REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

LANGUAGE DEVELOPMENT MILESTONES AND
PARENT RESOURCES FOR YOUNG DEAF/HARD OF
HEARING CHILDREN

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

REPORT DOCUMENT NO. 331

COMMONWEALTH OF VIRGINIA
RICHMOND
2020
Code of Virginia § 30-168.

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government.

The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care.

Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care.

For the purposes of this chapter, "health care" shall include behavioral health care.

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Preface

By letter from the Senate Rules Committee, the Joint Commission on Health Care was asked to study Senate Bill 1741 (Senator Edwards, 2019). The legislation would have required the selection of language development milestones, creation of parent and educator resources, and execution of annual language milestone assessments and results reporting for D/HH children zero to five years of age.

With input from a stakeholder workgroup, the study made several recommendations related to modifications of the content of Senate Bill 1741, as well as recommendations on possible legislative actions instead of – or in addition to – provisions contained in the bill.

Seven policy options were presented for consideration by Joint Commission on Health Care members who voted to take no action.

Joint Commission members and staff would like to acknowledge and thank those who assisted in this study including representatives from Virginia’s: Department of Behavioral Health and Developmental Services, Department of Education, Department for the Deaf and Hard of Hearing, Department of Health, and School for the Deaf and the Blind, as well as all other participants of the stakeholder workgroup.

The study and this report was assigned to and completed by Andrew Mitchell, Senior Health Policy Analyst at the Joint Commission on Health Care. He may be contacted at amitchell@jchc.virginia.gov.
Executive Summary

Senate Bill 1741 (Senator Edwards, 2018) would have required the selection of language development milestones, creation of parent and educator resources, and implementation of annual language milestone assessments and results reporting for D/HH children zero to five years old. During the 2019 Virginia General Assembly session, the bill was Passed By Indefinitely in the Senate Education and Health Committee, with a letter sent to the Joint Commission on Health Care by the Senate Rules Committee requesting a report.

Childhood hearing loss – while affecting fewer than 200 children born each year in Virginia – has historically adversely impacted children’s language acquisition and development. Although a variety of communication options exist – including sign-based languages (e.g., American Sign Language, spoken (oral-aural) language with or without visual supplements, and written language) – no consensus exists on which communication choices are optimal for language development/literacy for the 95% of D/HH children born to hearing parents. A system of services and supports exist in Virginia for young D/HH children, anchored by universal newborn screening and Early Intervention services for children less than three years old, and Early Childhood Special Education Services for children two to five years old.

Recommendations were made to revise several provisions contained in Senate Bill 1741. With input from a stakeholder workgroup convened for the study, recommendations were made to: define key terms, identify an alternative implementing agency, modify the basis by which milestones can be selected, use existing resource guides as the basis for the parent resource envisioned by the bill, provide the implementing agency greater authority over the contours of the advisory committee envisioned by the bill, and task the implementing agency with determining additional data points for the annual report envisioned by the bill.

Additional recommendations were provided as legislative actions that could be considered instead of – or alongside – the provisions of Senate Bill 1741. These included: using an existing multi-agency data system to report on literacy outcomes of D/HH children; requiring State agencies to integrate language milestones into existing resource guides for this population; strengthening agency initiatives to allow Medicaid reimbursement of Early Intervention services delivered by telepractice, as well as increasing provider capacities in delivering Early Childhood Special Education services; and identifying opportunities to develop programs connecting families of D/HH children with D/HH adults, including Deaf Mentor programs.

Seven policy options were presented for consideration by Joint Commission on Health Care members and they approved the option to take no action at that time.
LANGUAGEN DEVELOPMENT MILESTONES AND PARENT RESOURCES FOR YOUNG DEAF/HARD OF HEARING CHILDREN

Study Mandate

Senate Bill 1741 (Senator Edwards, 2018) would have required the selection of language development milestones, creation of parent and educator resources, and implementation of annual language milestone assessments/results reporting for D/HH children zero to five years old. During the 2019 Virginia General Assembly session, the bill was Passed By Indefinitely in the Senate Education and Health Committee, with a letter sent to Joint Commission on Health Care by the Senate Rules Committee requesting a report.

Background

Childhood hearing loss is a low incidence condition that historically has adversely affected children’s language acquisition and development. Nationally, two to three newborns per 1,000 experience hearing loss; by kindergarten, an estimated six children per 1,000 in U.S. are D/HH. Over 95% of these D/HH children are born to hearing parents (National Institute on Deafness and Other Communication Disorders 2016; Geers et al. 2017). In Virginia, approximately 130-170 children born each year are diagnosed with hearing loss by age three (Centers for Disease Control and Prevention 2019). Any degree of hearing loss raises risks of language delays, and historically, most D/HH children have arrived at kindergarten language-delayed (Lederberg et al. 2013). According to nationally-representative, standardized longitudinal data collected from 1969 until the early 2000s, the median reading ability of D/HH children graduating from high school was found to be at the fourth grade level, with only 10% of those children having achieved age-appropriate language skills (Lederberg et al. 2013; Hrastinski & Wilbur 2016; Qi & Mitchell 2012). However, significant improvements in hearing technologies – described further in the following section – may be positively changing achievement levels for more recent generations of D/HH children.

Communication Options

With the advent of advances in hearing technologies over the past several decades – including improvements in Cochlear Implants and hearing aids – a variety of sign- and non-sign-based communication options exist for D/HH children. Main communication options for D/HH children include sign language (e.g., American Sign Language [ASL]), spoken (oral-aural) language with or without visual supplements, and written language. In addition to these options, Table 1, below, lists other modes of communication recognized by the Virginia Department of Education. According to survey data from 2010 (not childhood-specific), around 69% of D/HH Virginians used spoken language only, 15% used sign language only, and the remainder used combinations of signed/spoken language (Gallaudet Research Institute 2011). Figure 1 highlights the most commonly used communication options by school-aged D/HH children in Virginia.
### Table 1.

**Other Languages/Communication Modalities Recognized by the Virginia Department of Education**

<table>
<thead>
<tr>
<th>Communication Modalities</th>
</tr>
</thead>
<tbody>
<tr>
<td>English-based Sign Systems (e.g., Signed English, Signing Exact English (SEE), Conceptually Accurate Signed English)</td>
</tr>
<tr>
<td>Simultaneous Communication (i.e., sign language &amp; spoken English)</td>
</tr>
<tr>
<td>Sign-Supported Speech</td>
</tr>
<tr>
<td>Written English</td>
</tr>
<tr>
<td>Gestures/Home Signs</td>
</tr>
<tr>
<td>Augmentative Assistive Communication</td>
</tr>
<tr>
<td>Tactile signing</td>
</tr>
<tr>
<td>Other languages (e.g., foreign spoken or signed languages)</td>
</tr>
</tbody>
</table>

**Figure 1.**

*Communication & Language*

Methods of Language & Communication

Deaf and hard of hearing children may be exposed to a variety of communication methods. These are used most commonly.

Source: (Virginia Commonwealth University 2016)
Fully accessing language is important regardless of the mode(s) of communication used by D/HH children. 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 (e.g., the development of D/HH children raised by fluent-signing Deaf parents is similar in trajectory to that of hearing children raised by hearing parents) (Luft 2017; Morgan 2011; Lederberg et al. 2013). There is also a consensus that acquisition of any language is foundational to literacy in any (other) language as well as broader social-cognitive development, and that such acquisition must begin early in life for full potential to be realized (Humphries et al. 2012; Humphries et al. 2014; Lederberg et al. 2013; Mayberry 2010). For children who receive Cochlear Implants, for instance, systematic reviews have found that the best language development outcomes occurred for those implanted earlier – although later implantation still facilitates development of expressive/receptive skills – even if children with Cochlear Implants generally do not reach age level language development due to their underlying disability (Ruben 2018; Bruijnzeel et al. 2016).

However, no consensus exists on which communication choices are optimal for language development/literacy for the 95% of D/HH children born to hearing parents. For D/HH children born to hearing parents and using sign language, systematic reviews indicate that their development exhibits negative differences from a typical development trajectory, although few studies exist on which to base conclusions (Lederberg et al. 2013). For D/HH children born to hearing parents and using spoken language, a systematic review from 2016 found that few studies have systematically assessed language outcomes for children with Cochlear Implants exposed to oral vs. signing communication methods, and that there is no evidence that sign language facilitates or interferes with spoken language development (Fitzpatrick et al. 2016). While a more recent study found negative associations between use of sign language and spoken language development among children with Cochlear Implants, causality remains unknown (Geers et al. 2017; Hall et al. 2017; Corina & Schaefer 2017).

