

Neurodevelopmental-behavioural paediatrics

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Purpose of review

Neurodevelopmental-behavioural paediatrics (NBP) is a field of medical practice that has arisen in response to recent changes in child health epidemiology. This review considers how the profession of NBP is addressing clinical need, and discusses possibilities for future development of the field.

Recent findings

Research publications relevant to NBP clinical practice focus primarily on cause (e.g. biology, imaging, neuropsychology), early detection, diagnostic methodologies and initial treatment strategies, with emphasis on psychotropic medication. Translation of this research implies that NBP clinical services should be undertaken using algorithmic methodologies, and evaluated against treatment attributable outcomes. These strategies and outcomes potentially define the central purpose of the profession; however, they may not be sufficient to best help the children seen.

Summary

Two sets of information inform and extend consideration of NBP purpose and strategy. Firstly, longitudinal and adult studies indicate that even with treatment, problems persist in adult life for a significant proportion of children with neurodevelopmental-behavioural disorders. Secondly, NBP clinical practice deals with significant, irreducible complexity and uncertainty, arising from both child-diagnostic and contextual factors. Complexity limits the extent to which evidence-based clinical algorithms are able to inform care. Suggestions for how to address both challenges are offered.

Keywords

complexity, neurodevelopmental-behavioural paediatrics, outcomes

INTRODUCTION

As a descriptor of community child health, the term 'new morbidity [1]' was first used more than 30 years ago. Although the 'new morbidity' is no longer new, the profile of issues characterised by this phrase continues to change. Central to this emerging epidemiology are problems of child development and behaviour. These problems are now common in the community [2], and prevalence appears to keep rising, notably for autistic spectrum disorder [3– 5]. It is unclear the extent to which this reflects increased incidence [6[•]] beyond the consequence of greater community awareness and detection [7].

These changes impact community/outpatient/ ambulatory health services. In Australia, for example, the proportion of paediatric consultations for child development and behaviour problems, both new and review, has risen to above 50% [8**]. Children with traditional medical problems, particularly, those of a chronic nature, present a high prevalence of co-occurring problems in the domains of development and behaviour [9].

Neurodevelopmental–behavioural paediatrics (NBP) describes the field of medical practice that

has arisen in response to this shifting need. Systems and nomenclature used to describe this work vary by country. In the United States, for example, there is distinction between developmental–behavioural [10], and neurodevelopmental disability [11] paediatrics. In the United Kingdom, with predominantly public health services, NBP is integrated into community paediatrics, along with child protection and public health [12]. The situation in Australia is similar to the UK [13], and here we have established an independent society to address the continuing education and advocacy needs for NBP professionals [14]. This article uses the term NBP as a generic descriptor for paediatric medical clinical work with neurodevelopmental and behavioural problems.

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KEY POINTS

- The changing profile of child health epidemiology continues to drive growth in neurodevelopmentalbehavioural paediatrics (NBP) as a profession.
- Research that informs clinical practice is necessarily restricted to questions that are answerable using available methodologies. This research potentially constrains the strategies and purposes of NBP.
- Research-informed clinical purpose directs practice towards interventions whose outcomes are considered mostly in the short term. By contrast, many neurodevelopmental-behavioural clinical problems persist, even with treatment, into adult life. Consideration of long-term outcomes should be central to the purpose of NBP as a profession.
- Research-informed clinical strategy utilises methodologies that are able to be characterised algorithmically. By contrast, many NBP clinical challenges are inherently imprecise, uncertain and complex. NBP practice would benefit from an explicit understanding and strategic response to clinical complexity.
- By addressing the challenges of long-term outcomes and clinical complexity, NBP is likely to grow towards a professional identity that is better defined. Most importantly, the children seen are likely to benefit from more successful professional practice.

Despite national variations in professional structures and associated training pathways, there remains a common set of challenges. In order to extend beyond traditional medical symptoms and signs, and deal with clinical phenomena related to child development (i.e. knowledge, skills, behaviour, change over time), NBP must work explicitly across the biological–psychological–social continuum. Inclusion of these layers adds complexity to the medically grounded profession of Paediatrics. This article considers the current state and ongoing challenges for NBP as a clinical discipline in light of these challenges and the available evidence base.

NEURODEVELOPMENTAL-BEHAVIOURAL PAEDIATRICS

Consider NBP within the context of adjacent medical groups (e.g. general paediatrics, psychiatry, neurology, rehabilitation). What does NBP offer that is unique, that differentiates the profession? Is there an NBP-specific vision of purpose, and associated strategies, that guide the pursuit of best practice?

The default approach to exploring this question is to examine published evidence used to inform the

profession. In doing this, one finds publications that continue to examine issues, such as early detection (e.g. [15]), organic cause (e.g. [16]), clinical diagnosis (e.g. [17[•]]). psychotropic medication (e.g. [18]), and nonpharmacological intervention strategies (e.g. [19]).

What does this set of publications tell us about the profession itself? The data and practice examined are of general interest across multiple professions. Furthermore, much of the diagnostic nomenclature used in NBP practice draws directly from psychiatric constructs [20]. Arguably, this is insufficient to characterize a unique NBP clinical practice identity.

