

INTRODUCTION

The purpose of the Hawaii Newborn Hearing Screening Program (NHSP) is to develop comprehensive and coordinated statewide Early Hearing Detection and Intervention (EHDI) systems of care that ensure deaf and hard of hearing (D/HH) children from birth to three years of age are identified through newborn hearing screening and receive timely evaluation, diagnosis, and appropriate intervention that optimize their language, literacy, and social-emotional development.

Hawaii data (2017) shows the need to improve towards the 1-3-6; screening, diagnosis, and early intervention national goal, particularly in ensuring babies receive a complete evaluation by three months and enroll in Early Intervention (EI) programs by six months. There is a need to intensify the collaboration with community partners to develop the system of care, as well as to strengthen provider education across the EHDI system.

NEEDS ASSESSMENT

Geography

Hawaii, situated almost in the center of the Pacific Ocean, is comprised of seven populated islands located in four major counties. Most of the population lives in the City and County of Honolulu (island of Oahu), concentrated in the Honolulu metropolitan area. The rural “neighbor island” counties are Hawaii, Kauai (islands of Kauai and Niihau), and Maui (islands of Maui, Molokai, and Lanai). The island geography greatly impacts access to health care. The majority of tertiary health care facilities and specialty/subspecialty services are located in the Honolulu metropolitan area on Oahu. Thus, neighbor island and rural Oahu residents often must travel to urban Honolulu for services. Inter-island flights cost approximately \$300 round-trip, which can be a financial barrier for residents needing services on Oahu. Public transportation is not adequate or non-existent on the neighbor islands. Residents in rural communities on Oahu may need an automobile or spend hours on a bus to travel to urban Honolulu for specialty services.

Demographics

In 2018, the state population was 1,420,491. By county, 69% (980,080 residents) live in the City and County of Honolulu, 14.1% (200,983 residents) in Hawaii County, 11.8% (167,295 residents) in Maui County, and 5.0% (72,133) in Kauai County.

A comparison of Hawaii with the U.S. (Table 1) shows that:

- Hawaii is one of the most ethnically diverse states in the U.S. with no single race majority. According to the 2017 American Community Survey (ACS), 23.3% of the population reported

¹ Hawaii State Department of Business, Economic Development & Tourism,
<http://files.hawaii.gov/dbedt/economic/databook/db2018/section01.pdf>,

two or more races, and the following single race proportions; White=25.0%, Asian=38.2%, Native Hawaiian or other Pacific Islander (NHOPI)=10.2%. The largest Asian single race sub-groups were Filipino and Japanese, and the largest NHOPI single race sub-group was Native Hawaiian.

- Hawaii has a larger proportion of foreign-born individuals than the U.S. general population. According to the 2017 ACS, 18.6% of Hawaii's population is foreign-born, the 6th highest percentage in the U.S. with many immigrants from Asia and the Pacific. Smaller groups of Hispanic immigrants have settled in parts of Maui and Hawaii Island.
- Hawaii has a higher proportion of people who speak a language other than English at home. Based on 2013-2017 ACS, an estimated 25.8% of Hawaii residents ages five years and over spoke a language other than English at home, compared to 21.3% nationally. An estimated 12.4% of Hawaii residents reported limited English proficiency (4th highest state ranking), compared to 8.5% nationally. Asian and Pacific Island languages comprise most of the other languages spoken in the home.

Table 1. Comparison of Demographics for Hawaii and U.S.¹

Race/ethnicity	Hawaii	U.S.
White alone	25.6%	76.5%
Black or African American alone	2.2%	13.4%
American Indian and Alaska Native	0.4%	1.3%
Asian alone	37.6%	5.9%
Native Hawaiian and Other Pacific Islanders alone	10.2%	0.2%
Two or more races	24.0%	2.7%
Hispanic (any race)	10.7%	18.3%
Foreign-born percent, 2013-2017	18.1%	13.4%
Speak a language other than English at home, percent of persons age five years+, 2013-2017	25.8%	21.3%

The above based on: U.S. Census Bureau, 2018, quick facts

<https://www.census.gov/quickfacts/fact/table/HI,US/POP815217>

Data Summary for Newborn Hearing Screening, Evaluation, Intervention, and Follow-Up

According to the most recent data available (2017):

Screening and LFU/D (Loss to Follow-Up/Documentation)

- Of 17,362 total state births:
 - a) 99.4% (17,205) were screened (excluding 47 infants who died or parents declined)
 - b) 98.3% (16,913 of 17,205) were screened before one month of age
 - c) 0.6% (110 of 17,362) were LFU/D for screening
- 271 of the total state births were homebirths. Of these homebirths:
 - a) 61.8% (162 of 262) received newborn hearing screening (excluding nine parents who declined)
 - b) 38.2% (100 of 262) were LFU/D for screening

Evaluation and LFU/D

- Of 171 children who did not pass screening:
 - a) 75.4% (129 of 171) received a diagnostic evaluation
 - 69.8% (90 of 129) received an evaluation by age three months
 - 30.2% (39 of 129) received an evaluation after age three months
 - b) 9.3% (33 of 171) were LFU/D (excluding nine infants that moved out of state/died/parents declined)
 - c) 61 infants were identified with permanent hearing loss

Of the 129 children who received evaluations, 61 were diagnosed with permanent hearing loss. These include: sensorineural (26), mixed (6), permanent conductive (5), type unknown (8), and auditory neuropathy (6).

Intervention and LFU/D

- Of 61 children who were diagnosed with permanent hearing loss:
 - a) 78.7% (48 of 61) were referred to EI services under Part C of the Individuals with Disabilities Act (IDEA),
 - b) 60.6% (37 of 61) were enrolled in EI
 - 70.2% (26 of 37) were enrolled before six months of age
 - c) 24.6% (15 of 61) were LFU/D for early intervention (excluding families that moved out of state or parents who declined)

Table 2: Hawaii LFU/D rates for 1-3-6 timeline for screening, evaluation, and EI

	2012	2013	2014	2015	2016	2017
Screening						
% screened by age 1 month	90.0%	90.6%	90.2%	98.6%	98.3%	98.3%
% screened (total, including age > 1 month old)	98.3%	99.2%	99.1%	99.2%	99.1%	99.4%
% LFU/D for screening	1.6%	0.8%	0.9%	0%	0%	0.6%
% births out-of-hospital (homebirths) LFU/D for screening	67.0%	49.5%	55.0%	42%	45.5%	38.2%
Evaluation						
% evaluated by age 3 months	50.6%	54.1%	60.5%	63.4%	81%	69.8%
% evaluated (total, including age > 3 months)	72.0%	75.0%	82.0%	83.7%	76.4%	75.4%
% LFU/D for evaluation	14.9%	17.9%	13.3%	9.4%	11.5%	19.3%
Early Intervention (EI)						
% enrolled in EI by age 6 months	69.4%	67.6%	54.3%	77.5%	64%	70.2%
% enrolled in EI (total, including > 6 months)	67.0%	56.0%	75.4%	54.1%	54.9%	60.6%
% LFU/D for EI	16.7%	31.0%	14.8%	9.5%	19.7%	24.6%

The data show:

- The screen by one-month rate improved significantly and remained steady in 2015-2017.
- The LFU/D rate for total hearing screening improved and remained close to 0%.
- The LFU/D rate in homebirth screenings decreased slightly but steadily.
- The evaluation rates decreased from 2015-2017. The LFU/D also increased significantly from 2015-2017.
- The EI enrollment rate has slightly improved in 2017. It remained low at 60%. However, the rate of EI enrollment by age six months improved from 2016.
- The LFU/D in EI increased in 2017.
- Hawaii has the highest prevalence rate of hearing loss in the nation, 3.5 per 1,000 newborns screened.

