Hawai‘i Practitioner’s Manual for Early Hearing Detection and Intervention

HEALTHCARE PROVIDER GUIDE

Hawai‘i State Department of Health
Newborn Hearing Screening Program

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http://hawaii.gov/health/family-child-health/eis/nhsp.html

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Aloha!

We are pleased to provide you with a copy of the Hawai`i Practitioner's Manual for Early Hearing Detection and Intervention. Inside, you will find information about the 1-3-6 plan for early hearing detection and intervention, and a wealth of related resources for use with infants and toddlers under your care. We appreciate all you do to assure that babies with hearing loss are identified as early as possible and receive support to minimize delays in language and cognitive development.

Thank you!

Hawai`i State Department of Health
Newborn Hearing Screening Program

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"Appropriate and necessary care for the infant with significant hearing loss should be directed and coordinated by the child's physician within the medical home, with support from appropriate ancillary services."

American Academy of Pediatrics (1999)[1]

INTRODUCTION

Hearing loss is common and easy to miss without testing. When hearing loss is not identified before six months of age, delays in speech and language acquisition and other preventable outcomes are likely to occur.

Families look to physicians and other providers within the medical home for answers and direction at each stage of the early hearing detection and intervention process. The purpose of this document is to update healthcare providers regarding current early hearing detection and intervention (EHDI) protocols and resources available to families in Hawai`i.

The Hawai`i Practitioner's Manual for Early Hearing Detection and Intervention includes information consistent with recommendations of the Joint Committee on Infant Hearing (JCIH), the American Academy of Pediatrics (AAP) and the American Speech-Language-Hearing Association (ASHA). It is not intended to replace a provider's clinical judgment for providing healthcare.

Role of the Healthcare Provider

The role of the healthcare provider is to assure that each baby under their care has access to:

- newborn hearing **screening before 1 month of age**, preferably before hospital discharge
- diagnostic audiological **evaluation before 3 months of age**, if the baby does not pass screening
- **medical evaluation** to determine the etiology of the hearing loss and assess for associated conditions
- **early intervention services and hearing aids before 6 months of age**, if the baby is diagnosed with sensorineural, permanent conductive or mixed hearing loss or auditory neuropathy
- **periodic monitoring for late onset or progressive hearing loss** for all infants and children, but especially if the baby has specific risk indicators

See Appendix D for related brochures and other information. Referral forms for newborn hearing screening (Hearing Screening Status form), early intervention (H-KISS Fax Referral Form), and the Children with Special Health Needs Program (Referral for Service form) are also provided in Appendix D.

Hawai`i Department of Health
Newborn Hearing Screening Program Overview

Three babies per thousand are born with some degree of permanent hearing loss.[2] Others develop hearing loss in early childhood. Fifty to sixty infants and toddlers are identified with hearing loss in Hawai`i each year.

In 1990, Hawai`i became one of the first states to require newborn hearing screening and follow-up. Since then, early hearing detection and intervention has become a national public health initiative endorsed by such groups as the American Academy of Pediatrics, the National Institutes of Health and the Centers for Disease Control and Prevention. The *Healthy People 2010* prevention agenda for the nation also includes early hearing detection and intervention objectives.

The Newborn Hearing Screening Program assists health care providers in assuring that babies born with hearing loss are identified and referred for appropriate follow-up services to support language acquisition and cognitive development. The three primary goals of the program are often referred to as the:

