

**WA REGISTER
FOR
AUTISM SPECTRUM DISORDERS**

2014 Report

FOREWORD

This 2014 Report of the WA Register for Autism Spectrum Disorders represents 16 years of continuous data collection. In this report, the 2014 data are compared to data from the preceding 15 years. Over the 16 years of operation, and particularly in the last five years, the Register has witnessed many changes in the diagnostic environment in which autism is diagnosed. In 2013, the DSM-5 criteria were introduced, which changed not only the criteria that define autism, but also condensed all previous autism spectrum conditions under one diagnosis, “Autism Spectrum Disorder”. The cases notified to the Register during 2014 contained a mix of both DSM-IV and DSM-5 diagnoses. Another change in diagnostic patterns has been the continual increase in the number of diagnoses occurring in the private practice sector. This has resulted in difficulties for the Register to ascertain complete numbers of diagnoses due to the nature of obtaining information in a voluntary way from so many different and new teams of clinicians in the field. This is reflected in the decrease in annual numbers of cases obtained by the Register in recent years. Despite this, we are proud to be the most successful prospective autism register in Australia by collecting data on a large number of cases over a long period of time. We thank the many clinicians and supporters of the Register who have enabled us to achieve this. The Register is also grateful to the government departments that have given financial support. The data continue to be accessed regularly by various organisations, government, researchers and individuals and have made a positive impact towards understanding autism better.

Dr John Wray

Spokesperson for the Advisory Committee.

INTRODUCTION

Background

Autism spectrum disorders include all autism-related conditions described in the DSM-IV (American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders IV-TR*. Washington DC: American Psychiatric Association) as Pervasive Developmental Disorders - Autism, Asperger syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder not otherwise specified (PDD-NOS). Under the DSM-IV definition, autism spectrum disorders are characterised clinically by significant impairment in three areas of development: a) social interaction; b) communication; and c) range of interests.

Since this Register began, the definition of autism spectrum disorders in Western Australia has been made using DSM-IV criteria. However, in May 2013, a revised version of the DSM was published (DSM-5), under which the previous autism categories became a single diagnostic category – Autism Spectrum Disorder. Under DSM-5, Autism Spectrum Disorder is characterised by difficulties in two domains: a) impairments in social communication and interaction and b) restricted, repetitive patterns of behaviour, interests and activities. The Register received its first notification of a DSM-5 diagnosed case in November 2013, with the diagnosis being made in October 2013. However, about one third of all cases reported in 2014 were diagnosed according to DSM-IV criteria.

Purpose and aims

The WA Autism Register serves as a primary resource to researchers, clinicians and service providers. It 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 and group changes over time. It is prospective, collecting information on people diagnosed in WA since January 1999. The Register has two main applications; 1) research (epidemiology, biology, psychology and longitudinal studies), and 2) planning for services (health, education and disability).

Information collected

The Register collects simple demographic and diagnostic information, including;

- Date of birth, gender, ethnicity, place of birth, 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 that consists of membership from major diagnostic institutions and service providers for people with autism spectrum disorders in WA. The Advisory Committee meets quarterly to discuss methodology, political concerns, ethical and diagnostic issues around data collection.

Confidentiality

The Register is bound by a confidentiality protocol (see Appendix). Information is stored securely at the Telethon Kids Institute. 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 and to recognise changes in diagnoses within the same person over time.

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.

2014 data

This report summarises data for people who were diagnosed in WA during the 2014 calendar year. Each year, a small number of cases who were not previously accounted for in earlier reports filter through the pathways of collection. Numbers of cases diagnosed 1999-2013 have been adjusted accordingly in this report. Brief comparisons between the 2014 year of data collection and the previous 15 years of collection are made.

