

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

May 8, 2015

The following persons attended the meeting: Marcus Allen, Nancy Bond, Terri Strange-Boston, Cornelia Deagle, Craig Derkay, Julie Durando, Patricia Eitemiller, Callie Ellis, Leslie Ellwood, Christine Eubanks, Ashleigh Greenwood, Ann Hughes, Sarah Kirchner, Jennifer MacDonald, Daphne Miller, Beth Musser, Debbie Pfeiffer, Irene Schmalz, Barry Strasnick, Antoinette Vaughan, and Kathleen Watts

Dr. Leslie Ellwood called the meeting to order

Introductions were done around the table. The agenda for the meeting was reviewed with the attendees. There were no additions to the agenda. The committee membership list was reviewed for updates. The Committee was reminded to complete a travel reimbursement form if necessary.

Department of Medical Assistance Services (DMAS)

A representative was not in attendance. No update

VNOC

Ann Hughes presented for VNOC. Provided background information on the organization and the services they provide. They will be providing a training June 24 and 25, 2015 covering dual-language needs for children with hearing loss. It will focus on working with children in homes where English is not the primary language. On June 23, 2015 the National Summit on Deaf Education will be held to discuss the topic of opening doors to life after high school. A flyer for this event will be provided electronically to share with the group.

Early Intervention

Terri Strange-Boston spoke for Early Intervention. The state office is busy. State teams have been set-up to re-evaluate the system and how referrals are being received.

Newborn Screening

Jennifer Macdonald spoke for Newborn Screening. SCID screening will go live on June 4, 2015. The regulations are in the final stages of public comment. Educational webinars will be provided at the end of May for providers. CCHD grant is winding down, however a no-cost extension was received from the Federal funder to complete some of the activities. CCHD emergency regulations went into effect in January. Transit time for NBS blood-spots are still an issue. The team is working on a 24 hour receipt at the lab after the testing is done.

Virginia Hearing Aid Loan Bank

Dr. Ellwood spoke for VHALB based on email received from Lisa Powley. The loan bank is celebrating its 10th anniversary. Department of Education has provided funding to purchase sound fields for classroom amplification.

Children and Youth with Special Health Care Needs

Marcus Allen spoke for CYSHCN. The new Bleeding Disorders Program Coordinator will begin work on Monday, May 11. She will be working with the Sickle Cell and Hemophilia programs. The Care Connection for Children Center at CHKD has developed a tool to be used in transition. An evaluation will be developed to evaluate the success of the tool. Encouraging families to have a medical home. Working on report the MCH and renewing contracts.

Family to Family Support

Irene Schmalz spoke for Family to Family Support via telephone. Attended first parent advocacy group meeting held in Williamsburg. Will be participating at an event in Northern Virginia on May 16. Participated in a home visit with a Spanish speaking family with the use of an iPad for translation. Referrals are down at this time and are hopeful that they will increase. Have received referrals from other sources than VDH.

VSDB

Debbi Pfeiffer spoke for VSDB. Due to budget limitations, staff are wearing many hats. Several positions are opened to be filled. Collaborating with UVA to provide online sign language courses for families. Producing a videotape on interveners who work with deaf/blind students. Did a statewide needs assessment and an evaluation for people with visual impairments.

Department of Education

Update on behalf of Wanda Council from DOE. Daniel Erwin is the new Education Specialist for Autism. Deaf Blind Project is up to age 22 with combined disabilities and DOE is hiring a Project Coordinator.

Deaf Blind Project

Julie Durando spoke for DBP. Currently wrapping up annual census on vision/hearing loss. Provided training for Early Intervention staff. In the process of hiring a Project Coordinator.

Partnership for People w/ Disabilities

No report.

VDH Updates

Ruth Frierson has resigned from position at VDH. Kathleen Watts has been recently hired with VEDHIP as the Quality Improvement Coordinator and Beth Musser in Policy & Evaluation. VEHDIP is currently in the process of implementing several system enhancements and updates to the VISITS system. The funding for the Virginia Hearing Aid Loan Bank has been approved for renewal. The EHDI program has received the HRSA grant award.

EHDI Data Presentation

Beth Musser from VDH provided a presentation on EHDI data. The percentage of children loss to follow-up looks as if it has increased from 2012 to 2013. Beth explained that the numbers for 2013 included children that were loss to documentation as well as follow-up and the 2012 data did not include the loss to documentation population.

Public Comment

There was no public comment

CMV Update

Kelly Dodson presented on CMV Risk Factors. Analysis of Risk Factors of Children who passed initial hearing screenings. The University of Utah and the University of Washington are currently screening all babies for CMV. The feeling is that CMV screening will eventually take place when a cost effective screening method is determined and there is data to reflect the effectiveness of a CMV treatment. The cost for screening in VA could be as high as six million dollars per year. Ninety percent of children screened for the virus may not get hearing loss even if they have the virus.

QILT

Kathleen Watts discussed what she has learned since joining the VEHDI team. She shared a copy of Communicate with your Child – a brochure that can be given to parents when their child is diagnosed with hearing loss. She will be working on an insert for the brochure with VA specific resources. One requirement of the HRSA grant is the establishment of a Quality Improvement Leadership Team. This team will work on development of PDSAs (Plan-Do-Study-Act) that will test changes which may result in improvement of the EHDI system. Anyone who is interested in being on this team needs to let her know. One tool she would like the team to consider using is the EHDI Self Assessment Tool, which was developed to measure the outcomes for children with hearing loss based on the most recent JCIH Statement.