

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

September 6, 2013

Draft

The following persons attended the meeting: Callie Beasley, Joanne Boise, Nancy Bond, Dena Buck, Sidnee Dallas, Darlene Donnelly, Leslie Ellwood, Ruth Frierson, Kathrine Gangeri, Scott Gregg (CARTS), Lacey Heckler, Ann Hughes, Valerie Luther, Daphne Miller, Kathleen Moline, Casey Morehouse, Janet Odishoo, Debbie Pfeiffer, Lisa Powley, Heather Strang, Terri Strange-Boston, Barry Strasnick, Sarah Varner, Antoinette Vaughan, and Dana Yarbrough

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 or changes. The membership list was distributed for corrections/updates. The new check box on the travel reimbursement form was explained.

Department of Medical Assistance Services (DMAS)

No update.

Partnership for People with Disabilities

The presentation was made by Dena Buck. The Partnership is working on training modules for ENTs, Audiologists and Home Visitors. These modules will go on the same website as the Early Intervention training (<http://eipd.vcu.edu/onlinetrainings.html>). Ruth Frierson and Ann Hughes reviewed the Audiology Training Module and found it to be very comprehensive. Other on line Audiology Modules were evaluated as well but they found this one to be the most beneficial to EHDI goals.

Virginia Network of Consultants (VNOC)

Ann Hughes made the presentation on VNOC. Its purpose is to provide consultant services for children who are deaf or hard of hearing in school divisions and state operated programs in Virginia. VNOC professionals have expertise in multiple areas as they relate to children who are deaf or hard of hearing. The school system can call on VNOC to assist families of children with a hearing loss. VNOC is funded by the Department of Education.

The Opening Doors and Unlocking Potential Conference was held August 6 & 7 in Charlottesville, Virginia. It was dedicated to Dr Debbie Pfeiffer in appreciation for her years of leadership and public service to the educators and students who are deaf and hard of hearing in Virginia. Ruth Frierson was a co-presenter on the opening session reviewing the status of Virginia according to the eight goals set forth in the National Agenda. In November 2013, they will be doing A Hearing Journey for parents.

Early Intervention

Terri Strange-Boston of the Infant and Toddler Connection has been working with Ruth Frierson to promote and improve the working process between EHDI and Early Intervention. Child outcomes have become a primary focus to determine effectiveness. There are three primary child outcomes

- Positive social emotional skills and relationships
- Acquisition and use of new knowledge and skills
- Use of appropriate behaviors to meet their needs

Measurements for these outcomes are being developed.

Newborn Screening

Kathleen Moline, Program Supervisor for the Newborn Screening program, gave an update on her unit. Severe Combined Immunological Deficiency SCID is being added to the newborn screening panel. They continue to work with UVA developing educational modules on critical congenital heart disease (CCHD). A survey was conducted to determine the needs of birth hospitals and birth centers in the implementation of CCHD. After receiving a 100% response rate, they plan to do conduct 4 webinars. One of the webinars may be of interest to the EHDI professions. The webinar will be focus on how to deliver the bad news to parents, provide emotional support, and an understanding of the condition. This is occurring in partnership with the state NICU's as Newborn Screening is working on the screening criteria of the sick newborn. They established a panel of neonatologists to determine the best timing and method to obtain blood spots on children and perform other aspects of their program. Newborn Screening continues to work with EHDI. They are now on Facebook and other social media. On Facebook, they are using the same colors and layout as EHDI so viewers will understand that this is all part of the Virginia Department of Health

Virginia Hearing Aid Loan Bank

Lisa Powley, Manager of the Virginia Hearing Aid Loan Bank (VAHALB), said they have 117 children using loaners. 763 families have used the bank since May 2005

Children with Special Health Care Needs

Sidnee Dallas, Program Administrator, Children with Special Health Care Needs, announced the Title V Block Grant was submitted July 15. On August 21, 2013 she went to Maryland with the State Office Director to sit before a panel of reviewers to discuss the program. In October, she will be going to the Care Connection Center in Charlottesville, Virginia.

Guide by Your Side

Dana Yarbrough made the presentation for Guide by Your Side.

GBYS was started in 2007. They provide emotional support to families and information on how to navigate through the system. From August 15, 2012 to August 15, 2013 they made a total of 113 referrals. Most of these babies were EHDI referrals. 41% of the children were less than 6 months old. In the beginning of the program referrals were primarily children over the age of 3. Now they are working with younger children. 43%

of them are referrals from Tidewater/Hampton Roads. There have been 8 Spanish speaking children referred to them. For the period August 15, 2012 to March 15, 2013 GBYS had 66 referrals. Information for the GBYS survey was obtained from 52 parents; but, all parents are questioned about their satisfaction with GBYS and the services we provide.

