## SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program
Virginia Department of Health
March 14, 2014

Draft

The following persons attended the meeting: Nancy Bond, Wanda Council, Darlene Donnelly, Leslie Ellwood, Kathrine Gangeri, Scott Gregg (CARTS), Ann Hughes, Valerie Luther, Daphne Miller, Debbie Pfeiffer, Lisa Powley, Irene Schmalz, Heather Strang, Sara Varner, Carol Weigle

Daphne Miller 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

No update

#### VNOC

Ann Hughes announced there had been 20 applicants for VNOC services so far this year. The annual Opening Doors Unlocking Potential Conference will be held July 29 & 30, 2014 in Charlottesville, Virginia.

# **Early Intervention**

No update

# **Newborn Screening**

No update

# Virginia Hearing Aid Loan Bank

Since 2005 there have been 819 applications for aids. In 2013 there were 104 and so far in 2014 22 applications. This included 96 one year olds and some children aged 3-10. The average loan time is 9 months with a 3 month extension. Once the warranty has expired on an aid it can be given to schools if they make a request.

# **Children with Special Health Care Needs**

Sidnee Dallas reminded the committee they are funded by HRSA. At the end of January, she and the office director met with the leadership of HRSA to discuss the future of the grant for their program. She is in the process of rewriting the grant to be submitted in July, 2014. This will include a section on EHDI. She will meet with Ruth Frierson, Program Manager for EHDI, to define what is needed.

## **Guide by Your Side**

Irene Schmalz distributed a summary of the program accomplishments as of March 14, 2014. Since August 2012, 150 families have been served. They are having a Guide training in April. The Tidewater area seems to be the most in need of Guides. Most referrals are from Northern Virginia followed by the Southeastern Virginia area. There will be a Meet and Greet on Saturday, March 29<sup>th</sup>, 2014 from 10 AM to 12 PM at the South County Public Library located on 6603 Merriman Road in Roanoke, VA 24018. Enrollment has been low for this event. A link to the videos of parents that have made a variety of communication choices can be viewed on the Center for Family Involvement website. A Sign Language brochure is still under development. Dana Yarbrough and Irene Schmalz will present at the National EHDI Conference in Jacksonville, Florida on Successful Strategies for Supporting Families. The next Meet and Greet is scheduled for 10/18/2014 in Chesterfield at John Tyler Community College in Chesterfield, Virginia.

## **Hands & Voices**

No update

#### **VSDB**

No update

# **Department of Education**

Wanda Council reported that DOE disseminates information to schools that will be of benefit to their students.

# Virginia Deaf/Blind Project

Valerie Luther stated it is a requirement of the Deaf Blind Project to send out an annual census. Getting results back is difficult. If a child has more issues than deaf/blind, it can be difficult to find them.

# **VDH** Updates

Kathrine provided updates on her projects:

- Currently averaging about 45-50 calls per week for failed initial screenings to parents. This number reported does not include additional calls to PCPs and hospitals as is often necessary.
- Working extensively on the EHDI Conference poster presentation titled: **Getting Down to Details, Building Awareness through Social Media.** Ruth Frierson and Kathrine will be presenting the poster on Monday of the conference (April 14) if anyone will be in attendance and wants to stop by, our location should be listed in the EHDI program. If at all possible at the next Advisory Committee meeting in June, we will attempt to bring the poster.
- Site visits have been completed to Langley Air Force Base, Virginia Hospital Center and Inova Loudoun Hospital. Three more site visits will be scheduled prior to August 31.
- Have continued acquisition and dissemination of relevant content for Facebook and measurement of results. To very broadly summarize currently, we are approximately 3,243 "Likes" (which means that we have that many followers) and then our average monthly "Reach" which is the number of unique visitors who have seen one of our

postings is approximately 38,000 people – and that is per month. As always, we invite Advisory Committee members to email us anything you feel would be important to post and we will take suggestions under consideration

Daphne provided updates on behalf of Antoinette Strayhorn, EHDI Follow-up Specialist II. Six facilities have been identified for possible site visits. One visit to Langley Air Force Base was completed. The next visit to Children's National Medical Center is scheduled on March 31, 2014. Four additional site visits to audiology facilities will be scheduled. Currently EHDI is drafting an "out of compliance" letter for facilities that have received notification about reporting results through VISITS and have failed to comply. The audiology and ENT training modules will be available after revisions are made.

## **HRSA Grant**

EHDI is applying for a new competitive grant cycle 2014-2017. Funds for this grant were reduced by \$50,000. Primary focus of this grant is improving follow up through small system changes using the Plan Do Study Act (PDSA) methodology.

#### **CDC Grant**

EHDI continues to work with OIM to complete the VISITS/VIIS linkage and the automated referral process to Early Intervention.

**Hearing Loss Outcomes**: Diagnosed from 01/01/2013 to 12/31/2013, Reporting Facility All Facilities, Hearing Los Status Permanent

	Total	Before 6 months	Between 6 & 12 months	After 12 months	Unknown diagnosis date
Total number Diagnosed with Hearing Loss	184	121	33	30	
Enrolled In Part C	72	50	13	9	
Linked to Family-to-Family Support	86	47	26	13	
Fit With Hearing Aids	40	22	16	2	

# Hearing Loss Referrals Diagnosed from 01/01/2013 to 12/31/2013, Reporting Facility All, Hearing Los Status Permanent

	Total	Before 6 months	Between 6 & 12 months	After 12 months	Unknown diagnosis date
Total Number diagnosed with hearing loss	184	121	33	30	
Referral to Part C	184	108	38	33	5
Linked to Family-To-Family Support	86	47	26	13	
Referred to Otolaryngologist	73	54	10	9	
Referred to Ophthalmologist	13	10	2	1	
Referred to Genetics	8	5	3	0	

The Committee asked: Where are the children that are not enrolled in Part-C? EHDI requests enrollment information on all children referred. However, not all local Part-C systems provide this information. The enhancement to VISITS will provide automated referrals to each system and will provide each system with an automated method to report enrollment information on each child referred to them by EHDI.

Sara Varner, Epidemiologist at the Virginia Department of Health, presented the 2012 VEHDI data, submitted to CDC. There are about 100,000 births a year. In 2012 98.3% of all infants born in Virginia were documented as screened. 99.2% of hospital born infants were screened before discharge. In 2011 16.7% were lost to follow up. In 2012 8.3% were lost to follow up. 108 children had a bilateral hearing loss (67%) and 53 were diagnosed with a unilateral loss (33%). EHDI's next step is to examine JCIH risk factors for late onset hearing loss and explore cases of transient and unknown hearing loss further.

## **Public Comments**

None

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## **CDC Grant**

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## **EHDI Workgroups**

There were no workgroup meetings on March 14, 2014.

Meeting adjourned at 1:16 pm.