

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

March 1, 2013

Final

The following persons attended the meeting: Frank Aiello, Marcus Allen, Nancy Bond, Deana Buck, Sidnee Dallas, Darlene Donnelly, Christine Eubanks, Ruth Frierson, Kathrine Gangeri, Kathy Guisewite, Ken Henry, Ann Hughes, Kathleen Moline, Casey Morehouse, Laura Olinger, Sheri Parcell, Lisa Powley, Barry Strasnick, Irene Schmalz, Antoinette Strayhorn, Sunney Wang, Susan Ward, Jill Young

Membership and Introductions: Marcus Allen, Sickle-Cell Program Coordinator.

DMAS

No update

Hearing Workgroup

Christine Eubanks, the workgroup continues to provide guidance, information, and feedback on VEHDIP educational materials for hospitals and the pre-natal population .

Partnership for People with Disabilities

Deana Buck, Program Group Leader, Early Childhood & Education, stated they were not able to get AAP certification through the Medical Society at MCV, for the VEHDIP trainings develop for primary care providers. The Partnership has created two EI training and information modules about hearing identification and treatment and the plan is to build another. Deana will be asking the committee to provide their expertise. The Part-C Early Intervention Managers on March 26 and VEHDIP will participate to provide training on the 1-3-6 Goals.

VNOC

Ann Hughes, Virginia Network of Consultants Coordinator (VNOC). VNOC will meet again this month to discuss what other organizations they should partner with in order to ensure accomplishment of their goals. In January, Ann attended the National Summit for Deaf Education in Austin Texas. The primary focus was centered on outcomes for children with hearing loss. On May 17th and 18th there will be workshop on developing spoken language methodologies.

Newborn Screening

Kathleen Moline, Program Supervisor for the Newborn Screening program at the Virginia Department of Health announced the Secretary of Health and Human Services has added Critical Congenital Heart Disease (CCHD) on the newborn panel. Basically the hospitals will use pulse oximetry screening, to determine the amount of oxygen in the blood and pulse rate to identify those babies that are at risk for a sudden event when going home. CCHD is responsible for numerous infant deaths. The program received a

HRSA grant to look at creating the infrastructure. UVA will develop a series of educational modules. The first will be on CCHD on March 28, 2013. One of the links with EHDI really pertains to what happens to children with multiple birth defects. Is there some correlation we can find? This is a three year grant and we are in first 6 months. Because AAP endorses screening it is being done in most hospitals. Testing is being done on well babies because there is no way to evaluate NICU babies properly. As the program develops we will move on to sick babies. Testing takes 3-5 minutes. A child has more than one chance to pass and we may turn up as many as 200 babies a year. We are looking at how smaller hospitals are going to be able to do the initial testing without having to transfer the child and how we can facilitate increased capacity. Newborn Screening is celebrating their 50th Anniversary nationwide. We are in public comment to add severe combined immunological deficiency SCID to newborn screening. Susan Ward, Vice President & General Counsel of the Virginia Hospital and Healthcare Association, has been helping with this project. Christine Eubanks, Audiologist, said she had seen articles on using a cheek swab instead of a urine test on the newborn.

Virginia Hearing Aid Loan Bank

Lisa Powley, Manager of the Virginia Hearing Aid Loan Bank (VAHALB), reported that as of February 28, 2013, 717 infants and children have used the VAHALB. They received 10 applications for hearing aids between November and December 2012.

Children with Special Health Care Needs

Sidnee Dallas, Program Administrator, Children with Special Health Care Needs, Virginia Department of Health, attended the National Association of Maternal and Child Health Programs Conference, and the primary focus was on health care reform and the potential impact on health care programs. Newborn Screening and the VEHDIP have been invited to meet with center directors to discuss collaborative opportunities.

Marcus Allen, State Sickle Cell Program Coordinator, indicated pediatric clinics through the state were providing services to children with Sickle Cell. His program has a community based program to help them link to services and provide social support.

Guide By Your Side

Irene Schmalz, Virginia Guide By Your Side (GBYS) Coordinator, reported she is in need of Parent Guide, especially in the Tidewater area. Currently the program has 10-12 guides and she is in the process of providing training for parents interested in becoming guides. GBYS has provided support for 62 families since August 2012. She also reported a need for a Spanish speaking guide. The program uses a translator whenever it's possible. GBYS has a Meet and Greet, for parents of children with hearing loss on March 9, 2013 from 10:00 a.m. – 12:00 p.m.

Hands & Voices

Bailey Clark is the Director for the Virginia Hands & Voices (H&V) Chapter, but did not attend this meeting. Casey Morehouse of the Virginia School for the Deaf and Blind provided an update on behalf of Bailey. H&V now has a website, a Facebook page, and a twitter account. The H&V Board consists of 10 members; 6 parent and 4 professionals.

On March 7, 2013 H&V will host their first Facebook “party”. Bailey submitted an article for the national H&V Communicator. Bailey Clark and Paul Johnson, VAH&V Board Treasurer, will attend the National EHDI Conference that will be held in Arizona in April. H&V continues to work towards obtaining their nonprofit status.

Casey introduced Kathy Guisewite, with the Small Steps Program. A parent – infant Education Program for families raising children who are deaf, hard of hearing, blind, low vision and deaf blind. They will serve children in the birth to age three range. Services through the program are free of charge to families. Currently there are no families in the program. They are anxious to begin their work and asked the committee to help promote the services offered by this program. Services include:

- Exploration of all communication modalities in a non biased manner.
- Professional consultations regarding the child’s situation.
- Home based services through the Individual Family Service Plan
- Comprehensive audiological diagnostic and evaluation services
- Exploration of amplification methods
- Monitoring child with a family history of hearing loss or middle ear pathology
- Transition planning from early intervention to school based services
- Opportunities for family networking and socialization
- American Sign Language classes.

