

**WA REGISTER
FOR
AUTISM SPECTRUM DISORDERS**

2001 Report

Published September 2002

FOREWORD

On behalf of the Advisory Committee, I am pleased to present the 2001 report of the WA Register for Autism Spectrum Disorders. We now have three years of continuous data collection and important conclusions about the prevalence of autistic disorders may be inferred. Happily, the Register has mechanisms in place that ensures a very high percentage of newly diagnosed cases are referred to the Register.

The Advisory Committee will be making important decisions about funding sources for the continuation of the Register. Most importantly, the Register is still thriving through the efforts of clinicians and families and a dedicated Registrar in a bid to improve our understanding of the autism spectrum disorders.

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 very 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
- 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 1 parent representative, 2 psychologists and 1 speech pathologist in private practice, 3 representatives from the major autism diagnosing centres (Disability Services Commission, the State Child Development Centre, and Princess Margaret Hospital), and 1 representative from the Autism Association of WA. Each member was nominated by the institution they represent. The Advisory Committee meets on a regular basis. Various issues are discussed and 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 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.

2001 data

This report summarises the data for people who were diagnosed in WA during the 2001 calendar period. Whilst finalising the data for the 2001 report, a small number of 1999 and 2000 cases not previously accounted for filtered through the pathways of collection. Brief comparisons between the 2001 year of data collection and the complete three 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.

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 2001 to fill in the information for each case and forward it to the Register:

Aasta Abbott, Linda Bradley, Carrie Buckland, Ritu Campbell, Martin Exell, Sandy Jackson, Jane Klinken, Jane Leslie, Karen Mason, Mary Oates, Carolyn Price, Lelle Taffyn, Jura Tender, Helen Wolfenden, John Wray.

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

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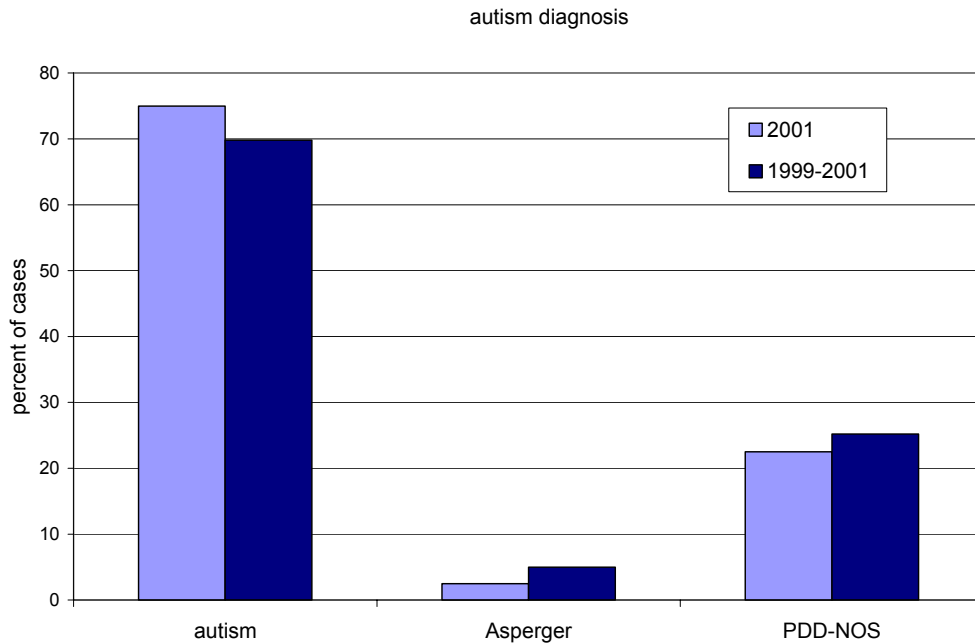
Dr Emma Glasson
Advisory Committee:
Dr John Wray (Spokesperson)
Dr Peter Chauvel
Mr Derek Cohen
Dr Hugh Cook
Mrs Bobbi McMullin
Mrs Kate Smith
Ms Jura Tender
Mrs Helen Wolfenden

STATISTICS

During the period January 1st 2001 to December 31st 2001, 204 people were diagnosed with an autism spectrum disorder in WA. This exceeded the 1999 and 2000 (revised) totals of 159 and 173 cases respectively.

