Language Development Milestones and Parent Resources for Young Deaf/Hard of Hearing Children

Joint Commission on Health Care September 4, 2019 Meeting

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Study Mandate – SB 1741

- SB 1741 (Senator Edwards) focused on Deaf or hard of hearing children 0-5 years old
 - Would have required stakeholder-involved process to create parent/educator resources
 - Would have required annual language milestone assessments and results reporting on deaf or hard of hearing children 0-5 years old
- SB 1741 was PBI'd in Education and Health and sent to JCHC for consideration

Background

Hearing Loss: Low incidence condition with historically high risk for language delay

- Incidence
 - 2-3 newborns per 1,000 experience hearing loss
 - By kindergarten, estimated 6 children per 1,000 in U.S. are D/HH*
 - 90-95% of D/HH children born to hearing parents
 - 130-170 children 0-3 years old in Virginia diagnosed annually with hearing loss (2011-2016)
- Historical impacts on spoken language development
 - Any degree of hearing loss raises risks of language/literacy delay
 - Most D/HH children arrive at kindergarten language-delayed
 - Median reading ability of D/HH 12th graders is at 4th grade level; 10% with age-appropriate language skills (2000 study)

Early language development positively affects overall development*

- Language is a system of communication
 - Examples: American Sign Language (ASL), English
- Language is different from communication modality
 - Language can be expressed in auditory, written and visual forms (e.g., spoken English (aural/oral), written English)
- Consensus exists that acquisition of any language:
 - Is foundational to literacy (in any language) and broader social-cognitive development
 - Must begin early in life for full potential to be realized

Opportunities for D/HH children to acquire spoken language have expanded*

- Main communication options for D/HH children include:
 - Sign language (e.g., ASL)
 - Spoken (oral-aural) language with or without visual supplements
 - Historically, low success rate for children with severest hearing loss
 - Written language (e.g., English)
- Since late 1990s, success with non-signing options has increased
 - Driven by improvements in hearing technologies (Cochlear Implants, hearing aids)/earlier hearing loss detection
 - Not all D/HH children eligible for/successful with technologies
- To date, no consensus exists on which communication approach(es) are optimal for language development/literacy

Multiple state agencies provide services / supports for D/HH children and families*

Age			
0 1	2	3 4	5
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	Individualized Education Program (IEP)- based Early Childhood Special Education (ECSE); (VDOE; The Virginia School for the Deaf and the Blind (VSDB))		
Virginia Hearing Aid Loan Bank (VDH)			
Virginia Project for Children and Young Adults with Deaf-Blindness (VCU)			
General information and referral services for the D/HH (VDDHH)			
VSDB outreach services (VSDB, VDOE)			
EHDI Learning Communities (VDH, VCU)			
1-3-6 Family Educator Program (VDH,VCU)			
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* See slide 43 – 47 of Appendix for additional detail

Data on Services/Supports for D/HH Children in Virginia

- Hearing screening/diagnosis
 - 98-99% of live births annually screened for hearing loss
 - Definitive diagnosis remains unknown for significant percentage of children with failed hearing screen
- Early Intervention (EI)
 - Annually, ~185-200 children 0-3 years old have hearing loss as eligibility reason
- Early Childhood Special Education (ECSE)
 - Annually, ~285-300 children 2-5 years old have deaf or hard of hearing as an eligibility disability category
 - % D/HH children transitioning from EI to ECSE unknown due to DBHDS EI data system limitations

Direct measures of language among D/HH children 0-5 years old not currently collected

- Individuals with Disabilities Education Act (IDEA) requires States to report on 3 broad child outcome measures for children with IFSPs/IEPs:*
 - Positive social-emotional skills
 - Acquisition and use of knowledge and skills
 - Use of appropriate behaviors to meet needs
- "Acquisition and use of knowledge and skills" is not a direct measure of language development

Literacy of young children with disabilities (including D/HH children) lags hearing peers

 Phonological Awareness Literacy Screening (PALS) kindergarten results:

• 3rd grade SOL English reading test results:



Source: VDOE

Considerations on Components of SB 1741

Major Components of SB 1741

- Development of Parent Resource*
 - Language development/literacy milestones (ASL, English)
 - Other information (e.g., communication, available services)
- Development of Educator Resource*
 - Language development/literacy assessment(s) (ASL, English)
- Integration of language milestone tracking into IFSP/IEP processes
- Report on language/literacy outcomes of D/HH children
 - Based on data collected from provider/educator assessments of language development/literacy
- DBHDS is identified as implementing agency, coordinating with VDOE and VDDHH

* To be developed with input of stakeholder Advisory Committee

Stakeholder Workgroup Input

- Stakeholder workgroup convened 4 times to discuss SB 1741 and related issues
 - Participants represented: 8 state agencies; 10 advocacy organizations; providers; D/HH persons; parents of D/HH children*
- Points of general consensus:
 - Early language acquisition is critical for full language and cognitive development, including literacy
 - Parents of D/HH children should be able to choose preferred language(s) and mode(s) of communication
- Points of continued disagreement:
 - Definition of language vs. communication modality
 - Need for additional Parent Resource
 - Composition/role of Advisory Committee
 - Need for language development data collection and reporting
- * See slide 49 of Appendix for additional detail

