

Instituting Parent Education Practices in the Neonatal Intensive Care Unit: An Administrative Case Report of Practice Evaluation and Statewide Action

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Background and Purpose. Infants born preterm are at high risk of developmental disabilities and benefit from early developmental intervention programs. Physical therapists with neonatal expertise are ideally suited to educate parents about ways to support their infant's development in the first months of life. However, administrative policies are needed to support the therapist in providing adequate parent education in the neonatal intensive care unit (NICU). This administrative case report describes the process used by a team of neonatal therapists to evaluate clinical practice, determine the need for change, and develop and implement a new parent education program in the NICU.

Case Description. Physical therapy parent education practices were evaluated in an academic medical center with a 36-bed, level-3 NICU. Physical therapists with neonatal expertise covered multiple units within the hospital each day. A series of focus groups, a small descriptive study, and staff discussion were used to evaluate parent education practices in this academic medical center. A new parent education program was developed based on data collected and literature to improve clinical care.

Outcomes. The new parent education model was implemented over the course of several months using overlapping initiatives. Administrative support for the change was developed through collaboration, open communication, and presentation of clinical data. In addition, this hospital-based program contributed to the development of a statewide initiative to educate parents of preterm infants about the importance of supporting development in the first months of life.

Discussion. A collaborative and data-driven approach to evaluating parent education practices supported the development of a new parent education practice while acknowledging the need to meet staff productivity standards and provide excellent care throughout the hospital.

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Approximately 11% of infants are born preterm in the United States each year.^{1,2} Although advances in technology have increased the survival rate of infants born preterm, long-term morbidity of the survivors remains a serious concern. Although the etiology of developmental delays is multifactorial, parent-infant interaction and family environment are strongly associated with infant development.³ Access to developmental and rehabilitative services after hospital discharge varies significantly from state to state.⁴⁻⁶ Many infants born preterm do not receive developmental services in the first months after hospital discharge.^{7,8} Pediatricians frequently provide a medical home, or primary care services, for infants born preterm. However, few are meeting the American Academy of Pediatrics' recommendations for developmental screening in the first years of life or referring infants for additional assessments.^{9,10} This paucity of services following neonatal intensive care unit (NICU) discharge places greater responsibilities on parents of preterm infants to provide developmentally supportive care at home. Parents are charged with providing an environment and opportunities that encourage development in an attempt to reduce the severity of developmental delays commonly observed in this population.

Both in the NICU and following discharge, parents have opportunities to support their infant's development through their day-to-day interaction and caregiving. Early parent-infant interaction has the potential to support social, emotional, and language development.¹¹⁻¹³ Parent-delivered activity programs can improve motor abilities of preterm infants.¹⁴⁻¹⁷ However, most parents acknowledge a need for information and anticipatory guidance on how to support their infant's development.¹⁸⁻²⁰ Pediatric physical thera-

pists with expertise in the NICU or neonatal therapists are ideal to meet these needs. However, implementation of a parent education program in the NICU requires significant planning and administrative support.

Providing parent education in the NICU presents some unique challenges. Infants born very prematurely may be cared for in the NICU for months before being discharged to the home. The NICU medical staff provides the majority of hands-on care for infants initially after birth, which may lead parents to believe they are not needed in the NICU. The NICU may be hours away from the family home, parents may return to work to preserve family medical leave benefits, and siblings generally are prohibited from visiting the NICU. These challenging circumstances may result in limited parent visitation if parents do not perceive a need to participate in the infant's care and support is not in place to address challenges. In addition, the educational and socioeconomic backgrounds of parents with infants in the NICU vary widely. Parent education programs must be designed to meet the diverse needs of all parents whose infants are in the NICU.

Staffing the NICU with experienced neonatal therapists who are available to provide parent education also can be a challenge. Therapists who provide care in the NICU frequently cover multiple units in the hospital and may not know when the parents are present in the NICU or may not be available when the parents visit. Administrative support is needed to develop a successful program for engaging parents in supporting their infant's development. Administrators must understand the value of and challenges to providing parent education in this environment. Adequate staffing, prioritization of NICU coverage, and scheduling flexibility also may be needed.

The purpose of this administrative case report is to describe the processes used by a neonatal therapy team to: (1) evaluate parent education practices regarding infant development and determine whether changes were needed, (2) use administrative processes to facilitate enhancements in parent education, and (3) implement the recommendations and contribute to a statewide initiative.