A variety of factors beyond communication choices also influence language acquisition. For example, a multi-state study on language outcomes of children six months to five years of age found that 28% to 47% of children exhibited normal language skills compared to hearing peers. Characteristics of children found to be associated with better expressive/receptive language skills included not having additional disabilities, having unilateral hearing loss, and mild or moderate hearing loss. Influential characteristics of the environment and family included early Intervention by six months of age, being born to Deaf parents, and having mothers with degrees beyond a high school diploma (Yoshinaga-Itano et al. 2014).

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1 ASL is a language distinct from spoken English or other spoken languages. It 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). (Mayberry et al. 2011)

2 Research indicates that D/HH children who do not acquire language until after age five have impaired lifetime ability to develop language fluency.
Virginia’s System of Services and Supports for D/HH Children

In Virginia, six State agencies support D/HH children through screening/diagnosis, developmental/education services and family support. The three primary services and supports are:

• The *Early Hearing Detection and Intervention (EHDI)* Program – overseen by the Virginia Department of Health (VDH) – which provides information/referral to families on newborn hearing screening, follow-up testing, and early intervention services. Ninety-eight to 99% of live births annually in Virginia are screened for hearing loss, although a definitive diagnosis remains unknown for a significant percentage of children who fail their hearing screen.

• The “*Infant & Toddler Connection of Virginia*” – overseen by the Department of Behavioral Health and Developmental Services (DBHDS) – which provides *Early Intervention* (EI) services to children up to three years old who are not developing as expected or have a medical condition that can delay normal development. EI services are funded by the Individuals with Disabilities Education Act (IDEA) “Part C” federal grant program for children with disabilities and families; and they are determined through an Individual Family Service Plan (IFSP), which outlines developmental goals and services to be accessed. In Virginia, children with hearing loss are automatically eligible for Part C services. Annually, up to 200 children zero to three years of age have hearing loss as an eligibility reason.

• *Early Childhood Special Education (ECSE)* services – overseen by the Virginia Department of Education (VDOE) – are specially designed instruction to meet the unique needs of children with disabilities. These services and supports are funded by the Individuals with Disabilities Education Act (IDEA) “Part B” federal grant program. ECSE services and supports are determined through an Individualized Education Program (IEP) which outlines educational goals/services to be accessed. In contrast to EI services, children with hearing loss are not automatically eligible for Special Education services. Instead, eligibility is based on the presence of a disability necessitating special education and related services.³ Annually, up to 300 children two to five years old have deaf or hard of hearing as an eligibility disability category. However, the percentage of D/HH children transitioning from EI to ECSE services is unknown due to DBHDS EI data system limitations.

The table on the following page provides an overview of all State agencies involved in providing services and/or supports to this population and their families. In addition, VDOE supports

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³ 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; and 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: the child’s language/communication needs; opportunities for direct communication with peers/professional personnel in child’s language and communication mode; academic level; and the full range of needs including opportunities for direct instruction in child’s language and communication mode.
providers through the Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing (VNOC). At the time of writing of this report, 25 consultants were listed as part of VNOC, including: Teachers of D/HH; audiologists; Speech-Language Pathologists; Interpreters; EI-certified providers; Psychologists; and Certified Behavioral Analysts. During the 2018-2019 school year, VNOC received 21 consultation requests.

Table 2. Virginia’s System of Services and Supports for Young D/HH Children

<table>
<thead>
<tr>
<th>Screening / diagnosis</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>VDH Early Hearing Detection and Intervention (EHDI) Program</td>
<td>0-5</td>
</tr>
<tr>
<td>Individualized Family Service Plan (IFSP)-based Early Intervention (EI); (DBHDS)</td>
<td>0-1</td>
</tr>
<tr>
<td>Individualized Education Program (IEP)-based Early Childhood Special Education (ECSE); (VDOE; The Virginia School for the Deaf and the Blind (VSDB))</td>
<td>2-5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Virginia Hearing Aid Loan Bank (VDH): lends hearing aids/FM systems for up to six months to children 18 years old or younger</td>
</tr>
<tr>
<td>Virginia Project for Children and Young Adults with Deaf-Blindness (VCU): program that provides 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</td>
</tr>
<tr>
<td>General information and referral services for the D/HH (VDDHH)</td>
</tr>
<tr>
<td>VSDB outreach services (VSDB, VDOE): webinars, trainings, events for family members of D/HH students; free audiologic evaluations for Virginia children 0-21 years old</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Peer Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>EHDI Learning Communities (VDH, VCU): program to bring families and professionals together to influence systems change and improve outcomes</td>
</tr>
<tr>
<td>1-3-6 Family Educator Program (VDH, VCU): 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</td>
</tr>
</tbody>
</table>


Language Development Measurement

Language development among D/HH children zero to five years old in Virginia is not directly measured in a standardized way. The federal Individuals with Disabilities Education Act (IDEA) requires states to report on three broad child outcome measures for children with IFSPs/IEPs: positive social-emotional skills; acquisition and use of knowledge and skills; and use of appropriate behaviors to meet needs. “Acquisition and use of knowledge and skills” – Indicator 7a/7b in terms of IDEA Part B and Indicator 3a/3b in terms of IDEA Part C – “involves activities such as thinking, reasoning, remembering, problem solving, number concepts, counting, and understanding the physical and social worlds. It also includes a variety of skills related to language and literacy including vocabulary, phonemic awareness, and letter recognition” (Department of Behavioral Health and Developmental Services 2018; Virginia Department of Education 2019a). While this indicator includes aspects of language acquisition, it cannot be considered a direct measure. Further, Virginia, like most states, does not require providers to use one specific instrument by which to measure this indicator. Instead, as highlighted below in Figure, Virginia’s agencies use the Child Outcomes Summary (COS) process to report data on federally required indicators. With COS, teams consider multiple sources of information – such as results from standardized assessments, parent input, provider/teacher observations – to rate progress and achievement on acquisition and use of knowledge and skills.

Figure 2. State Approaches to IDEA Part B/C Indicators Measurement (7a/b, 3a/b)

Beginning in preschool, however, standardized measures of achievement in literacy are collected by VDOE through the Phonological Awareness Literacy Screening (PALS) and Standards of Learning (SOL) tests. English literacy may be considered an outcome/proxy indicator for language acquisition because literacy cannot develop in absence of language development. The ability to meet written English benchmarks therefore implies a degree of language acquisition adequate to enable literacy proficiency – even if inability to meet written English benchmarks does not necessarily imply an inadequate level of language acquisition. Further, written English is the sole form of communication shared by all D/HH persons, making it comparable regardless
of communication choices of D/HH children. VDOE currently tracks literacy development of children in Virginia’s public schools beginning at the pre-k level through the Phonological Awareness and Literacy Screening (PALS) tests. These tests are administered in 131 of 132 Virginia school divisions, although some D/HH students are exempted from testing due to their underlying disability. According to recent PALS trend data pictured in Figure 1, the percentage of D/HH kindergartners on IEPs meeting literacy benchmarks has been not as high as that of kindergartners who are not on IEPs, but, since 2015/2016, higher than that of non-D/HH children on IEPs. Additionally, SOL-based literacy assessments begin in the third grade. As pictured below, the percentage of D/HH children passing SOL literacy assessments is similar to that of non-D/HH children on IEPs and substantially below that of those who are not on IEPs.

**Figure 3. Trends in PALS and SOL Results**

<table>
<thead>
<tr>
<th>Phonological Awareness Literacy Screening (PALS) kindergarten results</th>
<th>3rd grade Standards of Learning (SOL) English reading test results</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Graph showing trends in PALS and SOL results" /></td>
<td><img src="image" alt="Graph showing trends in PALS and SOL results" /></td>
</tr>
</tbody>
</table>

Sources: (Virginia Department of Education 2019c; Virginia Department of Education 2019b)

* May include children ever diagnosed with hearing loss but not in need of IEP-based accommodations

**Report recommendations on Senate Bill 1741**

**Major Components of SB 1741**

The provisions contained in SB 1741 were similar in content to those found in several bills introduced or passed in several other states, often referred to as Language Equality and Acquisition for Deaf Kids (“LEAD-K”) bills. SB 1741 was substantively similar to the first such bill passed in California in 2015 (California Senate Bill 210) and included the following provisions:

- Development of Parent Resource, to include language development/literacy milestones (in ASL and English) and other information (e.g., communication, available services), to

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4 Approximately one-third of D/HH kindergartners on IEPs were exempted from taking the kindergarten-level PALS, suggesting that PALS captures literacy outcomes for most of D/HH children on IEPs of kindergarten age. By contrast, approximately 80% of D/HH preschoolers on IEPs were exempted from taking a preschool-level version of PALS.
be developed with input of a stakeholder Advisory Committee whose composition was defined in the bill.

- Development of an Educator Resource, to include language development/literacy assessment(s) in ASL and English, to be developed with input of a stakeholder Advisory Committee.
- Integration of language milestone tracking into Individual Family Service Plans (IFSPs) and IEP processes.
- Annual reporting on language/literacy outcomes of D/HH children, based on data collected from provider/educator assessments of language development/literacy.
- DBHDS was identified as the implementing agency, coordinating with VDOE and VDDHH.

