

Virginia EHDI Program Advisory Committee Meeting

Friday, September 10, 2021

Meeting Minutes

Attendees: Valerie Abbott, Marcus Allen, Judy Alonzi, Wanda Council, Patricia Eitemiller, Christine Eubanks, Ashleigh Greenwood, Alison King, Terri Nelligan, Kara Norcross, Lindsey Richard, Alison Roepke, Irene A. Schmalz, Teri Urban

Interested Parties: Shiley Blake, Diana Caicedo, Tom Dowling, Mary Lynn Jones, Katrina Means-Reinecke, Chrissy Owens, Ira Padhye, Tracey Yurechko, Katherine Crawford, Samantha Clark

VDH EHDI Staff in Attendance: Parker Brodsky, Daphne Miller, Dora Opoku, Rafael Randolph, John Rogan, Deepali Sanghani, Antionette Vaughan,

DCLS Staff: Leigh Emma Lion

Valerie Abbott called the meeting to order at 9:00am. A review of the agenda was presented and approved. Minutes of the June 4, 2021 meeting were approved.

Standing Updates:

VNOC/Partnership for People w/Disabilities: T. Yurechko

- Completed seven (7) vnoc request and currently have two (2).

Early Intervention: T. Nelligan

- The Infant & Toddler Connection of Virginia (ITCVA) action report series focuses on efforts underway to improve the long-term sustainability of Virginia's Part C early intervention system. You have told us about the fiscal challenges and provider shortages you are facing on the local level. We hear you, we understand you, we appreciate your hard work, and we are working on your behalf every day to address these challenges. These are challenges we have faced and successfully addressed before in the ITCVA, and we can do it again by working together and focusing on actionable strategies to make improvements.

Actions to address Medicaid managed care challenges:

- DBHDS is continuing to work with DMAS to address ongoing challenges with securing interpreter services through some MCOs.
- The EI-MCO Workgroup convened by the Virginia Association of Community Services Boards (VACSB) is meeting quarterly, and will host a training on Part C for MCO care coordinators on July 19, 2021.

- Actions to address provider shortages:
- Virginia’s telehealth flexibilities established in the March 19, 2020 Medicaid Memo, including those related to early intervention, remain in effect and are expected to continue through the end of the federal public health emergency. Although the federal public health emergency order can only be reauthorized in 90-day increments, the U.S. Secretary of Health and Human Services has indicated in a letter to Governors the intent to continue the federal public health emergency through December 31, 2021.
- DMAS has posted for public comment proposed manual updates outlining policies for the permanent use of telehealth, including for early intervention. These new policies offer an exciting opportunity to maximize the accessibility of early intervention. They are available for public comment through June 23, 2021.
- Because of suggestions from the Infrastructure Work Group, the ITCVA state office has eliminated the requirement for certified practitioners to maintain a professional development plan and streamlined the documentation required to show completed training.

Actions to address broader fiscal picture:

- The Infrastructure Work Group is meeting every other month, with members sharing information with and soliciting input from constituents between meetings. Recent work has included the following:
 - Reviewed all Part C forms and identified changes to consider as we work with the selected vendor to incorporate our forms into the new statewide data system.
 - Gathered information from other states that use a regional or shared services approach for some or all aspects of Part C early intervention.
 - Currently analyzing across local systems the costs and revenues associated with system components (administration, system management, public awareness, training, etc.) to understand what helps keep these costs down.
 - Discussing how a shared services approach for some functions may (or may not) help to reduce costs and/or improve the system. Meeting notes and materials are available here.

National fiscal updates:

- Virginia is receiving \$5.1 million in American Rescue Plan (ARP) funding for Part C. These are one-time funds we expect to receive July 1, 2021. While we are still waiting for official written guidance from the U.S. Department of Education on use of these funds, indications are that they can be used for all the same purposes as our regular federal Part C funds. We will share additional information as soon as we receive the federal guidance and clear any state-level approvals, if required.

Newborn Screening: C. Crews

- The NBS Dried-Blood Spot Program is transitioning to new leadership, with Mary Lowe, RN, as the new Nurse Supervisor. The previous supervisor, Christen Crews MSN, RN has transitioned to the Program Manager of Newborn Screening and Birth Defects Surveillance Programs, previously held by Jennifer Macdonald.
- The program is in the process of a periodic regulation review in addition to the active regulatory action to add two disorders, Spinal Muscular Atrophy (SMA) and X-linked Adrenoleukodystrophy (X-ALD) to the core NBS panel for Virginia. The NBS-DBS program is also in the process of recruiting new nurses because of vacancies due to retirement and promotions.

Virginia Hearing Aid Loan Bank: L. Powley

- To date, 1485 children have used the loan bank. Just completed purchasing new aids and the updated inventory is posted on the HALB application.
- Everyone is very appreciative that due to covid we have extended the loan period to a year instead of 6 months. During covid the number of applications have not decreased.

Children & Youth with Special Health Care Needs: M. Allen

- September is sickle cell awareness month
- Proposal requested for an adult clinic
- Updating work plan for fiscal yr 2022 to put more focus on diversity and equality. Then use that data to help the people we are not reaching.
- Helping to fund hearing aid loan bank. Kara Norcross would like to join and help.
- Some clinics had to shut their doors because of covid.