The Early Hearing Detection & Intervention (EHDI) System in Hawaii

Below is information about the strengths and resources, and gaps and weaknesses in the various areas of the Hawaii EHDI system. The program is also supported by the Genomics Section staff and other resources within the Department of Health Children with Special Health Needs Branch.

EHDI Advisory Committee (AC)

Strengths and Resources

- The NHSP has a well-represented Advisory Committee. There are currently twenty (20) Committee members. Membership includes: an otolaryngologist; The American Academy of Pediatrics (AAP) Hawaii Chapter Champion; the Head Start Collaboration Office Coordinator; representatives from the Home Visiting program, the Newborn Metabolic Screening Program, Title V, and the Comprehensive Services Center (CSC) for the people who are Deaf, Hard of Hearing or Deaf-Blind; four audiologists, two of whom also represent the Hospital Newborn Screening programs; the EIS Part C Supervisor; and the EI Deaf and Hard of Hearing Specialist. There is a total of six parents on the AC, and one parent who is Deaf/Hard of Hearing (DHH). The Hawaii NHSP-AC advises the NHSP regarding policies and issues related to the EHDI system and reviews NHSP activities and progress toward the EHDI 1-3-6 goals. The group meets three times a year. The AC oversees the EHDI Quality Improvement (QI) activities, and committee members participate in the QI workgroups.

Gaps and Weaknesses

- The past Principal of the Deaf and Blind School was a member of the NHSP Advisory Committee. There have been changes in personnel in recent years and the Deaf School has not been able to send representatives to participate in the NHSP Advisory Committee. There is also no representation from Women Infants and Children Services (WIC) Branch and the state Med Quest (Medicaid) Program.
- All Committee members, parents, and professionals work full time. It is challenging to find a centralized location and a convenient time for the members to attend the meetings. Online video conferencing is utilized for smaller subgroup meetings. NHSP staff also solicits input from the AC members via emails.

- Parent members are not compensated.

Medical Home

Strengths and Resources

- AAP-Hawaii Chapter has designated Dr. Lynn Iwamoto as the EHDI Chapter Champion. Dr. Iwamoto has been very supportive of the NHSP. She is an active participant on the Hawaii NHSP AC. She meets regularly with the NHSP staff and assists in strategic planning and policy development. She also conducts training to medical staff and hospital screening program staff.
- Three years ago, in collaboration with the NHSP, Dr. Iwamoto launched a QI project to improve the follow-up rates for newborn hearing evaluation by educating healthcare providers through online education modules that focused on increasing physician confidence in discussing the screening process and follow-up with parents. Physicians who completed the training modules and the surveys received continuing medical education credits (CMEs). The results have been positive. The pre- and post-survey questions about improving the physician's confidence in caring for patients with hearing loss increased from 18% to 100%. 83% responded they have changed their practice after the training by identifying the screening results and making timely referrals.
- When an infant who does not pass screening is identified, the NHSP staff coordinate with the child's Primary Care Physician (medical home) to make timely referrals for audiological follow-up and/or EI services.

Gaps and Weaknesses

- Fifteen physicians signed up for the QI project, seven completed the training modules and received the CMEs. Greater effort is needed to market this training opportunity for PCPs.
- Non-medical providers who complete the training modules will not receive certification credit.
- There are about 200 infants who do not pass newborn hearing screening every year and more than 700 medical home providers. Some physicians admit that they do not have infant patients who need audiological follow-up or who are deaf or hard of hearing and therefore they are not familiar with the EHDI process. There is a big demand for physician training.

Screening Services

Strengths and Resources

- All twelve birthing facilities in Hawaii do newborn hearing screening. All facilities enter child-specific screening results in the NHSP web-based data system.
- Eleven birthing hospitals implemented the two-stage screening of OAE (otoacoustic emission) and AABR (automated auditory brainstem response). The inpatient referral rate has since decreased.
- The NHSP has developed agreements with a total of six private providers to perform hearing screening for home birth babies. The providers are on four islands: Oahu, Maui, Hawaii, and Kauai. The screening rate for home births increased from 31.5% in 2012 to 61.7% in 2018.

- Informational letters and brochures about newborn hearing screening and newborn metabolic screening are made available to families registering home births through birth registrars and from the midwives.
- Implemented the online training tutorial from the National Center for Hearing Assessment and Management (NCHAM) as part of the screeners' training protocol for use at the hospitals.
- Developed, printed, and distributed two brochures for new parents. The “Newborn Hearing Screening” brochure is provided prior to hearing screening and the “Can Your Baby Hear”, a developmental milestones brochure, is provided post-hearing screening to help parents identify signs of later-onset hearing loss.
- Screeners' competency checklist was developed and distributed to the hospital screening program for their use.

Gaps and Weaknesses

- The quality of screening services fluctuates when hospitals have changes in personnel. This was apparent in three birthing hospitals in 2018. One hospital had a new Nursery Manager and the other two had new screeners. The new staff did not receive sufficient training in screening and follow-up protocols. The loss to follow-up in outpatient screening at these three hospitals increased and data entry in the NHSP data system was delayed.
- The NHSP needs to provide outreach to midwives regularly and continuously, such as through the Midwife Alliance, to inform them about the availability of community screening resources, and to assure that they inform the new parents about the resources.

Diagnostic Audiologic Services

Strengths and Resources

- Three hospitals have Rehabilitation or Audiology Departments that provide follow-up diagnostic audiologic services to infants born at their hospitals.
- Infants who are born at the nine hospitals, including all neighbor island facilities, that do not have an affiliation with an audiologist are referred to the NHSP for follow-up and referral.
- Three audiology providers have contracts with the Department of Health (DOH) to provide diagnostic audiologic services to infants who are followed by the NHSP.
- Two of the DOH contracted audiologists perform diagnostic Auditory Brainstem Response (ABR) testing. In the past, there was only one contracted provider. All children need to travel to Honolulu for ABR testing. Starting in 2018, NHSP identified and contracted the second audiologist to provide services for children on Maui. Infants who reside on the island of Maui no longer need to travel to Honolulu for ABR and follow-up audiology services unless it is the parents' choice.
- The third audiologist only performs diagnostic OAE and behavioral audiologic testing (PAE), but she is the only provider who sees children under 2 on the island of Hawaii and Kauai. She travels to the island of Hawaii three times per month and one time a month on Kauai.

Gaps and Weaknesses

- Diagnostic ABR testing is not available in Kauai and Hawaii counties. Families must travel to Oahu for ABR diagnostic appointments. Travel and transportation challenges can contribute to delays in evaluation and increased LFU/D.
- A limited number of audiologists see children under two years old. While a statewide issue, the situation is more serious on neighbor islands. Lack of pediatric audiologists results in long waiting periods for appointments or a delay in identifying babies with hearing loss beyond three months.
- The military hospital submits child-specific screening results to the NHSP but not diagnostic information. Children who do not pass screening at this hospital are lost to documentation to the NHSP.
- The establishment of administrative rules or amendments to the existing statute that requires audiologists to provide findings of diagnostic audiology evaluations to the NHSP is needed.

