The Royal Australasian College of Physicians

Paediatrics & Child Health Division

A Consensus Approach for the Paediatrician's Role in the Diagnosis and Assessment of Autism Spectrum Disorders in Australia

This statement has been prepared at the request of the Child Development and Behaviour Special Interest Group of the Chapter of Community Child Health, Paediatrics & Child Health Division, The Royal Australasian College of Physicians

Authors: Dr Natalie Silove (RACP), Dr Roger Blackmore (RACP), Anthony Warren (Director, Young Children and Families, Autism Spectrum Australia (Aspect)) and Vicki Gibbs (Clinical Psychologist, Aspect), Dr Jacqueline Roberts (Consultant Speech Pathologist, University of Sydney)

Purpose

Recent epidemiological research indicates an increased prevalence in autism spectrum disorders (ASD). There has been some debate about whether this increase is a result of broadening of the diagnostic concept, diagnostic substitution, greater awareness, the use of more reliable diagnostic tools, and/or a true rise in incidence possibly due to an environmental risk factor.

Given the increased prevalence and the inherent difficulties in the assessment of such a heterogeneous disorder, there is the need for a concise outline of a comprehensive evidence-based diagnostic assessment process that is achievable within reasonable time frames and distances.

Accurate diagnosis of children with ASD can be difficult. There are, as yet, no biological markers. Diagnosis is on clinical judgement based upon DSM IV criteria. Currently, there is a wide variety of assessment approaches and models.

The significant diversity in the availability and specific expertise across Australia is recognized. The strongly advocated Multidisciplinary approach may occur in different models of care and require more than one consultation. Knowledge of locally available resources and expertise, both private and public, is required to ascertain the best referral pathway and the need to refer to other services.

This consensus statement focuses on the diagnostic pathways. It is most important to emphasize that the purpose of early diagnosis is to provide early intervention.

This consensus statement has been prepared to clearly enunciate current paediatric medical opinion about the best approach to the diagnosis and assessment of suspected ASD. However, the role of the paediatrician remains far more comprehensive and includes the ongoing medical care and support of the child and family.

Principles

1. Children and young people with autism spectrum disorder are valued and respected members of our community.
2. Population screening for ASD is not currently recommended in Australia.

3. There is a wide range of available resources and models of practice in Australia and no clear consensus about a preferred method of assessment. A consistent, reliable, evidence-based process for the assessment of autism spectrum disorders is required.
4. Parents, carers and children with autism spectrum disorder require information about the nature, structure and reliability of the assessment process.
5. The model of care proposed includes five stages that would:
    - be broadly applicable to any children with complex neurodevelopmental disorders and not exclusively to children with autism spectrum disorders
    - be applicable to children of all ages and developmental presentations
    - outline a process that may require an increase in complexity of assessment according to the needs of the individual child
    - acknowledge that the assessment process may require a significant amount of time and expertise to complete.
6. Carer participation during all stages of assessment, including opportunities to observe and discuss formal assessments is encouraged.

Multidisciplinary Diagnosis and Assessment of Autism Spectrum Disorders

Stages of assessment

Stage 1 Identification of concerns
Stage 2 General developmental and medical assessment
Stage 3 Autism Spectrum Disorder specific assessment
Stage 4 Discussion and intervention planning
Stage 5 Ongoing multidisciplinary management and review

Stage 1 Identification of concerns

Objective:

- **Identify as early as possible children who may present with an autism spectrum disorder.**

1. Acknowledge initial concerns regarding development and behaviour raised in the community by families, carers or service providers.
2. Use developmental screening tools, observation and parent interview to identify specific or global delays in individual cases.
3. Use clinical judgement regarding the possible presence of an autism spectrum disorder and do not rely solely on screening tools.
4. Take a comprehensive medical and relevant family history.
5. Undertake a full physical examination
6. Refer to appropriate therapists where specific difficulties are identified e.g. language delay, fine motor difficulties, and arrange a review appointment.
7. Reassure parents where development and behaviour are judged to be within normal limits and arrange a review appointment.
8. Encourage parents to initiate earlier review should they have ongoing concerns.
9. Expedite a full assessment and management by referral to the most appropriate diagnostic and assessment service when a global delay and/or autism are suspected. This service may be in the public or private domain, and may consist of a multidisciplinary team in one location or need to co-ordinate a number of specialists in different locations.
10. **Expedite early referral to appropriate agencies for intervention as a priority when the diagnostic assessment process is delayed.**

