

Autism Assessment and Diagnosis Guideline: Case Study

Autism Spectrum Disorder (ASD), also simply termed autism, is a persistent developmental disorder characterised by symptoms evident from early childhood. These symptoms can range from mild to severe and include difficulty in social interaction, restricted or repetitive patterns of behaviour, and communication challenges. There is no definitive test for autism; instead, diagnosis is made on the basis of developmental assessments and behavioural observations. Early diagnosis and intervention are associated with better outcomes. Developed by the Cooperative Research Centre for Living with Autism (Autism CRC) and approved by NHMRC, *A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders* (the Guideline) has helped to improve the accuracy and reliability of diagnostic decisions related to autism.



Origin

There is currently no known biological marker for autism, and variability in autism signs and symptoms – along with the considerable behavioural overlap with other developmental conditions – makes autism diagnosis a challenging clinical task.

However, early identification and diagnosis of autism provide more opportunities for early intervention, and this in turn can provide significant economic, social and health advantages and better long-term outcomes for affected individuals and their families.

Almost one third of National Disability Insurance Scheme (NDIS) participants have a primary diagnosis of autism, and 69% of NDIS participants on the autism spectrum are under 15 years of age.

A diagnosis of autism is usually associated with substantial lifetime costs, as people on the autism spectrum may face participation barriers in daily living, education and employment associated with their condition. Annually in Australia, an estimated \$4.5–7.2 billion cost is borne by people on the autism spectrum, their families, their community, and Australian governments. The cost of an individual not obtaining a correct diagnosis can be even higher.

Without a clear protocol for how to diagnose autism, individuals and families may not receive timely intervention and support.

Over 10,000 children under 12 years of age were newly diagnosed with autism across Australia in 2015 and 205,200 Australians were on the autism spectrum in 2018. This is about 1 in 125 people and represents a 25.1% increase from the 164,000 reported as on the autism spectrum in 2015.

Development

Aware of the benefits of early intervention, the autism community had for many years been requesting a national and consistent guideline for autism assessment and diagnosis. Consequently, in 2014 a review of ASD diagnostic practices in Australia was jointly commissioned by Autism CRC and the Australian Government Department of Social Services (DSS).

A key finding from this review was the considerable variability between Australian states and territories in diagnostic practices, including the quality and quantity of assessments administered, the professionals involved and the required experience of these professionals. The review concluded that this variability was highly likely to have contributed to uneven service provision across the states and confusion among clients undergoing diagnostic assessment.

The main recommendation of the review was that adopting a minimum national standard for ASD diagnosis in Australia would improve diagnostic practices and consistency across Australia and ensure that future diagnostic assessments were in keeping with best practice guidelines.

In June 2016, under the terms of a Collaboration Agreement, the National Disability Insurance Agency (NDIA) commissioned Autism CRC to develop Australia's first national guideline for ASD diagnosis.

Development of the Guideline was led by a Research Executive team consisting of Professor Andrew Whitehouse, Dr Kiah Evans, Professor Valsamma Eapen and Clinical Associate Professor John Wray.

Grants and Investments

NHMRC
NHMRC supported the development of the Guideline as part of its legislated role in approving third party guidelines, and also by supporting capability development for three of the authors, as follows:

- Professor Andrew Whitehouse**
- Project Grants: 2011, 2013, 2016, 2018
 - Career Development Fellowship: 2011
 - Centre of Research Excellence: 2013
 - Research Fellowship: 2015
 - Investigator Grant: 2020

- Professor Valsamma Eapen**
- Partnership Project: 2011, 2019
 - Project Grant: 2015, 2017, 2017
 - Centres of Research Excellence: 2019

- Associate Professor John Wray**
- Project Grant: 2010

Other Grants and Investments
Autism CRC received funding through the Australian Government's Cooperative Research Centres (CRC) Program. Development of the Guideline was supported by funding from the NDIA. In-kind support was provided by numerous Autism CRC participant organisations, in particular The University of Western Australia (including Telethon Kids Institute), University of New South Wales, Curtin University and The University of Queensland.