1-3-6 Plan for Early Hearing Detection and Intervention

Screening before age 1 month

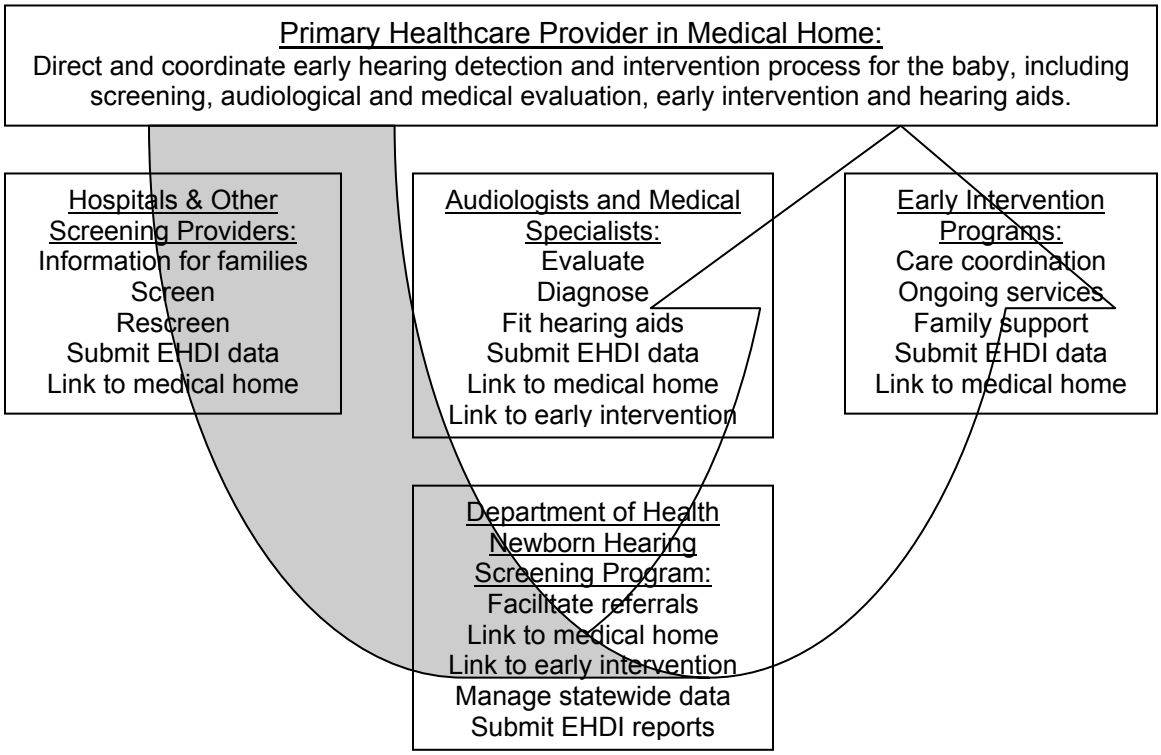
Diagnostic evaluation before age 3 months

Early intervention before age 6 months

Other Newborn Hearing Screening Program goals include:

- Identifying children with late onset or progressive hearing loss at the earliest possible time;
- Ensuring that all children with hearing loss have a medical home;
- Having a comprehensive early hearing detection and intervention tracking system to minimize loss to follow-up; and
- Monitoring progress towards state and federal EHDI goals and objectives.

Early Hearing Detection and Intervention Functions



SCREENING BEFORE 1 MONTH OF AGE

At the First Well Child Visit

☑ Check to see if the infant was screened for hearing loss during the inpatient stay. If the infant was not born at a hospital, it is likely that the baby has not been screened.

Screening Status	Action Required	Purpose/Resources
Passed both ears (OAE or AABR for well-babies; AABR if in a NICU for more than 5 days.)	Determine if baby should be monitored for late onset of hearing loss.	See page 1-4 for more information about monitoring for late onset hearing loss.
Did not pass	Assure that rescreening takes place before 1 month of age.	Contact the newborn hearing screening coordinator in the birthing hospital or the DOH Newborn Hearing Screening Program to arrange rescreening. See page 1-3 for locations.
Unknown or incomplete	Assure that screening takes place before 1 month of age.	Contact the birthing hospital's newborn nursery or the DOH Newborn Hearing Screening Program to request screening results and/or arrange screening. See page 1-3 for locations.

The likelihood of congenital hearing loss is approximately:

- 1 baby per 1000 in the well-baby population.
- 10 babies per 1000 for neonatal intensive care unit graduates.

Joint Committee on Infant Hearing Update (2006)[3]

SCREENING – continued

At the Second Well-Child Visit

☑ Check to see if outpatient screening has been completed for infants who missed or did not pass initial screening. This should be completed within 2–4 weeks of the initial screen.

Screening Status	Action Required	Purpose/Resources
Passed rescreen in both ears	Determine if baby is at high risk for late onset of hearing loss.	Both ears should be rescreened, as the baby's hearing may have changed since the previous screen. Rescreening should include AABR if the baby did not pass inpatient AABR or does not pass rescreening with OAE. See page 1–4 for more information about monitoring for late onset hearing loss.
Did not pass rescreen or needs evaluation instead of rescreen	Refer for evaluation and coordinate insurance pre-authorization.	See page 1–9 for more information about screening versus evaluation. Diagnostic ABR testing is available on Oahu and Maui for children residing anywhere in the state. Children on Kaua`i and the Big Island may first be referred to a local pediatric audiologist to confirm if diagnostic ABR is needed. See page 2–2 for pediatric audiologists.
Unknown or incomplete	Assure that screening takes place before 1 month of age.	Contact the birthing hospital's newborn nursery or the DOH Newborn Hearing Screening Program to request screening results or arrange screening. See page 1–3 for locations.

Resources for Screening

Phone numbers may change. If a more current number is needed, please contact the hospital's well baby nursery.

