Janaki Medical College Journal of Medical Sciences (2026); Vol.14 (2):133-140

JMCJMS

DOI: https://doi.org/10.3126/jmcjms.v14i02.98141

ISSN: 2091-2242
eISSN: 2091-2358

OPEN ACCESS

Perspective

Beyond the Bayley: The Imperative for Standardized, Comprehensive, and Accessible Long-term Neurodevelopmental Follow-Up

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Received: 29 January 2026
Revised: 7 July 2026
Accepted: 15 July 2026

Citation:
Kotha R. Beyond the Bayley: The imperative for standardized, comprehensive, and accessible long-term neurodevelopmental follow-up. Janaki Med Coll J Med Sci. 2026;14(2):133-140

ABSTRACT:

Background and Objectives: Advances in neonatal intensive care have substantially improved the survival of preterm and other high-risk infants. Nevertheless, many survivors experience persistent neurodevelopmental, behavioural, educational, and functional impairments extending into adolescence and adulthood. Although the Bayley Scales of Infant and Toddler Development remain the most widely used early assessment tool, their ability to predict long-term functional outcomes is limited, and considerable variability exists among neonatal follow-up programmes worldwide. The objective of this perspective is to critically examine the limitations of current neurodevelopmental follow-up strategies and propose a standardized, comprehensive, and accessible life-course framework centred on functional outcomes rather than early cognitive scores alone.

Materials and Methods: This perspective article synthesizes evidence from the contemporary literature on neonatal neurodevelopmental follow-up, developmental assessment tools, long-term functional outcomes, programme standardization, health equity, and family-centred care. Published guidelines, observational studies, systematic reviews, and expert recommendations were critically evaluated to formulate practical recommendations for future neurodevelopmental follow-up programmes.

Results: Current evidence indicates that early psychometric scores alone incompletely predict later neurodevelopment because developmental trajectories are influenced by brain maturation, neuroplasticity, environmental exposures, educational opportunities, family support, rehabilitation, and ongoing medical care. Significant heterogeneity exists in assessment tools, follow-up duration, eligibility criteria, and outcome reporting across centres, limiting comparisons between programmes and reducing opportunities for quality improvement. A standardized life-course model integrating functional performance, adaptive behaviour, participation, quality of life, patient-reported outcomes, and equitable access is therefore warranted.

Conclusion: Neurodevelopmental follow-up should evolve beyond isolated early developmental testing toward standardized longitudinal assessment emphasizing functional independence, participation, quality of life, and equitable access to multidisciplinary care. Adoption of harmonized outcome measures and life-course follow-up frameworks has the potential to improve clinical care, research comparability, and long-term outcomes for NICU graduates.

Keywords: Bayley Scales; neurodevelopmental follow-up; preterm infant; functional outcomes; neonatal intensive care; developmental assessment; quality of life; health equity; standardized outcomes.

INTRODUCTION

Remarkable advances in neonatal medicine have transformed the prognosis of extremely preterm and critically ill newborns, resulting in unprecedented improvements in survival. As mortality declines, attention has appropriately shifted toward optimizing long-term neurodevelopment, functional independence, educational achievement, mental health, and quality of life among survivors. Neurodevelopmental follow-up has therefore become an essential component of neonatal care rather than simply an adjunct after hospital discharge [1].

Despite these advances, long-term neurodevelopmental follow-up remains fragmented across healthcare systems. Considerable variation exists in eligibility criteria, assessment schedules, multidisciplinary involvement, developmental instruments, and duration of follow-up. Such heterogeneity limits meaningful comparisons between centres, complicates multicentre research, and contributes to inequitable delivery of developmental services [7-10].

Current follow-up programmes continue to rely heavily on early cognitive assessment using the Bayley Scales of Infant and Toddler Development. Although these instruments provide valuable information regarding cognitive, language, and motor development during infancy and early childhood, they do not fully reflect lifelong neurodevelopment. Successful long-term outcomes encompass adaptive behaviour, executive functioning, educational achievement, communication, emotional wellbeing, social participation, independence, and health-related quality of life [2-6,15-18].

Functional outcomes should therefore be regarded as complementary—and ultimately more clinically meaningful—than isolated early cognitive scores. A child with modest Bayley scores may later achieve satisfactory functional independence, whereas another with favourable early scores may subsequently develop learning disabilities, behavioural disorders, executive dysfunction, or psychosocial difficulties.