This literature collectively defines a default set of outcomes for NBP. In the absence of an alternative specified vision of purpose for the profession, clinical literature shapes the planning, funding and accountability of services. It both informs and constrains consideration of clinical best practice, training and ongoing research. The literature thereby defines how we help children.

Constructed in this way, is the profession of NBP able to best address the needs of children seen? We believe it is problematically limited. In this article, we consider data relevant to the broader question of NBP as a profession, from the dual perspectives of clinical purpose, and strategic methodologies necessary for effective care.

Clinical purpose

Clinical purpose refers to the set of outcomes against which a profession defines itself. It is the outcomes for which the profession takes responsibility, the goals towards which it strives to improve professional practice [10]. As noted above, the clinical evidence-basis [21] for NBP services implies purpose-by-default, thereby directly informing practice. Following detection and referral, the initial focus for NBP services becomes comprehensive diagnosis. The nature and extent of any intervention provided is funded and evaluated against diagnosisspecific, treatment-accountable outcomes that are mostly considered in the short-term. In our observation, this is often the case for public health services in Australia.

A different body of literature would suggest that this is not enough, and that short-range outcomes are best considered within a long-term vision of clinical need. NBP problems appear, in large part, to arise from biological causal mechanisms, with their expression modified by environmental factors [22^{••}]. Evidence from adult studies suggests that childhood aetiological changes commonly persist into adult life (e.g. [23–25]). Clinical research provides additional, persuasive evidence regarding persistence, but this is not straightforward. For chronic medical disorders of childhood, such as diabetes, the central challenge remains relatively linear (sugar control and related organ complications). By contrast, NB problems change over time, because of biological development, therapeutic interventions and changing contextual demands (e.g. school curriculum). As a result, clinical needs vary according to stages in the child and adolescent journey (e.g. [26,27,28^{••}]), continuing to change throughout adult life (e.g. [29[•]]).

Change over time becomes more unpredictable and nonlinear because of how individual children manage their predicament. Poor adaptation can lead to secondary problems beyond the direct consequences of the primary disorder. These secondary domains include mental health, education and employment, social function and criminal justice issues (e.g. [27,30–36]). In NBP, this compounding morbidity arises due not only the cumulative impact of underlying biological processes but also the quality of care integrated over time. At the core, it reflects the accumulated psychological experience and adaptive responses of the individual child [33].

In light of this compounding risk, we propose that the purpose of NBP be defined around what it seeks to achieve over time, beyond initial diagnostic and treatment activities undertaken. We have argued elsewhere [37^{••}] that the achievement of optimal long-term (transition to adult) clinical outcomes for children be explicitly adopted as a central purpose for the profession of NBP. Specifically, we recommend that all NBP clinical services commit to the optimisation of long-term outcomes, even if they do not provide the necessary longitudinal care themselves.

We would consider appropriate longitudinal care to extend beyond monitoring activities (e.g. management of medication), to actively address optimisation of current and future well being across all relevant areas of attributable outcome (e.g. skill, knowledge, function and social connectedness, behaviour, resilience, autonomy and self-efficacy, physical and mental health). Without explicit intention to optimize long-term outcomes, translated into successful longitudinal strategy, the risk remains that the children we see will fare poorly when they transition to adult life.

Longitudinal care and long-term optimisation is neither new nor unique to NBP. The US clinical training program in Neurodevelopmental Disability identifies longitudinal care as a key point of differentiation in comparison to Neurology [38]. Indeed, this professional agenda extends provision of care across the child and adult lifespan, an option not available to services constructed in paediatric context.

Clinical strategy

Consider the stages of clinical presentation summarised in Table 1. At the referral stage 1, information indicates a potentially linear path of diagnosis and treatment. With further information at stage 2, the clinical challenge becomes complicated. Clinical methodologies based on evidence-based practice are still reasonable, but professional expertise is required when considering priorities and strategy.

With the additional material of stage 3, the clinical challenge alters in a fundamental way. It is no longer possible to clearly differentiate salient diagnostic components from the network of causal interactions. As a result, it is no longer possible to reduce the situation to a set of prioritised, definitive diagnoses, each with predictable management pathways. The clinical picture has changed from complicated to complex.

Moving from stage 3 to stage 4, the complexity of the child's clinical predicament changes further, devolving into chaos. Clinical care is necessarily directed towards the resolution of crises, pausing any systematic consideration of rehabilitation and future developmental trajectory. In this article, we will not address the challenge of clinical work in this fourth quadrant of chaos, other than to note that crisis-reactive care is not uncommon in NBP clinical work, and deserves directed attention. It raises a unique set of challenges, for example, in the pathways for collaboration between services both within and beyond healthcare.