Considerations on Terms

- Several terms used in SB 1741 are subject to varying interpretations. Examples:
 - "English": can be spoken (oral), heard (aural), written
 - "Deaf": has clinical, functional, and cultural definitions
- Other terms commonly used by stakeholders have "industry" meanings. Example:
 - "Listening and Spoken Language": commonly cited communication modality (based on an aural-oral approach) and a branded provider certification system

Recommendation: If legislation similar in intent to SB 1741 is considered: 1) define key terms, including language, communication modality, forms of English, Deaf; 2) avoid branded terms

Considerations on Agency Roles in Implementation

- Expertise of DBHDS not specific to deafness; programming limited to children 0-3 years old
- VDDHH and VSDB agency missions relate more directly to D/HH persons
 - VDDHH's mission: promote accessible communication to D/HH persons
 - VSDB's mission (not identified in SB 1741): provide education to D/HH persons 0-21 years old
- VSDB's expertise most directly relevant to D/HH children
 - VSDB has preschool program (working to re-establish program for children 0-2 years old)
 - Supports language development in ASL, listening/spoken language
- VSDB estimated fiscal impact compared to DBHDS
 - VSDB: Years 1+2: ~\$120-\$130K; ongoing: ~\$26-\$40K
 - DBHDS: Years 1+2: ~\$200K; ongoing: \$33K

Recommendation: If legislation similar in intent to SB 1741 is considered: identify VSDB as implementing agency, coordinating with DBHDS, VDDHH, and VDOE to implement legislation's provisions

Considerations on Milestones and Language Development Assessments

- SB 1741 requires selection of "language developmental milestones from standardized norms"
 - Criterion unclear: standardization relates to process of administration; norms relate to type of assessment (e.g., "norm-referenced" vs "criterion-referenced")
- State-specific milestones would not be norm-referenced
 - Requiring milestone selection based solely on norm-referenced instruments could unduly limit choice of appropriate milestones
- Some commonly used instruments are not norm-referenced and/or standardized
 - Includes instrument recommended by Louisiana "LEAD-K Task Force"

Recommendation: If legislation similar in intent to SB 1741 is considered: modify basis for milestone selection (e.g., assessments that are "appropriate and technically sound")

Considerations on Parent Resource

- SB 1741 requires Parent Resource that "include[s] fair, balanced, and comprehensive information about [ASL] and English and respective communication modes as well as available services and programs."
- Through federal funds, VDH and VDOE currently support production by VCU of 2 parent-oriented resource guides*





- El-focused "Green" guide:
 - Is provided in printed form by VDH EHDI program to families of children 0-3 years old diagnosed with hearing loss
 - Does not contain information on language milestones
 - Is expected to begin revision process in 2020

Recommendation: Use "green" guide as basis for future versions of a parent resource that includes language development milestones

See slide 50 of Appendix for additional detail

Considerations on Stakeholder Advisory Committee

- SB 1741 requires 13-member Advisory Committee with precisely defined qualifications
- Legislating exact committee size/composition risks omitting relevant perspectives
- Similar legislation in other States has evolved to provide greater State agency authority over determining committee specifics*
- Greater definition of committee members' role is warranted
 - Knowledge and expertise relevant to milestone selection vs. information on programs/services may be different

Recommendations: If legislation similar in intent to SB 1741 is considered: 1) authorize implementing agency to determine committee size and skill set (with legislation stipulating minimum criteria to achieve balanced representation); 2) link committee members' roles to qualifications (e.g., milestone selection vs information on available programs/services for Parent Resource)

Considerations on Language Milestones, Assessments and IFSP/IEP Processes

- Requirement linking language milestones to IFSP/IEP processes is captured in current federal law
 - Under IDEA, parents currently can bring relevant materials to IFSP/IEP meetings – including observations from milestones
 - Anecdotally, parents or providers not aware of language development instruments or milestones (particularly for ASL)
- Mandated use of specific assessment instruments by providers would require DBHDS/VDOE regulatory changes
 - Similar to most States, local EI systems/Local Education Agencies not currently required to use specific assessment instruments*
 - Parents can currently request IFSP/IEP team to use specific language assessment instrument, but use of instrument is decided on case-by-case basis
- Annual language milestone assessments by IFSP/IEP teams could incur additional provider time and costs

Considerations on Language Development Milestones Report

- Data would represent subset of D/HH children in Virginia
 - Would not capture children without IDEA-based accommodations/services
- Data collection would incur agency costs
 - VDOE estimates fiscal impact of \$95K (Year 1), \$45K (thereafter)
 - Unknown fiscal impact for DBHDS
- Data collected would lack basis of comparison in Virginia
 - Language development outcomes not collected for other children
- Collecting data on characteristics of children assessed could more directly inform agency programming
 - Examples include: milestone achievement by geographic region or by communication approaches
 - Hearing loss low incidence could limit ability to disaggregate data

