

**Early Intervention Prematurity Workgroup**  
**8/31/2010 Meeting**  
**1:00 PM**

The meeting opened with introductions. Each participant shared their role in serving infants born prematurely as well as what they hope to accomplish through this work group. See attached Attendance List. Participants expressed the following **hopes and expectations for the workgroup**:

- Determine how to identify which children should be referred to early intervention and when
- Develop a plan to increase the knowledge and skills of early intervention providers about identifying which children are eligible for Part C and providing appropriate education, support and services for those children and their families
- Decrease or eliminate children “falling through the cracks” (which can include those never referred to Part C, those referred and not found eligible, etc.)
- Consistent education and materials for families and recognition of the importance of early intervention
- Development of a better catch net for babies born prematurely
- Increase ability of providers to determine Part C eligibility for babies with atypical development
- Close the developmental gap between children born at term and babies born prematurely
- Improved collaboration between NICU and early intervention; improving the transition process from NICU to home and community services
- Revision of the eligibility criteria for infants born preterm

**Which babies should be referred to EI? The group brainstormed the following:**

- Any baby who spends more than 7-14 days in the NICU.
  - Rationale: the literature is showing that brain development is different for premature babies including mental health issues.
  - The NICU is over-stimulating – too much odor, pain, light (Patricia Frank will pull the literature for this)
  - Any child in NICU more than 5 days will be identified as at risk for EDHI. Discussion followed about possibilities of tying into the EDHI follow up as a way to help prevent missing children who should be followed and/or referred for services
- EDHI will follow up children who are in NICU
- Criteria listed in summary from Dr. Subarna Dharia’s summary
  - The absence of neonatal neurologic findings such as reflexes, good muscle tone, strong cry, level of alertness, good eye contact and eye movements, tracking, and smile might indicate “atypical” development.
  - Respiratory complications that result in oxygen use or dependency (through ventilators, tracheostomy, nasal CPAP, apnea monitors), Chronic Lung Disease or BPD (Bronchopulmonary Dysplasia), Apnea of Prematurity, etc.

- Neurologic abnormalities like hypertonicity/hypotonicity, IVH and especially PVL (Periventricular Leukomalacia) which puts children at a higher risk for CP than IVH. Also, hearing and vision (ROP—Retinopathy of Prematurity) concerns are important. Brain malformations and neonatal seizures are definite red flags.
- GI infections/surgeries, Necrotizing Enterocolitis, Extent of GERD, NG Tube/G Tube insertion or any other feeding difficulties or oral/motor abnormalities, poor weight gain.
- Prolonged hospitalization (over 2 weeks), problems with bonding, Maternal history and exposure to drugs (illicit and prescription), sensory integration dysfunction.
- Low Apgar scores, Gestational age (as stated above, not only to include those below 32 weeks, but AT LEAST these babies), History of shock or low blood volume/infection (Sepsis) and exposure to ototoxic (toxic to hearing) medications (like Antibiotics).
- Patent Ductus Arteriosus and if surgery was needed to correct.

The group then brainstormed **possible “automatic eligibility criteria”** and agreed that the following should be considered:

- Babies born at 28 or less weeks gestation
- NICU stay of 28 days or more. .
- Babies with PVL

Approximately 100,000 babies are born in Virginia annually. 10-12% of those are premature (10,000 to 12,000 babies).

In order to modify the eligibility criteria for Virginia’s Part C System, the proposed changes must be submitted to and approved by the Virginia Interagency Coordinating Council (the Governor Appointed Advisory Board for the Infant & Toddler Connection of Virginia) and reviewed/approved by the Office of Special Education Programs (OSEP) which governs Part C.

Participants agreed to review the literature to see if there is support for recommending the three criteria suggested above. Participants will email references to Beth who will disseminate the information to the rest of the members of the workgroup.