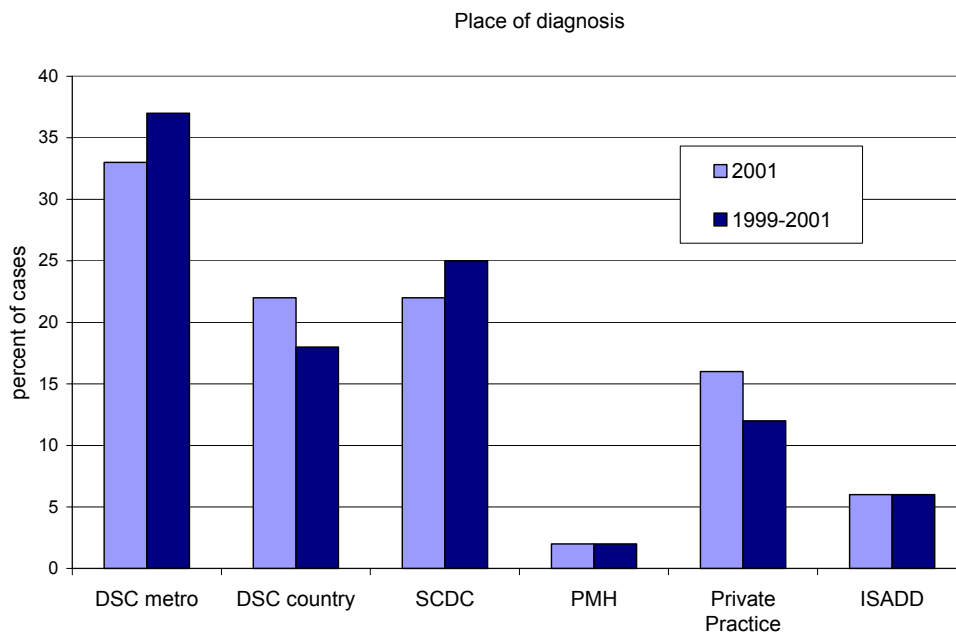
Diagnosis

In 2001, autism accounted for 75% of the diagnoses, PDD-NOS for 22.5% and Asperger syndrome 2.5%. No cases of Childhood Disintegrative Disorder were reported. Overall, between 1999 and 2001, 70% of cases were diagnosed with autism, 25% with PDD-NOS, and 5% with Asperger syndrome.



Place of diagnosis

In 2001, the metropolitan division of the Disability Services Commission (DSC) made 33% of the diagnoses, the DSC country division 22%, State Child Development Centre (SCDC) 22%, Princess Margaret Hospital (PMH) 2%, Intervention Services for Autism and Developmental Disorders (ISADD) 6%, and private practitioners 16%. Since January 1999, 37% of people have been diagnosed at the metropolitan division of DSC, 18% at the DSC country division, 25% at SCDC, 2% at PMH, 6% at ISADD, and 12% in private practice.



