

VIEWPOINT

Long-term outcomes for children with neurodevelopmental disorders: Are they core business for paediatricians?

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What happens to children with neurodevelopmental-behavioural disorders when they grow up? How much difference do paediatric services provided during childhood make to subsequent adult outcomes? Are long-term (transition to adult life) outcomes in this area of practice a core clinical responsibility for paediatrics, as they are with other paediatric chronic conditions?

As a relatively recent area of clinical care, neurodevelopmental-behavioural paediatrics (NBP) builds on a proud history. An endearing feature of paediatrics, from the earliest days, has been the extent to which it considers assessment, treatment and management of medical problems in the context of the whole child and family.¹ This aspect of paediatric care is growing in importance and relevance as the epidemiology of child health shifts from severe and acute pathologies towards longitudinal care of children with complex and chronic disorders.²

NBP could be considered the next step in the evolving journey of paediatric care.³ The clinical work explicitly addresses the full bio-psycho-social range of care. This presents two new challenges to traditionally trained paediatricians. The first is the need to broaden clinical knowledge and skills beyond the biological and learn how to work with problems that are defined around the intersection of psychological, social and behavioural phenomena.

The second challenge is a softening of biological foundations. For a proportion of children attending for NBP care, biological aetiology is identified. It may be progressive and require direct medical attention.⁴ In other cases, such as genetic conditions or acquired damage, the biology is known and presumed to be pathologically static. In both these situations, the relationship between presenting problems and biological causation is usually evident, allowing the provision of services with reasonable clinical certainty. However, for the remainder of children we see in NBP representing the greater proportion of the community clinical population, the detail of biological aetiology is likely to remain unknown for the foreseeable future.⁵

NBP Services and Clinical Uncertainty

This presents a challenge from the outset of clinical care. In traditional paediatrics, diagnosis incorporates known or presumed biological aetiology. As NB paediatricians, we learn to make

diagnoses that are defined by clinical phenotypes of developmental skill and behaviour patterns.⁶ To reduce uncertainty, we strive to optimise diagnostic validity and reliability.^{7,8} The research that guides us, however, is undertaken with methodology necessary to enable consistency and replication across published studies. This requires constraints such as age, social circumstances, patterns of comorbid problems and so on. These constraints do not necessarily reflect practice where clinical complexity may make it difficult to differentiate the extent to which presenting problems arise from intrinsic, as compared to external, causal processes.

Even if we are confident that problems are primarily intrinsic (i.e. biologically based), NBP diagnostic categories represent admixtures of clinical phenomena, each on an individual continuum of severity, with indistinct boundaries, and arising from a potentially heterogeneous set of causal biological processes. Each child is likely to have individual clusters of comorbid challenges. Furthermore, assessment at one point in time is unable to address the uncertainty that arises due to changes over time, which may move children into, or out of, diagnostic categorisation.^{9–11} In response to this uncertainty, diagnostic methodologies vary considerably.¹² They may be influenced further by non-clinical factors, such as the opportunities for intervention funding.¹³

Considering these challenges collectively, there is clearly a limit to which the uncertainty intrinsic to NB clinical diagnosis is able to be overcome, regardless of methodological rigour. This leads to a corresponding limit on the extent to which improvement in diagnostic methodologies will answer the question of how best to help children in NBP. Just undertaking assessment more comprehensively is not going to answer the question of what the profession of NBP should strive to achieve for the children seen.

The question of treatment presents greater challenges as the profession attempts to follow evidence-based medicine.¹⁴ The research utilised to guide this, by necessity, evaluates treatment effect as changes in symptom patterns and severity. Translating this into clinical service methodology is not straightforward, with uncertainty about what to provide for individual children and for how long.

Treatment research in NBP is hampered by a number of factors, including the absence of biological markers, the challenge of background changes over time due to child development and the complexity of individual clinical circumstances (such as comorbidity). Research methodologies address this variability by using short time frames, selectively filtered populations and limited clinical targets (e.g. attention-deficit/hyperactivity disorder behavioural symptoms¹⁵). This is necessary so that identified changes can be attributed to intervention with reasonable certainty. The constraints necessary for academic rigour, however, limit the

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extent to which this information can be translated into the clinical setting, particularly when individual child circumstances vary from what has been studied or the treatments provided cannot be readily replicated.