Recommendation: If legislation similar in intent to SB 1741 is considered: task implementing/coordinating agencies with determining which additional characteristics of children assessed can be collected/reported on to inform agency programming

Alternative Approaches to SB 1741

Build on existing informational resources

- Anticipated revision of existing "Green" resource guide provides platform for information on milestones
 - Revision could include process for stakeholder input on language milestone selection and/or provision of information on milestones developed in other States (e.g., CA, KS)
- Better align information provided by the State agencies directly involved with D/HH children
 - Multiple workgroup participants highlighted difficulty in knowing where to turn for information when diagnosis first received
 - Improved public understanding of roles of state agencies involved with D/HH children and families could be beneficial

Recommendations: Request State agencies to: incorporate language milestones into existing resource guides; ensure provision of information to families of D/HH children is consistently messaged, easily accessible and user-friendly

Use existing literacy data to track language development outcomes

- English literacy may be considered outcome/proxy indicator for language acquisition
 - Literacy cannot develop in absence of language development
 - Written English is the sole form of communication shared by all D/HH persons
- VDOE tracks literacy development of children in Virginia's public schools through:
 - Phonological Awareness Literacy Screening (PALS)
 - Assessed beginning from pre-kindergarten level to 3rd grade
 - Standards of Learning (SOL) literacy assessments
 - English/Reading assessments begin in 3rd grade

Use existing inter-agency data system to improve longitudinal literacy tracking

- Virginia Longitudinal Data System (VLDS) currently links data from 6 participating agencies, including VDOE
 - Onboarded VDOE data elements include PALS/SOL literacy test results and IEP disability categories
 - VDH is currently in process of onboarding EHDI data
 - DBHDS is in beginning stages of procuring a new EI data system and is not currently in position to onboard EI data
- Onboarding of VDH EHDI data could provide basis for longitudinal tracking of literacy outcomes for all children diagnosed with hearing loss

Recommendation: Use VLDS as basis for reporting on literacy outcomes of children diagnosed with hearing loss beginning at pre-kindergarten level

Lack of provider familiarity with hearing loss can be barrier to accessing services

- Screening: Providers may be hesitant to provide, and/or downplay, "bad" screening results to parents
 - Additionally, communication of failed screen may be lost in volume of information provided to new parents in hospitals
- Diagnosis: Lack of access to pediatric-experienced audiologists may result in missed diagnoses
 - While 24% of audiologists self-identify as pediatric specialists, only 2 audiologists in Virginia are board-certified
- Services: Limited number of EI/ECSE providers have thorough understanding of needs specific to D/HH children
 - 4% of Speech-Language Pathologists specialize in D/HH individuals

Build on existing agency initiatives addressing provider-side barriers

- For EI, geographic barriers to accessing DBHDS- recommended Teachers of D/HH remain
 - While DBHDS is seeking DMAS approval to cover telehealth-delivered EI services, recent DMAS memo clarifying existing telehealth policy does not address including new/changed coverage (e.g., EI services)
- For ECSE, role of VDOE-supported Virginia Network of Consultants (VNOC) could be expanded
 - VNOC currently provides Local Education Agencies (LEAs) access to providers experienced with D/HH children
 - LEA mentoring models from other States (e.g., CO) could be explored in context of leveraging existing VNOC capacities*

Recommendations: Strengthen existing agency initiatives to: 1) identify opportunities for Medicaid reimbursement of telehealth-delivered EI services; 2) increase provider capacities in ECSE services to D/HH children

* See slide 53 of Appendix for additional detail

Explore opportunities for early exposure of families to Deaf role models

- Importance of involvement of D/HH persons in systems of services/supports widely recognized
 - "All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH"
 - Goal #11 of Joint Commission on Infant Hearing (JCIH) Best Practices for EHDI/EI systems
 - Federal Health Resources and Services Administration (HRSA) funds program to increase D/HH involvement in EI system using mentors, guides, role models*
- However, multiple workgroup parents indicated difficulties in making contact with D/HH adults

Explore opportunities for early exposure of families to Deaf role models

- Several States support programs involving D/HH adults to provide information/EI services
 - "Deaf Mentor" program model emphasizes instruction in ASL, exposure to Deaf culture
 - NM Deaf Mentor program employs certified EI providers with developmental services reimbursable by Medicaid*
- 2019 Virginia Board for People With Disabilities report recommended addressing specific workforce area shortages, including Deaf Mentors
- (Limited) body of research suggests potential benefits of mentoring programs for language development and self-efficacy

Recommendation: Identify opportunities to connect families of D/HH children with D/HH adults through mentoring programs to increase uptake of EI services and assistance to families in sign- and non-sign-based communication

Policy Options 1 and 2

-Take No Action

-Introduce legislation and budget amendment based on SB 1741 with the following modifications:

<u>Define terms</u>, including: language, communication modality, English, deaf or hard of hearing