ACKNOWLEDGEMENTS

The notifiers

The success of the Register is dependent upon the ascertainment of new cases. We wish to thank the following people who forwarded registrations to the Register during the 2014 calendar year:

Sabine Afchani, Shannon Atkinson, Carole Caccetta, Ritu Campbell, Lynda Chadwick, Teresa Davidson, Sabrina de Beer, Nicola Fenelon, Sapna Jessy, Brad Jongeling, Jane Klinken, Francine Kyte, Wendy Marshall, Nikki Panotidis, Kate Smith, Tania Dawson, Sinead Brunning, Ashanthi Munasinghe, Bria Hosking, Julie-Ann Evans, Carolyn Lynch, Barbara Kennedy, Amanda di Russo, Geraldine Goh, Jennifer Hogan, Kellie Cassidy, Larni Mullan, Poh Gan, Riva Curtis, Sharyn Mascall

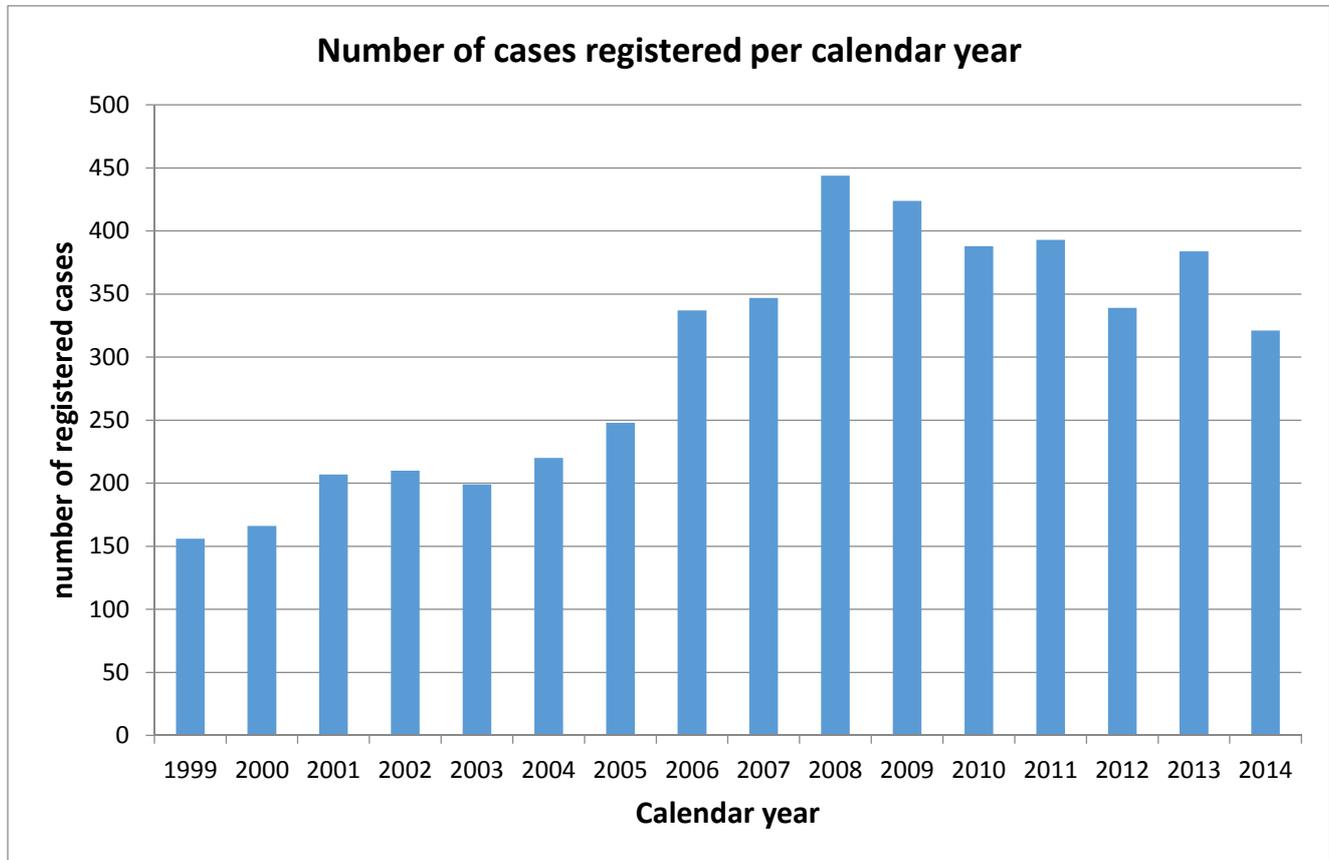
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STATISTICS

During the period January 1st 2014 to December 31st 2014, the Register was notified of **319** people who had been diagnosed with an autism spectrum disorder in WA. Since 1999 the Register has been notified of a total of 4783 cases. The decrease in the number of people registered since 2008 is considered to be a reflection of decreased case notification rather than a decrease in the actual rates of diagnosis.