The focus for this article is clinical complexity, with the central proposition that complexity is common, fundamentally irreducible and unavoidable. To begin with, complexity arises from the uncertainty intrinsic to NBP diagnostic science. There is heterogeneity of biological cause, even within single diagnostic categories [39-44]. Additional uncertainty arises because of heterogeneity of clinical phenotype and severity for individual diagnoses [45–48]. More fundamentally, uncertainty is built into our lexicon as the term 'diagnosis' is used to characterize a spectrum of entity types. At one end of this spectrum are diagnoses derived from medical investigations (e.g. Fragile X syndrome). At the other end are diagnoses based on patterns of behaviours observed, and considered against the observer's interpretation of normal (e.g. Attention Deficit Hyperactivity Disorder). Other NBP diagnoses fall between (e.g. Foetal Alcohol Spectrum Disorder, where causation is presumed to varying degrees of certainty). Finally, the term 'diagnosis'

Clinical stage	Information provided	Information complexity
(1) Referral information	Referral concerns: learning, and behaviour (mainly at school). Assessment information: ADHD rating scales with T scores >70	Simple. Definable issue with evidence-based clinical path
(2) Initial consultation	Discussion expands range of concerns to include literacy, social (bullying), high levels of screen time, and intermittent faecal soiling	Complicated. Each problem amenable to linear thinking Clinical judgement necessary to triage importance and prioritise management sequences.
(3) Parents talk to you without the child present	'X' is in long-term foster care. He was born to an 'at risk' pregnancy, complicated by probable drug and alcohol use. His early childhood included neglect and domestic violence. He has experienced several foster placements. Currently there is considerable stress at home regarding finances, and the challenge of managing 'X', who has temper tantrums at unpredictable times. They feel that the school 'doesn't get' and 'doesn't like' him	Complex: Linear thinking cannot accurately characterize each contributing issue, because of the network of interactions. This makes diagnostic formulation uncertain, with consequent uncertainty regarding management
(4) Review visit	'X has been excluded from school for physical bullying. His placement at home is likely to break down as they struggle to manage him. The foster-parent's marriage is under unsustainable stress	Chaotic: Fragments do not reflect a coherent whole. Management becomes crisis-reactive, to re-establish safety and stability

Table 1. Levels of complexity by clinical stage: boy 'X', aged 7 years

ADHD, attention deficit/hyperactivity disorder.

ascribes the locus of problems to the child, whilst clinical challenges arise also from factors external to the child, both current and past. An example is 'goodness-of-fit', a concept recognised in the study of child temperament more than 50 years ago [49].

Putting this together, clinical complexity arises from the number of contributing components and their interactions (as per stage 3 of the example above), in combination with layers of interactive uncertainty that is intrinsic to our diagnostic science. Considering this clinical challenge collectively as a 'complex system', definitions of cause (diagnosis) as well as the prediction of system behaviour over time (natural history), becomes impossible to model with algorithmic certainty.

Irreducible complexity arises independent of clinical competence (which remains essential!). This is important to understand, as the resulting uncertainty otherwise may generate a sense of professional inadequacy, such as 'Imposter Syndrome' [50[•]]. It potentially drives the quest to gather unnecessary additional diagnostic data.

As a scientific concept, complexity may be intuitively self-evident, however, a precise definition is not straightforward [51]. For clinical purposes, we define system complexity as a property arising from the interactivity of multiple components, amplified by the imprecision and uncertainty intrinsic to the components themselves. As the number of contributing factors and resulting level of interactivity increases, complexity arises when algorithmic methods are no longer able to adequately characterize current behaviour, or predict future behaviour of the system.

We argue that much of NBP, considered either at a point in time (cross-sectional) as well as across time (longitudinal), is inherently complex. As a result, there are clinical phenomena that arise because of the complexity itself. Examples include nonlinear rates and patterns of change over time, self-organisation and adaptation arising within the system, and the emergence of novel (nonpreexisting) properties [52].

In summary, clinical predicaments that are simple or complicated are amenable to algorithmic, evidence-based practices, interpreted through professional expertise. Chaotic situations require problem-reactive action. Complexity presents its own unique and interesting set of challenges. We propose that the profession of NBP respond intentionally and explicitly to the challenges of complexity as a necessary understanding that guides our clinical work. Some examples of what this might look like are presented in the next section.

MANAGING CLINICAL COMPLEXITY AND UNCERTAINTY

What is the best way to address complexity in clinical practice through diagnosis, early treatment

and longitudinal care? This question, by definition, is not answerable using best-practice algorithms. There is a need for additional concepts and related strategies. The following recommendations derive from first-principle clinical reasoning [53[•]], our own clinical observations, and the translation of professional literature from fields beyond medicine [54].

Diagnosis

Medical diagnoses traditionally communicate information regarding cause, patterns of expected symptoms and signs, natural history and treatment options. In NBP clinical practice, diagnoses form the foundation for clinical understanding and communication, treatment planning, administrative accountability, teaching and research. Across all these situations, we use the single descriptor 'diagnosis', yet the nature and specificity of information conveyed by diagnoses used in NBP varies considerably, as noted above.

Responding to this variability, we recommend a transparent response to diagnostic limitations. The goal of this is to define what is known, and address the degree of residual uncertainty across clinically relevant areas. One approach to this is the concept of 'formulation' [55], where diagnostic terminology is embedded in a larger information structure that attempts to capture salient areas (e.g. Table 2). A multiaxial process was incorporated into the fourth edition of the *DSM Diagnostic Manual* [56] for this purpose. The set of information appropriately

conveyed within formulation structures varies according to need (e.g. service funding and advocacy, professional communication, research).

Whilst biologically derived diagnoses remain stable as clinical complexity increases, diagnoses constructed from clinical data become less precise. This may reach a limit where diagnostic certainty is neither possible nor appropriate. In this situation, it is reasonable to conceptualize and communicate 'working diagnoses-as-hypotheses'. This implies that the working diagnosis is the best interpretation of the data at that time, but may well change as further information emerges. This methodology is similar to general processes of scientific enquiry.