Castle Medical Center	808-263-5270
Hilo Medical Center	808-974-4715
Maui Memorial Medical Center (Screening by Imua Family Services)	808-244-7467
Kaiser Permanente Moanalua Medical Center (Kaiser members only)	808-432-8292
Kapiolani Medical Center for Women and Children	808-983-8230
Kona Community Hospital	808-322-4416
Molokai General Hospital (Women's Health Center)	808-553-3145
North Hawaii Community Hospital	808-881-4771
The Queen's Medical Center	808-547-4213
Tripler Army Medical Center	808-433-3197
West Kauai Medical Center/KVMH	808-338-9431
Wilcox Memorial Hospital	808-245-1433

In addition to the birthing hospitals listed above, hearing screening is available through pediatric audiologists (see page 2-2). For more information, please contact the Department of Health Newborn Hearing Screening Program at 808-594-0042.

When to Pay Extra Attention to Hearing

Infants with late onset hearing loss often have no identifiable risk factors. Therefore a more inclusive strategy of surveillance for all children is recommended. All infants should be monitored for developmental milestones, auditory skills, parental concerns about hearing, speech, and language, and middle ear effusion. All infants should be evaluated with an objective, standardized screen of global development with a validated assessment tool at 9, 18, and 24-30 months or at any time if the parent or caregiver has concern.

Healthcare providers should pay extra attention to hearing and speech-language development if a baby does not pass the newborn hearing screening test in one or both ears. However, every child's hearing should be monitored periodically throughout early childhood because:

- Mild (but still developmentally and educationally significant) hearing loss may be present even if a baby passes a screening test.
- Hearing can change over time.

Middle ear status should be carefully assessed at all well-child visits by pneumatic otoscopy and/or tympanometry. Children with persistent middle ear effusion for 3 or months should be referred for otologic evaluation.

The Joint Committee on Infant Hearing suggests that the following indicators put an infant at risk for progressive or

delayed-onset sensorineural and/or conductive hearing loss.[4] In Hawai`i, these risk indicators are often called "hearing loss predictors" or "indicators". Children with risk indicators should be referred for an audiologic assessment at least once by 24-30 months of age. Children who have indicators with asterisks (*) have a higher probability of hearing loss and should have more frequent audiologic assessments. See "More About Medical Follow-up for Hearing Loss" on page 3-2.

Parental or caregiver concern regarding hearing, speech, language,* or developmental delay - Parents and caregivers are often the first to notice when their child is experiencing hearing, speech, language or developmental delays. Except for children with profound bilateral hearing loss, the chief concern first identified by parents regarding a child with hearing loss is usually "speech delay".

Family history of permanent childhood hearing loss (inherited)* - About 60% of hearing loss present at birth or beginning in the first few months of life is due to an alteration in one or more of an estimated 400 genes that can cause deafness.[5] If a family member had permanent hearing loss beginning in childhood, additional questions should be asked to find out if the hearing loss was acquired due to infection or trauma.

Neonatal intensive care for more than 5 days or any of the following regardless of length of stay: extra-corporeal membrane oxygenation (ECMO), assisted ventilation, exposure to ototoxic medications (gentamycin and tobramycin)*

or loop diuretics (furosemide/Lasix), and hyperbilirubinemia that requires exchange transfusion – Conditions that require prolonged neonatal intensive care may lead to permanent hearing loss.

In utero infections, such as cytomegalovirus (CMV), herpes, rubella, syphilis, and toxoplasmosis* – Infections that can cross the placental barrier and invade fetal tissue have been linked to sensorineural hearing loss in infants. The developing auditory system is at greatest risk during the first trimester of pregnancy. An infant's hearing is most likely to be damaged if the infection occurs during this period. These infections often go unrecognized due to a lack of clinical symptoms in the mother.

- Cytomegalovirus (CMV)*: CMV is a leading cause of fetal viral infection in the United States and can cause congenital or delayed onset sensorineural hearing loss that is often progressive. It can also cause other developmental disabilities.
- Herpes: Either herpes simplex 1 or 2 may cause severe to profound sensorineural hearing loss.
- Rubella: Rubella is commonly called "German measles." When hearing loss occurs, 50% of affected babies will have severe to profound hearing loss in both ears. Hearing loss may be progressive. In addition to hearing loss, this infection may cause heart disorders, low birth weight, developmental disability, and vision loss.

- Syphilis: Congenital syphilis may cause sensorineural hearing loss that is sudden, progressive, or fluctuating.
- Toxoplasmosis: This infection is caused by a protozoan parasite and affects approximately 1/750 newborns in the U.S. In addition to hearing loss, toxoplasmosis may cause seizures, developmental disability, and vision loss.

Craniofacial anomalies, including those involving the pinna, ear canal, ear tags, ear pits, and temporal bone – Hearing may be affected if the head, face, neck or ears are shaped or formed in a different way than usual. Other examples of craniofacial anomalies that may be associated with hearing loss include cleft palate, shortened neck, webbed neck, abnormal head circumference, aural atresia (missing outer ear) or microtia (small outer ear), or low set ears.