In short, where evidence-based medicine is followed in the planning and provision of NB clinical services, there is a resulting uncertainty regarding what interventions to offer and for how long. This applies at the level of both the service as a whole and for individual children. As a result, there is a diversity of treatment services offered across locations.¹⁶

In some places, services are classified as D&A, diagnosis and assessment. Presumably, this is followed by discharge with referral to services provided elsewhere, such as allied health, education and disability. In other services, some form of intervention is offered, such as one or more allied health therapies, for periods of time that may be defined by local constraints as much as clinical purpose. If psychotropic medication is prescribed, there is variation as to how this is initiated, evaluated and subsequently monitored over time. It may be a Medicare-funded public outpatient clinic, with the likelihood of changing professional staff and constrained durations. As services extend beyond diagnosis and initial treatment intervention, diversity grows with respect to what NB paediatricians do, for how long and for what purpose.

In summary, we would argue that the absence of definable biological aetiology leads to both limitations and diversity in assessment and treatment services provided in clinical practice. This is more evident when considering longer-term management. Collectively, this diversity undermines the cohesion and vision of purpose for the profession and, therefore, the capacity to advocate as a group for quality improvements and effective/efficient use of limited health resources.

What Research Can Tell Us

To address this uncertainty, consider what is known about biological aetiology for neurodevelopmental disorders. This issue has been, and continues to be, the subject of substantial research effort. From the earliest days, the clinical phenomena of 'soft' neurological signs were studied to help clinically differentiate between presumably biologically based problems and those arising due to other causes.¹⁷ Since that time, a variety of neuropsychological, neurophysiological, neuroimaging and genetic studies have characterised biological differences, presumed to be of aetiological significance. These findings point to heterogeneous and multifactorial causal processes, even within groups of children with the same clinical developmental diagnosis.^{18–22} This set of research findings identifies differences between clinical and control group comparisons, although the differences are usually insufficient to reach the levels of sensitivity and specificity necessary to inform individual care. Collectively, this body of research supports the proposition that, for the children with NB problems, a biological aetiology is probable, and the implication that whatever aetiology is present is more likely to be pathologically static rather than progressive.

What happens over time? Are neurodevelopmental problems able to be modified through intervention to the point that symptoms permanently resolve? Does the underlying biology abate spontaneously? Without biological markers to answer these questions, longitudinal and retrospective research utilises clinical data.

Multiple studies suggest that clinical challenges persist in many, perhaps the majority, of cases even if the profile of problems changes with time and developmental circumstances.¹¹ This situation is further complicated by cumulative maladaptive consequences across a diverse range of outcome areas, including in education, mental health, social dysfunction, vocational underachievement and crime.^{23–30}

From this group comparison and longitudinal data, it is reasonable to draw a number of conclusions. The first is that underlying biological aetiology probably persists in some form for a significant proportion of children with NB problems. The second is that these children continue to have an increased risk of poor adult clinical outcomes, even following short-term treatments. These adverse long-term outcomes may be either direct (reflecting the underlying biology) or indirect (arising from how the problem is managed and how the children themselves respond to the challenges they experience).

Implications for Professional Purpose

The authors believe that the prevalence and impact of adverse long-term outcomes compels a clinical response, even without the ability to measure the biological basis and progress of these disorders. We forward three lines of argument to support the recommendation that NBP paediatricians more intentionally, systematically and collectively embrace the challenge of management towards long-term outcomes as core business for the profession.

First, if it is possible to alter clinical trajectory over time, we can potentially make a powerful, positive clinical difference in the adult lives of the children we see. Second, at the level of society, and considering the prevalence of NB disorders,³¹ there is a social and economic argument if modest investment during childhood can be shown to alter the trajectory towards positive long-term outcomes. Finally, at a professional level, an explicit engagement with the question of long-term outcomes increases clarity regarding how NBP is understood as a professional domain of practice alongside other medical specialities (e.g. general paediatrics, child psychiatry, neurology, rehabilitation) as well as allied health professions within a multidisciplinary environment, non-health professionals (such as teachers), parents and service providers.

In summary, we believe that being accountable for, and purposefully working towards, positive long-term outcomes should be considered core business for NBP. If the profession continues to be seen as a set of diagnostic and treatment activities defined by clinical phenomenology, there will be ongoing uncertainty and inconsistency about what we as paediatricians can and should do for children and for how long. Even though individual characterisation of biological aetiology may not be available for diagnosis and treatment monitoring for some time to come, we can use what is known from current research to embrace the challenge of long-term outcomes with a reasonable degree of clinical conviction.