<u>Change implementing agency</u>: provide VSDB primary implementation authority, in coordination with DBHDS, VDOE and VDDHH

<u>Change requirements for constitution of Advisory Committee</u>: stipulate that VSDB will: 1) Determine *size* of Advisory Committee; 2) Ensure *balanced membership* in terms of: individuals who have expertise in the assessment/instruction of ASL, spoken English, English with visual supports, literacy; parents of children who are deaf or hard of hearing; individuals who are deaf or hard of hearing and those who are not

Stipulate that Parent Resource should be based on pre-existing resource guides

<u>Change basis of milestones</u> away from "standardized norms": Base milestone selection on currently available assessments that are appropriate for evaluating progress toward age-appropriate language, including American Sign Language, Spoken English, and English literacy

Require that milestone data include additional characteristics of assessed children that can best inform agency-level programming, as determined by VSDB and coordinating agencies

By letter of the JCHC Chair, request that VDOE conduct an analysis of literacy outcomes of children diagnosed with hearing loss, based on linking:

- a) existing VDOE literacy data collected for the pre-k level and higher with
- b) VDH Early Hearing Detection Intervention (EHDI) hearing diagnosis data (contingent upon availability of VDH data in the Virginia Longitudinal Data System [VLDS]).

A written report, which includes results of the analysis and recommendations for establishing a process for annual reporting by VDOE on literacy of children diagnosed with hearing loss based on existing literacy data, is to be submitted to the JCHC by October 31, 2020.

By letter of the JCHC Chair, request that VCU, in consultation with VDDHH, VDH, VDOE, and VSDB, incorporate language development milestones into or as an addendum to current and future versions of Virginia Resource Guides for Families of Children with Hearing Loss ("Green" and "Orange" guides).

Incorporation of language development milestones should include establishing a formal process for stakeholder input on milestone selection and non-milestone information to be included in future Resource Guide(s).

A report written by VCU, with VDDHH, VDH, VDOE, and VSDB input, is to be submitted to the JCHC by October 31, 2020.

By letter of the JCHC Chair, request that VSDB coordinate with DBHDS, VDDHH, VDOE, and VDH to ensure that information on hearing loss and relevant services made available by State agencies to parents of D/HH children 0-5 years old is comprehensive in scope and consistent in content regardless of each agency's specific areas of focus.

A report written by VSDB, with input from DBHDS, VDDHH, VDOE, and VDH, is to be submitted to the JCHC by October 31, 2020.

Introduce budget amendment (language only) requiring that DMAS work with DBHDS to provide Medicaid reimbursement for Early Intervention (EI) services delivered by telepractice.

A report written by DMAS with DBHDS input – submitted to the JCHC by October 31, 2020 – should provide a timeline for Medicaid reimbursement for EI services delivered by telepractice and identify any necessary enabling legislation, funding, regulatory or other changes to meet that timeline.

Introduce budget amendment (language only), requiring VDDHH, in consultation with DMAS, DBHDS, VDOE, VDH and VSDB, to explore opportunities to develop programs connecting families of D/HH children with D/HH adults – including mentoring programs by Deaf adults or other models – with the goal of increasing uptake of EI services by families and providing assistance to families in sign- and non-sign-based communication.

A report written by VDDH, with input from DMAS, DBHDS, VDOE, VDH and VSDB – to be submitted to the JCHC by October 31, 2020 – should provide a timeline for implementing programs to increase access to ASL instruction or, if barriers to doing so exist, identify any necessary enabling legislation, funding, regulatory or other changes required to address those barriers.

Public Comment

Written public comments on the proposed options may be submitted to JCHC by close of business on September 25, 2019.

Comments may be submitted via:

E-mail: jchcpubliccomments@jchc.virginia.gov

✤Fax: 804-786-5538

Mail: Joint Commission on Health Care P.O. Box 1322 Richmond, Virginia 23218

Comments will be provided to Commission members and summarized before they vote on the policy options during the JCHC's November 14th decision matrix meeting.

(All public comments are subject to FOIA release of records)
Appendix

Language Properties of ASL

- ASL exhibits all properties of a language with syntax (i.e., sentence structure), morphology (i.e., word structure), phonology (i.e., subword structure), and semantics (i.e., word/sentence meaning)
 - Research indicates that children who fully access any language – signed or spoken – achieve the same developmental milestones at the same rate and in the same sequence

Evidence on "Critical Period" for Language Acquisition

- Research indicates that D/HH children who do not acquire language until after age 5 have impaired lifetime ability to develop language fluency
- For those receiving Cochlear Implants, systematic reviews have found:
 - Best language development outcomes occurred for those implanted earlier, although later implantation still facilitates development of expressive/receptive skills
 - Children with Cochlear Implants generally do not reach age level language development due to underlying disability

