REPORT TO THE THIRTIETH LEGISLATURE
STATE OF HAWAII
2019

PURSUANT TO ACT 177, SESSION LAWS OF HAWAII, 2016:
RELATING TO HEALTH

2019 REPORT OF FINDINGS AND RECOMMENDATIONS
OF THE EARLY LANGUAGE WORKING GROUP TO SUPPORT
AGE-APPROPRIATE LANGUAGE DEVELOPMENT
FOR CHILDREN FROM BIRTH TO AGE FIVE YEARS
WHO ARE DEAF, HARD OF HEARING, OR DEAF-BLIND

PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
FAMILY HEALTH SERVICES DIVISION
DECEMBER 2018
EXECUTIVE SUMMARY

Hawaii consistently ranks as having the highest rate of newborns with permanent hearing loss in the United States (4.0 per 1,000 screened compared to 1.7 per 1,000 screened nationally in 2016). This means that each year in Hawaii there are about 55 infants born with hearing loss. Because most babies with hearing loss are born to hearing parents, this is a new experience for the parents and options or resources are not readily available for these families of children who are Deaf/Hard of Hearing/Deaf-Blind (D/HH/DB). Children who are D/HH/DB can have effective communication if given adequate and appropriate access to language within the critical years of development. Research shows that when children who are D/HH/DB are identified early and receive support, they can develop language on par with their peers.

Act 177 of the 2016 State Legislature established the Early Language Working Group (ELWG). The purpose of the Working Group is to make recommendations to the legislature on issues related to supporting age-appropriate language development for children age 0-5 years who are D/HH/DB. Although the Working Group formally sunset on June 2018, the group continued under the Hawaii State Department of Health (DOH), Family Health Services Division, Children with Special Health Needs Branch. By continuing the Working Group, members can address the systemic challenges and pilot some recommendations to see if additional resources are needed based on evaluation and findings of the pilots. The Working Group also plans to develop a strategic plan in 2019 to address the recommendations made in the 2018 report in the four areas of:

1. Resources to Families
2. Assessments for Children
3. Qualified Staffing and On-Going Training and Professional Development
4. Data Systems

These discussions enabled the Working Group to enhance the 2018 recommendations on the tasks assigned by the legislature: identify a resource guide for parents; identify tools used to assess and plan language development services; assess data availability; identify improvements to services; and identify improvements for transition from the DOH to Department of Education (DOE).

Per the legislation and tasks identified, the recommendations are as follows:

1. **Ensure there is a family-centered, culturally appropriate, comprehensive resource center available in person, via phone, and via the Internet for families to support parents with children who are D/HH/DB.** This resource center will be able to maintain an accessible statewide directory of comprehensive resources for families that includes events, programs, and services available. This may also be a resource specific to supporting young children’s language development by including information on developmental and language milestones for families and assessment tools for professionals. Funding is needed to support this resource center with staffing and technology to ensure it is accessible to families statewide.
2. **Ensure standardization and consistency of the tools used to assess children who are D/HH/DB.** The current standardized assessment tools were found to be inappropriate for D/HH/DB children. The Working Group finalized a matrix of adequate assessment tools to determine language evaluation tools to be made available for use by DOH and DOE. The Working Group will present this matrix to the DOH and DOE for statewide implementation, thus helping to standardize the assessment of children who are D/HH/DB.

3. **Ensure adequate qualified staff and professional development to support those working with children who are D/HH/DB.** Currently there is one Early Intervention Deaf Specialist who services approximately 80 families statewide and one DOE Speech Language Pathologist-Assessor for the Deaf, Hard of Hearing and Visually Impaired. Both departments have requested an additional staff person at the state level for greater support. However, there is a larger issue of workforce shortage of qualified staff and there needs to be a clear strategy to address this and provide classroom/direct services in the communities. Additionally, professional development needs to be available year-round on a consistent basis so those working with these young children may continue to develop their knowledge and expertise with the most up-to-date research and methods.

4. **Ensure there is a data collection system available that will help support language and literacy development for children who are D/HH/DB.** This data system will be able to collect demographic data of the number of children who are D/HH/DB; track and monitor children to ensure appropriate follow-up and no gaps in services; and identify the needs of these children and how to best support them. Currently there is no standardized way to collect information on children who may be D/HH/DB and thus Hawaii is not able to track and monitor services and performance of these children effectively.
I. BACKGROUND ON EARLY LANGUAGE WORKING GROUP

Language acquisition for children who are D/HH/DB is an issue that receives both local and national attention. According to the Hawaii DOE 2015 State Systemic Improvement Plan, only 14% of Deaf and hard of hearing (D/HH) students have demonstrated reading proficiency compared to students without a disability with demonstrated reading proficiency of 74%.

Chart 1. Percentage of Students Demonstrating Reading Proficiency

<table>
<thead>
<tr>
<th>Percentage of Students Demonstrating Reading Proficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015 Hawaii State Systemic Improvement Plan</td>
</tr>
<tr>
<td>Strive HI: Student Group Performance Report Hawai‘i</td>
</tr>
<tr>
<td>SY 2013-2014, age 3-21 years old</td>
</tr>
</tbody>
</table>

- 74% Students without Disabilities
- 14% Students who are Deaf and Hard of Hearing (Hearing Impaired)


In 2016, a group of parents, professionals, and community advocates worked together to join six states promoting the Language Equality & Acquisition for Deaf Kids (LEAD-K) legislation to promote language development and school readiness for young children who may be D/HH/DB. LEAD-K is a campaign in response to the alarming number of D/HH children arriving at school without age-appropriate language. According to LEAD-K, “When provided with access and opportunities, the Deaf child has normal ability to develop language. The Deaf child who has the foundation of language will acquire English literacy. The Campaign aims to end language deprivation through information to families about language milestones and assessments that measure language milestone achievement, and data collection that holds our current system accountable.” (www.lead-k.org/about)
Hawaii’s goal for language development is through whatever options work best for children and their family, whether it be through American Sign Language (ASL), Total Communication, Listening and Spoken Language, or any other communication mode. With this goal for language development, Hawaii became the third state, following California and Kansas, to have a bill with LEAD-K principles enacted into law. Act 177 of the 2016 Hawaii State Legislature established the Early Language Working Group. The purpose of the Working Group is to make recommendations to the legislature on issues related to supporting age-appropriate language development for children age 0-5 years who are D/HH/DB. The responsibility of the Working was to examine, research, and make recommendations for the following:

1) Resource guide for parents of children who are D/HH/DB that may include milestones of age-appropriate language development, websites related to deafness and hearing loss, national and state organizations and resources for families, terms and definitions related to deafness and hearing loss, and communication modes.