**Stakeholder Workgroup**

Recommendations provided in this report were informed by discussions of a stakeholder workgroup convened for the study. The purpose of the stakeholder workgroup was to discuss the content of SB 1741 and related issues and identify areas of general consensus or disagreement. Workgroup participants represented eight state agencies and 10 advocacy organizations, as well as providers, D/HH persons and parents of D/HH children. The workgroup met four times over the course of the study. Table , below, identifies organizations that were represented in at least one meeting.

<table>
<thead>
<tr>
<th>Advocacy Organizations</th>
<th>State Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>AG Bell Virginia</td>
<td>Department of Behavioral Health and Developmental Services (DBHDS)</td>
</tr>
<tr>
<td>American Academy of Otolaryngology</td>
<td>Department of Health Professions (DHP)</td>
</tr>
<tr>
<td>American Cochlear Implantation Alliance (ACI)</td>
<td>Board of Audiology</td>
</tr>
<tr>
<td>Deaf Grassroots Movement</td>
<td>Virginia Board for People with Disabilities (VBPD)</td>
</tr>
<tr>
<td>LEAD-K</td>
<td>Virginia Commonwealth University (VCU)</td>
</tr>
<tr>
<td>Northern Virginia Cued Speech Association (NVCSA)</td>
<td>Virginia Department for the Deaf and Hard of Hearing (VDDHH)</td>
</tr>
<tr>
<td>Northern Virginia Resource Center for Deaf and Hard of Hearing Persons (NVRC)</td>
<td>Virginia Department of Health (VDH)</td>
</tr>
<tr>
<td>Speech-Language-Hearing Association of Virginia (SHAV)</td>
<td>Virginia Department of Education (VDOE)</td>
</tr>
<tr>
<td>Virginia Association for Centers of Independent Living (VACIL)</td>
<td>The Virginia School for the Deaf and the Blind (VSDB)</td>
</tr>
<tr>
<td>Virginia Association of the Deaf (VAD)</td>
<td></td>
</tr>
</tbody>
</table>

Although there were some points of general consensus, several points of disagreement persisted throughout the workgroup’s discussions. The two major points of consensus – primarily philosophical – were that: early language acquisition is critical for full language and cognitive development, including literacy; and parents of D/HH children should be able to choose...
preferred language(s) and mode(s) of communication. The major points of continued disagreement included: definition of language vs. communication modality; the need for an additional Parent Resource; the composition and role of the Advisory Committee; and the need for language development data collection and reporting.

**Summary of Recommendations on SB 1741**

**Define key terms – including language, communication modality, forms of English, Deaf – and avoid branded terms**

Several terms used in SB 1741 are subject to varying interpretations and merit further definition. Examples include the terms “English” – which can be spoken (oral), heard (aural), or written – and “Deaf” – which has clinical, functional, and cultural definitions. Other terms commonly used by stakeholders have “industry” meanings. “Listening and Spoken Language”, for example, is a commonly cited communication modality based on an aural-oral approach, but also a branded provider certification system.

**Identify VSDB as the primary implementing agency, coordinating with DBHDS, VDDHH, and VDOE to implement legislation’s provisions**

Agencies other than DBHDS may be better positioned to oversee the implementation of the provisions of SB 1741. The technical expertise of DBHDS is not specific to deafness, and its programming is limited to children zero to three years old. Conversely, agency missions of VDDHH and VSDB relate more directly to D/HH persons. VDDHH’s mission is to promote accessible communication to D/HH persons (Virginia Department for the Deaf and Hard of Hearing 2019); however, the Department is not focused on children specifically and the preponderance of its programming is for adults. VSDB’s mission – not identified in SB 1741 – is to provide education to D/HH persons zero to 21 years old (Commonwealth of Virginia 2009). VSDB’s expertise may be most directly relevant to D/HH children. Of particular relevance to SB 1741, it offers a preschool program, although services do not currently extend to children less than 2 years old and its education focuses primarily on ASL even if it supports language development in listening/spoken language as well.

If VSDB were the implementing agency, the estimated fiscal impact of SB 1741 would be similar compared to DBHDS. VSDB estimated a fiscal impact of around $120K to $130K (for Years 1 and 2) and ongoing costs of around $26K to $40K to implement the provisions of the bill. By comparison, DBHDS estimated a fiscal impact of around $200K for Years 1 and 2, and ongoing costs of around $33K, when SB 1741 was introduced in the 2019 session.

Regardless of agency identified to implement the bill’s provisions, SB 1741 would require regulatory changes by DBHDS and VDOE and could incur additional implementation-related costs. The legislation requires that the Parent Resource envisioned by the bill “[e]xplain that parents may bring the parent resource to an Individual Family Service Plan (IFSP) or IEP meeting for purposes of sharing their observations about their child's development.” The provision is already captured in current federal law: under IDEA, parents currently can bring relevant materials to IFSP/IEP meetings – including observations from milestones. However,
parents or providers may not currently be aware of language development instruments or milestones, particularly for ASL. By contrast, the mandated use of specific assessment instruments by providers envisioned by SB 1741 would require DBHDS/VDOE regulatory changes: local EI systems/Local Education Agencies (LEAs) are not currently required to use specific assessment instruments for any federally reported indicators (see Language Development Measurement section). Parents can currently request that an IFSP/IEP team use a specific language assessment instrument, and while the IFSP/IEP team would be required to consider its use, the choice of instrument(s) would be decided on a case-by-case basis. Additionally, many language assessment instruments are proprietary, and requiring annual language milestone assessments by IFSP/IEP teams specific to this population could incur additional provider time and costs (even if incremental costs to local EI systems/LEAs for mandated set of tools is unknown at this time).

Modify basis for milestone selection
There are several reasons that SB 1741’s requirement to select “language developmental milestones from standardized norms” may not be appropriate. First, this criterion is unclear: according to federal definitions, standardization relates to the process of administration of an assessment (i.e., whether an evaluation can be consistently replicated (U.S. Congress 1992)), whereas norms relate to the type of assessment (e.g., whether an assessment is “norm-referenced” – comparable to peers – or “criterion-referenced” – comparable to standards)5. Second, if state-specific milestones differed in any way from norm-referenced instruments previously validated on other populations, such milestones would no longer be norm-referenced. Finally, requiring milestone selection based solely on norm-referenced instruments could unduly limit choice of appropriate milestones. For example, some commonly used instruments for this population are not norm-referenced and/or standardized (including an instrument recommended by a Louisiana “LEAD-K Task Force” considering similar legislation (Louisiana LEAD-K Task Force 2019)). Requiring assessments that are “appropriate and technically sound” could provide greater flexibility in milestone selection in line with the intent of SB 1741.

Use Virginia’s Resource Guide for Families of Children with Hearing Loss (“green” guide) as the basis for future versions of a parent resource that include language development milestones
Senate Bill 1741 requires development of a 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 two parent-oriented resource guides that provide information in line with SB 1741’s requirements. “Virginia’s Resource Guide for Families of Children with Hearing Loss” (also known as the “green” guide) contains information about hearing, hearing technologies, communication and language, EI and IEPs, and additional tools and resources for parents (Virginia Commonwealth University 2016). A printed version is provided by VDH’s EHDI program to families of children zero to three years of age who are recently diagnosed with hearing loss. First produced in early 2000s, it was revised in 2012 and 2016 and is expected to

5 SOL is an example of a criterion-referenced test.
undergo revisions beginning in 2020 (the existing printed stock is expected to last for two to three more years). The “Companion Guide for Children in Elementary School” (also known as the “orange” guide), covers ages two to 21 and contains information similar to the “green” guide” as well as additional information on schooling (Virginia Commonwealth University 2018). First produced in 2018, it is not expected to be revised in the near future.

**Authorize SB 1741 implementing agency to determine Advisory Committee size and skill set – with legislation stipulating minimum criteria to achieve balanced representation – and link committee members’ roles to their qualifications**

The specificity of the composition of the Advisory Committee required by SB 1741 risks omitting relevant perspectives. It requires the constitution of a 13-member Advisory Committee whose members have precisely defined qualifications (e.g., one credentialed teacher of students who are deaf or hard of hearing and who uses the dual languages of American Sign Language and English). In the context of 16 language/communication modality combinations recognized by VDOE and myriad sets of stakeholders relevant to D/HH children, the stakeholder workgroup could not reach consensus on an optimal Advisory Committee size or member skill sets. The approach outlined in the bill risks excluding knowledgeable candidates on technical grounds and/or duplicating skill sets of candidates with multiple qualifications.

Additionally, similar legislation in other States has evolved to provide greater State agency authority over determining committee specifics. As indicated in Table, Virginia has an opportunity to build on trends in other States by being less specific in Code and providing greater State agency authority over determining committee specifics.

