

About the Authors

The Diagnostic Process for Children, Adolescents and Adults referred for Assessment of Autism Spectrum Disorders: Assessment Providers' Version, is one of the projects completed so far by the Autism Accreditation Project Working Party. All of the members of this collaborative, cross-sectorial and cross-disciplinary working party have had extensive experience working in the field of Autism.

The working party consisted of Sarah MacDermott – Chair/Project Officer (Speech Pathologist); Sandra Robertson (Clinical Psychologist); Suzanne Midford (Clinical Psychologist); Ritu Campbell (Clinical Psychologist); Amanda Wilkins (Paediatrician), Annkathrin Franzmann (Paediatrician); Wendy Marshall (Speech Pathologist); and Karen Mason (Speech Pathologist).

The final “print version” of the booklet was reviewed and “signed off on” by the Inaugural Board of WAADF, Inc. prior to it’s initial printing in August 2005.

Acknowledgements

The Western Australian Autism Diagnosticians’ Forum, Inc. gratefully acknowledges the assistance of the following;

- Lotterywest, who provided funding for the initial printing of this document (2005).
- The Disability Services Commission, Western Australia, who provided the initial grant which established The Autism Accreditation Project in 2002. This publication is one outcome of that project.

The Western Australian Autism Diagnosticians’ Forum, Inc. would like to thank all of those individual practitioners who contributed their time and efforts to the development (particularly of the original source materials), review, proofreading and administrative production of this information booklet.

The Autism Accreditation Project Working Party wishes to acknowledge and sincerely thank Sarah MacDermott for her tireless efforts in the development of this booklet. Sarah has demonstrated excellent leadership skills in coordinating the thoughts, ideas and values from a range of professionals working in the field so that the booklet can truly demystify the often confusing and frustrating process that parents and individuals go through when seeking assessment. Without her patience, understanding and commitment to this project, production of this booklet would not have been possible.

Specific thanks go also to the following members of the Autism Accreditation Training Project Working Party for their collaboration, persistence, insight, thoughtful consideration and debate, and pure hard work: Sandra Robertson (Clinical Psychologist, SCDC), Suzanne Midford (Clinical Psychologist, Private Practice), Ritu Campbell (Clinical Psychologist, DSC), Amanda Wilkins (Paediatrician, Health Department), Annkathrin Franzmann (Paediatrician, Health Department), Wendy Marshall (Speech Pathologist, DSC), and Karen Mason (Speech Pathologist, DSC). Thanks also to Hugh Cook (Psychiatrist, Private Practice), Helen Knott (Speech Pathologist, SCDC), Kate Smith (Clinical Psychologist, DSC) and John Wray (Paediatrician, SCDC) for their invaluable suggestions and input. Additional thanks to Kate Smith for initiating this important project. This “booklet” unexpectedly became a project on its own, with the initial draft taking just over 5 months to complete (2003). The Working Party’s commitment is reflected in the excellence of the outcome, which is also a hallmark of teamwork at its best.

Dr. John Wray

Chair, WAADF

August, 2003

(Completion of initial draft)

Dr. Ritu Campbell

Coordinator, WAADF

August, 2003

Inaugural Board of WAADF, Inc., August 2005

(Completion of final revisions and printing)

The authors and reviewers have made every attempt to ensure the accuracy and completeness of this publication. Any inaccuracies or omissions are entirely unintentional and feedback identifying any such errors is welcomed. Comments or responses may be directed to the WAADF, Inc Secretary via the link at the website www.autismwa.org.au

The Western Australian Autism Diagnosticians' Forum, Inc (WAADF, Inc)

A BRIEF HISTORY

Beginning in the early 1990's, Western Australia has experienced a surge in autism related assessment referrals. This increase has been similar to that described in the international literature as occurring in the United Kingdom, Europe and North America during the same period. This trend continues today.