The Practice Setting: A Hospital NICU

Virginia Commonwealth University Medical Center is a 779-bed academic medical center with a 36-bed, level-3 NICU. At the time of this case report, the NICU cared for about 200 preterm infants per year, including infants requiring long-term hospitalization, surgeries, and extracorporeal membrane oxygenation. Physical therapy and occupational therapy services were provided throughout the hospital by 15.6 physical therapy and 13.4 occupational therapy full-time equivalents. Acute care management included an inpatient physical therapy manager and an inpatient occupational therapy manager. The inpatient managers reported to the director of rehabilitation services, who oversaw all inpatient and outpatient rehabilitation for the health system. Acute care therapists were organized into 2 approximately equal-sized teams responsible for providing therapy services to all 29 units throughout the acute care hospital. Therapists frequently attended weekly interdisciplinary rounds for units with extended lengths of stay to ensure patients' needs were met and to communicate with the medical staff. Meetings for program development and staff communication were frequently held during lunchtime with the support of management. Therapists were expected to have 50% billable time; however, this standard

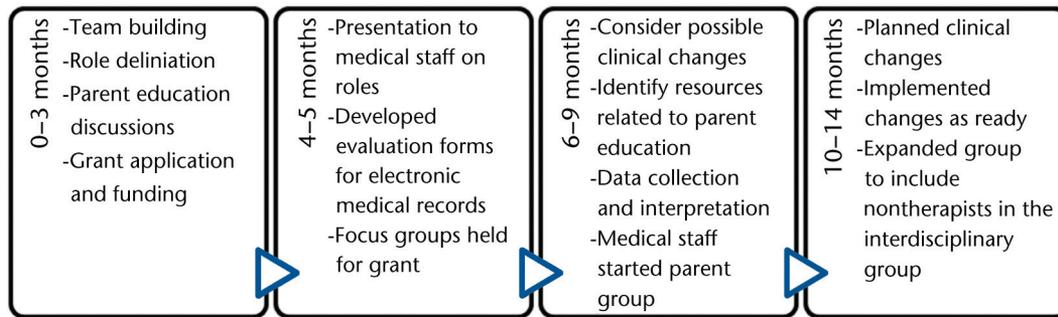


Figure 1. Time line for the evaluation, development, and implementation of a neonatal therapy modified parent education program.

was not strictly monitored at the time of this case report.

The neonatal therapy team at the time of this case report included 4 physical therapists and 2 occupational therapists with neonatal expertise. All of these therapists were assigned to the acute care therapy team, which provided care for all pediatric units as well as 10 other units. One of the neonatal therapists from each discipline provided primary coverage in the NICU on a rotating basis. Although assigned to cover the NICU, the therapists were still responsible for covering multiple other units assigned to their team. There was no clearly defined number of hours designated for providing care in the NICU. As a result, therapist time in the NICU was variable. The therapists were required to meet their hospital-wide productivity standards even while providing care in the NICU. Discipline-specific referrals were required for physical therapists or occupational therapists to evaluate or treat infants in the NICU. The therapists attended weekly interdisciplinary rounds as much as possible to request referrals on infants who were identified as having positioning, sensory, feeding, or developmental needs that warranted evaluation by a neonatal therapist. Therapy was provided in a multidisciplinary model in which both physical therapists and occupa-

tional therapists frequently evaluated infants and developed independent treatment plans.

The Administrative Issue

The NICU policies were being reviewed in preparation for a move to a new facility. The neonatal therapists determined that the timing was ideal to clarify the role of therapy in the NICU and began monthly meetings to clarify roles, develop recommendations for referrals, and discuss clinical care, staffing issues, and general program development in the NICU (Fig. 1). The inpatient physical therapy and occupational therapy managers were invited to these meetings initially to provide feedback on staffing and role deliniation. In general, managers were supportive of these lunchtime meetings, as they improved team morale, reduced duplicate referrals for the same services, and provided an opportunity for program development. At several of these meetings, therapists reported concerns about parent-infant interactions and a perceived lack of developmental play routines in infants returning to the NICU follow-up clinic. These concerns prompted discussion of the education provided to parents in the NICU. Therapists typically reported meeting with parents once, usually on the day of NICU discharge, to discuss development and provide suggestions for developmental activ-

ities to work on at home. Referrals were made for some infants to receive early intervention (part C of the Individuals With Disabilities Act⁶) based on the therapists' recommendation and parental interest. Therapists reported frustration with not being in the NICU when parents visited and difficulty scheduling meetings with parents while managing the rest of their caseload. During this time, one of the neonatal therapists was awarded a small pilot grant, which included some funds to evaluate parent education practices in the NICU.