2) Tools used to assess and plan language development services for children age 0-5 years who are D/HH/DB.

3) Data and availability of data on language and literacy development for children age 0-5 years who are D/HH/DB.

4) Improvements related to the statewide system of services that support age-appropriate language development for children age 0-5 years who are D/HH/DB.

5) Improvements related to the transition of children age 3 years from the DOH early intervention services to DOE services.

Requirements specified by Act 177 for Working Group members:

- One members is in each of 17 categories specified by Act 177
- Majority of the non-parent members are D/HH/DB
- At least one member represents Hawaii County, Maui County, or Kauai County
- At least one parent member is D/HH/DB
- Two parent members have children who are D/HH/DB and under age six years at the time of appointment to the Working Group

Appendix A lists the 17 past members of the Working Group appointed by the Director of Health. Appendix B lists the current members of the Working Group.

II. EARLY EXPOSURE TO LANGUAGE AND IMPACT ON BRAIN DEVELOPMENT

Language is “the method of communication, either spoken or written, consisting of the use of words in a structured and conventional way.” It is critical to recognize that language deprivation will impact a child’s ability to learn a broad range of skills necessary in becoming an effective and contributing member of society.

The Joint Committee on Infant Hearing (JCIH) was established in 1969 and composed of representatives from audiology, otolaryngology, pediatrics, and nursing. The Committee
explored the complexities of hearing loss and its effect on a child’s development, seeking to find newer and better methods to identify and serve the infants and their families. The JCIH 2007 Position Statement recognized that “All children with hearing loss should have access to resources necessary to reach their maximum potential” (http://pediatrics.aappublications.org/content/120/4/898).

In the 2013 Supplement, JCIH stated that “For the infant or young child who is D/HH to reach his or her full potential, carefully designed individualized intervention must be implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices, and proven models.” (http://pediatrics.aappublications.org/content/pediatrics/131/4/e1324.full.pdf),

An ELWG presentation (10/11/18) by Dr. Peter C. Hauser on “Deaf and Hard of Hearing Individuals’ Cognitive Development” emphasized that there is a critical period of brain development for language development. His research showed that early language deprivation affects cognitive development, school readiness, and executive function of the brain. He engaged with the ELWG members who asked questions on how to best promote language for children who are D/HH/DB. Moreover, the ELWG works to promote the enabling of parents to decide for themselves which communication mode would work best for their child and family.

A variety of communication modes are available for a child who is D/HH/DB. These methods¹ include:

- Listening and Spoken Language Method – utilizes speechreading (lipreading) and the maximal use of a child’s residual hearing for the development and production of speech.
- Manual Communication Methods – utilizes a child’s ability to communicate through visual stimuli such as fingerspelling and sign languages. These are examples of manual communication methods:
  - American Sign Language (ASL) is composed of positions and gestures made with the hands, body, and facial expressions to convey abstract concepts as with any spoken language. ASL has a distinct grammatical structure that is dissimilar to English.
  - Manual English uses many of the traditional ASL signs while maintaining the English word order and grammar to develop a child’s ability to read and write English.
  - Fingerspelling augments most sign language systems by using handshapes to code the letters of the alphabets as well as numbers.
  - Hawaii Sign Language, also known as Old Hawaii Sign Language and Pidgin Sign Language, is an indigenous sign language used in Hawaii.²
  - Cued Speech Method is a visual mode of communication that uses handshapes and placements in combination with the mouth movements of speech to make the phonemes of a spoken language look different from each other.

¹ Includes definitions and terms from California Department of Social Services website http://www.cdss.ca.gov/cdssweb/entres/pdf/ODA/CommunicationOptionsDHOH_Child.pdf
² https://www.ethnologue.com/language/hps
• Spoken Language Bilingual generally combines sign language and spoken language as complementary strategies for encouraging language development.
• Total Communication is an approach to Deaf education that aims to make use of several modes of communication such as signed, oral, auditory, written, and visual aids, depending on the needs and abilities of the child.

Once a child is diagnosed with a hearing loss, important decisions are needed about the child’s education, technology, and communication modes. Materials provided to the families should be objective to support families in making choices that best meet their child’s needs.

III. SERVICES AVAILABLE IN HAWAII

Services to children who are D/HH/DB vary across the state and among public and private programs and services. These include:

• DOH Newborn Hearing Screening Program
• DOH Early Intervention Services
• DOE Special Education
• DOE Hawaii School for the Deaf and the Blind
• Executive Office on Early Learning (EOEL) Public Pre-kindergarten Program
• Early Head Start and Head Start
• Private Early Childhood Programs

DOH Newborn Hearing Screening Program (NHSP)

The Hawaii DOH Newborn Hearing Screening Program (NHSP) helps to ensure all babies born in Hawaii receive a hearing screening by one month of age. State law requires that newborn hearing screening be complete to identify hearing loss as soon as possible so that children can receive timely early intervention services. Most babies are screened soon after birth while still in the hospital. Babies who are discharged from the hospital before a hearing screen is completed, as well as infants who are not born at a hospital, can still get a hearing screening. The NHSP provides the following services:

• Coordinates hospital hearing screening program on all islands.
• Helps families who did not receive a hearing screening at the hospital to make an appointment to get a hearing screening.
• Helps families make appointments for further hearing testing for newborns who do not pass the first screening and who need more testing (diagnostic evaluation).
• Helps families make appointments for hearing testing for children under three years old who passed the hearing screening as newborns but are later suspected of having a hearing loss.
• Refers families for early intervention services, such as speech and language therapy, and sign language courses.
• Provides information to families, health care providers, early intervention staff, and the public on hearing and hearing loss.
• Maintains statewide data on hearing screening results and follow-up.