For interest's sake, we would like to introduce a recent, novel methodology for managing diagnostic information in complex clinical situations. Network modelling has been used for some time as an analytic tool for complex systems [57], and is currently being explored as a mental health research tool [58^{••}]. Network models are assembled from all known relevant components (causal, symptomatic, contextual), then the relationships between components are defined and quantified (as best understood). Such models are atheoretical, making no presumptions about underlying latent constructs or about mechanisms beyond what can be reliably observed and evaluated [59].

Network models have advantages that address limitations inherent to current NBP diagnostic schemas. They have capacity to explore interactions between individual components and the full clinical

Table 2. Diagnostic formulation				
Area	Explanation	Example		
Categorical	Diagnoses for which the child has met category criteria	Specific Learning Disability (SLD-Literacy)		
Clinical	Functional problems Degree/severity	Reading, comprehension and spelling at 2 years below expected for age and intelligence		
Cause	Medical information regarding causation, known or presumed	Presumed to be of genetic origin based on positive family history		
Natural history	Implications of causal processes into the future	Underlying biological weaknesses are likely to persist (if genetically caused). There is evidence for treatment- related neuroplastic modification		
Neuropsychology	Domains/severity of neuropsychological weaknesses	Significant weaknesses in phonological awareness, executive function (sequencing, rapid autonomic naming) and working memory (auditory and visual/ spatial)		
Associated issues	Areas of the clinical predicament that influence function and outcome, and that influence management	Anxious temperament – ability to function, particularly in literacy, is reduced by stress He does not understand SLD, and is fearful that he is 'stupid' He is passionate about, and competent in ball-sports		

The following is an example of formulation for a child presenting with reading difficulty, used to address areas of knowledge that are not directly communicated through individual diagnostic categories. The audience is parents, teachers and therapists.

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picture. They are able to integrate components across the structural boundaries of formal diagnostic restrictions (such as comorbidity [60]). They integrate information from both the individual and their 'goodness-of-fit' context. By iterating models (where output of the model becomes the input for the next step), it is possible to experimentally examine changes over time. This enables modelling of the influence of clinical variables on the natural history of conditions [40] along with the potential impact of treatment interventions. Network models have been used to examine developmental questions, for example, the emergence of obsessive problems in Autism [61] and predictors of subjective well being as a long term outcome for individuals with ASD [62].

Initial interventions (towards short-term outcomes)

Whilst treatment options for simple and complicated clinical challenges are appropriately guided by evidence from clinical trials, informed by professional experience and judgement, what is the best response to complex situations? This question has been examined in the area of business management (e.g. Cynefin framework [54,63^{••}]). We have adapted this thinking to NBP clinical practice (Table 3).

The Cynefin response to complex business management predicaments is empirical and agile rather than algorithmic. Initial strategies are selected intuitively as well as from evidence-based algorithms. Over time, strategies that seem effective towards intended outcomes are reinforced, whilst those that appear to be ineffective may be altered or ceased. Strategies serve not only as interventions towards outcomes but also as 'probes' to examine areas that are not predictable, to learn more about the individual system through active feedback and modification.

Applying this thinking to NBP, uncertain clinical diagnoses could be formulated as 'hypotheses-tobe-tested', able to change as new information emerges. Modifying diagnostic understanding in this empirical way potentially leads to more adaptive goals, and successful short-term and long-term treatment.

Finally, approaching treatment as a complex clinical challenge specifically encourages strategies to arise from within the system itself, strategies not initiated or constrained by professional opinion. This allows the system to 'discover' potentially adaptive and unique solutions to these short-term clinical challenges.

Whilst the data is purely anecdotal, this approach has worked effectively in our own clinical practices, particularly, when families are included as partners in the formulating and testing of relevant hypotheses, and the search for the most effective interventions. Allowing families to be active in this process appears to support long-term empowerment as well as early clinical success. It is our observation that many NBP clinicians use this approach intuitively.

Long-term intervention

What is the best way for NBP clinical services to work towards optimal long-term outcomes? As noted above, we define this as 'optimising readiness for successful transition to adult life'. Given the persistent nature of aetiological biology, we suggest it to

Stage and Degree of complexity	Clinical Properties	Strategy
(1) Simple	Problem definition informs best practice pathway	Define the problem (diagnosis, severity) Management is informed by evidence such as practice guidelines
(2) Complicated	Relationship between problem and best treatment pathway requires both practice knowledge and professional judgement	Define multiple problems Manage using multiple algorithms, prioritised, interpreted and guided by clinical expertise
(3) Complex	Problem analysis beyond a certain level is not necessarily going to result in diagnostic certainty or inform best practice pathways of management. Both problem and management are better understood in retrospect, after exploring intervention options and their effects	Diagnosis becomes hypothesis-to-be-tested Professional judgement guides prioritisation and intervention strategy Response to intervention cannot be reliably predicted. Mistakes are part of learning what works, towards the defined goals of success After each strategy, review to learn, revise and adapt (stop, change, or increase)
(4) Chaotic	Multiple problems jostle for priority. Diagnostic modelling of cause and effect becomes unstable and incoherent	Respond to the most pressing need Work towards stability before any systematic clinical strategy is considered

 Table 3. Problem complexity level and related strategy

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be self-evident that this generally requires a structure of regular review across time, one that supports future-directed as well as problem-reactive care.