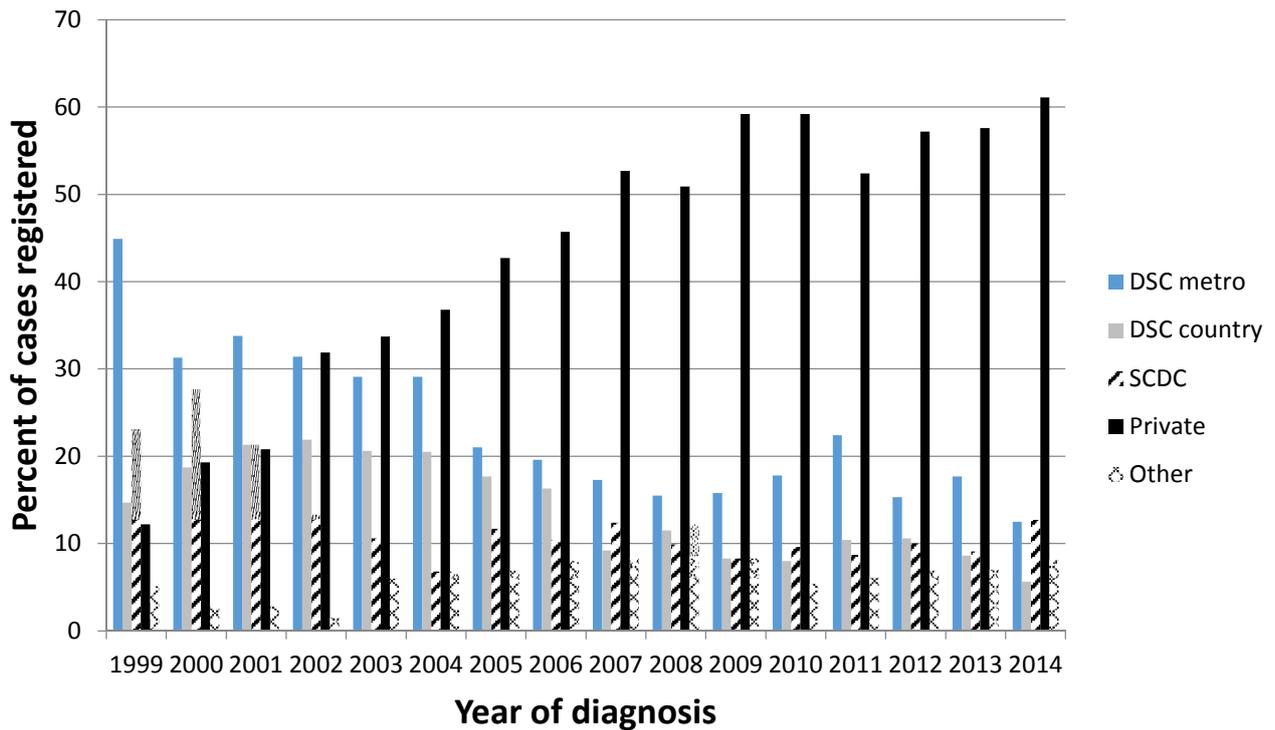
Diagnosis

In 2014, 70% of cases were diagnosed using DSM-5 criteria for Autism Spectrum Disorder and 30% of cases were diagnosed using DSM-IV criteria. Of the 95 cases diagnosed using DSM-IV criteria during 2014, Autism accounted for the majority of diagnoses with only one case of Asperger syndrome recorded. Overall, between 1999 and 2014, 5% of cases received an Autism Spectrum Disorder diagnosis using DSM-5 criteria, 76% of cases were diagnosed with Autism using DSM-IV criteria, 13% with PDD-NOS, and 5% with Asperger syndrome. The specific diagnosis was not recorded for 1% of cases.

Place of diagnosis

In 2014, 61% of the registered cases were diagnosed in private practice, 12% at the metropolitan division of the Disability Services Commission of WA (DSC), 6% from the DSC country division, 13% from the State Child Development Centre (SCDC), and 4% from other centres. The remaining 4% of cases did not report the place of diagnosis. Since January 1999, 48% of the notifications have been from private practices, 21% from the metropolitan division of DSC, 13% from the DSC country division, 12% from SCDC, and 4% from other centres. Place of diagnosis was not reported for 2% of cases.