### **What should trigger referral for those babies who don’t meet the above criteria?**

Dr. Brown said that the biggest categories of problems she sees are sensory integration and feeding. Discussion followed about when babies (who are not immediately referred because they meet the criteria listed above) should be referred to early intervention. Dr. Brown asked the Early Intervention Providers when they feel most comfortable starting services. Some of the providers on the workgroup also work in a NICU and stated they were comfortable at any time. Others indicated that they were more comfortable when the babies were a little older and developmental assessment tools could be used. (There is a lack of tools for assessing babies who have not reached their expected birth date).

Dr. Brown suggested that all families of babies born prematurely need education about development and red flags. She also suggested that babies need the first month at home after discharge from the hospital to “heal from the NICU”. Families need to get to know their baby and to get comfortable with taking care of the baby’s basic needs. Dr. Brown recommended evaluation when the baby is three months adjusted age.

**The group acknowledged the following challenges:**

- The NICUs across the state have different operating procedures and different follow up mechanisms
- Reimbursement for NICU follow up does not cover the cost of providing the service (if it is reimbursed at all)
- Follow Up is not consistent across the state
- Even when the NICU follow up is provided at no cost to families, not all families take advantage of the opportunity. (50% of babies seen in the Henrico NICU are followed in their follow up clinic)
- At least one NICU has indicated that they are relying on the Part C system to be the follow up for these children
- Part C is a system that provides services for eligible children rather than follow up or tracking for children at risk.
- Part C regulations require that the Individualized Family Service Plan be developed within 45 days of referral to Part C (though this can be delayed for family reasons).
- Timing of referrals to Part C is important because of the Part C timelines and because if a child is referred too early and not found eligible, the family and/or physician are less likely to refer later. That said, it is not uncommon for children to be referred later after initially being found ineligible.
- Physicians don’t know when to refer preterm babies to Part C (per comments to Joanne from physicians)
- Babies who are born prematurely are “expected to be low-tone” so this doesn’t necessarily trigger a referral; “typical for a premature baby” may prevent a baby from being determined eligible for Part C on the basis of atypical development

**The group concurred that any of the following issues should trigger a referral to early intervention as soon as the issue is noticed:**

- Hypotonia
- motor delays
- Feeding issues (choking, gagging, taking more than 30 minutes for feeding)
- Sensory issues (irritability, etc.)
- Self-regulation
- hyperextension

The group reviewed the proposed Purpose/Vision statements for the workgroup and agreed on the following:

1. Recommendations for automatic eligibility as well as criteria to guide referral sources in determining which infants should be referred to early intervention (and when) will be developed.
2. The workgroup will identify what education/training is needed and mechanisms to provide that education/training so that determination of eligibility of infants born prematurely made by providers with the knowledge, skills and experience necessary to determine typical versus atypical development for this population.
3. The workgroup will identify what training/education is needed and mechanism for such training so that the providers serving infants born prematurely have the necessary knowledge and skills to provide appropriate supports and services for these babies and their families.
4. Local support systems (throughout Virginia) will be identified so that families of babies born prematurely are informed about and/or referred to appropriate formal and informal community resources and agencies.
5. Individuals and Agencies that provide supports and services for infants born prematurely will collaborate and communicate with each other to assure that there are not gaps in services or duplication of services.

The workgroup decided to focus on prematurity and not low birth weight because the literature indicates that the prematurity is the bigger issue.

### **Review of Membership**

The group identified the following additional stakeholder groups as important for this workgroup: pediatricians, families of babies born prematurely, the Virginia Community Healthcare Association, and the Medical Society of Virginia.