Physical findings such as white forelock, associated with a syndrome known to include a sensorineural or permanent conductive hearing loss. A white forelock is a characteristic of Waardenburg's Syndrome, which may be associated with sensorineural hearing loss that can vary from profound to none.

*Syndromes associated with hearing loss or progressive or late-onset hearing loss** – Conditions such as neurofibromatosis, osteopetrosis and Usher's syndrome may cause progressive hearing loss. Other frequently identified syndromes that can affect hearing include Waardenburg, Alport, Pendred, Jervell and Lange-Nielson.

Neurodegenerative disorders,* such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome, cause both neurological functioning and hearing to deteriorate over time.

Culture positive postnatal infections associated with sensorineural hearing loss, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis* – Some postnatal infections may cause hearing loss in young children. The younger the child when the infection occurs, the greater the potential impact a resulting hearing loss may have on speech and language acquisition. Bacterial meningitis is a leading cause of acquired deafness in infants. Most cases result in bilateral severe to profound sensorineural hearing loss.

Head trauma, especially basal skull/temporal bone fracture requiring hospitalization* – Trauma that causes loss of consciousness or skull fracture, with or without bleeding from the ear, may result in conductive hearing loss due to bleeding, perforation of the tympanic membrane, or disruption of the ossicular chain. Sensorineural hearing loss may occur if the temporal bone housing the inner ear is damaged.

*Chemotherapy** – Chemotherapeutic agents such as cisplatinum and carboplatin are ototoxic and may lead to late onset or progressive sensorineural hearing loss.

More about Hearing Screening

Screening does not directly measure true hearing or the brain's ability to process sounds. Screening results indicate the likelihood of a greater than 30-40 dB hearing loss at the time of screening. As mentioned in the previous section, it is important to realize that some children with mild (but still developmentally and educationally significant) hearing loss may not be identified through screening and that hearing can change over time. Healthcare providers should therefore remain alert for possible hearing loss as they provide ongoing care for infants and young children, regardless of whether or not the child passed newborn hearing screening.

Screening Protocols

Most well baby screening programs in Hawai`i perform an otoacoustic emissions (OAE) screening test first, followed by an automated auditory brainstem response (AABR) screening test if the child does not pass OAE. NICU screening programs use AABR to better detect conditions such as auditory neuropathy or use a combination of OAE and AABR. Screening is available for homebirth babies on an outpatient basis at birthing hospitals and through pediatric audiologists. Both ears are screened, since hearing loss is developmentally and educationally significant even if only one ear is affected.

Well babies who do not pass OAE or AABR during the first stage of the newborn hearing screening process are referred for rescreening before 1 month of age. Both ears are

rescreened, as the baby's hearing may have changed since the previous screen. AABR is recommended if the baby didn't pass a previous AABR screen or only had an OAE. Babies who don't pass rescreening are referred for comprehensive diagnostic audiological evaluation, including auditory brainstem response (ABR) testing, before 3 months of age.

Diagnostic audiological evaluation is recommended instead of rescreening for babies not passing inpatient screening when:

- Their head, face, neck or ears are shaped or formed in a different way than usual, including babies who have atresia, microtia, Down syndrome or cleft palate; or
- They are in a NICU for more than 5 days; or
- They have other medical conditions that require diagnostic testing to determine hearing status.

Diagnostic auditory brainstem response (ABR) testing is available on Oahu and Maui for children born anywhere in the state. If the family prefers, children not passing hospital rescreening on Kaua`i or the Big Island may be seen by a pediatric audiologist on their home island for additional testing. If the local audiologist determines that a diagnostic ABR is needed, the baby will then be referred to Oahu or Maui for evaluation before 3 months of age. Children not passing newborn hearing screening on islands where diagnostic ABR testing is available are referred immediately for a diagnostic ABR and other tests to determine if they have a hearing loss.

With prior authorization, the Hawai`i Department of Health Newborn Hearing Screening Program can help with some test and travel costs, if not covered in full by the child's insurance.

Screening Methods

Either of the following methods can usually be performed by trained personnel in about 5 to 20 minutes. Babies are often screened after 12 hours of age. Screenings before 24 hours of age are more likely to be affected by the presence of vernix/debris in the ear canal. Screenings for older children are more likely to be affected by middle ear effusion.

Auditory Brainstem Response Screening (AABR)

In AABR screening, clicking sounds are introduced through an earphone or over-the-ear coupler. Electroencephalographic (EEG) response is measured through electrodes placed on the baby's head and neck. The equipment automatically generates a "pass" or "refer" screening result based on preset criteria.

