Reimagining Neonatal Follow-Up

An Equitable Model of Care Emphasizing Family and Child Function

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KEYWORDS

- Neonatal follow-up • Health care equity • Hybrid care • Neonatal outcomes
- Behavioral phenotype of prematurity

KEY POINTS

- Despite advances in neonatal intensive care units care, neonatal follow-up programs exhibit significant variability in staffing, care provision, and resource allocation.
- Key to behavioral phenotypes is the developmental principle that development is not binary but rather a fluid process that does not always happen in a smooth arc but can occur in fits and bursts.
- Rigid models of follow-up care are out of date with the evidence and potentially not delivering effective or cost-efficient care.

BACKGROUND

Neonatal Follow-up History

The initial goal of neonatal follow-up (NFU) was to assess outcomes resulting from care in neonatal intensive care units (NICUs), which were newly established, focusing on neonates rather than all pediatric patients.[1] These outcomes encompassed the identification of the potential sequelae of care, particularly in neonates who survived into the toddler period and exhibited disabling conditions such as cerebral palsy (CP), visual/hearing disability, or cognitive impairment.[2] Surveillance for such outcomes served as a quality check on new interventions, increases that might necessitate an evaluation of care efficacy. For years, as care in the NICU rapidly evolved and

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Pediatr Clin N Am 72 (2025) 93–109
https://doi.org/10.1016/j.pcl.2024.07.027
pediatric.theclinics.com
0031-3955/25/

new practices were implemented, these outcomes were evaluated with the contemporary epoch of care in mind.[2–4] However, recent trends indicate a shift toward more standardized and less fluctuant care, resulting in greater stability in the prevalence of these short-term outcomes.[5]

Furthermore, long-term, older adolescent and adult studies have demonstrated important, unmeasured outcomes around function and quality of life.[6] These studies have called into question the significance and relevance of the initial short-term measures of outcome.[7] Significantly, parents have questioned the importance of the reported toddler outcomes, articulating a need for outcomes related to function, such as a child's feeding abilities, sleeping regulation, hospitalizations, future behavioral skills, and progress in adaptive skills essential for learning with peers in preschool and school learning environments.[8]

As NICU care evolved, so too did NFU programs and the clinical expertise of caring for preterm infants as they grow. The initial goals for programs on outcomes documentation of major motor, neurosensory, and cognitive disability shifted toward developing expertise in identification and proactive intervention for a wider spectrum of health, neurodevelopmental, and behavior disorders. The Bayley Scales of Infant Development (BSID)—the most commonly used assessment tool in NDU—has been proven to have limited predictive accuracy for significant challenges[9,10] at older ages. However, other assessments have been identified that are highly accurate for the identification of specific outcomes, such as CP[11] and sensorineural hearing loss.[12] Children with ASD, once not diagnosed until 3 or 4 years of age at the earliest, are now being identified in the toddler period, enabling specific interventions to be initiated.[13] Similarly, children with CP, once not diagnosed until 2 years of age, are now being identified as early as 3 months of age, and targeted intervention is initiated.[14] The benefits of early intervention have also been well demonstrated, particularly with outcomes such as autism spectrum disorder (ASD),[13]CP,[14] sensorineural hearing loss,[12] and developmental disabilities.[15] Long-standing partnerships have been forged between NFU and early intervention programs,[16] and there is an increased recognition for more systematic neurodevelopmental surveillance and proactive interventions to optimize functioning, school readiness, and academic achievement.

CHALLENGES IN NEONATAL FOLLOW-UP

Despite advances in NICU care, NFU programs exhibit significant variability in staffing, care provision, and resource allocation.[17,18] A recent assessment in the United States, over a decade old, demonstrated tremendous variability in staffing and follow-up schedules[17] and mirrored the same pattern from a recent Canadian study.[18] Funding remains a pervasive issue,[17,18] affecting the educational experience for medical trainees, with limited guidance from certifying bodies like the American Board of Pediatrics or the Royal College of Canada in follow-up training other than to indicate its need.[19,20] Dual training in Neonatal-Perinatal Medicine and Developmental (Behavioral) Pediatrics has emerged but has challenges of additional training time, funding, and lack of mentorship. Fewer than 10 individuals are dually certified in the United States and Canada. Other dual training opportunities include Neonatal Neurology and Complex Care, which face similar obstacles.

