

**Early Intervention Prematurity Workgroup Meeting
Henrico Doctors Hospital
11/16/2010**

Attendance: See attached list

Membership

A number of new members have joined the group and were welcomed today. The group discussed representation, addressing the question of whether all essential stakeholder groups were represented. Possible additions suggested included:

- A physician or social worker from the MCV prematurity team. Terry Izzo and/or Stacey Dusing will follow up with the MCV team
- Family Practice. A family practice representative has been added. (Tarin A. Schmidt-Dalton, MD)
- Child care community. Discussion followed and the decision was made that for the work that is currently occurring this group does not need to on the workgroup. Rather, they need to be informed of the work and included when public awareness and training resources and activities are being developed and implemented. Joanne reported that the Virginia Department of Health has a mechanism for communicating with child care workers.

National Prematurity Day

Lisa Roday from the March of Dimes reported on events occurring at Henrico Doctors Hospital in recognition of Prematurity Month. She reported that a press conference is being held tomorrow during which Virginia's grade on the March of Dimes "Report Card to the Nation" will be announced. Last year the overall grade for the nation was a D and Virginia also received a D. The goal is to elevate public awareness about what a health care crisis prematurity is. 1/8 of the babies born are born premature. Today in Virginia 43 babies will be born prematurely. Susan Brown provided additional information about the press conference. A number of people will be speaking to provide information about the impact of prematurity on the community. Speakers include several workgroup members.

Education and Training for Early Intervention Providers

Cori Hill reported that the Training Team at the Partnership for People with Disabilities met yesterday and discussed the EI Prematurity training project. Decisions will need to be made about how/where this project will be prioritized in conjunction with other training projects currently underway. The next step is to convene a planning meeting with the EI Prematurity Workgroup members who volunteered to work on this project. These members include:

Stacey Dusing
Sandra Woodward
Tammy Torocsik
Kim Geissinger
Amy Kageals

Tina Hough
Cara Kiernan
Nancy Brockway
Patricia Hine
Deatrice Williams

Teresa Ziemba
Marie Anzalone
Pat Frank
Christine Eubanks

Hearing Loss

Issues with identification of hearing loss for premature babies, including missed screening, follow up testing and identification of late onset hearing loss were discussed. Discussion included concerns about insufficient audiologists trained and willing to perform diagnostic ABRs for premature babies. Christine Eubanks will follow up with Dr. Brown about specific concerns. This issue will also be brought to the attention of Ruth Frierson, Program Manager for the Virginia Early Hearing Detection and Intervention (VEHDI) and to the VEHDI workgroup for follow up.

Substance Exposed Babies

Martha Kurgans reported that she surveyed 10 CSBs regarding referral of babies born prematurely who are substance-exposed. Only one of the CSBs received referrals for substance exposed babies born prematurely and these referrals were not from the NICU. Discussion followed about gaps in practices. Every hospital has babies who are substance exposed. It is possible that hospitals are referring the children to CPS and not realizing that referral to the CSBs is also required by the Code of Virginia. The group agreed that education of hospitals about this requirement is necessary. The child of a substance abusing mother must be referred to CPS. The mother and child should be referred to the CSB during the investigative period.

Issues regarding referral and follow up for this population included:

- Referrals to the CSB
 - A major implementation issue is determining who within the hospital is responsible for the referrals. Hospitals are required to have a policy in place indicating who is responsible for the referral.
 - Are the child and the mother being referred to the CSB? Is it assumed that the CSB will refer the child to early intervention?
 - Why aren't babies being referred directly to EI instead of after the mom is seen by CSB? On the other hand, is this too early to refer these babies?
- What tools are being used to determine eligibility for substance exposed babies. Tools discussed include the Ages and Stages Social Emotional (ASQ SE) and the TABS. Martha is participating in development of a high-risk screening tool.

Possible mechanisms to address this issue include:

- Learn what is happening at hospitals
- Consider whether anything could/should be addressed from a licensing standpoint
- Inform hospitals that Medicaid will pay for developmental screenings

Next Steps:

- Martha will survey the CSBs and will contact some hospitals to learn about their process
- Martha may be able to add a couple questions to the Infant Mental Health Survey that will be sent to all CSBs.

Education of Families

Participants discussed the challenge of providing the right amount of information and education for parents of babies born preterm. Challenges include:

- Education about development varies from NICU to NICU across the state, including what is included in the education and who does it.
 - In some NICUs, the nurses are responsible for providing education about development; in others this responsibility belongs to therapists.
 - Therapist staffing varies across NICUs
 - Some NICUs provide extensive education and resources throughout the baby's NICU stay.
- The focus of the NICU is to keep the babies alive. It is important to have agreement from the NICU staff that education about development is important. NICUs may be reluctant to accept recommendations about education and training from an outside group.
- While licensure/policies require that developmental follow up be provided for Level 4 NICUs, there is not consistent interpretation about the definition of “developmental follow up”
- Transition from NICU to home is a challenging time for families as they are going from professional 24/7 care of their child(ren) to 24/7 responsibility themselves for their care. There needs to be a balance of providing the “right” information and the “right” amount of information so as not to be overwhelming.
- The American Academy of Pediatricians and the March of Dimes developed a brochure for families called “Supporting You and Your Preemie – Milestone Guidelines”. This brochure provides good information, though it does not provide information about temperament, sensory issues and other subtle issue.
- The March of Dimes has developed a number of educational materials that are available on their website. Dr. Brown is working with Sara Long of the March of Dimes to see if these materials can be put on disks to make them more accessible to families.
- Funding for development of educational materials and training needs to be determined. March of Dimes priorities are prevention of prematurity and empowering families to be advocates.

A Committee was formed to develop a single brochure that can be used in NICU's across the state. The purpose of the brochure is to educate parents of premature infants about their infants development, how it might differ from full term infants, red flags or symptoms to watch for, and where to seek EI resources if needs arise. Members include:

Stacey Dusing, PT, PhD,
Lead

Tricia Hine, SLP
Marie Anzalone, OT, ScD

Audrey Kane, OT
Susan Brown, MD

Theresa Ziembra was also suggested as a potential committee member.

Workgroup Workplan and Timelines

There are three distinct audiences to whom education and training needs to be directed: early intervention providers, parents and referral sources. The workgroup agreed that the initial focus

must be on educating EI providers and families. Timelines will be addressed at the January meeting after the to committees report back.

Two other strategies were mentioned for improving outcomes for premature infants:

- Establishing an early intervention system liaison for each of Virginia's NICUs
- Developing a mentoring program to match EI providers with professionals who have advance knowledge, training and experience with babies born prematurely.

Agenda Items for January 2011 Meeting

- Children with Hearing Loss (work to improve identification and follow up for this population) – Christine Eubanks
- Training Committee – Cori Hill or Deana Buck
- Parent Education (In NICU) Committee – Stacey Dusing
- PDSAs being conducted by the pilot sites participating in the VDH Medical Home Learning Collaborative – Margaret Hayman
- Referrals of children born to mothers who are substance abusing – Martha Kurgans
- Workplan Timelines
- Schedule meetings beyond March

Next Meeting: Tuesday, January 18 at 2:00 PM at Henrico Doctor's Hospital