**Table 4. Evolution of Advisory Committee Constitution in Other States**

<table>
<thead>
<tr>
<th>State</th>
<th>Year</th>
<th>#</th>
<th>Skills specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA</td>
<td>2015</td>
<td>13</td>
<td>- All members’ characteristics/skill sets inscribed in Code</td>
</tr>
</tbody>
</table>
| KS    | 2016 | 13 | - Characteristics/skill sets of 6 members inscribed in Code  
- 7 members are ex officio State agency representatives |
| GA    | 2017 | 13 | - All members’ characteristics/skill sets inscribed in Code |
| SD    | 2018 | 10 | - Characteristics/skill sets of 6 members inscribed in Code  
- Implementing agency can choose between 11 characteristics / skill sets for 4 members |
| IN    | 2019 |     | - Determined by implementing agency (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 |     | - Determined by implementing agency (Code includes three broad requirements related to Committee composition, and permits inclusion of up to 20 characteristics/skill sets) |

Finally, greater definition of committee members’ roles is warranted. The Advisory Committee has two different sets of tasks: selecting language development milestones; and providing information about available programs and services. The knowledge, expertise and perspectives
needed for each task are likely to be different as well. Linking committee members’ roles to their qualifications could clarify expected responsibilities (e.g., milestone selection vs information on available programs/services for the Parent Resource).

**Task implementing and coordinating agencies with determining which additional characteristics of children assessed can be collected and reported to inform agency programming**

Language milestone data required to be collected by Senate Bill 1741 would be limited in generalizability to Virginia’s D/HH children up to five years of age. The legislation requires assessment of and reporting on all children on Individual Family Service Plans (IFSPs)/IEPs up to five years of age. That population – children receiving EI services or on an IEP and who have hearing loss or hearing impairment as an IFSP/IEP eligibility category – represent a subset of all D/HH children zero to five years of age in Virginia. Any report based on those data would not capture D/HH children who do not receive IDEA-based services or accommodations, such as those with Section 504 plans through VDOE or those who receive no services/accommodations. It is unknown what percentage of total D/HH children zero to five years of age this report would capture.

Also, because language development milestones are not measured on any other group in Virginia, there would be no basis for comparing outcomes to other children in Virginia. (Such data could be used to track milestone achievement over time of this population without comparing to hearing peers or other groups.)

Evaluation of language development milestones would also incur costs. While SB 1741 calls for the report to be based on existing data reported federally, those data cannot be used to evaluate language development (see “Language Development Measurement” section). Because DBHDS was, at the time of writing of this report, in the initial stages of a process to procure a new EI data management system, the fiscal impact to DBHDS was unknown. VDOE estimated a fiscal impact of $95K in Year 1 and $45K thereafter for this data collection effort.

A report containing data points more finely disaggregated than in SB 1741 could more directly inform agency programming. The bill does not require that reporting of language development milestones be in any form less than the statewide aggregate. A lack of granularity of results could limit the report’s ability to inform agency programming. Systematic disparities in milestone achievement by geographic factors or communication approaches, for example, might serve as an empirical basis by which to affect agency-level funding. While there could be limitations on the ability to disaggregate data because hearing loss is a low incidence condition, the degree to which such limitations would limit reporting is unknown.
Alternative approaches to Senate Bill 1741

The following sections summarize recommendations for legislative action that Commission members may wish to consider in place of – or in addition to – provisions in SB 1741.

**Use the Virginia Longitudinal Data System (VLDS) as the basis for reporting on literacy outcomes of children diagnosed with hearing loss beginning at pre-kindergarten level**

Current initiatives to integrate Virginia agencies’ data may provide an opportunity to longitudinally track literacy outcomes of all children ever diagnosed with hearing loss before the age of three and who are part of the Virginia public schooling system. English literacy may be considered an outcome/proxy indicator for language acquisition since literacy cannot develop in the absence of language development. Additionally, written English is the sole form of communication shared by the great majority of D/HH children and is tracked by VDOE through PALS and SOL assessments beginning in preschool (see Language Development Measurement section). The Virginia Longitudinal Data System (VLDS) currently links data collected by six participating agencies – including VDOE – and VDH is currently in the process of onboarding EHDI data on children zero to three years old who were diagnosed with hearing loss (anticipated in early 2020). Once VDH EHDI data are onboarded to the VLDS, literacy outcomes tracked by VDOE at the kindergarten and early grade school levels (via PALS) and later grade school levels (using SOL testing) could be linked to those children’s hearing loss diagnosis. This would permit the longitudinal tracking of literacy outcomes of any child who was diagnosed with hearing loss through EHDI and attending a public school – including those who, through Cochlear Implants and/or hearing aids, participate in school without the use of an IFSP/IEP – not just children with hearing loss who have an IFSP or IEP with hearing loss as an eligibility disability category.

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

The anticipated revision of the existing “Green” Parent Resource Guide – provided to families of children zero to three years of age who are diagnosed with hearing loss by VDH’s EHDI program – can serve as a basis on which to integrate information on milestones. The revision process could include stakeholder input on language milestone selection and/or the provision of information on milestones developed in other States (e.g., existing milestones in California or Kansas) (California Department of Education 2018; K.S.A. 75-5397e Advisory Committee 2018).

In addition to printed Resource Guides, information provided by State agencies relevant to D/HH children could be better aligned. Multiple workgroup participants highlighted difficulty in knowing where to turn for information when a hearing loss diagnosis first is received. Additionally, how each agency fits into the system of services and supports is complicated and not always entirely evident to the public. Improved public understanding of roles of state agencies involved with D/HH children and families could be beneficial.
Strengthen existing agency initiatives to identify opportunities for Medicaid reimbursement of telehealth-delivered EI services and increase provider capacities in ECSE services to D/HH children

Because hearing loss is a low incidence condition, a lack of provider familiarity with hearing loss can be a barrier to the quality of services provided at each point of contact with the system of supports and services. At the time of screening, for instance, anecdotal evidence suggests that many providers are hesitant to provide “bad” screening results to parents, or downplay their potential significance out of fear of unduly alarming families. In other circumstances, failed screen information shared by hospital staff may not be absorbed by parents in the rush of papers to be signed and the excitement of going home (Yarbrough et al. 2018). 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 currently board-certified (Healthcare Workforce Data Center 2019a). In terms of services, a limited number of EI/ECSE providers have a thorough understanding of the needs specific to D/HH children: only 4% of Speech-Language-Pathologists (SLPs) specialize in needs specific to hearing loss (Healthcare Workforce Data Center 2019b).

Geographic barriers to accessing EI or ECSE services could be addressed through existing agency initiatives. For EI services, DBHDS maintains a list of Teachers of the Deaf and Hard of Hearing (ToDHH) qualified to deliver EI services. According to DBHDS, although the total number of ToDHH statewide is adequate to serve the EI needs of the State’s D/HH children, their geographic placement constitutes a barrier to accessing services outside of metropolitan areas. Although DBHDS is currently seeking DMAS approval to cover EI services delivered by telepractice, a recent DMAS memo that clarifies existing telehealth policy does not provide a process to include new/changed coverage (e.g., EI services). Allowing Medicaid reimbursement for EI services delivered by telepractice could address the geographical imbalance of ToDHH.

For ECSE services, the Virginia Network of Consultants currently provides Local Education Agencies (LEAs) access to providers experienced with D/HH children. Further, other states use LEA mentoring models that could be applicable to Virginia. Colorado’s Department of Education, for example, created a program using IDEA funding to address gaps between the increased use of Cochlear Implants and professionals experienced in addressing their communication needs (while the program originally focused on listening and spoken language, it has evolved to be more holistic). The program provides mentorship to professionals (e.g., educators, related service providers, administrators) to support education of D/HH children in school districts. Seven part-time mentors – whose qualifications include SLPs, ToDHH, interpreters and administrators – provide 200 to 400 hours each per year of support spanning preschool, grade school, and transition age levels. School districts are supported during a three-year period with a tapering level of technical assistance, and the Colorado Department of Education evaluates achievement of district-specific goals at four or five years (Colorado Department of Education 2019). Virginia could explore leveraging existing VNOC’s capacities to support a similar model (VNOC: Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing).
Identify opportunities to develop programs connecting families of D/HH children with D/HH adults, including Deaf Mentor programs, to increase uptake of EI services and assistance to families in sign- and non-sign-based communication

The importance of involvement of D/HH persons in systems of services/supports for D/HH children is widely recognized. A series of recommendations from the Joint Commission on Infant Hearing laid out the goal that “[a]ll children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH” (Joint Commission on Infant Hearing 2013). The potential impact that exposure to families unfamiliar with hearing loss and the implications it may have has been recognized at the federal level such as through a HRSA funded program to increase D/HH involvement in EI systems using mentors, guides, and role models (Hands & Voices 2019). However, for Virginia, multiple workgroup participants indicated that availability and/or affordability of resources in ASL instruction are limited compared to services for spoken language.