AABR screening provides information about the auditory pathway up to the brainstem, including the middle ear, the inner ear and the eighth cranial nerve. Central auditory processing and neuropathy problems, which are more likely when babies have conditions leading to prolonged NICU stays, can be detected. AABR screening is recommended for babies in the NICU, as well as for rescreening well-babies who do not pass otoacoustic emissions screening.

Otoacoustic Emissions Screening (OAE)

In OAE screening, an earphone with a built-in microphone is placed in the ear canal to introduce sounds (clicks or tones) and listen for cochlear outer hair cell response (otoacoustic emissions). If the outer hair cells of the cochlea have been damaged or if incoming sound is blocked before reaching the cochlea, otoacoustic emissions will not be produced. The equipment automatically generates a "pass" or "refer" screening result based on preset criteria.

OAE screening provides information about the auditory pathway up to and including the cochlea. Central auditory processing and neuropathy problems, which affect less than 1% of children with hearing loss, will not be detected by OAE screening. In Hawai`i, the well-baby population usually receives OAE screening. Well-babies who do not pass OAE screening are usually rescreened with AABR to obtain information about the auditory pathway up to the brainstem, including the middle ear, the inner ear and the eighth cranial nerve.

EVALUATION BEFORE 3 MONTHS OF AGE

At the Second or Third Well Child Visit

☑ For those children who did not pass rescreening, check that a diagnostic auditory brainstem response test (ABR) has been scheduled or completed.

ABR Results	Action Required	Purpose/Resources
Normal	Determine if baby should be monitored for late onset of hearing loss.	See page 1-4 for more information about monitoring for late onset hearing loss.
Unknown or incomplete	Under 3-6 months: Refer for unsedated ABR or other tests by an audiologist. Over 3-6 months: Refer for sedated ABR. Over 6 months: Refer for behavioral hearing test.	Sites that provide unsedated ABRs differ as to the maximum age they will evaluate. Children must be able to sleep soundly during the test. Not all sites offer sedated ABRs. Children must be awake and alert to respond for behavioral hearing tests. (Sedated ABR testing may also be required to determine hearing status.) See page 2-2 for pediatric audiologists.
Hearing loss	Refer for EI services and amplification before age 6 months. (Hearing aids can be fit by 1 month of age.)	Refer the child for EI services by calling the Hawaii Keiki Information Services System (H-KISS) at 808-594-0066 or toll-free at 1-800-235-5477. See page 3-1 for more about EI. See page 2-2 for pediatric audiologists.

Resources for Diagnostic Audiological Evaluation

Providers on this list applied for and were awarded contracts with the Department of Health to provide pediatric audiology services. For additional audiologists in your area, please consult your phonebook.

DOH Contracted Audiologists	Appt. Phone #
Audiology Associates Hawai`i (Oahu–Honolulu, Aiea)... *Provides unsedated ABR tests at both locations and behavioral tests in Honolulu.*	486-5000
Big Island Hearing Center, LLC (Big Island–Hilo)..... *Provides behavioral tests and hearing aids.*	935-1299
Castle Medical Center Audiology Department (Oahu) ... *Provides unsedated ABR tests for infants under 4 months old.*	263-5055
Hawai`i Professional Audiology (Oahu)..... *Provides behavioral tests and hearing aids.*	597-1877
Hawai`i Professional Audiology (Kauai)..... *Provides behavioral tests and hearing aids.*	245-1530
Island Audiology (Oahu) ..... *Provides behavioral tests and hearing aids.*	375-2253
June Uyehara-Isono, Inc. (Oahu, Big Island–Hilo, Kona) *Provides behavioral tests and hearing aids.*	877-524-1432
Kapiolani Medical Center for Women and Children (Oahu) *Provides sedated and unsedated ABR tests, behavioral tests and hearing aids.*	*Behavioral tests:* 535-7000, ext. 1 *ABR tests & hearing aids:* 983-8230
Kapiolani Medical Center – Pali Momi (Oahu) ..... *Provides behavioral tests and hearing aids.*	535-7000, ext. 1
Maui Medical Group (Maui)..... *Provides non-sedated click ABR tests, behavioral tests and hearing aids.*	242-6464

Auditory Brainstem Response (ABR) test=Baby is asleep or sedated
Behavioral test=Child is awake and alert (usually at least 6-7 months old)

More about Diagnostic Audiological Evaluation

Diagnostic Testing Protocols

Unless medically contraindicated, diagnostic audiological evaluation should be completed before 3 months of age for children who do not pass newborn hearing screening. The preferred protocol in Hawai`i is to administer ear specific:

- 1000 Hz tympanometry
- comprehensive otoacoustic emissions
- click auditory brainstem response (ABR)
- at least 500 and 4000 Hz tone burst ABR testing (tone burst ABR scores corrected for age when determining hearing status)
- bone conduction testing, if air conduction results indicate hearing loss

The preferred protocol for children over 6 months of age includes ear specific behavioral assessment of hearing instead of or in addition to ABR testing. The desire for behavioral hearing test results should not delay amplification, as protocols designed for use with infants are now available.[6]

Methods Used to Assess Hearing in Infants

Tympanometry

Tympanometry, including acoustic reflexes, is used to assess middle ear function. Due to the plasticity of a newborn's ear canal, low frequency (226 Hz) tympanometry is not considered accurate until approximately 6 months of age.

