

Project Title: Early Hearing Detection and Intervention Program

Organization Name: Washington State Department of Health Early Hearing Detection, Diagnosis, and Intervention (EHDDI) Program

Mailing Address:

1610 NE 150th Street; Shoreline, WA 98155

Primary Contact:

Karin Neidt, MPH, EHDDI Program Manager

Phone: 206-418-5609, Email: Karin.Neidt@doh.wa.gov

INTRODUCTION

The purpose of the Washington State Early Hearing Detection, Diagnosis, and Intervention (EHDDI) program's proposal is to create an EHDDI system of care that will ensure infants receive appropriate and timely hearing screenings, audiological evaluations, and early intervention (EI) services. Our overarching aims are to:

- Develop a culturally competent, comprehensive, and coordinated statewide EHDDI system to ensure that infants receive appropriate and timely newborn hearing screening, identification, and EI services.
- Increase knowledge and engagement in the EHDDI system among health professionals, partners, and families.
- Improve access to family-centered EI services for children who are deaf or hard of hearing (DHH).

NEEDS ASSESSMENT

Washington State encompasses over 66,000 square miles in the northwest corner of the United States. Its bordering states are Oregon to the south and Idaho to the east, with British Columbia on our northern border and the Pacific Ocean to the west. The Cascade Mountains divide the state into distinct areas, with central and eastern Washington containing more rural and agricultural areas. In 2018, approximately half of Washington's 7.4 million population (according to the Office of Financial Management) was concentrated in Pierce (Tacoma), King (Seattle) and Snohomish (Everett) counties in Western Washington. Population density estimates for 2019 range from 1,052 persons per square mile in King County to less than four persons per square mile in Garfield and Ferry counties (the southeast corner and the northeast corner of the state respectively).

The Washington State Health Care Authority created nine Accountable Communities of Health (ACH), which align with the state's Medicaid Regional Service Areas (see Figure 1). The ACHs were established to better align resources and activities to promote health equity across the state and address issues that affect health through local health improvement plans. ACHs focus primarily on health care, but also consider issues that affect health, such as education, income, housing, and access to care. While some ACHs are not yet fully developed, they provide a possible collaborative partner to support our project objectives.

Figure 1. Accountable Communities of Health (ACH) Regions in Washington. Okanogan and Klickitat Counties are transitional counties based on Medicaid regional service areas.



According to 2018 Washington State Office of Financial Management data, the majority of Washington's population identifies itself as White and non-Hispanic (69%). Other population groups, in order of largest numbers to smallest numbers, include Hispanics (13%), Asian-Pacific Islanders (9%), African Americans (4%), Multiracial (4%) and American Indian-Alaska Native (1%). Racial minorities and people of Hispanic origin increased from 20% of Washington's population in 2000 to 31% in 2018. According to the 2013-2017 American Community Survey estimates, approximately 17% of the population five years old or older speak a language other than English at home.

Counties east of the Cascade Mountains have the highest percentage of Hispanics by population. Yakima, Franklin, and Adams Counties in south central and southeast Washington have Hispanic populations of over 50%. In 2014, the Washington State Monitor Advocate Annual Report on Employment Services to Migrant Seasonal Farmworkers (MSFW) estimated that there were 160,000 farmworkers during peak season. The vast majority of these workers were MSFW and approximately 80% were in counties east of the Cascades. MSFWs face many barriers to accessing health services. Community and migrant health centers are the primary source of health care for this population.

Blacks and Asian/Pacific Islanders are predominantly located in urban areas west of the Cascades. Approximately 61% of Asian/Pacific Islanders and 52% of Blacks resided in King County alone in 2018. There are also 29 federally recognized and 7 non-federally recognized American Indian tribes throughout Washington with varying populations and land areas. Understanding these geographic and population demographics is essential to develop targeted interventions within hospitals and clinics in these communities.

Washington has shortages of certain types of health care providers as well as an uneven geographic distribution of health care and related services throughout the state. According to HRSA, as of December 31, 2018, there were 163 primary care Health Professional Shortage Areas (HPSAs) in Washington. The 2015 Washington Healthcare Access Alliance Report stated that there were 14.3 pediatricians per 100,000 population in urban areas and just 6 per 100,000 in rural areas.

According to the 2107-2018 National Survey of Children's Health, less than half of Washington's Children and Youth with Special Health Care Needs (CYSHCN) (45%) reported being in a medical home (primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective). CYSHCN in rural areas of Washington are less likely to have a medical home than those in urban areas. Families who are a racial and ethnic minority or in non-English primary language households are less likely to have a medical home and to report family-professional partnerships. Children with a medical home are more likely to receive timely care and access to appropriate care and family support services.

This project seeks to particularly serve children and their families in underserved communities or populations. These families experience barriers to accessing needed screening, identification, and EI due to one or more of the following factors: lack of needed medical and non-medical providers in rural areas, cultural and linguistic factors, inadequate health insurance, and poverty. We will seek to conduct outreach to families and providers, engage communities, and implement quality improvement (QI) strategies in historically marginalized groups and rural areas of Washington. EHDDI program staff are also currently participating in a pilot project to incorporate a focus of health equity in all contracts for maternal and child health services. We will continue our collaboration with internal partners and external local health partners and contractors to ensure health equity is a guiding principal of this project.

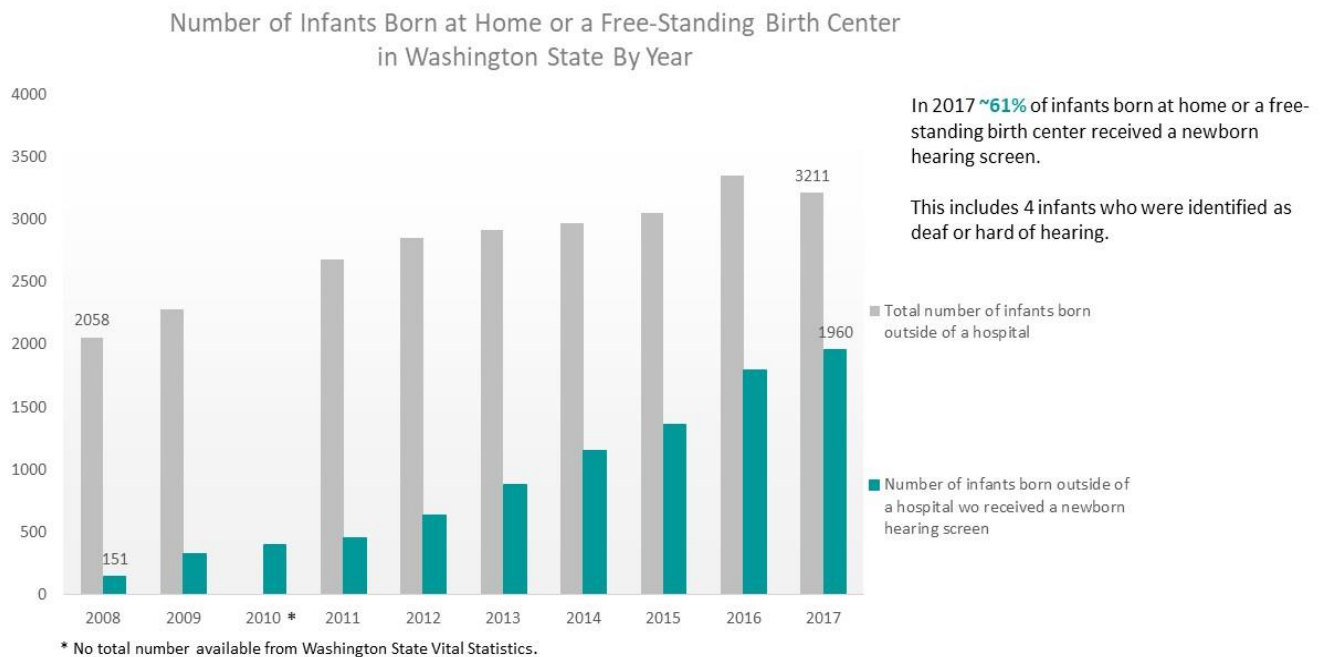
Appropriate and Timely Newborn Hearing Screening

In 2017, 87,349 births occurred in Washington. There are currently 62 birthing hospitals and 14 free-standing birthing centers. Newborn hearing screening is not mandated in Washington, but all birthing hospitals perform universal newborn hearing screening and report results to the Department of Health EHDDI program using a card associated with the newborn screening dried blood spot card. This method of data collection improves efficiency by ensuring efforts, such as collection of demographic information, are not duplicated between the Newborn Screening (NBS) program and the EHDDI program.