Most health insurance plans cover the cost of newborn hearing screening. Arrangements can be made if families do not have insurance or cannot afford the cost. There are two types of screenings: Otoacoustic Emission (OAE) to find out if the inner ear responds to sound, or Automated Auditory Brainstem Response (AABR) where tiny electrodes are taped to the baby’s head to find out if the brain senses sound.

If the baby does not pass the hearing screening, parents are asked to return to the hospital for another screen within two weeks. If the baby does not pass the additional screen, an audiologist should be seen to do a hearing test. The baby’s doctor or hospital staff may help to make an appointment to have a hearing test or the NHSP can also assist. If a child is diagnosed with hearing loss, families will work with the baby’s doctor, audiologist and other health care providers to decide what services are important for their child. The child may be referred to DOH early intervention services for services based on the needs of the child and family.

**DOH Early Intervention Services (birth to 3)**

The DOH Early Intervention Section (EIS) is responsible for ensuring that early intervention services mandated under federal law are provided. Public Law 108-466 which is referred to as Individuals with Disabilities Education Act (IDEA) of 2004, Part C, mandates that a state provide early intervention services to infants and toddlers from birth to age three years. EIS is a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, age birth to three years and their families.

Early intervention services are provided to assist a child in five developmental areas:

- Physical (sits, walks)
- Cognitive (pays attention, solves problems)
- Communication (talks, understands)
- Social or emotional (plays with others, has confidence)
- Adaptive (eats, dresses self)

A child is eligible for services if the child has a developmental delay or has a condition with a high probability of resulting in a developmental delay in one or more of the above areas. A developmental delay means that a child’s development is below his/her age level. Services are available on all islands through public and private early intervention programs. Services are available at no cost to families and no income restrictions. However, whenever possible, payments may be accessed through Medicaid or private medical insurance with parental permission.

Children diagnosed as D/HH/DB are eligible for early intervention services because these are conditions that have a high probability of resulting in a developmental delay. Once a child is referred to EIS, a care coordinator is assigned to the family and will help them through the early intervention process. A developmental evaluation is conducted to determine if the child meets
the eligibility criteria for services. If a child is eligible, the child receives services based on an Individualized Family Support Plan (IFSP). This plan is created by a team that includes the family and care coordinator. The following services are provided if needed:

- Assistive Technology
- Audiology
- Care Coordination
- Family Training, Counseling and Home Visits
- Nursing
- Nutrition
- Occupational Therapy
- Physical Therapy
- Sign Language and Cued Speech
- Social Work
- Special Instruction
- Speech-Language Pathology
- Vision Services

Parents and/or caregivers are coached on how to help their child learn and grow. Early intervention specialists support parents in helping their child develop.

**DOE Special Education (age 3-5)**

The Hawaii DOE operates the IDEA Part B program, which provides special education for children 3-5 years of age. Special education is specially designed instruction and services to meet the unique needs of students with disabilities and can include academic services, speech-language services, psychological services, physical and occupational therapy, and counseling services. The DOE provides these services at no cost to families to anyone age 3 to 5 years who demonstrate a need for specially designed instruction after an eligibility determination.

Federal IDEA and state regulations require the Hawaii State DOE to provide a free appropriate public education (FAPE), which includes a continuum of services for students who are eligible for special education and related services.

Special education services are made available to any student age 3 to 22 who demonstrates a need for specially designed instruction, after an eligibility determination. An evaluation will determine the nature and extent of the student’s needs. Evaluations are comprised of separate assessments which may include: academic performance, communication skills, general intelligence, health, vision, hearing, social and emotional status, and motor abilities. If a student is eligible for special education, services are provided to the student through an Individualized Education Program (IEP).

If the family would like their child to be considered for Preschool Special Education, they need to contact the child’s home school, which is the neighborhood school that the student attends and request an evaluation. The request can be made by:
• Verbally, in person, or by phone;
• In a written letter, faxed, or e-mailed; or
• On the State of Hawaii Request for Evaluation form.

In completing the Request for Evaluation form, parents are to indicate areas of concern that they feel their child is having, even if these concerns may not be considered as educational.

The school may invite the parent to a meeting, consisting of teachers, and possibly the counselor and/or principal, to discuss the student’s needs. The team may review student records, grades, test scores, etc., to determine whether an evaluation is appropriate and to determine what type of assessment(s) is needed. The school will respond within 15 days if an evaluation will or will not be conducted. Parental consent will be required for an evaluation to be conducted.

**DOE Hawaii School for the Deaf and the Blind (age 3-21)**

At the Hawaii School for the Deaf and the Blind (HSDB), all faculty are certified teachers of the deaf and use American Sign Language (ASL) to teach a standards- and research-based curriculum. Teachers and educational aides use ASL as the learning focus in extended learning time to build students’ first language proficiency, which will bridge the English language learning for students. Students participate with Kalani High School for Oahu Interscholastic Association sports activities that are not offered at the School. Enrollment starts at age three and the dormitory program is available for children beginning at age eight. Neighbor island students are flown home every weekend to maintain close family ties. The school pays for the cost of the home-going program, including airfare and ground transportation. The school provides ASL classes to parents at the campus and in rural communities on Oahu. Opportunities for volunteering on campus by parents are strongly promoted.

HSDB is a special school within the Honolulu district and parents cannot enroll students directly into HSDB. All students in Hawaii must enroll in their local school district. Once the child is enrolled in the local school district, the IEP team will determine the best educational placement for the child. Placement decisions are based on multiple data sources, as well as input from the student, parent, teachers, and related service providers. If the IEP team, which includes the parents, determines that HSDB is the best educational placement based on Least Restrictive Environment – academically, socially and emotionally – the IEP team will recommend the child transfer to HSDB.

