

Developmental Supports for Newborns and Young Infants with Special Health and Developmental Needs and Their Families: The BABIES Model^{☆,☆☆}

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Fragile newborns and young infants who are born with a likelihood of lingering developmental concerns require specialized assessment and intervention based on their unique developmental needs. Often these infants are identified as categorically eligible for early intervention and nursing services, based on their medical condition at birth. The medical involvement of many of these infants adds complexity to the evaluation and/or provision of services, let alone how to best provide supports for their families. Increasing data regarding the regulatory disorganization of young infants which leads to later cognitive and mental health challenges provide a rationale for appropriate assessment and intervention strategies for this population. A recent survey of educational needs of Colorado professionals working with this population revealed that many early intervention providers felt only “slightly” prepared to evaluate newborns and young infants and that most providers felt they could benefit from more training on assessment and intervention with this population. Best practice for this increasing population includes specialized and evidence-based training and capacity building necessary to prepare professionals to evaluate, intervene, and support their unique fragility and emerging developmental competencies. The current study describes the development and components of the BABIES approach to supporting early intervention professionals and nurses to best integrate relationship based developmental supports for fragile newborns and young infants.

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Despite national and state efforts to reduce the early birth and prevention of congenital anomalies, the prevalence of early born and medically fragile infants has increased rather than decreased in the United States over the last decade, and the rate of preterm births has only decreased slightly to 12.2%, missing the goal of 9.6%.^{1,2} These statistics reveal not only increasing demands for in-hospital attention to support infants' development, but also to incorporate family centered approaches. Infants who spend the first days, weeks, and months in the Newborn Intensive Care Unit (NICU) typically have ongoing health and developmental challenges.^{3,4} Both very early born infants, late preterm, and early term infants experience increased re-hospitalizations and increased primary care physician visits within the first months after discharge when compared with term born infants.⁵ Similarly, cognitive, motor, speech, and mental health problems for these infants are increased well into early childhood and adolescence.⁶⁻⁸

Many infants are now discharged before their term due date, meeting physiologic and feeding milestones at least for brief periods of time,⁹⁻¹³ but well before consistent and reliable stability is reached.¹¹ Parents report increased stress of having a vulnerable infant which begins in the NICU and extends well into the first year of the infants transition to home. The infant's family may or may not have access to necessary health

and developmental support, including information, guidance, and consultation that are needed during the transition to the family's home.^{4,14}

Three resources are typically available in the United States to infants who begin their lives in the NICU and their families to assist with developmental support. Early intervention (EI), through the Individuals with Disabilities Education Act, Part C, is available through a federally mandated program and managed by individual states.¹⁵ Each state determines eligibility for EI services through either identification of developmental delay or likelihood of developmental delay.¹⁶ These “presumptive eligibility” guidelines are typically used in NICUs to identify infants who have a medical diagnosis which typically results in developmental delay (eg, Down syndrome or hydrocephalus). Some, but not all states utilize the approach of identifying infants who are presumptively eligible while still in the NICU, and facilitate a referral to the community resources.^{17,18} Many states also refer infants with identifiable health and developmental problems to either home visiting nursing or public health nursing. Typically those infants who have ongoing medical needs such as feeding tubes, ventilators or total parenteral nutrition are provided home nursing part or full time, or with weekly visits to assist and support the family. Public health nursing in most states typically addresses family support needs and care coordination, but a few state programs also provide direct services to medically fragile infants and their families. Other EI resources are provided when the baby was originally hospitalized or within medical homes where the family is able to access most physical health, mental health and EI services in one location, preferably in the family's community.¹⁹

Infants who transition from the NICU to their home and who have been referred for EI or nursing services should receive an Individualized Family Service Plan (IFSP) to meet the developmental goals for the individual infant in the context of the family's needs and aspirations. Typically, the infants are referred to EI or nursing specialists who have a health, speech and language, physical, or occupational therapy background for practice with young children. Many of these community professionals have a general developmental background or have received their basic education in pediatric or child therapies specific to their area of expertise. Guidelines for therapists and nurses practicing in the NICU have been developed by the respective professional organizations, and some guidelines also have a focus on work in the EI field.^{20–24} Many have also attended post-bachelor's continuing education with a focus on development of young children. However, few of those professionals have likely received basic or graduate level education or preparation for working with the specific needs of newborn and young infants with special health and developmental needs as they transition from the NICU.

