SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program
Virginia Department of Health
December 6, 2013
Final

The following persons attended the meeting: Elizabeth Allen, Marcus Allen, Callie Beasley, Joanne Boise, Nancy Bond, Wanda Council, Julie Durando, Leslie Ellwood, Christine Eubanks, Ruth Frierson, Katherine Gangeri, Scott Gregg (CARTS), Ken Henry, LaToya Hill, Ann Hughes, Ralston King, Valerie Luther, Daphne Miller, Casey Morehouse, Laura Olinger, Debbie Pfeiffer, Irene Schmalz, Heather Strang, Terri Strange Boston, Antoinette Vaughan, Carol Wiegle, Jill Young

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 Committee was reminded to complete a travel reimbursement form if necessary.

Department of Medical Assistance Services (DMAS)

No update

Partnership for People with Disabilities

I don't have any information on a presentation for this section

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. VNOC handles 25-30 children per school year. Last year they had 28 referrals. All together 190 children have been serviced. Their focus is how the communication and connection between EHDI and Early Intervention can be improved.

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.

Newborn Screening

No update

Virginia Hearing Aid Loan Bank

As of December 5, 2013, 791 children have used the Loaner Bank. The surveys that are returned continue to be positive and the families are very appreciative that this service is available for their children.

Children with Special Health Care Needs

Marcus Allen made the presentation on behalf of Sidnee Dallas who was unable to attend. Their focus at this time is on maternal/child health funding and transition programs. By transition he meant the child moving from a pediatrician into adult care by a physician.

Guide by Your Side

GBYS was started in 2007 to provide emotional support to families and information on how to navigate through the system

Irene Schmalz made the presentation on their activities from September through November 2013.

- The total number of families referred – 19. Six of them were Spanish Speaking families.
- On October 19, 2013 there were 50+ attendees at the Virginia Beach Meet and Greet.
- They had 10 videos in stock but another 10 were developed with captioning. One of the videos was shown for the committee. To see other videos, go to http://video.com/channels/612192.
- Their sign language listing has a completed draft but they anticipate more will be added before the updates and edits begin.
- Their Facebook Page is up and running! Videos will be posted twice a month.
- In February 2014 training of new guides the Virginia Beach/Tidewater area will begin.
- Future Meet & Greets are planned for Roanoke in April 2014 and Chesterfield in October 2014.
- Their presentation, "Strategies and Ideas for Supporting Families to be Effective Advocates" has been accepted for presentation at the 2014 EHDI Annual Meeting.
- Training on Visual Phonics is planned for Mechanicsville.

Hands & Voices

Casey Morehouse spoke on behalf of Hands & Voices. The Virginia Chapter leadership; Chair, Treasurer, and GBYS Parent Coordinator, conducted a teleconference with the National Office of Hands & Voices staff and received guidance and assistance in how to achieve the objectives set for the chapter and increase collaboration with GBYS. . The Virginia Chapter is still waiting for it's nonprofit status application to be reviewed by the IRS. However there is at least a one year backlog of applications to be reviewed before Virginia Hands & Voices application will be assigned to a IRS case manager. The Board will be considering other sources of revenue in the meanwhile. A review of Virginia Hands& Voices Board members was presented to the VaEHDI's Advisory Board members.

VSDB

Presentation was made by Casey Morehouse. The Virginia School for the Deaf and the Blind has a broad array of specialized support services for their students. Providers are full participants in the educational planning process and deliver services in accordance with students' Individual Education Programs (IEPs). Following the consolidation, VSDB is now serving a large number of children who are DeafBlind. Extensive renovations and capital improvements at VSDB have been completed to update and consolidate space. The Deaf and Blind Departments are sharing spaces within the new facilities rather than being in separate buildings. This has been a positive experience for all students. VSDB will be celebrating it's 175th anniversary in 2014.

Casey shared a professionally developed DVD which explains the function of the school and present testimonials to its effectiveness

Department of Education

Presentation was made by Wanda Council. She reported that the Code of Virginia requires school boards to distribute information to the parents of students who are hearing impaired or visually impaired. Guidance documents and other resources are available at the Virginia Department of Education website and can be shared with parents. She distributed information comparing IDEA (The Individual with Disabilities Education Act) and the Deaf Bill of Rights. A list of resources available to teachers and parents was also distributed. House Bill 1344 (the Deaf Child's Bill of Rights) amended the Code of Virginia by adding a section 22.1-217.02 relating to special education; in particular children identified as deaf or hard of hearing. This requirement expands on the special considerations section of the Individualized Education Program (IEP) of the individual with Disabilities Education Act (IDEA 2004).