**Executive Office on Early Learning (EOEL) Public Pre-Kindergarten Program**

In partnership with the DOE, the EOEL Public Pre-Kindergarten Program serves children prior to the year of kindergarten eligibility. There are currently 23 participating schools statewide, with plans for expansion. Each classroom is limited to 20 children. Children must be age four on or before July 31 of the current school year. Priority for enrollment is given to children whose families meet the income requirement of 300% of the Federal Poverty Guidelines for Hawaii or meet other priority categories, such as homelessness, foster care, IDEA, and English Language Learner.
When a child with IDEA/special education services requires placement in a general education setting (per the Least Restrictive Environment), the school principal may determine that the EOEL pre-kindergarten classroom meets the general education placement requirement. The child is then enrolled in the EOEL Public Pre-Kindergarten Program providing the he/she meets the age requirement and the total enrollment in the respective classroom does not exceed 20.

If a child is already enrolled in the EOEL Public Pre-Kindergarten Program and is then later determined to require IDEA/special education services, the IEP team will determine the child’s services/supports and placement. If the child requires general education placement and the school principal determines the EOEL pre-kindergarten classroom to be the location for the child’s general education placement, the child continues enrollment in the EOEL Public Pre-Kindergarten Program.

Because children in the EOEL Public Pre-Kindergarten Program and children already receiving IDEA services are enrolled as DOE students, the DOE/Special Education oversees the IEP and placement process and addresses any provision for the child’s IDEA services.

**Early Head Start (prenatal to three) and Head Start (children three to five)**

Early Head Start (EHS) and Head Start (HS) is a federally-funded program that is delivered in Hawaii to support the growth and development of children. EHS programs serve infants and toddlers under the age of three and pregnant women. EHS programs provide intensive comprehensive child development and family support services to low-income infants and toddlers and their families. HS promotes school readiness of children under five from low-income families, through education, health, social and other services. Since 1972, HS has had a federal mandate to enroll children with special needs, including those who are deaf or hard of hearing. Children with documented special needs through an IFSP or an IEP have priority for enrollment if spaces are available. EHS has entered into a Memorandum of Understanding (MOU) with DOH/NHSP (pending approval) to strengthen partnership with the NHSP around referrals and follow-up assessments to identify children with hearing loss early and to ensure appropriate services.

**Private Early Childhood Programs (birth through five)**

Some early childhood programs accept children who are D/HH/DB. People Attentive To Children Hawaii (PATCH) is a statewide resource and referral agency that may help parents and families connect with child care options for families.

**IV. CHALLENGES TO PROVIDING APPROPRIATE SERVICES TO CHILDREN**

The interspersing of services amongst different State Departments and some privately funded services, with the lack of availability of all services in every community, leads to disparity issues for children who are D/HH/DB. The overarching departmental processes combined with inadequate and under qualified professionals may cause misplacement for a child who is D/HH/DB.
The Working Group reflected on challenges that families experience as their children move across settings from DOH’s family-centered services to the DOE student-centered model. Having continuity in curriculum, personnel, and level of family support is a significant concern.

The Working Group consistently commented that there are concerns related to communication supports within DOE for D/HH/DB children across the state. There continues to be a need to provide a variety of communication modes to support children to meet their communication needs in an appropriate setting.

The Working Group noted there were inconsistencies when placement was discussed with DOE D/HH itinerant teachers at the IEP team meeting. Consistency is critical in facilitation of in-depth discussions of student needs related to the continuum of placements for the IEP team, which includes the family, to consider in order to make an informed decision.

The Working Group further identified additional areas of improvement related to the flow of communication between DOH and DOE. Families are underprepared during the entire process of the transitions that is also apparent at other entry points for their education (families moving to Hawaii, families change in communication option, etc.). This lack of adequate preparation leading up to transitions creates confusion within the family and failure to plan the course of action as it relates to their choice of placement.

The main areas of concern are:

- Lack of availability of all programs in every geographic community.
- Lack of available qualified staff in Hawaii.
- Lack of a data system able to track demographic data and assessment data.

**Lack of Availability of Programs in Geographic Communities**

Hawaii has referred to the lack of continuum of services and programs on each island, in each district, and in each community. Parents may be forced to choose what is available in their community as opposed to what works best for their families. Sometimes there may be gaps with professionals who may be trained in one modality but must deliver in a different program. There are often different resources available in different geographic areas. Because DOH EIS works with contracting agencies, there are contracting and procurement issues that need to be addressed for fluidity of parent choice amongst programs in their community.

**Lack of Available Qualified Staff**

Finding qualified teachers, specialists, and staff is a challenge for both DOH and DOE. Hawaii’s ELWG would like to ensure that there are qualified personnel for all language modalities. Both Departments have historically faced challenges with finding qualified staff and the high cost of living in Hawaii makes it difficult to recruit and maintain qualified personnel. This is a larger workforce issue that is problematic to the State and in isolated communities.

Another challenge is providing consistent training and technical assistance to staff to ensure they are knowledgeable on best practices, current research, and cutting-edge methodology in serving children who are D/HH/DB. Hawaii was fortunate to take advantage of opportunities to provide
training such as the recent SKI-HI and Teresa Caraway training that was provided by the Maternal and Child Health Leadership Education in Neurodevelopmental Disabilities (MCH LEND) Program and DOH NHSP (Universal Newborn Hearing Screening grant). However, an on-going training calendar that contains information on webinars, in-person trainings, learning modules, etc., needs to be available statewide.

**Department of Health Early Intervention:**

Hawaii’s Early Intervention Section uses the Primary Service Provider (PSP) model which builds on and provides resources to assist family members and caregivers to enhance children’s learning and development through everyday learning opportunities. In this way, any member of the early intervention team may be working with a child who is D/HH/DB. Hawaii’s early intervention program has a specialist who provides deaf and hard of hearing support to children and families statewide. In this model, anyone on the team who works with children may be the primary service provider who works with the family and brings in other providers as needed. This may be the Speech Language Pathologists, Special Education Teacher, or any other team member.

