2004 were known to be of Indigenous Australian heritage. Since 1999, 12 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 224 (94%) people diagnosed in 2004. Of these, 91% were born in Australia. Three people were born in South-East Asia, two were born in the British Isles, two in New Zealand, one in South Africa and one in the USA. Since 1999, 5% of people who had information known about their country of birth were born outside of Australia.

Cognitive abilities

During 2004, 103 (44%) of the 237 cases diagnosed had a 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 another two cases, only a verbal or a performance score was obtained and for 10 further cases only some subtest scores were available. For 64 cases (27%), 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 9 cases (4%), and no information on either intellectual or developmental ability was available for 49 cases (21%). Where limited results were obtained it was often with the younger children or those with limited compliance for completing formal assessments. 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 89 cases (38%) in 2004, intellectual disability was not present, as determined by either a full-scale test score above 70 points or an informal clinician estimate. Since 1999, 52% of the 1223 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 36% of all diagnosed cases do not have intellectual disability.

Adaptive behaviour

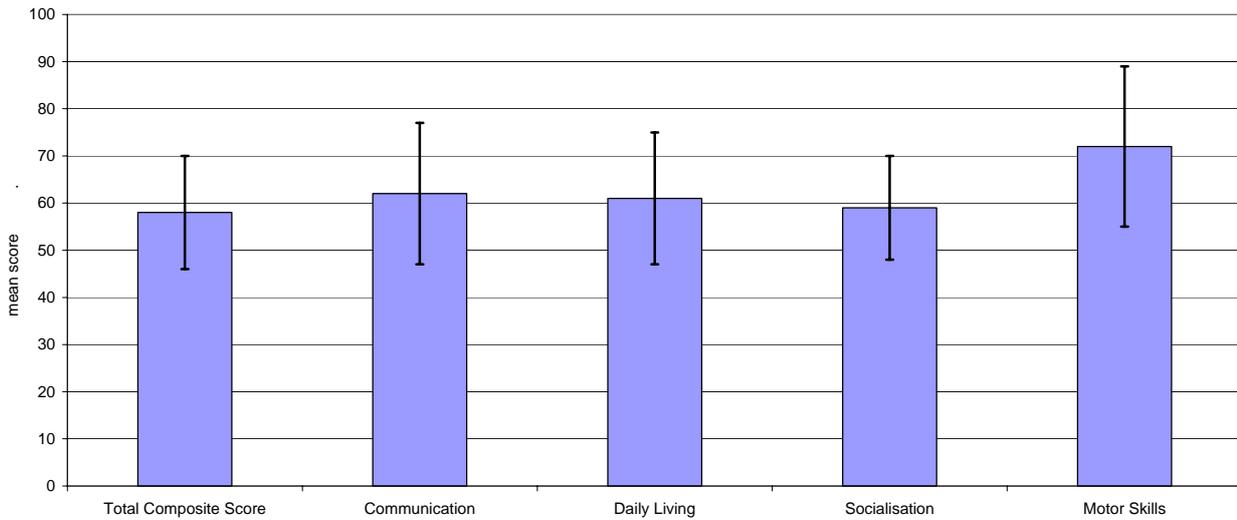
Adaptive behaviour is a person's ability to adapt to and manage their surroundings. An adaptive behaviour assessment measures areas of independence, physical skills, and interpersonal relationships; and makes a comparison to other persons of the same age. Since 1999, most children diagnosed with an autism 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 2004 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
Total Composite Score	168	58	24-118	12
Communication domain	172	63	30-129	16
Daily Living domain	172	59	19-109	15
Socialisation domain	171	59	18-102	12
Motor Skills domain	109	72	33-110	16

Mean ABA domain scores for cases diagnosed 1999-2004



Primary language at home

Six people (2.5%) diagnosed during 2004 were reported to have a language other than English at home. Over the 1999-2004 period, 6% of people spoke a language second to, or other than, English at home.