Public Comment

No public comments

VDH Updates

Daphne Miller presented the following information on Hearing Loss

	Total	Before 6 months	Between 6 and 12 months	After 12 months
Total Number Diagnosed with Hearing Loss	157	105	28	24
ENROLLED IN PART C	58	41	9	8
LINKED TO FAMILY-TO-FAMILY SUPPORT	73	40	21	12
REFERRAL TO PART C	157	95	34	24

This report has been pulled by Diagnosis date from Jan 1st 2013 to Dec 2nd 2013.

Ruth Frierson discussed the Saturation Project the EHDI program undertook. Each of the follow up staff and the program manager was given a sector to go in and distribute information about EHDI. Hopefully this will improve the education and referral processes that exist.

Work is still being done to improve the distribution of information between EHDI and Early Intervention. As of now our Follow up Coordinator calls in the referrals to the EI agencies. A module is being developed where Early Intervention can access VVests and receive auto referrals through the system.

Kathrine Gangeri spoke on EHDI's Social Media which is working well. We have information on Facebook, You Tube. Positive responses have been received on both locations.

We now have a prenatal CD, What Can Your Baby Hear Now, to promote interest in the program.

Deana Buck has offered to help with revisions to the training module for audiologists.

The next EHDI conference will be April 2014. Kathrine Gangeri will present on social media Irene Schmalz is doing presentation on Guide by Your Side in Virginia. At the last conference we were able to have 3 parents attend.

EHDI had to justify why we continue to fund GBYS. It has been very successful with success being measured by the number of children receiving services who are under 12 months of age. The parent resource guide is the best EHDI has ever had and has been very well received.
GBYS is a candidate for the Better Hearing and Speech award by (Hamilton Relay 2013 Better Hearing and Speech Recognition Award. Based on surveys over 80% are satisfied with the Guide by Your Side program.

The EHDI HRSA grant will be cut by $50,000. GBYS cannot continue without Hands and Voices. Getting Hands and Voices up and running has been a challenge. The Advisory Committee has been asked to come up with options to keep funding at the level that exists. The Hearing Aid Loan Bank also needs help due to budget cuts.

LaToya Hill was introduced to the committee. She is here to do a comprehensive evaluation of the program. It will include stakeholders, audiologists, PCP's and EHDI. The last evaluation was in 2008. The committee was asked what information they wanted analyzed. Leslie Ellwood wanted to know how many doctors have navigated a child through the process. If they have no do they know where resources are if they need help. Joanne Boise would like information about home visiting – what they do, how they help EHDI. How do they work with the pediatricians? Casey Morehouse wanted information on how many people are afraid to navigate through the system. Who do the families trust and would ask for help. Christine Eubanks asked about the WIC office. Could they have our information for their clients? It was decided as part of the process to identify who the stakeholders are and what is their knowledge of EHDI. Ruth Frierson asked that hospitals and audiologists be included. Marcus Allen brought up undocumented aliens. Social Service is a way to reach them. But, Social Services want the parent's social security number. If the parent will not provide they deny services to children. The group would like to know who is actually doing newborn hearing screenings in the hospitals. How do they communicate results to families? Is a nurse present when the child is tested and results transmitted? Medically fragile children were brought up as to when and how they get screened and receive services. Late onset hearing loss children -- How are we doing capturing the 18 to 24 moth follow up children? What are the follow-up processes used by doctors. Casey Morehouse felt physicians are still going by the old regulations for children that have passed with a risk indicator

Lunch break

The Advisory Committee broke into workgroups to discuss EHDI issues.

Antoinette Vaughan presented the findings of the Audiology Work group. Members of the group were Christine Eubanks, Ken Henry, Casey Moorehouse, Heather Strang, Jill Young, Antoinette Vaughan

Advisory Work-Group Summary

During the work-group session a surprise quiz or "learning device," was given to the audiologist although one participant was not an audiologist. There were 6 quizzes taken. The purpose of the quiz was to see how informed audiologist are regarding the EHDI Program's mission, goals, target population, and the Virginia state guidelines for best practice and reporting results to VEHDIP. The quiz consisted of 10 questions with only an average of 1.3 answered incorrectly. The questions answered incorrectly primarily pertained to EHDI's mission statement or the use of VISITS system. Overall however, everyone did well.