Even with regular services, however, the question remains regarding what to do at clinical visits, towards achievement of optimal long-term goals. Potential answers to this question may be informed by the very nature of complex systems, which have properties that are potentially harnessed towards achievement of positive long-term outcomes for children. A well documented property of complex systems is self-organisation [64,65]. Related concepts are those of 'emergence [66]' and 'adaptation [67[•]]'. Collectively these refer to behaviours of complex systems that arise without being directed or fuelled by centralised, expert knowledge, energy and control. They represent adaptive changes arising from the systems themselves, beyond the contribution of professional instruction.

Enabling system properties to augment clinical work has many potential benefits that are outlined in Table 4. To explore how this may be undertaken in practice, we offer a series of clinical steps (Table 5). These recommendations are not intended to replace evidence-based interventions, but to occur alongside, in order to allow efficient, effective, flexible, adaptive and unique solutions to arise from systems themselves.

Following these steps in our own longitudinal NBP practice, we have observed children's 'systems' evolve and adapt in a positive way. This level of evidence is anecdotal only, and it does not apply to all families. When successful, in the initial phase there may be strong reliance on professional input, with significant input of clinical energy towards resolution of problems. With time, however, professional input becomes less frequent, as families discover and share unique solutions to their child's predicament. Similarly, many children become more proficient at managing their own developmental difficulties. In this way, a greater proportion of clinical conversation becomes the reflection on what has been achieved, coupled with strategic consideration of future optimisation.

Table 4. Benefits of a 'systems' approach to long-term outcomes				
Parameter	Traditional expert model	Systems model		
Time	Professional time is necessary for each step in progress	Professional time guides the system, but is not necessary to generate each step along the way. Much of the work happens outside professional time		
Expense	Expensive (professional time)	Cost-effective (professional time is informative, educative, supervisory and facilitatory)		
Energy	Energy arises from the expertise and efforts of the professional/s	Energy arises from the opportunities and passions of all members of the child's systems		
Solutions	Solutions are constrained by the professional knowledge-base	Solutions are generated from a diverse system base, allowing unique ideas to emerge		
Control	Activities of the system are dictated and controlled centrally	Control is diffuse and self-organising, constrained by the ingredients of the system and collective agreed purposes		
Flexibility	Strategies are defined and dictated by the professional	Strategies can adapt in real time, without waiting for the next consultation		
Ecology	Strategies are relatively generic	Strategies are adaptive to unique ecological constraints and opportunities		
Initial treatment purpose	Goals are defined by the clinical model of diagnosis, treatment and intended treatment outcome	Goals can be prioritised systemically, and include those not directly implied by the diagnosis such as reduction in distress, self-efficacy, ecological adaptation		
Long-term purpose	Goals are constrained by the diagnostic model (e.g. reduction and normalisation of symptoms)	Goals are potentially more diverse, such as optimisation, prevention, resilience, developing strengths, building autonomy		
Communication and review	Constrained and episodic, as determined by appointments	Continuous and opportunistic, allowing more rapid adaptation and propagation of new knowledge		
Autonomy	Expert model does not necessarily imply autonomy as an outcome	The individuals in the system, and the child themselves, work intentionally towards autonomy in the management of what cannot be overcome		

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Table 5. Utilizing complexity within a child's 'system'

(1) Define long-term outcome as a purpose, from the outset.

Health systems that administer NBP clinical care evaluate activities against outcomes. If the accounting is restricted to the short-term, it is not easy to undertake activities in the short-term intended towards long-term outcomes. This problem has been addressed in other areas of paediatric services. In the care of a newly presented diabetic child, for example, short-term intervention extends beyond treating the presenting ketoacidosis, to include education and upskilling of the family and child about diabetes, a short-term activity towards a longterm outcome. It is expected that regular review will support the child well into the future. To properly explore how best to set up a child's world (system) for optimal long-term outcomes requires opportunity space to do so.

(2) Define the child's system: who needs to be involved?

Who exerts influence on the child's well being? The group can be in direct contact with the child (e.g. parents, extended family, teachers), or influence indirectly (e.g. school principal). In systems theory, the concept of 'boundary' formally differentiates what is, and is not, included in the system [68]. We suggest having this discussion with the family early, towards the goal of including, as much as possible, all key members of the child's world.

(3) Develop a unified narrative.

What is the best 'story' that communicates salient information to those in the system? Narrative appears to be an effective tool for communication in complex systems [56]. Components of this story may include the child's presenting struggle and its implications (functional, behavioural, psychological), presumptions of causation and natural history, short-term strategies and goals, resilience factors and long-term vision for the child. The story can be informed by, but not necessarily restricted to, the child's diagnoses. How is this story best determined, documented, communicated to and negotiated with, the individuals within the child's system? How might it change over time?

(4) Empower those in the system to self-organize.

