

Autism, autistic spectrum and the need for better definition

To avoid confusion, the term “autistic spectrum disorders” should only be used as the collective term for a group of defined disorders

AUTISM IS a severe neurodevelopmental disorder associated with considerable personal suffering, parental burden and community cost. In recent reports, the prevalence of autism has varied widely from five to 67 cases per 10 000 children, an increase compared with the 3.5–4.5 cases per 10 000 children reported in the 1970s.^{1,2} This apparent prevalence increase has raised considerable public concern, particularly as it has been temporally linked to the introduction of the measles–mumps–rubella (MMR) vaccine. However, recent epidemiological investigations found no causal link between autism and the MMR vaccine.^{3,4} The increase in prevalence might indicate a true increase in incidence, but most of the increase can be accounted for by changes in case-finding methods and diagnostic criteria, and by differences in sample sizes, and the age range and intellectual ability of the populations studied.³ The increase in numbers identified has led to a corresponding increase in demand for services.

The predominant international approach to diagnosis used by the *ICD-10 classification of mental and behavioural disorders*⁵ and the *Diagnostic and statistical manual of mental disorders*, 4th edition [DSM-IV],⁶ groups autistic conditions in the category pervasive developmental disorder (PDD) and specifies criteria for the subtypes autistic disorder, Asperger’s disorder and atypical autism (PDD – not otherwise specified [PDD-NOS]) (Box). Recently, some confusion has been introduced, as there is a general move away from the term PDD towards the term autistic spectrum disorder (ASD), which has been used in at least four different ways.

1. To refer to a broader group of conditions sharing a “triad of impairments” in social interaction, verbal and non-verbal communication and imagination. Wing⁷ introduced the term ASD for this purpose. These conditions include the PDDs, but also disorders of empathy and deficits in attention, motor control and perception.⁸ The term ASD implies a continuum of disturbance in each of these three domains and has led to empirical studies of the continuum of social reciprocity which has implications for testing the clinical validity of categorical diagnostic subtypes of ASD.^{9,10} Contemporary genetic studies of autism provide evidence of a broad phenotype of social disability, anxiety, depression and unusual personality traits, and a complex interaction of several genes.¹¹ It is not known whether specific patterns of genetic abnormality or the interaction of other risk factors with a common genetic predisposition operate to produce different developmental outcomes, such as severe language disability. Ultimately, genetic studies will determine the validity of categorical diagnoses. In the meantime, for this broad phenotype construct of ASD to have better research and clinical utility each subtype requires international consensus on the discriminating diagnostic criteria, and reliable methods to measure the continuum of each domain.

Pervasive developmental disorders: broad diagnostic criteria

Autistic disorder (DSM-IV) Childhood autism (ICD-10)	Asperger’s disorder (DSM-IV) Asperger’s syndrome (ICD-10)
■ Social interaction disability	■ Social interaction disability (as for autistic disorder)
■ Language delay and communication disability	■ No delay in language
■ Restricted, stereotyped behaviour	■ Restricted stereotyped behaviour (as for autistic disorder)
■ Onset before age 3	■ No delay in cognitive development (DSM-IV only)

Other subtypes: Rett’s disorder, childhood disintegrative disorder, atypical autism (PDD-NOS).

DSM-IV = *Diagnostic and statistical manual of mental disorders*, 4th edition.⁶
ICD-10 = *ICD-10 Classification of mental and behavioural disorders*.⁵

2. To describe a continuum of intellectual ability among children with PDD — from normal IQ levels (functioning at a high level) through to severe levels of intellectual disability. Some argue that autism is a single-spectrum condition, with the observed differences resulting from different levels of intellectual ability, and that subtypes (eg, Asperger’s disorder) are not empirically justified.¹² Other studies have used the criterion of significant delay in language development to differentiate children with autism who function at a high level from those with Asperger’s disorder. They have found higher levels of psychopathology in children with Asperger’s disorder,¹³ and significant differences in executive function and motor planning between these two groups.¹⁴