A “Deaf Mentor” program model connects families with D/HH children born to hearing parents to D/HH adults. The Deaf Mentor program model emphasizes instruction in ASL and exposure to Deaf culture. A limited body of research indicates that deaf mentoring programs may be beneficial for language development and self-efficacy (Watkins et al. 1998), although the research base is small and has not been systematically studies enough to draw firm conclusions. Several States support Deaf Mentor programs using both federal IDEA funds and state funding. In New Mexico, for example, certified EI providers offer developmental services reimbursable by Medicaid (New Mexico School for the Deaf 2019). Although a 2019 Virginia Board for People With Disabilities report recommended Deaf Mentors as one strategy to address specific EI-related workforce area shortages (Virginia Board for People with Disabilities 2019), the Commonwealth of Virginia does not currently support this model through funding or programming.

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6 For example, the five goals of a 3-year cooperative grant (2017-2020) between HRSA and Hands & Voices are: families with D/HH children and organizations serving families with D/HH children are partners in EI in every state; support families in becoming leaders in the EI system; increase family to family support; families increase knowledge of language, literacy, and social emotional development for children; and increase D/HH involvement in EI system using mentors, guides, and role models

7 The goal of New Mexico’s program is to ensure that families have tools for D/HH children to communicate and maximize their learning opportunities. Deaf Mentors – who are certified EI developmental specialists with Bachelors/Masters training - have experience with a variety of communication modalities and work with families one to two times per week to teach principals around literacy and early communication foundations/skills based on SKI-HI/VL-2 curricula. Children diagnosed as D/HH are automatically referred to the program and are eligible for services up to 6 years old, and around 250 children are served annually (families typically receive services for around 2.5 years). Through a Memorandum of Understanding with the state Medicaid agency, services are billable to Medicaid as a developmental service (this arrangement was approved by the state Medicaid agency 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).
Policy Options and Public Comment

Seven policy options were provided to Commission members for consideration. Comments were received by 261 individuals and 8 organizations. Of the 265 individuals submitting comments, 151 were Virginia residents, 80 were out-of-State (OoS) individuals, and 34 were of unknown residence.

95% of comments received were one of four form letter comments:
- Form letter #1 supported policy option #2 (in addition to taking positions on other policy options)
- Form letters #2, 3 and 4 opposed policy option #2 (in addition to taking positions on other policy options)

Comments were received by the following organizations:

Form letter #1:
- Howard Rosenblum, Chief Executive Officer, National Association of the Deaf (NAD)
- Board of Directors (unsigned), Virginia Registry of Interpreters for the Deaf (VRID)

Form letter #3:
- Lisa Christensen, President, American Academy of Audiology (AAA)\(^8\)
- Donna Sorkin, Executive Director, American Cochlear Implant Alliance (ACIA)
- Barbara Kelley, Executive Director, The Hearing Loss Association of America (HLAA)\(^9\)
- Julia Bellinger, Manager, Government Affairs, International Hearing Society (IHS)

Non-form letters:
- Shari B. Robertson, President, American Speech-Language-Hearing Association (ASHA)
- Hilary Piland, Public Policy Manager, Virginia Association of Community Services Boards (VACSB)
- Samantha Marsh Hollins, Assistant Superintendent Department of Special Education and Student Services, Virginia Department of Education (VDOE)

Non-form letter comments were received by the following individuals:
- Judy Alonzi
- Vicki Harrington
- Anne Hughes
- Renee Maxwell
- Leah Muhlenfeld
- Deborah Pfeiffer
- Gianina Thornton
- Jacob Thornton
- Irene Schmalz
- Joan Franklin (OoS)
- Vicki Harrington (OoS)
- Elizabeth Weyerhaeuser (OoS)

\(^8\) American Academy of Audiology’s comments did not adopt the exact same language as form letter #3 but was substantively similar.

\(^9\) HLAA’s comments did not adopt the language of form letter #3 but supported recommendations made by AAA and ACIA.
### Overview of comments

<table>
<thead>
<tr>
<th>Comments</th>
<th>Individuals</th>
<th>Organizations</th>
<th>Of individuals, # comments:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>In-State</td>
</tr>
<tr>
<td>Form letter #1</td>
<td>236</td>
<td>2</td>
<td>127</td>
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<td>Form letter #2</td>
<td>10</td>
<td>0</td>
<td>10</td>
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<tr>
<td>Form letter #3</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Form letter #4</td>
<td>2</td>
<td>0</td>
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</tr>
<tr>
<td>Other comments</td>
<td>11</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>265</strong></td>
<td><strong>9</strong></td>
<td><strong>151</strong></td>
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</table>

<table>
<thead>
<tr>
<th>Policy Option</th>
<th>Support</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 1</strong>: Take No Action</td>
<td>Form letter #3&lt;sup&gt;10&lt;/sup&gt;</td>
<td>Form letter #1</td>
</tr>
<tr>
<td></td>
<td>Includes: AAA, ACIA, HLAA, IHS</td>
<td>Includes: NAD, VRID</td>
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<tr>
<td></td>
<td></td>
<td>Form letter #2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Deborah Pfeiffer</td>
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<tr>
<td></td>
<td></td>
<td>Joan Franklin (OoS)</td>
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<td></td>
<td></td>
<td>Elizabeth Weyerhaeuser (OoS)</td>
</tr>
<tr>
<td><strong>Option 2</strong>: Introduce legislation and budget amendment based on SB 1741 with the following modifications:</td>
<td>Form letter #1 (with modifications noted below)</td>
<td>Form letter #2</td>
</tr>
<tr>
<td></td>
<td>Includes: NAD, VRID</td>
<td>Form letter #3</td>
</tr>
<tr>
<td></td>
<td>Form letter #2</td>
<td>Includes: ACIA, HLAA, IHS</td>
</tr>
<tr>
<td></td>
<td>Deborah Pfeiffer</td>
<td>Form letter #4</td>
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<tr>
<td></td>
<td>Joan Franklin (OoS)</td>
<td>Anne Hughes</td>
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<tr>
<td></td>
<td>Elizabeth Weyerhaeuser (OoS)</td>
<td>Leah Muhlenfeld</td>
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<tr>
<td></td>
<td></td>
<td>Irene Schmalz</td>
</tr>
<tr>
<td>Define terms, including: language, communication modality, English, deaf or hard of hearing</td>
<td>Comments in form letter #1, Jacob and Gianina Thornton: include ASL</td>
<td></td>
</tr>
<tr>
<td>Change agency assigned to lead the implementation of SB 1741: from DBHDS to VSDB, in coordination with DBHDS, VDOE and VDDHH</td>
<td>Comments in form letter #1: change to VDDHH</td>
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<td>Continued…</td>
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</table>

<sup>10</sup> Support for policy option #1 stated as a 1<sup>st</sup> preference. However, form letter #3 also supports other policy options.
<table>
<thead>
<tr>
<th>Policy Option</th>
<th>Support</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change requirements for constitution of Advisory Committee: stipulate that</td>
<td>• Comments in form letter #1:</td>
<td></td>
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<tr>
<td>VSDB will: 1) Determine size of Advisory Committee; 2) Ensure balanced</td>
<td>must include better balance between English and ASL</td>
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<tr>
<td>membership in terms of: individuals who have expertise in the assessment/</td>
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<tr>
<td>instruction of ASL, spoken English, English with visual supports, literacy;</td>
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<tr>
<td>parents of children who are deaf or hard of hearing; individuals who are</td>
<td></td>
<td></td>
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<tr>
<td>deaf or hard of hearing and those who are not</td>
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<td></td>
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<tr>
<td>Stipulate that Parent Resource should be based on pre-existing resource</td>
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<td>guides</td>
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<tr>
<td>Change basis of milestones away from “standardized norms”: Base milestone</td>
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<td></td>
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<tr>
<td>selection on currently available assessments that are appropriate for</td>
<td></td>
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<tr>
<td>evaluating progress toward age-appropriate language, including American</td>
<td></td>
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<tr>
<td>Sign Language, Spoken English, and English literacy</td>
<td></td>
<td></td>
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<tr>
<td>Require that milestone data include additional characteristics of assessed</td>
<td></td>
<td></td>
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<tr>
<td>children that can best inform agency-level programming, as determined by</td>
<td>• Form letter #1</td>
<td></td>
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<tr>
<td>VSDB and coordinating agencies</td>
<td>Includes: NAD, VRID</td>
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<tr>
<td>Continued…</td>
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<tr>
<td>Policy Option</td>
<td>Support</td>
<td>Oppose</td>
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</tbody>
</table>
| **Option 3:** 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. | • Form letter #2 (if tracked by modality, age of access to chosen modality, age of implantation, access to ASL models, etc.)  
• ASHA  
• Deborah Pfeiffer  
• Jacob and Gianina Thornton | • Form letter #1 Includes: NAD, VRID  
• Form letter #3 Includes: ACIA, HLAA, IHS  
• Form letter #4  
• Leah Muhlenfeld |
| **Option 4:** 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. | • Form letter #2  
• Form letter #3 Includes: AAA, ACIA, HLAA, IHS  
• Form letter #4 (with alternate suggestion)  
• ASHA  
• Judy Alonzi (with alternate suggestion)  
• Leah Muhlenfeld  
• Deborah Pfeiffer  
• Jacob and Gianina Thornton | • Form letter #1 Includes: NAD, VRID |