Percent of cases per place of diagnosis, 1999-2014



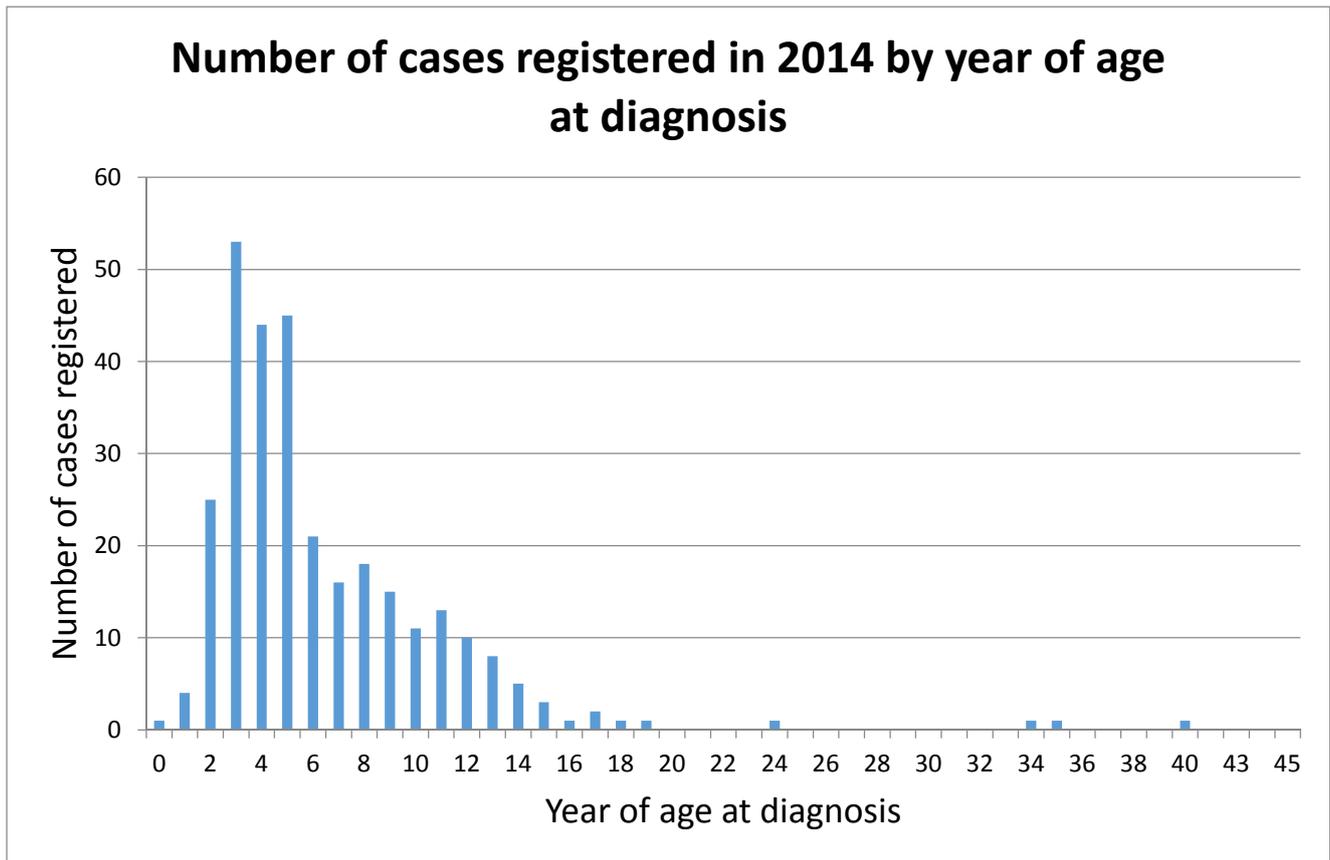
Comorbid conditions

In 2014, 56 people (17%) were reported to have at least one comorbid medical condition, and 186 (58%) were reported as not having any other condition. The remaining 79 people (25%) did not have this item completed. Of the 56 people with a reported comorbidity, 28 cases had Attention Deficit (Hyperactivity) Disorder, six had epilepsy and four had a known chromosomal disorder. Since 1999, 31% of cases with a response recorded for this section of the data collection form (n=3,458) were reported to have a comorbid condition.