Comorbid conditions

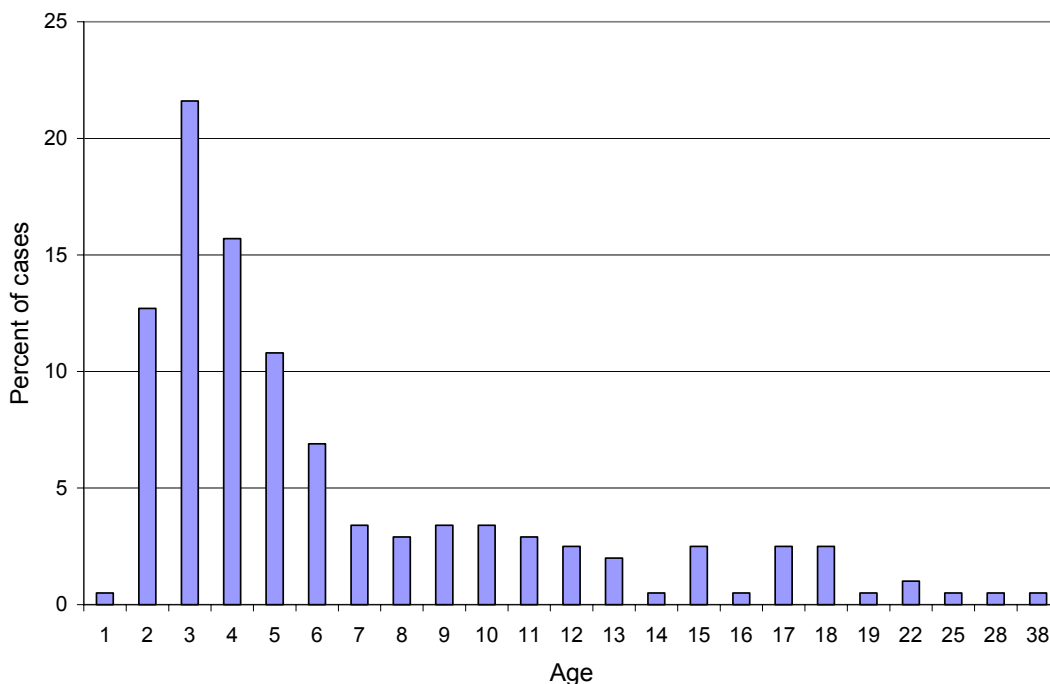
In 2001, 77 people (38%) were reported to have at least one comorbid condition, and 94 (46%) were reported as not having any other condition. The remaining 33 people did not have this item completed but it is likely that many of these did not present with another condition if the clinician did not report a positive finding. Of the 77 people with a reported comorbid condition, 27 had Attention Deficit (Hyperactivity) Disorder, 36 had intellectual disability, 16 had epilepsy, 2 had cerebral palsy, 1 had a known chromosomal disorder, and 23 had another less common condition. The numbers of people reported to have intellectual disability may be underestimated, and partly reflects the large percentage of people for whom a level could not be ascertained (17%).

Comorbid condition	number of people diagnosed in 2001 with condition	% of 2001 cases with a comorbidity response (n=171)	% of 1999, 2000, and 2001 cases with a response (n=394)
ADHD/ADD	27	16%	17%
Intellectual disability	36	21%	24%
Epilepsy	16	9%	10%
Cerebral palsy	2	1%	3%
Chromosomal	1	1%	2%
Other	23	13%	13%

Age at diagnosis

In 2001 the age at diagnosis ranged from 23 months to 38 years with a median age of 4 years of age. Approximately 50% of cases were diagnosed by 4 years of age, 75% by 9 years, and 90% by 15 years of age. Of the 27 people who were aged 13 years or over at the time of diagnosis, 16 (59%) were given a diagnosis of autism, 7 were diagnosed with PDD-NOS, and 4 people were diagnosed with Asperger syndrome. Overall, between 1999 and 2001, the median age at diagnosis was 4 years of age (range 15 months to 43 years).

Year of age at diagnosis



Gender

As expected, many more males were diagnosed than females during 2001 (162 males, 42 females), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:3.9. Overall, the female to male ratio for the cases diagnosed since 1999 is 1:4.2 (104 females, 432 males).

Ethnicity

Information on ethnicity was stated for 117 (57%) of the 2001 cases. Of these, 76% described both parents of Caucasian descent. For the 24% of cases with at least one parent of non-Caucasian heritage, most were from neighbouring Asian countries. Four people of Indigenous Australian heritage were diagnosed during 2001. Since 1999, 17% of cases with information about ethnicity have had at least one parent of non-Caucasian heritage.

Country of birth

Details of country of birth were available for 184 people diagnosed in 2001. Of these, 92% were born in Australia. Eight people (4%) were born in the United Kingdom, five (3%) were born in Asia, and two (1%) were born in other regions. Since 1999, 8% of people who had information about their country of birth were born outside of Australia.

Cognitive abilities

Clinicians reported that for 17% of cases diagnosed during 2001, non-compliance meant that a level of IQ could not be determined, and many other cases had incomplete assessments. For the 118 people for whom either a verbal IQ, performance IQ, or a full scale IQ could be estimated, 56 (45%) had at least one score within the range of intellectual disability.

For the cases diagnosed during 2001, a verbal IQ score was available for 61 cases (30%), ranging between 46 and 155 (median score 87). A performance IQ score was available for 64 cases (31%), ranging between 48 and 155 (median score 90). A full-scale IQ score was calculated for 67 cases (33%), ranging between 42 and 160 (median score 84). Performance scores were higher than verbal scores by an average of 7 points.