This increasing demand for services in Western Australia has been met by a dynamic and increasingly cross-disciplinary and cross-sectorial response. Professionals in the area have consistently sought to support and inform each other as well as the increasing number of families being referred for assessment, diagnosis and intervention. The resulting stream-lining of assessment protocols and the development of a specialized training format for professionals who wished to become specialized assessors, have been two of the most significant outcomes so far. The following series of events has seen an ever increasing number of specialized assessors working across the private and public sectors, and in both metropolitan and country areas.

In 1988, following requests from the Autism Association of Western Australia (AAWA) – formerly the Association for Autistic Children in W.A. Inc. - for state-government funding, a Ministerial Working Party (MWP) was established to examine the situation of Autism in Western Australia. Just prior to this, in 1987, the Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition Revised (DSM-III-R) was published. This edition continued to apply the DSM-III's developmental framework to the diagnosis of Autism but also broadened the diagnostic criteria. This revised framework informed and directed the MWP's efforts and shaped their recommendations for diagnostic practices in Western Australia. These recommendations, outlined in reports published in 1988 and 1989, required a thorough developmental evaluation which included clinical assessments by a paediatrician, a clinical psychologist and a speech pathologist. It is notable that psychiatric evaluation was not required for children as Autism was by now considered to be a developmental disability.

The working party also recommended:

- a) the establishment of a "Central Diagnostic Process" which required that all children with a suspected Autism Spectrum Disorder be referred to a specialised diagnostic team located centrally at PMH;
- b) that the existence of this specialised team be widely publicised to all appropriate professionals and agencies; and

- c) that the central diagnostic team be responsible for “determining a diagnosis, recommending appropriate treatment and maintaining a register”.

These recommendations were informally implemented by a group known as the Central Diagnostic Panel (CDP) which was established in 1991. This was the first time that a uniform diagnostic approach was sought in Western Australia. Members included representatives from the State Child Development Centre (SCDC), Princess Margaret Hospital for Children (PMH), the Autism Association of Western Australia (AAWA), and Disability Services Commission – *Mildred Creak Centre (DSC-MCC). *Mildred Creak Centre was transferred from the Health Department to Disability Services Commission in July 1992. The panel was chaired initially by Peter Chauvel, Paediatrician, PMH. The CDP had recognised status to diagnose and its diagnostic decisions were accepted by the Education Department of Western Australia.

The CDP continued to meet throughout the 1990's to review and reach diagnostic decisions in regard to presented cases. The members of the CDP also encouraged and supported:

- The development of specialist autism assessor training programs. These programs began in 1994 and initially were provided primarily at PMH and SCDC. Assessor training in recent years has been provided mostly by specialist staff working at DSC (metropolitan and country services) and SCDC;
- The establishment of cross disciplinary assessment and reporting protocols in 1996;
- The documentation of formal standards for the assessment, reporting and assessor training required for the provision of Autism Spectrum Disorder (ASD) assessment and diagnostic services to children in Western Australia, in 1998.

Towards the end of 1998 it was agreed that a formal group would be formed to facilitate regular discussion of clinical issues related to ASD assessment and diagnosis. The Inaugural Meeting of the Autism Clinical Diagnostic Forum (The Forum) was held on November 6th, 1998. The stated aims of the group at this meeting were;

1. to develop state-wide standards for diagnosis that concur with international standards;
2. to ensure standards are met by all professionals making ASD diagnoses and subsequent referrals to DSC;
3. to ensure consistent interpretation of diagnostic criteria, and
4. to establish standards for training and/or accreditation of assessors.

It was agreed that The Forum's format would include group discussion and case presentations. Initially, members consisted predominantly of metropolitan based DSC, SCDC and PMH staff. However, the inclusion of both country and private

practitioners, as well as representatives from non-assessing disciplines and service providers, was actively pursued from the time of The Forum's inception.

The Forum's focus has always been on the discussion of clinical issues and not the politics of the field. This common focus has been of primary importance in the ongoing development and maintenance of this collaborative and inclusive group.

By mid 1999, The Forum had ratified a set of standards for conducting adult ASD assessments that were developed by a select sub-committee. By the end of the year there was cross-disciplinary agreement by clinicians, based on international practices, of the criteria used in diagnosing Asperger's Syndrome and PDD-NOS.