This apparent discrepancy reflects the dynamic nature of neurodevelopment. Brain maturation continues throughout childhood, while neuroplasticity, family environment, educational opportunities, rehabilitation services, socioeconomic conditions, nutrition, and chronic health conditions collectively influence developmental trajectories. Consequently, correlations between infant developmental scores and later functional outcomes are frequently modest despite careful early assessment [2-6]. Accordingly, this perspective argues that future neonatal follow-up should move beyond reliance on isolated early psychometric testing toward a standardized, comprehensive, equitable, and life-course approach integrating functional performance, adaptive behaviour, quality of life, family-centred outcomes, and participation across childhood and adulthood.

Redefining Success in Neonatal Neurodevelopmental Follow-up

For more than five decades, the Bayley Scales of Infant and Toddler Development have represented the international standard for early neurodevelopmental assessment in high-risk infants. Their strengths include standardized administration, extensive normative data, and the ability to identify infants requiring early developmental intervention. Consequently, they remain indispensable in neonatal follow-up programmes and clinical research.

However, increasing evidence demonstrates that Bayley scores should not be interpreted as definitive predictors of lifelong neurodevelopment. Several longitudinal studies have reported only modest associations between Bayley performance at 18–24 months and later cognition, academic achievement, executive functioning, behavioural health, and adaptive functioning during school age [2-6].

The principal reason for this limited predictive validity is that infant neurodevelopment remains highly dynamic. Ongoing cortical maturation, synaptic remodelling, neuroplasticity, environmental enrichment, educational opportunities, rehabilitation services, family support, and socioeconomic circumstances continue to influence developmental trajectories well beyond infancy. Consequently, early psychometric assessment captures only one point within an evolving developmental continuum rather than an individual's ultimate functional potential [2-6].

Moreover, standardized cognitive scores alone cannot adequately measure many outcomes valued by children, families, educators, and healthcare providers, including independence in daily living, communication, participation in school, emotional wellbeing, social integration, employment potential, and overall quality of life [15-18]. Therefore, neurodevelopmental follow-up programmes should complement cognitive testing with longitudinal functional assessment rather than replacing one measure with another. Table 1 compares

Table 1. Cognitive Scores versus Functional Outcomes in Long-term Neurodevelopmental Follow-up

Traditional Cognitive Assessment	Comprehensive Functional Assessment
Early developmental scores	Adaptive behaviour
Cognitive quotient	Activities of daily living
Language score	School participation
Motor score	Executive functioning
Developmental classification	Emotional wellbeing
Single assessment age	Longitudinal assessment
Clinic-centred	Family-centred
Limited predictor of adult functioning	Better reflects lifelong independence and participation

traditional cognitive assessment with comprehensive functional assessment, illustrating why life-course evaluation provides a more meaningful understanding of neurodevelopment than reliance on early psychometric scores alone [2-6,15-18].

This framework illustrates that cognitive assessment remains an important component of neonatal follow-up but should be integrated with broader functional outcomes to better characterize lifelong neurodevelopment and patient-centred wellbeing.

The Need for Standardization Across Follow-up Programmes

Marked variation currently exists in neurodevelopmental follow-up programmes regarding eligibility criteria, assessment schedules, personnel, developmental instruments, and outcome reporting. Such heterogeneity reduces opportunities for benchmarking, limits collaborative research, and impairs quality-improvement initiatives across neonatal networks.

Future programmes should therefore adopt standardized assessment protocols using harmonized terminology, predefined assessment ages, validated developmental instruments, and a minimum Core Outcome Set applicable across institutions and countries. Standardization would facilitate multicentre comparisons, improve evidence synthesis, enhance benchmarking, and ultimately improve the quality and equity of neonatal follow-up services.

Dismantling Barriers to Accessible and Equitable Care

Improving neurodevelopmental outcomes requires more than standardized assessment tools. Geographic distance, financial constraints, shortages of trained professionals, fragmented healthcare systems, and social determinants of health continue to prevent many high-risk infants from receiving appropriate long-term follow-up. Families living in rural and resource-limited settings frequently experience difficulties attending repeated specialist visits, leading to delayed identification of developmental concerns and missed opportunities for early intervention [11-14].