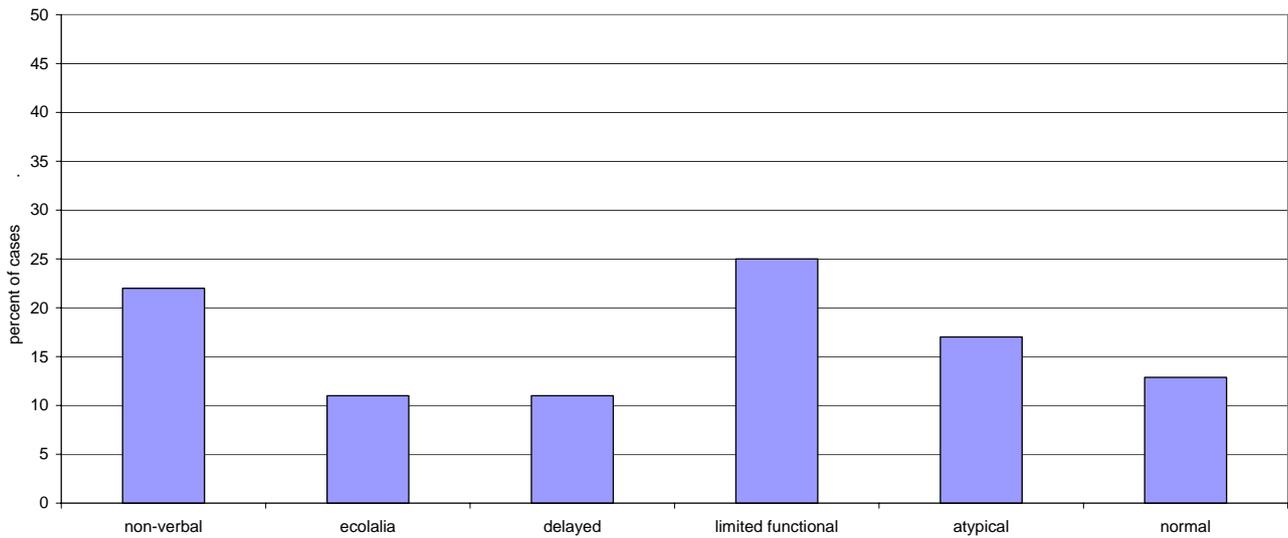
Language skills

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

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

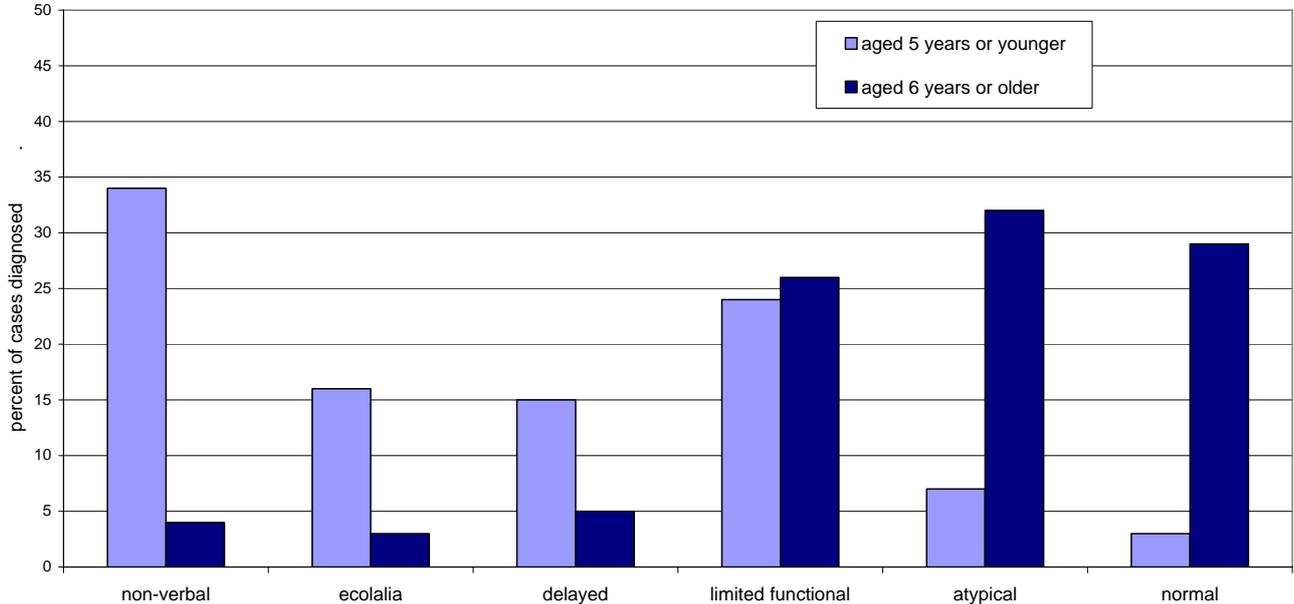
Of the people diagnosed in 2004 who had a language level recorded (202 cases), 15% were described as non-verbal, 11% as having echolalia or jargon, 11% as limited functional, 33% as having delayed language, 16% with atypical language, and 13% were developing age-appropriate language at the time of diagnosis.

Language ability for cases diagnosed 1999-2004



The level of language skills typically varies 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 1999-2004



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 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. 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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