Another long-standing challenge for NFU programs has been follow-up adherence. No-show or lost-to-follow-up rates are a consistent challenge, especially among non-English-speaking or Black families.[21] One common theme is the cost to families.[22] While Canada provides a socialized health care system, and therefore, visits for health care are free of direct cost, there is the cost of time off from work or transportation and parking. For those in the United States, copays from insurance and the above challenges compound the cost and limit attendance. Further to the cost, there is a common experience of parental trauma from the NICU experience and reigniting this trauma, returning to a health care facility with their preterm child for assessment.[23] The location for NFU programs is often in tertiary centers, located in urban areas not proximal to rural families, requiring extensive travel to attend follow-up.[22,24,25] Lastly, for those where travel is essential for NFU care, weather can pose a significant challenge for several months of the year, limiting access to needed appointments.[24]

OUTCOMES OF PRETERM CHILDREN

What has emerged from years of data collected has informed the behavioral phenotype of the preterm child.[26] This behavioral phenotype includes a spectrum of strengths and challenges across attention, behavior, regulation, and peer social skills. The common biological etiology of this behavioral phenotype after extreme prematurity is brain dysmaturation resulting from preterm birth and includes causal pathways of aberrant environmental exposures of the NICU, separation from parents, stress, and inflammation.[26–29] Encapsulating behavior patterns into these behavioral phenotypes allows greater ease of identification and earlier intervention[27] for the spectrum of attention, executive function, regulatory behaviors, and social skills that underlie school and community success. Key to behavioral phenotypes is the developmental principle that development is not binary but rather a fluid process that does not always happen in a smooth arc but can occur in fits and bursts. Rather than normal or abnormal, most development is characterized as typical or expected, variant or still within the range of expected but on the outer aspect of expected. Atypical development, including problem behavior or development, is environmentally mediated and improves with environmental modifications. Finally, there is disordered development or behavior, presenting in multiple environments and interfering with day-to-day function.[30] Key to the behavioral phenotype for the preterm is that challenges may emerge as problems and/or disorders rather than exclusively disorders.[26] Specifically, there is a wide spectrum of impacts that require attention to a whole child framework of neurodiversity.

Preterm infants exhibit notable strengths within this framework, often characterized by reported happiness and resilience. Parents frequently admire their child’s survival and developmental progress aligning with expectations.[9] For each child, the challenges may ebb and flow in terms of the developmental stream impacted and age, as gaps present only when that area of the dysmature cortex is developmentally expected.[31] The presence and degree of functional impact is variable, with some unaffected, others minimally impacted, and others more impacted.[26] Generally, the more preterm the child, the more pronounced the challenge and its functional impact.[26] It is rare to have one isolated challenge; rather, they often present with a constellation of challenges.[26] It is equally important that the spectrum of these disorders do not preclude developmental progress, learning, and social success.

The minority of preterm survivors has significant morbidity characterized by disabling disorder, such as CP, vision or hearing impairment, and cognitive impairment.[2,26] The prevalence of these outcomes varies widely, ranging from 3% to 25%, contingent upon gestational age and specific diagnostic criteria.[4,26] Many preterm survivors experience minor challenges with motor skills, behavioral regulation, learning skills, language and communication, and social skills.[26] Motor challenges include visual motor discrepancies, making copying and creating images or letters difficult.[32,33] Learning to write and then writing to learn becomes challenging, as the effort is more effortful and inefficient. In some preterm children, there is an increased possibility of developmental coordination disorder presenting with persistent challenges mastering day-to-day functional motor tasks, for which practice does not improve performance.[34] Identification and specific cognitive approaches to improve function.[35] Behavioral regulation with increased attentional weakness/attention deficit disorder and executive function challenges are more common in the former preterm.[26,33] Tasks with directions in series are often inaccurately followed. Persistence in tasks can be exquisitely challenging for a preterm child, particularly for those tasks that are more difficult.[33] Emotional regulation can also be more erratic in the preterm child, with preterm children presenting with greater emotional lability.[36] Learning disabilities in reading, mathematics, and written language are more common in the former preterm and can be late to be diagnosed, exacerbating greater behavioral problems.[26,33] Much less common is intellectual disability.[26,33,37] Communication difficulties manifest across various dimensions, such as language comprehension, auditory processing, articulation, and sentence complexity.[26,33] Socially, preterm children have been described as more nomadic, preferring adults or older children over peer engagements, potentially influenced by language challenges or comorbidities such as ASD.[26,37,38] However, empirical data on ASD prevalence among preterm populations remain sparse, albeit suggestive of heightened vulnerability among extremely premature infants.[38]