A family-centred model should therefore integrate developmental surveillance with social support services, community-based rehabilitation, nutritional counselling, caregiver education, and coordinated referral pathways. Addressing social determinants of

health is essential for reducing disparities and ensuring equitable developmental outcomes across diverse populations.

Telehealth represents an important complementary strategy rather than a replacement for face-to-face assessment. Virtual developmental consultations, caregiver coaching, developmental screening questionnaires, multidisciplinary case discussions, and hybrid follow-up clinics can improve access for families living in underserved regions while reducing travel burden and healthcare costs. Telehealth may also improve programme retention and facilitate timely referrals when developmental concerns are identified. Nevertheless, standardized in-person developmental assessments remain essential whenever detailed neurological examination or formal psychometric testing is required.

Embracing Comprehensive Long-Term Functional Outcomes

The definition of successful neonatal care should extend beyond survival and early developmental scores to encompass lifelong health, participation, independence, and quality of life. Functional outcomes including adaptive behaviour, communication, executive functioning, school achievement, emotional wellbeing, employment readiness, social participation, and independent living better reflect the real-world experiences of NICU graduates than isolated psychometric scores obtained during infancy [15-18].

Longitudinal assessment should therefore continue beyond early childhood whenever feasible, recognising that neurodevelopment evolves throughout childhood, adolescence, and adulthood. Such an approach allows clinicians to identify emerging learning disabilities, behavioural disorders, mental health conditions, executive dysfunction, and social challenges that may not be apparent during infancy.

Recommended Core Outcome Set for Neonatal Neurodevelopmental Follow-up

To improve consistency across programmes and facilitate multicentre research, we propose that future neonatal follow-up programmes adopt a minimum Core Outcome Set consisting of:

1. Neurological examination
2. Cognitive development
3. Language development
4. Motor function
5. Adaptive behaviour
6. Functional independence
7. School readiness and academic achievement
8. Executive functioning
9. Behavioural and mental health
10. Vision and hearing
11. Growth and nutrition
12. Health-related quality of life
13. Parent-reported outcomes
14. Family wellbeing and caregiver burden
15. Healthcare utilisation and participation in early intervention programmes

Standardized reporting of these outcomes would improve comparability among studies, strengthen evidence synthesis, facilitate benchmarking across neonatal networks, and support international collaboration.

Proposed Conceptual Framework: Beyond the Bayley Model

Figure 1 illustrates the proposed "Beyond the Bayley" life-course framework for neonatal neurodevelopmental follow-up. The model emphasizes that standardized early assessment, including neurological examination, Bayley assessment, and medical risk evaluation, should serve as the starting point rather than the endpoint of developmental surveillance. Lifelong functional outcomes, adaptive behaviour, quality of life, school participation, mental health, family-reported outcomes, standardization, equitable access, multidisciplinary care, and telehealth collectively define successful neurodevelopmental follow-up.

This conceptual framework emphasises that Bayley assessment should serve as the starting point rather than the endpoint of neurodevelopmental follow-up. Lifelong functional outcomes, patient-reported outcomes, standardized assessments, multidisciplinary care, and equitable access