The EHDDI program followed nearly 86,070 infants born in Washington State in 2017. Of these infants, 97% received a hearing screen before one month of age (99% in total were screened). We received hearing screening results for approximately 60% of the 3,211 infants born out-of-hospital in Washington. The EHDDI program follows infants who are born out-of-hospital only if a hearing screen is sent to the program because we do not receive birth rosters from midwives. Since 2008, the EHDDI program has worked with midwives to improve awareness of newborn hearing screening and has offered opportunities for midwives to receive newborn hearing screening equipment, as well as training on how to screen infants and report results to the

EHDDI program. Because of this work, the percent infants born out-of-hospital who received a newborn hearing screen increased from just 7% in 2008 to 61% in 2017. Figure 2 illustrates the increase in the number of out-of-hospital births who received newborn hearing screening from 2008 to 2017.

Figure 2. Chart showing the number of infants born out-of-hospital who received newborn hearing screening compared to total number of infants born at home or a free-standing birth center.



Hospitals and midwives in Washington generally have a two-stage screening protocol. Infants are screened at the hospital before discharge and if they do not pass this initial screening, they are referred for a second hearing screen. Infants who do not pass their rescreen are then referred to audiology. The EHDDI program works regularly with hospital personnel and midwives to help them improve their newborn hearing screening techniques, care for their equipment, and implement QI strategies. We also use EHDDI data to analyze trends in screening and encourage hospitals to change practices based on our findings.

For example, we found in 2017 that both Southwest Medical Center and Legacy Salmon Creek Medical Center in Clark County, a county in the southwest corner of Washington that borders Oregon, had high percentage of loss to follow-up for infants who did not pass their initial hearing screening. Of the 60 infants born at Southwest Medical Center who did not pass their initial hearing screening, 10 (17%) did not receive needed follow-up hearing services. At Legacy Salmon Creek Medical Center, of the 89 infants who did not pass their initial hearing screening, 11 (12%) did not receive needed follow-up hearing services. Using these data we were able to identify there was an issue and then strategize solutions. In this case, we knew that both of these hospitals did not have outpatient hearing screening programs. Therefore, we recommended that

the hospitals implement outpatient hearing screening and establish a consistent and clear system of setting return appointments for outpatient hearing screenings.

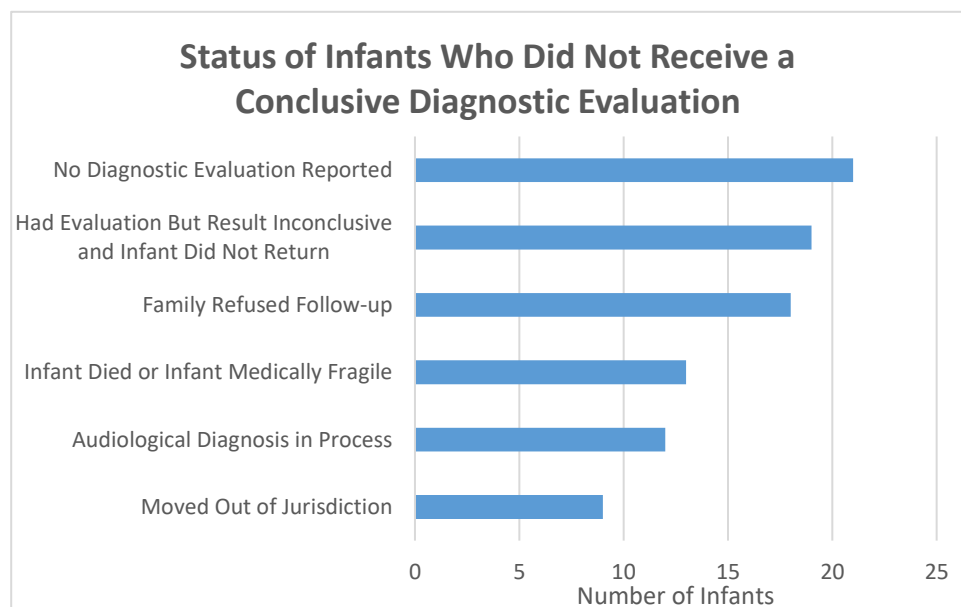
Appropriate and Timely Diagnostic Follow-up

Audiologists report diagnostic results, risk factor information, and referrals to the EHDDI program through our secure online EHDDI-Information System (IS) or by faxing the results to the EHDDI program. We use this information to inform our follow-up to providers and families, conduct quality assurance and improvement, analyze program performance, and report to our federal funders.

The EHDDI program submits data to the Center for Disease Control and Prevention (CDC) each year through its Hearing Screening and Follow-up Survey (HSFS). For infants born in 2017, we reported that 339 of the 934 infants (36%) who did not pass their final screen were lost to follow-up or documentation (LTFD). This is a significant decrease in loss to follow-up from 2009 when it was 73%. However, we still want to make significant improvements in regard to this measure. Of note, this statistic includes infants who both did not pass their initial screen and required a second hearing screen and 687 infants who were referred for a diagnostic evaluation with an audiologist after not passing their newborn hearing screening. When evaluating the EHDDI system in Washington, we usually separate these two points of LTFD and use the EHDDI statistics that can be found on our [website](#). We do this because the follow-up needed for these two groups of infants is different (screening vs. diagnostic evaluation), as is their risk for hearing loss. For the remainder of this section of the needs assessment, we will specifically refer to the 687 infants who were referred to audiology after not passing their hearing screenings.

438 infants (64%) born in 2017 and referred to audiology after not passing their newborn hearing screening were found to not have a hearing loss. 157 infants were identified as DHH. This equals an incidence of 2 per 1000, which is within the expected range of 1-3 per 1000 births. However, 92 infants (14%) referred to audiology did not receive a conclusive diagnostic evaluation. Figure 3 illustrates the EHDDI program’s current follow-up information for these infants.

Figure 3. Chart showing the follow-up status for infants born in 2017 who were referred to audiology, but did not receive a conclusive diagnostic evaluation.



The EHDDI program regularly evaluates and refines our follow-up protocols for infants who need diagnostic evaluations. Every month we send audiology clinics faxes with the names of infants referred to their clinic who we do not have a conclusive diagnostic result. When a child needs a diagnostic evaluation, EHDDI staff coordinates with the child's medical home and audiologist to ensure that best practices recommendations are understood and being followed.

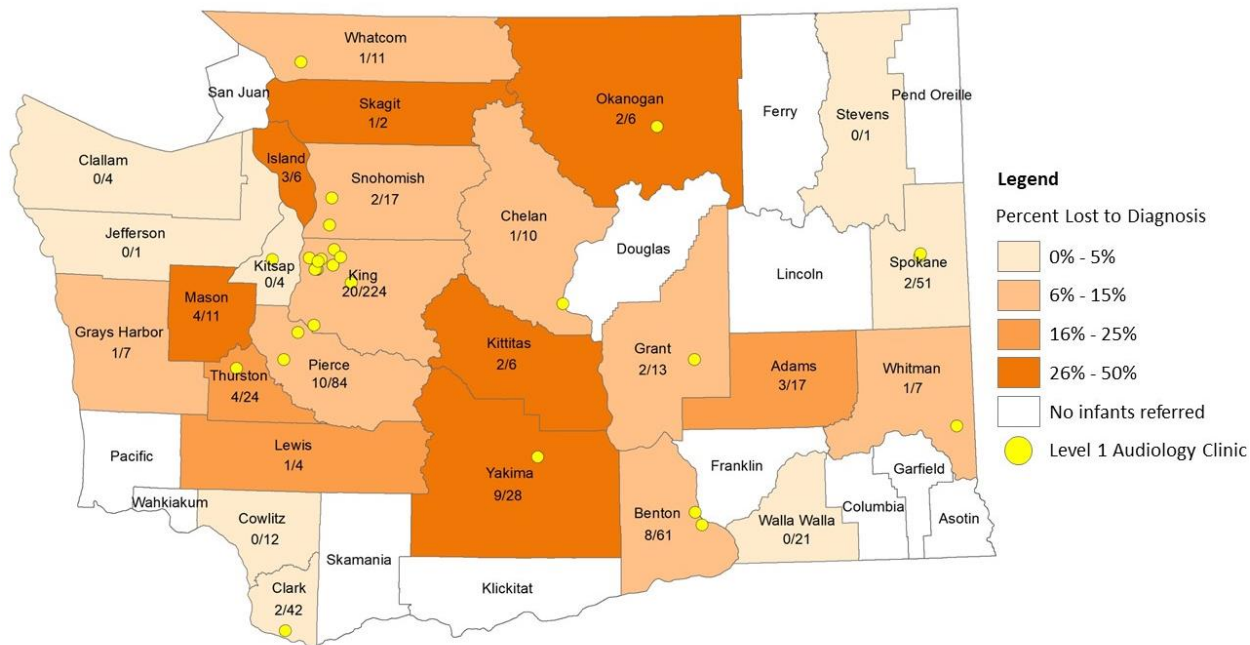
Over the past several years, the EHDDI program used QI methodology (Plan-Do-Study-Act (PDSA) cycles) to test and implement various follow-up strategies to reduce loss to follow-up after a child was referred to audiology. Some of the protocols implemented included:

- Sending parents a letter and helpful resources when their child was referred to an audiologist.
- Contacting audiology clinics to verify referrals were received and appointments were scheduled.
- Texting parents when they had an open audiology referral but had not contacted the audiology clinic to schedule an appointment.
- Contacting referral coordinators in the medical home when an audiology referral was delayed or missed.
- Texting or calling parents when they did not bring their child to the audiologist for an evaluation.

