

Neurodevelopmental & Behavioural Paediatric Society of Australasia

Working together to improve care and understanding

NBPSA members provide expert medical advice on assessment and care of children with neurodevelopment and behavioural problems.

The Society is a unique source of impartial information and consensus in this specialty area.

Neurodevelopmental and behavioural paediatrics

How the human brain and the nervous system develop before birth and during childhood is called neurodevelopment. Children's brains are all different and their abilities, temperaments and behaviours change as they grow. However, some children's brains are wired a little differently to others leading to neurodevelopmental and behavioural (NDB) conditions. Children with these conditions can experience difficulty with attention, have motor, language or speech problems, trouble learning or socialising and can sometimes display unusual or aggressive behaviours.

A number of NDB conditions include the word 'spectrum'. A child at one end of the spectrum may only need minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care.

NDB conditions include those described by a **constellation of symptoms that can be mild to severe, frequent and impairing** e.g. Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Learning and Language disorders and Conduct disorders.

Some NDB conditions have a **known underlying cause** e.g. Foetal Alcohol Syndrome Disorder (FASD) and genetic disorders such as Fragile X Syndrome and Down Syndrome. Environmental risk factors such as childhood trauma, use of tobacco, or illicit drugs during pregnancy, socioeconomic deprivation and exposure to certain contaminants may also affect neurodevelopment.ⁱ

Sometimes there is **no known cause** for a child's significant developmental difficulty.

Does diagnosis matter?

Children have a wide variety of abilities, ways of thinking and behaviours, all of which change over time. This makes diagnosis very complex. Children who are medically unwell, sleep deprived, bullied or distressed can sometimes display similar behaviours to those seen in NDB disorders. Locking in a diagnosis prematurely may result in harm to the child, with a lost opportunity for successful transition to adulthood.

Helping families prioritise

Specialist neurodevelopmental and behavioural paediatricians work with children and families to address any immediate stress points and plan how the child can realise their full potential. Paediatricians work with psychiatrists, general practitioners and other medical and allied health professionals on what might be causing a child's behaviour and then help families prioritise actions and navigate the complexity of the health, education and social services sectors.

Numbers appear to be rising

Latest Australian data shows six in every ten children seen by paediatricians in outpatient clinics had a neurodevelopmental or behavioural problem newly diagnosed. Top conditions were ASD, ADHD, sleep disturbance, learning difficulty and behaviour concerns. ii

6 in every 10 outpatient children



Experts estimate that five per cent is a realistic upper limit of US children with ADHD, but by 2011 several US states reported rates above 13 per cent among both boys and girls.ⁱⁱⁱ A reported 7.4 per cent

of Australian children 4-17 years have ADHD ^{iv} and ASD numbers are rising in Australia and New Zealand.

It is unclear why numbers are rising. It could be that awareness improves the rate of referral for care or that perverse funding incentives drive the demand for diagnosis of specific

▲ 0.4% (1.8% to 2.2%) ASD 18,000 children

1.4% (1.4% to 2.8%) ASD 41,900 children

5-9 yrs

New Zealand 2011-12, 2016-17^{vi} Australia 2009, 2015^{vii}

conditions to attract educational and disability support services. v

Given the significant differing behaviours experienced by children, the functional and care needs of a child, not the diagnosis, should be the determining factor in gaining access to child support services

It is important to get it right. The community cost for treatment of NDB conditions is high. In New Zealand, for example, the cost of Foetal Alcohol Syndrome Disorder is estimated at \$450 million each year, with a productivity loss of \$49 million to \$200 million annually due to the community impact of disease and premature death. viii

Early intervention

Children who have significant reading or behaviour problems are at a higher risk of delinquency, dropout, poverty, unemployment and incarceration. Getting the timing right for early interventions is critical to helping them achieve their potential. ix.x

From the age of 12 months **Sharon** was placed in front of the TV to help keep her quiet. She was non verbal and had limited play skills, something her parents thought would sort itself out. School was the first time anyone other than Sharon's family had an opportunity to review her. By the time she saw a neurodevelopmental paediatrician eighteen months later, she was disinterested and disruptive in school and was unable to read. An earlier paediatrician review would have helped understand the cause of Sharon's behaviour with more targeted, timely intervention.

Public health

Public health specialist neurodevelopmental paediatricians operate at both an individual and population health level. They advise health systems and communities on how to protect children from violence, improve parental literacy and grandparent care, reduce alcohol consumption during pregnancy and recommend safe screen time limits for children.

In grade 4 **Robert** threw chairs at his teachers and had significant learning delay. He dropped out of school and ended up in juvenile justice. Robert was later found to have a mild intellectual disability as part of Foetal Alcohol Syndrome Disorder. Earlier NDB paediatric assessment may have led to earlier identification of his strengths and vulnerabilities and allowed interventions which would have been likely to improve his behaviour.

Stopping alcohol exposure during pregnancy can stop children like Robert suffering these lifelong disabilities.

About the Society

The vision of the Neurodevelopmental and Behavioural Paediatric Society of Australasia (the Society) is to help children with neurodevelopmental and behavioural challenges, their families and their treating clinicians, to be the best they can be.

The Society brings together medical experts from across Australia, New Zealand and South East Asia who provide integrated care and support for children and families. The Society includes paediatricians, paediatric neurologists, psychiatrists, general practitioners, career medical officers and specialist physician trainees.

97 per cent of children under 12 newly diagnosed with Autism Spectrum Disorder in Australia in 2015 were assessed and diagnosed by paediatricians.xi

Established in 2012 the Society has grown with many doctors seeing the benefit of membership in supporting their individual practice and improving quality care for children and families. As an affiliate of the Royal Australasian College of Physicians, the Society provides the highest level of physician expertise. Running professional seminars and conferences for members and allied health professionals working in neurodevelopmental and behavioural paediatrics, the Society fosters the most up to date practice across Australasia.

Impartial consensus advice

Having no single diagnostic focus ensures that the Society provides individuals, organisations and governments with impartial, consensus medical advice on the complex array of behaviours, assessments, diseases and interventions in NDB paediatrics.

With its rapidly expanding member base and a focus on consistency of care and application of evidence based research, the Society plays a unique role in promotion and uptake of agreed standards and guidelines. This is important in reducing unwarranted variation in assessment, diagnosis and treatment, something that has been identified across Australia and New Zealand. Xii

There are 5200 paediatricians across Australia and New Zealand. xiii

Over half of all Australian paediatric practice is in neurodevelopmental and behavioural problems.^{xi}

A caring culture

It takes a special kind of person to see children with complex needs that do not lend themselves to a quick fix. The increasing demand for NDB paediatric care is managed by doctors who have a long term focus on getting the best outcomes for kids. These highly expert doctors are kind and compassionate and have a caring, collegiate culture.

The Society is unique in providing these doctors with strong local and international networks. This allows collective wisdom in treating children and families with complex problems as well as improvements in quality of care, while supporting medical resilience.

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