In addition to the provision and recommendation of information and initial strategies, what is the best way to enable the child's system to explore self-generated solutions? What do the individuals in the child's system need, to innovate and work towards both the short-term and long-term goals identified in the collective story? This process necessarily encourages strategies that may actually not be successful, as a step in the exploration of what is possible and most effective. Feedback within the system then allows strategies that do not work to diminish and cease, whilst those that are successful can be supported and developed.

(5) Encourage regular, effective communication.

In order for the child's system to effectively explore what is possible, a level of active communication over time is required between the individuals involved. The set of people who constitute the system will invariably change. What is the best way to establish and maintain this communication? Given structural differentiations (e.g. between health and education), this model may be 'hub and spoke', with the family at the centre, both sharing and receiving information.

NBP, neurodevelopmental-behavioural paediatrics.

CONCLUSION

NBP has arisen in response to changing child health epidemiology. We present two challenges confronting the profession. The first is long-term (adult transition) outcomes. Until this is identified as an explicit purpose for NBP, the examination of how best to achieve best long-term outcomes is likely to remain overlooked.

The second challenge is complexity. NBP clinical situations are often complex and uncertain, yet the research that informs practice presumes certainty. As a result, it is not possible to establish algorithmic 'best practice' responses to complex clinical predicaments.

'Current Opinion' encourages consideration beyond evidence-based practice. We present these opinions in the hope that they will stimulate academic exploration and clinical dialogue, towards better outcomes for the children we see.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

of special interest

- of outstanding interest
- American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health: The pediatrician and the "new morbidity". Pediatrics 1993; 92:731-733.
- Boyle CA, Boulet S, Schieve LA, et al. Trends in the prevalence of developmental disabilities in US children, 1997–2008. Pediatrics 2011; 127: 1034–1042.
- Baio J. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. MMWR Surveill Summ [Internet]. 2018 [cited 2019 May 28];67. Available at: https://www.cdc.gov/mmwr/volumes/67/ss/ ss6706a1.htm. [Accessed 28 May 2019]

- Russell G, Collishaw S, Golding J, et al. Changes in diagnosis rates and behavioural traits of autism spectrum disorder over time. BJPsych Open 2015; 1:110-115.
- Christensen DL, Maenner MJ, Bilder D, et al. Prevalence and characteristics of autism spectrum disorder among children aged 4 years - Early Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2010, 2012, and 2014. Morb Mortal Wkly Rep Surveill Summ 2019; 68:1–19.
- 6. Fombonne E. Editorial: the rising prevalence of autism. J Child Psychol
 Psychiatry 2018; 59:717-720.

This editorial discusses the methodological challenges of estimating ASD prevalence. The question is of importance as it informs the public health question of the extent to which the true (presumably biologically driven) incidence is increasing.

- Kogan MD, Vladutiu CJ, Schieve LA, et al. The prevalence of parent-reported autism spectrum disorder among US children. Pediatrics 2018; 142:; pii: e20174161.
- 8. Hiscock H, Danchin MH, Efron D, *et al.* Trends in paediatric practice in Australia: 2008 and 2013 national audits from the Australian Paediatric Research Network. J Paediatr Child Health 2017; 53:55-61.

This publication documents the changing profile of problems presenting to the paediatricians' office over a 5-year period in Australia. The study methodology is robust. Findings have significant implications for paediatric training, health service planning and research.

- Rhodes A, Sciberras E, Oberklaid F, et al. Unmet developmental, behavioral, and psychosocial needs in children attending pediatric outpatient clinics. J Dev Behav Pediatr 2012; 33:469–478.
- Soares N, Baum R, Patel D. Developmental-behavioral pediatrics education in the United States: challenges in the midst of healthcare evolution. Int J Med Educ 2017; 8:396–399.
- NDD Program Directors Home [Internet]. [cited 2019 May 17]. Available at: http://www.nddtraining.org/. [Accessed 17 May 2019]
- Community child health sub-specialty [Internet]. RCPCH. [cited 2019 May 17]. Available at: https://www.rcpch.ac.uk/resources/community-childhealth-sub-specialty. [Accessed 17 May 2019]
- Physicians TRAC of The Royal Australasian College of Physicians [Internet]. The Royal Australasian College of Physicians; [cited 2019 May 17]. Available at: https://www.racp.edu.au/trainees/advanced-training/advanced-trainingprograms/community-child-health. [Accessed 17 May 2019]
- Neurodevelopmental and Behavioural Paediatric Society of Australasia -NBPSA [Internet]. [cited 2019 May 28]. Available at: https://nbpsa.org/. [Accessed 28 May 2019]
- Ibañez LV, Stoep AV, Myers K, et al. Promoting early autism detection and intervention in underserved communities: study protocol for a pragmatic trial using a stepped-wedge design. BMC Psychiatry 2019; 19:169.
- Mithyantha R, Kneen R, McCann E, Gladstone M. Current evidence-based recommendations on investigating children with global developmental delay. Arch Dis Child 2017; 102:1071–1076.
- Kulage KM, Goldberg J, Usseglio J, et al. How has DSM-5 affected autism diagnosis? A 5-year follow-up systematic literature review and meta-analysis. J Autism Dev Disord 2019; https://doi.org/10.1007/s10803-019-03967-5.
- [Epub ahead of print] [Accessed 15 August 2019]

Moving from DSM-4 to DSM-5-based diagnoses has reduced the estimated prevalence of autistic disorders. This increases the significance of studies showing increased prevalence. It also demonstrates the limitations of diagnoses based on consensus clinical criteria.