Commonly reported comorbid conditions	number of people diagnosed in 2014 with condition	% of 2014 cases with a comorbidity response (n=242)	% of 1999-2014 cases with a response (n=3,458)
ADHD/ADD	28	12%	13%
Epilepsy	6	2%	4%
Cerebral palsy	0	0%	<1%
Tuberous sclerosis	0	0%	<1%
Chromosomal	4	2%	2%

Age at diagnosis

In 2014 the age at diagnosis ranged from less than two years of age to 40 years with a median age of 5 years (n=302 cases had age data available). Approximately 50% of cases were diagnosed by 5 years of age, 75% by 8 years, and 90% by 12 years of age. Overall, between 1999 and 2014 the median age at diagnosis was five years of age (range eight months to 57 years, for n=4,244 cases where age data were available).



Gender

As expected, more males than females were diagnosed during 2014 (231 males, 77 females, 13 cases with missing information), which is consistent with the gender bias in autism. This represents a female to male ratio of 1:3. Overall, the female to male ratio for cases registered since 1999 is 1:4.6 (3,534 males, 775 females, 474 unspecified).

Aboriginality

Four persons diagnosed during 2014 were recorded as being of Indigenous Australian heritage. Since 1999, 81 cases on the Register have been recorded as being of Indigenous Australian heritage.

Country of birth

Details of country of birth were available for 297 people (93%) diagnosed in 2014. Of these, 273 (92%) were born in Australia. Eight people were born in the United Kingdom, two in New Zealand, eight from various countries in Asia, and six people from elsewhere in the world. Since 1999, 11% of people who had information known about their country of birth were born outside of Australia.

Cognitive abilities

Information regarding cognitive functioning is collected in a number of different ways by the Register. Clinicians can report scores from formal tests, such as the Wechsler Intelligence Scale for Children (WISC) or the Griffith Mental Developmental Scales. Additionally, clinicians are asked to provide a clinical indication of whether the person has an intellectual disability (ID) at the time of diagnosis. In the following section, data regarding formal test scores are reported, followed by clinician indications of ID. As indicated below, there are few cases where a clear indication of intellectual functioning is provided, often a result of the young ages or non-compliance of children at the time of diagnosis. As such, the data reported below should be interpreted with caution as they are unlikely to be representative of all persons diagnosed.

Formal test scores:

In 2014, 86 of the 321 cases on the Register (27%) reported using at least one formal test during assessment. The most commonly used test was the Wechsler Preschool and Primary Scale of Intelligence (24 cases), followed by The Griffith Mental Developmental Scale (24 cases) and the WISC (17 cases). Other tests used included the Bayley Scales of Infant Development (18 cases), The Leiter International Performance Scale (6 cases), The Leiter R Brief IQ (2 cases) and the Wechsler Abbreviated Scale of Intelligence (1 case).

During 2014, 20 (7%) of the 307 cases had a level of intellectual ability reported from a full-scale 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 20 cases (7%). Results from cognitive assessments were not available for the remaining 86% 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.

Indication of intellectual disability:

The available data were collated to reflect four categories related to intellectual functioning: No Intellectual Disability; Confirmed Intellectual Disability; Vulnerable for Intellectual Disability; Insufficient Evidence to Determine Level of Intellectual Functioning. The criteria for each of these categories are described below. If a clinician assessment of the child's functioning was available, this was used as the primary indication of intellectual functioning. This may be indicated by written description of the child's functioning (e.g. average, superior etc.) or by selecting one of the available checkboxes on the data collection form (i.e. Previous testing indicated no ID; Testing not required as no indication of ID; Testing attempted but not successful; Person has a recognised ID; Person is vulnerable for ID). If a clinician assessment of functioning was not available then a full scale test score (or completed subscales) was used to determine the child's level of functioning.

No Intellectual Disability: defined as either (i) clinician indicated that there is no evidence of ID (ii) a full scale score 70 or above; (iii) subscale scores of 70 or above in the absence of a full scale score; (v) or an estimate of ability in the low range or above.