In 1999, data collection began for the WA Register for Autism Spectrum Disorders. The Register is a unique population-based register of all known individuals newly diagnosed with an ASD diagnosis in Western Australia. The Register has had close links with The Forum since its inception, and its ongoing success reflects the collaborative provision of data by all assessing clinicians. Reporting protocols have also been established to maximize the ease and efficiency of data collection. To date it is estimated that approximately 90% of identified cases of ASD in this state are included in the database.

The years 2000 to 2005 have seen the ongoing refinement and documentation of ASD assessment and diagnostic processes and practices across all service sectors in the State.

The current edition of the DSM (DSM-IV-TR) was published in 2000. The practices of clinicians who work in the Autism field in Western Australia have continued to reflect these updated guidelines as well as the significant growth in knowledge, and the ongoing research, which is currently underway, both within this country and around the world.

In September 2001, The Forum membership agreed to form a working party to explore the possibility of developing a formal training process which would lead to assessor accreditation. Founding members for this working party initially convened in June 2002. Following a successful grant application to DSC in October 2002, the working party then became the Autism Accreditation Training Project Working Party with a funded project officer. This project has continued beyond its initial funding and its scope has grown substantially. One of the outcomes of this project has been the development of both the assessors' version and the family and service providers' version of this publication. Once its DSC funding was completed, the Accreditation Project came under the auspices of The Forum (later WAADF, Inc.). Options for ongoing funding are being consistently explored by the WAADF, Inc. Board and to date include some short-term interim funding provided by PMH.

The Forum continued to evolve and by December 2002 the membership had elected its first formal office-bearers. As a response to the growing needs of The Forum's membership, and the potential future needs of the Accreditation Project, the group then made the decision to become incorporated. The Western Australian Autism Diagnosticians' Forum, Inc. (WAADF, Inc.) was incorporated on May 7th, 2004. WAADF, Inc meetings continue to be held quarterly and are still an essential point of contact for professionals working within the field.

The formation of WAADF, Inc. is the result of the cumulative efforts, vision, knowledge and compassion of a wide range and number of professionals. These individuals have been deeply influenced by the families with whom they have worked. They have also continued to build on the legacy of the many other doctors, psychiatrists, psychologists, speech pathologists and social workers who have preceded them. Many of the professionals who helped found the professional Autism community in Western Australia were staff at PMH, the Mildred Creak Centre, Hillview Clinic and the Autism Association, and while some continue to work in this area, others have since retired or moved on to other settings. The clinicians working in this field, both in the past and continuing into the present, are deeply committed to the care and support of the individuals and families with whom they work, as well as to the ongoing development of their own and their colleagues' skills.

Significant Milestones in the Development of WAADF, Inc

Publication of DSM-III-R 1987

Ministerial Working Party established 1988

- Resulted from pressure from the AAWA for state-government funding
- Recommendations contained in reports published in 1988 and 1989 highlighted the need for a consistent diagnostic process and a central diagnostic team

Central Diagnostic Panel (CDP) established 1991

- Chair: Peter Chauvel, Paediatrician, PMH.
- Members included representatives from:
- State Child Development Centre (SCDC)
 - Princess Margaret Hospital for Children (PMH)
 - Disability Services Commission (DSC)
 - Autism Association of Western Australia (AAWA)

Adherence to CDP procedures were supported by:

- DSC Referrals Committee
- Department of Education's Aide Allocation Committee.

Specialist autism assessor training programs – began in 1994

- Training was initially provided mainly by Peter Chauvel, Paediatrician, at PMH and Jura Tender, Clinical Psychologist, at SCDC.
- Specialist training programs were also supported by other members of the Central Diagnostic Panel (CDP) including Trevor Parry, Paediatrician at SCDC and SCDC staff; Anne Lawson, Speech Pathologist at DSC and DSC's Mildred Creak staff; and Joan McKenna-Kerr, CEO of AAWA and AAWA staff.
- Training in recent years has been provided primarily by experienced staff working at DSC (both metropolitan and country services) and SCDC.

