Early Intervention Prematurity Workgroup Meeting
9/21/2010

Attendance: See attached list

Membership
New members have been added and will continue to be added as the workgroup identifies additional stakeholder groups.

Criteria Being Considered for Automatic Eligibility for Part C

The three criteria under consideration include:

Gestational Age of 28 weeks or less
PVL
NICU stay of 28 days or longer

Workgroup members discussed the evidence that is available regarding these criteria as predictors of developmental delay and/or disability including:

- Unimpaired Outcomes for Extremely Low Birth Weight Infants at 18-22 Months of Age (http://pediatrics.aappublications.org/cgi/content/abstract/124/1/112)
- Sensory Development in the Fetus, Neonate, and Infant: Introduction and Overview (Graven and Browne)

See reference list.

Discussion included:

- All preterm infants are at risk
- The more preterm infants will be more at risk for medical sequelae (brain bleeds) as well as the impact of the sensory overload of the NICU environment (longer stays)
- 75% of children born at 28 weeks or less gestational age will have disabilities or delays, though it may not be apparent which category an individual child will fall in until the child is 3 or 4 months old.
- PVL has a high correlation with CP
- Children who are in the NICU 28 days are longer are those who have more serious conditions
- While the research reports and literature are important, data is not available about which and how many children received services, what services were received and at what age they received services.
- Would Part C eligibility of these babies shift the responsibility of all services and education to the Part C System?
    - Part C provides coordination of services as well as supports and services for eligible infants and their families. It does not replace existing services.
- Review of data from the Virginia Department of Health.
- Can the Part C system handle the increased number of children?

- Currently, the Part C system is serving less children than expected (by OSEP and based on population statistics)
- Services are provided as necessary to meet identified Individualized Family Service Plan (IFSP) outcomes. An infant and their family may need only service coordination or may need more extensive services
- The Medicaid Early Intervention Services program provides reimbursement for Part C services for infants who have Medicaid.

Issues were again articulated by the group:

- Inadequate data (which, how many children receive follow up, referrals for services; how many are referred to EI and found ineligible; etc.) While Virginia has electronic birth certificates, NICU stays are not captured on these at this time.
- The need for consistent education of all parents of babies born preterm when the baby is discharged from NICU
- Lack of clarity or policy regarding who is responsible for education of the family when the baby is discharged from the NICU
- Inconsistent follow up by hospitals (system and family barriers to follow up)
- Needs of families for support and education when they bring the baby home from the NICU. (Need to be aware of potential for post partum depression)
- Medical community not extensively trained about this population unless they have a special interest. Medical community has given families the wrong message for years.
- Early Intervention referral sources (physicians, hospitals, etc.) need to know the criteria for early intervention eligibility.
- Children are referred to soon to EI and found ineligible
- More and more information is becoming available (research) about the impact of prematurity; some issues may not be identified until a child is in a classroom setting.

Dr. Brown stated that babies who spend time in the NICU need time after discharge to adjust to the home environment and "recover" from the NICU. She highlighted intervention considerations/focus for babies discharged from the NICU:

- Address equipment needs
- Prevent abnormal patterns. Watch for torticollis and asymmetry
- More active intervention is appropriate when the baby is around 3 months old.
- Feeding
- Teaching families what to look for and when to contact the Physician or follow up clinic.

Local differences in NICU follow up were discussed:

- Henrico Doctor's Hospital has a well established NICU follow up program
- Bon Secours is working to develop NICU follow up
- A follow up clinic at Children's Hospital of Richmond is available for babies served at VCU-MCV NICU clinics

- Fairfax has lots of overlap. The NICUs have follow up clinics and the Health Department also provides follow up

Strategies to consider

- Dr. Brown suggested a statewide awareness/education campaign for physicians and families about what is and is not typical for preterm babies so physicians will know when to refer and families will know when to see help.
    - Engage state and community partners for public awareness and education.
    - Margaret Hayman reported that this education fits nicely with a current Health Department project (Virginia Systems Improvement Grant: Medical Home Learning Collaborative) which includes 14 practices (private physician groups, community health centers, Military practice and university affiliated practice) are focusing on the use of validated screening and referral of children for services.
    - Develop work flow for what needs to happen with these babies (service pathway)
- Education and training of early intervention service coordinators and service providers
    - Identification of babies who should be eligible for Part C Services
    - Appropriate intervention strategies for preterm babies
- Part C involvement in NICU – and/or connection of Part C with discharge planners in the NICU
- Identify agencies and organizations currently providing supports and services for preterm babies and their families
    - Identify who is doing what; identify gaps
    - Consider interagency agreements

Decision: The group agreed to recommend the addition of the three criteria above as automatic Part C eligibility "conditions" **after** work is done with additional stakeholders and in conjunction with a with a multifaceted approach that includes timelines and strategies to address key issues impacting the follow up and care of babies born prematurely.

Components of the Multifaceted Plan could include:

- Development of recommendations for follow up and intervention for infants born prematurely including what education and support should be provided at what points (and by whom), when babies should be referred to Part C and other community resources, and what are the appropriate supports and services these babies and their families should receive
    - Family education and support when baby is discharged from NICU
    - Family education and support during the initial weeks/month(s) that the baby is home from the hospital
    - Referrals to part C and community resources
    - Medical follow up
- Education and training of providers and service coordinators
- Education and training of referral sources
- Public awareness about what preemies need

- Public Awareness about what Part C does (family and partners)
- Plan for education of families when babies are discharged from the NICU
- Plan for follow up with families after the baby is discharged from the NICU
- Coordination of organizations and resources involved with this population
    - Identification of existing resources (community and state organizations and resources) and gaps
    - Identification current initiatives
    - Identify partners (ex. March of Dimes) to assist with Public Awareness, funding issues, etc.
- Communication of EI Prematurity recommendations to stakeholders via
    - Infant & Toddler Connection of Virginia Technical Assistance Update
    - VICC Meeting Discussion
    - Virginia Chapter of the American Academy of Pediatrics communications
    - Communication with Developmental Pediatricians
    - Communication with state NICUs
    - Communication with hospitals that have Level One and Level Two nurseries (Can hospital association assist?)
    - Virginia Early Hearing Detection and Intervention Advisory Committee

Participants were asked to consider and bring to the next meeting:

- Suggestions for content for the education and training needs that have been identified
- Are there educational materials currently available that could be used?

Agenda for Next Meeting:

- Develop the message to present to the various stakeholder groups about the proposed automatic criteria
- Draft the workplan for the group including timelines
- Discuss the educational content and available materials brought forward by the group
- Discussion presentation for the December 1, 2010 Virginia Interagency Coordinating Council Workgroup

Confirmed meeting schedule is 2:00 to 4:00 PM on the following dates:

- October 25, 2010 at the VACSB -
- November 16, 2010 – Henrico Doctors
- No meeting in December
- January 18, 2011 - Henrico Doctors
- February 15, 2011 – VACSB
- March 15, 2011 - VACSB