- A number of pediatricians are on the workgroup, but were not able to attend today's meeting. Joanne will follow up with Dr. Moskowitz who is the president of the Virginia Chapter of the American Academy of Pediatrics to see if he will be able to participate or would like to appoint another AAP- VA representative.
- Dr. Brown will contact families to see who is interested in participating
- Joanne will contact the Virginia Community Healthcare Association
- Susan Ward will contact the Medical Society of Virginia

### **Measurement and Data**

The group brainstormed data and measures that could be used to understand the current situation, to support evidence-based decision making and to measure results. Suggestions included:

- Increase in well child visits, increases in immunization rates
- Changes in social, emotional, physical development
- Numbers served
- Numbers found ineligible initially, then re-referred and found eligible for Part C
- Age at referral

- Numbers who declined services
- Child outcomes (OSEP indicator)
- Long-term outcomes (following children's progress from birth [birth records] through school)

#### **Data Sources:**

- Part C: The Part C system currently collects data on the number of preterm and low birth weight babies, but only for those who go on to receive Part C services. The Part C system is developing expanded data capabilities and when the expanded system is in place there will be much more data available. Beth will check to see if it is possible to identify with the current data system the range and average age at referral. Gathering information about children referred but not eligible would require development of tracking systems at the local level. Beth will check to see if any local systems are currently tracking this.
- Health Department – electronic birth certificate. Joanne will look at the information to see if it is possible to determine what number we'd expect to be eligible for Part C based on the criteria discussed today. The birth certificate info can provide the number of premature babies born at each hospital.

#### **Education and Training**

The following education and training needs were identified:

- Education of all families of babies born prematurely (Whose responsibility is this?)
  - (soon after the baby's birth) on patterns of development, developmental milestones and red flags
  - As babies grow and develop
- Education of referral sources, including NICUs, NICU follow Up clinics, pediatricians, family practice physicians about which babies should be referred to early intervention
- Education of EI providers, including service coordinators
  - Determining Part C eligibility for babies born prematurely
  - Appropriate services for preterm babies
  - Skills training for direct service providers

#### **Mechanisms and challenges of training and education were brainstormed.**

- Awareness training as well as skills training is needed
- The AAP newsletters can be used to disseminate information to pediatricians
- The Infant & Toddler Connection of Virginia Technical Assistance Monthly Update is a mechanism to provide information to all certified early intervention practitioners
- A video/DVD for parents prior to the baby's mom's discharge from the hospital could be considered (though this is a busy time and may not provide the most opportune time for learning).
- Ongoing ads about premature babies' development – so the information for families is there when they need it

## **Neonatal Intensive Care Units (NICU) and NICU Follow Up Clinics**

The group pooled their information about which hospitals in Virginia have NICUs and NICU Follow Up clinics:

- Henrico Doctors (Richmond Area)
- MCV – CH Follow Up Clinic (Richmond Area)
- Bon Secours (Richmond Area)
- Inova Fairfax (Northern Virginia)
- Carillion (Roanoke Area)
- Kings Daughters (Tidewater)

### **Additional discussion and information:**

- While it is recognized that resources are limited and not all babies born prematurely can be served by the Part C system, identifying and serving those who can benefit from the supports and services makes better use of resources since research indicates that early services reduce later needs and costs.
- More and more information is becoming available about preterm babies
  - Problems, including sensory and motor issues have been identified for “late preterm” babies
  - The American College of Obstetrics and Gynecology is considering redefining prematurity as 39 or less week’s gestation (as opposed to the current 37 weeks).
  - Once a baby is born prematurely, their brain is always different than a full term baby’s.

### **Meeting Schedule: Third Tuesday of the Month (except October) from 2:00 to 4:00 PM**

- Sept 21, 2010
- October 26, 2010
- Nov 16, 2010
- No meeting in December
- January 18, 2011
- February 15, 2011
- March 15, 2011

### **Assignments**

- Gather literature that addresses the proposed automatic criteria (everyone) and send to Beth who will disseminate to the full group
- Invite additional members (Dr. Brown, Susan Ward, Joanne Boise)
- Look at data available through VDH and DBHDS (Joanne Boise, Beth Tolley)
- Share with the group the questions that are being asked parents during NICU Follow Up visits (Dr. Brown)
- Find a location for future meetings with better acoustics to accommodate phone participants.