

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

June 8, 2012

FINAL

The following persons attended the meeting: Callie Beasley, Nancy Bond, Deana Buck, Derek Chapman, Darlene, Donnelly, Leslie Ellwood, Christine Eubanks, Kathrine Gangeri, Scott Gregg-CART Services, Valerie Luther, Daphne Miller, Casey Morehouse, Debbie Pfeiffer, Heather Strang, Antoinette Strayhorn, and Sunney Wang

Agenda was reviewed and approved.

Membership and Introductions

No new members.

Report from DMAS

No update.

Hearing Workgroup

The workgroup met its original goal; establish a family to family support system in Virginia. The focus of the Workgroup will change to address other areas of need. Some areas being considered are; review of children over the age of 3 that would not be captured through the audiology web-base reporting system, development of education and awareness materials for all stakeholders, considering best delivery methods for the target audience, and meeting the training needs of home visitors.

Partnership for People with Disabilities

We have had more interest in people taking the two modules posted on the national list serve. Facebook posted a little quiz that will direct people back to the modules. They generate a certificate hoping to take modules and ybred to make modules for home visitors.

Virginia Network of Consultants (VNOC)

Update provided by Kathrine Gangeri as provided by Ann Hughes;

VNOC – 2011-2012 school year:

35 service requests in process to date – 28 were child/student specific; 7 were for staff development sessions.

Trainings – LSL – Integrating the Cottage Acquisition Scales for Listening, Language and Speech (CASLLS) in Classroom and Therapy Environments for Children Who Are D/HH (3/31) and Follow up webinars: Early Childhood Planning and Elementary Focused Planning (4/21) 49 educators (SLPs, teachers of d/hh) participated in this training and the follow up sessions.

Upcoming Activity:

June 13 – Will conduct a visual phonics for ECSE, PreK and K educators for Rockingham County Public Schools.

June 26 – 27 – Opening Doors – Unlocking Potential 2012! Starting with Assessment: Language, Literacy and Students who are Deaf or Hard of Hearing in Charlottesville. This is the 6th annual two-day state-wide Professional Development Session designed for teachers of the d/hh, related

service providers and all who work with children who are d/hh. The keynote speaker is Martha French, author of Starting with Assessment: A Developmental Approach to Deaf Children's Literacy. Information including the complete schedule with descriptions of each session is posted on the ODUP 2012 website: <http://openingdoorsunlockingpotential.shutterfly.com/July-10-12> – Radford University Summer Institute: Developing Listening Skills and Spoken Language in Children with Hearing Loss (Sponsored in part through the TA Center for Children who have D/HH) – the annual summer training opportunity for educators working with children who are d/hh and working to develop listening and spoken language skills. <http://www.radford.edu/-rudhh/>

Department of Education

Debbie Pfeiffer announced Doug Cox, Assist Superintendent of Education is retiring as of July 1. John Eisenberg is now in his place. He had a good background in deaf blindness and goes to bat for the children. John got a bill in the general assembly this year regarding assistive technology purchased by schools for children. The tools can be sold to other educational facilities or families which is a very positive move. Legislation was tabled this past year re deaf children's bill of rights initiated by the rep from Stanton but we plan to work to move that forward. Deaf Blind training will be held in June, funded by DOE, for paraprofessionals, teachers and intervener training. Ten people will be funded to attend Utah University's training. 64% of the people they have trained to work with the deaf/hh met state qualifications, which is up from 9% in previous years. They have 356 interpreters in the public schools. Budget cuts at DOE are expected. They have asked the oral preschool program at ODU to try and find another source of funding. They are trying to help them locate a home for the program along with funding. They want to keep it at ODU because it gives them a chance to do studies on the program's effectiveness. Other organizations are helping by funding whatever part of the program they can.

Part-C Early Intervention

No updates provided.

Newborn Screening

Update presented by Kathrine Gangeri as provided by Kathy Moline
Received a Health Resources and Services Administration grant for a 3 year demonstration project for Critical Congenital Heart Disease. They will be partnering with UVA and five other hospitals to look at pulse oximetry screening which is a non invasive method of monitoring oxygenation of patient's hemoglobin. Sudden Combined Immunological Disease (SCID) has been recommended by the Genetic Advisory Committee to be added to the newborn screening panel. A workgroup is being formed and a nurse has been hired to lead the efforts. The program is working on becoming paperless by July 1, 2012 by receiving faxes directly to our desktops.