We believe that our increased outreach to families and providers contributed to the decrease in loss to follow-up after an infant is referred to audiology from 45% in 2009 to just 12% in 2017 (excludes infants who passed away or were medically fragile).

Figure 4 illustrates geographically the percent infants born in 2017 who were LTFD after being referred for a diagnostic evaluation. The yellow dots on the map indicate Level 1 audiology clinics that provide complete diagnostic testing for children birth to six months of age. Infants were assigned to a county based on their hospital of birth. Counties with the highest LTFD (between 26% and 50%) are colored dark orange. Three of these counties are in the central region of the state, which has a high percentage of Hispanic residents. For example, Yakima County's population is over 45% Hispanic and the county had a 32% loss to follow-up after a referral to audiology in 2017. National data (National Survey of Children's Health 2017-2018) show that Hispanic children are much less likely to have a medical home than white, non-Hispanic children (60.4% compared to 41.9%). While there are many factors that likely contribute to infants not receiving necessary audiology services (insurance coverage, income, etc.), having a medical home is known to improve care and support access to services. We will work with our partners to ensure that the family-centered medical home is integrated into the care and services for children, especially within Hispanic and underserved communities.

Figure 4. Map of Washington showing the percent of infants born in 2017 lost after being referred for an audiological evaluation by county of birth. (Note: because the numbers are small the numerator and denominator are also provided.)



Appropriate and Timely EI Services

The Department of Children, Youth, and Families (DCYF) Early Support for Infants and Toddlers (ESIT) program administers Washington State’s Individuals with Disabilities Education Act (IDEA) Part C EI system. In 2014, the EHDDI program established an electronic linkage with the ESIT program to collect EI data for infants who are DHH. The linkage allows audiologists to refer infants to the ESIT program electronically through EHDDI-IS and the EHDDI program to receive EI data from the ESIT program for these infants. The EHDDI program also receives EI data from the ESIT program if a Family Resources Coordinator (FRC) indicates in the ESIT system that a child was diagnosed with a hearing loss. FRCs are the primary Part C care coordinators for infants referred to the ESIT program.

This linkage allows our programs to share data accurately and efficiently, but there are several challenges we encountered and are addressing. One issue with the current exchange is that an infant’s diagnostic results are not sent to the ESIT program when an audiologist refers an infant to the ESIT program through EHDDI-IS. This requires audiologists to fax the results to the ESIT program, as well, causing them to do extra work to refer an infant. We plan to collaborate with our EHDDI-IS vendor and the ESIT program to enhance the electronic linkage so that diagnostic information is transferred with the EHDDI-IS referral.

We are also working with the ESIT program to educate FRCs on how to use the ESIT data system to report that an infant has a hearing loss. FRCs do not always indicate this diagnosis in the ESIT system or, if they do, report it in a miscellaneous text field that the exchange does not

recognize. This is especially true for infants who are already receiving services due to another qualifying diagnosis at the time they are identified as DHH. If a hearing loss is not reported correctly, the case is not flagged as a record that should be sent to the EHDDI program. Through persistent outreach to FRCs, we hope to increase the number of infants who are DHH for whom we receive EI information.

Through our linkage with the ESIT program and communications with FRCs and audiologists, we found that 68% of infants born in 2017 and identified as DHH in the EHDDI system were enrolled in EI services. Of those enrolled, we found that only 58% of infants began services before six months of age, as recommended by the Joint Committee on Infant Hearing (JCIH). The EHDDI program did not receive information about age of enrollment for 16% of infants. We plan to work with our partners to increase the number of infants who are DHH who receive EI services and also improve reporting of an infant's date of enrollment. We plan to do this in part by increasing support for families at the time their child is identified as DHH and continuing our activities to build access to quality EI services. This includes working with Washington's multiagency Birth to Three Sensory Taskforce, which consists of individuals from EHDDI, ESIT, Center for Deaf and Hard of Hearing Youth (CDHY), Office of Deaf and Hard of Hearing (ODHH), and Washington State School for the Blind (WSSB). The Sensory Taskforce meets quarterly to discuss linkages needed to ensure that families of children who are DHH, deafblind, or visually impaired from across Washington receive appropriate and timely screening, diagnostic, early intervention, and family support services.

Over the past several years, the EHDDI program has used QI methodology (PDSA cycles) to test and implement strategies to reduce loss to follow-up to EI. Some of the protocols implemented included:

- Contacting audiologists to ensure the EI referral was placed.
- Contacting Part C providers to ensure the EI referral was received.
- Communicating with the Part C program when the EHDDI program did not receive the date of a child's initial Individual Family Service Plan (IFSP).

These QI activities contributed to our significant increase in percentage of infants reported as enrolled in EI services from just 23% in 2009 to 68% in 2017. They also helped us identify and address miscommunications between audiologists and FRCs about placing and receiving referrals for EI services. For example, in Clark County, referrals for EI are sent to an educational service district that houses both contracted educational audiology services and EI services. Audiologists were referring newly identified infants to the educational audiology department with the intention that they would be evaluated for EI services. At the time, referrals were not being shared between these departments which resulted in delays in enrollment or not enrolling children in services. Educating audiologists about the difference between these two departments and encouraging communication and sharing of referrals between departments within the educational services district increased the percentage of infants reported as enrolled in EI services.

Our partnership with the ESIT program has allowed us to collect better data with regard to infants identified as DHH who may have missed or passed their newborn hearing screening and were not actively being followed by the EHDDI program. The number of infants born in 2017 and identified as DHH after not passing their newborn hearing screen was 157, but we found approximately 10 more infants who were identified as DHH through information we received from the ESIT program. Table 1 provides a summary table with EI enrollment status for all 169 infants identified as DHH.

Table 1. Part C EI enrollment status for infants born in 2017 who were identified as DHH in the EHDDI-IS.

| County of Residence | Infants Who are DHH | Enrolled in Services | Family Declined Services | Not Eligible | Not Currently Enrolled | Other* | % Total Not Enrolled (Declined, Not Eligible, Not Enrolled) |
|---------------------|---------------------|----------------------|--------------------------|--------------|------------------------|-----------|---|
| Adams | 2 | 1 | 1 | 0 | 0 | 0 | 50% |
| Benton | 4 | 2 | 0 | 1 | 0 | 1 | 25% |
| Chelan | 1 | 0 | 1 | 0 | 0 | 0 | 100% |
| Clallam | 2 | 1 | 0 | 0 | 0 | 1 | 0% |
| Clark | 6 | 4 | 2 | 0 | 0 | 0 | 33% |
| Cowlitz | 3 | 3 | 0 | 0 | 0 | 0 | 0% |
| Grant | 4 | 3 | 0 | 1 | 0 | 0 | 25% |
| Grays Harbor | 2 | 1 | 1 | 0 | 0 | 0 | 50% |
| Island | 3 | 1 | 1 | 0 | 0 | 1 | 33% |
| Jefferson | 1 | 1 | 0 | 0 | 0 | 0 | 0% |
| King | 47 | 34 | 8 | 0 | 1 | 4 | 19% |
| Kitsap | 2 | 2 | 0 | 0 | 0 | 0 | 0% |
| Kittitas | 2 | 1 | 0 | 1 | 0 | 0 | 50% |
| Lewis | 3 | 2 | 0 | 0 | 1 | 0 | 33% |
| Mason | 2 | 1 | 1 | 0 | 0 | 0 | 50% |
| Pierce | 26 | 17 | 4 | 1 | 3 | 1 | 31% |
| Skagit | 1 | 1 | 0 | 0 | 0 | 0 | 0% |
| Snohomish | 19 | 14 | 3 | 0 | 1 | 1 | 21% |
| Spokane | 15 | 10 | 3 | 0 | 0 | 2 | 20% |
| Stevens | 2 | 1 | 1 | 0 | 0 | 0 | 50% |
| Thurston | 7 | 5 | 2 | 0 | 0 | 0 | 29% |
| Walla Walla | 1 | 1 | 0 | 0 | 0 | 0 | 0% |
| Whatcom | 8 | 6 | 2 | 0 | 0 | 0 | 25% |
| Whitman | 1 | 0 | 0 | 0 | 0 | 1 | 0% |
| Yakima | 5 | 3 | 1 | 0 | 1 | 0 | 40% |
| Grand Total | 169 | 115 | 31 | 4 | 7 | 12 | 25% |

*Other: Family moved out of state or infant is unable to receive EI due to medical reasons.