**Department of Education Special Education:**

Hawaii’s Special Education Task Force has a Workgroup to address the problems that arise in special education program:

- Lack of sufficient flexibility at school level to deploy resources as desired when positions are allocated to schools.
- Lack of sufficient transparency on allocation decisions made at the Complex Area level in the distribution of Special Education positions and funds.
- Lack of sufficient accountability at school level to ensure best practices and appropriate services.

DOE has a Committee working to address the allocation formula which will examine equity issues, transparency levels, considerations of student needs, and dollars to schools vs. positions. Thus, the needs of the students who are D/HH/DB are caught in the larger system of funding allocations, availability of qualified staffing, and shortages in disparate communities. Having qualified and adequate personnel in the following positions statewide would help to ensure consistency in staffing across the state:

- Deaf Itinerant
- Educational Audiologist
- ASL Interpreters
- ASL Teachers
- Auditory/Oral Teachers
- Educational Assistants, Paraprofessional Tutors, Support Staff
- Speech Language Pathologists with specialized training

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3 Information from Special Education Fiscal Allocation handout on SPED fiscal allocation workgroup 1 of the Special Education Task Force Summative Report, May 2018.
- Assessors
- Educational Interpreters
- Audiologists

**Lack of Data System**

Data is collected in various state departments and agencies. Hawaii has a Statewide Longitudinal Data System (SLDS) that links information from early learning through higher education and the workforce. Hawaii’s SLDS only captures a marker of Yes or No (Y/N) for a 504 disability and unless a child is identified as needing a 504 accommodation, this information is not entered. Also, it does not always capture the type of disability and cannot be used to identify if the child is D/HH/DB. Although the federal Office of Special Education Programs (OSEP) requires states to compile data on children with special needs, for family privacy and confidentiality issues, data for communities where there are low numbers of children are not identified. The lack of a data system makes it difficult to find demographic data and to track assessment data. Without a data system with real-time information, it is hard to track and follow up on children or to monitor which communities may have higher rates of children who are D/HH/DB. As a result, it is difficult to allocate or predict the resources needed or if there is a need for more targeted outreach. Without common tools to assess children, it is hard to know how Hawaii is making successful improvements with children. Children who are D/HH/DB are often assessed using tools designed for children who are hearing which makes it difficult to accurately measure progress.

**Table 1. Number of Children Born who are D/HH/DB**

<table>
<thead>
<tr>
<th>Indicators</th>
<th>2015</th>
<th>2016</th>
<th>2017 (Preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td># births</td>
<td>18,388</td>
<td>17,995</td>
<td>17,353</td>
</tr>
<tr>
<td># screened</td>
<td>18,235</td>
<td>17,841</td>
<td>17,199</td>
</tr>
<tr>
<td># not pass screening</td>
<td>245</td>
<td>165</td>
<td>176</td>
</tr>
<tr>
<td># diagnostic evaluations</td>
<td>205</td>
<td>126</td>
<td>126</td>
</tr>
<tr>
<td># confirmed permanent hearing loss</td>
<td>74 (30.2%)</td>
<td>71 (43%)</td>
<td>60 (34%)</td>
</tr>
<tr>
<td># enrolled in EI services</td>
<td>40</td>
<td>39</td>
<td>34</td>
</tr>
<tr>
<td>Prevalence</td>
<td>4/1,000</td>
<td>4/1,000</td>
<td>Pending</td>
</tr>
</tbody>
</table>

*Source: Data from DOH Newborn Hearing Screening Program*

**Table 2. 2016-17 Number of Children ages 0-3 who are D/HH/DB Receiving Early Intervention Services**

<table>
<thead>
<tr>
<th>Indicators</th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td># Children age 0-3 years who are D/HH/DB receiving early intervention services</td>
<td>102</td>
<td>141</td>
</tr>
</tbody>
</table>

*Source: Data from DOH Early Intervention Section. Unduplicated children age 0-3 years with an IFSP with ICD-10 codes H90.0-90.8 or H91.0-91.9.*
DOH is unable to provide specific data on language development and literacy development. This information is maintained in individual records of each child and is not easily retrievable. EIS is in the process of contracting a data system vendor to replace the current database. This will be a web-based data system that will provide real-time information about each child in the early intervention system. The real-time data will provide DOH with access to information (e.g., language scores, IFSP, transition conferences, etc.) about children in early intervention who are diagnosed D/HH/DB.

Table 3. School Years 2015-2016 and 2016-17 number of children ages 3-5 who are eligible for DOE special education services in hearing-related disability categories

<table>
<thead>
<tr>
<th>Disability Category</th>
<th>School Year 2015-2016</th>
<th>School Year 2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaf-blindness</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Hearing impairments</td>
<td>34</td>
<td>38</td>
</tr>
</tbody>
</table>


“Hearing impairment” refers to “an impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance. It also includes a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects a child’s educational performance.” (Source: Collection Documents – Child Count and Educational Environment, https://www2.ed.gov/programs/osepidea/618-data/collection-documentation/index.html#datadocs)

In the “multiple disabilities” category, there were 69 children in School Year 2015-2016, and 59 children in School Year 2016-2017. No information is available on the subset of these children who have hearing loss. Information is maintained in DOE individual student files and is not easily accessible.

Table 4. 2015 - 2017 Number of Children ages 3-5 who are served in an EOEL Pre-K Classroom who are D/HH/DB

<table>
<thead>
<tr>
<th>Indicators</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
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</thead>
<tbody>
<tr>
<td>Deaf-blindness</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Hearing Disability</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Source: Information provided by EOEL.
IV. RECOMMENDATIONS AND NEXT STEPS

Recommendations were developed in the 2017-18 work of the ELWG. 2018 focused on refining the recommendations to work toward implementation. Subgroups worked around the clarifying four areas:

1. Resources for Families
2. Assessment Tools for Providers
3. Qualified Personnel and Staffing
4. Data Systems

**Recommendation 1: Ensure Resources are Available for Families Statewide**

The ELWG found that families want a resource that will provide 1) objective information about the continuum of communication and technology options, 2) access to Deaf mentors, 3) individuals knowledgeable about D/HH/DB to teach parents how to engage and communicate with their child, and 4) related resource materials. Resources for families come in many forms. The ELWG would like to see a consistent practice of providing information and ensuring supports are available for children statewide.

