

Virginia Early Hearing Detection Intervention Advisory Committee Meeting

Friday, June 3, 2022, 10:00 AM-3:00 PM

Hybrid Meeting

Virginia Hospital and Healthcare Association

[4200 Innslake Dr Suite 203, Glen Allen, VA 23060](#)

<https://vdh.zoom.us/j/92139891729>.

Attendees: Valerie Abbott, Marcus Allen, Judy Alonzi, Robin Bliven, Wanda Council, Patty Eitemiller, Christen Eubanks, Ashleigh Greenwood, Alison King, Terri Nelligan, Kara Norcross, Ira Padhye, Eric Raff, Irene Schmalz, Tracey Yurechko

Interested Parties: Shirley Blake, Lisa Eickel, Valerie Luther, Eileen McCartin, Lynn Odom, Julie Saum, Silvana Thorpe

VDH Staff in Attendance: Katherine Barrett, Christen Crews, Deridra Few, Daphne Miller, Rafael Randolph, John Rogan, Deepali Sanghani, Sukhmani Soni, Antoinette Vaughan

Interpreters: Bernice McCormack & Elaine Hernandez

Advisory Committee Business: Meeting called to order at 10:02 am

Introductions/Roll Call

Co-Chair Valerie Abbott

Review of Agenda

Chair: Ashleigh Greenwood

Agency Standing Updates

The VA Network of Consultants (VNOC)/ Partnership for People with Disabilities:

T. Yureckho

- Opening Doors - Unlocking Potential: Practices in Perseverance to Inspire Possibilities registration is now open until June 6, 2022. Several sessions that might be of interest to parents and Early Intervention (EI). If you are interested in viewing information regarding ODUP and registering for this event, please visit the website. Virginia Network of Consultants continues to support school divisions across the Commonwealth. If you want to keep up with events happening at the TAC-DHH, please complete the following form: <https://airtable.com/shrgJBAmME9gYXjWz> to join our weekly mailing list.

Infant and Toddler Connection of Virginia/Early Intervention:

T. Nelligan

Updates for the Infant & Toddler Connection of Virginia:

- In the process of implementing a new Early Intervention data system, Tracking, Reporting, and Coordinating for Infants & Toddlers (TRAC-IT) which will become the new Early Intervention system of record and replace ITOTS. The Early Intervention program's needs for analysis of program trends and costs will be met with the new data system. As you can imagine this is a big undertaking and includes a lot of time from the state and localities.
- In the process of creating a data sharing agreement with VDH/VEHDI with assistance from DaSY, a national Part C Technical Assistance group.
- Working to enhance the statewide system's ability to provide services to children who are deaf or hard of hearing by providing technical assistance to a local early intervention system which is creating a "clearinghouse" for providers which will allow other interested local early intervention systems to contract with the clearinghouse to purchase services from providers who are trained and experienced in language development in the DHH 0-3 population. Grafton Specialty Services Program will be presenting information about its program at the upcoming Unlocking Doors conference coordinated by the Partnership for People with Disabilities this summer. GSSP will begin to recruit providers of early intervention services who have expertise working with the deaf and hard of hearing soon after. GSSP will also be presenting information about their new program at upcoming regional meetings for local system managers and inviting each to contract for services beginning in late summer early fall.
- Represented on the deaf mentor project which is creating a program for deaf mentors who use American Sign Language. 15 deaf mentors and one program coordinator will be selected to begin the program.

Newborn Screening (Dried Blood-Spot and CCHD):

C. Crews

The Newborn Screening program has no major updates, but the implementation of testing for SMA and XALD started March 2022. The Newborn Screening Program is in the process of recruiting for both a senior nurse and short-term follow-up nurses. The NBS dried-blood spot Program is in the process of rebranding the program from “Virginia Newborn Screening Program” to “VA Newborn Bloodspot Screening Program” to decrease confusion with stakeholders as there are multiple newborn screening programs within VDH.

Virginia Hearing Aid Loan Bank:

L.Powley

The Virginia Hearing Aid Loan Bank has received ten (10) applications from parents for hearing aids. Additionally, the program is preparing to purchase new hearing aids.

Children and Youth with Special Health Care Needs (CYSHCN):

M. Allen

Covid had a big impact on the CYSHCN program. CYSHCN is currently working with hospitals in the state to help bring numbers back up, working hard to get numbers back to where they were in 2019 prior to COVID. The data shows that the program could do a better job reaching out to more rural families and minority groups. A statewide dashboard was created to view data.