After the quiz, the EHDI FSII (Antoinette Vaughan) inquired about mixed hearing loss. The type of test that is most likely to give this type of diagnosis, audiology recommendations for such, and follow-up for such babies was inquired about and discussed during the session by the FSII. It was concluded that primarily a bone conduction ABR and tympanometry combined are the tests that are most likely to give such a diagnosis and that these babies should be referred to an ENT and, or their PCP for medical management with subsequent audiology follow-up within a month or depending upon the child's circumstances. Also discussed and well established by all audiologist in attendance is that mixed hearing loss is considered permanent hearing loss due to the sensorineural component however, what is usually unknown to an audiologist at the time of the diagnosis is how much or what percentage of hearing loss is present. The FSII discussed the need convey this permanent hearing loss in their report to the state EHDI Program in an effort to prevent delayed EI services. Dr. Ken Henry suggested that as it pertains to reporting conductive hearing loss in VISITS, that a pop up in parenthesis should occur when the user selects conductive/transient indicating that this choice can delay EI services. However all in attendance agreed that VISITS should be changed to reflect mixed hearing loss selection as a permanent hearing loss.

Lastly, what was briefly discussed were microtia and atresia. Atresia was confirmed by the work-group to be permanent hearing loss due to the facts that at present, the baby has the condition and subsequent surgery years later will not guarantee the child will be able to hear at that future time. However, microtia does not in itself equal hearing loss and this group of audiologist recommended bone conduction ABR as the best method of testing children with this condition in order to determine if permanent hearing loss does exist.

Kathrine Gangeri represented Early Intervention.

AC Workgroup Minutes 12/6/13

GOAL: Creating network of service providers specializing in Deaf/HH services for early interventionists to use as a resource

Workgroup Members: Irene Schmalz, Valerie Luther, Terri Strange-Boston, Carol Weigle, Ann Hughes, Sidnee Dallas (Marcus Allen was in for Sidnee), Leslie Ellwood, Lizzie Allen, Kathrine Gangeri

Kathrine Gangeri took minutes this session.

Previously this workgroup was to focus on public awareness efforts but due to funding this goal was replaced with goal listed above. There has been a gap identified in that there is a lack of a "network listing" for EI providers to reference to get appropriate services to families. Another component of this is that some existing service providers have not become "EI certified".

1) How can we build awareness with existing service providers to become EI certified if they have not already done so? How can we get the word out to make this happen?
2) Once we have the current listing of certified service providers, where can we house this information? On a website? Which site? Then how do we promote?

Teachers of the Deaf and HH, Speech Language Pathologists and other therapists may wish to become EI certified which involves taking various modules to become a specialized provider.

Ann Hughes stated that there are approx. 250-300 teachers of the deaf who we could reach out to get certified if they are not. She has this listing. Terri Strange-Boston offered that perhaps we could also leverage our EHDI Facebook presence to promote to other professionals who may follow us in that venue.

Terrie Strange-Boston mentioned that EI specialists are affiliated with a local system, the deaf/hh service provider would want to be licensed pro, complete modules and then affiliate with EI systems. That way the Infant and Toddler Connection could have a list of all the teachers, service providers etc so that EI has the resources they need on a web site or database.

Kathrine Gangeri and Marcus Allen stated it would be best to do a web page hosted on an existing site for this network because that way Care Connection for Children, etc. could reference the list as well.

The group talked about venues to get the word out to EI providers about this and it was determined there were 2 conferences in July: ODUP and Shining Stars that could be good opportunities.

Kathrine Gangeri offered to draft a letter that would invite professionals to get certified and work with Terri Strange-Boston on crafting this. (DRAFT DUE to TERRI BY JAN 15, if not sooner)

Letter should be finalized by end of January, 2014.

Kathrine Gangeri agreed to manage phase 1 of this through end of January, 2014.

Phase 2 will require leadership from another workgroup member and focus on dissemination.

NICU Workgroup

Ruth Frierson facilitated the NICU workgroup (Nancy Bond, Callie Beasley, and Ruth Frierson)

Goal: Develop recommendations/protocols for managing infants in with extended stays in the NICU.

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:

- Extended stay was categorized as any infant with a hospital stay of 31 days and longer
- Revise the VISITS Hospital Pending Report by adding a column for NICU stay designation. This column can only be checked/selected when the hospital stay is at 31 days and longer.
- Develop a new letter from VDH EHDI for parents of infants with an extended stay.
- Revise VISITS to incorporate this letter.
- Letter will be generated, printed, and distributed by the hospital discharging the child to home, at the time of discharge. (This will ensure families receive the necessary communication from VDH, with appropriate resources, and also ensure that families whose children expire do not receive letters from VDH. This process will require hospital participation and "buy-in".)

Next steps:

- Revise VISITS to add a NICU stay designation.
- Develop letter.
- Collaborate with Virginia Hospital Healthcare Association (VHHA) representative on revision recommendations.
- Develop process and implementation recommendations.
- Develop a requirements document for additional revisions to VISITS, based on recommendations.
- Provide training to hospitals and stakeholders on use of NICU letter.

Health Disparities Workgroup

No one attended the Health disparities workgroup discussion.

The next meeting will be held in March 2014. No date was set

2:43 adjourn