Stage 2 General assessment

Objectives:

- **Establish the child's developmental/intellectual age equivalents.**

- **Identify any overriding medical aetiology and coexisting health problems –for example hearing and vision impairment.**
- **Identify by observation and history behaviours consistent with autism spectrum disorder.**

As part of the multidisciplinary general assessment Paediatricians:

1. Sight all available reports from therapists and educators, recent and past, including preschool, child care and school. This allows consideration of behaviour and development across a variety of environments over time.
2. Actively consult with those involved in the care of the child about the extent and nature of difficulties in development and behaviour including social interaction, communication, interests and play.
3. Observe, where possible, the general behaviour, social interaction, play and communication of a child in a natural setting amongst peers, such as child care, family or preschool. This may include video recording of the child in natural family and play settings. Observations made in the clinic may be all that is possible. Opportunities for this are enhanced by provision of toys and an indoor/outdoor play area.
4. Conduct formal assessment to establish the preschool-age child's developmental levels and adaptive skills, or refer to a psychologist or occupational therapist to do so if more appropriate.
5. Refer school-aged children to a Psychologist for comprehensive psychometric and adaptive skills assessment.
6. Ensure that a psychosocial evaluation of the family is conducted and appropriate support and intervention resourced.
7. Refer to a Speech Pathologist for a Speech and Language/Communication assessment.
8. Refer to an Occupational Therapist when there are identifiable motor, play, sensory or self care difficulties.
9. Perform a full general physical and neurological examination, hearing and vision assessment, appropriate pathological investigations, and genetic investigations such as karyotype and DNA for fragile X. Referral to specialist clinics such as genetics, sleep disorders and neurology as required.
10. Provide a diagnosis of one of the autism spectrum disorders fulfilling DSM-IV or ICD-10 classifications at the conclusion of *Stage 2*. For DSM-IV these are Autistic Disorder 299.00, Asperger's Disorder 299.80 or Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism) 299.80. For ICD-10 these are Childhood autism F84.0, Atypical autism F84.1 or Asperger's syndrome F84.5...
11. Consider and discuss the risk of recurrence of ASD or associated developmental disorders.
12. Identify co-morbid disorders for example ADHD and mental health issues.
13. Proceed to Stage 4: Discussion and Intervention Planning, when a clear diagnosis has been made. If the diagnosis remains unclear proceed to Stage 3: Autism Spectrum Disorder specific assessment.

Stage 3 Autism spectrum disorder specific assessment

Objective:

- **To provide a tertiary assessment to determine whether or not a child's clinical presentation is consistent with the diagnosis of an autism spectrum disorder.**

1. Active review of all information gathered and procedures performed at *Stage 2*, and updates and supplements as required.
2. Consider available local resources able to provide this assessment or refer to a diagnosis and assessment specialist team, where there is uncertainty about diagnosis

or where for example, educational, adaptive and psychosocial factors combine to complicate the presentation, requiring an autism spectrum disorder specific assessment.

3. Employ the use of autism specific observation and parent interview tools where necessary. **Examples** of these include the Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview – Revised (ADI-R) and Diagnostic Interview for Social and Communication Disorders (DISCO). These tools require specialist training, and experience, and additional time and resources.
   Naturalistic observations in home, preschool and school settings may also be appropriate.
4. Consider differential diagnosis and identifies co-morbidity.
5. Recognise the high support needs and intervention requirements of the child who presents with a complex neurodevelopmental disorder for whom a diagnosis of one of the autism spectrum disorders is not met.
6. Formulate the diagnosis according to the relevant DSM-IV or ICD-10. The diagnostic formulation also summarises general development, psychometric assessment results, language and communication assessment information and other specific assessment information as maybe relevant and appropriate.