Although there have been great improvements with regard to data collection, substantial barriers still exist related to the EI system in Washington, including the state's decentralized model for funding EI service, lack of knowledge about best practices for EI, Washington not having standards for services, and not enough appropriate resources available for families who are of low socioeconomic status, minorities, or non-English speakers. We plan to work with our partners to test strategies to alleviate these barriers. These strategies include connecting families with family support services as part of the Individualized Family Service Plan (IFSP) process, providing more direct support and resources for FRCs when a child is identified as DHH, supporting distance technology (tele-intervention or tele-support) to meet the needs of families, conducting trainings for audiologists, FRCs and service providers, and creating standards for EI programs using the 2013 JCIH EI Supplement to their 2007 position statement.

Family Support and Engagement

Since 2010, the EHDDI program has partnered with the Washington State Chapter of Hands & Voices to support family engagement and education, as well as implement the Guide By Your Side™ (GBYS) program to provide parent-to-parent support for families of children who are DHH. Families are to the GBYS program through a referral process. Referrals are sent to the GBYS program by EI providers, audiologists, EHDDI follow-up staff, and self-referrals by families. Due to Health Insurance Portability and Accountability Act (HIPAA) constraints and guidance from the Washington State Assistant Attorney General, the EHDDI program cannot automatically refer infants to the GBYS program without parent consent. Therefore, ongoing outreach to audiologists, EI providers and other EHDDI professionals is necessary to ensure there awareness of the GBYS program, particularly among new providers.

In 2017, Washington State Hands & Voices performed a gap analysis for the EHDDI program based on stakeholder feedback. Methods to collect quantitative and qualitative data included one-on-one interviews, an online survey, and a community café event that gathered a diverse population of families and providers to provide feedback. The gap analysis looked at family/caregiver access to five areas:

- Deaf Mentors/Role Models
- Parent-To-Parent Support (one-on-one support by trained parents)
- Opportunities to connect, bond, and support one another (social media or other social events)
- Opportunities to practice skills or gain knowledge in workshops or trainings (such as ASL SEE, IDEA Advocacy training, etc.)
- Advocacy and Leadership Training opportunities and access to use these skills

Of the 123 on-line survey respondents, 37% ranked “access to non-biased parent support, information and resources for families with DHH, deafblind, or deaf plus children” as their number one priority for Washington State to address. Sixty-five percent of respondents who listed this as a priority ranked it as their first, second, or third priority (of five).

Figure 5 illustrates the barriers to parent-to-parent support reported by families in the survey. Lack of awareness was the most common barrier reported.

Since establishing the GBYS program in 2010, the number of families matched with a parent guide has steadily increased from 25 parent matches in 2011 to 56 matches in 2018. However, with approximately 170 infants identified as DHH annually in our State, there is still much room for improvement in connecting families with the GBYS program.

Beyond the one-on-one matches with Parent Guides, Hands & Voices also factors in a continuum of active and passive family engagement methods to reach families. This includes connecting families to the Hands & Voices website. Within the last year of collecting data we had 1,374 visits to our website, with Google.com being our top referring domain Hands & Voices also has 366 subscribers to their quarterly e-newsletter and 62 paying members. In addition, Hands & Voices has 972 followers and 912 likes of its Facebook page. They hosted a number of outreach and family networking events in 2018, where they connected with 154 individuals. It is our goal to increase the number of families connected to Hands & Voices, as well as have farther reach to more diverse families.

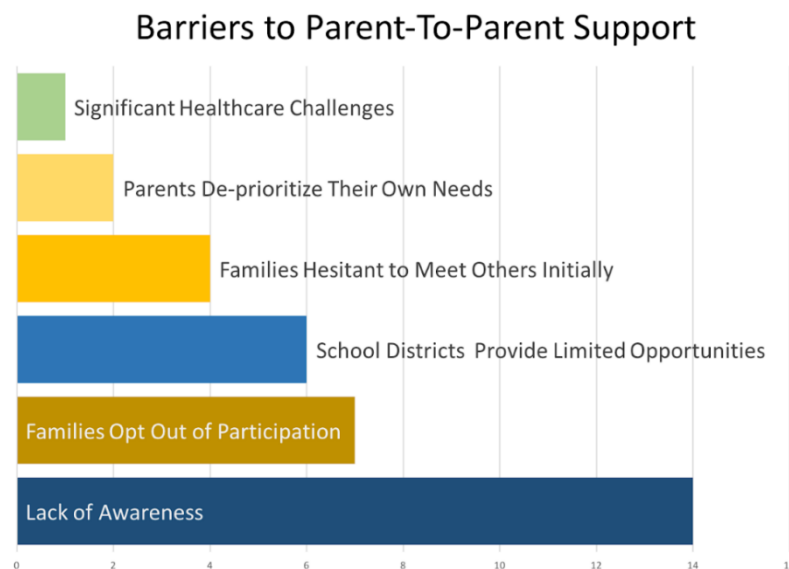
Collaborative Partners

The EHDDI program’s efforts to support and sustain the EHDDI system in Washington require many collaborative relationships. Below are some of the groups with whom EHDDI staff routinely work and who have a leading role within Washington’s EHDDI system. Attachment 4 contains letters of support from specific individuals and programs that will contribute to the elements of the work plan in this proposal.

- Members of the Deaf Community and Parents of Infants who are DHH

The EHDDI program has always recognized members of the Deaf Community and parents of infants who are DHH as valuable partners in developing best practices for screening and EI services. They serve on “consumer panels” in educational offerings we host, provide feedback about proposed EHDDI activities, and will participate in our EHDDI advisory group.

Figure 5. Barriers families accessing parent-to-parent support in Washington State.



- Washington State Birthing Hospitals

Universal Newborn Hearing Screening (UNHS) programs are located within individual birthing hospitals. Currently there are 62 birthing hospitals in Washington. As of 2006, all Washington birthing hospitals voluntarily implemented UNHS programs. Hospital staff are responsible for nearly all aspects of UNHS program development and maintenance.

- Licensed Midwives

Approximately 3% of Washington State births occur at home or freestanding birth center. The EHDDI program provided hearing screening equipment and training to midwives, as well as worked with Bastyr University's Midwifery Program (the region's only accredited Master of Science degree in direct-entry midwifery) to add hearing screening information to their curriculum. Currently 46 midwives offer hearing screening services for infants.

- Primary Care Providers

Primary Care Providers (PCPs) are crucial figures in the EHDDI process since they are the EHDDI program's primary contact and act upon the recommendations we provide. To support the Patient-Centered Medical Home model, the EHDDI program contacts PCPs when an infant does not pass screening and needs follow-up services. PCPs also routinely contact the EHDDI program to provide additional information (e.g., infant referred to audiologist, infant moved out of state, etc.) or to request hearing test results on file.

- American Academy of Pediatrics (AAP)

The EHDDI program works closely with our Washington State AAP Early Hearing Detection and Intervention (EHDI) Chapter Champion, Dr. Emily Gallagher, to educate providers on best practices related to newborn hearing screening and follow-up. She provides guidance to the EHDDI program as needed and collaborates with us to develop materials for providers and families.

- Audiology Clinics

Audiologists provide the critical step of identifying infants who are DHH by performing diagnostic evaluations on infants who do not pass their hearing screen. They assist in reviewing proper protocols in hearing screening and diagnostic evaluations. Finally, they work with the EHDDI program to collect and report diagnostic results and referral information through an external secure web-based extension of EHDDI-IS.

- Early Support for Infants and Toddlers (ESIT) Program (IDEA Part C)

The EHDDI program works with ESIT to promote newborn hearing screening and follow-up in the community and among ESIT's Family Resource Coordinators to improve service coordination. EHDDI and ESIT established an interagency data sharing agreement and electronic linkage. This data exchange allows audiologists to use EHDDI-IS to refer infants to the ESIT program and the ESIT system to send EI records to the EHDDI program for infants who are DHH.