Cross disciplinary assessment and reporting protocols established - 1996

Developed by:

- Jay Witherspoon, Speech Pathologist, DSC and Kate Smith, Clinical Psychologist, DSC using as a basis protocols previously developed by Jura Tender, Clinical Psychologist, Autism Association and Helen Bolton (formerly Wolfenden), Speech Pathologist, Autism Association

Standards for ASD assessments for children formally documented – 1998

Authors included:

- Martin Exell, Clinical Psychologist, SCDC
- Trevor Parry, Paediatrician, SCDC
- Gail Hobson, Speech Pathologist, SCDC
- Peter Chauvel, Paediatrician, PMH
- Angus Buchanan, Manager, Specialist Country Services, DSC
- Debbie May, Speech Pathologist, Specialist Country Services, DSC

Formation of the Autism Clinical Diagnostic Forum (ACDF) - 1998

- Inaugural Meeting – November 6th, 1998
- Inaugural Chairperson 1998 – Kate Smith, Clinical Psychologist, DSC
- Participants included representatives from;
 - DSC Autism Centre
 - DSC Specialist Country Services
 - PMH
 - SCDC
 - The Centre for Clinical Research in Neuropsychiatry.
- Disciplines represented included psychiatry, paediatrics, clinical psychology, speech pathology, social work and epidemiology
- The ACDF gradually becomes known as the Autism Diagnosticians' Forum (The Forum)

Standards for ASD assessments for adults established – June & July 1999

Working party authors included:

- Joan McKenna-Kerr, CEO Autism Association
- Hugh Cook, Psychiatrist
- Martin Exell, Clinical Psychologist
- Carrie Buckland, Speech Pathologist
- Kate Smith, Clinical Psychologist

Standards for Asperger's Syndrome diagnosis reconfirmed - July 1999

Document confirming the recognition and acceptance of the use of Catherine Lord's diagnostic process for the diagnosis of Asperger's Syndrome circulated to all Western Australian autism assessors.

Standards for PDD-NOS diagnosis agreed on in 1999 and reconfirmed in 2002

- Cross disciplinary agreement reached to use the guidelines developed by Professor Butelaar of the Netherlands in diagnosing PDD-NOS, December 1999.
- Reconfirmation of the use of the same criteria and terminology via contact with Professor Volkmar's team in June 2002.

WA Register for Autism Spectrum Disorders began collecting data - 1999

The Register has collected diagnostic and demographic information on all newly diagnosed cases in Western Australia since January 1999. The collected information includes the number and ages of people diagnosed, the severity of disability, as well as shared biological, psychiatric and developmental features. The Register serves as a research tool and provides data to assist in the planning of health, education and disability services.

Publication of DSM-IV-TR 2000

Standards for ASD assessments provided by DSC Specialist Country Services documented - January 2000

Authors included:

- Debbie May, Speech Pathologist
- Carrie Buckland, Speech Pathologist
- Trish Webb, Speech Pathologist
- Lelle Taffyn, Psychologist

Statement of Autism Assessment Standards Across DSC Autism Centre and SCDC – January 2000

Authors;

- DSC Autism Centre and SCDC Staff
- Based on standards drawn up by DSC Specialist Country Services

Standards for ASD assessments provided by Private Practitioners documented - 2001

- Initial draft authored by Sandy Gray, Speech Pathologist and Derek Cohen, Clinical Psychologist, on behalf of The Forum membership

Autism Diagnosticians' Forum – formal office-bearers elected 2002

- The Forum membership decide to formally elect office-bearers - September 2002
- Election of Autism Diagnosticians' Forum office-bearers held December 2002:
 - Chairperson 2002 - 2004 – John Wray, Paediatrician, SCDC
 - Meeting Coordinator 2002 - 2004 – Ritu Campbell, Clinical Psychologist, DSC