3. As a description of symptom severity. For example, the Department of Education and Training in Victoria uses the Childhood Autism Rating Scale¹⁵ completed by clinicians to provide a cumulative score on the severity of some autistic symptoms to assist in determining funding for education aides. Applying the concept of severity to a disorder that has multiple diagnostic criteria is problematic. For example, a child with autism might have relatively better developed language skills and only a few untroublesome rituals, but may have severe social withdrawal. Can a concept of overall severity be meaningfully applied to such a child and might it overshadow the recognition of a potentially treatable comorbid condition such as anxiety, depression, or attention deficit hyperactivity symptoms? Children with autism who function at a high level are referred to by some as having mild symptoms,¹² even though there is evidence that they are often handicapped by high levels of psychopathology.¹³

4. As a developmental concept. Autistic spectrum is used to describe how skills, such as language, might improve relatively over time so that some children with autism might move from being less able to being more able.¹⁶

Use of the term ASD is likely to persist, but to avoid confusion it should be confined to the collective term for a group of defined disorders. Wing used it to promote access to services otherwise denied to young people with autism functioning at a high level.⁷ This problem still exists, for example in Victoria. Such children do not meet the criteria for funding for an education aide, even though they have a range of severe social, emotional and behavioural problems. Should the inclusion criteria for services be broadened to include the full range of social, emotional and behavioural needs, or, to contain costs, should they be confined to intellectual ability?

Behavioural and educational approaches to treatment have received the best empirical support.¹⁷ Therefore, allocation of increased funding to support a flexible range of behavioural, educational and family support programs, based on a comprehensive assessment of the diagnostic and cognitive profile and the emotional and behavioural needs of all young people with a PDD, is likely to prove the most economical use of resources in the long term.

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Maternal deaths in Australia

The latest triennial review of maternal deaths showed a rise in the maternal death ratio. Whether this represents a new trend or just a statistical fluctuation remains to be seen

THE REPORT ON MATERNAL DEATHS IN AUSTRALIA, 1994–96¹ was released in September 2001. It is the eleventh in a series of triennial reports that detail maternal deaths in a case summary format. The principal aim of the Report is to improve the quality and safety of healthcare during pregnancy and the puerperium through the education of obstetric practitioners.

The Report defines a “maternal death” as the death of a woman while pregnant or within 42 days of the pregnancy being delivered or terminated, and classifies maternal deaths occurring in Australia into three categories:

- Direct deaths, resulting from obstetric complications of the pregnant state;
- Indirect deaths, resulting from pre-existing disease or disease that developed during pregnancy and was not due to obstetric causes, but which may have been aggravated by the physiological effects of pregnancy; and
- Incidental deaths, due to condition(s) occurring in pregnancy, in cases where the pregnancy is unlikely to have contributed significantly to the death.

The current Report documents the first rise in the maternal death ratio in Australia since the 1988–1990 triennium — a rise from 10.9 deaths per 100 000 confinements in 1991–1993 (total number of deaths, 84) to 13.0 deaths per 100 000 confinements in 1994–1996 (total number of deaths, 100). Of particular concern is the finding that the rise in the number of deaths was almost exclusively in the “direct deaths” category (see Box). However, as the rise was non-significant in a statistical sense, we will not know, until the next two triennial maternal death reviews are completed, whether this represents the beginning of a new trend or just a statistical fluctuation in very rare events.

Although a high proportion of the direct deaths (22/46 [48%]) involved the presence of avoidable or preventable factors, the lack of uniform assessment of avoidable factors across all States and Territories, and the absence of any single factor that could account for the rise in deaths, suggests the apparent increase in avoidable factors should be interpreted with caution.

