

**Early Intervention Prematurity Workgroup Meeting Agenda**  
**Location: Virginia Association of Community Service Boards (VACSB)**  
**9/13/2011**

**Attendance:**

Nancy Brockway, Susan Brown, MD, Mary Beth Cox, Stacey C. Dusing, Heidi Faustini, Kim Geissinger, Sandi Harrington, Ginny Heuple, Patricia Hine, Tina Hough, Linda Lindsey-Hoy, Martha Kurgans, Kerry Shultz, Beth Tolley, Karen Walker, Susan Ward, Mary Anne White, Sandra Woodward

**Development of Online Training Module**

Nancy Brockway reported that the subgroup is on the third draft of the prematurity training modules. There will be 5 or 6 sections and will include videos.

**NICU Brochure**

The draft is with the graphic designer.

**NICU Contacts**

The tabulation of information provided by local system managers about contacts with hospitals was sent to members prior to the meeting. The group discussed reasons for the low response rate and missing information. It was suggested that the lack of response may reflect the fact that many local systems do not know who to contact at the hospitals. Therefore a different approach to gathering this information may be more effective. So:

1. Susan Ward will send Dr. Brown a list of all the hospitals with birthing units.
2. Dr. Brown will work with Judy Matthews, head of Women's and Children's Services at Henrico Doctor's Hospital to complete as much of the information as possible.
3. Dr. Brown will share the information that has been gathered at the next meeting, and next steps for completion of the contact list will be determined at that time.

**Getting Children into EI Services**

Email communication among members last month indicated that there were delays for children being served through early intervention after discharge from the NICU in several places across the state. Issues include:

- Lack of knowledge of some Part C systems about Part C policy and practices
- Communication challenges
- Possible provider shortages

Karen Walker shared information about a recent referral that occurred prior to the child's discharge from the NICU which allowed her to meet the family in the hospital as well as the hospital discharge planner in order to prepare for the child to move right into early intervention as soon as the child is discharged.

Karen is leading efforts by the Richmond Region Early Intervention System Managers to work with staff of area hospitals to facilitate referral of the babies to early intervention prior to discharge. Karen would like for the referral to occur 10 days prior to the child's discharge. Karen has a meeting scheduled tomorrow with St. Mary's and she will schedule meetings with other hospitals

Beth Tolley reported that the Infant & Toddler Connection Technical Assistance Staff will provide information and guidance to System Managers about improving the process of getting children into services after discharge from the NICU.

Concern was expressed about a lack of consistency across the state and a desire for consistent processes/approaches.

### **Drug Exposed Babies**

Martha Kurgans reported that there continues to be a lack of knowledge about the need to refer babies who are in withdrawal to early intervention. Stacey Dusing reported that (at VCU NICU) referrals to early intervention are usually handled by the NICU PT or OT, but babies in withdrawal are not automatically referred to the NICU PT or OT. The Infant & Toddler Connection of Fairfax, Falls Church receives most of their referrals of children who are substance exposed from Child Protective Services. Hanover and Henrico have started seeing more referrals of substance exposed babies. Martha said that it is important for families to be connected to the Community Service Boards (CSB). CSBs can follow up on the referrals to early intervention. Martha reminded the group that a template has been created for referral of newborns to CSBs.

### **Early Intervention Services for Babies Born Prematurity**

Discussion included:

- Some families are not ready for early intervention when the baby is discharged from the NICU
- Not all babies need direct services when discharged from the NICU
- There is evidence that exposing a child to different play strategies impacts outcomes
- It is not know what "service coordination only" means in different systems across the state:
  - How do the EI systems "monitor" the child's development?
  - How/when is a determination made about whether a child needs direct services?
  - Need to continue to maintain the individuality of supports and services to meet individual child and family needs.
- What should be in place to monitor the child to be sure they are developing as they should?
  - NICU Follow Clinics cannot serve this role across the state because:
    - They are not available in all areas. (There is not funding and infrastructure support for NICU Follow Up Clinics).
    - Not all families go to the clinics

- Dr. Brown reported that about 65% of the families referred to their Follow Up Clinic attend, but of those 65% who keep the first appointment, 98% continue with the follow up.
  - Relying on Pediatricians is not an effective strategy
  - Relying on parents to identify developmental issues is not effective for most families. [Parent education, information and support is critical and effective provision of information includes repetition of key information].
- Education of families about development should begin in the hospital with the neonatologist.
- Some families do not want people coming into their home.

There was recognition that new challenges are created as headway is made with improving referral of babies to early intervention, including having sufficient numbers of highly trained practitioners.

One of the roles of this workgroup is to identify and participate in the development of educational and training materials in order to meet the needs of families and early intervention practitioners.

- The group discussed the critical importance of consistency across the educational and training materials including the NICU brochure, the training modules and the mini lesson. Stacey, who is the Chair of the American Physical Therapy Association Neonatology Special Interest Group and who is involved with research about prematurity, was asked to review these informational and educational materials for consistency of the message as well as content (reflecting current evidence).
- A suggestion was made that providers be required to take these trainings once they are available. Local systems may want to build such a requirement into contracts with providers who serve babies born prematurely.

### **March of Dimes**

March of Dimes handouts were distributed to participants who attended the meeting in person. Dr. Brown reported that the March of Dimes approach has been focused on prevention, but the organization is very involved with educating families about prematurity. They also lobby the insurance companies for coverage for services. Dr. Brown reported that insurance issues with follow up services include lack of insurance coverage, and/or difficulty meeting the co-pay, coverage of therapy if a therapist sees a child in a follow up clinic and the same discipline is providing early intervention services, and/or the procedures that are required for insurance reimbursement. Dr. Brown requested that as work is directed toward improving insurance coverage for early intervention, coverage for babies born prematurely be included in the discussions.

Susan Ward reported that the Virginia Hospital and Healthcare Association has resources for communicating with member hospitals including newsletters and special publications. They also have a website, [www.vhha.com](http://www.vhha.com), which can include links to information.

**Next Meeting: November 8, 2011 at 2:30 PM**

**\*\*\*\*\*Please note that this is a different date and time than originally planned\*\*\*\*\***

**Agenda topics:**

- Updates
  - NICU Brochure – Stacey Dusing
  - Training Module – Nancy Brockway
  - Mini Lesson – Tina Hough
- Identification of NICU contacts - Dr. Brown
- Consistency of Early Intervention Follow Up
- Children with hearing loss
- Insurance challenges and strategies
- Systems Improvement Project Report - Margaret Hayman/Mary Beth Cox