Continued…
<table>
<thead>
<tr>
<th>Policy Option</th>
<th>Support</th>
<th>Oppose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option 5</strong>: 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.</td>
<td>• Form letter #1 (“in combination with policy options 2 and 7”) Includes: <strong>NAD, VRID</strong>&lt;br&gt;• Form letter #2 (concerns about VSDB as coordinating agency)&lt;br&gt;• Form letter #3 (concerns about VSDB as coordinating agency) Includes: <strong>AAA, HLAA, IHS</strong>&lt;br&gt;• Form letter #4 (ensure comprehensive involvement in decisions with service provision organizations)&lt;br&gt;• Leah Muhlenfeld&lt;br&gt;• Deborah Pfeiffer&lt;br&gt;• Joan Franklin (OoS)&lt;br&gt;• Elizabeth Weyerhaeuser (OoS)</td>
<td>• <strong>ACIA</strong></td>
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<tr>
<td><strong>Option 6</strong>: 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.</td>
<td>• Form letter #2&lt;br&gt;• Form letter #3 Includes: <strong>AAA, ACIA, HLAA, IHS</strong>&lt;br&gt;• Form letter #4&lt;br&gt;• <strong>ASHA</strong>&lt;br&gt;• <strong>VACSB</strong>&lt;br&gt;• Leah Muhlenfeld&lt;br&gt;• Deborah Pfeiffer</td>
<td>• Form letter #1 Includes: <strong>NAD, VRID</strong></td>
</tr>
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</table>

Continued…
**Policy Option**

**Option 7:** 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.

**Support**
- Form letter #1 (“in combination with policy options 2 and 5”)
  - Includes: NAD, VRID
- Form letter #2 (if programs increase family support)
- ASHA (if Deaf Mentors include D/HH Individuals who use ASL, spoken language or combination of communication options)
  - Deborah Pfeiffer
  - Jacob and Gianina Thornton
  - Joan Franklin (OoS)
  - Vicki Harrington (OoS)
  - Elizabeth Weyerhaeuser (OoS)

**Oppose**
- Form letter #3
  - Includes: ACIA, HLAA, IHS
- Form letter #4
- Leah Muhlenfeld

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**Subsequent Actions by the Joint Commission on Health Care**

During the Joint Commission’s 2019 Decision Matrix meeting, JCHC members voted to Take No Action.

**JCHC Staff for this Report**

Andrew Mitchell, Sc.D.
Senior Health Policy Analyst
Citations


Department of Behavioral Health and Developmental Services, 2018. *Virginia’s Child Outcomes Booklet*, DBHDS.


Hands & Voices, 2019. Family Leadership in Language & Learning (FL3).


Virginia Board for People with Disabilities, 2019. Assessment of Virginia’s Disability Services System: Early Intervention, Richmond, VA: VBDP.


Virginia Department for the Deaf and Hard of Hearing, 2019. About VDDHH.


Virginia Department of Education, 2019b. Kindergarten PALS results (FOIA request), Virginia Department of Education.

Virginia Department of Education, 2019c. SOL Test Results.


Appendix – Content of form letters

Form letter #1

I am writing to you as a [Deaf Adult/Deaf Advocate/Deaf Professional/ASL Interpreter/Teacher of the Deaf/Family Member] for Deaf children.

Thank you for taking the time to study SB 1741 – Language Development Milestones and Parent Resources for Young Deaf/Hard of Hearing Children (hereafter ‘Deaf’). I would ask that you take the following action on the policy recommendations made by Andrew Mitchell, Senior Health Policy Analyst.

Policy Option 1 – **Please vote no to taking no action.** Choosing policy option one, will continue the status quo of systematic language deprivation of Deaf children.

Policy Option 2 – **Please vote yes to introduce legislation and budget amendments based on SB 1741 with the following modifications**

- Define terms, including: language, communication modality, English, deaf or hard of hearing
  *Must include a definition of ASL as well.*
- Change implementing agency: provide VDDHH* primary implementation authority, in coordination with DBHDS, VDOE and VSDB*.
- Change requirements for constitution of Advisory Committee: stipulate that VDDHH* 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
  *But that it must be updated to include a better balance between Languages: English and ASL. (Currently ASL guide is a separate publication and is not always given to parents of the Deaf.)*
- Change basis of milestones away from “standardized norms”. *Standardized norms are available from the Ski-Hi Program in Florida and from the California Schools for the Deaf*
- Require that milestone data include additional characteristics of assessed children that can best inform agency-level programming, as determined by VSDB and coordinating agencies *We support this demographic data collection on Deaf children regardless of how many disabilities they may have.*

Policy Option 3 - Please vote no on policy option 3. The analysis on literacy outcomes for children who are Deaf/Hard of Hearing should already be in practice. An analysis of literacy alone is insufficient - the concern here is the full acquisition of the child’s first language, as a foundation for English literacy. This does not address the need for VDOE to select milestones for use in assessing Deaf/Hard of Hearing children’s acquisition of ASL.

Policy Option 4 - Please vote no on policy option 4. It is insufficient for the state to only 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. Professionals in the field of Early Intervention and Early Childhood Education must be training on assessing these milestones and data must be collected to ensure state accountability for the language acquisition of Deaf/Hard of Hearing children. 

Policy Option 5 - Policy option 5 is only appropriate if it is selected in combination with Policy Options 2 and 7. It is unfortunate that the state agencies that serve Deaf/Hard of Hearing children do not already collaborate 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.

Policy Option 6 - Please vote no on policy option 6. ASL is a visual, tactile language. Physical touch is required for teaching ASL to a Deaf/HH child, especially during the critical language years (birth to five years old). Physical touch is used to model the sign location on the child’s body and to teach the appropriate sign movement and handshape. At times, when communicating in American Sign Language, physical touch is required as an attention getting technique, especially for young children. Due to the tactile and visual nature of ASL/Deaf Culture, telepractice is not 100% accessible for Deaf children (especially from birth to three years old). ‘In-Person’ language modeling that allows for physical touch is necessary for effective language exposure and adequate language acquisition.

Policy Option 7 - Please vote yes on policy option 7 in combination with Policy Options 2 and 5. Virginia is in desperate need of programs that connect families of D/HH children with D/HH adults - including mentoring programs by Deaf adults. Virginia is also in need of programs that increase access to ASL instruction for families with D/HH children. These programs are sorely needed, but do not alone address the issues raised in SB 1741. We ask that you please vote yes on policy option 7 in combination with recommending legislation and budget amendments based on SB 1741.

Thank you for your attention and consideration of this critical issue in Virginia. We look forward to seeing the positive impacts that Policy Options 2, 5, and 7 (in combination) will bring to Deaf/Hard of Hearing children in Virginia!
Thank you for your time and consideration of my comments on the Language Development Milestones and Parent Resources for Young Deaf/Hard of Hearing Children policy options. I am a parent of a deaf young man, a Cued Language Transliterator, and a member of the Northern Virginia Cued Speech Association, and I have an interest in the decision of the Commission.

I was appalled that the report produced by the Virginia Joint Commission on Health care completely ignored evidence that Cued Speech provides access to spoken language on the level that of received by typically-hearing children, even for profoundly deaf children who may receive limited benefit from hearing technology. Severely to profoundly deaf/hard-of-hearing children (D/HH) who use Cued Speech score as well as hearing children using the Developmental Sentence Score for expressive language (Berendt, et al 1990). This is because Cued Speech conveys spoken language visually; research shows that even profoundly deaf Cued Speech users have near-perfect visual reception of spoken language (Uchanski, et al 1990). Cued Speech is also linked to consistent, positive literacy outcomes for D/HH children, with or without hearing technology. For example, Illinois School for the Deaf found that where, nationally, D/HH children can expect a 2-month academic gain in a single school year, students whose IEP included cued English as the mode of instruction could demonstrate a 1-2 year academic gain in a single school year (Giese 2016). Furthermore, in Minnesota’s school district #917, literacy gains among deaf cuers were also 1 year in a single school year (Kyllo 2010). And, as the Commission’s report pointed out, English literacy is the universal measure of language among all American deaf/hard-of-hearing populations.

