

**REPORT TO THE  
TWENTY-NINTH LEGISLATURE  
STATE OF HAWAII  
2017**

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

**2016 Interim Report of Findings 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**

**SUBMITTED BY:**

**EARLY LANGUAGE WORKING GROUP**

**CONVENED BY:**

**State of Hawaii  
Department of Health  
Department of Education  
Executive Office on Early Learning**

**DECEMBER 2016**

## EXECUTIVE SUMMARY

The Early Language Working Group was established by Act 177 of the 2016 State Legislature. 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 deaf, hard of hearing, or deaf-blind (D/HH/DB).

The 17 members of the Working Group were selected to meet the requirements of Act 177 and were appointed by the Director of Health.

Two meetings in October and November 2016 focused on interim findings related to the resource guide for parents of children who are D/HH/DB. While some resources are available, additional balanced, resources and services are needed to support age-appropriate language development for children age 0-5 years who are D/HH/DB. The shortage of deaf educators in Hawaii in part reflects the nationwide shortage of deaf educators. Access to Deaf Mentors and a Parent Coordinator are noteworthy findings..

The Working Group will continue to meet in 2017. The Working Group will submit its final report of findings and recommendation to the 2018 Legislature.

## REPORT

### Early Language Working Group

The Early Language Working Group was established by Act 177 of the 2016 State Legislature. 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 deaf, hard of hearing, or deaf-blind (D/HH/DB). Working Group responsibilities are 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 choices;
- 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 concerning the statewide system of services that support age-appropriate language development for children age 0-5 years who are D/HH/DB.
- 5) Improvements concerning the transition of children age 3 years from the Department of Health (DOH) early intervention services to Department of Education (DOE) services.

These are the requirements specified by Act 177 for Working Group members:

- One member 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, Maui, 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

Members were selected through a process that involved distribution of a nomination request, requests to potential members, and designation of agency members. Attachment 1 lists the 17 current members of the Working Group appointed by the Director of Health. Several appointed members were involved in developing drafts of the bill that subsequently was enacted as Act 177. Non-parent members who are D/HH/DB were users of American Sign Language (ASL) or hearing aids. While 17 members were initially appointed, one member subsequently declined prior to the first meeting. The vacant member position was filled prior to the second meeting.

The Workgroup has expressed concerns about the ability to maintain the appropriate ratio of Deaf and Hard of Hearing participants as well as the required composition of stakeholders.

As required by Act 177, the Working Group was convened by the DOH, DOE, and Executive Office on Early Learning (EOEL).

#### Working Group Meetings

Two meetings were held in 2016 prior to the submission of this report to the State Legislature. The October 24 meeting included discussion of the Sunshine law, Act 177, and common terminology. It also included an initial discussion of Hawai'i and national resources for families of children who are D/HH/DB. The November 21 meeting focused on finalizing the report to be submitted to the 2017 Legislature.

The Working Group will continue to meet in 2017. The Working Group will submit its final report of findings and recommendations to the 2018 Legislature.

#### Interim Findings

The following are interim findings on subject area 1) resource guide for parents of children who are D/HH/DB, one of the five areas required by Act 177.

While some resources are available, additional resources and services are needed to support age-appropriate language development for children age 0-5 years who are D/HH/DB. The shortage of deaf educators in Hawaii in part reflects the nationwide shortage of deaf educators. Resources in the community for families do not present a balanced perspective or view of the future possibilities for children. Families would benefit from the restoration of the parent coordinator position or increased capacity to address family needs in early intervention, as well as access to Deaf Mentors.