Confirmed Intellectual Disability: defined as either (i) clinician indicated child has recognised ID; (ii) a full scale score 69 or below; (iii) subscale scores of 69 or below in the absence of a full scale score; (iv) or an estimate in the extremely low range.

Vulnerable for Intellectual Disability: defined as either (i) clinician indicated child is vulnerable for ID (ii) or clinician indicated that testing was not successful. (By convention in Western Australia, young children assessed for autism spectrum disorders who are noncompliant are considered to be at risk or vulnerable for having intellectual disability.)

Insufficient Evidence to Determine Level of Functioning: defined as either (i) incomplete test scores (ii) no indication of ID provided (iii) or an unclear estimate of ability.

According to the criteria outlined above, 158 cases (49%) in 2014 did not have an intellectual disability at the time of diagnosis, as determined by either a full-scale test score above 70 points or an informal clinician estimate. Intellectual disability was confirmed in 19 cases (6%) of cases. There were 54 cases (17%) who were considered vulnerable for intellectual disability. There was insufficient evidence to determine the intellectual functioning of the remaining 90 cases (28%).

Using the same criteria outlined above, between 1999 and 2014, 43% of all reported cases did not have an intellectual disability at the time of diagnosis, 13% were confirmed to have an intellectual disability, a further 14% were considered vulnerable for intellectual disability and there was insufficient evidence to determine the level of functioning the remaining 30% of cases.

Primary language at home

Thirty three people (10%) diagnosed during 2014 were reported to have a language other than English at home. Over the 1999-2014 period, 10% of cases were reported to speak a language second to, or other than, English at home.

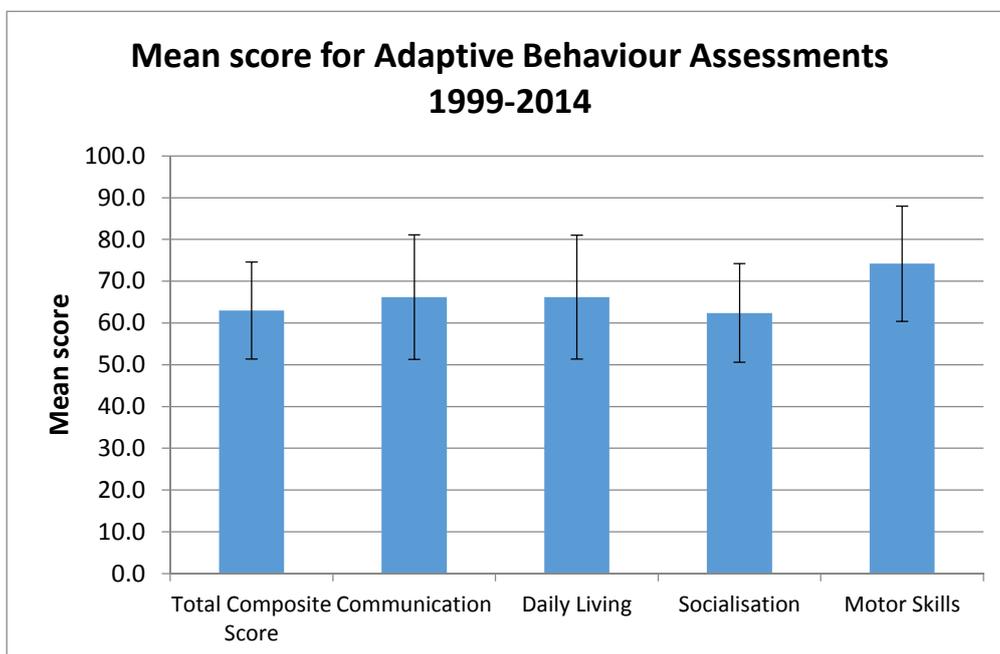
Adaptive behaviour

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 cases reported during 2014 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 on the Register since 1999. (NB: 10 cases (1999-2014) were excluded due to reported Vineland scores less than 20 points).

Domain	Number of cases with a score	Mean score	Range of scores	Standard deviation
<i>Total Composite Score</i>	141	64.8	45-93	8.6
Communication domain	143	68.4	32-120	14.9
Daily Living domain	142	66.9	32-104	11.5
Socialisation domain	143	63.1	49-100	8.2
Motor Skills domain	137	73.7	27-124	11.9



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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