Transition to school can be tumultuous as many educators are unaware of this phenotype, and identification requires discrete, specific assessment, which is costly and time-consuming.[26,39,40] Moreover, discontinuation of follow-up programs and early intervention services by the age of 3 years deprives families of ongoing support, exacerbating challenges associated with navigating the complexities of the preterm behavioral phenotype.[17,18,26] In addition, limited requirements exist for pediatric trainees or developmental-behavioral/neurodevelopmental pediatrics on the behavioral phenotype of prematurity, leaving health care practitioners ill-equipped to provide expert guidance and consultation to affected families.[19,20]

The underlying etiology of the behavioral phenotype of prematurity is the dysmaturation of the preterm brain[28,29]—the combination of epigenetics, environment, and inflammation.[28,29] For the preterm brain, development in the third and possibly the second trimester occurs in the unnatural environment of the NICU. Separated from its parent, introduced to novel environmental stimuli with sounds through air, touch, pain, and gravity, the brain develops differently.[28,29] At a genetic level, changes in gene methylation signal the brain's adaptive nature to its experience.[41,42] At a cellular level, cells are programmed to receive input. Some inputs are premature and excessive, leading to connections and pathways that may not be intended. The input is absent or minimized in others, leading to diminished connectivity.[26,28,29] Exacerbating this is the vulnerability to injury, with cells not having protective mechanisms to manage stressors such as excessive oxygen exposure, which leads to oxidative injury or inflammation.[29] At the sensory system level, the input received by the preterm infant is altered and isolated, and it has been hypothesized to contribute to future dysregulation.[42] In utero, the child experiences most sensory input in a multimodal manner; a sound is muffled through amniotic fluid, providing auditory input and associated vestibular input as the fetus startles or moves to the sound. In the NICU, however, with the confines of gravity and essential tubing, sensory inputs become isolated and splintered from the expected multimodal input.[42] The result is cellular loss, diminished cortical volume, diminished and altered connectivity, sensory dysregulation, and potentially more significant injury superimposed on this dysmaturation.[28,29,41,42]

At a developmental level, the impact of this complex interaction between the developing brain, a novel environment, and parental separation is a difference in musculature development. Historically referred to as transient abnormal neurologic signs, this describes the preterm motor pattern with extensor posturing, scapular retraction, and diminished flexural strength.[43,44] This pattern tends to improve over the first 2 years of life and, historically, has been a confounding finding with attempts to identify CP early.[45]

Additionally, the etiology of the behavioral phenotype of prematurity is also rooted in the injury to parents.[26,46] For many parents, the NICU is a foreign place with a novel language, culture, and expectations.[47,48] Parents having experienced the NICU have a greater likelihood of postnatal depression, anxiety, and posttraumatic stress, and this increased possibility is not selective for the birth parent only but affects both parents.[48,49] There is strong evidence demonstrating that parental mental health impacts the process of attachment.[50] This increased possibility of mental health challenges for parents,[48,49] combined with a child that has experienced ongoing daily dysregulation with variable sensory exposures[42] and consequently is not regulated themselves,[26,37] leads to significant potential challenges with attachment.[50]

CHANGES DRIVING CHANGE

The Pandemic and Telehealth

The pandemic with severe acute respiratory syndrome coronavirus 2, or coronavirus disease 2019 (COVID-19), presented an opportunity within the health care crisis. Before the pandemic, virtual telehealth had been mired in proprietary technology, ongoing challenges to accessibility with technology not being equitably distributed, and privacy concerns.[51] To accommodate limited access to health care during COVID-19, these challenges at a global level quickly dissolved, and virtual visits became a new normal and were implemented in NFU.[52,53] While limitations to this forum for health care were identified, benefits have persisted, particularly around accessibility for families, the opportunity for families to interact with providers without having to leave their homes, and minimizing costs for many families.[54,55] It was feasible to coordinate additional consultants on the virtual visit as this could be done from one's office rather than commuting to a mutual space for assessment.[56] Lastly, for non-English speaking families, there was the benefit of adding an interpreter online rather than the interpreter having to travel to the assessment space.[55–57] As COVID-19 has become less of a day-to-day concern, the use of virtual health has also diminished. Other challenges in addition to inconsistent implementation has been uncertainty in reimbursement depending on insurance, organization, and state/country.[57]