Early Intervention Services

Strengths and Resources

- The DOH EI Section provides EI services for children age 0-3 years with or at biological risk for developmental delay, as required by Part C of IDEA. A care coordinator is assigned to each enrolled family. The care coordinator assists with the development of the Individual Family Services Plan (IFSP) and ensures the provision of needed services. Other specialty services include assistive technology, audiology, family training, counseling, home visiting, health services, medical services (diagnostic/evaluation), nursing, occupational therapy, physical therapy, psychology, social work, special instruction, speech language pathology, transportation, and vision. Services are provided statewide through state and purchase-of-service contracted programs.
- The DOH EI Administrative Rules were revised and approved in October 2013. Children with permanent hearing loss, bilateral or unilateral loss, are considered eligible under the biological risk category, even without developmental delay.
- NHSP staff work with the EI D/HH specialist to support families enrolled in EI programs. Coordinated by the contracted family organization and in collaboration with the D/HH specialist, the NHSP has sponsored several social/educational events that bring together parents and children who are D/HH in social settings to provide fun and informational activities.
- The NHSP collaborates with EI to have families consent to share information between the two programs. The EI Section has a database field to indicate if families receiving EI have consented. The database can be matched with HI*TRACK to identify children in common.

Gaps and Weaknesses

- EI follows the Family Educational Rights and Privacy Act (FERPA) requirement. The EI referral agency will not release information about the status of a child's referral to the NHSP unless parents sign a consent form. Since NHSP staff contact parents over the phone, it is difficult to obtain written consent. Without written parental consent, tracking the status of the

referral is challenging. The referrals may be lost in the process. NHSP staff do not find out until months later. These cases may become lost to follow-up or result in a delay in enrollment.

- Further streamlining the EI process to share follow-up information with the NHSP is needed. About 90% of D/HH infants identified from newborn hearing screening are referred to EI every year; only 55-60% are enrolled. Some may withdraw after enrollment. NHSP and EI need to work together to develop strategies to encourage EI enrollment and to offer options to those who are not enrolled.

Tracking and Follow-Up

Strengths and Resources

- The Project coordinator and NHSP social services aide assist families of children needing follow-up. Responsibilities include working with hospitals to schedule outpatient re-screens; contacting families, physicians, and audiologists to set evaluation appointments; and making EI referrals if permanent hearing loss is confirmed.
- NHSP tracks and follows-up with each child until age three for ongoing audiological evaluations and EI enrollment. NHSP staff works closely with the medical home to ensure timely referrals are made. When the child turns three, the EI care coordinators will assist the family with transition planning. If the child is not enrolled in EI, NHSP send discharge letters to inform the medical home to encourage the continuation of services.

Gaps and Weaknesses

- The NHSP is not able to follow-up with births (e.g., home births) known to Vital Records but not known to the NHSP based on the Deputy Attorney General's interpretation of the Vital Records state law.
- Delay in data entry and failure to make appropriate referrals to NHSP by the hospital staff is challenging for NHSP staff to track and make timely referrals.

Data Management

Strengths and Resources

- The NHSP contracts with the National Center for Hearing Assessment and Management (NCHAM) to use the HI*TRACK software for EHDI tracking and surveillance. Birthing hospitals enter screening results and demographic information in the web-based HI*TRACK system, to facilitate accurate reporting and timely referral. Diagnostic results and EI referral/enrollment information are entered in HI*TRACK by NHSP staff upon receipt of information from audiologists, Part C care coordinators, primary care providers (PCPs), and families.
- With the support of the NCHAM Help Desk, NHSP staff learn to use the latest versions of HI*TRACK as they become available, including data entry techniques, identifying children who need follow-up, and printing management reports such as the annual CDC reports and letters to physicians.
- The CSHNB research statistician links the NHSP and Newborn Metabolic Screening Program (NBMSP) screening databases monthly. The combined linked database provides a more complete database for NHSP follow-up and reporting purposes.

- The CSHNB research statistician receives permission from EIS to share with NHSP the list of children who are referred to EI and their enrollment status. Even though it is not a comprehensive list since only those parents who sign the public health information (PHI) consent form is on the list and there is a two months delay, it has been helpful to track hearing status for some.

Gaps and Weaknesses

- In most hospitals, HI*TRACK is not linked to the electronic medical records system. Hospital staff must manually enter the child's demographic information in HI*TRACK. It is time-consuming. Some hospitals only enter the minimal information and leave out information such as the contact phone and mailing address, and primary care physician's (PCP) name. It is difficult to identify the child's record in the database for follow-up.
- The military hospital provides screening data but not diagnostic information. Children who do not pass screening at this hospital become lost to documentation. Children diagnosed with hearing loss at this facility are not entered in the state EHDI system.
- Turnover in hospital data entry staff or malfunction of the computer system may result in missing screening information in HI*TRACK.

Family Support

Strengths and Resources

- The Comprehensive Service Center (CSC) for people who are deaf, hard of hearing and deaf-blind at the University of Hawaii is the family organization contracted by the NHSP to implement and run family support activities. The coordinator at the CSC is the parent of a deaf child. Some staff and/or volunteers are deaf adults.
- The NHSP sponsors parents to attend educational classes offered by the CSC (e.g., ASL and shared reading).
- CSC organized social/educational events, “Ohana Time” for families and started a listserv to share information about resources.
- The NHSP sponsors the EHDI Advisory Committee parent representative to attend the annual EHDI Conference. In 2019, one parent from Hawaii was nominated as the Family of the Year at the EHDI conference.
- Fifteen parents attended the Parent Conference facilitated by trainers from the National Hands & Voices. Four of these parents are members of the NHSP Advisory Committee.
- The Deaf Mentors Training was offered to about twenty-five deaf individuals. The Deaf Mentors program sponsored by the Children with Special Health Needs Branch was piloted and offered to families with children in EI.
- ASL interpreters are contracted to interpret at the Ohana meetings, EHDI AC meetings, and trainings. Foreign language interpreters are available if needed.

Gaps and Weaknesses

- Greater effort is needed to identify and recruit family leaders on the neighbor islands.
- Ongoing cultural competency training is needed. Multicultural peer workers or families themselves may be good resources for cultural sharing and awareness.

Statutes and Regulations

Strengths and Resources of the system

- Newborn hearing screening began in Hawaii in 1990, with passage of a law that mandated the DOH to develop methodology to establish, implement, and evaluate a statewide program for early identification of and intervention for hearing loss in infants; and develop guidelines for screening, identification, diagnosis, and monitoring of infants with hearing loss.
- In 2001, the newborn hearing screening law was amended, with efforts initiated by the Children with Special Health Needs Branch (CSHNB) of the DOH. Hawaii Revised Statutes (HRS) §321-361 to 363 require the screening of all infants born in the state, except for babies whose parents/guardians object to screening based on religious beliefs. The law also requires birthing facilities to report screening results to the DOH to ensure a statewide system of screening, diagnostic evaluation, and intervention for all newborn infants with hearing loss. The NHSP is established to coordinate the statewide EHDI system.
- The Hawaii Revised Statutes defines “infants” as a child from birth to 36 months of age. NHSP has been tracking and following-up on the audiological need of each child until three years old.

Gaps and Weaknesses

- The establishment of administrative rules is now necessary to implement the specifics of the law. The NHSP has drafted rules that have been reviewed by the Deputy Attorney General, but further revisions are needed. The lengthy process of establishing administrative rules has 34 steps.
- The HRS does not specify that audiologists are mandated to report diagnostic results to the NHSP. Audiologists who do not have contracts with the DOH can refuse to submit diagnostic reports to the NHSP, resulting in underreporting of children with hearing loss. In 2019, the DOH submitted a request to amend the HRS to mandate audiology reporting of diagnostic information. The bill did not pass and will be reintroduced in 2020.