- Washington State Hands & Voices

The EHDDI program works with and supports the Washington State Chapter of Hands & Voices. Hands & Voices is a parent-driven, non-profit organization dedicated to supporting families with children who are DHH, without a bias towards communication options. They advocate for families, host events, and provide the Guide By Your Side™ (GBYS) program. GBYS trains parents of children who are DHH to become Parent Guides, who provide unbiased emotional support and resources to other families of children with hearing loss or suspected of having a hearing loss. Some Parent Guides serve on our statewide EHDDI team, attend the National EHDI Meeting, and provide feedback about educational materials that the EHDDI program develops.

- Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program

The CYSHCN program has a full-time Family Engagement Coordinator (FEC) who takes a leadership role in promoting systems of care that include the family perspective. The FEC, engages families and individuals with special needs to develop culturally competent, community based services and leads efforts to mentor and support families. The EHDDI program will work closely with the FEC to involve families and connect with new organizations that support families. The manager of the CYSHCN program manager is also a member of the EHDDI Advisory Group.

- University of Washington Leadership Education in Neurodevelopmental and Related Disabilities-Pediatric Audiology Training Emphasis (LEND-PATE) Program

For ten years, the University of Washington (UW) participated in the LEND-PATE program to train pediatric audiologists to acquire the leadership skills to improve outcomes for children who are DHH and their families through early identification and intervention. The EHDDI program will continue collaborating with the LEND program to identify and remove barriers to identification and EI for children who are DHH, particularly in minority and underserved communities. The EHDDI program also contracts with the UW to provide educational opportunities to those who perform newborn hearing screening, pediatric audiologists, and other professionals involved in EI services for children who are DHH and their families. This effort is achieved through the Washington State EHDDI Learning Community (WSELC) with the goals of improving the outcomes of children and their families by establishing core best practices and guidelines. WSELC works with the EHDDI staff to develop resources and guidelines for the Washington State EHDDI community.

- Department of Health Newborn Screening (NBS) Program

The EHDDI program collaborates closely with the NBS program. Hospitals report hearing screening results via the dried blood spot newborn screening card. Also, patient demographic information and hospital birth roster data from the NBS program's data system populate the EHDDI tracking and surveillance system.

METHODOLOGY

In the Needs Assessment section of this application, we describe the current EHDDI system and outline barriers that prohibit infants who are DHH from being identified early and receiving timely services. To address the needs outlined, the Washington EHDDI program will focus on four primary areas:

- 1) Engage and coordinate all stakeholders in the Washington State EHDDI system to meet the goals of this program.
- 2) Engage, educate, and train health professionals and service providers in the EHDDI system.
- 3) Strengthen capacity to provide family support and engage families with children who are DHH, as well adults who are DHH, throughout the EHDDI system.
- 4) Facilitate improved coordination of care and services for families of children who are DHH through the development of mechanisms for formal communication, training, referrals, and data sharing between early childhood programs.

Engage and coordinate all stakeholders in the Washington State EHDDI system to meet the goals of this program.

As described in the Needs Assessment, the Washington State EHDDI program has a coordinated infrastructure that helps to ensure all newborns born in the state receive a newborn hearing screening by one month of age, those who do not pass receive a comprehensive diagnostic evaluation by three months of age, and those identified as DHH receive EI service by six months of age. This infrastructure depends on close relationships with primary care providers (PCPs), midwives, hospital screening staff, audiologists, Part C Family Resources Coordinators (FRCs), family based organizations, and other professionals. The Washington EHDDI program also uses an information system (EHDDI-IS) to track infants, manage infant follow-up through contacting providers and families, and perform data analysis. During this project, the EHDDI program will leverage its established infrastructure and partnerships to ensure infants receive timely and appropriate services and engage stakeholders to conduct QI activities to reduce loss to follow-up and documentation (LTFD).

Through analyzing data and receiving guidance and input from families and EHDDI providers, we will identify existing gaps and challenges in Washington State's EHDDI system. We will identify a minimum of two areas for improvement to address throughout the project based on the needs that are identified. EHDDI staff will report annually to HRSA on our progress towards addressing these issues using a QI approach. Areas of improvement that we will consider include:

- Ability to meet the 1-3-6 recommendations
- Expansion of screening up to age three
- Loss to follow up/documentation
- Provider outreach and education
- Data collection
- Telehealth

- EI referral and enrollment
- Outreach to underserved populations
- Late onset hearing loss
- Partnerships across Title V and other early childhood programs
- Family engagement and family support

We will use the Model for Improvement framework for our QI activities to improve the EHDDI system. With the help of our partners, we will identify and implement change strategies to test through “Plan – Do – Study – Act” (PDSA) cycles.

Plan: Data from our tracking and surveillance system will be used to identify communities with high LTFD rates. We will partner with families and providers to identify other ways to measure and evaluate the EHDDI system, design strategies of change and determine how to measure success. Strategies will incorporate the specific needs of the community and area where improvement is needed. As appropriate, will include National Initiative for Children’s Healthcare Quality (NICHQ) small tests of change that have already shown positive results. In cases where NICHQ strategies would not meet the needs of the community or area of improvement, we will develop novel change strategies to improve the system.

Do: EHDDI program staff and our community partners will implement interventions designed in the planning phase. We will monitor data and document problems, successes or unanticipated consequences that occur throughout the intervention.

Study: We will analyze data to measure improvements to the EHDDI process in each participating community, then communicate these findings to our partners.

Act: If the QI activities prove effective, we will continue using them. If we do not meet QI goals, we will use what we learned to improve the strategies or develop new interventions and begin a new cycle.

Successful strategies will be spread throughout the state through the help of our family partners and EHDDI advisory group. We will use EHDDI data to identify other communities that would benefit from implementing the strategy. EHDDI staff will work with our partners where the strategy was successful to garner participation in other communities. Providers and other professionals will be more likely to participate if the change strategy is reinforced by colleagues in their field.

The Washington State EHDDI program has a nationally recognized website (www.doh.wa.gov/earlyhearingloss) that we will maintain through this project. Our website provides families and professionals with culturally appropriate, accurate, and comprehensive information about newborn hearing screening, diagnostic audiological testing, and EI services for children who are DHH. The content is designed to allow families to make important decisions for their children in a timely manner. Our website includes links to our “Resource Notebook for Families of Children Who are Deaf or Hard of Hearing” (available in [English](#), [Spanish](#), [Russian](#), [Chinese](#), [Vietnamese](#), [Somali](#)), which includes information about support services, assistive hearing technologies and communication opportunities.

During this project, the EHDDI program will establish and maintain our partnerships for referral, training, and information sharing with various Washington State organizations and programs. Many of these groups are listed under Collaborative Partners in the Needs Assessment section of this proposal (page 11). By the end of the first year of this project, and revised annually, we will complete an assessment of current partnerships and identify additional key partners who could help address gaps in the EHDDI system.

We will expand our current infrastructure to better support the collection and reporting of hearing screening or diagnostic results for children up to the age of three. EHDDI staff will identify and convene collaborative partners who are engaged and interested in early childhood hearing screening to discuss expanding Washington State’s infrastructure. By the end of the second year of this project, we will work with our stakeholders to draft a plan that outlines the resources, key stakeholders, partnerships, and services necessary for this expansion. This effort will depend on finding collaborative partners in other public health programs within Washington State, including possible alignment with the Children and Youth with Special Health Care Needs (CYSHCN) Program, Home Visiting Program, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and Early Head Start.