Discussion: 1) Resource guide for parents of children who are D/HH/DB

WRITTEN MATERIALS	
WHAT DO WE KNOW? <i>What resources are available?</i>	WHAT DO WE NEED TO KNOW?
<p>Websites for families of children who are D/HH/DB include universities, research sites, DOH, National Institutes of Health (NIH), <i>National Center for Hearing Assessment and Management (NCHAM)</i>, Centers for Disease Control and Prevention (CDC), Gallaudet University, Hands and Voices. Some written information may not be understood by families with lower reading levels or have English as a second language.</p> <p>“Hawaii State Resource Guide for Families of Children with Hearing Loss”, from the DOH Newborn Hearing Screening Program, is provided to families by the DOH Early Intervention Section (EIS) Deaf and Hard of Hearing (D/HH) Specialist. This resource guide includes information about types and degrees of hearing loss, amplification and other devices, communication opportunities (milestones for language development, language choices), and early intervention services.</p> <p>Materials (including brochures) about cochlear implants and guides on the hearing screening process are available, but they are not balanced in communication options.</p> <p>The paperwork was overwhelming and perhaps not all families will be able to read through everything</p>	<p>How can families be guided in finding balanced written materials, including materials at lower reading levels and in other languages?</p> <p>How can families of children who are D/HH/DB get the “Hawaii State Resource Guide for Families of Children with Hearing Loss”, if they do not receive services of the DOH EIS D/HH Specialist?</p> <p>When an infant is initially screened through Newborn Hearing Screening Program what resources are immediately made available to families?</p> <p>What is the standard operating procedure for Newborn Hearing Screening? What about procedures for the neighbor islands?</p> <p>Where are the “places” that have these resources?</p>

**FAMILY TO FAMILY SUPPORT**

<p align="center"><b>WHAT DO WE KNOW?</b> <i>What resources are available?</i></p>	<p align="center"><b>WHAT DO WE NEED TO KNOW?</b></p>
<p>Parent volunteers help families and reach out to other families.</p> <p>Guide by Your Side is a model program with a guide assigned to a family going through the process. This program is available in other states through the Hands and Voices organization, which was created by parents to support parents.</p> <p>American Society for Deaf Children is another organization and a resource for families.</p> <p>Deaf Mentorship is another best practice to support families.</p>	<p>How can more Hawaii families be assisted and supported with a parent-to-parent guide to services and resources?</p> <p>How would we re-establish and sustain the position of the Parent Coordinator under the Newborn Hearing Screening Program?</p> <p>What assistance does the Hawaii Chapter of Hands and Voices need to establish the Guide by Your Side program in Hawaii?</p> <p>What is the Department of Health's intention related to contract a Deaf Mentorship Program?</p> <p>Where can families access information about the social/emotional development for Deaf children?</p> <p>Where can families go so their children can interact with other Deaf children?</p> <p>How can we support families when the communication mode chosen by the family is not working for the child?</p>

<b>MEDICAL SERVICES</b>	
<b>WHAT DO WE KNOW?</b> <i>What resources are available?</i>	<b>WHAT DO WE NEED TO KNOW?</b>
<p>Medical providers provide information mainly about oral education and cochlear implants. Referrals are mostly for audiology services, cochlear implants, or hearing aids. Information and referrals may not be balanced related to communication options.</p> <p>A referral algorithm that identifies supplemental preventive services for Deaf children does not exist. Referrals to specialists (e.g., ophthalmology, geneticists) are not uniformly applied.</p> <p>Families who have grandfathered plans to the Affordable Care Act cannot access habilitation services.</p> <p>There are not as many private Speech Language Pathology providers who provide aural/oral therapy on the neighbor islands.</p>	<p>How can medical providers provide more education to parents about the importance of early ASL instruction from birth, even if cochlear implants are chosen by the parent? What are other referral sources for medical providers?</p> <p>How can we make assistive technology more affordable for families?</p> <p>How do we educate the medical community? Could the Deaf community develop a referral list of experienced providers?</p> <p>Does AAP (American Academy of Pediatrics) have guidelines?</p> <p>What can we do for children when their hearing aids or implants are not working? What can we do for children when their appliances are not an effective intervention?</p>