Virginia Department of Health

Ruth Frierson, Program Supervisor for the Virginia Early Hearing Detection and Intervention Program (VEHIP), reminded the Committee of the Annual EHDI Conference on April 14-16, 2013 to be held in Glendale, Arizona. There are now ten different tracks available for participants.

As everyone else we have received notice from CDC and HRSA to expect cuts to our next grant awards, which begin July 1 and September 1, respectively. We received some carryover funds to help support the H&V activities, in order to continue to provide GBYS support services for families.

Kathrine Gangeri, of the EHDI Program Follow-up Specialist, reported that the VEHDIP Facebook page continues to gain recognition. The page now has 650 “Likes”. We have also started advertising on YouTube with the previously developed *Loss & Found* videos in English and Spanish. VEHDIP is currently revising the “Can Your Baby Hear?” brochure that is given to parents at birth hospitals. The committee was asked to review it and provided their comments and recommendations. The VEHDIP Workgroup has also initiated the development of a prenatal education brochure which is also in its final draft. In December, Ruth and Kathrine attended the Sound Beginnings conference in DC at Gallaudet University. Families discussed the range of emotions upon discovering their child was diagnosed hearing loss and their experiences with a variety of services. We continue to conduct site visits to hospitals to review the newborn hearing screening process.

Ruth Frierson, explained that VEHDIP will be participating in Early Hearing Detection and Intervention Pediatric Audiology Links to Services (EHDI-PALS) as a way to approve sites that provide follow-up testing and diagnosis. EHDIPALS.org currently contains 17 approved audiology facilities in Virginia. Please refer audiologists to apply to be an approved facility at www.ehdipals.org.

Antoinette Strayhorn, EHDI Program Follow-up Specialist, reported that VEHDIP participated in a survey of primary care providers and otolaryngologists, developed by National Center for Hearing Assessment and Management. The survey is meant to measure the knowledge of providers on the EHDI process and was mailed to over 600 providers in January and February. We continue to conduct site visits to audiology offices, to review the follow-up process.

Ruth Frierson reported on behalf of Daphne Miller that we will be participating in the Part-C Systems Managers training on March 26, 2013. *Loss & Found* were sent to home visiting programs that serve pre-natal and high risk mom's; Healthy Families, CHIP of Virginia, and Resource Mothers.

Shuhui Wang presented the 2011 EHDI data submitted to CDC. The data indicate that infants are receiving follow-up screening at a younger age. The lost-to-follow-up rate has also drastically decreased from 64% in 2010 to 17% in 2011. Dr. Strasnick, requested that this data on lost-to-follow-up and hearing losses be broken down by geographic areas, and presented at the next VEHDIP AC meeting.

Public Comment

No public comment.

Parents as Teachers Program

Sheri Parcell from Parents as Teachers (PAT) described the program as an evidence-based early childhood home visiting framework that builds strong communities. The model emphasizes parent-child interaction, development centered parenting and family well-being in their work with families. There are four interrelated and integrated components of the model: personal visits, group connections, screening and resource network.

Infants enrolled prior to 4 months of age have their hearing screened before 7 months of age. Infants over 4 months are screened within 90 days of enrollment.

If the testing facility is unable to use OAE or pure tone audiometry, the parent's report or documentation that the child's hearing has been checked by a healthcare provider within the last 12 months can be used as the hearing screening portion of the complete annual screening. For those newborns who fail the newborn hearing screening at the hospital they should return to their provider for follow up. If the family is not following up on the refer result it is important that the parent educator works with them to do so.

One of the issues PAT faces is the use of an OAE. There are those facilities that do support the guidelines of PAT and those who do not choose to purchase and use OAE equipment for testing because of the cost of the equipment and the need for training on this equipment. A process for reporting results to EHDI has not been developed. PAT and EHDI will continue to work together to search for opportunities to collaborate to ensure all children receive follow-up and that necessary resources are shared with PAT educators, as well as sharing results with EHDI.

Hearing Loss Discussion; Atresia, Auditory Neuropathy, and Transient

Christine Eubanks of MCV audiology did a presentation on Atresia, Auditory Neuropathy and the use of “transient” to describe a hearing loss.

When microtia is present there is no external ear. If atresia is present there is no ear canal and there can be testing.

With Auditory Dyssynchrony/Neuropathy: when patients have normal outer hair cell function in the cochlea but sound information is not transmitted to the auditory nerve and brain properly.

Audiologists are used to using different terminology than what we present in the VISITS database and they would like to see changes in the drop down choices. The EHDI Program Manager pointed out that the drop down choices are those used by CDC and cannot be changed at this point.

An error message was displayed showing that audiologists are not able to enter a child’s record to see what other types of tests have been done. Ruth indicated this should be fixed by the end of the month.

The use of “unknown” and “transient” is confusing to the audiologist. Dr Aiello suggested we add the following information to our website and instructions: *“Unless there is fluid in the ears, the loss is conductive, there is a malformation or the audiologist is not sure at this point select unknown.”*

Ruth out there has been much discussion on what type of equipment should be used at what age to diagnose a hearing loss. A group of committee members will work to outline what is acceptable and when.

Next Meeting Date: 06/07/2013

Meeting Adjourned at 3:00 pm