

Viewpoint

## Models of care in neurodevelopmental-behavioural paediatrics

**Brad Jongeling**<sup>1,2,6,7</sup>

**Gehan Roberts**<sup>2,3,4,5</sup>

<sup>1</sup>Child Development Service, Western Australia

<sup>2</sup>Neurodevelopmental and Behavioural Paediatric Society of Australasia

<sup>3</sup>Centre for Community Child Health, Royal Children's Hospital,

<sup>4</sup>Population Health, Murdoch Childrens Research Institute,

<sup>5</sup>Department of Paediatrics, University of Melbourne, Melbourne, Victoria, Australia

<sup>6</sup>Department of Paediatrics and Child Health, University of Western Australia

<sup>7</sup>Department of Paediatrics, Joondalup Health Campus

### Contact:

Dr Brad Jongeling, Child Development Service, 189 Royal Street, East Perth WA 6004, Australia

Phone: (61) 08 9222 4222

Email: [Brad.Jongeling@health.wa.gov.au](mailto:Brad.Jongeling@health.wa.gov.au)

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## Abstract

In Australia, children with developmental-behavioural (DB) presentations experience large variations in both access to specialist health care and in the care they receive by specialists. A recent survey of members of the Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) confirmed that this variation persists even among public services provided by paediatric doctors with a special interest in this field. In this article, we discuss the challenges of establishing a single model of DB paediatric care and set out principles of best practice in the field. An essential part of working towards excellence in care involves defining our outcomes, utilising standardised measures, collecting systematic data, working in partnership with families to address their concerns and goals, participating in reflective practice, and demonstrating a willingness to change current practice based on the results.

## What is developmental-behavioural paediatric care?

**Developmental-behavioural (DB)** paediatric care is a core part of general paediatrics. Data from the Australian Paediatric Research Network (APRN) show that in Australian general paediatric outpatient clinics, the proportion of children presenting with DB conditions rose from 48% to 60% for new consultations and from 54% to 66% for review consultations, from 2008 to 2013.<sup>[1]</sup> The top 5 new diagnoses reported by general paediatricians were Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder (ADHD), sleep disturbance, learning difficulty and behaviour concerns.<sup>[1]</sup>

The Royal Australasian College of Physicians, recognising this area of practice as an unmet training need for the paediatric workforce,<sup>[2]</sup> has introduced 6 months of mandatory training in 'Developmental and Psychosocial Paediatrics' for all paediatricians and has also established the Chapter of Community Child Health, defined as "a branch of Paediatric Medicine focussed on the health and development of children in a broader community context". Members of the Chapter are expected to have "significant expertise or engagement in community child health or the domains of child protection, child development and behaviour and/or child population health".<sup>[3]</sup>

Despite these advances in training and credentialing, defining DB paediatrics remains a challenge in the Australian and New Zealand context. In Australia and New Zealand, paediatricians are specialists, and do not work in primary care. Those who primarily see children with DB concerns may argue that they are sub-specialists in this field, but general paediatric colleagues, especially those who work in regional and rural settings may argue, with equal merit, that this skill-set is required of all paediatricians. In order to support doctors who work in this field, the Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) formed in 2012. NBPSA is an organisation for doctors who have a specialist clinical or academic interest in neurodevelopmental paediatrics.<sup>[4]</sup> Although the membership initially comprised a small number of doctors who primarily saw children with DB concerns in their clinical practices, membership has risen rapidly (from 51 in 2013, to over 400 in 2018), with the largest contributor to membership growth being general paediatricians who would like to further develop their skills in DB practice. Michael McDowell, foundation president of NBPSA, argues in a recent publication in this journal, that DB paediatrics should adopt the long-term optimisation of

functional outcomes as its key clinical goal.<sup>[5]</sup> This Viewpoint paper encourages clinicians to embrace the inherent uncertainty in this work, and to work towards understanding not just the neurological basis of a clinical presentation, but also the interaction of ecological, social, psychological and behavioural factors which both impact presentation and act as part of the determinants of outcome.<sup>[5]</sup>

Based on these converging areas of interest, we may broadly define DB Paediatrics as the provision of paediatric care to children whose developmental and behavioural trajectories vary substantially from neurotypical peers, who have functional impairment due to these variations and who are likely to have multifactorial aetiological processes contributing to their presentations. The purpose of the clinical interaction with the child and family varies depending on the child's age, the stage of clinical interaction (assessment versus long term care) and context – including family, child and societal expectation. The initial assessment period should focus on understanding the child, exploring a medical diagnosis or co-morbidity, considering functional skills, documenting developmental level or difficulties, and arranging investigations. It may also involve pragmatic support such as facilitating access to funding and providing help with minimising symptoms causing distress to the child or their carers. In all clinical interactions the overarching goal should be optimising the child or young person's overall quality of life and long-term outcome.