The EHDDI program enjoys a strong collaborative stakeholder network that we continually utilize to improve the EHDDI system in our state. In 2017 we established a multidisciplinary EHDDI advisory group, which we will continue to convene throughout this project. The group will meet in-person twice a year (in the fall and spring) and via phone/online conferencing twice a year (in the winter and summer). At least 25% (currently 27%) of committee members will be parents of children who are DHH or individuals who are DHH. The current members of our advisory group are:

| Stakeholder Name | Affiliation |
|-------------------------|---|
| Adrienne O'Brien | Early Support for Infants and Toddlers Program (Part C) |
| Alice Anderson | Yakima Children’s Village |
| Angie Ahn-Lee | Snohomish County EI Program |
| Anna Dodd | Hearing Speech and Deaf Center |
| Betty Gilchrist | Spokane Ear, Nose and Throat |
| Christine Griffin | Parent of Child who is DHH Interim Director of Hands & Voices |
| Claudia Foy | Office of the Deaf and Hard of Hearing Deaf Community Member |
| Debra Lochner Doyle | Department of Health, Screening and Genetics Unit |
| Emily Gallagher | American Academy of Pediatrics - Seattle Children's |
| Jill Bargones | Family Conversations |
| Katie Eilers | Department of Health, Office Director (Title V) |
| Kavita Krishna | Parent of Child who is DHH |
| Kimberly Arthur | Parent of Child who is DHH Seattle Children's Center for Children with Special Needs |
| Kris Ching | Center for Deaf and Hard of Hearing Youth |
| Laura Coen | Parent of Child who is DHH |

| | |
|------------------|---|
| Laura Gramer | Parent of Child who is DHH Deaf Community Member |
| Lisa Mancl | University of Washington Audiology |
| Maura Berndsen | Listen and Talk |
| Michelle Hoffman | Department of Health, Children and Youth with Special Health Care Needs (Title V) |
| Rick Haun | Center for Deaf and Hard of Hearing Youth |
| Ryan Guzman | Office of Superintendent of Public Instruction |
| Teri Rogalski | Hearing Screening Coordinator, Pediatrix Medical Group |

The EHDDI Advisory Group will play a major role in helping us to build upon the existing EHDDI infrastructure and develop processes to implement this project and plan for sustainability. We will work with our advisory group and Department of Health leadership to create a plan to sustain key elements of the project after the period of federal funding ends. Some of the objectives outlined in this project support sustainability by the nature of their activities. For example building the leadership and advocacy skills of families with children who are DHH will naturally stimulate system change and motivate continued outreach to other families. Other objectives for this project cannot be sustained without finding other funding sources. For example, maintaining the EHDDI tracking and surveillance system to ensure that newborns receive appropriate and timely hearing screening, audiological evaluations, and EI services.

By the end of the second year of this project, we will work with our EHDDI Advisory Group and the Department of Health’s Multicultural Work Group (an advisory and coordination group for agency diversity and cultural competency activities) to develop a plan to address diversity and inclusion in the EHDDI system. This plan will outline a path to ensure that our activities are inclusive of and address the needs of the populations it serves. EHDDI program staff are also currently participating in a pilot project to incorporate a focus of health equity in all contracts for maternal and child health services. We will continue our collaboration with internal partners and external local health partners and contractors to ensure equity is a guiding principal of this project.

Engage, educate, and train health professionals and service providers in the EHDDI system.

In order to increase health professionals’ engagement within and knowledge of the EHDDI system, we will partner with our AAP Chapter Champion, LEND director, and family partners to conduct educational outreach about the EHDDI system, best practices, and the importance of appropriate and timely services. Through webinars, in-person trainings, and written materials, we will conduct outreach and education to medical and non-medical providers and other resource providers for children who are DHH in the following areas:

- The importance of timely screening, diagnosis, referral, and enrollment into EI services, specifically meeting the 1-3-6 recommendations.
- The need for hearing screening up to age three to identify, diagnose, and enroll into EI those infants who pass a newborn screen but later develop hearing loss.

- The benefits of a patient/family-centered medical home and family engagement in the care of a DHH child.
- The importance of communicating accurate, comprehensive, up-to-date, evidence-based information to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communications modalities, as appropriate.
- General Washington State-specific EHDDI system information, including screening, diagnostic, and EI statistics and resources generated by the EHDDI program.

The EHDDI program will partner with the University of Washington Center on Human Development and Disability (CHDD) to conduct the WSEL. The purpose of WSEL is to support professionals across disciplines and geographies, to connect, share ideas and results, and learn from each other and families through both in-person and virtual interactions. WSEL will provide three webinars each year and in the spring will host a daylong meeting that can be attended in person or virtually. Learning community participants align around common goals to improve outcomes for children who are DHH and their families.

Strengthen capacity to provide family support and engage families with children who are DHH, as well adults who are DHH, throughout the EHDDI system.

Throughout this project, the EHDDI program will involve family partners in the development and implementation of our activities. Families of children who are DHH will take on a leading role within our outreach, education, QI activities, and advisory group. We will contract with a family organization(s) to support family participation and leadership within the EHDDI system. We will assist their efforts to engage families in underserved areas, provide culturally and linguistically appropriate resources, and provide state-wide outreach to healthcare providers and families on the importance of the EHDDI system.

The EHDDI program will support family engagement throughout the continuum of family advocacy and leadership (Figure 6). For hearing parents and caregivers who don't have knowledge of the Deaf community or the experience of self-advocacy, this journey begins when the family learns that their child is DHH and they are learning to advocate for their own child and family's needs. As a family develops the skills and self-efficacy to take care of their child and support their child's communication, some parents or caregivers seek to engage in advocacy or leadership to support other children and families. Our program will promote the development of essential skills for parents and caregivers who are advocating for their own child as well as those who choose to engage in advocacy on behalf of others.

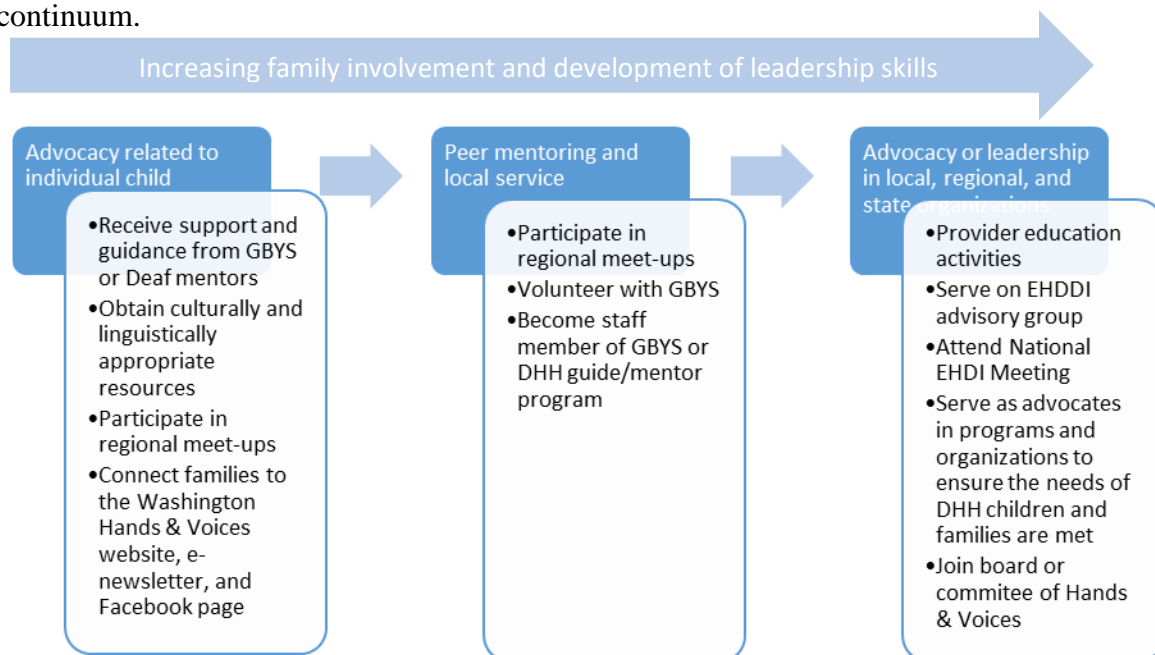
In the first stage, which starts with diagnosis, we will support family leadership by contracting with Hands & Voices to support their GBYS Program. The GBYS Parent Guides are trained to provide support to families whose child has been recently identified as DHH, without bias toward a particular communication option. The Parent Guide are also trained by Hands & Voices to assist families with ensuring their needs are met, connecting them with individuals who can help, and giving them tools to be good advocates for themselves in the future.

We also propose supporting family advocacy and leadership through contracting with Hands & Voices to host regional meet-ups and workshops for families with children who are DHH. Hands & Voices has ample experience hosting events and connecting with individuals and families of children who are DHH. These meet-ups will provide social learning opportunities for families to meet with other families, discuss concerns, learn information to support their child, connect with deaf mentors, and make plans to sustain the relationships and connections they make at the meet-ups. The meet-ups will also be a time where the EHDDI program can learn about barriers that families are encountering, connect families with information and opportunities to advocate, and identify emerging family leaders.

Family advocacy and leadership within the EHDDI system is also very important. Building upon the GBYS support to families and the regional meet-ups, we will seek to increase family advocacy and leadership. We will contract with Washington Hands & Voices to conduct outreach and education to inform families about opportunities to be involved in different roles within the EHDDI system. This includes collaborating with various leaders and policy makers in addressing the challenges to and providing solutions for the EHDDI system.