The perceived problem was that parents were not given adequate information or taught to anticipate their infant's need for support to prompt motor, language, and cognitive development. This administrative case report outlines the steps a neonatal therapy team took to evaluate current therapy practices for parent education, determine whether a change was needed, and implement a clinical practice change. In addition, the practice change implemented by this neonatal therapy team contributed to a statewide recommendation for discharge teaching in the NICU environment.

Evaluating the Existing NICU Parental Education Practices

Over 6 months, 2 primary data collection strategies were adopted to evaluate the current NICU practices for educating parents about ways to encourage motor development (Fig. 1). First, a focus group was held to evaluate parents' knowledge of developmental issues specific to preterm infants and to identify parents' preferred methods for learning about development (see Dusing et al²⁰ for details). Based on the findings from this first focus group, a second focus group was held to present educational information to parents and evaluate the change in their knowledge immediately prior to and after the session.²⁰ Next, a descriptive study was conducted to determine whether providing a single education session had potential for enhancing parents' play routines with their infant. Five parents of preterm infants participated in an educational session with a physical therapist prior to hospital discharge, consistent with clinical practice described by this neonatal therapy team. The educational session included information on developmental expectations and play routines to encourage "tummy time" and limit time in seating devices. The 5 infants returned to the NICU follow-up clinic or the Motor Development Laboratory in the Physical Therapy Department at Virginia Commonwealth University for developmental assessment at 3 months of adjusted age. Parents completed a questionnaire designed to assess the amount of time the infant spent in various play positions.²¹ Therapists' time to participate in the focus groups and assessment sessions outside of routine clinical care was funded by a grant.

The findings from the first focus group suggested that parents did not have concrete ideas about how to

interact or play with their babies at home.²⁰ In addition, the parents did not know the developmental milestones or "red flags" they should be looking for in the first months of life. However, the results of the second focus group demonstrated that parents who participated in an educational session showed improved knowledge of ways to support their infant's development at home.²⁰ The descriptive data from the 5 parents who received a one-time parent education session close to NICU discharge showed that they did not utilize many of the recommended strategies during the infants' first months at home. Parents reported their infants spent more than twice as much time being held or placed in a seat than playing on a flat surface. This finding is the opposite of what was encouraged in the education session. Infants preferred to be supported in a sitting or standing position more often than being positioned prone. These findings were discussed by the neonatal therapists, who reached the consensus that although parents were able to learn the concepts presented in a single session, one visit with the parents immediately prior to NICU discharge was not adequate to encourage implementation of the strategies to support their infants' development at home. Review of literature on successful parent education programs, the focus group findings, and descriptive study findings led the team to determine that a more extensive parent engagement and education approach was necessary to encourage developmentally supportive parent-infant interactions.

Developing a Modified Parent Education Approach

Monthly neonatal therapist meetings continued for an additional 3 months with a focus on developing a parent education intervention that had strong potential for improving

parent-infant interactions and parents' readiness to support development after NICU discharge (Fig. 1). The primary goal of the modified parent education plan was to engage parents in developmental activities prior to NICU discharge and encourage them to advocate for their infant and provide opportunities for developmental play after NICU discharge. Both the inpatient physical therapy and occupational therapy managers were invited to each meeting to enhance administrative support for the parent education program. The managers and therapists worked together to problem solve a way to maximize billable hours while meeting the goals of the program and complying with hospital policies. The collaboration during these meetings was crucial to establishing ongoing support for the new program.

Three primary strategies were identified to engage parents and enhance education on development in the NICU (Fig. 2). First, therapists identified a need to introduce developmental principles to parents much earlier in the NICU stay, providing multiple opportunities to review material.¹² Second, parent education needed to be provided in a variety of formats to meet all learning styles and review material multiple times.²⁰ Third, therapy and nursing staff needed to join forces to promote developmental care during all caregiving to ensure parents received a consistent message about the importance of development.

