

## Early Intervention Prematurity Workgroup January 18, 2011

Attendance: See Meeting Attendance List

### Children with Hearing Loss

- Christine Eubanks reported that MCV is making efforts to open additional slots for sedated ABRs. Sedated ABRs require an OR and the presence of physician. These must be coordinated with ENT. They have been able to do more un-sedated ABRs, but these can be done most successfully only for babies who can sleep through the test (younger babies). They are working on the process to get infants in for testing more quickly.
- Ruth Frierson, Program Manager for the Virginia Early Hearing Detection and Intervention (VEHDI) reported that VEHDI has found that children are delayed in getting a diagnosis because there are not enough Audiologists interested and able to do the required diagnostic testing on very young children.
  - The number of audiologists on the VDH approved list has increased from 46 to 52 audiologists. Audiologists must have the required diagnostic equipment to be on the approved list.
  - There are not specific qualifications for audiologists to do pediatric testing.
  - There are no audiologists on the approved list between Richmond and the North Carolina border. Transportation is an issue
- Ruth reported that now that the hearing screening results are linked to vital records, the VEHDI program can account for almost all children born in Virginia hospitals. Now they have positive and negative results in the system. In addition, the VEHDI program has added staff and enhanced the follow up process. They are aware of delays in reporting and they follow up. They are able to identify barriers to diagnosis and referral for services earlier and can provide assistance sooner. They have found that direct personal communication for follow up has been much more successful than letters.
- Discussion followed regarding refusal of some audiologists on the approved list to do the appropriate test and the resultant delay in diagnosis. Christine said that the process is sometimes altered when an ENT is involved who follows a different approach than the VEHDI protocol. Ruth indicated that a balance must be struck between having enough audiologists on the list and making the criteria more stringent. Participants asked if it was possible to have an asterick or some kind of indication for audiologists who are able and willing to do the sedated ABRs on very young children. Ruth said that VEHDI is now able to track, then follow up with audiologists who have not followed the VEHDI protocol. They have identified two locations that continuously screen rather than getting to the ABR. It doesn't make sense to make major changes based on data that shows issues with only two audiologists. VEHDI is also clarifying protocols. The protocols are clearer and more refined.
- Dr. Brown recommended that the VEHDI program look at the premature population differently than the general population. Ruth reported that the VEHDI program is in the process of updating protocols and regulation to be in alignment with the 2007 JCIH recommendations. She said that Pediatricians and families are receiving letters based on the 2007 recommendations, but some hospitals are still recommending that babies be seen every 6 months based on what is on the VEHDI web and on earlier JCIH recommendations. Dr. Brown reported that the AAP recommendations call for testing every 6 months.

- Kerry reported that from a parent's perspective it is very frustrating, time consuming and expensive to go to multiple appointments for something that should be done in the first appointment (appropriate hearing testing). She recommended that there be something on the website to indicate which audiologists are willing and able to do the appropriate testing.

**Plan:**

- Ruth will take back to VDH a recommendation that there be a indication on the list for audiologists who are willing to do ABRs for very young babies.
- Ruth indicated that they will consider adding a question to the survey for the audiologists. Joanne indicated that they may be able to look at the data specific to the premature babies. Joanne and Ruth will discuss this further. This will be an agenda item for the March meeting.

**Training Committee**

Four committee members presented a webinar January 4 for early intervention providers on prematurity. The webinar updated the providers on the new diagnosed conditions that qualify babies for early intervention (Periventricular Leukomalacia, gestational age of 28 weeks or less and NICU stay of 28 days or more), and information that can be used to determine if the baby is exhibiting atypical development. 128 individuals participated and provided feedback. Information was also provided by participants about continuing educational or resource needs. These included:

- Resources
  - List of discharge planners
  - Good books for parents
  - Course recommendations for providers
  - Printed materials for families
- Education/Training
  - Feeding
  - Vision for premature babies
  - Indepth discussion on assessment tools
  - Regulation state, medical management
  - What to look for atypical development
  - Case study
  - How to calculate adjusted ages for assessments
  - More on motor
  - Social-emotional
  - Understanding NICU discharge reports

Cori will send the feedback results to those who are interested. Contact Cori at [cfhill@vcu.edu](mailto:cfhill@vcu.edu)

Cori reported that the EI provider Training subcommittee will have their first meeting on January 27. The group will discuss mechanisms for training including additional webinars, adding a landing pad (best of best resources) for prematurity to the Early Intervention Professional Development Training portal ([www.eipd.vcu.edu](http://www.eipd.vcu.edu)) and other training mechanisms including mentoring opportunities.