Evidence on Language Development and Communication Modes

- Sign language
 - Development of D/HH children of fluent-signing Deaf parents similar in trajectory to development of hearing children of hearing parents
 - Development of D/HH children of hearing parents exhibits differences from typical development trajectory (although few studies exist on which to base conclusions)
- Spoken language
 - 2016 systematic review found that:
 - Few studies have systematically assessed language outcomes for children with Cochlear Implants exposed to oral vs. signing communication methods
 - There is no evidence that sign language facilitates *or* interferes with spoken language development
 - More recent study found negative associations between use of sign language and spoken language development among children with Cochlear Implants, but causality is unknown

Evidence on Language Outcomes

- Multi-State study on language outcomes of children 6 months – 5 years of age found:
 - 28% 47% of children exhibited normal language skills compared to hearing peers
 - The following characteristics tend to be associated with better expressive/receptive language skills

Children's characteristics:

- No additional disabilities
- Unilateral hearing loss
- Mild or moderate hearing loss

Environmental/family characteristics:

- Early Intervention by 6 months of age
- Deaf parent(s)
- Mothers with degrees beyond a high school diploma

Common Communication Options

Communication & Language



Source: Virginia's Resource Guide for Families of Children with Hearing Loss Additional languages / communication modalities recognized by the Virginia Department of Education include the use of:

English-based Sign Systems

- Signed English
- Signing Exact English (SEE)
- Conceptually Accurate Signed English

Simultaneous Communication

 Sign language & spoken English Sign-Supported Speech

Written English

Gestures/Home Signs

Augmentative Assistive Communication

Tactile signing

Other languages (e.g., foreign spoken or signed languages)

Virginia Agency Services/Supports for D/HH Children 0-5 Years Old

- Screening/diagnosis
 - Early Hearing Detection and Intervention (EHDI) Program: provides information/referral to families on newborn hearing screening, follow-up testing, early intervention services
- Services
 - Early Intervention (EI): known as "Infant & Toddler Connection of Virginia", provides EI supports/services to children 0-3 years old not developing as expected or with medical condition that can delay normal development
 - Services and supports determined through an Individual Family Service Plan (IFSP)
 - Early Childhood Special Education (ECSE): specially designed instruction to meet unique needs of children with disabilities
 - Determined through an Individualized Education Program (IEP)

Virginia Agency Services/Supports for D/HH Children 0-5 Years Old (2)

- Services (con't)
 - Virginia Hearing Aid Loan Bank: lends hearing aids/FM systems for up to six months to children <18 years old
 - Virginia Project for Children and Young Adults with Deaf-Blindness: program providing technical assistance, training, distance education, and networking information to families, teachers, service providers of individuals 0-21 years old with both hearing and vision loss
 - VSDB outreach services: Webinars, trainings, events for family members of D/HH students; free audiologic evaluations for Virginia children 0-21 years old
- Family Peer Support
 - EHDI Learning Communities: program to bring families and professionals together to influence systems change and improve outcomes
 - 1-3-6 Family Educator Program: Trained parents who visit birthing hospital newborn screening teams/audiology clinics to talk about hearing screening practices and how to get infants back for another test of their hearing

IDEA Part B and C Services

- Early Intervention (EI) (ages 0 3)
 - DBHDS administers Individuals with Disabilities Education Act (IDEA) "Part C" federal grant program for children with disabilities and families
 - Individualized Family Service Plans (IFSPs), for children eligible for El services, outline developmental goals/services to be accessed
 - Children with hearing loss automatically eligible for Part C services
- Early Childhood Special Education (ECSE) (ages 2 5)
 - VDOE administers IDEA "Part B" federal grant program for children with disabilities
 - Individualized Education Programs (IEPs) for children eligible for ECSE services outline educational goals/services to be accessed
 - Children with hearing loss not automatically eligible for Special Education services (eligibility based on presence of disability necessitating special education and related services)

Federal Requirements for Individualized Education Program Eligibility Determination

- To determine IEP eligibility, 34 C.F.R. §300.304 requires education agencies to:
 - Use a variety of assessment tools and strategies to gather information and not use any single measure or assessment as sole criterion for determining eligibility
 - Use technically sound instruments
 - Administer assessments: 1) in child's native language/mode of communication unless it is not feasible; 2) by trained personnel; 3) in accordance with producer's instructions
 - Use assessments for purposes for which measures are valid/reliable
- 34 C.F.R. §300.324(a)(2)(iv) requires education agencies to consider "special factors" that include:
 - Child's language/communication needs
 - Opportunities for direct communication with peers/professional personnel in child's language and communication mode
 - Academic level
 - Full range of needs including opportunities for direct instruction in child's language and communication mode

State-Supported Programs for Providers

- Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing (VNOC)
 - Currently, 25 consultants part of network (including: Teachers of D/HH; audiologists; Speech-Language Pathologists; Interpreters; EI-certified providers; Psychologists; Certified Behavioral Analysts)
 - During 2018-2019 school year, 21 consultation requests were received

IDEA Part B/C Data On Acquisition And Use Of Knowledge And Skills

- El data (IDEA Part C Indicators 3a and 3b):
 - Current DBHDS data system unable to disaggregate indicators by disability eligibility
- ECSE data (IDEA Part B Indicators 7a and 7b):