**DOH EIS AND DOE SERVICES**

<p align="center"><b>WHAT DO WE KNOW?</b></p> <p align="center"><i>What resources are available?</i></p>	<p align="center"><b>WHAT DO WE NEED TO KNOW?</b></p>
<p>DOH EIS has one <b>D/HH Specialist for the entire state. The D/HH Specialist’s services, which include information on communication options and guidance on available resources, have been very valuable to families. More D/HH Specialist services are needed on Neighbor Islands. Some Early Intervention (EI) staff are not knowledgeable about working with children who are D/HH/DB.</b> The current caseload is 90 with the potential for 180 infants and toddlers across all the islands, statewide. This D/HH Specialist must fly across the islands to serve all the children and families. On the neighbor islands, in particular, the D/HH Specialist serves as the primary ASL language instructor for families.</p> <p>More staff resources for DOH EIS and DOE are needed for children who are D/HH/DB. Issues are insufficient funding, recruitment and retention, insufficient qualified staff in Hawaii, nationwide shortage of deaf educators and educators for the blind, no training program in Hawaii, advertising at universities that teach education, and lower salaries in Hawaii compared to mainland salaries.</p> <p>Families may not aware of the range of methodologies that may be available to communicate with their child.</p> <p>Schools may not be aware of or convey the range of communication methodologies and placement options to families.</p> <p>DOH lost funding for the Shared Reading program with the closure of the Gallaudet Regional Center.</p> <p>There are not enough ASL intervention service providers, ASL instruction, ASL interpreters, and Teachers of the Deaf on the neighbor islands.</p>	<p>How can EIS have more D/HH Specialists?</p> <p>How can EIS re-establish a deaf mentor program for families of children who are D/HH/DB?</p> <p>How can EIS provide more support to Neighbor Island families of children who are D/HH/DB?</p> <p>How can EI specialists be better prepared to work with families of children who are D/HH/DB? How can EIS assure that EI specialists are knowledgeable about sign language and language milestones?</p> <p>How can DOH EIS and DOE obtain additional qualified staff?</p> <p>Could a protocol be devised as a “pre-IEP” interaction to insure family understanding of services from communication options through placement?</p>

## Attachment 1

### EARLY LANGUAGE WORKING GROUP MEMBERS

11/21/16

<u>Member Position</u>	<u>Name</u>	<u>Island</u>
Parent of a child who is deaf, hard of hearing, or deaf blind (D/HH/DB) who uses American Sign Language (ASL)	Nikki Kepo'o	Oahu
Parent of a child who is D/HH/DB who uses oral language	Ed Chevy	Oahu
Parent of a child who is D/HH/DB who uses a cochlear implant device	Julie Whitaker	Oahu
Parent of a child who is deaf-blind	Danielle Ledo Glade	Oahu
Individual who is D/HH/DB who uses ASL	Colleen Cidade	Oahu
Individual who is D/HH/DB who uses oral language	Colin Whited	Oahu
Credentialed teacher who uses ASL for children under age 6 years who are D/HH/DB	Angel Ramos, EdD	Oahu
Credentialed teacher who uses oral language for children under age 6 years who are D/HH/DB	Kari Fillinger	Maui
Early intervention specialist who works with infants and toddlers using ASL	Jennifer Blohm	Oahu
Early intervention specialist who works with infants and toddlers using oral language	Gwen Murakami	Oahu
Audiologist or speech language pathologist with knowledge of language assessment and intervention for children who are D/HH/DB	Jennifer Hokulani Tarnay	Oahu
Representative from English as a second language community	Emily Jo Noschese	Oahu
Representative from Disability and Communication Access Board/Department of Health (DCAB/DOH)	Amanda Kaahanui	Oahu
Representative from Newborn Hearing Screening Program (NHSP/DOH)	Gwen Palmer	Oahu
Representative from Early Intervention Section (EIS/DOH)	Jill Taosaka	Oahu
Representative from Department of Education (DOE)	Kristine Takekawa, AuD	Oahu
Representative from Executive Office on Early Learning (EOEL)	Coleen Momohara	Oahu