Collaborations

Guided by a Steering Committee comprised of representatives from 12 national peak bodies, development of the Guideline involved extensive consultation across Australia with all key stakeholder groups including: adults on the autism spectrum; caregivers; client and advocacy groups; clinicians; individuals; government policy makers; and public and private clinical service organisations.

The process included: eight workshops held in capital cities across Australia attended by over 250 participants; viewpoint and Delphi surveys; interviews with autistic adults; an online submission completed by 225 respondents; and written submissions received from 160 stakeholders.

Overall, more than 1,200 organisations and people from across Australia provided direct input into the Guideline. The final Guideline included more than 1,000 pages of research evidence and was peer-reviewed by international experts.

The Guideline defines:

- a tiered process of assessment to facilitate accurate and efficient assessment
- the qualifications, knowledge and experience required of health professionals who can be part of the assessment and diagnostic process
- a description of the information that needs to be collected and appropriate settings during assessment
- resources to help health professionals during ASD assessment.

Outcomes and Impact

The Guideline recommendations were approved by NHMRC in July 2018 for a period of five years, and the Guideline itself was published in October 2018.

Since publication, more than 15,000 individuals in Australia and overseas have registered to access the Guideline and it is now being used by paediatricians, psychologists and other diagnostic service providers around Australia.

The Guideline provides a backbone for the development and delivery of a clinical care pathway for individuals on the autism spectrum and others with neurodevelopmental challenges.

The development and implementation of a consistent, national guideline for autism diagnosis in Australia has provided the community with greater equity in access to a rigorous and comprehensive autism assessment, transparency in the diagnostic and decision-making processes, and confidence in the accuracy and reliability of diagnostic decisions.

Research is currently underway to determine current adherence rates for each Guideline recommendation across Australia, along with perceived barriers and facilitators to Guideline implementation. Findings will inform ongoing implementation and evaluation activities that aim to address Practice Points outlined in the Guideline.

DSS is also working with national peak bodies to support uptake of the Guideline recommendations.



Professor Andrew Whitehouse

Professor Whitehouse is the Research Strategy Director of Autism CRC, the Angela Wright Bennett Professor of Autism Research at Telethon Kids Institute (The University of Western Australia) and an NHMRC Senior Research Fellow. Professor Whitehouse trained and practised as a speech pathologist before becoming a full-time researcher. His research program focuses on clinical intervention trials for infants and children on the autism spectrum and the development of effective policies to ensure equity in service provision.

Dr Kiah Evans

Dr Evans is an Autism CRC Project Leader, and Senior Research Officer in the Autism Research Team at Telethon Kids Institute. Dr Evans is a registered occupational therapist with a PhD and a Graduate Certificate in Research Commercialisation. She has undertaken research examining the experiences of people on the autism spectrum and their caregivers. Dr Evans is currently leading a program of research focused on the assessment of functioning and Guideline implementation.

Professor Valsamma Eapen

Professor Eapen is an Autism CRC Program Director (Early Years), a child psychiatrist at South West Sydney Local Health District, Professor and Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales, and Stream Director of Early Life Determinants of Health (ELDoH) Clinical Academic Group within SPHERE, an NHMRC-accredited Advanced Health Research and Translation Centre. Professor Eapen has clinical expertise as a child psychiatrist assessing and treating children on the autism spectrum, along with research and teaching experience in neurodevelopmental disorders (including ASD).

Associate Professor John Wray

Clinical Associate Professor Wray is a developmental paediatrician at the Child Development Service of Western Australia, and at McCourt Street Paediatrics. He has clinical expertise assessing and treating children on the autism spectrum, along with expertise in research and establishing best practice standards for the diagnosis of ASD.

Autism CRC

Autism CRC was established in 2013, funded through the Australian Government's CRC Program. Autism CRC was the world's first national, cooperative research effort focused on autism, and provides the national capacity to develop and deliver evidence-based outcomes through collaboration with the autism community, research organisations, industry and government. Currently, Autism CRC has 56 participant organisations and other partners based around Australia and internationally.