**Parent Education (In NICU) Committee**

Stacey reported that the group has communicated via email and regular mail. The brochure work will be supported by the Infant & Toddler Connection of Virginia for graphic design and

funding. The subcommittees focus is not to modify the existing brochure “Supporting You and Your Preemie – Milestone Guidelines” published by the AAP and March of Dimes, but rather to create a new brochure that provides more in-depth information for parents and bridges the gap between discharge and when the family connects with the follow up clinic or early intervention. The subcommittee recommended that the developmental information go up to 6 months or a year in order to have space to provide additional information. The subcommittee suggested including:

- Making the transition to home
- More information on state regulation, behavior and sensory issues
- Adjusting age for prematurity
- How babies communicate through behavior (“I’m ready to interact, not ready”)
- Ideas for calming
- Signs to look for
- Developmental play; daily opportunities for play
- Developmental milestones up to 6 or 12 months adjusted age
- Information about early intervention
- How to contact early intervention (perhaps a space to fill in the local EI System information for each family)

Discussion followed:

- Pros and cons of including milestones up to age 3 versus more in-depth information with less milestone information
- Possibility of pairing the Infant & Toddler Connection of Virginia Milestones brochure with this new brochure
- Parent input:
  - include space to fill in the specific Local Early Intervention System information on the front
  - Include information about what early intervention (what is it, what services are provided, who qualifies)
  - Warning signs
  - Parent rights
- Pros and cons about the amount of information that should be provided
  - Too much is overwhelming and will not be read
  - This is the golden opportunity to provide information to parents of all babies born prematurely, many who will not be followed in NICU follow up clinic and who are not automatically eligible for early intervention immediately upon discharge from the NICU.
- Participants agreed that “red flag” information is needed, including atypical behavior and state regulation, milestone information, when and why families should contact EI and how to contact EI.
- Including information to help families transition to caring for their premature baby at home is very important
- There is a wealth of information and resources from the March of Dimes and AAP, but it is not always easy to find
  - Dr. Brown is working with the March of Dimes to obtain permission to have their information transferred to disks that can be used in NICUs to educate families
  - Including links to resources on the brochure may or may not be helpful
- It is important to utilize existing resources where available and not duplicate already existing resources.
- More parent input is needed

**Plan:**

- Increase parent participation on the subcommittee.
  - Kerry offered to join the committee
  - Stacey will contact the other parents on the EI Prematurity Workgroup and invite them to participate in the development and/or review of the brochure
  - Stacey will obtain input from parents with whom she works who represent additional socio-economic levels
- Stacey will report back at the next meeting

**Medical Home Learning Collaborative**

Margaret Hayman reported on the work of the Virginia Department of Health Medical Learning Collaborative. Through this project which involves 14 medical practices (public, private, military, pediatric, family practice, university), they have developed brochures and educational programs aimed at changing behaviors. A major focus of the project is to increase developmental screening by the medical practices using the ASQ-3. They have used the PDSA (Plan-Do-Study-Act) process to implement practice changes. Through the PDSA method, practices learned:

- Introducing the screening (ASQ-3) in the waiting room is not effective. They moved it to the exam room
- The group that wanted to do the survey electronically learned that more than 60% of the families are computer literate and had access to a computer
  - 91% of the families said they would complete the survey in the waiting room if a computer were available
- Families were receptive (not defensive). They wanted to learn about development and wanted to take activities home to work with their children
- The screening didn't disrupt the office flow
- All of the practices are expanding their screening beyond the ages initially targeted through the collaborative

The medical practices may be willing to pilot some of the training and resources developed by the EI Prematurity Workgroup.

**Identifying Hospitals with NICUs**

Kathleen Moline reported that VDH has a list of the hospitals across the state. The list doesn't identify which have NICUs, but does identify which provide general, intermediate, specialty and subspecialty newborn care. The group discussed the need to keep all hospitals that care for newborns informed about the workgroup efforts since babies move between hospitals and care units.

**Plan:**

- Kathleen will send Beth a list of all the hospitals that have newborn units
- Beth will draft a letter to the hospitals (Director of Newborn Services) to inform them of the EI Prematurity Workgroup efforts including the additions to the EI eligibility criteria, development of materials. The letter will also include a request for the names and contact information for discharge planners for ongoing communication.

## **Workplan Timelines**

- Training Subcommittee will report next month on sequence (and possibly timeline projections) for training and resource development.
- Parent Brochure Subcommittee will provide a project timeline at the next meeting
- Letter will be sent to all hospitals with newborn units prior to the March meeting
- Referral Source Communication and Education
  - Need to provide ongoing communication to AAP, Family Practice Physicians and NICUs/Hospital
  - Education efforts need to occur after materials have been developed and EI provider training is in full swing

## **AAP Grant**

Dr. Brown reported that the AAP has big push to provide education about developmental issues and is providing grants to groups working to serve more children and to create materials. This information has been shared with the Partnership for People with Disabilities to see if they can assist with applying for a grant.

## **Quality of Early Intervention Services**

Dr. Brown commented that the staff expertise and quality of services for preterm babies provided through early intervention systems across the state varies and asked how this might be addressed to assure consistency across early intervention systems. Beth reported that the state early intervention professional development efforts as well as the statewide monitoring and supervision provided by the Part C Office are mechanisms to improve quality and consistency of supports and services across the state.

## **Next Meeting: March 15, 2011 at the VACSB**

Agenda Items:

- Follow Up – VEHDI Program information
- Training Workgroup
- NICU Parent Brochure
- Communication with Hospitals
- Infants born to Mothers who are Substance Abusing

## **Future Meeting Schedule**

The group decided to change the meeting frequency to every other month. The February 15 meeting is cancelled. Future meetings are now scheduled for:

March 15, 2011 (VACSB)

May 17, 2011 (VACSB)

July 12, 2011 (Henrico Mental Health and Developmental Services - West)

Sept 20, 2011 (VACSB)

November 15, 2011 (VACSB)