### **Warranted vs. unwarranted variation in developmental-behavioural care**

Given the broad scope of practice described above, it seems unavoidable that variation in care is the norm. A December 2014 unpublished cross-sectional audit of paediatric cases managed by members of NBPSA who work in large, public, metropolitan child development services showed a broad range of practice patterns in the management of a range of conditions. 4,500 children were under paediatric management at the time of audit, of whom 46% were of primary school age and 26% early childhood. More than 36% of children (1,637) had a disability diagnosis including the following most common diagnosis – autism (18%), global developmental delay (13%), intellectual disability (6%), syndrome diagnosis (2.4%) and chromosomal anomaly (1.5%). Thirty percent of children had multiple developmental diagnosis. 22% of the cases (1,020 children) had ADHD with 72% prescribed medication. Despite the service aiming to provide a standardised approach to assessment and treatment, variations across sites and paediatricians were seen for a range of measures, including the use of questionnaires, the type of diagnoses they manage, medication prescription rates and type and review frequency. Variation in practice often occurs where evidence for treatment and practice is limited and consensus guidelines are scarce. This is a clear area of need in DB paediatrics.

Given the above example, it is likely that across Australia and New Zealand variation in DB practice is common. Possible explanations may be the paediatrician's training and experience, or local issues such as locally defined psychosocial determinants of health, access to state funded multi-disciplinary services, and availability of NDIS or disability services. Therefore, while standardisation of care is a worthy goal, it is unrealistic to aim to eliminate all variation in aspects of DB paediatric care. Some variation in care is unavoidable (e.g. due to policy differences between states and territories, state versus federal funded services) or desirable (e.g. when it supports patient and family centred care).

However, efforts should be made to minimise unwarranted variation (e.g. in provision of effective care, care that lacks evidence or is associated with harm, or care that varies due to availability of resources).<sup>[6]</sup>

### Care according to Postcode

The issue of a “postcode lottery of service provision” was seen in Western Australia in 2006 as a major block to providing equity of service. A major reform process arose out of a review conducted by the Health Reform Implementation Taskforce (HRIT)<sup>[7]</sup> which found that the varied history of each child development centre had resulted in a fragmented service with different models of care and approaches to therapy for developmentally delayed children. This review referred to a ‘postcode lottery’ in which:

... many children received insufficient intervention, too late for it to be truly “early” with a commensurate increase in the need for ongoing therapy.<sup>[8]</sup>

The reform process began in 2007 and resulted in the formation of a single metropolitan Child Development Service which forms part of an integrated child and adolescent community health service and led to a number of practical measures including:

- the completion of the first service-wide evaluation (the Consumer Perspectives Project) to obtain feedback from consumers and health professions;
- the development of a continuum of care framework which articulates eligibility criteria and the full range of services offered;
- the development of clinical pathways for a range of common conditions;
- standard referral and intake processes;
- Service level agreements/Memoranda of Understanding with the Child and Adolescent Mental Health Service (CAMHS), the Disability Services Commission (DSC), and the WA Country Health Service (WACHS); and
- the development of an information management system, the Child Development Information System (CDIS).<sup>[8]</sup>

This continuing reform has resulted in postcode no longer being as strong a factor in service eligibility and provision in metropolitan Perth.

The complexity and uncertainty of DB paediatric care should not stop us from attempting to reduce unwarranted variation in care. Identifying the elements of safe and effective practice (e.g. adherence to national or international guidelines when they are available, and peer supervision and consensus-based practice when they are not) and integrating these with child and family preferences are worthy goals. The Perth metropolitan Child Development Service experience demonstrates that the growth in the use of electronic medical records, online data collection platforms and shared databases make it possible for us to compare our practice with those of our peers, to define benchmarks, and to measure our progress.