For the purpose of this discussion, newborns and young infants are defined as those infants who were born early, with special health care or developmental needs or whose primary caregivers have social, medical, economic, or mental health risk factors which lend toward challenges with parenting²⁵ found to compound the likelihood of later developmental challenges, and up to approximately 6 months corrected age. This time

frame focuses in general on the “fourth trimester,” a time when newborns are both recovering from medical interventions and are developing a basic foundation of regulatory skills on which to build more typically defined developmental milestones.

Browne and Deloian²⁶ explored the prevalence of babies in Colorado who were either born preterm or with documented congenital anomalies and medical conditions necessitating more intervention than typical infants and toddlers might need. They recognized the lack of services for the needs of this large population and developed a definition of infants with special health care and developmental needs. The neonate category was defined as

“An infant diagnosed at birth with a medical condition that requires supplemental technology or medication for survival past one month of age, hospitalization for more than three weeks after birth, and/or has early regulation, feeding, state or motor concerns that require supportive and/or therapeutic intervention. In addition, it can be anticipated that they will need more than the typical clinic visits for health concerns during the first six months after birth, and/or their family will need supplemental professional assistance to manage daily care.”

This definition reflects the early health and developmental needs often overlooked by typical classifications of infants who require added supports after discharge from the NICU.²⁷

Evidence for Supporting Newborns and Young Infants Transitioning Home from the NICU

Four areas of research provide a rationale for specific and focal education for those providing supports and services to newborns and young infants and their families as they transition home from the NICU. First, there has been documentation of the importance of individualized, family supportive developmentally supportive care (IDC) in the NICU to enhance developmental and family outcomes.^{28–30} Largely led by the work of Als and colleagues, the Newborn Individualized Developmental Care and Assessment Program has documented significant improvement in medical, neurodevelopmental and family outcomes for high risk preterm, late preterm and intrauterine growth restricted infants.^{31–39} With the documentation of the potential impact on brain and neurobehavioral development, IDC is now becoming recognized as a standard in both national and international NICUs. Studies of infants who receive IDC also reveal an earlier discharge to home, many times prior to the baby's due date. What has not been as well recognized is the importance of continuing the IDC philosophy and approaches for those infants who are still regarded as in their “fourth trimester” and beyond. Many early born and medically fragile infants continue to need supports for developmental progress long after discharge, as they typically need more time post discharge and well into their first year to show typical developmental organization.

The second area of research which shows promise in supporting the development of newborns and young infants as they transition to the community are the studies that focus on assisting the primary caregiver (typically the parent) to understand the behavioral communication of their young infant and to enhance the interaction and co-regulation of the dyad. Based on both the work of Achenbach and Raugh,⁴⁰ the Mother Infant Transaction Program and relationship-based intervention programs have shown preterm infants to have significantly improved long term school achievement, behavior, brain organization parent/infant interaction, and lowered parent stress.⁴¹⁻⁴⁷ Emerging evidence of an adaptation of the Newborn Individualized Developmental Care and Assessment Program approach for infants discharged home demonstrate a significant impact on infant development and parental mental health.^{48,49}

The third area of research identifies and defines regulatory disorganization as a risk factor for later developmental organization and cognitive function. Emerging studies define self-regulation as "...the process of regulating an emotional state and organizing a behavioral response to experiences."⁵⁰

However, it is more complex for newborns and young infants. Typically infants begin to develop self-regulatory skills in the first few months when they emerge from their primary caregiver's external regulation to their own ability to react to the sensory input from the environment. Early problems with self-regulation in the first year, such as excessive crying, feeding, and sleeping problems may resolve with maturity, but a significant proportion of children persist in maladaptive responses to environmental inputs and are unable to use self-regulation skills to adapt to those inputs.^{51,52} Wolke and colleagues found that high risk infants (those re-hospitalized after discharge) were shown to have regulatory disorganization in the areas of feeding, sleeping and crying with implications for later development and altered parent/infant relationships.⁵³⁻⁵⁵ Having more than one of those three areas of difficulty increases the likelihood of later cognitive and mental health issues (eg, attention deficit disorder, tantrums, hyperactivity) as the infant grows into toddlerhood. Infants born very preterm are at significant risk for regulatory disorganization, but there is documentation of an increased incidence of these issues in late preterm and early term infants as well.^{56,57} As identified by parents in the early months after the infant's birth, problems of excessive crying and fussiness,^{52,58} difficulties with eating (see article on feeding by Ross and Browne, this issue) and lack of or disorganized sleeping are major challenges not only for the infant's development but also for family functioning.⁵⁹⁻⁶¹

The fourth area of research examines the mental health needs of parents who care for their fragile infant. Not only has the NICU experience been stressful for most mothers and fathers, but the incidence of maternal anxiety and depression can significantly impact dyadic interaction and the subsequent organization and development of their baby.⁶²⁻⁶⁶ Although many NICUs do not screen for mental health issues in parents, studies that have focused on identifying maternal depression have documented a significant proportion of mothers who are affected during pregnancy, in the NICU, and as they transition home. Many times, maternal mental health issues are not documented until long after discharge.