Virginia Hearing Aid Loan Bank (VHALB)

Forty applications, for hearing aids, were received between January and May 31, 2012. Six hundred and twenty children have been served by the loan bank since May 2005. Hearing aids were recently purchased giving them a good inventory. As of June 6th they have \$174.00 to pay audiologists until the end of June. Surveys were recently sent to those that have completed their loaner trial. All responses were positive. Lisa continues to promote the program at Community events and plans to attend the Opening Doors Unlocking Potential Conference in June.

Children with Special Health Care Needs

No update provided.

VDH/EHDI Report

Kathrine Gangeri presented for VDH. EHDI is fully staffed. The Policy and Evaluation unit has not hired a Surveillance and Evaluation Coordinator. However, Sunney Wang is providing some of the data requests for EHDI. We continue to do site visits to hospitals and audiology facilities. The findings of the hospital visits indicate a need for training of hearing screeners on communicating results to families. The audiology site visit findings indicate additional training is required to increase understanding of protocols and follow-up procedures. Currently EHDI does not have an inventory or printed educational materials. The workgroup will focus on identification of existing materials and the development of materials in addition to best delivery methods for *Just in Time* education of stakeholders. An Audiology training module for the new on line reporting module for audiologists will be a part of VISITS. We have been getting feedback during the training sessions and will use it to refine our system. We hope to be able to roll it out in July. The VISITS link to VIIS is going forward. It will enable us to share hearing information on the immunization registry. *Loss and Found* PSAs will start airing the week of June 25 and will air for 3 weeks in the Richmond and Tidewater markets. We will monitor the response to them through the toll free number. VEHDI has met with the Home Visiting Consortium and will make some revisions to their training based on their recommendations. The plan is to add this training to our training website and to the Home Visitors training website. We received communication from a parent communicating her disappointment in receiving a bill of \$334 for her child's hearing screening. The parent proposed to give parents the option to decline to have the hearing screening and in lieu of having the child screened after discharge at a facility where it would be less expensive. Dr. Ellwood recommended we gather more information on the prevalence or potential prevalence of this issue and the benefit for the extra cost in a proposed legislation rather than having legislation created on the basis of the parent complaint. Nancy Bond suggested we look at home many tests the baby had to reach the charge. Some parents object to the need for the test when their child passes. It was pointed out that Pediatrix allows some patients to do a payment plan to cover their testing. Deana felt it created a difficult situation if a parent had to quiz the tester about who they worked for – hospital or contractor. Daphne announced the RFP for Guide By Your Side has been completed. EHDI will provide a progress update as the process continues.

Other Updates

Deana Buck announced there would be a meeting on June 18 to get guidance on dealing with the budget reductions for local systems. They have a 30% increase in the number of children served but funding is going to affect this. They have a 30% increase in the number of children served but funding is going to affect this. They have started a new Medicaid reimbursement program which is adding to the challenges they are facing at this time. They will bring information from the June 18, 2012 meeting back to the Advisory Committee..

Casey Morehouse announced their school has been under construction for 3 years due to combining the two locations. They will begin moving into the new or renovated buildings for the next school year..

VISITS Audiology Demonstration

Daphne and Antoinette provided a demonstration of the new audiology reporting module in VISITS. An on-line training will be developed for users of this module. It was suggested that a person not receive a user ID and password until they have completed their on line training to prevent incomplete or incorrect entries in VISITS.

Public Comment

No public comment

Presentation on Risk Factors Assoc. with Bi-lateral Hearing Loss

Derek Chapman presented on the Analysis of Risk Factors Associated with Bilateral Hearing Loss. The main goals of the study were to analyze the prevalence of JCIH risk factors in children with confirmed bilateral hearing loss and assess the presence of co-occurring birth defects in children with confirmed bilateral hearing loss (BHL). Data were extracted from the VISITS Database to include EHDI and VaCARES information. In summary 29% of children with BHL loss had a JCIH risk factor. Most commonly reported risk factors were family history of hearing loss, stigmata or syndromes associated with hearing loss, and neonatal indicators. Among children with BHL, 34% also had a co-occurring birth defect. When children with BHL also had at least one JCIH risk factor, a co-occurring birth defect was present 53% of the time. Further studies were recommended to examine the relationship between the etiology underlying BHL risk factors and co-occurring birth defects.

2010 and 2011 Surveillance Data Presentation

2010 Lost to Follow Up Rate for Virginia was 29.9% which dropped to 21% in 2011. This follow-up rate is for infants with a failed screening that have received at least 1 re-screening and does not consider those infants without a final diagnosis. VEHDI data indicates that in 2010 Virginia identified 70% of the expected hearing loss cases and in 2011 56% of expected hearing losses have been identified.

Next Meeting

September 14, 2012

Meeting adjourned at 2:15 p.m.