Since 1999, 57% of cases had an estimate of cognitive function as measured by either a verbal, performance, or full scale assessment score.

Primary language at home

Fifteen people (8%) diagnosed during 2001 were reported to have a language other than English at home. Over the 1999-2001 period, 8% of people spoke a language second to, or other than, English at home.

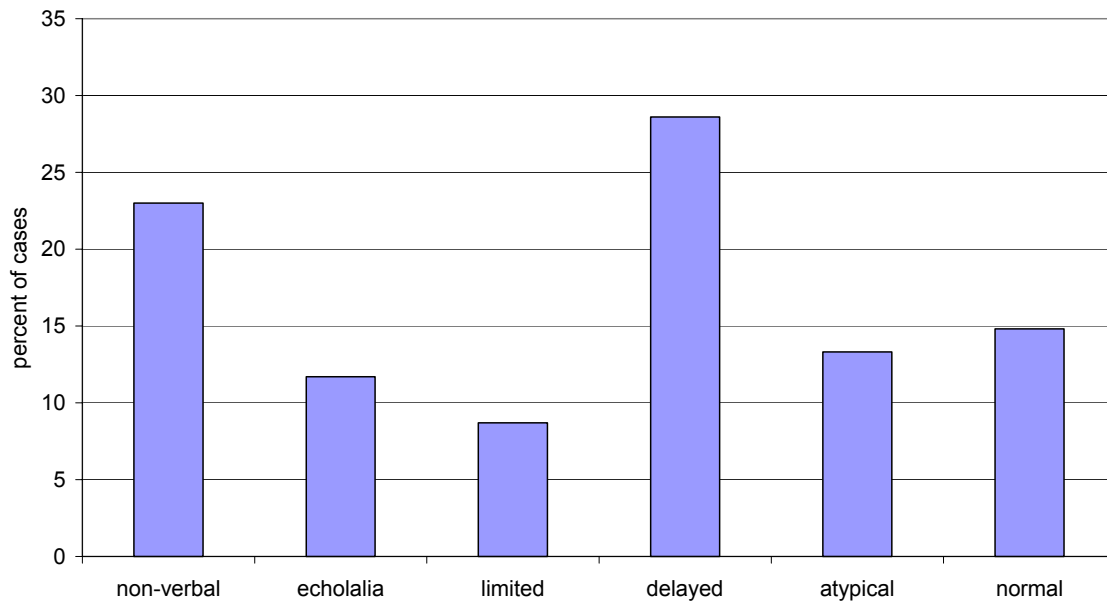
Language skills

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

1	Non verbal	<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

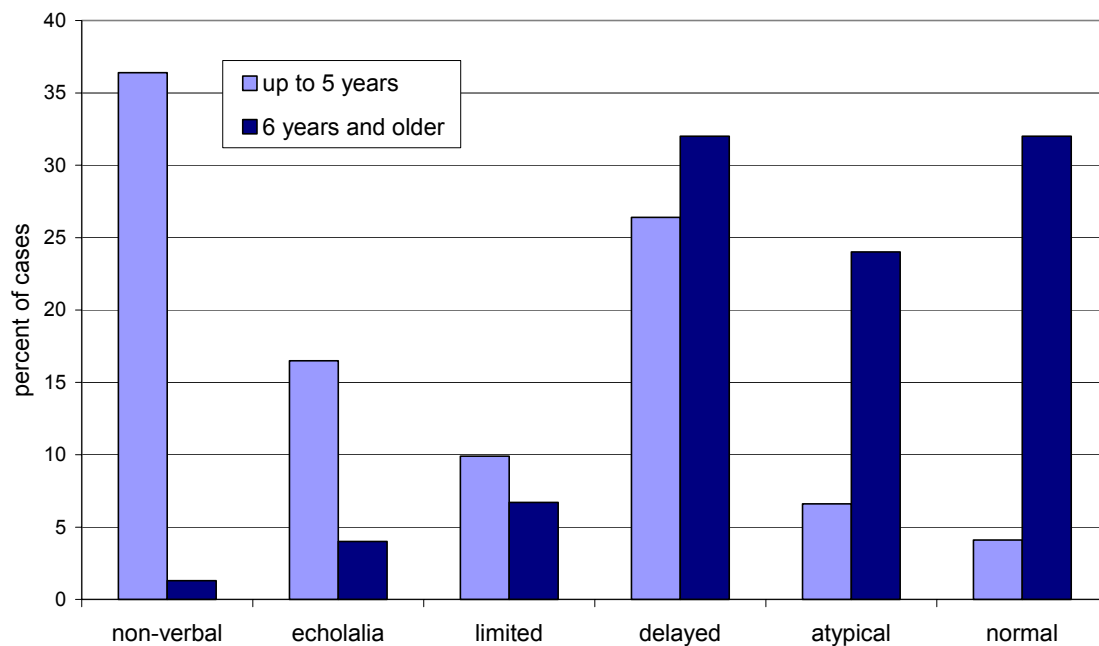
Of the people diagnosed in 2001 who had a language level recorded, 23% were described as non-verbal, 12% as having echolalia or jargon, 9% as limited functional, 29% as having delayed language, 13% with atypical language, and 15% with normally-developing language at the time of diagnosis.