Family Voices

Another seismic change to NFU has been an increasingly vocal parent advisory groups that have formed partnerships with networks such as the Vermont Oxford Network and Canadian Neonatal Follow-Up Network (CNFUN), and others. Adding to this are a growing population of NICU providers who have gained experience as parents/grandparents of a child in the NICU.[58] This new generation of parents/grandparents have provided greater insight into outcomes of importance to parents and families, and the outcomes they identify do not align with those deemed important by medicine.[8,9] Rather challenges around feeding and sleeping regulation, admissions to hospital, breathing, and behavioral and school-based difficulties have been raised as outcomes that are more relevant to families.[9] These outcomes align with those deemed significant by Rosenbaum and colleagues,[59] with emphasis on “F” words; function by doing what you can, fitness for proactive health, fun by having a passion for the achievable, family and friends for support and encouragement, and a future of possibilities. Implementing protocols to better measure and reflect these important parent-identified outcomes is an ongoing goal.

Early Detection

Early identification has emerged as feasible and associated with better functional outcomes for both ASD[13] and CP.[14] In the preterm population, both conditions have an increased incidence with decreasing gestation.[3,4,26,37] For ASD, the pathway remains unchanged from that of term children, with a focus on screening for social communication and behavior skills early.[13] For the preterm child, however, with features consistent with possible ASD, a full assessment is warranted. There are no current guidelines for assessment and diagnosis. Drawing upon other populations with comorbid and potentially confounding developmental conditions, the practice of a full assessment for autism using a standardized tool, the Autism Diagnostic Observation Schedule, second edition, is recommended.[14,60] CP, however, has clear care guidelines demonstrating the feasibility of early identification with precise established tools and the benefit of early intervention.[13,45] When used in combination, neuroimaging and clinical tools of the General Movement Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE) have demonstrated synergy with early identification.[11] The GMA is an observational assessment of the quality of an infant’s (preterm to 20 weeks postterm) whole-body movements and has been correlated to underlying neurologic integrity. The HINE is a standardized neurologic examination of an infant between 2 and 24 months, including tone, posture, reflexes, and reactions, as well as asymmetric findings.[11,14] This shift places greater emphasis on earlier and more comprehensive NFU visits.

Flexible and Responsive Care

Lastly, harmonized care has been demonstrated to be feasible.[61] In Ontario, the centralized health care system prioritized a system of NFU that was equitable and accessible.[61,62] Identified challenges were familiar to those described for all NFU programs, including disparity in staffing and funding, inconsistent schedules, distance to care and travel, and cost with time off from work and/or parking.[61] Additionally, there was the challenge of the large geographic region of Ontario, with some families requiring flights to attend appointments and weather.[61] The Provincial Council of Maternal and Child Health (PCMCH) assembled a working group to evaluate the status of follow-up across the province and then attempt to harmonize the system. Over 3 years, the group demonstrated that while there was variability in staffing, there was a consistent commitment to the families and their children and a unifying interest in care provision closer to home.[61,62] With this, the group identified a “touchpoints” approach to care, focusing on the child’s and family’s developmental needs.[61] The group used this touchpoints approach to facilitate harmony in schedules. The recommendations did not mandate specific neurodevelopmental assessments but rather allowed each specific team to identify the tool that suited their individual staffing capacity and skill set.[61] A shared care model was developed with families and children having the option to have care in follow-up programs closer to home, in close collaboration with the tertiary center for support.[61,62] The more immature the child, the greater the involvement of the tertiary team, to allocate resources to those in need.[61,62]

ALTERNATIVE MODELS OF CARE

Other models of care have been proposed that have either collaborated with NFU programs or, in some settings, merged. Complex care is a field that evolved to provide medical coordination of care for children with complex medical conditions, requiring multiple subspecialty providers.[63] This medical model centers the child and family with the local pediatrician and therapy team. There are established contacts with the complex care coordination team in the subspecialty center for both parents and providers.[64] This hub-and-spoke model has allowed for better care coordination in more rural environments and minimized travel and cost to parents with focused trips, providing as much exposure to providers as needed and possible.[64] This model has also allowed local providers to be more empowered to provide the required and supported care.[63,64]