Early initiation of parent education. The quantity of education provided in the days immediately preceding discharge can be overwhelming for parents and may result in some parents forgetting information.¹⁹ To reduce parental stress and increase knowledge transfer, we made fundamental changes

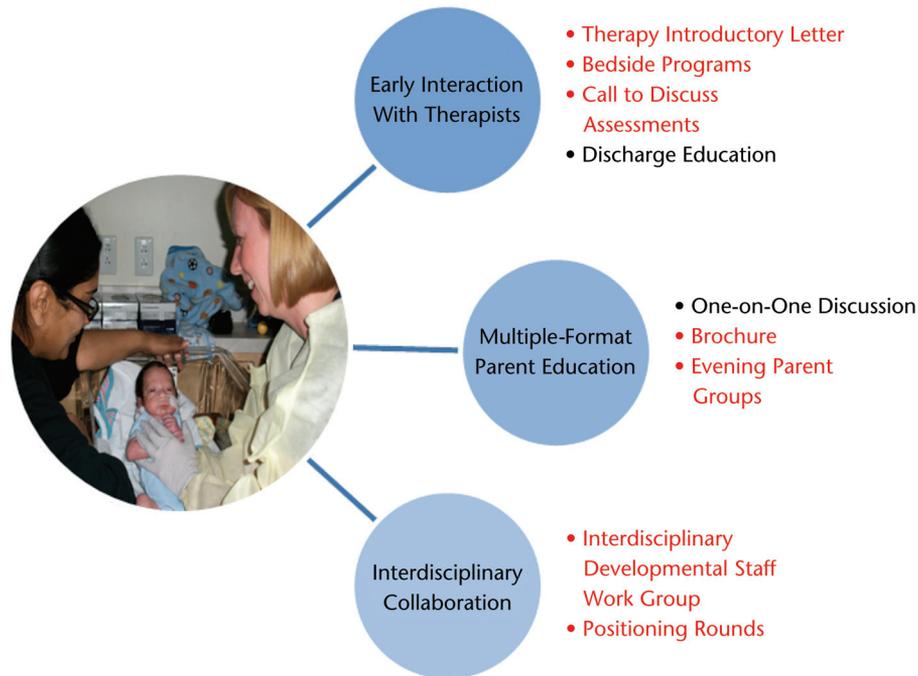


Figure 2. Modified parent education program in the neonatal intensive care unit. Red text represents newly developed educational practices.

to the timing of our educational strategies.

We initiated contact with parents using a letter about the role of therapists in the NICU and inviting them to call the therapists. A bedside educational program was developed for each infant and included observed stress signs, sources of stress, and strategies to calm the infant, consistent with the synactive theory of development.²² The bedside program was developed by the therapist in consultation with the nurse and with the parent, if present. Parents were invited to call with questions and encouraged to schedule a time to meet with the therapist for subsequent therapy sessions, which included re-evaluation and bedside program updates, direct intervention if warranted, and motor evaluation using the Test of Infant Motor Performance prior to NICU discharge.²³ Parent education sessions were combined with billable therapy sessions when appropriate.

Throughout the infant's NICU stay, parents were encouraged to engage with the infant in a developmentally supportive way and, as the infant approached discharge, to develop play routines and discuss ways to support development at home. These clinical changes resulted in a minimum of 3 telephone calls or letters to parents from the neonatal therapy team in an attempt to engage the parents in developmental dialogue weeks prior to the infant's NICU discharge. Therapists' treatment times blended therapist-delivered intervention with parent education whenever possible. By beginning parent education earlier, the parents were encouraged to practice facilitating developmentally appropriate play activities, utilizing developmentally appropriate positioning equipment, and monitoring their infant's response to interaction with the ongoing support of a therapist.

Multiple education formats. In addition to one-on-one meetings with parents, 2 other formats were implemented based on feedback from the focus groups and research: evening group education sessions and a brochure.^{20,24} An evening parent education group was initiated in collaboration with the medical staff using funds from a community grant. Each month a different developmental topic was presented by a neonatal therapist, physician, nurse practitioner, or nurse, followed by discussion and a light dinner. Typically, 5 to 7 parents attended these evening education sessions. The meetings were coordinated by NICU staff, limiting the amount of planning time required by therapists. Therapists who participated in an evening session were allowed to flex their hours to keep their weekly hours constant. No billable units were generated from these meetings; however, parents requested additional therapy referrals or meetings with the therapists following some sessions. A bro-

chure titled *Supporting Motor Development of Premature Infants* was developed to provide a written overview of the materials covered during parent-therapist meetings. The brochure provided information on developmental expectations, positioning for play, and play suggestions. The initial development of the brochure was part of a student project in the Virginia Leadership Education in Developmental Disabilities (Va-LEND) Program, reducing the therapist time required to create it. The use of the brochure increased efficiency in providing a home program for each infant prior to discharge.