These 4 areas of research point to the necessity for EI professionals and nurses who provide services to newborns and young infants to not only know typical medical issues that plague these fragile infants but also to know the developmental foundations and mental health issues that need to be addressed in the context of the family's ongoing relationship with their newborn or young infant.

Colorado's Professional Development Efforts

In 2000 Colorado began an innovative approach to enhancing the capacity of EI and nursing professionals' supports of infants' transitions to the NICU and in their first months after discharge. With the recognition that the IFSP addressed developmental needs of the older infant rather than being more specific to the developmental needs of newborns and young infants, a new "transitional" IFSP was developed. Entitled the BEGINNINGS IFSP, it was developed to be used for infants in the NICU who were transitioning to EI and nursing community services.^{18,67} The BEGINNINGS IFSP and the later developed BABIES approach were formulated with principles of the synactive theory as a foundation,⁶⁸ and based on successful developmental intervention findings for premature born infants in the NICU.^{28,34,36,37,39,69,70} The BEGINNINGS process was instrumental in identifying infants eligible for Part C and public health nursing support, and addressed the foundational elements necessary for later developmental milestones and positive outcomes. In collaboration with Early Intervention Colorado, the State Part C lead agency, statewide workshops were offered to all professionals who provided services to newborns and young children.

With a recognition that many EI and nursing professionals might need further education on elements of the IFSP in order to provide specific intervention strategies. In collaboration with Early Intervention Colorado, a statewide online survey of providers was conducted in 2009 to determine the then current education and clinical experiences of EI providers who worked in the field with newborns and young infants. Results were obtained from 190 EI providers and nurses representing 9 different disciplines for a 38% return rate. Seventy-six percent of respondents indicated that they would *definitely* or *probably* like to have more education on how best to evaluate newborns and young infants and 86% were *definitely* or *somewhat interested* in further education on how to provide services to newborns and young infants. Topics of interest to most of those indicating interest were socio emotional development, motor development, sleep wake cycles, state regulation, self-soothing, and feeding. The results of the statewide survey prompted the development of a training program that addressed the specific developmental needs of newborns and young infants.

Development of the BABIES Learning Collaborative

A learning collaborative approach acknowledges the previous education and expertise of the skilled professionals, and builds on their experiences in the field to provide particular

evidence based approaches. The BABIES and PreSTEPS^{71,72} models, which are acronyms for the components of the approach (see below) provided a structure for learning and discussion.⁷³ A particular emphasis was on evidence-based assessment and intervention for an infant's Body function (biophysiologic organization), Arousal and sleep, Body movement, Interaction with others, Eating, and Self soothing. Support for families included specific approaches to supporting the parent-infant relationship and focused on the evidence-based best practices of Predictability and continuity, Self-soothing supports; Timing and pacing, Environmental modifications, Positioning and handling, and Sleep and arousal organization. Rationale and evidence to support these components of the training are described below.

BABIES

The BABIES approach addresses the evidence based areas of neurodevelopmental organization that are necessary during the first few months after birth in order to lay a sound foundation for later more typically recognized developmental milestones. Each of the components addresses major achievements that must be mastered by the infant in the context of his or her supportive relationship with the primary caregiver, as described in the PreSTEPS component of the model. A brief description and rationale for the areas addressed in the BABIES and PreSTEPS approach follows.

Body Function (Biophysiologic Organization)

Fragile newborns and young infants have a higher incidence of visits to their primary care provider and the emergency department for physiologic concerns of the respiratory and digestive systems. Additionally, they are significantly more likely to be re-hospitalized after discharge from the NICU for physiologic reasons.^{5,74} From a developmental perspective, in the first few months after birth, babies are still working to stabilize their breathing, color, digestion, and temperature in order to be able to manage more sophisticated milestones. The training focuses not only on foundations of how to observe the Body Functions of newborns, but also on how to identify when these functions are impacted by sensory or social input. Furthermore, the curriculum identifies common medical conditions that have significant impact on the regulation of an infant's body function such as gastroesophageal reflux, constipation and/or diarrhea, vomiting, irregular breathing, cyanosis, etc.