Center for Family Involvement at VCU-Family to Family

I. Schmalz

€ **Family-to-Family Support:**

- Twelve families were referred by the EHDI program to the 1-3-6 Family Educators and information collected from the 1-3-6 Family Educators matched with the families were entered into VISITS shared plan of care.
- **1-3-6 Family Educator updates**
 - The CFI and EHDI program are piloting a 1-3-6 Family Educator with cCMV experience. Lisa Eickel joined the project this reporting period.
- **1-3-6 Family Educator meetings and events attended**
 - March 13 – March 15, 2022 EHDI Conference
 - April 21, 2022 VNOC
 - April 24, 2022 Virginia EHDI Stakeholders Meeting
 - May 17, 2022 (1-3-6 FE Virtual)
- **Diversity, Equity and Inclusion training:**
 - 48 EHDI stakeholders completed the DEI training provided by the Center on Inclusive Communities and VA EHDI program.
- **Family Materials:**
 - cCMV presentation to CFI and PPD staff slated for early Fall. A Spanish version about cCMV will be developed by Fall.
 - 1-3-6 FE will invite more Spanish speaking families to participate in the Caminos virtual group based in Richmond.

- Closed Facebook group has been created for parents, caregivers with children diagnosed with hearing loss. The name of this FB group is called: Virginia Families of Children with Hearing Loss, Deaf or Hard of Hearing. Invitations to parents, caregivers will be emailed by June 6, 2022.
- Questions: Please contact Irene Schmalz at ischmalz@vcu.edu

Virginia School for the Deaf and the Blind (VSDB):

R. Bliven

The Virginia School for the Deaf and the Blind is gearing up for the next school year. VSDB plans to create a YouTube channel and add videos using American Sign Language (ASL). A big focus next year will be on ensuring VSDB has resources for ASL classes. VSDB is preparing and working on outreach efforts for the 2023 school year.

Lindsey Richard is on leave and will be back in October 2022, all emails should go to Robin Bliven.

Virginia Department of Education

W. Council

HB 649/SB 265 Children who are deaf or hard of hearing; language development, assessment resources - This new legislation becomes effective July 1, 2022.

· “Requires the Department of Education, in coordination with the Department for the Deaf and Hard-of-Hearing and the Department of Behavioral Health and Developmental Services, to:

- select, with input from an advisory committee that the bill establishes, language developmental milestones and include such milestones in a resource for use by parents of a child from birth to age five who is identified as deaf or hard of hearing to monitor and track their child's expressive and receptive language acquisition and developmental stages toward English literacy;
- disseminate such resource to such parents;
- select existing tools or assessments for educators for use in assessing the language and literacy development of children from birth to age five who are deaf or hard of hearing;
- disseminate such tools or assessments to local educational agencies and provide materials and training on their use; and
- annually produce a report that compares the language and literacy development of children from birth to age five who are deaf or hard of hearing with the language and literacy development of their peers who are not deaf or hard of hearing and make such report available to the public on its website.”

Upcoming meetings:

- Opening Doors-Unlocking Potential 2022: “Practices in Perseverance to Inspire Possibilities”, June 22-24, 2022 - This virtual event is Virginia’s 16th annual professional development institute for professionals and parents/families who support students who are deaf and hard of hearing. A variety of session topics focusing on effective strategies to positively impact literacy development and academic outcomes for students will be presented.
- Creating Connections to Shining Stars 2022 - July 19-21, 2022 (Hotel Roanoke & Conference Center & Virtual) - This hybrid conference is a collaborative event among Virginia's Part C, Early Intervention and Part B, Preschool Special Education programs. The focus will be promoting and supporting the implementation of evidence-based practices in inclusive settings for infants, toddlers, and young children, both with and without disabilities.

Virginia Deaf-Blind Project:

I. Padhye

Completed child count with 20 new identifications of children for the Deaf-Blind Project.

Virginia Department for the Deaf and Hard of Hearing (VDDHH):

E. Raff

Eric Raff mentioned that he brought Lynn Odom, who is involved with setting up the deaf mentor program and taking over the role as the supervisor of the deaf mentor program as of April 25, 2022. VDDHH is fully staffed with just one vacancy.

VDDHH is recruiting a Support Service Provider (SSP) for deaf blind children in schools in order to provide intervention services. This is designed to support children after school and to help them live independently.

The Deaf mentoring project is in the development phase and in the process of being set up. VDDHH is in the process of interviewing for a deaf mentor coordinator. The plan is to recruit 15 deaf blind mentors between July and August and provide training in October. The Deaf Mentor Project will be up and running hopefully by November. Additionally, the plan will include cued speech, Listening and Spoken Language (LSL). The Coordinator would most likely be a deaf adult but does not have to be.

Eric Raff is working on securing a RFP for caption services for post-production videos, live meetings, and virtual meetings.

Virginia Chapter of Hands & Voices:

T. Urban

Virginia Hands & Voices continues to provide unbiased support to families across the Commonwealth, mostly through a virtual connection. To date, we have held five events in 2022, which continues to average about one event per month. We have received very positive feedback from virtual panels and roundtable discussions with deaf and hard of hearing adults. These virtual events have been very well attended and we have received requests for more of this type of programming.