Virginia School for the Deaf and the Blind: R. Bliven

- Started role in July 12th just moved here from North Carolina
- Set up membership for online itinerants. Each teacher granted membership to every family on their caseload.
- Working on workshop for autism

Department of Education: W. Council

- Launched Healthy Back-to-school website
- Focusing on early childhood education

Deaf-Blind Project: I. Padhye

- 3 new infants enrolled

Virginia Department of the Deaf and Hard of Hearing: E Raff

Learn the Signs. Act Early: D Buck

- No update

VA EHDI Update:

Went live with texting in 2018, trying to think of outside the box ways to communicate with our families.
ASL Connect Summer Session

- Began on May 30, 2021 and completed on July 24, 2021.
- 12 families participated and 96 live sessions were held.
- On average: participants frequency of ASL use throughout the day with child
 - Prior to 1st session: 71% “few,” 23% “sometimes,” and 6% “all the time”
 - After last session: 24% “few,” 42% “sometimes,” and 34% “all the time”
- Survey asked 4 questions about The Connector and 100% of respondents were positive about The Connector.
- 92% of 13 respondents felt the 30-45 minute session length was “just right.”
- 100% of 15 respondents indicated a “very positive” experience with the program.
- Out of 12 respondents, 17% were “satisfied” with the Care Packages and 83% were “very satisfied.”
- Of 13 respondents, 100% would recommend other families to participate in the program.

JCIH 2019 revised guidelines

- Preterm NICU infants at 3 months with prolonged hospitalization have diagnostic eval prior to discharge from NICU
- Infants identified as deaf/hard of hearing could then be referred directly for EI or audio follow up at time of discharge
- Hospitals/agencies should designate a physician/provider to oversee medical aspects of EHDI program

iPad distribution for children with hearing loss

- VA EHDI has 100 ipads for families that do not own a personal computer. The iPads will be used to learn ASL from online classes.

Virtual Lunch and Learn 3 – Part Series

- Meet the Geneticist: September 14
- Meet the Audiologist: September 22
- Meet the Otolaryngologist: September 29

VA EHDI DATA 2020:

- Total births: 97,400
- Total documented as screened: 95,424
- Total screened before 1 month: 93,214 (97.7% of infants screened)
 - Total pass overall: 93,719
 - Total did not pass (initial and rescreen): 1,705
 - *Approximately 3,000 did not pass initial*
 - Total Documented as Not Screened: 1,976

Total Not Screened

- Total not screening: 1705
- Lost to follow/up: 1,321

Diagnostic Data

- Total number that failed both initial and rescreen and are in need of diagnostic evaluation: 1,705
- Total with no hearing loss: 822
- Total diagnosed with permanent hearing loss: 107
- Total with non-permanent, transient hearing loss: 173

No Documented Diagnosis

- Total Without Diagnosis: 776
- Total Lost to Follow/up: 687

Intervention Data

- Total Cases of Permanent Hearing Loss: 107
- Total referrals to Part C EI: 107
- Total enrolled in Part C EI: 56
- Total enrolled before 6 months: 47
- Total enrolled after 6 months: 9

Public Comment:

No public comments

Parent Story – Katrina Means-Reinecke

Pregnancy and birth

- Normal pregnancy Heartburn/morning sickness
- Cold flu illness at around 6/8 weeks gestation
- Birth at 39 weeks via C-section July 2020
- No birth complications
- Was not tested for CMV at or prior to birth

Diagnosis

- Failed newborn screening test in right ear twice
- Multiple hearing test while awake-inconclusive
- Sedated ABR in January 2021 concluded right moderate to moderate – severe sensorineural hearing loss in right ear
- Minimal information from pediatrician/advocated for kidney ultrasound

Hearing aid acquisition

- Received Oticon hearing aid in March 2021
- Minimal support/ information provided
- Retention issues

Medical Care

- Multiple appointments (audiologist, ENT ,Ophthalmologist , Geneticists)
- Denied genetic testing by insurance/large cost share for hearing aids
- Speech therapy 30 minutes every other month (private)
- Early Intervention Services provided through IFSP 8 hours every 6 months

Medical Conditions

- Recently diagnosed eye conditions (amblyopia, hyperopia, anisometropia)
- Awaiting results for genetic testing
- Usual labs for metabolic panel / retest in one week (extremely low aldosterone, low iron, high alkaline phosphatase and high A/G Ratio)
- MRI and hearing test are not showing correlating information / sedated ABR in 2 weeks
- Audiologist and ENT have started to explore option of unilateral cochlear implant

Services

- Enrollment in EI
- Enrollment in military based special needs program
- Exceptional Family Members Program (EFMP) – no available services
- Tricare ECHO program-qualified for enrollment but have no services
- Child Care Connection
- Attempted Medicaid Waiver-Denied

Need for Services

- Therapy provided per month maximum 1 hr and 30 minutes
- ASL sign language
- Intensive therapy for retention of hearing aid and other durable medical equipment
- Lack of services for hearing loss compared to other diagnosis that display similar symptoms and delays example Autism
- Financial assistance/grants approval based on high household income

Workgroups Overview:

JCIH Workgroups

- Legislative Workgroup
- Parent Perspectives/Quality Improvement
- JCIH Workgroup
- ENT Workgroup

Next Advisory Committee meeting is December 3rd, 2021

Meeting adjourned at 11:25 am.