Information, Education, and Training

Strengths and Resources

- The NHSP coordinates an annual Hospital Screening Coordinators meeting. Representatives from the screening hospitals attend this face-to-face meeting. NHSP staff provide EHDI updates, share and discuss issues and concerns. A special presentation based on training needs is also scheduled at the meeting.
- The NHSP co-sponsored the Hospital Nurse Manager Task Force annual meeting. The nurse managers received copies of their screening program report cards. The supervisors’ role in quality assurance of the newborn hearing screening program was discussed.
- A quality improvement activity on screeners’ competency was completed. The “Screeners Competency Checklist” was finalized and shared with the Nurse Managers.
- NHSP staff presented at the annual Hawaii Early Childhood Conferences and the Home Visitors Conference providing education about the importance of early identification and intervention services for DHH children.
- The online Hawaii Practitioners Manual for medical home and service providers is completed and posted on the NHSP website at <http://health.hawaii.gov/genetics/programs/nhsp/>.

- The NHSP brochures “Hawaii Newborn Hearing Screening Program,” “Can your Baby Hear?,” the Family Resources Guide, and other resources are also posted on the NHSP website.
- The NHSP Coordinator offers in-service training on EHDI to EI providers upon request.
- The AAP Hawaii Chapter Champion launched the online QI project to improve the follow-up rates for newborn hearing evaluation by educating healthcare providers through online education modules that focused on increasing physician confidence in discussing the screening process and follow-up with parents. The NHSP provided monthly EHDI data to track progress, assisted in reviewing the training slides, and participated in the interactive forum with participants.

Gaps and Weaknesses

- Further education is needed for medical and health care providers, community health centers, EI providers, midwives, hospital staff, and families regarding the importance of timely follow-up for hearing concerns and information on effective practices, protocols, and resources.

Collaboration with Stakeholders

- The Memorandum of Agreement between NHSP and each of the five Early Head Start (EHS) Programs in Hawaii was signed and executed in 2019. The Coordinator of the State Head Start Collaboration Office assisted the collaboration with the EHS programs. The process took several years.
- The NHSP Coordinator is a member of the Honolulu Community Action Program (HCAP) Head Start Health Advisory Committee.
- The NHSP partners with the University of Hawaii Center on Disability Studies Deaf and Blind Project and shares training information.
- The NHSP Coordinator participates at the DOH Title V Developmental Screening Committee (Title V State Performance Measure) and the Wellness and Comprehensive Screening Committee of the State Early Childhood Action Strategy Initiative meetings and advocates for ongoing hearing screening in early childhood.
- The Early Language Working Group was established by Act 177 of the 2016 State Legislature, with the purpose to make recommendations to the legislature on issues related to supporting age-appropriate language development for children age birth to five years who are deaf, hard of hearing, or deaf-blind (D/HH/DB). The NHSP Coordinator is a member of the working group. There are five parents and/or deaf adult members in the committee.
- The Department of Education receives the federal Preschool Development grant and is tasked to submit a strategic implementation plan. The NHSP Coordinator participates with the Health and Family Wellness Workgroup, advocating for ongoing vision, hearing, and developmental screening.
- The NHSP works closely with the state audiologist at the Children with Special Health Needs Branch, the Early Childhood Coordinator, the EIS D/HH Specialist and the CSC, family organization, and planned several statewide trainings.
- The NHSP is a partner with the Consortium for Hearing Evaluation, Rehabilitation, and Intervention for the State of Hawaii (CHERISH). CHERISH is facilitated by the UH School of Medicine, Communication Sciences and Disorder Department, and the focus is to discuss

teleaudiology. Dr. James Hall is also a member of the Consortium. He offered to train Hawaii and the Pacific region programs to implement teleaudiology.

Gaps and Weaknesses

- NHSP's collaboration with the federally funded Hawaii Home Visitation Program needs to be strengthened and expanded to other private non-profit home visiting programs.
- NHSP needs to reach out to other stakeholders who work with the DHH children.

Financing

Strengths and Resources

- Based on the 2019 Hawaii Kids Count data, 96% of children under age 18 in Hawaii have insurance coverage.
- Newborns of parents who have Quest or Medicaid are automatically covered under the mother's insurance for thirty days after birth. This helps to ensure there is no break in insurance coverage for the newborn.
- The NHSP uses state general funds to assist uninsured and underinsured families with access to screening and audiologic evaluation.
- The NHSP reimburses contracted providers who screen homebirths and who are not eligible for insurance payments.
- The NHSP has three state-funded, permanent staff positions (coordinator, social services aide, office assistant). Two positions, the project coordinator and the research statistician, are grant-funded.

Gaps and Weaknesses

- Insurance provides airfare for one parent and the infant to travel to Honolulu for audiology evaluation. It becomes a burden to the family to travel due to loss of wages, arranging child-care for the other children in the family, or if the parent needs help traveling with the infant.

Technical Assistance

Strengths and Resources

- The NHSP provides technical assistance to hospital screening staff regarding screening and follow-up procedures and training on the use of the equipment.
- The NHSP arranged for the company that sells hearing screening equipment to provide on-site training on the two-stage screening at the birthing hospitals and at contracted community providers' clinics.
- The HI*TRACK Help Desk and/or the NHSP staff provide technical assistance to screening program data entry staff regarding transferring or entering screening data in the HI*TRACK database.
- The NHSP staff offer hearing screening training to community programs that conduct ongoing screening on young children.
- The Genomics Section is the lead for telehealth in the Family Health Services Division. Workforce development to implement more telehealth activities is currently underway. The Genomics Section will be providing technical assistance for the NHSP in the implementation of teleaudiology.

Gaps and Weaknesses

Technical assistance is time-consuming, and it can be expensive to provide for neighbor island staff due to the travel costs. We have limited staff time to provide a lot of technical assistance.

STRATEGIES FOR IMPROVEMENTS

Screening, evaluation, and intervention services for children/families:

- Facilitate the development of hospital screening program quality assurance plans to ensure the quality of screening and that hospital screening procedures are in place and implemented.
- Reduce the need for outpatient screening to improve the loss to follow-up.
- Advocate for mandatory reporting of diagnostic evaluation results to reduce the loss to documentation.
- Explore different options to increase diagnostic audiology evaluation services on neighbor islands.
- Improve data tracking system to ensure early identification of children who are LFU/D at each stage of the EHDI process.
- Streamline the EI referral process and improve communication between the NHSP and EI.
- Develop protocols to follow-up with children who pass newborn screening but who are at risk for late-onset early childhood hearing loss.
- Develop an evaluation plan to track the progress of program objectives on an ongoing basis.
- Offer alternate options for parents whose D/HH child is not enrolled in EI.

Advisory Committee

- Maintain the existing well represented AC with 20-25 members and at least five parents and/or DHH representatives.
- The Advisory Committee meets at least three times a year, approves the work plan, and provides advice on the work plan activities.
- Identify new community stakeholders and invite them to join the AC.
- Explore alternate options to engage AC members.

Family Support

- Contract the Comprehensive Services Center for the Deaf, Hard of Hearing and Deaf/Blind (CSC) to plan, organize, and coordinate parent support activities.
- Engage parents/family members in all aspects of the EHDI system.
- Explore options to compensate parent leaders.
- Develop a virtual comprehensive user-friendly resource website.
- Parents express the needs for a centralized place where new parents receive non-biased information and learn how to navigate the system. The “One-Stop Center” for parent support will be piloted at the CSC.
- Identify and engage DHH adult leaders to support new parents.