Through our partnership with WSELC and Hands & Voices, we will facilitate partnerships among families, health care professionals, and service providers to ensure that providers understand the best strategies to engage families. We will build off the work already begun by WSELC through education that focused on partnering with families, challenging conversations, and self-care. For example, in November, WSELC hosted a webinar focused on family-centered, culturally-sensitive, individualized care with effective communication and collaboration between professionals and family members. Using these conversations and partnerships as a stepping stone, we will continue to build infrastructure and capacity for family engagement and family support in the Washington State EHDDI system.

Figure 6. Activities and ways to serve or advocate at each stage of the family engagement continuum.



The EHDDI program will invite established and emerging family leaders to participate in planning, implementation and evaluation. Family leaders will assist us with the provider education activities, participate in our EHDDI advisory group and WSELG, and guide QI activities. To ensure that families who receive training have ample opportunity to be actively engaged throughout the EHDDI system, we will also collaborate with other agencies, programs, and organizations to identify their specific needs for parent engagement and leadership. We will identify how other organizations could use a family consultant to facilitate their work and help them partner with families with children who are DHH to meet those needs.

We will also seek engagement and input from the Deaf community and other adults who are DHH. Currently there are no DHH Role Model, Mentor, or Guide programs in Washington State, but we are currently working with Hands & Voices to survey families about their preferences and expectations related to receiving support from adults who are DHH. We will use the results from this survey to better understand the needs of families and the type of program(s) and services they feel are would be the most beneficial. In addition, Hands & Voices, ODHH, and CDHY are considering implementing statewide adult mentorship, role model, or other DHH adult or teen/young adult support programs. The EHDDI program will partner with these programs to help assist coordination and conduct outreach to families and providers to ensure they are aware and understand the different services provided by these programs.

Facilitate improved coordination of care and services for families of children who are DHH through the development of mechanisms for formal communication, training, referrals, and data sharing between early childhood programs.

As previously described, the EHDDI program established a data sharing agreement and electronic linkage with the Washington's Part C program, the ESIT program. We will continue and build upon this partnership to improve service coordination between the family, their medical home, audiologists, and the ESIT program. Our electronic exchange and data sharing agreement with the ESIT program will provide the foundation for collecting and evaluating EI referral and services data and identifying areas for improvement.

The EHDDI program will work closely with the ESIT program to address barriers to enrollment into EI and improve coordination between early childhood programs. The ESIT program's Training and Technical Assistance Manager and Program Consultant participates on the EHDDI advisory group and chairs the EHDDI Advisory Group's Early Support Services Workgroup. The purpose of this workgroup is to gather information about the current status of care coordination for early support services and make recommendations for how to improve the process for enrolling families with children who are DHH. The EHDDI program will continue to participate in and support this workgroup through this project. We will work with our partners to share findings and disseminate resources generated by the workgroup. To communicate with our stakeholders, we will utilize the EHDDI program's contact lists and the ESIT program's email listserv, which has a broad subscription base of families, EI providers, and other EI and special education professionals.

In the past year, the EHDDI program collaborated with our family partners and EHDDI advisory group to create resources to assist families at the time a child is referred to audiology or EI services. These materials were created at the recommendation of the EHDDI advisory group. The EHDDI program will work with our stakeholders to ensure families are able to access these resources and support Part C care coordinators in providing these materials to families. These educational resources are:

- [Hearing Tests for Children – What to expect before, during, and after your child’s hearing test](#) (Booklet)
- [Family Voices About the Importance of Early Hearing Detection](#) (Video)
- [Resource Notebook for Families of Children Who are Deaf or Hard of Hearing](#) (Spiral Notebook)

Additional Efforts to Promote and Sustain the EHDDI System

It is important for EHDDI staff and partners to participate in the National EHDI Meeting in order to learn about activities, research, and novel ideas that are occurring nationwide. It is also an excellent way to energize individuals to participate in and improve the Washington State EHDDI system. The EHDDI program will contract with Hands & Voices to send one parent to the National Meeting and, separately, the EHDDI program will budget for another parent and two EHDDI staff members to attend the meeting. The Washington State EHDDI program manager will facilitate the State Stakeholders meeting, which is scheduled as a session during the National EHDI Meeting. This time provides an opportunity for Washington stakeholders to come together at the beginning of the national meeting to connect and discuss Washington specific successes, challenges, and opportunities.

Sustaining the Washington EHDDI program is a constant discussion. We successfully secured a small amount of general state funds in 2008 when it was unclear if the program would be successful in receiving additional federal funds (i.e., a competitive grant cycle). In 2017 we were able to secure another small amount of state funding to provide technical assistance to hospitals and audiology clinics. However, the state funds provided cover only a third of existing staff and clearly do not allow for ongoing QI efforts. We discussed the possibility of raising the states’ newborn screening fee, however this is strongly opposed by the state hospital association. We also considered asking hospitals to pay a “follow-up subscription fee” based on the number of births at their facility annually as well as incentives for low refer/missed screen rates. This subscription fee idea recognizes that in most states with mandates, the hospitals are held accountable for the follow-up whereas in Washington, the EHDDI program takes on this work on their behalf. With the guidance from the EHDDI Advisory Group, we will look for new ideas and continue to negotiate with the hospital association and our State Board of Health on what is the least expensive and most actionable alternative to supporting the EHDDI program long-term.

Optional Needs Assessment Project

Attachment 7 of our application package contains the EHDDI program’s plan and budget for the optional, one-year needs assessment project to determine the educational needs of health care

professionals and service providers who interact with families at the time a child is identified as DHH.

WORK PLAN

This proposal is intended to support the development of Washington State’s systems of care to ensure that children who are DHH are identified through newborn and early childhood hearing screening and diagnostic services and receive family-centered EI to optimize language, literacy, cognitive, social, and emotional development. Attachment 1 of this application includes our Work Plan, which contains our proposed specific project goals, objectives, and activities to address our previously described needs. Each activity in the Work Plan has a defined timeline, person(s) responsible, and measures for each proposed strategy that we will use to determine completion, timeliness, and impact. Additionally, in Attachment 1 we are submitting a logic model to illustrate the framework for the design and management of our proposed project.

RESOLUTION OF CHALLENGES

We do not anticipate delays for the majority of the activities described in the Work Plan. However, the below table outlines some of the challenges that may be encountered and the approaches we will use to resolve them.

| Challenges | Approaches to Resolution |
|---|---|
| HIPAA and FERPA regulations restrict data sharing between public health entities and Part C EI programs, as well as | We will work within guidance we received from the State Attorney General to establish and refine protocols that maximize our ability to ensure infants receive timely and appropriate services. |
| Finding culturally and linguistically diverse families to participate in outreach and leadership efforts. | We will rely on our diverse partners to connect us with these families. Family support organizations will provide a crucial access point for connecting with families in culturally and linguistically diverse communities. We will also use publicly accessible community information and data to connect with these groups. |
| EI systems vary in each county since the ESIT program gives authority and local responsibilities of Part C services through contracts with Local Lead Agencies. | We will continue our work with the multiagency Sensory Disability Taskforce to promote a statewide plan that outlines the steps and linkages that need to occur to ensure that families from across Washington receive appropriate and timely services throughout the EHDDI process. We will also explore ways to promote tele-intervention in communities with limited resources and access to the full spectrum of communication options. |
| A family’s decision to enroll in family-to-family services depends on their comfort level and readiness to meet other families. Some | As soon as we are aware of a confirmed identification, the EHDDI program will send families information about family-to-family support services (GBYS program) and make referrals to GBYS when we receive |

| | |
|---|--|
| <p>families may not be prepared to receive these services before their child is six months of age, even if they are identified as DHH before three months of age.</p> | <p>parent consent. We will work with our parent partners to distribute materials to a variety of providers to help ensure families can learn about these services at many points during the EHDDI process. The EHDDI program will also track multiple measures related to enrollment into family-to-family services to better understand the number of families who receive information about GBYS, how many contact GBYS, and how many are matched with a parent guide.</p> |
| <p>Currently Washington State does not have a DHH Guide or Mentor program.</p> | <p>The Office of Deaf and Hard of Hearing is planning to implement a DHH Mentor program and Washington Hands & Voices is considering beginning a DHH Guide program in the summer of 2020. We will partner with both of these groups to promote the programs when they are established and collect data on the age a child is enrolled in the program. If they are not established, the EHDDI program will continue to work with its partners to create opportunities for families to meet with deaf or hard of hearing adults.</p> |

EVALUATION AND TECHNICAL SUPPORT CAPACITY

EHDDI staff will use process measures and outcome measures to monitor ongoing performance to achieve program goals. The Work Plan (Attachment 1) identifies the timeline, person(s) responsible, and process measures for each proposed activity that we will use to determine completion, timeliness and impact. To evaluate outcomes, EHDDI staff will use data from the EHDDI-IS and information from our partners to measure progress in achieving our goals. Every six months we will use the EHDDI-IS to conduct a detailed analysis of our diagnostic and EI data to evaluate our strategies associated with increasing the percentage of infants who receive timely and appropriate hearing screens (Goal 1), decreasing loss to follow-up after a referral to audiology (Goal 2), improving timeliness of diagnostic evaluations (Goal 2), and improving the proportion of infants who are DHH who receive timely and family-center EI services (Goal 3). This detailed analysis will include:

- Number of infants identified as DHH,
- Percent of infants lost to follow-up/documentation after referral to audiology,
- Percent of infants with hearing loss identified by three months of age,
- Percent of infants with hearing loss who received EI services by six months of age, and
- Percent of infants lost to follow-up/documentation after referral to EI.