language levels for people diagnosed in 2001



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, and people aged 6 and over were more likely to be described as having language present but with peculiar characteristics.

language level by age group for cases diagnosed in 2001



Adaptive behaviour

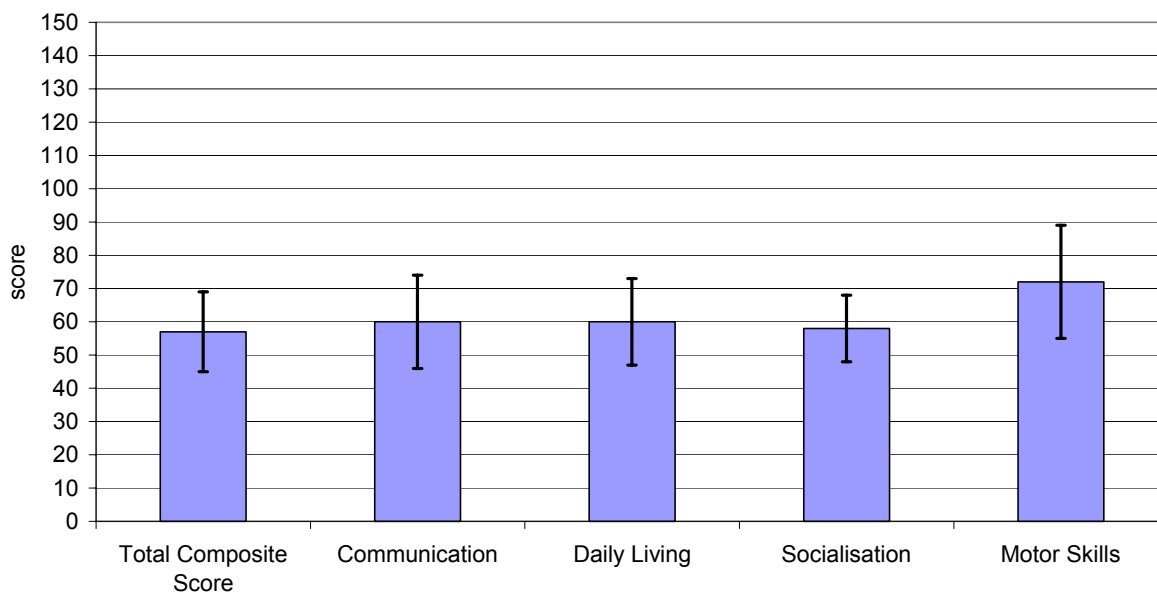
Adaptive behaviour is a person's ability to adapt to and manage their surroundings. An adaptive behaviour assessment measures areas of independence, physical skills, and interpersonal relationships; and makes a comparison to other persons of the same age. For most people diagnosed with autism since 1999, adaptive behaviour was 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 mean the person is functioning below what is expected for that person's age, and a score of less than 70 means that difference is 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 2001:

Domain	Number of cases with a score	Mean score	Range of scores	Standard deviation
Total Composite Score	343	57	20-119	12
Communication domain	342	61	20-130	14
Daily Living domain	342	61	19-106	14
Socialisation domain	341	58	20-99	11
Motor Skills domain	278	72	20-152	18

Mean adaptive behaviour score for each Vineland domain
- cases diagnosed in 2001 (n = 133)



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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