**A. Develop a “Warm Welcome” for Families of Children who are D/HH/DB**

The Working Group reflected that a consistent workflow and “welcome” for families of newly diagnosed children was needed. From the initial hearing screen until kindergarten entry, there are a myriad of potential touch points and interfaces between the medical community, DOH, DOE, and families. The ELWG would like to develop a “Welcome Letter” for families of any age or coming into the state that provides impartial information on the continuum of options for families of children who are D/HH/DB. It would also include information on community resources available for families and age-appropriate language development for their young child.

In clarifying the interests of the families, it was expressed that a system of family support needs to be strengthened to help shepherd families through the following processes:

- navigating the medical service delivery system,
- acquisition of skills and knowledge to communicate with their child(ren),
- supporting the needs that come with changes in development, experience and transitions across settings,
- process of determining a communication mode for their child,
- providing resources to assist in effectively communicating, and
- navigating the health and education systems.

The “welcome letter” may be given to families at any of these touchpoints.

**B. Promote Milestones of Age Appropriate Language Development**

The Working Group curated materials of age-appropriate infant and toddler speech and language milestones for children who are D/HH/DB. A subgroup reviewed currently available checklists designed for families to better support their understanding of the progression of communication
milestones for children who are D/HH/DB. Milestones are general guidelines for use by parents and community members. The subgroup recommended providing links and/or copies of the following milestones:

a) California Department of Education milestones
   https://www.cde.ca.gov/sp/ss/dh/sb210langmilestones.asp
b) Ontario Infant Hearing Program
   Developmental milestones in American Sign Language and Developmental milestones in spoken language
   http://www.children.gov.on.ca/htdocs/English/earlychildhood/hearing/brochure_services.aspx
   0-30 month’s speech and language milestones:
   http://www.children.gov.on.ca/htdocs/English/documents/earlychildhood/speech/Speech-EN.pdf
   Preschool speech and language:
   http://www.children.gov.on.ca/htdocs/English/documents/earlychildhood/preschool/Preschool-EN.pdf
c) ASL Stages of Development, California School for the Deaf
d) Hawaii Newborn Hearing Screening Program Ages and Stages

C. Develop Statewide Directory of Comprehensive Resources

The Working Group made this recommendation based on discussion regarding the need for a directory that families can access that would include resources on programs and services, as well as local events for children who are D/HH/DB. Since programs, services, and events may not be available in all communities, information may need to be categorized as to what is available statewide, countywide, island-wide, and/or in each community. This directory may include national and local resources. The Working Group curated a listing of national and local resources as well as established criteria for inclusion in the listing. It is envisioned that this will need to be updated annually and posted on partner agencies’ websites.

D. Implement a Comprehensive, Culturally Appropriate, Family Centered Resource Center

The Working Group was concerned that not all families may have access to the Internet, and some may prefer to talk in person or communicate via the phone. This recommendation assures that information on the different communication modes are available to families to explore. Providing information about these communication modes can help families who may not have access to the Internet. Hawai’i’s NHSP will be piloting a “Center” that is accessible via the Internet, telecommunication, as well as in person for parents and caregivers of children who are D/HH/DB who are up to three years of age. The Working Group recommends a website for families in Hawaii to access information on the array of communication and technology options
in an impartial and comprehensive manner. This website would include testimonials from families on different types of communication modalities and technology. By having a well-resourced website, parents would be able to explore all modes of communication and technology and make well-informed decisions that best meet the needs of their child.

**E. Establish a Parent-to-Parent Support Network**

Other states have found that parent-to-parent support networks are an important component for parents of children who are D/HH/DB. Parent-to-parent support is described as parents with lived experiences providing support to each other and is recognized as a distinctive and important type of support system. These types of support networks provide positive assistance in sharing strategies and problem-solving challenges as they arise. Hawaii’s Working Group reaffirms this researched finding and recommends that Hawaii establish a parent-to-parent support network as they promote family well-being, networking, and connection to resources for families.

**F. Implement a Deaf Mentor Program to Support Families in Early Intervention**

The Working Group felt it important to ensure consistency across systems and availability statewide to learn about the continuum of communication modes. A Deaf Mentor program is designed to provide families with opportunities to learn about different communication modalities and interface with adults using those modalities. The Working Group recommends that a program such as SKI-HI be used to train and certify deaf mentors. SKI-HI is a curriculum that is a comprehensive family-oriented program for children who are D/HH/DB and contains information written in a user-friendly layout for parents. Service providers, families and parents, early interventionists, para-educators, teachers, childcare providers, and early childhood specialists can use SKI-HI programs and educational materials. Currently there is a pilot of the Deaf Mentor Program and its evaluation will help determine if this should be implemented statewide.

**Recommendation 2: Promote the Use of the Matrix Assessment Tools for Children**

Assessments are formal tests used by professionals in assessing the child to determine eligibility and appropriate services. The Working Group realized through its review and investigation that there are no appropriate standardized assessment tools that are stand-alone instruments to track language development for infants and toddlers across the various communication modalities. Existing tools used to evaluate speech and language of infants and toddlers who are D/HH/DB are not normed on D/HH/DB children. Service providers typically use a battery of language samples, existing tools and clinical judgement to help formulate general impressions. The service providers have, over time, acquired a number of tools which they have adapted to assist with treatment/intervention planning and monitoring of progress. The lack of appropriate instruments for D/HH/DB children under 5 years of age leads the Working Group to believe that children are underassessed.

It was clarified that families and professionals are seeking ways to: 1) assess the child’s speech and language levels, 2) develop goals and objectives for speech and language development, and 3) measure and track progress for speech and language development.
The Working Group has assembled a matrix of assessment tools which is found in Appendix C. It has been vetted and approved by the ELWG and will make recommendations to the DOE and DOH for standardized implementation.

