



## Uses & Aims of the Register

The causes of autism spectrum disorders are currently unknown, but there is general agreement that there is no single cause.

By gathering information provided by clinicians and parents, the Register aims to provide data that will assist with:

- increasing the understanding of the nature of autism spectrum disorders
- knowing how many people are diagnosed in WA each year
- learning more about the geographical distribution in WA
- understanding the possible reasons behind the world-wide trend of increasing numbers of diagnoses
- providing diagnostic and statistical information for clinicians, service providers, educators and researchers
- helping to guide the planning of state resources to cater for the needs of individuals with autism as well as their families and carers



## Further Information

If you have any questions or comments about the WA Register for Autism Spectrum Disorders, or if you would like to receive copies of past annual reports, please contact one of the names below:

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# All About The Autism Register



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## Who is Involved in the Register?

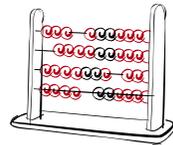


The Register is a joint venture between all major diagnostic centres for Autism within Western Australia and is managed by a representative committee of professionals and consumers.

Organisations involved in the Register include:

- Disability Services Commission
- State Child Development Centres
- Department of Education and Training
- ISAAD
- Princess Margaret Hospital
- Autism Association of Western Australia
- Clinicians from private practice

## Inclusion on the Register



Developing a complete picture of autism spectrum disorders in WA needs everyone who has been diagnosed to be included on the Register.

Only diagnostic information is given to the Register by the diagnosing clinicians.

Permission is required, from the parent of a minor or the individual with a diagnosis, to allow identifying information to be kept on record.



## What are Autism Spectrum Disorders?

Autism Spectrum Disorders include:

- Autism
- Asperger's Syndrome
- Pervasive Developmental Disorder not otherwise specified (PDD-NOS) and
- Childhood Disintegrative Disorder

There is a wide range of symptoms associated with autism and a wide range in the severity of impairment. Symptoms usually appear early in life but individuals with milder symptoms or Asperger's Syndrome may not be identified until school age or sometimes even later.

While individuals may present with different characteristics, they all have difficulties in three core areas of development:

- a) socialization
- b) communication, and
- c) atypical repetitive behaviors.

An individual who has difficulties in these areas combined with delays or deficiencies in their early language development will usually be given an autism diagnosis.

An individual whose early language development was 'on track' but who has difficulty with social skills, social language and atypical behaviours will usually be diagnosed as having Asperger's Syndrome.



## What sort of Information is kept on the Register?

Clinicians provide basic demographic information such as gender, date and place of birth and number of siblings. They also provide some diagnostic information from assessments of language, adaptive behaviour and cognition. Parental, or diagnosed individual's, permission must be provided to also include name and postcode with each entry.

## Information is Confidential



The information kept on the Register is treated as **strictly confidential** and will only ever be used for the purposes for which they are intended. Information will **NOT** be given to third parties and will **NOT** affect ways in which the person diagnosed, or their families, receive benefits, care or preferences in respect to education, employment, finances, insurance or medical care. All data are stored at the Telethon Institute for Child Health Research and are firewall and password protected.



## Who has Access to the stored Information?

Any person or organisation requesting information from the Register must approach the Advisory Committee. Identifying information such as names are not released without parent or patient consent.