In 2012 we had 20 guides and in 2013 we have added 7 or 8 new guides. Approximately 30% of families were matched with a guide. We also do referrals to Hands and Voices. Bailey Vincent has been very good at social networking and getting information out about Hands and Voices.

Hands & Voices

Casey Morehouse is the Chair of the Board of Directors for Hands and Voices. She circulated a copy of the Hands & Voices Communicator for the Committee's review and encouraged them to get a subscription. They have not been able to get their nonprofit status reinstated. They are up against delays and promises of getting it done. Hopefully, it will be done this fall.

VSDB

The 2013-2014 school year started on Sunday, August 25th with student registration.

Renovations at the school have been completed and include a new playground and a new audiology suite. VSDB will be celebrating their 175th anniversary in 2014. They are the second school for the deaf and blind established in this country. They will have a yearlong celebration with events occurring throughout the year. Both the Deaf and the Blind Alumni associations are putting together plans. She urged everyone to consider visiting VSDB during 2014 to see the new additions and changes on the campus.

VSDB's Parent Infant Education and Outreach Services are expanding and reaching out to families, early intervention agencies and local school systems across the state. This is at no charge to EI or families. They are finishing a professionally produced video of differing lengths that will be used on their website as well as at conferences, presentations and in public service announcements to get the word out about VSDB.

Patricia Trice is the new principal. She has a long history of service to Virginia's children who are deaf or hard of hearing and is well known across the state as an educator, an RID certified interpreter and interpreter trainer.

Department of Education

Ann Hughes announced DOE is recruiting for an education specialist.

Virginia Department of Health - EHDI

There is a new interested party for the Committee, Elizabeth Allen. She was at the EHDI Conference this year and has a lot to offer us. She was not able to attend today's meeting but asked that a flyer for Families to Families be distributed. It is for gatherings for families with young deaf and hard of hearing in the Hampton Roads area. It will be

the 4th Saturday of each month at the Church of the Good Shepherd, 7400 Hampton Boulevard, Norfolk, VA 23505.

Antoinette Vaughan informed the committee that year two of the HERSA grant concluded August 31, 2013. 6 Audiology site visits were required, 7 were completed. Two were in Roanoke. Three were in Northern Virginia. One was in Portsmouth and one in Winchester, Virginia. At the site visits, EHDI pals was encouraged and promoted. The list of approved audiologists on the back of our weekly parent/pcp letters is from the EHDI Pals website. Those who noticed their names were not on the list were encouraged to join. There's ongoing Audiology out-reach in which audiologists receive a phone call and an email regarding VISITS and/or EHDI PALS websites. We conducted a teleconference on ENTS, audiologists and home visitors. We discussed protocols, exams, referrals and how some of those issues will be in the training module for Audiologists. The rough draft of the audiology training module was submitted for stakeholders to review and offer feed-back for editing. The deadline to participate was Sept 5th 2013

Kathrine Gangeri informed the committee that 6 hospital site visits were done to complete the HRSA grant year goal. Marketing materials were developed for our awareness campaign which included a new poster, the pamphlet "Can Your Baby Hear?" which is ready for distribution to hospitals and a new prenatal piece "What Can Your Baby Hear Now?" which includes lullabies for children. Kathrine let attendees know that samples were available for AC members at this meeting. VEHDI's Facebook page now has 1,414 likes which puts the program's Facebook page very close the number of likes for NCHAM, EHDI's national organization. You Tube advertising began in January and we have averaged 22,644 views per month. Kathrine continues to do follow up calls to families of children who did not pass their newborn hearing screening in the hospital which can average approximately 60 calls per week.

Daphne Miller presented information on children with a hearing loss. In 2012 207 children were reported to us as having hearing loss. 202 were referred to Early Intervention. 133 were reported before 6 months of age, 43 after 12 months of age and 26 after 6 months of age. Pandora commercials were released and met with great success.

Ruth Frierson stated EHDI received the 3rd year HRSA grant. With the funds received she hopes to obtain teleaudiology. The budget will have to be revised first. We had a visitor from HRSA who wanted to meet with those receiving HRSA grants. She was thrilled by what the VEHDI program has accomplished.

Pandora and regular radio ran the ads EHDI produced. They averaged 22,000 clicks to the website created to record visits generated by the ads. We passed industry standards and Pandora's own industry standards.

In 2012 we did two weeks of ads on television in the Tidewater and Richmond area. There was some increase in response but nothing near what we have gotten from the ads on Pandora, radio and other social networks we are using.

We completed the prenatal brochures because the Can Your Baby Hear was not getting the response we hoped for. We did two pilot tests on the Can Your Baby Hear. We called the families reported to us and none of them had any knowledge of the brochure. We thought the problem may be the timing so we are trying to capture parent's attention prior to delivery.