Stage 4 Discussion and intervention planning

Objectives

- **Provide the parents with clear summaries of the assessment information and the diagnostic formulation.**
- **Enable parents to discuss assessment outcomes and contribute to intervention planning.**
- **Provide a comprehensive assessment report**

This stage includes:

1. Feedback to parents regarding diagnostic conclusions including comprehensive summary of assessment results and observations with examples from the assessment to explain the presentation in terms of the triad of impairments.
2. Discussion of recommendations and referral to other agencies if applicable. This also provides opportunities for parents to ask questions and seek further clarification and information.
3. Discussion of principles of interventions and setting achievable and realistic goals developed in consultation with the family.
4. Providing an opportunity for parents to raise and discuss the role of Complementary and Alternative Interventions.
5. Provision of a comprehensive assessment report. The purpose of the assessment report is to summarise the assessment process, and assessment outcomes, to answer the diagnostic question, to communicate clearly and justify diagnostic conclusions, to document thoroughly all findings for the benefit of future professionals who may work with the child, and to outline agreed recommendations clearly. The assessment report states clearly which DSM-IV or ICD-10 diagnosis applies to the child with a description of criteria that are fulfilled. The report includes description of general development or psychometrics and specific language and communication abilities.

Stage 5 Multi-disciplinary management and review

Objectives

- **Embark upon appropriate interventions in a timely fashion**
- **Identify a case manager and a supporting framework to guide intervention**
- **Review progress at appropriate intervals**

1. Assist in identifying a case manager or key worker. Most likely this will be the parent or carer of the child. However this is not always the situation and Paediatricians and other agencies also fulfil this role, often in partnership.
2. Consult with and refers to agencies that provide a range of generic and specific interventions that are as far as possible evidence based and appropriate to the needs of the child and family.
3. Maintain vigilance for co morbid medical disorders which may impact on progress and require specific medical intervention i.e. epilepsy, sleep disorders, gastrointestinal conditions, anxiety disorder, OCD, ADHD and depression. Children with complex neurodevelopmental disorders experience the same childhood illnesses as their neurotypical peers and physical examination and management is aided when they are familiar with their paediatrician.
4. Review progress and the needs of the child and family according to changes expected over time as the child develops.
5. Reappraise developmental and behavioural parameters, should the developmental trajectory or clinical presentation change over time.

In summary, the Paediatrician

- provides comprehensive medical assessment and management
- acknowledges and responds to developmental and behavioural concerns as early as possible
- plays an active part in a multidisciplinary evidence-based diagnostic and assessment process
- provides a guiding written report
- assists to identify a key worker for families
- participates in this process over several consultations
- forms a partnership with parents
- advocates for the fact that many children who have complex neurodevelopmental disorders do not meet DSM – IV Criteria for an autism spectrum disorder and require significant intervention and support.
- advocates both locally and more widely for inter-agency service coordination, collaboration, research and community education
- advocates strongly for early intervention at all ages
- Engages in ongoing education in the areas of diagnosis, assessment and intervention