In addition, addressing parental mental health is crucial in any model of care for families navigating NICU experiences. Strategies for managing parental anxiety and depression in the NICU have encompassed parental education, involvement in day-to-day care, and counseling.[65] Evidence has demonstrated heterogeneous findings with mixed impacts on parental anxiety and depression.[65,66] One counseling approach utilizes cognitive behavioral therapy, as this has had strong evidence in generalized anxiety disorder models.[67] In this context, one is taught to examine one's thoughts and appreciate the gap between the thoughts and reality and then to learn skills to manage this gap.[67] In the NICU reality, however, most parental worries are based firmly on reality, and as such, this may account for the lack of consistent evidence. A model demonstrating early feasibility is Coached Enhanced Neonatal Transitions, which utilizes a nurse-based coaching model providing greater parental capacity and consistent contact within the health care system. It added a component of mental health support, acceptance and commitment therapy (ACT).[68] ACT teaches parents to identify and focus on their values, acknowledging their concerns but keeping them in the context of that which is important to them.[68] In doing so, the worry and anxiety are shifted from a position of focus to one of peripheral vision, present but not obscuring the view of what matters. Early evidence from this approach has demonstrated feasibility.[68]

An attempt at addressing the inequity in access to care provision of care and one that attempts to address the needs of the child and family, as well as one that continues to allow for ongoing data for quality assurance, has been described. This model of NFU has been called “E-Nurture” and includes a hybridized approach to care, with virtual and in-person visits, weaving principles from complex care models, opportunities from COVID-19 and virtual care, and the experience from PCMCH's working group.[52,61,62] This concept of “touchpoints” is critical to the schedule of visits, reflecting a concept from Dr Brazelton, describing those developmental moments that can lead to struggle or conflict within a family.[52,69] They are moments of growth for the child and family.[69] When presented as such, positive elements can be appreciated, and the steps to work forward appear more proactive.

Merging this with parental values of outcomes is critical, both clinically and for reporting and quality monitoring. Recently, the CNFUN assembled teams of those involved in follow-up and parents to identify priorities in data collection.[70] Outcomes to be collected and reported were reprioritized to include those parents deemed important, with attention to feasibility.[70] Seven domains were identified: child well-being/happiness, quality of life/function, socioemotional and behavioral outcomes, respiratory, feeding, sleeping, and caregiver mental health.[70] At the 18 to 24 month research-based data collection visit, measures were identified to measure these outcomes. While these data are important and the screeners feasible, modifications are essential in order to reap a clinical benefit. Feeding challenges are often identified early following discharge, with failure to thrive peaking at 4 months corrected age as the sucking reflex integrates.[71] Capturing a feeding challenge at 18 months is important as it adds to the body of evidence but will not provide timely intervention. Similar benefits and challenges exist with the other identified domains to measure.

OPPORTUNITY TO CREATE NEONATAL FOLLOW-UP FOR THE FUTURE

Given the limitations in NFU care delivery and the innovative research being done to address them, there is tremendous opportunity to develop and test alternative, more effective models of care. This is imperative for 3 critical reasons. First, implementing and disseminating new advances in the early detection of CP and ASD will allow earlier initiation of outcome-changing therapeutic interventions. Second, the behavioral phenotype of prematurity often presents in subtle ways, requiring specialized serial assessments not commonly used today. Third, improving longer term outcomes requires longer term supports beyond the preschool period that currently marks the scope of routine NFU.