Arousal and Sleep

One of the primary developmental steps for newborns and young infants is to become more predictable and regulated in clarity and predictability of states, transitions, as well as sleep/wake cycles.^{61,75} Yet it is one of the least well-developed systems at birth and takes the majority of the first year to become predictable and regulated. The training focuses on

understanding the development of arousal and sleep cycles, duration, and predictable changes in sleep activity that parallel brain development in the first year. The curricula also focuses on strategies to assist families to support appropriate sleep and arousal development and to address common sleep concerns of parents of newborns and young infants.

Body Movement

Newborn motor development can be predictive of later modulation or of developmental delay.^{76,77} However, young infants often have motor challenges that are not always readily discernible in the early newborn period and are embedded in other emerging developmental systems.^{78,79} Content in the motor section of BABIES training focuses on early evaluation of motor tone, posture, and movement, and strategies to support parents' ability to optimize motor organization and supportive positioning, handling, and movement.

Interaction with Others

Last to emerge in the newborn period is the ability of the infant to come to robust alertness and begin to have visual and auditory responsiveness with their caregivers and others. Although most newborns are capable of social exchange, parents often have difficulty in interpreting the state availability and social bids of infants. Social interaction is also typically impacted by sensory and often overwhelming social bids of primary caregivers. Early interaction and exchange is likely the most salient precursor of socio emotional development in later infancy and into the toddler years. Social interaction and the impact of poorly organized interaction on later development is typically the least well understood by professionals but is an essential and foundational component of understanding early relationships in infant development. This component emphasizes the impact of social regard on parenting, including how to optimize and extend social interaction when appropriate, and how to determine when a baby needs breaks from social interaction.

Eating

Eating is a foundational developmental milestone for infants. However eating is a neurodevelopmental process and is not typically well established at birth, particularly for infants born preterm or with medical complications.⁸⁰ However, it is often the most concerning of the developmental steps for families if it does not go well. Of the identified regulatory difficulties in the first months after birth, feeding is prominent in babies who demonstrate disorganization of regulation which has long-term consequences.^{53,81} Emphasis is placed on how successful eating develops, what typical eating and feeding challenges that infants and families face, typical solutions to challenging eating/growing issues, and what resources are available for complex eating disorders.

Self-soothing

Foundational to an infant's ability to regulate all of his or her systems in order to optimize development is the emerging success at self-soothing. Infants who are successful at using others for soothing and then to use their own strategies are better able to learn and develop in a more typical pattern. Infants who are born medically compromised have more difficulty with the development of self-soothing strategies and are often irritable and/or have difficulty consoling themselves. Infants who have difficulties with self-soothing, or who cry extensively, are of particular concern for parents.^{52,58} One of the primary identified components of difficulties with regulation, crying, or the inability to soothe, contributes significantly to regulatory disorganization and to parent distress. The curriculum emphasizes how to determine effectiveness of infants' particular self-soothing behaviors or lack thereof and provides strategies for assisting family members to develop approaches to support self-regulatory strategies for their infant.

PreSTEPS

PreSTEPS⁸² provides a framework for identifying and supporting strengths that the caregiver, typically the parent, provides to assist the infant with organization towards their own developmental goals. The following 6 components are included in the curriculum.

PREDictability and Continuity

Parents' ability to provide predictable sensory inputs, caregiving, and nurturing create a foundation for trust and stability in newborns and young infants. The curriculum includes an emphasis on identification of predictable family schedules, strategies and approaches, and amplifies the need for the infant to experience these predictable, familiar routines in order to optimize infant development.

Self Soothing Supports

Many infants, due to their hospitalization or early birth, may not have effective self-soothing capabilities and will require support from their parent to calm from crying, or get into restful periods either for sleep or for social interaction. Parents often intervene appropriately when their infant needs consoling and organizing of their behavior, but may not have a large compendium of strategies for an infant who is typically more demanding. The curriculum focuses on identification and support of the parent's current strategies for supporting their baby's self-soothing. Additionally, it provides exploration of other approaches to assist parents who may have a baby who is difficult to console.

Timing and Pacing

Infants, in particular those with developmental and/or medical conditions, need to have sensory, caregiving, and social

inputs timed according to their ability to react to them in a growth producing manner. Often caregivers do not understand the behaviors that are indicative of the baby becoming overwhelmed by an interaction that is too fast or too abrupt for them to deal with. The curriculum emphasizes how to understand how infants behaviorally communicate overload and how to support families in their timing and pacing of input to their infant.