Chronic Care in Other Areas of Paediatrics

Other areas of paediatric medicine have embraced this challenge, albeit with the capacity to use markers of biological pathology. The package of care is built around a collective vision of

optimising the long term and undertaken with intentional longitudinal service structures that work at multiple clinical levels. Using the example of diabetes, paediatric care is optimised short term (e.g. diagnosis and treatment of ketoacidosis), but services are then booked regularly. Clinicians work to address the causal biology where possible; maintain optimal symptom management (stability of diabetic control); minimise the secondary impact (progressive organ damage); educate and include the child's world (home and school) in their disease and its management; build each child's knowledge, autonomy and empowerment; and embed these strategies within a child's quality of life (lifestyle, function, social participation, mental health). Education of children and families may include action plans for unforeseen events such as infections. Whilst interventions at social and functional levels may produce only limited benefit to the disease course and treatment outcomes within short time frames, the cumulative benefit of this multifaceted approach over time has changed the life experience and long-term prognosis for many children who have chronic medical disorders.^{32,33}

In some areas of current NBP practice, continuing care is provided with a full awareness of long-term outcomes. These include clinics where known medical problems (such as cerebral palsy) require ongoing review, developmental paediatric services, mostly in the private sector and particularly where the prescription of psychotropic medication is maintained over time. It is our understanding that many individual clinicians address the question of long-term outcomes intentionally with families in their practice, providing advice and support around how this may be achieved.

The central question for this viewpoint is whether considering and addressing long-term outcomes comprises a core responsibility for NBP rather than an optional consideration depending on clinical circumstances and preferences. We believe it should be.

If we are to work collectively towards this goal, three issues deserve consideration. The first is to formally incorporate long-term outcomes as a core health-care responsibility in NB clinical services, teaching and training. The second is to address the practical challenge of providing long-term continuity of care, and the final consideration is how we build clinical skills and knowledge around how to help children successfully over longer time frames.

Start with the end in mind

Current clinical teaching of NBP occurs primarily in public outpatient settings. In Australia, however, these services are biased towards assessment and diagnosis, along with variable sets of intervention options (e.g. medication, referral to services, therapies) provided for variable periods of time. Collectively, the clinical experiences that dominate training in NBP are likely to be constructed around arbitrarily constrained periods of time. This runs the risk of communicating the training message that 'this is what we do' as a profession.

We are not arguing for public services to provide long-term care for all children. Contrasting with paediatric diabetic care, when a child and family present for the first time, they do not leave hospital with just a diagnosis, prescription and instructions regarding immediate care. They will also be given an understanding that diabetes is a long-term condition, that adult outcomes are important and that optimised stability of care over time is the key determinant of long-term health and well-being. They should

have a plan for how that continuity of care is to be undertaken in practice, even if that care is not to be undertaken by the diagnosing service.

Are we able to do something similar in NBP? To what extent is it possible to incorporate a formal consideration of long-term outcomes into current clinical services, teaching and training? This is more challenging when the aetiology has not been clarified and without biological markers to evaluate progress. Furthermore, continuing care is distributed across multiple groups, particularly education. Arguably, however, the medical profession is best set up for consistent, future-oriented longitudinal thinking, advocacy and care.

An important step forward is already underway with the recently updated Community Child Health Advanced Training Curriculum, which includes consideration of long-term outcomes. This introduces a competency-based framework for trainee assessment using Entrustable Professional Activities³⁴ as an alternative to time-based training. We would like to see these EPA competencies formally embrace the question of long-term management.

Continuity of care

Current paediatric services in Australia for NBP are provided across multiple settings, including public hospital and community, not-for-profit and private. Within these sectors, different models of care are offered and for different durations of time. How do we approach the question of continuity of care with our mixture of service delivery options? Without centralised capacity for planning, it is not possible to co-ordinate what is provided for children. Given the constraints of funding, it is unlikely that public clinics for NBP have greater capacity to extend care longitudinally.

It is also unlikely that we will find the answer by copying other countries that have different models for service delivery. In the USA, services are primarily provided within a managed care architecture funded by insurance companies. The profession of paediatrics is a primary care rather than a consultant speciality, lending itself more readily to long-term continuity of care.³⁵ In the UK, private clinics are uncommon. Community health services are predominantly provided through the National Health Services and organised through settings responsible for defined geographical regions.³⁶ The UK and USA, in different ways, are able to provide continuity through pathways of care not readily available in Australia.

We will need to find our own solutions to the question of how we support and guide parents and children over time. In Australian paediatrics, we already have models for continuity of care for other medical conditions. It should be possible to adapt these. For children seen in public clinics, it is an achievable discharge outcome, for example, to educate parents regarding the importance of continuity and link them with paediatric services that have the capacity to provide ongoing care, in either public or private settings. There are further options possible through building specialist–primary care partnerships.