We distributed the NCHAM Training DVD for screeners on August 2, 2013. We thought it would help standardize the testing process. We learned the DVD's do not match the on line training 100%. NCHAM was not aware of this. Everyone was encouraged to go on line to the NCHAM website to take the training there in order to receive a certificate which was not available on the DVD.

The site visits done with Kathrine Gangeri and Antoinette Vaughan opened our eyes as to what is being done by Audiologists and their understanding of the EHDI program. We are working on getting Early Intervention access to VISITS. We have spoken with the developers and they believe it can be accomplished in a few months.

We are funding GBYS which benefits us in ways we did not anticipate including promoting awareness of our program.

At the Meet and Greet in Fredericksburg, 66 parents and children attended. We plan to repeat the process at a later date.

Irene Schmalz, who is deaf, won an award for doing so much for other deaf people and raising awareness among the public.

We continue to try to educate parents in the Richmond and Roanoke areas. We plan to contact as many as possible by phone, email or knocking on doors. EHDI will also go to Obygyns hoping to increase follow up in these locations. If it works, we will provide information on the process for the entire state.

Our Follow Up Specialist is targeting hospital screeners and parents. The Follow up Specialist II will target audiologists and parents. The Program Manager will target Parents and Medical Homes. We will use our brochures, poster and to reach out.

Public Comment

No public comments

AAP Packet Review

Leslie Ellwood stated AAP was becoming more active and would like to become part of programs geared for the deaf and hard of hearing. He distributed a copy of Virginia Pediatrics with an article he developed. It discusses the EHDI process and the necessity

for the involvement of the child's Medical Care Home and Audiologist. Detailed instructions were provided as well as a glossary of terms and a sequence of events. The full packet of information is available online at www.aap.org/pedhic/ehdi.

Sara Varner of the Virginia Department of Health did a statistical presentation on hearing loss for 2011 and 2012. Graphics showed that the length of time to reach diagnosis is going down. Age at diagnosis of permanent hearing loss in 2010 was 251 days, 2011 149 days and in 2012 88 days of age. She pointed out that children born in a particular year may be diagnosed in a different year.

EHDI has found if the family does not get that follow up call, the child usually does not get follow-up.

12 35 lunch break

The committee broke down into workgroups to discuss EHDI Issues

Kathrine Gangeri facilitated the **EHDI Educational Awareness Workgroup**. During today's meeting we focused on the audience of building PCP awareness about EHDI and goals for newborn hearing.

Some possible ideas for how we can better inform and engage PCPS included the following:

- VIIS Collaboration (Kathrine Gangeri) – once VIIS linkage complete, train the VIIS trainers on 1-3-6 so that they may present this as a new feature to the system
- AAP Newsletter (Dr. Ellwood) – Jane Davis is the Chapter Champion RAM office. Dr. Ellwood suggested we could approach her about putting in an article of content
- Major pediatric meetings across the state
 - Peds at Williamsburg (September)
 - UVA (Spring)
 - VCU (July)
 - Fairfax (November)
 - CHKD – (Fall 2014. EHDI could have speaker there- they start planning for this in Spring maybe Dr. Aiello could present?)
- Awareness piece for peds (Kathrine Gangeri.) – something that could go out with teleaudiology talking about OAE, ABR, and auditory neuropathy. Hearing tests aren't just tone testing, etc.
- Teleaudiology (Kathrine Gangeri) – piggyback off of the teleaudiology idea and have this transport visit PCP offices with awareness pieces – see above

- Seek at Social Media Groups (Terri Strange-Boston) – perhaps join a pediatric group on Linked in to post information for the group about hearing

NEXT MEETING: Focus on messaging for peds and how do we reach out to ENTs?

Ruth Frierson facilitated the NICU workgroup (Craig Derkay, Nancy Bond, Jan Odishoo, Frank Aiello, Sara Varner, Callie Beasley, Sidnee Dallas, and Ruth Frierson)

The workgroup is tasked to develop recommendations/protocols on managing infants in the NICU for an extended period of time. This time can be determined by any infant with a NICU stay of 3 months and longer.

Existing issues:

- According to Virginia EHDI Protocols infants receive their hearing screening prior to discharge and this creates a delay in screening and diagnosis when a child is in the NICU for an extended period of time without their hearing screening.
- No screening during an extended NICU stay can result in a delayed diagnosis and delayed services.
- Hearing screening results cannot be reported to the VDH through VISITS because the reporting system allows reporting screening only after discharge from the hospital.
- Hospitals are contacted to check on the status of each infant who remains on the pending list for an extended period of time.
- Hospitals/VISITS hearing users are not able to report infants on pending list because of an extended NICU stay.
- Current internal hospital systems of tracking are “people dependent”.