Interdisciplinary collaboration. Interdisciplinary care supports the development of best clinical practices in the NICU.^{25,26} The program described in this case report was developed by therapists who were well established and trusted as providers in the NICU. To strengthen implementation and initiate an interdisciplinary expansion of parent education, the neonatal therapists utilized 2 primary strategies. First, the therapists worked with the nursing staff to develop an interdisciplinary NICU developmental group. The purpose of this collaborative group was to evaluate NICU policies and practices (not neonatal therapy practices) that related to development. Second, the NICU therapists began conducting “positioning rounds” once per week with a focus on raising developmental awareness in the NICU and increasing collaboration among disciplines in the NICU. During positioning rounds, the physical therapist and occupational therapist walked through the NICU to observe infant positioning and developmental supports. Infants who could benefit from a position change or additional supports were identified, and the nurse caring for the infants was engaged in conversation about

the infants’ needs. If needs were identified, the therapist requested orders to evaluate the specific infant. Initially, these positioning rounds took 45 to 60 minutes to complete; however, as developmental support improved in the NICU, positioning rounds decreased to 15 to 30 minutes.

The Outcome: Hospital-based Changes and Potential Impact on Parent Education Practices in NICUs Statewide

Hospital-Based Changes

Implementation of each hospital-based change was completed over 3 to 5 months (Figs. 1 and 2). Initiatives in each area overlapped, supporting the global goals of the project and increasing efficiency of implementation. Therapists were already well established and trusted in the NICU, and the NICU staff was willing to support changes in therapy services to benefit infant and family care. Meeting the therapy needs throughout the hospital without compromising care in the NICU was a high priority. Neonatal therapists worked with the therapists on their acute care therapy team to develop a plan to maintain productivity while covering all necessary hospital units. The therapists covering the NICU were assigned units with high average productivity to balance out the slightly lower productivity levels in the NICU. However, the neonatal therapists maintained flexibility to cross-cover high-priority visits in other units. This team collaboration and mutual respect for all patients were essential in supporting the neonatal therapy program.

With the support of management, neonatal therapists were able to dedicate blocked time to provide NICU services. During these blocks

of time, NICU staff knew the therapists would be available and could encourage parents to visit. When therapists were not providing direct patient care, they made telephone calls to parents, updated bedside programs, or worked on NICU-specific projects. Therapists were permitted to flex their work schedule if needed to cover evening hours for parent meetings. These changes allowed a smooth implementation of the modified parent education practices without reducing overall productivity or increasing the burden on other therapists. The neonatal therapists were more efficient with their time in the NICU, available for parent meetings, collaborated more regularly with nursing staff, and had fewer missed visits in the NICU.

Statewide Recommendations

About a year after the hospital-specific modifications in parent education practices were in place, a work group was established by the Commonwealth of Virginia’s early intervention program, Infant and Toddler Connection of Virginia.²⁷ The purpose of the Early Intervention Prematurity Workgroup was to improve early intervention services for infants born preterm through revision of the state’s automatic eligibility criteria for early intervention services, enhancing early intervention staff education, improving collaboration between hospitals and community programs, and providing resources for educating parents on the importance of development. The first author is a member of this work group, which includes policymakers, early intervention service coordinators, neonatologists, pediatricians, therapists, and parents of infants born preterm from across the Commonwealth of Virginia. The work group has succeeded in advocating for a policy change expanding the automatic eligible criteria for early intervention to include all preterm infants born at 28

weeks of gestation or less, all infants with periventricular leukomalacia, and all infants who were admitted to the NICU for at least 28 days.