High frequency (1000 Hz) tympanometry is therefore preferred for children under 6 months of age, although this procedure may not be available in every location.

Comprehensive Otoacoustic Emissions (OAE) Testing

OAE testing is used to identify outer hair cell dysfunction in the cochlea. Comprehensive, frequency specific OAE testing should be performed to help determine hearing status.

Auditory Brainstem Response (ABR) Testing

ABR testing is used to assess functioning of the cochlea, auditory nerve and auditory brainstem pathways. Comprehensive ABR tests are the accepted method of evaluating infants who are less than 6 months developmental age. Click and frequency-specific tone burst ABR tests allow an estimation of hearing thresholds for diagnostic purposes and hearing aid fitting. They may also indicate the possibility of conductive hearing loss. Tone burst ABR scores should be corrected for age when determining hearing status. Bone conduction ABR testing should be provided if air conduction results indicate hearing loss.

Behavioral Assessment

Behavioral hearing tests should be provided to validate physiological results. Behavioral test results become more accurate as a baby approaches 6 months of age. Bone conduction behavioral testing should be provided if air conduction results indicate hearing loss.

Department of Health Programs

Upon request, the Newborn Hearing Screening Program assists families in scheduling appointments for infants who need diagnostic evaluation to rule out permanent hearing loss. Children under three years of age who are not eligible for Part C early intervention can participate. Health insurance is billed first, if the child has coverage. The Department of Health is billed last. Families are not billed.

The Department of Health is Lead Agency for Part C early intervention (EI) in Hawai`i. Part C Care Coordinators assist families of EI enrolled children in scheduling evaluations, hearing aid related services (not including purchase of hearing aids), and auditory rehabilitation. Families are encouraged to allow health insurance to be billed first, if the child has coverage. The Department of Health is billed last. Families are not billed. EI has a lending library which includes FM systems.

For income eligible families, the Children with Special Health Needs Program can assist families of children diagnosed with hearing loss in obtaining ongoing evaluations, hearing aids, and hearing aid related services. Health insurance is billed first, if the child has coverage. The Department of Health is billed last. Families are not billed.

The Department of Health also has loaner hearing aids available for short term loan to children enrolled in EI and/or the Children with Special Health Needs Program. For more information, call 808-733-9067.

More about Hearing Loss

Types of Hearing Loss

Hearing loss can be present from birth or acquired after birth. About 60% of congenital hearing loss is associated with genetic causes.[5] For many children, the associated clinical findings regarding the etiology (cause) of their hearing loss is important in patient care. See Appendix D for additional information from the Hawai`i Genetics Program.

Hearing can change over time and the incidence of hearing loss increases with age. According to statistics compiled by the National Institute on Deafness and Other Communication Disorders (NIDCD), hearing loss affects 17/1000 children under age 18 and 314/1000 adults older than age 65. Nearly 28 million Americans have hearing loss in at least one ear.[7]

Conductive hearing loss occurs when sound cannot pass through the outer or middle ear into the inner ear. It can be caused by reversible conditions such as impacted wax, a punctured eardrum, fluid in the middle ear, or a middle ear infection. Conductive hearing loss can often be corrected through medical treatment or surgery. Without treatment, conductive hearing loss may become permanent.

Permanent conductive hearing loss occurs when sound cannot pass through the outer or middle ear into the inner ear due to conditions that cannot be corrected by medical

treatment or surgery or due to conditions that are expected to be of life-long or long-term duration. It can be caused by acquired conditions such as middle ear scarring from ear infections or injury and by congenital conditions such as aural atresia (no ear) or microtia (small ear).

Sensorineural hearing loss occurs when the auditory nerve or hair cells in the inner ear are damaged. Causes may include noise, aging, infection, head trauma, toxic medications or an inherited condition. Researchers estimate that 30-40% of children with confirmed hearing loss also demonstrate developmental delays or other disabilities.[4] The most commonly found additional disability is visual impairment. Mild cognitive disabilities are the next most common. Specific learning disabilities are third.

Mixed hearing loss occurs when both conductive and sensorineural hearing losses are present.