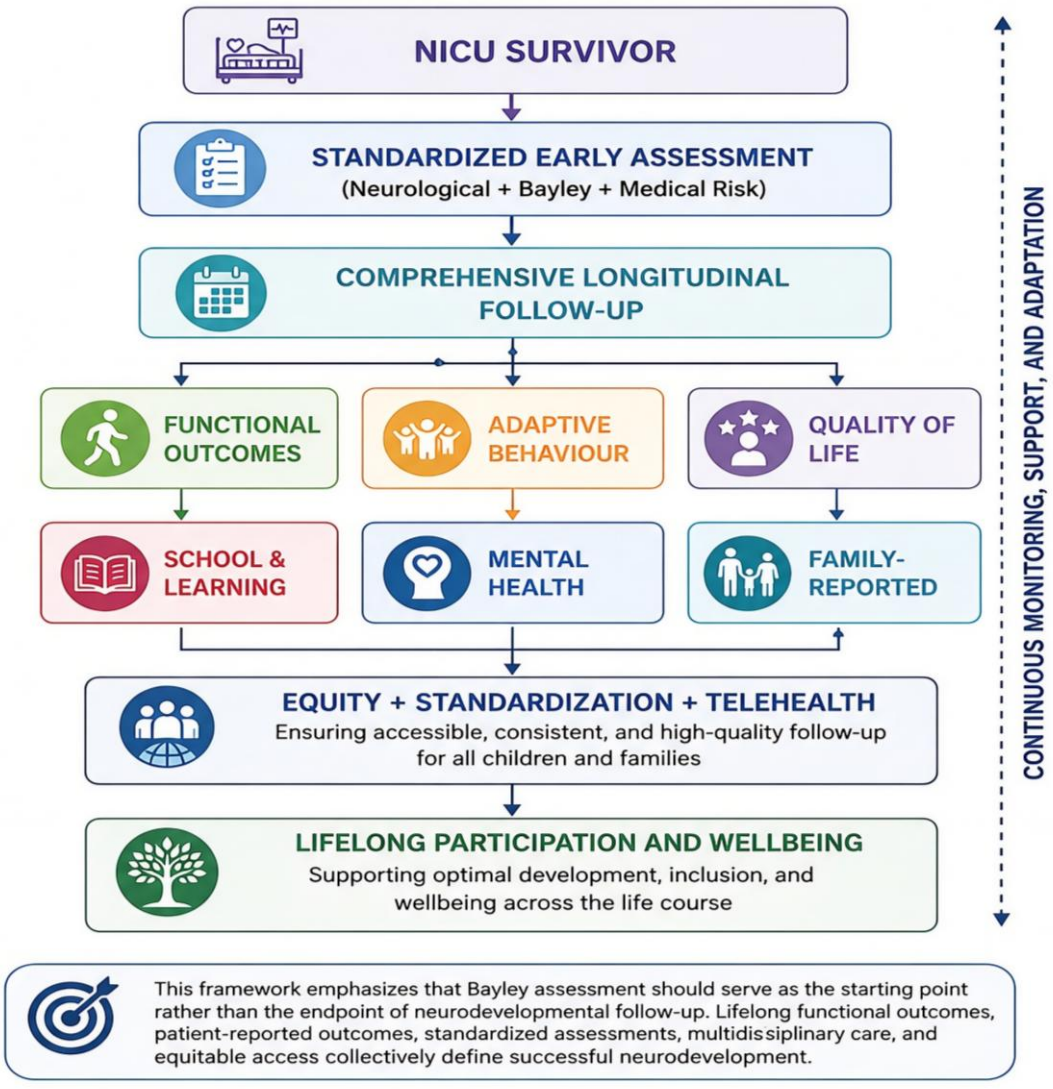

Figure 1. Beyond the Bayley: A Life-Course Framework for Neurodevelopmental Follow-up

collectively define successful neurodevelopment.

CONCLUSIONS

The remarkable improvement in neonatal survival represents one of modern medicine's greatest achievements. However, ensuring that survivors achieve their full developmental potential now constitutes the next major challenge. Although the Bayley Scales remain valuable for early developmental assessment, they should no longer be regarded as the sole indicator of long-term neurodevelopmental success.

Future neurodevelopmental follow-up programmes should adopt standardized life-course frameworks incorporating functional outcomes, adaptive behaviour, quality of life, patient-reported outcomes, and equitable access to multidisciplinary services. Harmonized Core Outcome Sets, standardized reporting, telehealth-supported care, and international collaboration will improve research quality while promoting equitable, patient-centred care for all NICU graduates.

Moving beyond isolated early psychometric testing towards comprehensive lifelong assessment represents not merely a methodological refinement but an essential evolution in neonatal care that aligns outcome measurement with what ultimately matters most to children, families, clinicians, and society.

ACKNOWLEDGEMENTS

The author acknowledges healthcare professionals involved in neonatal follow-up programmes whose clinical experience continues to improve long-term outcomes for high-risk infants.

AUTHOR CONTRIBUTIONS: conceived the perspective, reviewed the literature, interpreted the evidence, drafted the manuscript, critically revised the intellectual content, and approved the final manuscript- **RK**

CONFLICT OF INTEREST: The author declares no conflict of interest.

Funding: None

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