

Early Intervention Prematurity Workgroup Meeting Agenda
Location: Virginia Association of Community Service Boards (VACSB)
5/24/2011

Attendance: Joanne Boise, Nancy Brockway, Susan Brown, MD, Stacey Dusing, Christine Eubanks, Heidi Faustini, Patricia Frank, Sandi Harrington, Cori Hill, Patricia Hine, Linda Lindsey-Hoy, Cara Kierman, Alison Standring, Mary Swiggum, Beth Tolley, Tammy Torocsik, Deatrice Williams,

Welcome to new members: Heidi Faustini (parent, Arc of Virginia) and Mary Beth Cox (Virginia Community Healthcare Association)

Provider Training Group

Cori reported that the three subgroups continue to be very active in developing training resources:

- The *Resource Landing Pad* on the Early Intervention Professional Development website (www.eipd.vcu.edu) will include “the best of the best resources” including evidence based practices, print materials, online resources, and Virginia guidance related to prematurity. Mary Swiggum and Jen-Barnes Maddox are working on this. It is expected that the resources will be posted within the next 10 days or so.
- The *online module* that is being developed will provide basic information about prematurity in the form of tips and information to know to support the premature child when he/she comes home from the NICU. The individuals working on the modules represent a variety of disciplines including physical therapy, occupational therapy and speech-language pathology. The group is currently working on the second draft. The target audience is providers, though some families may be interested. The online modules are expected to provide very practical information.
- The third subgroup is developing a *mini-lesson* which will include videos and will be very interactive. Participants will watch a video, then respond to questions related to the video. Development of the mini lesson is on hold until the online module is further along so that these two training resources will be complementary. The purpose of the online modules is to teach; mini-lessons are intended to provide the opportunity to apply what is learned.

Cori reported that additional videos and pictures of babies are needed for the training resources.

Christine Eubanks recently spearheaded development of a “deaf and hard of hearing” resource landing pad which be featured in the June 7 “Talks on Tuesdays”.

Brochure Development

Stacey reminded the group that the purpose of the brochure is to support families who are transitioning their baby from the NICU to home and is intended to be used with existing brochures (AAP/March of Dimes “Supporting You and Your Preemie” brochure (<http://www.nann.org/pdf/Preemie.pdf>) and the new Part C “What is Early Intervention”

brochure). It is being designed to provide information that is not included in these existing brochures.

A draft of the text for the brochure was forwarded to members prior to the meeting and was discussed in depth during the meeting. Highlights of the discussion included:

- Have a positive title and positive focus
 - “Taking Your Preemie Home: What You Need to Know Now
- Emphasize the importance of paying attention to development now (not waiting months before paying attention to the child’s development)
- Capture the importance of the parents’ role in helping their child develop: Parents are their child’s first and best teacher
- Information needs to be included about adjusting for prematurity including when to stop adjusting
 - Need to consider how best to present this information so that it makes sense to parents. Possibilities include:
 - “How old is your baby from your due date” or “how many months early was your baby born”
 - Include a tool to fill in the date the baby was born and the due date. Person explaining the brochure could assist family with completing the math
 - While info is included in one of the other brochures, it is important to be included in this one also. Explaining how to adjust for prematurity one way in one brochure and a different way in another could be helpful.
 - Recognize that the recommendation for how long to adjust for prematurity varies
 - Most standardized tool adjust to 24 months
 - Different facilities and professionals adjust using different criteria
 - It’s probably best to recommend adjusting up until the child is 18 – 24 months.
- Detailed information cannot be included in a brochure. Important concepts need to be included to make parents aware of potential issues (red flags) and serve as a point for discussion (standing, for example)
- Include information about contacting physician as well as contact information for early intervention
- It is recommended that the text be at a 6th grade level.

The brochure group will make revisions based on today’s input. A request was made for input about graphics, pictures, and clip art. David Mills, Part C Office, will coordinate work to develop the layout and graphics after the text is finalized. One suggestion was to make this larger than the typical brochure and include a pocket for the other brochures.

The brochures will be available online for printing by NICUs. Decisions about dissemination of the printed brochures will be made later.

Communication with Private Insurance Companies

The Part C Office has a strong relationship with the Department of Medical Assistance Services. While staff have been working to improve communication with and education of commercial insurance companies about early intervention, there has been limited progress with this. Dr. Brown offered to see if Sara from the March of Dimes would be willing to facilitate work with the commercial insurance companies. Beth and Dr. Brown will follow up on this possibility.

Dr. Brown suggested that we see if Sarah Long from the March of Dimes to help with communication with private insurance companies. Beth and Dr. Brown will follow up.

Contacts for Hospitals with Newborn Units

A form is being developed for dissemination to Early Intervention System Managers to identify contacts (and contact information including email addresses) for Virginia's hospitals with newborn units.

Grant Proposal

Stacey reported that she is working on a re-submission of a grant to the Department of Education for a Clinical Trial of Early Physical Therapy to Advance Sitting and Reaching in Infants with Motor Impairments. The goal is to demonstrate that by advancing motor abilities such as sitting and reaching, cognition, problem solving and preschool readiness are enhanced. It is a national multi-center trial. Stacey indicated that letters of support are needed. She will provide information to members via email.

Next Meeting: July 12, 2011

Agenda topics:

- Provider training update (Cori Hill)
- NICU Brochure update (Stacey Dusing)
- Babies born substance exposed (Martha Kurgan)
- Contacts with hospitals with newborn units (Beth Tolley)
- Work with commercial insurance companies (Beth Tolley)