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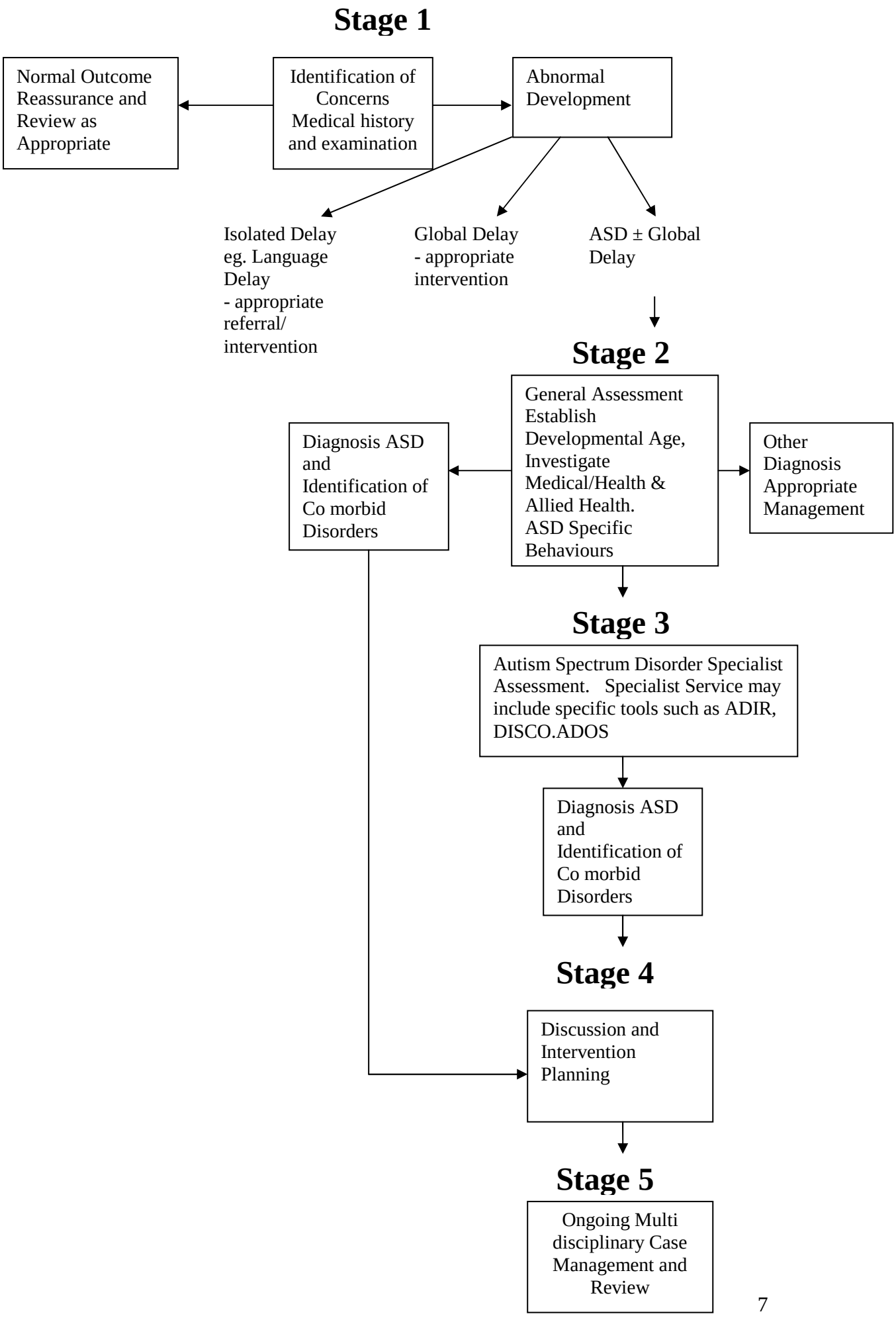
Stage 1
Normal Outcome Reassurance and Review as Appropriate
Identification of Concerns Medical history and examination
Abnormal Development
Isolated Delay eg. Language Delay - appropriate referral/ intervention
Global Delay - appropriate intervention
ASD ± Global Delay
Stage 2
General Assessment Establish Developmental Age, Investigate Medical/Health & Allied Health. ASD Specific Behaviours
Diagnosis ASD and Identification of Co morbid Disorders
Other Diagnosis Appropriate Management
Stage 3
Autism Spectrum Disorder Specialist Assessment. Specialist Service may include specific tools such as ADIR, DISCO.ADOS
Diagnosis ASD and Identification of Co morbid Disorders
Stage 4
Discussion and Intervention Planning
Stage 5
Ongoing Multi disciplinary Case Management and Review