The life course health development framework has yielded greater insight into the trajectory of a diagnosis, factors that promote resilience, and practices to promote wellness and minimize disease.[72] Jonathan Litt and colleagues[73] explored the application of the life course model of care to NFU, revealing barriers stemming from fragmented systems, outdated NFU structures, and misaligned priorities. The life course model underscores the need for care across a lifespan, starting in the NICU and transitioning to the clinic with an emphasis on the health and development of the child and family, particularly as it relates to function, delivered in an equitable and accessible way.[73] Advocating for a strengths-based approach, “working toward the ‘possible,’” aims to optimize existing resources for families and the child.[73] Fundamental principles to the life course model include health development with an integrated care team, acknowledging that a longitudinal approach is needed for systems of care; the complexity of health development with an ongoing interaction of the individual and environment, thus necessitating a system of care that is nimble to the many influences; timing of care sensitive to the unfolding needs of the child and family, particularly during sensitive windows; plasticity, which describes the responsive nature of the developing individual to environmental influences better described with the language of possibility rather than “fatalism”; thriving as optimizing health offers greater opportunities for success; and harmony between family needs and goals and system structures.[71,73] An opportunity exists to merge concepts of alternative models of care, including the hybrid touchpoints approach of E-Nurture, with the life-course approach, parental priorities to allow the collection of essential outcomes in real-time, using evidence to determine the timing of administration of specific tools, therefore allowing timely intervention. This model of care is described in **Table 1**. Critical to this model of care described in **Table 1** is the understanding that this can be achieved using the local resources and with integral incorporation of the pediatrician/family physician as well as family drawing from the complex care literature,[63,64] in collaboration with NFU. Parent education is a goal throughout every stage, empowering the parent to be the expert and providing consistency and more significant equity in care delivery. Additionally, developmental screening or assessment tools were chosen for feasibility and cost, using tools freely accessible as first-line choices. While the BSID has fallen under criticism for failing to provide the information that parents need/want, it does provide a comprehensive evaluation of the child with a structured opportunity to

Table 1
Touchpoint focused follow-up schedule*

Age	Touchpoint	Mode of Visit and Objective	Tool Recommended	Staffing	Intervention
Before discharge	Preparing to transition home	In-person or virtual, pending parental preference Introduction to the team and goal of the program	Written information or in-person introduction	Any team member	Assure that virtual access is possible Review medical history for triaging
1 wk after discharge	Making a place in the family	Virtual Objectives: 1. Transition to home 2. Feeding practices 3. Sleep	Virsual feeding assessment/ questionnaire Weight measurement Edinburgh Postnatal Depression Scale	Medical/nursing Social work Psychology	Referral for feeding support Mental health resources utilized Safe sleep counseling Confirm early intervention (EI) referrals are in place Determine if additional visits or subspecialty visits are needed
4 wk after discharge	The mental health of parents	Virtual Objectives 1. Mental health screening of parents 2. Initiation of early surveillance for cerebral palsy 3. Medical follow-up 4. Feeding 5. Sleep	Edinburgh Postnatal Depression Scale Assessment of general movements (parents can provide video) Virtual feeding assessment or questionnaire Sleep hygiene	Medical/nursing Social work Psychology Therapy	Referral for mental health support Liaise with subspecialty providers Referral for EI if not done Teaching around time in prone Sleep hygiene principles reviewed Feeding principles reviewed

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Table 1
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Age	Touchpoint	Mode of Visit and Objective	Tool Recommended	Staffing	Intervention
4 mo	Roles established in the family and rituals needed	In-person/virtual possible Objectives 1. Examination for early signs of cerebral palsy 2. Medical follow-up/ growth parameters 3. Feeding and introduction of solids	Assessment of general movements HINE Feeding surveillance Sleep surveillance	Medical/nursing Therapy	Tummy time Advance to solids reviewed (expected in future) Sleep hygiene
8 mo	Emerging independence	In-person/virtual possible Objectives 1. Examination for early signs of CP 2. Medical follow-up/ growth 3. Feeding and solids 4. Emerging independence safety and transition postures	HINE Feeding surveillance Sleep surveillance	Medical/nursing Therapy	Transition postures reviewed. Feeding strategies with the shift from feeding to eating Sleep hygiene
12 mo	Standing and walking	Virtual or in-person Objectives 1. Assessment of motor skills 2. Introduction to discipline with newly independent infant 3. Sleep hygiene. 4. Feeding	HINE Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS) Survey of Well-being in Youth and Children (SWYC)	Medical/nursing Therapy	Coaching on pulling to stand/walking. Behavior management strategies Referral for structured playgroup or daycare interaction

