Management of assessments and diagnoses for children with autism spectrum disorders: the Western Australian model

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ABSTRACT

- Autism spectrum disorders (ASDs) are severe developmental conditions that require specialised intervention and lifelong support.
- Recent increases in ASD prevalence have prompted new initiatives in Western Australia to improve the consistency of assessments and to more accurately monitor diagnostic trends within the population.
- WA has implemented statewide guidelines for the assessment of ASDs, has developed an open forum for clinicians to discuss issues relating to the assessment process, and supports a statewide register of newly diagnosed cases.
- These initiatives have led to improved consistency across assessments, allowed analysis of diagnoses over time, and promoted cohesiveness among autism assessors.
- These strategies potentially provide an alternative model for other states and territories that wish to strengthen and assimilate ASD assessments.

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Autism is a developmental disorder characterised by impairments in social interaction, communication and behaviour. The estimated prevalence of autism is 1–2 per 1000 children, and up to six per 1000 for all autism spectrum disorders (ASDs),[1,2] a category that also includes Asperger syndrome and "pervasive developmental disorder not otherwise specified". The causes of ASDs are largely unknown. Clustering of diagnoses in families suggests a genetic component and a high degree of heritability,[3] but the possible mechanisms are poorly understood. Information about biological characteristics in early childhood is also severely lacking.

ASDs are diagnosed using clinical criteria described in the *International classification of mental and behavioural disorders* (ICD-10) classification system[4] or the *Diagnostic and statistical manual of mental disorders* (DSM-IV).[5] Symptoms are often noticed by 12 months of age,[6] but affected individuals show large differences in their presentation.[7] Diagnosis usually occurs around 3–4 years of age when social and communication milestones are not achieved. Apart from the number and pattern of criteria present, there are no other measurable physical or psychological markers to distinguish between the ASD diagnoses. Although the diagnostic criteria seek to distinguish between autism and Asperger syndrome on the basis of early developmental characteristics (such as language development), in practice there is often little to distinguish the autism and Asperger profiles, as many children with autism develop language.[5,8]

The prevalence of ASDs has increased globally for the past two decades.[9,10] It is unknown to what degree different factors are having an impact, such as new diagnostic practices, younger ages at diagnosis, increased awareness and diagnostic training opportunities for professionals, increased media reporting, and heightened awareness and pursuit of diagnoses by parents with concerns about their child's development. In the absence of explanation, families and the general public remain concerned at the increasing number of diagnoses, as do clinicians and service providers who are under-resourced to cope adequately with the increasing demands associated with assessments, case management, service provision and education.

Over the past 20 years, the number of new diagnoses per year in Western Australia has increased nearly 20-fold, and now, more than 200 children are newly diagnosed with an ASD each year.[11,12] Assessment centres and service providers have become highly pressured, resulting in lengthy waiting periods for school-aged children, and a shift towards private practice for more rapid assessments (Box 1). Each year, in addition to those who receive an ASD diagnosis, a similar number of children who are referred for assessment do not present with the required number of criteria to receive a formal diagnosis within the spectrum. This represents a significant developmental health issue that demands urgent investigation into the antecedents of, and explanations for, the observed increases.

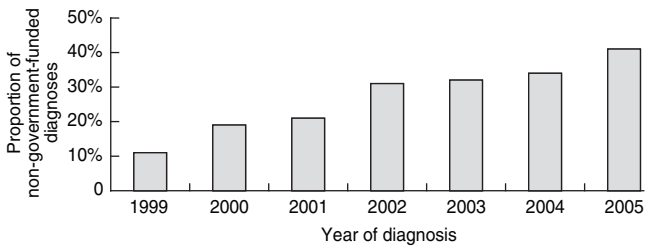
There have been a number of recent initiatives in WA to help manage ASD assessments more effectively, clarify diagnostic pathways, improve the quality of assessments, and monitor the number of diagnoses made each year across the state. These include formal documentation of recommended assessment and diagnostic processes, the creation of an open membership forum for autism diagnosticians, and promoting collaboration between clinicians and the existing statewide autism register. Ultimately, such measures will help streamline the referral process; reduce waiting times for families, thus hastening intervention; improve assessment quality; provide a better bridge between assessments and service delivery; provide high-quality data, promoting effective research; and enhance communication between clinicians, service providers and families.

Recent WA initiatives

1. Development of strategies for consistent ASD diagnoses across WA

In 1991, a Central Diagnostic Panel, consisting of eight clinicians representing different organisations and disciplines, was established to encourage a uniform approach to diagnostic decisions, service eligibility, reporting requirements and assessor training for ASD assessments and services to children throughout WA.[13] At that time, less than 20 people per year were diagnosed with an ASD.[11] As the number of referrals and diagnoses increased during the 1990s, so did the need for a more formal arrangement for streamlining assessments and eligibility requirements. In 1997, the Disability Services Commission (DSC) was nominated as the primary agency to distribute government early-intervention funding for children diagnosed with ASDs in WA. For children with an ASD diagnosis to be accepted as eligible for consideration of early intervention, diagnoses must now incorporate assessments by a

1 Proportion of non-government-funded autism spectrum disorder diagnoses in Western Australia, 1999–2005



team of three independent health professionals (a paediatrician or psychiatrist, a psychologist, and a speech pathologist) (Box 2). Assessments for adolescents (aged 12–17 years) and adults are required to be carried out by a clinical psychologist, a paediatrician (for adolescents) and/or a psychiatrist, and to include a formalised speech pathology assessment, if needed. For each assessment, a standardised cognitive or developmental instrument, an adaptive behaviour assessment, a speech assessment, and the current DSM criteria are used (Box 3). A supplementary assessment of family functioning by a social worker is used at one institution.