The disparity between Indigenous and non-Indigenous maternal mortality rates has previously been observed² and

Summary of key findings from the *Report on maternal deaths in Australia, 1994–96*¹

- The 1994–1996 Australian maternal mortality ratio was 13.0 per 100 000 confinements, compared with the 1991–1993 ratio of 10.9 per 100 000 confinements.
- In the 1994–1996 triennium, there were 100 maternal deaths, of which 46 (46%) were direct deaths, 20 (20%) were indirect deaths and 34 (34%) were incidental in nature. This represented an increase of 19% in the number of deaths compared with the 1991–1993 triennium.
- The increase in deaths occurred almost exclusively in the direct deaths category: 27 (32%) direct deaths were reported in the 1991–1993 triennium, compared with 46 (46%) direct deaths in 1994–1996.
- There was an increase in the proportion of direct maternal deaths in which avoidable factors were considered to be possibly or certainly present from 7 (26%) of 27 deaths in 1991–1993 to 22 (48%) of 46 deaths in 1994–1996.
- The principal causes of direct maternal deaths remained pulmonary embolism (8 deaths [17%]), amniotic fluid embolism (8 deaths [17%]) and pre-eclampsia (6 deaths [13%]). Cardiorespiratory disease was the most common cause of indirect maternal death, with 10 (50%) indirect deaths falling into this category, while the leading causes of incidental death were injuries (16 deaths [47%]), neoplasms (5 deaths [15%]) and cerebrovascular disease (4 deaths [12%]).
- The Indigenous maternal mortality ratio (34.8 deaths per 100 000 confinements) remains about three times that of the non-Indigenous maternal mortality ratio (10.1 deaths per 100 000 confinements).

remains an issue of concern. The Indigenous maternal mortality rate did decline, from 41.4 to 34.8 deaths per 100 000 confinements, between the 1991–1993 and 1994–1996 reviews. However, changes in ascertainment of Indigenous status over the past nine triennia make it difficult to determine whether there has been a consistent decline, particularly among direct Indigenous maternal deaths.

A number of factors may have contributed to the increase in deaths in the most recent triennium. In other countries,³ improved ascertainment of maternal deaths through the use of multiple data sources, including vital statistics and hospital morbidity collections, has resulted in the identification of more deaths. However, in the latest Australian Report, only three of the 12 deaths identified using additional data sources were direct deaths. The changing risk profile of women becoming pregnant may account for some of the increase in deaths. Many women are delaying child-bearing,⁴ leading to an older cohort of women being pregnant and at increased risk of maternal death.⁵ Furthermore, with advances in technology an increasing number of women who previously were unable to have children because of infertility or complex medical problems are now having children. Also to be considered is the largely unevaluated impact on maternal death rates of the implementation of multiple models of delivery of obstetric care as well as the larger structural changes in healthcare delivery. Both require further investigation.

Despite recent publicity to the contrary, the rise in maternal deaths does not appear to be attributable to the increasing caesarean section rate. The proportion of maternal deaths associated with caesarean section has remained higher than

the proportion of all caesarean births over the past four triennia. However, despite rising caesarean section rates (18.4% of all births in 1991–1993 and 19.4% in 1994–1996), maternal deaths associated with caesarean section, excluding those on recently dead or moribund women, fell from 29.8% of deaths in 1991–1993 to 24.0% in 1994–1996. There are no data causally relating the rising caesarean section rate with the increase in the number of maternal deaths.

With a small number of deaths from a range of very different causes, it is difficult to draw meaningful conclusions about the impact of the many factors purported to relate to maternal death in Australia. Furthermore, without the availability of the 1997–1999 and probably the 2000–2002 results, it cannot be determined whether the increase in deaths represents a new trend or merely an aberration.

Overall, the risk of maternal death during pregnancy and the puerperium remains small. Although differences in definition and collection procedures make international comparisons difficult, Australia appears to compare well with other developed countries, having a similar adjusted maternal mortality ratio to Canada, and a lower ratio than New Zealand, the United States and the United Kingdom.⁶ With improved general health status and family planning and increased access to general and specialised healthcare, maternal mortality declined considerably in the 20th century. Nevertheless, life-threatening complications still occur, often unpredictably and relatively more often among Indigenous women. It is therefore important that we closely monitor and review all maternal deaths and develop a surveillance system for severe maternal morbidity to ensure the health and safety of all women during pregnancy and the puerperium. The inclusion of pregnancy tick-boxes on Australian death certificates and the use of a standardised national maternal death reporting form should facilitate more accurate reporting of maternal deaths in the future.

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