Acquisition and use of knowledge and skills	Made progress*		Proficient**	
	2016-2017	2017-2018	2016-2017	2017-2018
All Disability Categories	95%	95%	47%	44%
Hearing Impairment / Deaf and Hard of Hearing	74%	56%	55%	46%

Source: VDOE

- * Of children below age expectations, % who substantially increased rate of growth by age 6 or when exited program
- ** % children functioning within age expectations by age 6 or when exited program

Stakeholder Workgroup Participants

Advocacy organizations

- AG Bell Virginia
- American Academy of Otolaryngology
- American Cochlear Implantation Alliance (ACI)
- Deaf Grassroots Movement
- LEAD-K
- Northern Virginia Cued Speech Association (NVCSA)

State agencies

- Department of Behavioral Health and Developmental Services (DBHDS)
- Department of Health Profession (DHP) Board of Audiology
- Virginia Board for People with Disabilities (VBPD)
- Virginia Commonwealth University (VCU)

- Northern Virginia Resource Center for Deaf and Hard of Hearing Persons (NVRC)
- Speech-Language-Hearing Association of Virginia (SHAV)
- Virginia Association for Centers of Independent Living (VACIL)
- Virginia Association of the Deaf (VAD)
- Virginia Department for the Deaf and Hard of Hearing (VDHH)
- Virginia Department of Health (VDH)
- Virginia Department of Education (VDOE)
- The Virginia School for the Deaf and the Blind (VSDB)

Current Parent Resources

- Virginia's Resource Guide for Families of Children with Hearing Loss ("Green" guide)
 - Contains information about hearing, hearing technologies, communication and language, EI and IEPs, additional tools and resources for parents
 - Printed version provided by VDH EHDI program to families of children 0-3 recently diagnosed with hearing loss
 - Existing printed stock is expected to last for 2 3 more years
 - First produced in early 2000s; revised in 2012 and 2016; expected to undergo revisions beginning in 2020
- Companion Guide for Children in Elementary School ("Orange" guide)
 - Covers ages 2-21
 - Contains information similar to Resource Guide as well as additional information on schooling
 - First produced in 2018; not expected to be revised in near future

Evolution of State Agency Roles in Stakeholder Advisory Committees

- CA (2015): 13 members, all of whose characteristics / skill sets are inscribed in Code
- KS (2016): 13 members
 - Characteristics/skill sets of 6 members are inscribed in Code
 - 7 members are ex officio State agency representatives
- GA (2017): 13 members, all of whose characteristics / skill sets are inscribed in Code
- SD (2018): 10 Committee members in which:
 - Characteristics/skill sets of 6 members are inscribed in Code
 - Implementing agency can choose between 11 characteristics/skill sets for 4 members
- IN (2019): Implementing agency determines number of members
 - Code includes two broad requirements related to Committee composition to "[e]nsure that the membership of the advisory committee includes a balanced representation of deaf or hard of hearing perspectives"
- ME (2019): Implementing agency determines number of members
 - Code includes three broad requirements related to Committee composition, and permits inclusion of up to 20 characteristics/skill sets

State Approaches to IDEA Part B/C Indicators Measurement (7a/b, 3a/b)

- Most States use the Child Outcomes Summary (COS) process to report data on federally required indicators
 - With COS, teams consider multiple sources of information (e.g., results from standardized assessment, parent input, provider/teacher observation)



Colorado Deaf Mentor Program

- Program origin: to address gaps between increased use of Cochlear Implants and professionals experience in addressing their communication needs
 - Originally focused on listening and spoken language but has evolved to be more holistic
- Program provides mentorship to professionals (educators, related service providers, administrators) to support education of D/HH children in school districts (not mentorship for D/HH children by Deaf adult)
 - Mentors qualifications include: administrators, SLPs, ToDHH, interpreters
 - 7 part-time mentors; provide 200-400 hours each per year) spans preschool, grade school, and transition age levels.
- School districts supported during 3-year plan, with tapering technical assistance
 - Colorado Department of Education evaluates achievement of districtspecific goals at 4 or 5 years
- Program funding: IDEA

HRSA-Supported Family Leadership in Language and Learning (FL3) program

- 3-year cooperative grant between HRSA and Hands & Voices (2017-2020)
- 5 goals are:
 - 1. Families with D/HH children and organizations serving families with D/HH children are partners in EI in every state
 - 2. Support families in becoming leaders in the EI system
 - 3. Increase family to family support
 - 4. Families increase knowledge of language, literacy, and social emotional development for children
 - 5. Increase D/HH involvement in EI system using mentors, guides, and role models