## **Future directions: lessons learned from the Child Development Service reform**

Without data, in the absence of existing literature that can be readily applied to the presenting problem of the child in our clinic, all we have left to guide our individual practice is anecdote, past medical experience and memory: all notoriously unreliable methods of informing practice. However, collecting important data at baseline and follow-up, and using the electronic medical record to integrate these data with hypothesis-driven trials of interventions, may give us a way forward.<sup>[9]</sup>

Many of the guiding principles developed as part of the Perth metropolitan Child Development Service reform are relevant for paediatric DB services generally. Some specific principles are discussed below.

**Partnerships:** Parent Partnership and strengths-based approach (focusing on shared decision-making and coaching/goal-setting with active parent involvement); use of natural learning opportunities; relationships-based practice; teamwork; interagency collaboration; and an outcomes-based service, all within a responsive service.

**Electronic database:** The electronic medical system introduced in 2007 also facilitated greater monitoring of wait-lists, data on diagnosis, treatment and therapy and awareness of practice variation. This led to the more recent reforms, including a move to a First Appointment (intake and service planning) model, introduction of a range of Parent Information Workshops, joint paediatric and allied health clinics and paediatrician-led developmental nurse clinics. Further plans include providing differing levels of service provision according to need, working in collaboration with clinical nurses in a supervised assessment and management approach, standardising patient flow and assessment, and case conferencing and telehealth models of assessment.

**Standardised questionnaires:** Traditionally, measures of service provision and clinical management in the Child Development Service have involved questions about parent satisfaction and knowledge. However, increasing awareness of the need to document outcome of service (beyond solely parental satisfaction) has meant that other standardised measures of child and family function need to be considered. Tools such as the Strengths and Difficulties Questionnaire (SDQ), Clinical Global Impression (CGI) scale, and the Parenting Stress Index (PSI), in addition to online screening tools such as the Ages and Stages Questionnaire and the Conners Early Childhood scales, are being considered. These may be used prior to and/or following assessment or intervention to measure change in child function or in parental stress as a way of evaluating child and family outcome. Electronic medical record systems allow a more streamlined ability to record such data as part of a clinical model, embedding outcome-based research in clinical design.

## **Principles of 'best practice' care in developmental-behavioural paediatrics**

A best practice model of care should be able to embrace warranted variation (the needs and preferences specific to the patient population under consideration) while minimising unwarranted variation (non-adherence to effective care strategies, care determined by availability of resources or postcode, variation which exists because of lack of evidence or consensus). In aiming to move to a new paradigm in DB care we suggest the following key principles:

- Understand/ define the population the DB service is responsible for.
- Clearly define the responsibilities of the different levels of service, with pathways for primary care services to feed into secondary and tertiary care (e.g. Health Pathways).
- Ensure that the entry point to the service starts with a broad developmental assessment (not a diagnosis-based assessment), and includes assessment of function, identifying areas of concern, differential diagnosis, and hypotheses about priorities for intervention.
- Set up a contract with the patient and family around goals and expectations.
- Address the parents' and child's primary concerns while also allowing the clinician to use their knowledge and clinical skills to guide assessment, diagnosis, management and advice.
- Use electronic data collection options to support assessment, diagnosis and monitoring of treatment.
- Consider a national minimum dataset to allow benchmarking and comparison and document outcome – both short and long-term data.
- Consider an agreed approach to diagnostic assessments and standardise elements of the clinical assessment whenever possible (e.g. questionnaire use in ADHD, standardised developmental assessments).
- Work with allied health partners utilising a range of options including joint assessments, case conferencing or Telehealth.
- Provide information about online supports and programmes, especially for families who experience difficulty attending regular appointments.
- Ensure clear communication with families, GPs, and other stakeholders such as educators.
- Request consumer input and feedback.

## Conclusions

DB concerns are extremely common in paediatric practice and make up the majority of the concerns presenting to general paediatricians. Doctors who care for children and families with these concerns (whether as part of a general paediatric service or a dedicated DB-focussed service) should aim to practice within a group of unifying principles that inform their care. No matter what the purpose or goal of the current visit or clinical interaction, we suggest that the clinician partner with the child, family and other stakeholders to aim for the overarching goal of optimising the child or young person's overall quality of life and long-term outcome. In a field where the existing literature is often insufficient to inform day-to-day practice, we suggest a data-driven, outcomes-focussed approach, using reflective practice to inform practice at both the individual and health service level.

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