The Early Intervention Prematurity Workgroup developed a set of recommendations for parent discharge education in NICUs across the state to support communication among parents, NICU providers, and community early intervention programs. One major component of this initiative was the development of a brochure to be disseminated to parents in NICUs across the state in collaboration with the Infant and Toddler Connection of Virginia's public awareness program. The purpose of this brochure, titled *After the NICU: Promoting Your Premature Baby's Development at Home*,²⁸ was to educate parents on the value of play, ways to support developmentally appropriate play, and developmental red flags. This new brochure was designed to fill a gap in existing publicly available literature and to support education prior to NICU discharge across the state.²⁸ The Infant and Toddler Connection of Virginia's Early Intervention Prematurity Workgroup issued a statement and mailed a letter to all NICUs across the state recommending the use of 3 brochures to educate parents on the importance of development and the availability of early intervention services. The recommended brochures included the newly designed *After the NICU: Promoting Your Premature Baby's Development at Home*,²⁸ *Supporting You and Your Preemie: Milestone Guidelines for Premature Babies*,²⁹ and *What Is Early Intervention*,²⁷ all of which can be downloaded for free from the Internet.

Our team's experience implementing a new parent education program in the NICU directly supported the first author's participation in the statewide work group. Our team's

experience developing and using a brochure designed for our hospital enhanced our contribution to the statewide initiative. In collaboration with the experts on the work group, the brochure was expanded to include developmental red flags, feeding issues, and other developmental domains not included in our brochure, which focused on motor development. This statewide initiative provides a necessary resource and guidance to NICUs across the state to promote parent education on development prior to their infants' NICU discharge.

Discussion

Physical therapists practicing in the NICU are in an ideal position to provide parents of infants born preterm with an introduction to supporting their infant's development.^{26,29} Education provided in the NICU helps parents incorporate developmental activities into their infant's daily routine, can improve the infant's developmental abilities, and reduces parents' anxiety.^{11,12,14,26,30} However, administrative policies need to support the time and energy required to educate parents using evidence-based methods. Therapists, medical staff, and administrators need to value parents as a key to supporting infant development and work together to develop and implement educational programs without compromising productivity and quality of care.

This administrative case report highlights how one academic medical center evaluated the quality of the parent education practices in the NICU, modified care based on hospital-specific findings and literature on best practice, and implemented a new parent education program during a 14-month period. The therapists engaged their administrators throughout the process and garnered support from other therapy staff through open commu-

nications and provision of evidence supporting the use of parent education in the NICU. Each strategy implemented was evidence based and sustainable with the current NICU staffing, requiring no additional resources from the hospital administration. Creativity, dedication, and flexibility on the part of the administration and the therapists were essential.

Blocking times to provide care in the NICU was the biggest challenge faced in the implementation of this program. Therapists were proactive and discussed the goals of the program with the entire acute care therapy team during the development and implementation of the program. Neonatal therapists were able to develop a plan to support all therapists on their team, while providing ideal care in the NICU.

In addition to prompting change in a single hospital, our team contributed to a statewide initiative to support parent education prior to NICU discharge. The expansion of our hospital's written materials will provide NICUs across the state with a valuable resource for parent education. Evaluation and implementation of parent education in other NICUs will need to be individualized. However, this administrative case report and the statewide initiative can serve as an example of how a neonatal therapy team evaluated parent education practices and developed a plan to support development of preterm infants during the transition from the NICU to the home.

To our knowledge, there are no published studies on how to administer or implement therapy programs in the NICU. The recently updated neonatal competencies and practice guidelines provide recommendations for models of services and document the need for parent education in the NICU.^{26,30} However, garnering

administrative support for these types of highly specialized programs is a challenge faced by many neonatal therapists. Although this case report does not provide direct evidence for our parent education strategies, it does provide an example of how therapy practices can be evaluated, updated using evidence, and implemented. Neonatology was recently approved as a subspecialty in pediatric physical therapy by the American Board of Physical Therapy Residency and Fellowship Education. Neonatal physical therapy fellowships are in development to train the next generation of neonatal therapists. However, administrative support is needed to ensure neonatal therapists have dedicated time to provide evidence-based care, including parent education.

This administrative case report provided one example of how a neonatal therapy team evaluated, developed, and implemented a program enhancing clinical services. A collaborative approach is needed throughout the process to recognize the challenges for administrators as well as neonatal therapists in this specialized area of practice.

All authors provided concept/idea/project design, writing, data collection, and participants. Dr Dusing provided data analysis, project management, and fund procurement. The authors thank the NICU staff, physical therapy and occupational therapy staff and management, and Infant and Toddler Connection, Early Intervention Prematurity Workgroup members who contributed to this project. Special thanks to Daniel Riddle, PT, PhD, FAPTA, who provided early feedback on the manuscript.

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