- Arnett A, Stein M. Refining treatment choices for ADHD. Lancet Psychiatry 2018; 5:691–692.
- Monz BU, Houghton R, Law K, Loss G. Treatment patterns in children with autism in the United States. Autism Res 2019; 12:517–526.
- Diagnostic and statistical manual of mental disorders: DSM-5 [Internet]. Fifth edition Arlington, VA: American Psychiatric Publishing; 2013.
- Sackett DL, Rosenberg WM, Gray JA, et al. Evidence based medicine: what it is and what it isn't. BMJ 1996; 312:71-72.
- **22.** Grayson DR, Guidotti A. Merging data from genetic and epigenetic approaches to better understand autistic spectrum disorder. Epigenomics
- productes to better understand autistic spectrum disorder. Epigenomics 2016; 8:85–104.

The increased incidence of developmental disorders, such as ASD has driven the field of NBP. This publication provides some understanding of how this increase may have come about, in the absence of social or genetic changes sufficient to explain this epidemiological changes.

- Riddle K, Cascio ČJ, Woodward ND. Brain structure in autism: a voxel-based morphometry analysis of the Autism Brain Imaging Database Exchange (ABIDE). Brain Imaging Behav 2017; 11:541–551.
- Rüsseler J, Becker P, Johannes S, Münte TF. Semantic, syntactic, and phonological processing of written words in adult developmental dyslexic readers: an event-related brain potential study. BMC Neurosci 2007; 8:52.
- 25. Sörös P, Hoxhaj E, Borel P, et al. Hyperactivity/restlessness is associated with increased functional connectivity in adults with ADHD: a dimensional analysis of resting state fMRI. BMC Psychiatry 2019; 19:43.
- Rasmussen P, Gillberg C. Natural outcome of ADHD with developmental coordination disorder at age 22 years: a controlled, longitudinal, communitybased study. J Am Acad Child Adolesc Psychiatry 2000; 39:1424–1431.

- Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. J Autism Dev Disord 2008; 38:739-747.
- 28. Hechtman L, Swanson JM, Sibley MH, et al., MTA Cooperative Group.
- Functional adult outcomes 16 years after childhood diagnosis of attentiondeficit/hyperactivity disorder: MTA results. J Am Acad Child Adolesc Psychiatry 2016; 55:945–952.

The MTA study provides quality longitudinal data that ADHD is not a transient disorder, that the use of symptomatic medication as the primary treatment strategy may not alter the long-term natural history of ADHD, and that adult function when ADHD persists can be poor.

29. Robison JE. Autism prevalence and outcomes in older adults. Autism Res
2019; 12:370-374.

As paediatricians we are easily distracted by the issues of the present. This study reminds us of what life may look like for the children as we see further into the future, particularly if our work fails to alter the trajectory of development in a positive direction over time.

- Bryan K, Garvani G, Gregory J, Kilner K. Language difficulties and criminal justice: the need for earlier identification. Int J Lang Commun Disord 2015; 50:763-775.
- Zalsman G, Shilton T. Adult ADHD: A new disease? Int J Psychiatry Clin Pract 2016; 20:70–76.
- Farooq R, Emerson L-M, Keoghan S, Adamou M. Prevalence of adult ADHD in an all-female prison unit. Atten Deficit Hyperact Disord 2016; 8:113–119.
 Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental
- health in autistic adults. J Autism Dev Disord 2018; 48:473–484. **34.** Rösler M, Retz W, Retz-Junginger P, *et al.* Prevalence of attention deficit-/
- hyperactivity disorder (ADHD) and comorbid disorders in young male prison inmates. Eur Arch Psychiatry Clin Neurosci 2004; 254:365–371.
- Roux AM, Shattuck PT, Cooper BP, et al. Postsecondary employment experiences among young adults with an autism spectrum disorder. J Am Acad Child Adolesc Psychiatry 2013; 52:931–939.
- McCarthy J, Chaplin E, Underwood L, et al. Characteristics of prisoners with neurodevelopmental disorders and difficulties. J Intellect Disabil Res 2016; 60:201–206.
- McDowell MJ, Lesslie JM. Long-term outcomes for children with neurodevelopmental disorders: Are they core business for paediatricians? J Paediatr Child Health 2018; 54:469–473.

This publication (by the same authors of this review) expands the argument for formally incorporating the achievement of optimal long-term (adult transition) outcomes as central to the visible purpose for NBP as a profession.