This protocol has been enhanced and strengthened in recent years using input from diagnosing clinicians and relevant support agencies throughout WA. Regular discussion occurs at meetings of the Western Australian Autism Diagnosticians' Forum (WAADF; see below) to ensure efficient management of referrals, assessments, diagnoses, eligibility, and access to services across the state. To be recognised as an experienced assessor, a clinician must demonstrate specialty skills and knowledge in the area of autism and adhere to the assessment and diagnostic reporting standards and procedures identified by the DSC. These are the same standards and procedures that are published and recommended by the WAADF.[13]

The DSM criteria (as currently set out in the fourth edition, text revised version [DSM-IV-TR])[5] are central to the diagnostic process and are supplemented with assessments of language, cognitive or developmental ability and adaptive behaviour. Alternative explanations for the observed symptoms, including hearing deficits or fragile X syndrome, are also considered. The diagnostic instruments typically include one or more of the following standardised instruments, depending on the person's age, abilities and test compliance: the Griffiths Mental Development Scales,[14] Bayley Scales of Infant Development,[15] Stanford–Binet Intelligence Scale,[16] Wechsler Intelligence Scale for Children,[17] Wechsler Preschool and Primary Scale of Intelligence[18] or the Reynell–Zinkin Scale.[19] If the children are non-verbal, the Leiter International Performance Scale[20] may be used. Additionally, the Vineland Adaptive Behavior Scales[21] and the Clinical Evaluation of Language Fundamentals[22] and/or a Peabody Picture Vocabulary Test[23] are commonly used. The Autism Diagnostic Observation Schedule[24] and the Autism Diagnostic Interview — Revised,[25] which are intended for use by trained clinicians, are often used in comprehensive ASD evaluations. The Social Communication Questionnaire,[26] a screening questionnaire based on the original Autism Diagnostic Interview — Revised, is occasionally included in the diagnostic process.

Service provision may be requested directly through the DSC and/or through a range of DSC-funded agencies. Support can be offered through the DSC if the child is younger than school-age and has an intellectual disability or developmental delay, or if the child is school-aged and has an intellectual disability. A child who is school-aged and does not have an intellectual disability may be offered support from another DSC-funded agency.

2. Formulation of an autism diagnosticians' forum

Since November 1998, quarterly education and discussion forums have been held among clinicians to review standards, processes and clinical issues in the assessment of ASDs in WA. Membership is open to clinicians and other interested parties from any sector. Membership is voluntary, but individuals are encouraged to register in order to keep abreast of current practices. In 2006, the WAADF had 87 financial individual and organisational members. The disciplines of paediatrics, psychology, speech pathology, education and disability management are represented at meetings, and most attendees are metropolitan-based.

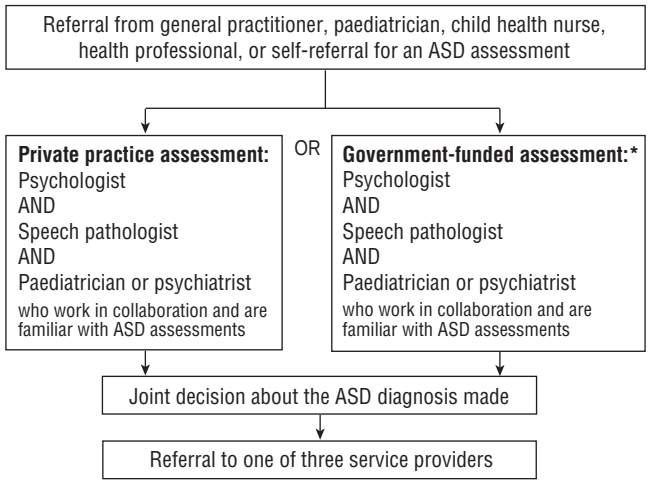
In 2004, the WAADF became incorporated, and now recommends standards for assessment procedures throughout the state (http://www.waadf.org.au). In addition, the WAADF informs practitioners of service delivery changes and new developments in assessment processes, facilitates the interpretation of diagnostic criteria, and provides an opportunity for case discussion and presentation of research findings. The WAADF has produced booklets documenting current diagnostic assessment strategies. These are available in various versions directed at parents, clinicians and service providers.[13]

3. Development of a statewide autism register

A statewide autism register was initiated in 1999 to monitor the number of people receiving a new ASD diagnosis each year.[12] Financial assistance for the register has been provided by the health, disability and education sectors of local government. The register activities are supported through the WAADF, which ensures that clinicians are updated on changes and current progress.