Auditory neuropathy affects a small number of children with hearing loss. Although many appear to be NICU graduates, the exact prevalence of auditory neuropathy is unknown. This disorder is identifiable through combined use of OAE and ABR tests. This disorder is characterized by normal OAE results and absent or abnormal ABR results, suggesting functioning outer hair cells with abnormal neural conduction. Some children with auditory neuropathy benefit from amplification.

Unilateral vs. Bilateral Hearing Loss

Children with hearing loss in one ear should receive the same medical assessment to determine etiology as children with bilateral hearing loss, as well as audiological follow-up to monitor for progressive hearing loss and early intervention to support language acquisition. Some will develop bilateral hearing loss by the time they enter school. Many will experience early language delays and may have difficulty understanding speech depending upon the amount of background noise or their distance from the person speaking.

Degrees of Hearing Loss

Children without amplification who have mild hearing loss may be unable to hear as much as 50% of spoken language. Those with moderate hearing loss may be unable to hear as much as 90% of spoken language. Thus, any degree of hearing loss should be considered developmentally and educationally significant. The Hawai`i Department of Health utilizes the scale from the Centers for Disease Control and Prevention annual Early Hearing Detection and Intervention data report when describing degree of hearing loss:

Degree	Responds at
Mild Hearing Loss:	21-40 dB
Moderate Hearing Loss:	41-70 dB
Severe Hearing Loss:	71-90 dB
Profound Hearing Loss:	91 or greater dB

EARLY INTERVENTION BEFORE 6 MONTHS OF AGE

When a Hearing Loss is Identified

☑ Check that the family has enrolled the child in Early Intervention (EI) services, and is able to access resources for specialty medical services and hearing aids.

Service	Required Action	Purpose/Resources
Early Intervention Services	Refer for EI services by calling the Hawaii Keiki Information Services System (H-KISS).	See pages 3-3 and 3-5 for more information about EI. H-KISS can be reached at 808-594-0066 or toll-free at 1-800-235-5477.
Medical Services	Provide/refer for complete head/neck exam for craniofacial anomalies, otologic evaluation, ophthalmologic evaluation, and genetics evaluation.	Medical evaluation is needed to help determine etiology of the hearing loss, to assess for related conditions, and to provide recommendations for medical treatment.
Hearing Aids and Other Assistive Listening Devices	Refer for medical and otologic evaluations for management of hearing loss and to obtain medical clearance for hearing aids. Refer to pediatric hearing aid provider.	See page 3-4 for a list of pediatric hearing aid providers. Management of OME should not delay hearing aid fitting. See Appendix D for patient checklist.

30-40% of children with confirmed hearing loss will demonstrate developmental delays or other disabilities.

Joint Committee on Infant Hearing (2007)[4]

More about Medical Follow-up for Hearing Loss

Every infant with confirmed hearing loss and/or middle ear dysfunction should be referred for otologic and other medical evaluation. Essential components of the medical evaluation include a complete medical history, family history of childhood onset permanent hearing loss, physical exam, and indicated laboratory and radiographic studies.

If etiology of the hearing loss is unknown after the initial evaluation, the following should be considered:

- CT of temporal bones for cochlear abnormalities and to assess for potential candidacy for cochlear implant.
- Ophthalmologic exam
- EKG
- Urinalysis
- CMV testing
- Genetic evaluation

Refer for developmental pediatrics, neurology, cardiology and nephrology evaluations (as needed). Specialists should have pediatric expertise.

Resources for Early Intervention

Part C early intervention services are available on all islands and are provided at no cost to the family. Families are encouraged (but not required) to allow providers to bill health insurance first, if the child has coverage.

In Hawai`i, children with developmental delays and/or diagnosed conditions or environmental factors that put them at-risk of developmental delay are eligible for Part C early intervention.

- Children with sensorineural, permanent conductive, or mixed hearing loss in one or both ears are automatically eligible for Part C early intervention services in Hawai`i.
- Fluctuating conductive hearing loss does not make a child automatically eligible for Part C early intervention services in Hawai`i.

To make a referral, please call the Hawai'i Keiki Information Services System (H-KISS) information and referral line:

Oahu: 594-0066
Toll-free from Neighbor Islands: 1-800-235-5477
(Voice and TTY available)

Telephone hours: Monday-Friday, 8:30 a.m. to 3:00 p.m.
If calling after hours, please leave a message. See Appendix D for the H-KISS fax referral form. Upon referral, H-KISS will contact the family with information about early intervention services in their area. A care coordinator will be assigned to assist the family during intake and help them obtain services.

Resources for Pediatric Hearing Aid Fitting

Providers on this list applied for and were awarded contracts with the Department of Health to provide pediatric audiology services. For additional providers who dispense pediatric hearing aids in your area, please consult your phonebook.