Different strategies are likely to be necessary in differing settings. Paediatricians will need to drive the conversation, with a clinical conviction towards continuity of care. If we do not, responsibility will continue to rest with parents, to answer the questions of what support and intervention is needed for their children and for how long.

Table 1 Example clinical observations

This table lists some practice-based observations from clinical care of children over time. We have observed that a child may be more likely to do well in the long term if:

Initial clinical arrangements

- Both parents (where possible) are requested to participate from the outset and on an ongoing basis
- The child is included from the outset and increasingly over time, actively and appropriately from a developmental perspective, in discussions regarding their concerns, beliefs and the decision making around what to do

Response to diagnosis

- Parents have time, space, permission and support to grieve, adapt and accept the information about their child, maintaining and optimising attachment and unconditional love
- Parents have time and opportunity to engage with the implications of diagnosis, towards the goal of compassion-based adjustment of expectations, to what is reasonable and sustainable for the child, even before they discuss treatment activities
- The long term is discussed from the outset: What is a priority for the child when they transition to adult life? How do they prioritise mental health outcomes (optimism, hope, resilience, personal empowerment) alongside relevant behavioural and functional outcomes?

Continuing care

- Alongside ongoing treatment outcomes, the child's mental health is kept in the foreground during longitudinal care and monitored as the central measure of ongoing success, a form of developmental 'glycosylated haemoglobin'
- Parents work together, with a 'whole of family' approach to supporting the child over time
- Parents have understanding and support regarding how to assemble, align, sustain and direct therapeutic 'teams' of key individuals in their child's life (e.g. teachers, grandparents)
- Parents learn how to evaluate potential interventions in the context of time frames and intended beneficial (functional) outcomes rather than be tempted or pressured into plausible, open-ended treatment activities without evaluation and accountability
- Rather than just wait for and respond to problems as they arise, parents learn how to look ahead, to prepare for potential challenges and to consider how to continue optimisation
- Parents are provided with clear recommendations regarding the frequency of routine visits (e.g. 4–6 monthly), what the discussion agenda will include at the next visit (creating goals) and under what circumstances to consult earlier (e.g. if the situation deteriorates to a certain degree)
- Parents and schools work within a shared understanding of the child's problems (including presumptions of causation), the intended short- and long-term priority goals and a framework to structure communication and collaboration over time
- Parents have a vision of managing the longer-term future, particularly with regards to the necessary strategic partnerships they will need to build

Building clinical knowledge and skills towards long-term outcomes

Even if we were able to see all NB children on a regular basis until transition to adult life, what clinical management strategies would be most efficient and effective? Long-term research currently available, either retrospective or longitudinal as noted above, tends to be observational rather than intervention-based. Intervention research over longer time periods, such as with the long-term use of stimulant medication,³⁷ can even be somewhat demoralising.

To undertake meaningful long-term treatment research is a large and complex challenge. Until such evidence is available, we believe we must more intentionally share what we know from current practice. Each child receiving longitudinal clinical care in clinical practice is an 'N-of-1' study. We can work towards methodology for observing, synthesising and communicating practice-based evidence (PBE).³⁸ We then need opportunities to share and reflect on this information within structures for professional communication and education where the nature of this information is understood and respected, despite inherently weaker levels of evidence quality.

PBE observations from longitudinal clinical care potentially form the foundation for hypotheses that can be more formally examined as PBE. A set of such observations is presented in Table 1. The authors propose that discussion of long-term outcomes, and how they might be best attained, is a worthwhile

topic for workshops within conferences, clinical meetings, case discussions and other forms of clinical exchange.

Conclusion

NBP is a developing field of specialist practice where, as with other paediatric chronic conditions, substantial clinical morbidity associated with NB conditions extends beyond the immediate years, across teenage years and into adult life. NBP differs from traditional forms of medical care, however, with a necessary emphasis on social, psychological and behavioural clinical phenomena rather than the underlying biology, which is often not known.

As medical specialists, we add value to the lives of children with medical investigations, prescription of medications, referrals for others to help, our advice and our professional gravitas as advocates. What outcomes, however, do we aim to achieve and take responsibility for? Services for other paediatric chronic disorders work to balance the immediate needs of children with the construction of foundations and processes necessary to optimise long-term outcomes. This has come about with intentional conversation, research and training; the exploration of appropriate service structures for continuity of care; and the development over time of a broad set of clinical methodologies.

The proposal of this viewpoint is that NBP, as a relatively new area of clinical activity, should collectively adopt the achievement of optimal long-term treatment outcomes for children as a core

professional responsibility. We have the opportunity to make a powerful positive difference across the life course for this group of biologically vulnerable children.

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