We will also use EHDDI-IS data to identify geographic areas, cultural groups, and pediatric and audiology practices where there are high loss to follow-up to audiology and EI, so we can better direct our efforts and strategies. For this project, we will work with our partners to develop, implement, and evaluate the Washington State EHDDI program’s current evaluation plan. We will create a team to provide feedback on the evaluation plan and reports. We will also ask our

partners to help promote the use of the evaluation findings for improvements, planning, and decision making within the EHDDI system.

Data sources other than EHDDI-IS may also be used, as needed and available (Goal 5). For example, we will collect data on the number of families who receive GBYS support, attend the regional meet-ups, and participate in the advocacy trainings. We will also ask families to complete evaluations after each of these activities. To help measure the success of our training and outreach activities (Goal 4), at the start of each training, we will define appropriate measures, identify how those measures will be obtained, and outline a timeframe for collecting these data. At the end of each training or outreach activity, we will also ask participants to complete an evaluation.

The Washington EHDDI Manager has Master of Public Health in epidemiology from the University of Washington and over ten years of experience in tracking screening rates and follow-up statistics for the EHDDI program, including for previous Center for Disease Control and Prevention (CDC) and HRSA grant projects. She calculates and reports program data to our stakeholders and the CDC annually.

The EHDDI program can also access to staff in the Department of Health Office of Family and Community Health Improvement (OFCHI) Surveillance and Evaluation (S&E) Section, which consists of multiple epidemiologists and research assistants, to assist in the construction of surveys and if more sophisticated statistical analyses is required. S&E staff have extensive experience with data collection, analysis, and reporting; process and outcome evaluation; and continuous QI.

ORGANIZATIONAL INFORMATION

The EHDDI program is currently part of the Screening and Genetics Unit within Office of Family and Community Health Improvement (OFCHI), Division of Prevention and Community Health (PCH) in the Washington State Department of Health. Attachment 5 illustrates our current organizational structure. The agency's mission is to protect and improve the health of people in Washington State. Our aims fits with the PCH Agenda for Change focus area of "promoting policies and systems that increase the number of people who are healthy at every stage of life to provide a healthy start." The Screening and Genetics Unit works to improve the health of people with, or at risk of, genetic disease or congenital abnormalities by:

- Serving as a resource for accurate, up-to-date information.
- Promoting educational opportunities for health and social service providers.
- Evaluating quality, trends, and access to services.

OFCHI is the Title V Agency in Washington State and works to promote and develop an environment that supports the optimal health of all women of childbearing age, infants, children, adolescents, and their families. Programs within OFCHI include: the Screening and Genetics Unit, CYSHCN, Child Health and Adolescent Health, Community Health Worker Training, Family Planning, Pediatric Transforming Clinical Practice Initiative, and Essentials for

Childhood. Within the Office of the Secretary, we have access to the Center for Public Affairs (C4PA), which provides culturally and linguistically competent and health literacy services. We have worked with them many times to create culturally competent health promotion materials, which have been well received by audiologists, parents, and EI providers in Washington and Oregon. As much as possible, our materials are translated into the most common non-English languages spoken in Washington (e.g. English, Chinese, Vietnamese, and Russian). All of our materials are on our website (www.doh.wa.gov/earlyhearingloss). Some of our most recent products are:

- [How Newborn Hearing Screening Helps Children](#) (Video)
- [Family Voices About the Importance of Early Hearing Detection](#) (Video)
- [Hearing Tests for Children – What to expect before, during, and after your child’s hearing test](#) (Booklet)
- [Resource Notebook for Families of Children Who are Deaf or Hard of Hearing](#) (Spiral Notebook)

The Newborn Screening (NBS) program resides in the Office of Newborn Screening, within the Division of Disease Control and Health Statistics. Since EHDDI and NBS staff work together closely, EHDDI staff are co-located with the NBS follow-up staff at the public health laboratories in Shoreline, Washington (just north of Seattle). Staff from both programs use an integrated follow-up surveillance system built and maintained by Neometrics. Since organizationally, the NBS and EHDDI programs are in different divisions, program managers interact on a weekly basis concerning issues such as space, staff or shared programmatic costs or activities.

While hearing screening currently is voluntary in Washington State, the Screening and Genetics Unit has historically been successful in securing state general funds from the legislature to support the EHDDI program. The first occurred in 2005 when the program requested and received \$125,000 annually for EHDDI. In 2008, we were able to secure an additional \$60,000 in state funds to support technical assistance activities that could no longer be supported through HRSA funds. Currently, the Screening and Genetics Unit received approximately \$325,000 annually, although a large portion of these funds are to support genetic services outside of EHDDI.

The Screening and Genetics Unit currently has 6.0 full-time equivalents (FTEs), most of whom participate in this project in some way. The unit manager for this unit, Debra Lochner Doyle, MS, LCGC, has historically overseen all aspects of the Unit’s activities as well as coordinating genetics and EHDDI related activities across the agency. However, Debra is retiring in mid-November 2019 and will not be listed as a key personnel for this project. Attachments 2 and 3 contain detailed job descriptions and biographical sketches of the following key personnel for this project:

EHDDI Manager/Principal Investigator, Karin Neidt, MPH, is the principal investigator for the EHDDI grants, manages the EHDDI program, coordinates EHDDI follow-up, analyzes data, compiles and distributes data reports, evaluates QI activities, manages data system updates,

convenes weekly EHDDI team meetings, participates in hospital site visits, and will take a primary role in coordinating advisory group meeting and learning communities. She will manage the ongoing maintenance contract with Neometrics, including working with internal Department of Health Information Technology staff and EHDDI follow-up staff to make system changes. She also currently manages the EHDDI program's contract with the University of Washington for the Washington State EHDDI Learning Community (WSELC).

Health Services Consultant 3/ EHDDI Follow-up Coordinator, Marcie Rider, AuD, FAAA, develops and implements EHDDI program policies and procedures pertaining to pediatric audiology and diagnostic follow-up for infants who do not pass their newborn hearing screening, completes day-to-day follow-up actions (phone, fax, letters) triggered by the EHDDI tracking and surveillance system, does data entry to the system as additional information is learned based on the actions taken, and participates in audiology trainings and provider site visits. She will assist in coordinating learning communities, QI initiatives, and family engagement activities.

Health Services Consultant 3/ EHDDI Follow-up Coordinator, Julie Walker, CHES, MPH, completes day-to-day follow-up actions (e.g., phone, fax, letters) triggered by the EHDDI tracking and surveillance system, completes data entry to the system as additional information is learned based on the actions taken. She participates in hospital site visits to review follow-up protocols and implement targeted improvement strategies. For this project, Julie will also be taking on the role of universal newborn hearing screening QI lead and assist with family engagement and DHH adult-to-family support initiatives. Julie currently manages our contract with Hands & Voices to help achieve our goals related to parent engagement, leadership, and support.

In addition, the following individuals will also be integral to this project:

Secretary Senior, Cindy Cole, handles day-to-day logistical operations and clerical support for all Screening and Genetics staff.

Data Analysis and Quality Assurance Consultant, Anne McHugh, MPH, will assist in identifying data elements affecting data quality, help identify sections of the population at greatest risk of loss to follow-up or loss to documentation, identify key epidemiological indicators of the EHDDI program, support evaluation of the effectiveness of the EHDDI-IS, and assist us in determining the strengths and weaknesses of the EHDDI-IS to establish priorities for improvements.

Staff from the Grants Management Office further support the Screening and Genetics Unit, handling federal financial reporting. A Budget Program Specialist works with Screening and Genetics Unit staff to ensure all fiscal accounts are entered into the state fiscal monitoring system, and meets with program staff monthly to monitor accounts. In addition, a warrants officer processes warrants authorized for payment by program staff and enters these payments into the fiscal monitoring system.