New Mexico School for the Deaf (NMSD) Deaf Mentor Program

- Program goal: ensure that families have tools for D/HH children to communicate and maximize their learning opportunities
- Deaf Mentors:
 - Are certified EI developmental specialists with Bachelors/Masters training who work with families to teach principals around literacy and early communication foundations/skills based on SKI-HI/VL-2 curricula
 - Have experience with variety of communication modalities to work
 communication approach chosen by families
 - Provide in-home services 1 2 times per week
- Children diagnosed as D/HH automatically referred to program and are eligible for services up to 6 years old
 - ~250 children served annually, with family typically receiving services for ~2.5 years
- Through Memorandum of Understanding with state Medicaid agency, services are billable to Medicaid as a developmental service
 - Arrangement based on 18 months of data indicating D/HH children receiving Deaf Mentor services scored higher on measures of development compared to those without service

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Article 1 of Chapter 3 of Title 37.2 a section numbered <u>37.2-314.1</u> as follows:§ <u>37.2-314.1</u>. Language development for children who are deaf or hard of hearing; assessment resources for parents and educators; advisory committee; report.

A. For the purposes of this section, "language developmental milestones" means milestones of development aligned to the existing instrument used to assess the development of children with disabilities pursuant to federal law.

B. The Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall establish an advisory committee for the purpose of soliciting input from members on the selection of language developmental milestones for inclusion 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 the child's expressive and receptive language acquisition and developmental stages toward English literacy. The advisory committee shall consist of 13 nonlegislative citizen members, the majority of whom shall be deaf or hard of hearing and all of whom shall have experience in the field of education of individuals who are deaf or hard of hearing. The advisory committee shall include:

1. One parent of a child who is deaf or hard of hearing and who uses the dual languages of American Sign Language and English;

2. One parent of a child who is deaf or hard of hearing and who uses only spoken English, with or without visual supplements;

3. One parent of a child who is deaf or hard of hearing and who uses only spoken language, with cued visual supplements.

4. One credentialed teacher of students who are deaf or hard of hearing and who use the dual languages of American Sign Language and English;

5. One credentialed teacher of students who are deaf or hard of hearing who teaches at an accredited private, nonsectarian elementary or secondary school;

6. One expert who researches language outcomes for children who are deaf or hard of hearing and who use the dual languages of American Sign Language and English;

7. One expert who researches language outcomes for children who are deaf or hard of hearing and who use spoken English, with or without visual supplements;

8. One credentialed teacher of students who are deaf or hard of hearing whose expertise is in curriculum and instruction in the dual languages of American Sign Language and English;

9. One credentialed teacher of students who are deaf or hard of hearing whose expertise is in curriculum and instruction in spoken English, with or without visual supplements;

10. One advocate for the teaching and use of the dual languages of American Sign Language and English for children who are deaf or hard of hearing;

11. One advocate who is an oral-aural specialist for children who are deaf or hard of hearing;

12. One early intervention specialist who works with infants and toddlers who are deaf or hard of hearing using the dual languages of American Sign Language and English; and

13. One credentialed teacher of students who are deaf or hard of hearing whose expertise is in American Sign Language and English language assessment.

C. No later than March 1, 2020, the Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall provide the advisory committee established pursuant to subsection A with a list of all existing language developmental milestones from standardized norms and any relevant information regarding such language developmental milestones for possible inclusion in the parent resource set forth in subsection D. No later than June 1, 2020, the advisory committee shall recommend language developmental milestones for inclusion in the parent resource and may make recommendations for tools or assessments to be included in an educator resource set forth in subsection E for use in assessing the language and literacy development of children from birth to age five who are deaf or hard of hearing. No later than June 30, 2020, the Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall select language developmental milestones for inclusion in the parent resource and inform the advisory committee of its selections.

D. The Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall, after considering the recommendations submitted by the advisory committee, select language developmental milestones for inclusion in a resource, and develop such 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 the child's expressive and receptive language acquisition and developmental stages toward English literacy. Such parent resource shall:

1. Be appropriate for use, in both content and administration, with children who use American Sign Language, English, or both;

2. Present the language development milestones selected pursuant to subsection B in terms of typical development of all children in a particular age range;

3. Be written for clarity and ease of use by parents;

4. Be aligned to the Department's and Department of Education's existing infant, toddler, and preschool guidelines, the existing instrument used to assess the development of children with disabilities pursuant to federal law, and state standards in English language arts;

5. Make clear that parents have the right to select American Sign Language, English, or both, for their child's language acquisition and developmental milestones;

6. Make clear that the parent resource is not a formal assessment of language and literacy development and that parents' observations of their child may differ from formal assessment data presented at an Individual Family Service Plan (IFSP) or Individualized Education Program (IEP) meeting;

7. Explain that parents may bring the parent resource to an IFSP or IEP meeting for purposes of sharing their observations about their child's development; and

8. Include fair, balanced, and comprehensive information about American Sign Language and English and respective communication modes as well as available services and programs.

The Department, the Department of Education, and the Department for the Deaf and Hard-of-Hearing shall jointly disseminate the resource to parents of children from birth to age five who are deaf or hard of hearing.