Community collaboration and public education:

- Engage community stakeholders including family members of DHH children and DHH individuals to identify training needs and develop training plans for health care providers, parents, and EI providers.
- Reach out to medical homes to increase their knowledge of the Hawaii EHDI system and to strengthen collaboration between NHSP and the medical home.
- Advocate for on-going annual hearing screening. Identify community partners who are interested in conducting hearing screening. Then provide training and technical support to these partners.
- Partner with the Early Language Working Group that makes recommendations to the legislature supporting age-appropriate language development for children age birth to five years who are D/HH/DB (deaf/hard of hearing/deaf/blind). There are four focus areas in the recommendation:
 - a) resources for families,
 - b) language assessments for D/HH/DB children,
 - c) qualified staffing and on-going training and professional development, and
 - d) a data collection system that will help support language and literacy development for D/HH/DB children
- Support the Vision and Hearing Program bill to be submitted to the 2020 legislature to increase the early identification of children with vision and hearing loss by establishing consistent protocols for hearing and vision screening and follow-up.
- Participate in the Hawaii Early Childhood Action Strategy Ongoing Health and Wellness Committee. The Committee is working on the Preschool Development grant coordinated by the Executive Office on Early Learning (EOEL) and the Department of Human Services (DHS). This committee is one of the five workgroups under the grant and is responsible for developing the strategic plan for promoting early childhood health and family well-being for children age birth to five.
- Work collaboratively with the state audiologist, the early childhood community, medical home, service providers, and early interventionists to develop the Hawaii EHDI system from birth to three years old.

Training

- Develop and implement a needs assessment and training plan for medical providers, audiologists, early interventionists, and other service providers.
- Continue the online physician training QI project coordinated by the AAP Hawaii Chapter Champion. Based on the existing modules, develop different tracks for other providers.
- Develop training and resources for providers and parents related to language choices. Comprehensive and unbiased information about language development and communication options is critical for parents to make decisions for their child and family.

METHODOLOGY

Overall Goal: By March 31, 2024, the Hawaii Newborn Hearing Screening Program (NHSP) and its partners will develop the state systems of care to ensure that children who are D/HH are identified through newborn, infant and early childhood hearing screening, and receive diagnosis and appropriate early intervention to optimize language literacy, cognitive, social and emotional development.

Objective 1: By March 31, 2024, increase to 98% the number of infants that completed a newborn hearing screen before one month of age, excluding infants who are in the NICU (2017 baseline data 97.7%)

Strategy 1.1: By March 31, 2021, NHSP will establish collaboration with at least two District Health offices on the neighbor islands to identify and screen infants who are homebirths.

Measures

1.1.1 The NHSP will provide the screening equipment and train the Children with Special Health Needs Section Social Workers and/or the Public Health Nurses located in the District Health Offices to conduct hearing screening.

1.1.2 The Vital Records Office staff at the District Health Offices identify infants who need hearing screening when their parents visit the office to obtain the birth certificate.

1.1.3 Establish procedures between the Vital Records Office, the screeners, and NHSP to recruit, screen, and report screening results.

Strategy 1.2: Parents will download the EHDI PALS mobile application to help them keep track of audiology and related appointments for their infants.

Measures

1.2.1 The NHSP will issue and distribute a letter to inform parents about the EHDI PALS mobile application.

1.2.2 Birthing hospitals will provide the letter about the app and explain the function of the app to parents of infants who need to return for outpatient screening.

1.2.3 The same letter will be provided to the audiologists and medical providers to be distributed to the parents who have not downloaded the app.

Strategy 1.3: Improve the NHSP data tracking system to identify and follow up with infants who have not completed initial screening or outpatient rescreening by two weeks.

Measures

1.3.1 The NHSP research statistician will generate a monthly list of infants who have not completed hearing screening at two weeks old. The NHSP staff will send a reminder to the hospital for their follow-up.

Strategy 1.4: Identify hospitals that have a high loss to follow-up for outpatient screening and conduct quality improvement activities to help improve the screening rate.

Measures

1.4.1 Monitor screening rate and referral rate of these hospitals to measure improvement.

Strategy 1.5: Increase the awareness of midwives about the one-month screening goal.

Encourage midwives to share the information with new parents to improve timely screening for homebirths.

Measures

1.5.1 Streamline the procedures for midwives to report newborn information to NHSP.

1.5.2 NHSP contacts parents of homebirths to schedule hearing screening when the birthing information becomes available.

Objective 2: By March 31, 2024, increase to 85% the number of infants that complete a diagnostic audiological evaluation before three months of age (2017 baseline 53.6%)

Strategy 2.1: Streamline the referral procedures to ensure infants who need audiological evaluation are referred in a timely manner.

Measures

2.1.1 The research statistician will generate a monthly list of infants who do not pass or miss newborn hearing screening.

2.1.2 The list will be matched with the referrals received from the hospital screeners.

Reminders for a data update will be sent to the screeners if there is any discrepancy between the two lists.

2.1.3 The project coordinator will determine the needs for follow-up and initiate a referral to the audiologist for evaluation when a child is one month old unless a referral has already been made.

Strategy 2.2: Revise the Hawaii Statutes to require audiologist reporting of diagnostic results to NHSP to minimize the loss to documentation.

Measure

2.2.1 Submit the proposal to amend the Hawaii Revised Statute to require audiological reporting to NHSP for the Governor's consideration for inclusion in the 2020 legislative packet.

2.2.2 If the Hawaii Revised Statute is amended, NHSP will develop reporting guidelines for the audiologists.

Strategy 2.3: Conduct training for physicians, audiologists, and other providers on how to communicate diagnostic results to parents.

Measure

2.3.1 A training needs assessment and training plan will be developed and implemented by March 2021.

2.3.2 Develop and implement training strategies. Advisory Committee members, parents, and community stakeholders with expertise in the various disciplines will be involved in planning and/or conducting the training.

Strategy 2.4: Audiologists will enter diagnostic results in the HI*TRACK database system to ensure timely reporting.

Measure

2.4.1 A quality improvement activity will be implemented to train selected audiologists who agree to enter diagnostic results in the NHSP database system.

2.4.2 Policies and guidelines will be developed to ensure confidentiality and accuracy of reporting.

Objective 3: By March 31, 2024, increase to 80% the number of DHH infants that are enrolled in Early Intervention services before 6 months of age (2017 baseline 42.6%)

Strategy 3.1: Schedule quarterly meetings with EI administrative staff to review and discuss referral and recruitment issues.

Strategy 3.2: Develop training tools for medical, health, and other service providers to explain EI services to new parents of DHH children.

Measure

3.2.1 A quality improvement activity will be implemented to develop the training tool with input from the parents and the providers.

3.2.2 The tool will be piloted and finalized by December 2021.

Strategy 3.3: Conduct parent survey or parent focus groups to find out the benefits of EI services and reasons for refusing EI services.

Measure

3.3.1 By March 2021, the parent survey will be completed.

3.3.2 Based on the parent input, a strategic plan to support family enrollment in EI will be developed and implemented.

Objective 4: By March 31, 2021, establish baseline data to determine the number of families enrolled in family-to-family support services by no later than six months of age

Strategy 4.1: Pilot the “One-Stop” Parent Resource Center (One-Stop Center).

Measure

4.1.1 A “One-Stop Center” committee which includes NHSP staff, family organization representatives, parents, DOH partners, and community stakeholders will be established by April 1, 2020.

4.1.2 Contract the family organization to coordinate the pilot project.

4.1.3 The “One-Stop Center” will include but not limited to the following components: Parent Liaison, EHDI website, group educational/social activities, parent partners, D/HH partners.