Workgroup recommendations:

- Continually assess child’s health in preparation for a hearing screening.
- Perform hearing screening on infants in the NICU for an extended period of time at the corrected gestational age of 35 weeks.
- Revise VDH VISITS Reporting system to allow hospital users to identify infants in the NICU, directly on the pending list, and allow VDH users to view this designation.
- Revise VDH VISITS to allow reporting of inpatient hearing screenings, inpatient re-screenings, and inpatient diagnosis, for infants in the NICU. *(Research impact on these changes to; CDC reporting, letter generation, diagnosis, referrals to services, and follow-up processes).*

- Develop internal automated hospital systems for tracking infants in the NICU with an extended stay, in need of; screening, re-screening, diagnosis, and reporting to VDH EHDI.

Next steps:

- Review impact statement.
- Review letters and make revision recommendations.
- Finalize draft recommendations.
- Share with neonatologists and stakeholders.

Daphne Miller facilitated the Health Disparities workgroup which was composed of Lisa Powley, Ann Hughes, Daphne Miller.

- Working with school nurses to educate on the importance the NBH follow-up
- Using materials to educate OBGYN's & PCP's offices
- UVA has a teen outreach center , connecting with teen centers around the state to provide education on the NBH screen and the importance of follow-up
- RAM (Remote Area Medical Van) getting an idea of the services this medical van provides and seeing if a collaboration is possible to provide rescreening to families.
- Tele- audiology Van or Tele -audiology sites check into the feasibility of each option.
- Camp Holiday Trails provide a presentation to the school nurses(Lisa Powley) next meeting is March 20th
- We would like to find out “How many hospitals have hospital educators? “
- Reaching out to churches with information on EHDI program
- Asking hospitals to make appointments for children before leaving the hospital and encouraging hospitals to provide EHDI's contact information to families who fail.
- Connecting with Newborn screening on the webinar to provide resources to hospitals on how to deliver the news of a child failing the NBHS (Kathleen Moline)
- Finding a spokesperson a celebrity to get the message out of the importance of Early hearing and detection and intervention
- Expanding the role of Parent Guides to reach out to parents who failed the newborn hearing screen. Helping with transportation and guiding them through the process of the NBHS.
- Reaching out to Social Workers, Eligibility workers and WIC to provide education on the importance of the NBHS and follow-up.

- Sending prenatal information to school nurses to provide parents with information before the birth.

Antoinette Vaughan facilitated the Audiology workgroup which included Casey Morehouse and Heather Strang.

Heather Strang from Pediatrix and Casey Morehouse from the VA School for the Deaf and Blind participated in this work-group. Pass with risk babies were discussed and the need to have a complete diagnostic by age 2 which should include an ABR. Heather Strang stated that they are currently practicing this as part of their current internal protocols however they have been contemplating a change due to the fact that parents are often leery about sedation and said that a mother refused this procedure for her baby this month. Subsequently I inquired about the number of ABR's they encounter monthly and she said, "We do about 3 or 4 per week." Then I highlighted that this means only about 1/12 would actually refuse the procedure per month which is a small amount. Another issue mentioned by Heather Strang is that Children's National are unable to perform sedated ABR's and refer these to Pediatrix. She said that she and Jill Young is the only 2 audiologist which could present a problem if they start getting a large influx of referrals for sedated ABR test. Casey Morehouse's concern is that she's not able to perform a sedated ABR and often times find that the babies are too old for natural sleep testing. Both audiologist agree that there are other means of testing which can determine if a child has hearing loss while ruling out auditory neuropathy. Per Casey Morehouse, if acoustic reflexes are present this means there's no auditory neuropathy. I informed the 2 of them that the VA EHDI program manager (Ruth Frierson) did inform a Roanoke facility that a VRA + an ear specific test are acceptable for older babies per the national recommendations. However, when asked by Heather Strang is this state protocol, I told both ladies this will be discussed in the office since VISITS currently do not accommodate this test procedure as a complete diagnostic exam.

Transients and Inconclusive were discussed briefly. I inquired about the reasons why a baby would remain in such a status for a long period of time. The 2 reasons provided are as follows: transportation issues and therefore the families don't return, or the baby has multiple medical problems which are prioritized as higher concern by the parent and PCP. When asked why is it that I often see multiple inconclusive from the same facility, Casey Morehouse stated the facility should refer the patient out to the PCP or another facility that may be able to perform more in depth testing. In conclusion, Heather Strang said she will email me the ID number for the child whose mother refused the ABR this month, in addition to some ID numbers for babies they are now diagnosing while in NICU. She said that she has been having difficulty entering a diagnosis since these types of babies are in-patient, VISITS wants to enter this diagnostic as an initial.

Meeting adjourned