Autism Accreditation Project Working Party (AAPWP) established – October 2002

- September 2001 – agreement to form a working party to address accreditation of the diagnostic process
- June 2002 – Working Party convened
- October 2002 to March 2004 – funding from Disability Services Commission to employ project officer.
- AAPWP members:
 - Sarah MacDermott – Chair/Project Officer, Speech Pathologist
 - Sandra Robertson, Clinical Psychologist
 - Suzanne Midford, Clinical Psychologist
 - Ritu Campbell, Clinical Psychologist
 - Amanda Wilkins, Paediatrician
 - Annkathrin Franzmann, Paediatrician
 - Wendy Marshall, Speech Pathologist
 - Karen Mason, Speech Pathologist
- June 2004 – WAADF Inc. accepted responsibility for the ongoing support and development of the project. Options for ongoing funding are being consistently explored by the Board. The accreditation project is ongoing (2005).
- August 2005 – publication of *The Diagnostic Process for Children, Adolescents and Adults referred for Assessment of Autism Spectrum Disorders: Assessment Providers' Version and Family and Service Providers' Version*

WAADF, Inc Incorporated – May 7th, 2004

Inaugural Board members:

- Chair -Sarah MacDermott, Speech Pathologist
- Vice-Chair - Ritu Campbell, Clinical Psychologist
- Secretary - Wendy Marshall, Speech Pathologist
- Treasurer - Suzanne Midford, Clinical Psychologist

Ordinary Members:

- Kate Smith, Clinical Psychologist
- Jura Tender, Clinical Psychologist
- Peter Chauvel, Paediatrician
- Alana Maley, Psychologist
- Emma Glasson, Research Fellow,
- Robyn Weinstein, Speech Pathologist
- John Wray, Paediatrician

The Western Australian Autism Diagnosticians' Forum, Inc.

VISION AND GOAL STATEMENT

The Western Australian Autism Diagnosticians' Forum, Inc. (The Forum) meets quarterly to discuss standards, processes, and clinical issues in the assessment and diagnosis of autism spectrum disorders in Western Australia. Members include clinicians across the disciplines of speech pathology, paediatrics, psychiatry, social work, psychology and research, who are working in the government, non-government and private sectors.

The Forum aims to inform practitioners of new developments in the assessment and diagnostic process, establish standards for consistent practice across WA, facilitate interpretation of diagnostic criteria, inform practitioners of service delivery and research developments, and provide opportunity for case discussion.

Training Information

For professionals in the fields of speech pathology, psychology, paediatrics or psychiatry, who wish to become recognized as specialist Autism assessors, please refer to the following information sources:

For current training options information contact:

Disability Services Commission

Metropolitan Autism Services

- up until October 1st, 2005, (08) 9472-1598
- As of October 1st, 2005:
 - South of the River; Myaree Office, (08) 9329 2300
 - North of the River, Joondalup Office, (08) 9301 3800

Specialist Country Services (08) 9426-9374

State Child Development Centre (08) 9481-2203

For Autism Accreditation Training Project (currently in development)

Contact the current WAADF, Inc. Chairperson or Secretary at
www.autismwa.org.au

The Western Australian Autism Diagnosticians' Forum, Inc

ENDORSEMENT STATEMENT

The Western Australian Autism Diagnosticians' Forum, Inc. (WAADF, Inc.) supports and endorses this booklet as a reflection of the currently recommended guidelines and standards for the provision of autism spectrum disorder assessments within Western Australia. In addition, WAADF, Inc. asserts that the information contained within this booklet has the following characteristics:

- 1. it identifies the current best practices in the area of Autism Spectrum Disorder assessment and diagnosis as practised in Western Australia at the date of printing (2005);*
- 2. it represents active policies upon which the Autism Accreditation Training Programme, currently in development, is based; and*
- 3. it represents an active consensus, by WAADF Inc's membership, as to the policies, procedures and standards that apply to the provision of autism spectrum disorder assessments within Western Australia at the date of printing (August 2005).*

Dr. John Wray

Chair, WAADF
August, 2003

(Completion of initial draft)

Dr. Ritu Campbell

Coordinator, WAADF
August, 2003

Inaugural Board of WAADF, Inc., August 2005

(Completion of final revisions and printing)