E. The Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall, after considering any recommendations submitted by the advisory committee, 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. Such tools or assessments shall:

1. Be in a format that shows stages of language and literacy development;

2. Be selected for use by educators to track the expressive and receptive language acquisition and developmental stages toward English literacy of children from birth to age five who are deaf or hard of hearing; and

3. Be appropriate, in both content and administration, for use with children who are deaf or hard of hearing and who use American Sign Language, English, or both.

The Department, the Department of Education, and the Department for the Deaf and Hard-of-Hearing shall jointly disseminate the tools or assessments selected pursuant to this subsection to local educational agencies and provide materials and training on their use. Such tools or assessments may be used by a child's IFSP or IEP team, as applicable, to track the expressive and receptive language acquisition and developmental stages toward English literacy of such child or to establish or modify IFSP or IEP plans.

F. In addition to the powers and duties set forth above, the advisory committee may:

1. Advise the Department, the Department of Education, and the Department for the Deaf and Hard-of-Hearing or its contractor on the content and administration of the existing instrument used to assess the development of children who are deaf or hard of hearing in order to ensure the appropriate use of such instrument for the assessment of the language and literacy development of children from birth to age five who are deaf or hard of hard of hearing; and

2. Make recommendations regarding future research to improve the measurement of the language and literacy development of children from birth to age five who are deaf or hard of hearing.

G. If a child from birth to age five who is deaf or hard of hearing does not demonstrate progress in expressive and receptive language skills as measured by one of the educator tools or assessments selected pursuant to subsection E or by the existing instrument used to assess the development of children who are deaf or hard of hearing, such child's IFSP or IEP team, as applicable, shall explain in detail the reasons why the child is not meeting or progressing toward the language developmental milestones and shall recommend specific strategies, services, and programs that shall be provided to assist the child's progress toward English literacy.

H. No later than August 1, 2020, and no later than August 1 of each year thereafter, the Department, in coordination with the Department of Education and the Department for the Deaf and Hard-of-Hearing, shall produce a report, using existing data reported in compliance with the federally required state performance plan on students with disabilities, 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 shall make such report available to the public on its website.

I. The Department, the Department of Education, and the Department for the Deaf and Hard-of-Hearing shall comply with the provisions of the federal Individuals with Disabilities Education Act (20 U.S.C. § 1400 et seq.) and the Family Educational Right and Privacy Act (20 U.S.C. § 1232g) in carrying out the provisions of this section.

Slide 4 (Hearing Loss: Low incidence condition with historically high risk for language delay)

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- Fitzpatrick, E. et al., 2016. Sign Language and Spoken Language for Children With Hearing Loss: A Systematic Review. Pediatrics, 137, pp.1–17.
- Hrastinski, I. & Wilbur, R., 2016. Academic Achievement of Deaf and Hard-of-Hearing Students in an ASL/English Bilingual Program. Journal of Deaf Studies and Deaf Education, 21, pp.156–170.
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- Qi, S. & Mitchell, R., 2011. Large-Scale Academic Achievement Testing of Deaf and Hard-of-Hearing Students: Past, Present, and Future. Journal of Deaf Studies and Deaf Education, 17, pp.1–18.

Slide 5 (Early language development positively affects overall development)

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Slide 6 (Opportunities for D/HH children to acquire spoken language have expanded)

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- Humphries, T. et al., 2014. What Medical Education can do to Ensure Robust Language Development in Deaf Children. Medical Science Education, 24, pp.409–419.

Slide 8 (Data on Services/Supports for D/HH Children in Virginia)

- Centers for Disease Control and Prevention, 2019. Annual Data Early Hearing Detection and Intervention (EHDI) Program.
- Department of Behavioral Health and Developmental Services, 2019. Virginia Early Intervention Data (personal communication).
- Slide 10 (Literacy of school-age children with disabilities (including D/HH children) lags hearing peers)
- Virginia Department of Education, 2019. SOL Test Results.
- Virginia Department of Education, 2019. Kindergarten PALS results (FOIA request).

Slide 15 (Considerations on Agency Roles in Implementation)

- Commonwealth of Virginia, 2009. Code of Virginia Title 22.1, Chapter 19: The Virginia School for the Deaf and the Blind (§22.1-346),
- Virginia Department for the Deaf and Hard of Hearing, 2019. "About VDDHH" (https://www.vddhh.org/downloads/VDDHHAgencyBrochure.pdf)
- Slide 16 (Considerations on Milestones and Language Development Assessments)
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Slide 22 (Build on existing informational resources)

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Slide 25 (Lack of provider familiarity with hearing loss can be barrier to accessing services)

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Slide 40 (Evidence on Language Development and Communication Modes)

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Slide 41 (Evidence on Language Outcomes)

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Slide 42 (Common Communication Options)

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- Virginia Department of Education, 2019. *Personal Communication*.

Slide 48 (IDEA Part B/C Data On Acquisition And Use Of Knowledge And Skills)

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Slide 50 (Current Parent Resources)

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Slide 53 (Colorado Deaf Mentor Program)

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Slide 54 (HRSA-Supported Family Leadership in Language and Learning (FL3) program)

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