Strategy 4.2: Guidelines to measure family to family support will be defined and baseline data determined by March 2021.

Objective 5: By March 31, 2024, the number of families enrolled in family-to-family support services by no later than six months of age will be increased by 20%

Strategy 5.1: Service providers offering family to family supports will report data to NHSP.

Measure

5.1.1 The contracted family organization will hire a “Parent Liaison” to coordinate the “One-Stop Center,” to organize and provide parent support services.

5.1.2 New parents will be offered the opportunity to sign up with the Parent Liaison when their child is identified DHH.

5.1.3 The Parent Liaison will support the parents as they navigate the EHDI system and connect the parents with other parents and DHH adults.

5.1.4 The family organization will submit quarterly reports to NHSP.

Objective 6: By March 31, 2024, the number of families enrolled in DHH adult-to-family support services by no later than nine months of age will be increased by 10% from the baseline data

Strategy 6.1: The DHH adult-to-family support services will be established.

Measure

6.1.1 NHSP will partner with the Deaf Mentor Program, the Children with Special Health Needs Branch, parent representatives, EI, and the family organization to define the DHH adult-to-family services, a component of the “One-Stop Center.”

6.1.2 The roles and qualifications of the DHH adults who provide family support services will be defined.

6.1.3 Recruit and train DHH adults to provide family support services.

6.1.4 Policies and procedures to refer and connect new parents to the DHH adults will be developed.

Strategy 6.2: The DHH adult-to-family support services will be offered to parents and the data tracked.

Measure

6.2.1 The Parent Liaison at the “One Stop Center” will be the central point of contact to connect families with DHH individuals.

6.1.3 Number of families referred to the DHH individuals for family support will be documented, tracked, and reported to NHSP.

Objective 7: By March 31, 2024, the number of health professionals and service providers trained on key aspects of the EHDI system will be increased by 10%

Strategy 7.1: The training needs assessment for health professionals and service providers will be completed by March 2021.

Measure

7.1.1 NHSP will contract with a researcher to conduct an assessment of the training needs of pediatricians, audiologists, early interventionists, and other health professionals.

7.1.2 A training plan will be developed by December 2021.

7.1.3 Baseline data will be collected before the implementation of training activities and will be used to measure progress.

Objective 8: By March 31, 2022 NHSP will convene the stakeholders' workgroup to develop a state plan to expand the infrastructure for hearing screening for children up to age 3.

Strategy 8.1: NHSP will identify community stakeholders who are conducting hearing screening or who may be interested in conducting hearing screening.

Strategy 8.2: NHSP will convene stakeholder meetings to develop the state plan. The state plan will ensure the system activities are inclusive of and address the needs of families with children age birth to three. The plan will outline the partnership and resources needed for implementation, as well as, a system for data collection and reporting.

RESOLUTION OF CHALLENGES

Challenges in designing and implementing Work Plan activities	Approach to Address Challenges
Engaging families who reside on the neighbor islands to participate in the learning community and to assist with program planning is challenging.	Collaborate with the District Health Offices to recruit parent leaders on each island. Utilize video conferencing or conference calls for meetings.
Lengthy contract procedures required by the state to contract with family organizations to provide family support and training may delay establishing the contract with the contracted organization.	Small contracts involve different procedures and in general take less time to obtain approval. Divide the tasks into different phases and different components, contract various family organizations to execute the tasks when appropriate. Negotiate the scope of service and prepare Request for Information prior to award to facilitate a faster contract process.
Three birthing hospitals' Audiology Departments do not consistently report follow-up evaluation, hearing disposition,	The DOH will submit a request to the Legislature to mandate audiology reporting to NHSP. The NHSP will develop guidelines for reporting of screening and evaluation results.

Challenges in designing and implementing Work Plan activities	Approach to Address Challenges
or intervention information to NHSP, resulting in loss to documentation and delay in EI services.	
A shortage of pediatric audiologists on neighbor islands continues to be a challenge. Infants must fly to Oahu for diagnostic ABR, which may delay the process of early identification of hearing loss and therefore delay in receiving early intervention services.	The NHSP has a contract with the audiologist on Maui to perform diagnostic ABR. She moved from the mainland U.S. to the island in 2018. The NHSP will continue to identify new audiologists who see infants for diagnostic ABR. NHSP will contract and arrange transportation for the audiologists to service the neighbor islands other than Maui.
Sharing data among programs or community providers which service the same target population is a challenge due to the HIPPA (Health Insurance Portability and Accountability Act) and FERPA (Family Educational Rights and Privacy Act) requirement.	Create a universal consent form signed by the parents to allow the sharing of information among programs. Initiate a dialogue with stakeholders to find out the requirements and explore the possibility of a shared data system. The stakeholders or community partners include but not limited to: NHSP, DOE, EI, and Children with Special Health Needs.

SUSTAINABILITY

The approach to sustainability is based on the incorporation of best practices into policy/procedures, and increased knowledge and improved practices of state and community providers. Currently in place or planned:

- Three NHSP positions (Program Coordinator, Social Services Aide, and Office Assistant) are permanent state-funded positions. These positions will continue program activities to assure statewide newborn hearing screening and follow-up after the federal grant ends.
- The Project Coordinator position has been changed from an exempt position to a civil service position. This gives a greater chance that the position will be supported by the state general fund when federal funding is not available.
- The new research statistician position has been established and position filled. This is also a civil service position supported by the grant. The CSHNB research statistician will continue to support and work with the NHSP research statistician in data merging and analysis.

- The CSHNB will continue to support the NHSP. The Title V/CSHCN Director fully supports improving newborn screening and will continue to work with the NHSP in efforts toward reducing LFU/D.
- The CSHNB audiologist and the Early Childhood Coordinator are important partners in the development of the state plan for hearing screening of children up to age three.
- Hawaii law mandates newborn hearing screening and requires birthing facilities to report screening results to the DOH. Administrative rules with detailed requirements for screening and follow-up are in the process of being established, as are program policies. The NHSP is working with hospitals to develop organizational hearing screening policies that reflect the NHSP policies.
- All birthing facilities except one are providing newborn hearing screening and have the capability to do two-stage screenings.
- Six providers on four islands are contracted to screen infants who are not born at the hospitals.
- A web-based HI*TRACK data system is in place for the sharing of information between hospitals and the NHSP.
- A new integrated child health profile data system is being developed for the Newborn Screening, Birth Defects, and Children with Special Health Needs Programs which will be interoperable with the new Early Intervention Services data system.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

Staffing

The Principal Investigator is Sylvia Mann, the Supervisor of the Hawaii Department of Health (HDOH) Genomics Section. Ms. Mann is a board-certified genetic counselor with experience as a Principal Investigator/Project Director for multiple federally funded public health grants, contracts, subcontracts, and projects. For over 20 years, Ms. Mann has built and maintained relationships with people, programs, and organizations within and outside of Hawaii to work collaboratively on activities she oversees. Ms. Mann has extensive experience in facilitating meetings, workgroups, and project activities; community engagement; provider and family education; administering grants, including complying with federal and institution policies, budget and progress monitoring; and project evaluation.

For evaluation of project activities, the Family Health Services Division has an evaluation unit which has epidemiologists and research statisticians available to provide assistance to the project.

