Neonatal Follow-up Programs

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Infants born prematurely are at greater risk for healthcare challenges:

- Neurodevelopmental delay, sensory impairment, hearing and vision loss

Follow-up programs provide early identification and intervention.
Follow-up programs are designed for former Neonatal Intensive Care Unit (NICU) patients and the providers understand the challenges these children face relative to their illnesses, and time in the hospital.

Recent literature has shown that late premature infants (between 34 and 37 weeks gestation) are at increased risk for neurological delay compared to full-term infants.
American Academy of Pediatrics: Recommendations

- Follow-up programs should be multidisciplinary and focus on evaluating for developmental milestones.
- NICU patients should receive care from a healthcare professional who is experienced with high-risk infants.
- Referral criteria have been suggested, but have not been accepted universal.
The Problem

- Recommendations have been made about what referral criteria should be, but no formal guidelines have been developed.

- Programs determine their own referral criteria.

- This may leave some children not receiving support if they were born at one hospital versus another.
This study aims to understand current practices of Neonatal Follow-up Programs within New England states and compare how they relate to current recommendations of best practice.

Neonatal follow-up programs were surveyed to assess each program’s referral criteria, the duration of services provided, and coordination of care between families and other healthcare or early intervention service providers.
What differences are there among Neonatal Follow-up programs in New England?

- Programs were evaluated to assess what types of supports are in place for families who have children with an increased risk of experiencing developmental delays.

- Comparisons were made to understand similarities and differences among referral criteria and were evaluated by looking at current literature and best practice guidelines.
Neurodevelopmental Follow-up programs identified in New England
- Connecticut (2)
- Rhode Island (1)
- Massachusetts (2)
- New Hampshire (1)
- Vermont (1)
- Maine (1)

Directors of these programs were the target participants
A survey was designed and then reviewed with professionals in the field on Neonatal Follow-up (not professionals eligible to take the survey)

The survey was internet-based on SurveyMonkey

Once IRB approval was obtained, emails were sent to the Directors with a link to the survey

A follow-up email was sent about a week after initial email invitation
Results - Demographics

- 4 Programs Responded (50% Response Rate)

- Each response was from a different state which made the state representation 4 out of 6 states in New England

- All of the responding programs were directly affiliated with a neonatal intensive care unit that is classified as at least a Level III center
Results – Referral Criteria

- There were differences among referral criteria for gestational age at birth:
  1. Program – Refers <33 weeks
  1. Program – Refers <32 weeks
  1. Program – Refers <30 weeks
  1. Program – Refers <27 weeks

- All of the programs have updated their referral criteria in the past three years, which may indicate that all of these programs are following current recommendations and making changes based on new research and findings in neonatal outcomes.
Results - Overview of Neonatal Follow-up Program

- 3 out of 4 programs have someone who meets with families prior to discharge to discuss the purpose of the follow-up program and the logistics of a typical visit.
- At least half of the responding programs had the following disciplines in their follow-up programs:
Results - Duration of Care

- Once follow-up services are no longer provided to former NICU patients, all of the programs refer their patients to other resources.

- Half of the programs refer to the child’s local school district for early intervention services.

- At least one program refers to either a Developmental Pediatrician, Birth to Three, and/or Head Start.
• Funding is a concern for many programs and is likely the barrier for more consistent referral criteria

  ○ This gap in care means that there may be an inequality among the services that children receive in different parts of states and regions

• Funding issues may not be changed in the near future, so former NICU patients must be able to receive appropriate care from a pediatrician who is experienced in the care of premature infants.

• Families should be aware that their premature infant is at an increased risk of developmental delays and should have assistance in selecting an appropriate pediatrician.