Cued Speech is the only modality that provides D/HH children complete access to the spoken language of their home, regardless of how well they are able to use hearing technology. For instance, cueing families in Virginia use cued Arabic and cued Hebrew, and the Northern Virginia Cued Speech Association is offering workshops this fall in cued Spanish. Research shows that D/HH children gain the most language when they have access to the language of the home via Cued Speech, in addition to cued English at school (Hage, C. et al 1989).

Moreover, the Commission is ignoring entire Virginia school districts and Virginia families who have chosen to use cued language via the Cued Speech system at home, at school, or both, including those in: Fairfax County, Prince William County, Arlington County, Stafford County, and the city of Williamsburg.

Before stating my positions in support of or against the Commission’s proposed policy options, I urge the Commission to keep oversight or management of a policy on children who are deaf and hard of hearing within the Department of Behavioral Health & Developmental Services (DBHDS) in coordination with other agencies within the Virginia Early Hearing Detection and Intervention system. The recommendation for the Virginia School for the Deaf and Blind (VSDB) to have oversight over the development of policies and resources will not effectively serve the needs of all children and families. VSDB serves children whose primary language is American Sign Language (ASL) and the school personnel have limited knowledge and resources to serve children who use spoken language with or without Cued Speech, which comprise the majority of children with hearing loss in our state and around the country. Most infants and young children with permanent hearing loss use Listening and Spoken Language (LSL) (60-70%), 10-15% use Cued Speech, and 6-9% use American Sign Language (ASL) (White, K. R. 2018).
The VSDB does not have an oral program for those who choose to use LSL, and the VSDB does not support the use of Cued Speech to provide access to spoken language. In contrast, DBHDS and the Virginia Department of Education (VDOE) staff have expertise in, and access to, the full range of all options and communication modals such as LSL, Cued Speech, Total Communication, ASL, and the language of the home if not English (Spanish, Korean, etc.).

Regarding the proposed Policy Options:
I support:

· Option Four. It is logical to incorporate language milestones into current VCU resource guides.
· Option Six. Medicaid covering early intervention services via telepractice would benefit many of Virginia’s children, not just those who are D/HH. Lack of transportation or long distance is a hindrance for all types of therapy (speech, physical, occupational).

I support, with qualification:

· Option Three. I fully support this option, only if the data collected to track D/HH children’s literacy in Virginia is in a format to support meaningful interpretation i.e. tracked by modality, age of access to chosen modality, age of implantation, access to ASL models, etc. This means VDOE must consult experts in the Virginia Early Hearing Detection and Intervention (EHDI) system, to include the Northern Virginia Cued Speech Association.
· Option Five. It is important for parents and families to have access to all unbiased information. The agencies listed are already involved in the updating and dissemination of resources. I reiterate concerns about the School for the Deaf having oversight over State agencies.
· Option Seven. I support expansion of D/HH mentorship opportunities—but only if D/HH mentors are matched with families to support the family’s language goals. Furthermore, providing a timeline for “implementing programs to increase access to ASL instruction” does not support the mission of existing federal legislation, which is to protect the rights of children with disabilities and their families. Programs must increase family support, which includes access to all resources, not just ASL instruction.

I do not support:

· Option One. Taking no action is not an option unless agencies and service providers are held accountable by Virginia laws and regulations to build on existing resources; ensure fair, balanced representation of Cued Speech in resources; and treat D/HH children who use Cued Speech as distinct groups when tracking literacy and language outcome data. The National Center for Hearing Assessment and Management reported in 2018 that families reported receiving the lowest quality information about Cued Speech compared to other options like LSL, Total Communication, or ASL (White, K.R. 2018). There is room for improvement within the state EHDI systems to provide higher quality information about Cued Speech to families.
· Option 2. The reintroduction of another bill for the fourth year in a row on this issue is a distraction from ongoing improvements.
Thank you for your time and consideration of my comments on the Language Development Milestones and Parent Resources for Young Deaf/Hard of Hearing Children policy options. I am a parent and have an interest in the decision of the Commission.

[Personalized content about individual background and perspective]

Before commenting on the policy recommendations, I would like to urge the Commission to keep oversight or management of a policy on children who are deaf and hard of hearing within the Department of Behavioral Health & Developmental Services (DBHDS) in coordination with the other agencies. The recommendation for the Virginia School for the Deaf and Blind (VSDB) to have oversight over the development of policies and resources will not effectively serve the needs of all children and families. VSDB serves children whose primary language is American Sign Language (ASL) and the school personnel have limited knowledge and resources to serve children who use spoken language, which comprise the majority of children with hearing loss in our state and around the country. Most children have mild to moderate hearing loss and function well with technology and listening and talking. Most infants and young children with permanent hearing loss use Listening and Spoken Language (LSL) (60-70%), 10-15% use Cued Speech, and 6-9% use American Sign Language (ASL) (White, K. R. 2018).

The VSDB does not have an oral program for those who choose to use LSL. Their emphasis is on meeting the needs of children with profound hearing loss and/or blindness who have chosen to make limited use of 21st century technology—hearing aids and cochlear implants. In contrast, DBHDS and the Virginia Department of Education (VDOE) staff have expertise in, and access to, the full range of all options and communication modals such as LSL, Cued Speech, Total Communication, ASL, and the language of the home if not English (Spanish, Korean, etc.).

The report contains outdated and erroneous statements. The report referenced a since debunked 2000 study that median reading ability of D/HH 12th graders is at 4th grade level; 10% with age-appropriate language skills. Not only does this statement combine all types of hearing loss into one category, it ignores numerous more recent studies that show quite the opposite, especially for those children who are implanted around 12 months of age. These include the Dettman et. al, 2013; Dornan et al., 2010; Geers 2011, and Nicholas 2007 peer reviewed studies.

Moreover, the report states that children with a CI do not obtain age level language development due to “underlying disability”. In fact, the 2017 Geers study found that over 70% of children who received cochlear implants at an early age and did not use sign language achieved age-appropriate spoken language.

I support:

- Option One. Taking no action is the simplest due to improvements already underway by the VDOE and forthcoming changes to resources. Additionally, a continued legislative battle distracts from implementing current and future improvements to the system.
- Option Four. As there are milestones developed or being developed, it is logical to incorporate them into the current VCU resource guides.
- Option Five. It is important for parents and families to have access to all unbiased information. The agencies listed are already involved in the updating and dissemination of resources. I reiterate concerns about the School for the Deaf having oversight over the
other agencies with long and robust experience in educating and working with children across the scope of hearing loss.

- Option Six. Medicaid covering early intervention services via telepractice—would benefit many of Virginia’s children, not just those who are deaf and hard of hearing. Lack of transportation or long distance is a hinderance not only for all types of therapy (speech, physical, occupational).

I do not support:

- Option 2. The reintroduction of another bill for the fourth year in a row on this issue is a distraction from ongoing improvements.
- Option 3. As the state already tracks literacy within the school system, Option Three is unnecessary and introduces confusion as to the difference between language and literacy.
- Option 7. If the Board were to consider Option 7 and a deaf mentor program, it must ensure that all forms of communication and parent choices are supported. The EHDI Act of 2017 supports programs and systems that “foster family-to-family and deaf and hard hearing consumer-to family supports” and makes no mention of a Deaf mentor program. Referencing a “Deaf” mentor program does not satisfy the need for options across the continuum including mentors with varying levels of hearing loss and diverse ways of communicating—including spoken language. I do not support Option 7 as currently described.

Thank you again for your time and consideration of this matter.
In order to be respectful of your busy schedule, I have provided the policy options I feel may assist Virginia in improving systems, and which I feel would be extremely detrimental to current and future families of children with hearing loss.

**WE SUPPORT**

**Policy Option 1**  Take No Action  
Justification: The mandates put forth in this bill are ones that are suggested by the LEAD-K national organization in California. The Commonwealth of Virginia already provides resources for children with hearing loss and their educators, we already follow developmental hierarchies for normal development for all children with disabilities, and we are in compliance with the federal and state mandates that require ongoing assessment and recommendations for children with hearing loss. We have problems with service provision for children with hearing loss in our state, but we need to empower our state agencies to make the needed improvements. This bill will not address or solve those problems. Instead, it will only financially-burden our already-struggling state agencies with activities and tasks that do nothing to solve the actual problem.

**Policy Option 4**  Incorporation of Language Development Milestones  
Justification: We support with an alternate suggestion. Developmental milestones for children who do not have hearing loss already been fully-established and numerous resources are readily available which include them. Based on discussions during the workgroup meetings, a resource including ASL milestones has also been developed, but is constantly evolving. Although we do not have opposition to including them, we have two issues that should be considered:

1. If resources are already published and available for language development milestones, would it be more cost-efficient to purchase one of these resources versus add them to the resource and pay additional publication fees for additional printing;

**Developmental Norms for Speech and Language**  
[https://www.asha.org/slp/schools/prof-consult/norms/](https://www.asha.org/slp/schools/prof-consult/norms/)  

If ASL developmental milestones exist but are still being developed, would it be more cost-efficient to also purchase this accepted resource (VCSL) and provide the most recent version to families? Otherwise, if new editions become available and a new state resource is not due for updating, we would be providing families with an outdated version until a new Resource Guide can be updated and financed.