Data collection forms are distributed regularly to clinics and clinicians known to conduct assessments, and clinicians are encour-

2 Referral process for ASD diagnoses in Western Australia for children aged up to 12 years



ASD = autism spectrum disorder. * Including child development centres, children's hospitals and the disability sector. ◆

3 Summary of regular team assessment details for autism spectrum disorder diagnoses in Western Australia for children aged up to 12 years

Paediatric/psychiatric assessments

- General physical and neurodevelopmental examination, including hearing
- Comprehensive developmental history, with an emphasis on global functioning and achievement of developmental milestones, using parent/caregiver interviews and a review of available case history information
- Comprehensive medical history with an emphasis on excluding other medical conditions that may contribute to the current presentation
- Laboratory testing
- Review of past and current developmental strengths and needs
- Review of past and current assessments of socialisation, communication and behaviour
- Arrangement for psychiatric assessment if needed
- Interviews with other relevant people if necessary (eg, teachers, child care staff and therapists)

Speech pathology assessments

- Formal and/or informal testing of speech and language skills
- Functional evaluation of communication skills in various relevant environments
- Developmental history, with an emphasis on communication development, resulting from interviews with parents/caregivers and a review of available case history information
- Review and assessment of past and current abilities, strengths and needs in the areas of language, social communication and play
- Review and assessment of current testing results in terms of diagnostic criteria
- Interviews with other relevant people if necessary (eg teachers, child care staff, other therapists)
- Observation in the home, educational or broader social settings as necessary

Psychological assessments

- Formal assessment of intellectual functioning/development or a review of assessments made within the past 2 years. If a standardised assessment is not possible, informal assessment techniques are used to estimate intellectual functioning
- Standardised assessment of adaptive functioning for pre-primary-school-aged children
- Developmental history, with an emphasis on behavioural and adaptive functioning, relevant background information, history and context of the family, using parent/caregiver interviews and a review of available case history information
- Review and assessment of past and current developmental abilities, strengths and needs
- Review and assessment of current testing results in terms of the diagnostic criteria (taking into account the systematic impact on the child's behaviour)
- Interviews with other relevant people if necessary (eg, teachers, child care staff, and therapists)
- Observation in the home, educational or broader social settings as necessary

Social work assessment (undertaken only at the State Child Development Centre)

- Observation in the home, educational or broader social settings as necessary, in order to assess family functioning using structured and non-structured interviews and questionnaires
- Assessment of family expectations of the diagnostic process and post-diagnostic period
- Assessment of family strengths and weaknesses, including support structures, mental health, stressors, resilience and finance
- Support and advocacy for the child and family
- Attendance at the multidisciplinary team meeting and provision of a report
- Subsequent support of the family in the post-diagnostic period (eg, advocacy for services, entitlements for special payments, grieving process in relation to the diagnosis) ◆

aged to forward information to the register at the time of diagnosis. For the patient's name, postcode and date of birth to be recorded with the diagnostic details, patient or parental consent is required. At the clinician's choosing, diagnostic details may be forwarded to the register without confidential information, which could be volunteered at a later date, or left as an unidentifiable entry.

Annual comparisons are made between the number of cases received at the register and the number of cases diagnosed at major centres and private practices. Missed cases identified by comparing the diagnostic information are added annually as anonymous entries. Information is not collected on people whose condition is diagnosed outside WA and who later take up residence in WA.

Between 1999 and 2005, more than 1440 people were recorded on the register, averaging over 200 new diagnoses a year. Parental permission to store confidential information was received in 41% of all cases, the remainder being anonymous entries, with year of birth and sex attached to the diagnostic information. Confidential information is stored securely. It is used to avoid the collection of double entries, and helps to communicate with clinicians in the event of missing or unclear data. It is estimated that the register collects most new diagnoses made on children in WA, given the small number of pathways to assessments and services that exist. The number of missed cases is difficult to estimate, as the register uses all known pathways to collect cases, but any missed cases would most likely be in older children or adolescents who are diagnosed through private practice, have mild ASD symptoms, have other primary diagnoses, or move out of WA after being assessed. A significant number of adults who have a mental and social incapacity that may be best explained by an ASD may also remain undiagnosed in the community and would not be accounted for in the register numbers.

Discussion

The initiatives described here for developing consistent autism assessment methods and monitoring new cases are unique to Australia, and WA is one of few places internationally to develop uniform assessment and reporting methods within a specific region.[27] The implementation of these endeavours means that WA can create consistency within the diagnostic process, facilitate clearer assessment and service intervention pathways, monitor the

number of people diagnosed, observe changes over time, and provide population-based data for research purposes. These developments represent a strong commitment by local clinicians to maintaining high-quality diagnostic practices.

A central website was developed to consolidate information about WAADF, the WA autism register, local autism research projects, and other autism information (http://www.autismwa.org.au). A collaborative clinical and research working environment has emerged that promotes clear diagnostic processes and supports local autism research. These endeavours can be well utilised in future years to collect research data and interpret findings using information about diagnostic trends. Aspects of the WA practices may be useful as a model in other areas where effective diagnostic and monitoring strategies for ASDs are needed.

Competing interests

None identified.

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