Environmental Modification

Newborns and young infants with developmental or medical concerns are typically sensitive to incoming sensory inputs, which they react to in a vigorous and sometimes disorganizing manner. The curriculum assists learners in how to detect the effects of a range of sensory inputs on infant organization and how to support caregivers in not only modulating sensory input but in helping the infant to react in a more generative manner to sensory input.

Positioning and Handling

Depending on the motor ability and responsiveness of newborns and young infants, positioning and handling can either help modulate or disorganize their motor equilibrium. The curriculum details motor development and responsiveness to positioning and handling, and addresses questions about optimal positioning and handling particularly during typical family daily activities and routines.

Sleep and arousal supports

One of the most challenging issues for families is the development of sleep routines and stability in the first year after birth. Sleep issues are of particular concern if the infant is ill or needs additional medical supports such as suctioning or tube feeding. The curricula assists the learner in how to support families to optimize typical sleep routines, and to address common sleep issues that families encounter, particularly with newborns and young infants who have begun their lives with disrupted sleep and arousal.

Learning Collaborative

The BABIES and PreSTEPS curriculum content⁷³ provides an evidence-based structure for participants to integrate not only into their previous EI and nursing expertise but also adds specific information regarding the particular developmental needs of fragile newborns and their families using a learning collaborative approach (LC). The Colorado LC pilot program provided technical assistance to experienced EI and nursing professionals who met on a monthly basis to further develop their evaluation, intervention, and systems building skills. The LC included in-depth application of the IFSP for newborns and young infants using the BABIES, PreSTEPS assessment and intervention education, case studies, and guided practicum experiences.

The overall goal of this approach was to build capacity of EI and nursing professionals through the use of training opportunities

and the LC that would produce competent, recognized leaders, specialists, and resources within communities and who would ultimately provide optimal services to families with newborns and young infants with special health and developmental needs. In particular, there was a focus on infants and families transitioning from the NICU to their home community.

Process and outcome data were collected on a regular basis and revealed the following results of participation in the pilot learning collaborative. Knowledge of the particular developmental needs of fragile newborns, young infants and their families for these experienced EI providers increased by 10% in each area evaluated. Referrals and service provision to these particular EI providers increased from 33 to 52 per cent over the year-long learning collaborative. Most impressive was the change in practice to a family supportive, relationship based approach rather than a therapy goal specific approach to their work. For example, the providers' primary practice goal of supporting the infant/parent relationship when they began the learning collaborative was 28% and, after, was 100%.

Outcomes of the LC were evaluated qualitatively as well. All respondents reported positive outcomes in their comments. Examples of responses to the question "How has participating in the learning collaborative changed the way you approach your work with newborns and young infants?" are demonstrated by the following comments.

"It has completely changed the way I work with babies, children, and their families. I look at the baby as a whole now, and realize that small changes can have positive and negative impacts. I work completely different with the parents, and am so much more aware of their contributions. I never realized how much babies actually communicate (other than crying), and how to read all of their subtle cues".

"The importance of the caregiver/baby relationship piece in the first six months of life. No longer using a traditional "therapy model" of working on a specific goal in one area, but focusing on the relationship piece a lot more. Focusing more on the physiologic/state/motor systems and how they are integrated and how they relate to the function of a baby. Has been really rewarding to see the progress in the relationship piece and how this affects the baby".

Summary

Increasing numbers of fragile newborns, including those born very preterm, late preterm and early term transition from the NICU to their home with continuing health and developmental challenges. Along with documented adverse medical and neurodevelopmental outcomes, parents experience increased stress and in many instances mental health issues

prompting the need for more evidence based and appropriate supports after discharge from the NICU. Earlier discharge and immature developmental organization emphasize the critical period during which individualized, relationship based developmentally supportive care continues to be necessary. Evidence of infant regulatory disorganization which is typical in this population has been related to later adverse cognitive, socio-emotional, and mental health outcomes. Infants and families need informed professionals who can provide supports and services to assist them during this critical period of development, yet few educational programs address the specific developmental needs of newborns and young infants.

EI and nursing professionals in Colorado have indicated their need for comprehensive and collaborative educational programs focused on supporting these families after NICU discharge and into the first few months after discharge. The BABIES approach was developed and piloted to meet that challenge. The BABIES program focuses on the specific developmental needs of newborns and young infants and provides a framework for assessment and intervention in order to address health and regulatory disorders in the first few months after birth. Additionally, and more importantly, it provides a relationship based framework to support families in dealing with health and developmental challenges typical in this population. Nurses in particular have a broad understanding of the special health and developmental needs of fragile infants transitioning from the NICU; and can effectively use the in-depth learning collaborative to inform specific and supportive relationship based intervention approaches.

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