Additional Baby HEARS Project team members include:

Staff	Experience, Skills, Knowledge
Po Kwan Wong, MPH Newborn Hearing Screening Program Coordinator	NHSP Coordinator since October 2008 Experience in planning and program development related to public health, early childhood programs, and social-emotional development of young children Experience working with families in multi-cultural, low-income settings Leader of the Hawaii Team for NICHQ Learning Collaborative B Responsible for the performance measure on newborn hearing screening in the yearly Title V application/annual report. Experience in building partnerships and engaging community stakeholders
Jasmine Jones Project coordinator	Project coordinator since January 2009 Knowledge of Speech Pathology and Audiology (B.S.) Manages the HI*TRACK database system Member of the Hawaii Team for NICHQ Learning Collaborative B Provides technical supports on newborn hearing screening and data management
Jin Dong, Ph.D. Research statistician	Starts at NHSP in October 2019 Over ten years' experience in research studies Prior to joining NHSP, worked at the Department of Business, Economic Development and Tourism, responsible for the 2018 Hawaii Census Data report
Michelle Takemoto, MS, CGC Project Specialist	Project specialist with the Hawaii Genetics Program Experience in participating and overseeing research activities Experience in developing publications for lay audiences and peer-reviewed publications
Lloyd Miyashiro CSHNB Research statistician	Background in planning, designing, implementing, and managing statistical information systems since 1990 Analysis of NHSP data for state/federal reports since 2000 Designed/implemented monthly data linkage procedures for use in joint quality assurance activities of the Newborn Hearing and Metabolic Screening Programs
Pauline Mui Technical Assistant	Maintains the Genomics Section website Over 15 years' experience in graphic design and data systems

Staff	Experience, Skills, Knowledge
Amelia Enright, MA, CCC-A NHSP Audiologist Consultant	Part-time NHSP Audiology Consultant contracted since 2006 Hospital newborn hearing screening coordinator since 1994 Audiologist serving newborns through adults since 1994 Member of the Hawaii Team for the NICHQ Learning Collaborative B and the EHDI Advisory Committee
Lynn Iwamoto, MD AAP-Hawaii Chapter EHDI Champion	EHDI Champion since 2003 Knowledge of the system of health services for newborn hearing screening and follow-up Experience in providing and arranging continuing medical education sessions for physicians and other health care providers related to newborn hearing screening/follow-up Medical knowledge regarding hearing loss. Member of the Hawaii Team for the NICHQ Learning Collaborative B and the EHDI Advisory Committee
Patricia Heu, MD, MPH Chief, CSHNB	Experience in planning and developing new processes and programs Experience and general knowledge of the NHSP Member of the Hawaii Team for NICHQ Learning Collaborative B Reports have included the Title V needs assessment and performance measures for children with special health care needs (CSHCN), CSHNB surveys, and CSHCN data reports
NHSP Advisory Committee	Decades of cumulative experience with health care, education, public health, program development, grant advisory committees The NHSP Coordinator is the facilitator. Other members include, but are not limited to, AAP Chapter Champion, research statistician, grant PI, ENT, EI Supervisor or designated staff, parent representatives, state audiologist, audiologists from private practice, ENT, Metabolic Screening Program, Head Start Project coordinator

Evaluation Methods

Process and outcome evaluation methods will be used to assess the attainment of project outcomes and effectiveness/efficiency in attaining those outcomes. The NHSP plans to use a mixed-method evaluation including planning, formative, and summative evaluation:

- **Planning evaluation:** was initiated as the project proposal and Work Plan were developed. Project outcomes, activities, and timelines were identified.
- **Formative evaluation:** will assess ongoing project activities. This ensures progress according to stated outcomes and within desired timelines. Formative evaluation information will be fed back to the NHSP, and NHSP Advisory Committee to re-evaluate, revise, and improve the functioning of project activities.

- **Summative evaluation:** will assess the success of activities. Summative evaluation will be important after formative evaluation measures have revised project activities. Conclusions and recommendations will be made based on project outcomes. Valid, reliable, and standardized indicators in line with community goals and values will be utilized when available. As the project progresses over time, a formative evaluation will further refine measurement activities to evaluate and monitor activities. Evaluation methods used to assess program outcomes and effectiveness/efficiency of the project in attaining goals and objectives include but are not limited to:
 - The NHSP Coordinator and Project coordinator will conduct a monthly review of the processes and timelines of accomplishing activities according to the Work Plan. Challenges or reasons for not accomplishing activities or not meeting due dates will be identified and documented.
 - The EHDI Advisory Committee will assess program performance by reviewing LFU/D data and 1-3-6 data, trends, program or pilot strategies, and progress in implementing activities.
 - The projector coordinator and research statistician will conduct monthly QI on the data entered by the hospitals in the HI*TRACK system. The hospital screening coordinators will be informed if there is a discrepancy and will be asked to take necessary corrective actions.
 - The project coordinator and research statistician will analyze NHSP data and determine the 1-3-6 and LFU/D rates for screening, audiologic evaluations, and intervention services. Data will be provided annually on screening, audiologic evaluations, or intervention services by timing of services to meet the EHDI 1-3-6 timeline. The NHSP will use this data to track progress and identify issues and concerns. The following measures will be monitored:

Measure	Numerator	Denominator
Screening by one month	# of infants receiving screening (total and by hospital or home births) <u>by one month</u> excludes deceased and parental refusals. Total # of infants receiving screening excludes deceased and parental refusals. <i>Source: HI*TRACK database</i>	# of births <i>Source: HI*TRACK database</i>
Audiologic Evaluation by three months	# of infants who did not pass hearing screening and receive diagnostic audiologic evaluation <u>by three months</u> excludes deceased, parental refusals, or families moved out of state. Total # of infants who did not pass hearing screening and receive diagnostic audiologic evaluation excludes deceased, refusals or families moved out of state. <i>Source: HI*TRACK database</i>	# of infants who did not pass hearing screening <i>Source: HI*TRACK database</i>

Early Intervention by six months	<p># infants with permanent hearing loss who are enrolled in EI services <u>by six months</u> excludes parental refusals or families moved out of state.</p> <p>Total # of infants with permanent hearing loss who are enrolled in EI services excludes parental refusals or families moved out of state</p> <p><i>Source: HI*TRACK database. Data on children receiving EI is from NHSP referrals of children with permanent hearing loss to EI, or from the EI database</i></p>	<p># infants with permanent hearing loss</p> <p><i>Source: HI*TRACK database (or NHSP files) which has data from audiologist records or EI Care Coordinator reports</i></p>
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- The NHSP will use the National Initiative for Children's Healthcare Quality (NICHQ) Model for Improvement for the following interventions:

Intervention	Quantitative Measure (preliminary)
Develop quality assurance guidelines, including screeners' talking points, to support the hospital screening programs and reduce the need for outpatient screening.	<p>Guidelines are developed, revised, and approved within the work group's identified timeline.</p> <p>Proportion of hospitals that have up-to-date hearing screening guidelines that include the four identified items (listed in methodology).</p> <p>Proportion of screeners (by hospital and overall) who complete the NCHAM online training curriculum within one month of assignment to screening role.</p> <p>Percentage of screening report cards that are accessed by an authorized user within one week of dissemination.</p> <p>Percentage of infants completing outpatient screening post-intervention, compared to the percentage of infants completing outpatient screening pre-intervention.</p> <p>Once the intervention is refined and expanded beyond the initial test site, pre-and post-intervention outpatient screening rates will be compared at the state level.</p>
Pilot teleaudiology between Oahu and the neighbor islands.	<p>The available resources at the pilot site(s) will be assessed to create a needs assessment report.</p> <p>The cost of pre-intervention assessment (travel to Oahu for an ABR) will be compared to the cost of post-intervention assessment (ABR by teleaudiology).</p> <p>The reliability of the ABR results obtained by teleaudiology will be compared to the reliability of an in-person ABR.</p> <p>The feasibility of expanding teleaudiology sites will be determined based upon family and audiologist satisfaction with the pilot study (generated by surveys) and knowledge of the neighbor island resources (generated through needs assessment).</p>