**Recommendation 3: Ensure there is Qualified Staffing Statewide**

In a review of system challenges, the Working Group established that there continues to be a need for qualified deaf educators in DOH and DOE to service children and families statewide in all modes of communication. Even with utilizing national recruitment vehicles, the challenge remains to fill positions. Relating to building family capacity to communicate with their child, American Sign Language (ASL) classes are not easily accessible or conveniently available statewide.

In addition, the Working Group established the need to support different communication modes in different settings across the State, and particularly on the neighbor islands. Limited options are discussed with families, noting a need to increase the variety of educational placements which support the various modes of communication to meet the student’s needs. Families may often accept whatever communication curriculum is available within their school district instead of being offered appropriate and effective communication choices for their child. The district and geographical restrictions, along with inconsistent servicing teams, create additional barriers for families to provide language acquisition to their D/HH/DB child(ren).

**A. Develop a Network of Specialized Service Providers for Early Intervention**

The Working Group recognizes that there is a shortage of specialized service providers statewide to service all children birth through age three in the EI system. To address this shortage, the Working Group recommends a network of specialized service providers be created to include ASL specialists, listening and spoken language specialists, Deaf educators, Care Coordinators knowledgeable on D/HH/DB issues and services, and other professional staff knowledgeable in working with D/HH/DB. Currently EIS only has one Deaf and Hard of Hearing Specialist who provides services for all D/HH/DB children statewide.

**B. Strengthen the Network of Specialized Service Providers within Department of Education**

This may include ASL specialists, spoken language specialists (e.g., Speech/Language Pathologist), cochlear implant specialists, Deaf educators (e.g., hearing itinerant teacher), etc. This recommendation mirrors that of the EIS system, to build capacity within the DOE and support the individualized needs of each child in their educational placement.

**B. Implement Professional Development Opportunities on Topics Relevant to D/HH/DB**

Currently DOH and DOE provide educational products, online courses, workshops, guided observations, and trainings to those who work with children who are D/HH/DB to ensure a comprehensive research-based learning environment. As has been shown, collaboration between the departments can lead to shared resources and leveraging of funds to provide more training opportunities to both providers and families. Resources and information will promote effective programming and provision of services, support colleagues and inter-professional collaboration, and provide ongoing learning and development. Having the departments work collaboratively to
develop the professional learning series on a broad range of topics relevant to D/HH/DB children and their families will provide for better networking and improved quality of services. It would be ideal if there could be a professional development program to train and certify professionals who work with children who are D/HH/DB. The ELWG recommends that professionals who work with children who are D/HH/DB receive appropriate training on assessment, provision of services, and tracking of progress for all modes of communication.

**Recommendation 4: Develop a Data System for Children who are D/HH/DB**

The Working Group validated that current data systems within the DOH and DOE do not have readily available information on the number of children with hearing loss by type and degree, nor does it have information on the child’s communication modes.

The DOH and DOE are able to report the numbers of children who meet the federal eligibility category criteria of deaf, hard of hearing and deaf-blind, but are unable to report the number of children who have hearing loss whose primary eligibility in another eligibility category, e.g., developmental delay, autism, other health impairment, etc. As a result, data on the current number of children who are D/HH/DB may be higher than the actual number of children who have been identified as having a hearing loss. The numbers also do not reflect the relation of other developmental delays due to delay in language acquisition.

The ELWG recognizes that there are many changes happening with the data systems for both DOH and DOE. It is envisioned that the new data systems will be able to provide more information about children who are D/HH/DB in order to make program improvements to best service the needs of these children and families. In the meantime, ELWG recommends the DOH amend the newborn hearing statute to include follow-up evaluation reporting requirements. Currently the DOH NHSP is unable to accurately track or follow-up with infants who do not pass hearing screening because reporting of the data to DOH is not mandated. The ELWG recommends that the statute for NHSP is amended to require that audiologists performing diagnostic hearing evaluation of the infant who does not pass screening, or any infant who receives diagnostic hearing evaluation beyond screening, shall report evaluation results to the department. This will serve as a starting point to ensure there is data for young children birth through three years of age.
### Early Language Working Group Members
As of August 2017

<table>
<thead>
<tr>
<th>Member Position</th>
<th>Name</th>
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<td>Julie Whitaker</td>
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<td>Individual who is D/HH/DB who uses ASL</td>
<td>Colleen Cidade</td>
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<tr>
<td>Individual who is D/HH/DB who uses oral language</td>
<td>Colin Whited</td>
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<tr>
<td>Credentialed teacher who uses ASL for children under age 6 years who are D/HH/DB</td>
<td>Angel Ramos, EdD</td>
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<tr>
<td>Credentialed teacher who uses oral language for children under age 6 years who are D/HH/DB</td>
<td>Kari Fillinger</td>
<td>Maui</td>
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<td>Early intervention specialist who works with infants and toddlers using ASL</td>
<td>Jennifer Blohm</td>
<td>Oahu</td>
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<td>Early intervention specialist who works with infants and toddlers using oral language</td>
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<td>Oahu</td>
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<tr>
<td>Audiologist or speech language pathologist with knowledge of language assessment and intervention for children who are D/HH/DB</td>
<td>Jennifer Hokulani Tarnay</td>
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<tr>
<td>Representative from English as a second language community</td>
<td>Emily Jo Noschese</td>
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<tr>
<td>Representative from Disability and Communication Access Board/Department of Health (DCAB/DOH)</td>
<td>Amanda Kaahanui</td>
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<td>Representative from Newborn Hearing Screening Program (NHSP/DOH)</td>
<td>Gwen Palmer</td>
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<td>Carole Duran</td>
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<tr>
<td>Representative from Executive Office on Early Learning (EOEL)</td>
<td>Coleen Momohara</td>
<td>Oahu</td>
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## APPENDIX B. LIST OF CURRENT ELWG MEMBERS