**The Standardized Visual Communication and Sign Language Checklist for Signing Children (VCSL)**  
Laurene Simms, Sharon Baker, M. Diane Clark  
*Sign Language Studies, Volume 14, Number 1, Fall 2013, pp. 101-124*  
*Published by Gallaudet University Press DOI: 10.1353/sls.2013.0029*

**Policy Option 5**  Assignment of VSDB as the Coordinating Agency  
Justification: We support with qualification. If VSDB is to become the coordinating agency for this project, other state education agencies and programs charged with service provision for children with hearing loss must be comprehensively involved with any decisions made. We believe this is necessary because:

1. Residential schools for the deaf have historically been the home of individuals who claim membership in Deaf culture, where the primary language used is American Sign Language. Recently, these schools have
attempted to embrace as bilingual-bicultural approach that claims to teach ASL and English, but this philosophy still does not include oral methods of communication, including listening and spoken language and Cued Speech. As one of the oldest schools for deaf in the country, VSDB’s history and current culture is synonymous with this philosophy. There are no employees or programs at VSDB that are qualified or appropriate for any child whose family has chosen an oral method for language development for their child. As such, other agencies must be involved to maintain unbiased and equitable program development;

2. Only statewide programs, such as DBHDS (Early Intervention) and VDOE, have the reach to ensure that any recommendations made will be able to be rolled out across the state. VSDB only has jurisdiction on their campus.

**Policy Option 6**  
**Budget Amend. Requiring DMAS to Review Reimbursement for Telepractice**
Justification: Due to the lack of qualified professionals statewide and the financial and physical obstacles that are very real deterrents for many families seeking appropriate intervention for their child, telepractice is the service provision vehicle for the present and future. Much research has provided evidence of its effectiveness and its ability to bring much-needed services to individuals who would otherwise not have access to them

**WE DO NOT SUPPORT**

**Policy Option 2**  
**Legislation and Budget Amendment**
Justification: This bill will not address or solve the problems we have with service provision for children with hearing loss in Virginia. Instead, it will only financially-burden our already-struggling state agencies with activities and tasks that do nothing to solve the actual problem. None of the proposed changes will affect the system-wide change necessary to improve outcomes of these children.

Furthermore, the development and process for passing this highly-controversial bill will prove to bog down the legislative process for the fourth year in a row and distract from the actual issues we should be working to improve.

**Policy Option 3**  
**Analysis of Literacy Outcomes**
Justification: An accurate analysis of literacy outcomes of all children with hearing loss is impossible without a completed overhaul of the current data collection system. Review of past data would only deliver data that is incomplete, skewed and misrepresentative. One cannot make any valid decisions based upon invalid data.

As mentioned previously, many children who use listening and spoken language reach age-appropriate levels of language and literacy early in their school years. As such, they are no longer tracked by the Individualized Education Plan (IEP). Because of this, their scores are assimilated into the Standards of Learning assessments and not separated from the rest of the student population.

**Policy Option 7**  
**Deaf Mentor Program**
Justification: At this juncture, there is no language in federal or state mandates that endorses a Deaf mentor program, which is inherently biased and inequitable to all other languages and communication methods due to its designation of “Deaf” as a cultural reference. Currently, many listening and spoken language families receive support through personal contacts made through professional connections or through support groups or social media. It seems that, if a list of resources for Deaf mentors should be developed and housed, it should be through VSDB. This school has access to generations of their graduates who may be willing to meet and be involved in the lives of children who use ASL. This does not seem to be a need necessary of a state budget amendment, when the need can be satisfied through other existing means.
It is my hope that this Commission will ensure the best possible outcomes for children with hearing loss by supporting current state agencies and by making sure these children have access to the healthcare that allows for the best possible outcomes for these children.
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)

* D/HH: Deaf or hard of hearing
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

* See slides 38 - 39 of Appendix for additional detail

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

* See slides 40 – 42 of Appendix for additional detail
Multiple state agencies provide services / supports for D/HH children and families*

<table>
<thead>
<tr>
<th>Age</th>
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<th>2</th>
<th>3</th>
<th>4</th>
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<td><strong>Services</strong></td>
<td>Individualized Family Service Plan (IFSP)-based Early Intervention (EI); (DBHDS)</td>
<td>Individualized Education Program (IEP)-based Early Childhood Special Education (ECSE); (VDOE; The Virginia School for the Deaf and the Blind (VSDB))</td>
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<td>Virginia Hearing Aid Loan Bank (VDH)</td>
<td>Virginia Project for Children and Young Adults with Deaf-Blindness (VCU)</td>
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<td>VSDB outreach services (VSDB, VDOE)</td>
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<td>EHDI Learning Communities (VDH, VCU)</td>
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<td></td>
<td>1-3-6 Family Educator Program (VDH, VCU)</td>
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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

* See slide 48 of Appendix for additional detail

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*

  ![Image 1](virginias-resource-guide-green-1.png)
  ![Image 2](virginias-resource-guide-green-2.png)

- EI-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)

* See slide 51 of Appendix for additional detail
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

* See slide 52 of Appendix for additional detail

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*

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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

* See slide 54 of Appendix for additional detail

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

* See slide 55 of Appendix for additional detail
Policy Options

Policy Options 1 and 2

- Take No Action

- Introduce legislation and budget amendment based on SB 1741 with the following modifications:
  
  Define terms, including: language, communication modality, English, deaf or hard of hearing

  Change agency assigned to lead the implementation of SB 1741: from DBHDS to VSDB, in coordination with DBHDS, VDOE and VDDHH

  Change requirements for constitution of Advisory Committee: 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

  Change basis of milestones 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
Policy Option 3

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.

Policy Option 4

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.
Policy Option 5

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.

Policy Option 6

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.
Policy Option 7

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

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
- Manualized English (MDE)
- 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

<table>
<thead>
<tr>
<th>Screenings/diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Hearing Detection and Intervention (EHDI) Program:</strong> provides information/referral to families on newborn hearing screening, follow-up testing, early intervention services</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Intervention (EI):</strong> known as &quot;Infant &amp; Toddler Connection of Virginia&quot;, provides EI supports/services to children 0-3 years old not developing as expected or with medical condition that can delay normal development</td>
</tr>
<tr>
<td>• Services and supports determined through an <strong>Individual Family Service Plan (IFSP)</strong></td>
</tr>
<tr>
<td><strong>Early Childhood Special Education (ECSE):</strong> specially designed instruction to meet unique needs of children with disabilities</td>
</tr>
<tr>
<td>• Determined through an <strong>Individualized Education Program (IEP)</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services (con't)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Virginia Hearing Aid Loan Bank:</strong> lends hearing aids/FM systems for up to six months to children &lt;18 years old</td>
</tr>
<tr>
<td><strong>Virginia Project for Children and Young Adults with Deaf-Blindness:</strong> 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</td>
</tr>
<tr>
<td><strong>VSDB outreach services:</strong> Webinars, trainings, events for family members of D/HH students; free audiologic evaluations for Virginia children 0-21 years old</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Peer Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EHDI Learning Communities:</strong> program to bring families and professionals together to influence systems change and improve outcomes</td>
</tr>
<tr>
<td><strong>1-3-6 Family Educator Program:</strong> 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</td>
</tr>
</tbody>
</table>
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 EI 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

• EI 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):

<table>
<thead>
<tr>
<th>Acquisition and use of knowledge and skills</th>
<th>Made progress*</th>
<th>Proficient**</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Disability Categories</td>
<td>95%</td>
<td>95%</td>
</tr>
<tr>
<td>Hearing Impairment / Deaf and Hard of Hearing</td>
<td>74%</td>
<td>56%</td>
</tr>
</tbody>
</table>

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)
  - 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)

- **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)
  - 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

  - 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 "ensure 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)

Source: ECTA Center
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 pre-school, grade school, and transition age levels.
- School districts supported during 3-year plan, with tapering technical assistance
  - Colorado Department of Education evaluates achievement of district-specific 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

SB 1741 (Senator Edwards, 2019 Session)

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 37.2-314.1 as follows:

   § 37.2-314.1. 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 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 Rights and Privacy Act (20 U.S.C. § 1232g) in carrying out the provisions of this section.
References

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

References

Slide 5 (Early language development positively affects overall development)
• 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.

References

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

Slide 15 (Considerations on Agency Roles in Implementation)

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Slide 53 (Colorado Deaf Mentor Program)

Slide 54 (HRSA-Supported Family Leadership in Language and Learning (FL3) program)
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Slide 55 (New Mexico School for the Deaf (NMSD) Deaf Mentor Program)
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