Identify and request reports for infants who may be lost to documentation but have been followed-up by the audiology department of a birthing hospital.	<p>Meeting between the military hospital representative and CSHNB Administrator is scheduled and completed.</p> <p>The percentage of diagnostic reports provided to the NHSP (either by copy or entry into HI*TRACK) pre-meeting, as compared to the percentage of diagnostic reports provided to the NHSP post-meeting.</p> <p>The percentage of military hospital infants identified with permanent hearing loss pre-meeting, as compared to the percentage of military hospital infants identified with permanent hearing loss post-meeting.</p>
Collaborate with audiologists and PCPs to ensure children are referred to EI as soon as a permanent hearing loss is identified.	<p>The number of referral forms received from audiologist's pre-intervention, as compared to the number of referral forms received from audiologist's post-intervention.</p> <p>Once the intervention is refined and expanded beyond the initial test site, the rates of referral forms received from audiologists pre- and post-intervention will be compared at the state level.</p> <p>The percentage of infants enrolled in EI before age six months pre-intervention, as compared to the number of infants enrolled in EI before age six months post-intervention.</p> <p>Once the intervention is refined and expanded beyond the initial test site, the rates of infants enrolled in EI before age six months pre- and post-intervention will be compared at the state level.</p>
The Comprehensive Services Center for the D/HH/DB to provide parent support.	<p>The number of families completing follow-up to diagnosis when family support is provided compared to the current baseline.</p> <p>The percentage of infants enrolled in EI before age six months when family support is provided as compared to the number of infants enrolled in EI before age six months at the current baseline.</p> <p>Quarterly progress submitted to NHSP.</p>
Family engagement in advisory committee and NHSP activities is increased.	<p>Number of parents and individuals with hearing loss that participates on the advisory committee and for NHSP activities are tracked.</p> <p>Working together survey is used to assess family participant perception of collaboration with NHSP activities.</p> <p>Improvements are made based on feedback from family participants to provide better opportunities for family engagement.</p>
Pediatric Provider knowledge about congenital hearing loss and EDHI program is increased.	<p>Do survey to collect the current level of knowledge about congenital hearing loss and the EDHI program.</p> <p>Implement the AAP Champion continuing education series to education providers.</p> <p>Do post-tests after continuing education and every six months.</p> <p>Document knowledge gain and retention over time.</p>

Additional information about who is responsible for each activity, timeline, and evaluation can be found in the Work Plan in attachment 1.

ORGANIZATION INFORMATION

Applicant Agency Experience and Capacity

The DOH organization chart is in Attachment 5. The NHSP is under the CSHNB's Genomics Section. CSHNB is one branch in the Family Health Services Division (FHSD) of the Hawaii State DOH. The other two branches are the Maternal and Child Health Branch (MCHB) and the Women Infants and Children Services (WIC) Branch. FHSD is the state agency responsible for the state Title V Maternal and Child Health Block Grant. The CSHNB Chief is the Title V CSHCN Director.

The mission of the FHSD is: "*To improve the health of women, infants, children, and adolescents and other vulnerable populations and their families, by: increasing public awareness and professional education about the importance of a life-course perspective; advocating for systemic change that addresses health equity and the social determinants of health; and assuring a system of health care that is family/patient-centered, community based.*"

FHSD goals include:

- All infants, children, and adolescents, including those with special health care needs, will receive appropriate services to optimize health, growth, and development; and
- Access to quality health care shall be assured through the development of a comprehensive, coordinated community-based, patient/family-centered, culturally-competent system of care.

Within the CSHNB, there are three sections: the Children with Special Health Needs Section, the Early Intervention Section, and the Genomics Section. The NHSP is one of four programs in the Genomics Section. The other three programs are the Newborn Metabolic Screening Program, the Birth Defects Program, and the Genetics Projects. The NHSP works towards appropriate and timely screening, diagnostic audiological evaluation, and referral for EI services. It sets standards and guidelines; provides education to health professionals, EI providers, and the general public; facilitates ongoing activities of the hearing screening system; provides training and technical assistance; and provides assistance with follow-up for rescreening, evaluation, and/or referral to EI services. The NHSP has three state-funded staff: Program Coordinator, Social Services Assistant, and Office Assistant.

Personnel Resources

CSHNB programs/staff pertinent to newborn hearing screening:

- **CSHNB Chief:** provides general oversight of the Genomics Section. Assists with grant applications, progress reports, data review, and other areas. The CSHNB works with Hilopa‘a, AAP-Hawaii Chapter, and University of Hawaii/ Department of Pediatrics on efforts toward the six national goals for the CSHCN (family partnerships, screening, medical home, adequate insurance, community-based systems, and transition to adult life).

- **Genomics Section Supervisor:** provides direct oversight of the NHSP, including assisting with grant applications and progress reports, managing personnel, providing technical support for various NHSP activities, and assisting with policy and program development.
- **Administrative Services Unit:** provides fiscal support including accounting, reports on grant fiscal status, and oversight to ensure that appropriate fiscal procedures are followed.
- **Research statistician:** assists in the analysis of NHSP data and linking of the NHSP and NBMSP databases, WIC, and birth records. The Research statistician works with the NHSP Coordinator to analyze the NHSP database and provide reports as needed.
- **Newborn Metabolic Screening Program (NBMSP):** assures that infants born in Hawaii are satisfactorily screened for over 25 primary disorders which may have serious consequences, such as intellectual disability or death, if not identified and treated early. The NBMSP and the NHSP work together on education for midwives on the importance of newborn screening.
- **Early Intervention Section (EIS):** responsible for statewide EI services for children age birth to three years with developmental delays or biological risk, including hearing loss (assistive technology, audiology, family training, counseling, home visiting, health, medical diagnostic/evaluation, nursing, occupational therapy, physical therapy, psychological, social work, special instruction, speech language pathology, and transportation).
- **Children with Special Health Needs Program (CSHNP):** provides information and referral, outreach, care coordination, social work, and nutrition services for CSHCN age 0-21 years. Financial assistance for medical services is offered to eligible children without other resources. The CSHNP Audiologist works with the NHSP as needed.
- **Genetics Projects:** plans, develops, and implements statewide genetics activities; develops activities to promote the prevention, detection, and treatment of genetic disorders; and provides genetics education for the professional and general community. The Genetics Project staff has actively worked with the NHSP related to genetic services for children with hearing loss.

Other Committees Relevant to EHDI

Newborn hearing screening committees:

- The EHDI Advisory Committee advises the NHSP regarding policies and other issues related to the EHDI system, and reviews NHSP activities and progress toward the EHDI 1-3-6 goals. It meets up to three times per year.
- The Hospital Newborn Hearing Screening Coordinators Committee addresses screening policies, procedures, and issues in the hospital setting. It meets face-to-face annually.

Technology Resources

- **Website**

The NHSP website, <http://health.hawaii.gov/genetics/programs/nhsp/> is an important resource used to disseminate information to providers and the general public. The website contains general information about the NHSP, educational materials, and data about newborn hearing screening in Hawaii. The webmaster works within the Genomics Section, so updates and revisions are easily made to the website.

- **Videoconference/Telehealth/Webinars**

Through the use of the HIPAA compliant videoconference program “Zoom,” videoconferences with project partners, telehealth with families, and informational webinars can be arranged. Webinars can be recorded and made available on the website for future viewing.