18 mo	Independence and limit setting	In-person Objectives 1. Developmental assessment of learning, language, and motor skills 2. Surveillance for social and behavioral skills 3. Data collection for reporting, if applicable (should include measures of well-being, function, feeding, and sleeping)	Comprehensive developmental assessment (Bayley Scales of Infant Development offers historical and international reference, Mullen) SWYC WIDEA-FS	Therapy Psychology Medical/nursing	Referral for further evaluation of Autism if concerns Daycare or playgroup Behavior management strategies Speech and language strategies reviewed
36 mo	Preschooler, an emerging sense of self	Virtual or in-person Objectives 1. Developmental assessment of learning, language skills 2. Surveillance for social communication skills 3. Behavior Surveillance 4. Preparation for school	SWYC +/− more in-depth assessment as indicated with Bayley Scales or Mullen	Therapy Psychology Medical/nursing	Referral for daycare playgroup or preschool Behavior management

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Table 1
(*continued*)

Age	Touchpoint	Mode of Visit and Objective	Tool Recommended	Staffing	Intervention
4–5 y	Neighbor—community growing for child	Virtual screen: in-person as indicated Objectives 1. Surveillance of skills to transition to school 2. Behavior and self-regulation	SWYC Canadian Pediatric Society, Preschool/ Kindergarten Teacher questionnaire	Medical/nursing Therapy	Referral for therapy as indicated Encourage group activities Public school is funded and available based on corrected age
7–8 y	Learning skills	Virtual screen: in-person as indicated Objectives: 1. Identification of learning differences 2. Behavior screening	SWYC Canadian Pediatric Society, Preschool/ Kindergarten Teacher questionnaire Vanderbilt ADHD Diagnostic Rating Scale If indicated, a tool for screening learning abilities: Kaufman Brief Intelligence Test Kaufman Test of Educational Achievement	Medical/nursing Psychology Therapy	Collaborate with local school board to share results and work to achieve necessary learning provisions Behavioral management Specific to attention and impulsivity Collaborate with the primary physician for possible ADHD pharmacotherapy

*Key to this model is awareness of the behavioral phenotype of prematurity and diligence with screening for the above touchpoints, with intervention provided. Children may be identified at any stage along this trajectory as having a significant neurodevelopmental condition, including CP, autism, or deafness. These children benefit from specific early identification to enhance opportunities to acquire function. Referral to specific therapeutic interventions is beyond the scope of this article, but it includes referral to appropriate subspecialty medical providers as well as therapy. However, these referrals and interventions do not preclude them from ongoing surveillance and screening for aspects of the behavioral phenotype of prematurity.

evaluate skills.[10] It also provides essential historical references and comparability, allowing programs to evaluate the quality of their care and categorize a child's skills.[10]

SUMMARY

NFU has grown and developed like the babies it has followed. It has morphed from a clinic structured for surveillance on outcome metrics to providing data identification and intervention to one working to reflect the outcomes that matter to parents.[1,2,9,70,72] Ongoing challenges with lack of follow-up training, inconsistent provision of care, and inequitable service allocation are critical barriers to effective, family-focused care.[17–20] Rigid models of follow-up care are out-of-date with the evidence and potentially not delivering effective or cost-efficient care. A hybrid model of care, with creative collaboration with local community resources and access to expertise in the behavioral phenotype of prematurity, can be developed specifically for each community resource and tailored to geography. Consistency in care can be achieved by espousing the model of touchpoints for care visits, informed by parental feedback and evidence, and emphasizing parents' education of their children through collaboration with local online resources and tertiary centers. Our overall emphasis is on collaboration for thriving, functioning, and participation. In this way, we can optimize longer term child health, developmental and functional outcomes, and parental well-being.

CLINICS CARE POINTS

- Most preterm infants survive without significant disability.
- Many, however, will have 'minor' challenges with various aspects of their development, including moving, regulating behavior, learning, communication and language, and social skills. Often, there are multiple areas of challenge amidst other areas of strengths.
- The pattern specific to preterm survivors has been referred to as the behaivoral phenotype of prematurity.
- Neonatal follow-up has evolved from one of surveillance to one of early identification and intervention, focusing on those outcomes identified as important by parents.
- Challenges persist around staffing, funding, and training with results in inconsistent and inequitable care.
- Rigid models of care perpetuate the challenges. Focusing on touchpoints and working with local resources to provide care can alleviate some challenges with care provision.

DISCLOSURE

The authors have no commercial or financial conflicts of interest to disclose.

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