Some second quarter highlights include a virtual happy hour, a virtual presentation focusing on siblings of DHH children, a fundraising event at Chipotle in Roanoke, and a virtual panel of Deaf adults discussing the importance of social/emotional health among DHH children. We have also been working closely with the Deaf Mentor Program team to bring this program to Virginia. We hope to launch the program in the late fall and offer the SKI HI training to Deaf Mentors in October. We are eager to provide services to families and continue to receive multiple requests per month from families and professionals seeking the support of a Deaf Mentor.

Looking ahead, we will be gathering at an outdoor amphitheater in Alexandria for the play, *Birds of a Feather*, and presenting at the Opening Doors Unlocking Potential Conference in late June. Our Board of Directors will be meeting at the end of the quarter to finalize details about a workshop we plan to host in Roanoke, and possibly Northern VA, at the end of October/early November. Families are constantly searching for answers when it comes to educational advocacy and we are hoping to provide a four-hour workshop designed to support parents along their journey in the educational system, social/emotional health, etc.

While many of our events continue to be virtual, we look forward to meeting folks in person once again. Connecting virtually certainly has its down-side, however, it has allowed us to connect with so many more families and professionals of DHH children across the Commonwealth on a more regular basis.

Review of Meeting Minutes

A review of minutes from the last six (6) meetings. Minutes were voted on and approved for the following meetings:

- March 6, 2020
- December 4, 2020
- June 4, 2021
- September 10 2021
- December 3, 2021
- March 4, 2022

All members (11 members) approved pervious meeting minutes with a physical quorum present on-site.

Voting VA EHDI Co-Chairs

A.Greenwood

Ballots were distributed to AC members to vote for the VA EHDI Co-Chairs. Votes were collected and tallied. Judy Alonzi and Valerie Abbott were announced as the new Co-Chairs effective September 9, 2022.

EHDI Regulatory Review

EHDI AC Committee

Christen Crews introduced the regulatory review process which can take 18-24 months.

The AC member's discussed and voted to amend Chapter 80 regulations title to: "Regulations for Administration of the Virginia Early Hearing Detection and Intervention (VA EHDI) Program and Information Monitoring System" - accepted by all (11 members)

Vote and discussion to amend definitions as below (12VAC5-80-10):

- Auditory brainstem response (ABR)- **“objective measurement of the activity of the cochlea, auditory nerve, and auditory brainstem pathways. For use in NICU and/or well baby nursery”**
- At risk means considered to be in a status with a significant probability of having or developing hearing loss as a result of the presence of one or more factors identified or manifested at birth **or soon after birth.**
- Audiological Evaluation - **“means those physiologic and behavioral procedures required to evaluate hearing, identify hearing status, and diagnose hearing loss”**
- Addition of : cCMV- means congenital cytomegalovirus

- **Failed newborn hearing screening means the final newborn hearing screening that resulted in a fail in one or both ears prior to discharge from hospital or other birthing place or center**
- **OAE “an objective measurement of cochlear outer hair cell function. For use in the well baby nursery.**
- **Part C- full statement reads as “means the state early intervention services program that provides developmentally necessary speech and language therapy,.....”**

Public Comment

Terri Nelligan would like to give a special thanks to Ashleigh Greenwood for her role as chair to the AC for two terms.

EHDI Programmatic Updates

D. Miller/D. Sanghani/ A. Vaughan

The EHDI program is in the 3rd year of the HRSA grant. The Statewide Learning Community meeting is postponed to early Fall 2022. The EHDI program has three (3) new interns, Ayanna Cheek, Deridra Few, and Sukhmani Soni. The EHDI program facilitated the Workplace Diversity, Equity, and Inclusion training sessions with Virginia Center for Inclusive Communities (VCIC). The results were reviewed from the Diversity and Inclusion survey conducted on EHDI AC members and interested parties at the March 2022 EHDI AC meeting.

VA EHDI program staff discussed available resources for families of children who are deaf or hard of hearing. The VA EHDI program has iPads available for families. These iPads will be available while supplies last. Free online American Sign Language (ASL) classes are also offered through ASL Connect at Gallaudet University.