- NDD Program Directors Training Pathway [Internet]. [cited 2019 Apr 13]. Available at: http://www.nddtraining.org/trainingpathway.html. [Accessed 13 April 2019]
- Lenroot RK, Yeung PK. Heterogeneity within autism spectrum disorders: what have we learned from neuroimaging studies? Front Hum Neurosci 2013; 7:733.
- van Borkulo C, Boschloo L, Borsboom D, et al. Association of Symptom Network structure with the course of [corrected] depression. JAMA Psychiatry 2015; 72:1219–1226.
- Marquand AF, Rezek I, Buitelaar J, Beckmann CF. Understanding heterogeneity in clinical cohorts using normative models: beyond case-control studies. Biol Psychiatry 2016; 80:552–561.
- 42. Chaste P, Klei L, Sanders SJ, et al. A genomewide association study of autism using the Simons Simplex Collection: Does reducing phenotypic heterogeneity in autism increase genetic homogeneity? Biol Psychiatry 2015; 77:775-784.
- Sherr EH, Michelson DJ, Shevell MI, et al. Neurodevelopmental disorders and genetic testing: current approaches and future advances. Ann Neurol 2013; 74:164–170.
- An JY, Claudianos C. Genetic heterogeneity in autism: from single gene to a pathway perspective. Neurosci Biobehav Rev 2016; 68:442–453.
- Poletti M, Carretta E, Bonvicini L, Giorgi-Rossi P. Cognitive clusters in specific learning disorder. J Learn Disabil 2018; 51:32–42.
- Kofler MJ, Sarver DE, Spiegel JA, et al. Heterogeneity in ADHD: neurocognitive predictors of peer, family, and academic functioning. Child Neuropsychol 2017; 23:733–759.
- **47.** Tordjman S, Cohen D, Coulon N, *et al.* Reframing autism as a behavioral syndrome and not a specific mental disorder: implications of genetic and phenotypic heterogeneity. Neurosci Biobehav Rev 2017; 80:210.
- Masi A, DeMayo MM, Glozier N, Guastella AJ. An overview of autism spectrum disorder, heterogeneity and treatment options. Neurosci Bull 2017; 33:183–193.
- 49. Thomas A, Chess S. Temperament and development. 1977.
- 50. LaDonna KA, Ginsburg S, Watling C. 'Rising to the level of your incompetence': what physicians' self-assessment of their performance reveals about
- the imposter syndrome in medicine. Acad Med 2018; 93:763–768. The presence of clinical complexity, imprecision and uncertainty in NBP clinical practice is a challenge for doctors who are used to getting things right. Unless we have an objective understanding of complexity, and respond to this rationally, the danger is that we doubt ourselves unnecessarily. If this occurs, it may influence how we practice.
- Ladyman J, Lambert J, Wiesner K. What is a complex system? Eur J Philos Sci 2013; 3:33–67.

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- Complex system. In: Wikipedia [Internet]. 2019 [cited 2019 May 18]. Available at: https://en.wikipedia.org/w/index.php?title=Complex_system&oldid=896757066. [Accessed 18 May 2019]
- 53. McDowell M. Child with multiple problems: clinical complexity and uncertainty. J Paediatr Child Health 2018; 54:1084-1089.
- This article, also by the author of this review, expands the discussion of managing
- clinical complexity.
 54. Kurtz CF, Snowden DJ. The new dynamics of strategy: sense-making in a complex and complicated world. IBM Syst J 2003; 42:462–483.
- O'Keeffe M, Macaulay C. Diagnosis in developmental-behavioural paediatrics: the art of diagnostic formulation. J Paediatr Child Health 2012; 48: E15–E26.
- Bell CC. DSM-IV: diagnostic and statistical manual of mental disorders. JAMA 1994; 272:828-829.
- 57. Strogatz SH. Exploring complex networks. Nature 2001; 410:268-276.
- 58. Borsboom D. A network theory of mental disorders. World Psychiatry 2017;
 16:5-13.

This article provides a good summary of network theory and models applied to mental health disorders. We see no reason why it cannot be used for child development disorders.

- 59. Fried EI, Epskamp S, Nesse RM, et al. What are 'good' depression symptoms? Comparing the centrality of DSM and non-DSM symptoms of depression in a network analysis. J Affect Disord 2016; 189: 314-320.
- Cramer AOJ, Waldorp LJ, van der Maas HLJ, Borsboom D. Comorbidity: a network perspective. Behav Brain Sci 2010; 33:137–150.

- Ruzzano L, Borsboom D, Geurts HM. Repetitive behaviors in autism and obsessive-compulsive disorder: new perspectives from a network analysis. J Autism Dev Disord 2015; 45:192–202.
- Deserno MK, Borsboom D, Begeer S, Geurts HM. Multicausal systems ask for multicausal approaches: a network perspective on subjective well being in individuals with autism spectrum disorder. Autism 2017; 21:960–971.
- 63. Snowden DJ, Boone ME. A leader's framework for decision making. Harv Bus ■ Rev 2007; 85:68–76.

This article provides a rational consideration of informational complexity in business management. It draws from earlier work (citation [54] above), introducing vocabulary, analysis and strategy for different levels of real-life situational complexity.

- Comfort LK. Self-organization in complex systems. J Public Adm Res Theory J-PART 1994; 4:393–410.
- 65. Kauffman SA. The origins of order: self-organization and selection in evolution.
 Oxford: Oxford University Press; 1993; 740.

We commend the work of this author to those who wish to further understand how complexity in biological systems creates opportunity for evolutionary change.

66. Goldstein J. Emergence as a construct: history and issues. Emergence 1999; 1:49-72.

67. Holland JH. Complex adaptive systems. Daedalus 1992; 121:17-30.

We commend the work of this author to those who wish to further understand complexity from a theoretical and mathematical perspective.

 Schoening B. Boundaries and complex adaptive systems. Insight 2008; 11:22-23.