### Early Language Working Group Members

As of August 2018

<table>
<thead>
<tr>
<th>Member Position</th>
<th>Name</th>
<th>Island</th>
</tr>
</thead>
<tbody>
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<td>Parent</td>
<td>Nikki Kepo’o</td>
<td>Oahu</td>
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<tr>
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<td>Ed Chevy</td>
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<td>Parent</td>
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<td>Parent</td>
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<td>Individual who is D/HH/DB who uses oral language</td>
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<td>Darci Singlehurst</td>
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<tr>
<td>Credentialed teacher who is Deaf and Hearing Itinerant Resource Teacher</td>
<td>Christy Chadwick</td>
<td>Maui</td>
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<tr>
<td>Credentialed teacher who uses oral language for children under age 6 years who are D/HH/DB</td>
<td>Jennifer Blohm</td>
<td>Oahu</td>
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<td>Early intervention specialist who works with infants and toddlers using ASL</td>
<td>Charlene Robles</td>
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<td>Early intervention specialist who works with infants and toddlers using oral language</td>
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<tr>
<td>Audiologist or speech language pathologist with knowledge of language assessment and intervention for children who are D/HH/DB</td>
<td>Emily Jo Noschese</td>
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<td>Representative from English as a second language community</td>
<td>Po Kwan Wong</td>
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<td>Representative from Newborn Hearing Screening Program (NHSP/DOH)</td>
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<td>Representative from Executive Office on Early Learning (EOEL)</td>
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APPENDIX C. TOOLS USED TO ASSESS AND PLAN LANGUAGE DEVELOPMENT SERVICES FOR CHILDREN AGE 0-5 YEARS WHO ARE DEAF, HARD OF HEARING, OR DEAF-BLIND
Tools Used to Assess and Plan Language Development Services
For Children Age 0-5 Years who are Deaf, Hard of Hearing, or Deaf-Blind
(April 19, 2018)

The following list is a compilation of assessment tools, checklists, inventories, screening and comprehensive protocols, and resources for professionals who provide clinical advice in the programmatic planning of Deaf, Hard of Hearing, or Deaf-Blind children. This list is dynamic and is not exhaustive. Professionals may use one or more tools, along with observation and professional judgement, to derive recommendations for planning and benchmarks for child development. Familiarity, training, child and family circumstance and needs are drivers in the selection of tools used.

The qualification on levels are based on protocols stated by each tool’s manual.

This list was developed and approved by members of the Early Language Working Group to meet the requirement of Act 177 to develop a matrix of tools that can be used to assess and plan language development services for children from birth to age five years who are deaf, hard of
<table>
<thead>
<tr>
<th>Name</th>
<th>Area of Assessment</th>
<th>Type</th>
<th>Population</th>
<th>Age</th>
<th>User Qualifications</th>
<th>Method</th>
<th>Result Format</th>
<th>Link</th>
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<td>Visual Communication and Sign Language Checklist (VCSL)</td>
<td>ASL</td>
<td>Checklist</td>
<td>ASL regardless of level of hearing</td>
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<td>Qualification B</td>
<td>Observation</td>
<td>Skill level</td>
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<td>Checklist</td>
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<td>KPI format, report format, both</td>
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<td>Children pre and post-CI</td>
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<td>Children pre and post-CI</td>
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<td>Parent Interview tool</td>
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<td>Parent Interview tool</td>
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<td>Children pre and post-CI</td>
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<td>Parent Interview tool</td>
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<td>Children pre and post-CI</td>
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<td>Parent Interview tool</td>
<td><a href="http://www.earlville.edu/earlville/education/special/audiology/services/ClockListening">Link</a></td>
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<tr>
<td>Name</td>
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<td>Population</td>
<td>Age</td>
<td>User Qualifications (who can administer)</td>
<td>Method (Parent Report, Observation) Both</td>
<td>Result Format</td>
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<td>Rossetti Infant Toddler Language Scale</td>
<td>Language English</td>
<td>Assessment</td>
<td>All children regardless of level of hearing</td>
<td>Birth - 3yrs</td>
<td>Qualification C</td>
<td>Both</td>
<td>Age level</td>
<td><a href="https://www.linguisystems.com/products/product/displayItem?id=10092">https://www.linguisystems.com/products/product/displayItem?id=10092</a></td>
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<td>Carolina Picture Vocabulary Test (CPVT)</td>
<td>Sign Vocabulary</td>
<td>Assessment</td>
<td>DHH who use sign</td>
<td>4 - 11:5 yrs</td>
<td>Qualification C</td>
<td>Observation</td>
<td>Age/Grade level</td>
<td><a href="http://www.speechandhearing.org">http://www.speechandhearing.org</a></td>
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<tr>
<td>Communication Matrix</td>
<td>Communication</td>
<td>Assessment</td>
<td>Any child with DA or in early levels of communicative development</td>
<td>0-2 yrs or older, depending on comm. development</td>
<td>Qualification A</td>
<td>Both</td>
<td>Skill level</td>
<td><a href="https://communicationmatrix.org">https://communicationmatrix.org</a></td>
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</table>

* (Current research indicates that children with hearing loss may be more vulnerable to sensory processing disorder. Additionally, to ensure a comprehensive approach to educational planning for the child who is deafblind accurate assessment of sensory functioning (primarily vision and hearing) is essential. Given this, the Sensory Profile is included in this list.) Schum states: Nearly 40% of all children with hearing loss present with secondary handicapping conditions such as: learning disabilities, syndromes and Sensory integration difficulties. [https://rampages.uis.len/files/Psychological%20Assessment.pdf](https://rampages.uis.len/files/Psychological%20Assessment.pdf)


Bharadwaj, Daniel and Matzke findings suggest that children with CI may be at risk for SPD. [https://pdfs.semanticscholar.org/c7df/785f702161a4e4eb6514258907e6a6baa9.pdf](https://pdfs.semanticscholar.org/c7df/785f702161a4e4eb6514258907e6a6baa9.pdf)

<table>
<thead>
<tr>
<th>Curriculum Kits: Assesses where child is in auditory/speech development</th>
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<tbody>
<tr>
<td>Auditory Speech and Language (AuSPlan) Skills Pyramid Levels 1-5</td>
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