VA EHDI reviewed stakeholder outreach. Six new OAE machines were distributed to out of hospital birthing centers and 2 remain to be distributed. Birth center outreach and virtual hospital site visits are ongoing. Three virtual site visits were done in April and one in May

Events and activities:

- March 13-15 2022 virtual EHDI Annual Meeting
- April 5-6 virtual NYMAC
- April 8-9 virginia Society of Otolaryngology
- June 22-24 virtual Opening Doors Unlocking Potential
- July 19-21 Creating Connections to Shining Stars

Parent Story

S. Thorpe

Silvana Thorpe shared her family story and journey with her child's screening and diagnosis process with the Advisory Committee.

cCMV Updates

D. Sanghani

Targeted CMV screening was implemented in September 2020. There are a few brochures on the VA EHDI website. PCPs are being encouraged to get access to VISITS. Ongoing outreach with parents regarding child's results and follow ups (letters and phone calls). The following data was presented for January 1, 2021 to December 31, 2021:

- 3,255 children received CMV Screen
- 3,046 had a result of Not Detected
- 172 had unsatisfactory specimens
- 37 had a result as detected
- 66 children received Confirmation testing
- 5 children were confirmed to have cCMV on urine CMV PCR.

EHDI Regulatory Review Continued

Reviewed and discussion on the following:

- Definition of Part C: means the state early intervention services program that provides developmentally necessary speech and language therapy, occupational therapy, physical therapy, and assistive technology services and devices for children from birth to age three who are eligible for services under Part C of the Individuals with Disabilities Education Act (20 USC §§ 1431-1444) and Virginia law.
- 12VAC5-80-75- Risk Indicators:
 - B: **Change to Committee from Group**: "The Virginia EHDI Program Advisory Committee ~~group~~ shall provide guidance with the development and maintenance of the list of specific risk indicators."
 - C: **Change to review as needed from biennially, remove more frequently and add THE to JCIH**: "The list of specific risk indicators shall be maintained in a guidance document, which shall be reviewed **as needed** *at a minimum biennially*. The list of specific risk indicators may be changed or amended *more frequently* as needed to reflect changes in standards of care or updates **to the Joint** Committee on Infant Hearing recommendations."
 - Review and discussion on incorporating JCIH risk factors for early childhood hearing loss table, possibility of including table in packet. Consensus from the committee to keep section D as is in regulations.

- 12VAC5-80-80: Responsibilities of Chief medical officer
 - 1: **change wording and remove words as follows:** 1. **Ensure** ~~Cause~~ that all infants ~~receive~~ ~~should to be given~~ a hearing screening test prior to discharge ~~after~~ ~~birth as appropriate for the level of newborn services provided as defined in~~ [12VAC5-410-443](#) B of the Regulations for the Licensure of Hospitals in Virginia.
 - A: **change language to:** “VDH recommends the use of automated instrumentation that provides a pass/fail outcome as the initial hearing screening device for hospitals.” And remove the existing language : “*Infants in general or intermediate newborn services shall have both ears screened at the same time for hearing using either ABR or OAE testing prior to discharge after birth, but no later than one month of age.*”
 - B. **Change language to:** “The two methodologies generally considered as effective for universal newborn screening are: Auditory brainstem response (ABR) and Otoacoustic emissions (OAE) (as defined in 12VAC5-80-10)
 - 2A: **Change to add the bold words in existing text:** “Infants who fail initial hearing screening in one or both ears using ABR testing shall not be rescreened using OAE testing. Infants who fail rescreening shall be referred for an audiological evaluation.”
 - 2B: **Change to add the bold words in existing text:** “Infants who fail initial hearing screening in one or both ears using OAE testing may be rescreened using OAE or ABR testing. If the infant fails subsequent testing in one or both ears, the infant shall be referred for an audiological evaluation.”
 - 3.. **Change language to:** “For infants who did not receive a hearing screening due to transfer to another facility, only the hospital discharging the infant to home should report the infant’s hearing screening results. Remove the existing language: “written notification shall be made upon transfer to the health care provider in charge of the infant's care that testing was not completed. The hospital discharging the infant after birth is responsible for conducting an appropriate hearing screening test, except for infants who have been transferred to a lower level of newborn service care from another facility providing neonatal intensive care services to that infant for more than five days.”
 - **Change language to add and remove words as follows:** “**Ensure** ~~Cause~~ all infants are ~~to be~~ assessed for risk indicators associated with hearing loss prior to discharge after birth as defined in [12VAC5-80-75](#).”
 - 4a. **Change the language as follows add and remove:** “For infants who pass hearing screening and are found to have one or more risk indicators associated with hearing loss, inform the parent of the need for a diagnostic audiological assessment ~~by~~ between 12 to 24 months of age, or as recommended by the JCIH”

- **4b: “ For infants who fail hearing screening and are found to have one or more risk indicators associated with hearing loss, inform the parent of the need for a rescreening or diagnostic audiological assessment immediately. Additionally an audiological assessment between the ages of 12 to 24 of months should be completed, or as recommended by the JCIH.”**
- **Add JCIH definition: “JCIH” refers to the Joint Committee on Infant Hearing.**
- **Stopped Regulatory review at 4B of Section 12VAC5-80-80**

Next meeting: September 9, 2022 at Virginia Hospital Healthcare Association.

Adjournment

Meeting adjourned at 3:01 pm