DOH Contracted Audiologists who Provide Hearing Aids	Appt. Phone #
Big Island Hearing Center, LLC (Big Island-Hilo)	935-1299
Hawai`i Professional Audiology (Oahu)	597-1877
Hawai`i Professional Audiology (Kauai)	245-1530
Island Audiology (Oahu)	375-2253
June Uyehara-Isono, Inc. (Oahu, Big Island-Hilo, Kona)	877-524-1432
Kapiolani Medical Center for Women and Children (Oahu)	983-8230
Kapiolani Medical Center - Pali Momi (Oahu)	535-7000, ext. 1
Maui Medical Group (Maui)	242-6464

More about Early Intervention and Hearing Aids

Early Intervention (EI)

Many families are shocked to find out that their infant has a hearing loss. Parents may need assistance and emotional support as they learn more about their baby's diagnosis and how hearing loss can affect development. Early Intervention (EI) is key to optimal outcomes and should begin as soon as hearing loss is identified. EI services, including family support and information, can begin even before a hearing aid is received. The lead agency for EI in Hawai`i is the Hawai`i State Department of Health Early Intervention Section. See Appendix D for more information.

Audiological evaluations, auditory rehabilitation and hearing aid related procedures, such as dispensing fees, ongoing hearing aid checks and ear molds, are covered by EI for enrolled children. Use of health insurance is encouraged, but not required. Note: Part C Early Intervention does not cover surgery, sedation, medication, doctor visits, or the purchase of hearing aids.

Clearance for Hearing Aids

State law requires that medical clearance be obtained before hearing aids are provided for a child. The JCIH-2007 Position Statement states that management of otitis media with effusion should not delay the prompt fitting of amplification.[4] Hearing aids can be fit as early as one month of age.

Loaner Hearing Aids and FM Systems

Initial hearing aid fitting for newborns often requires more flexibility and options than may be needed for older children and adults. The Hawai`i State Department of Health maintains a hearing aid loan bank, located with the Children with Special Health Needs Program (CSHNP), to provide 6 month loaner hearing aids for children enrolled in Early Intervention or the Children with Special Health Needs Program. In addition, the Early Intervention Section (EIS) has several FM systems for short-term loan to families of children enrolled in Early Intervention. This allows audiologists the time and flexibility to complete the assessment process and modify hearing aid and FM system recommendations according to the changing needs of the child. See Appendix D for contact information for CSHNP and EIS.

Payment for Hearing Aids

Hearing aids are expensive and may not be covered by a child's health insurance. Medicaid and QUEST plans cover some types of pediatric hearing aids. Families of children who are eligible for the Children with Special Health Needs Program (CSHNP) may also receive help with payment for pediatric hearing aids, if state funds are available. See Appendix D for more information about CSHNP.

In cases of financial hardship, families who are over income for Medicaid, QUEST and CSHNP may apply to the Department of Health Early Intervention Section (EIS) for

assistance in purchasing hearing aids for EI enrolled children. If state funds are available, EIS will help with some of the purchase costs. Insurance and any other funding sources will be billed first if the child has coverage, and then EIS will be billed. Families are responsible for any remaining costs.

Cochlear Implants

Nearly all children who are Deaf or Hard of Hearing initially receive amplification through personal hearing aids. Some children who are Deaf do not benefit from the use of hearing aids and may be candidates for cochlear implants. Evaluation for cochlear implantation can begin as soon as the hearing loss is identified. Usually, implantation does not occur until approximately 12-18 months of age.

Cochlear implants require extensive rehabilitation and a team approach to assessing candidacy. In Hawai`i, cochlear implant surgery is available on Oahu at such locations as Kaiser Moanalua Medical Center, Kapiolani Medical Center for Women and Children, The Queen's Medical Center and Tripler Army Medical Center. For more information, please contact these hospitals or an audiologist who provides pediatric audiology services.

APPENDIX A

References

[1]American Academy of Pediatrics (1999). Newborn and infant hearing loss: Detection and intervention. Task Force on Newborn and Infant Hearing. *Pediatrics, 103 (2),* 527-530. Available online at: www.pediatrics.org
http://www.pediatrics.org/cgi/content/full/103/2/527

[2]White, K.R. (October, 1997). *The scientific basis for newborn hearing screening: Issues and evidence.* Invited keynote address to the Early Hearing Detection and Intervention (EHDI) Workshop sponsored by the Centers for Disease Control and Prevention, Atlanta, Georgia. Reference retrieved on January 13, 2007 from the National Center for Hearing Assessment and Management (NCHAM)'s *Universal Newborn Hearing Screening Fact Sheet,* at: www.infanthearing.org
http://www.infanthearing.org/resources/fact.pdf

[3]Vohr, Betty (March, 2006). *An Update from the Joint Committee on Infant Hearing.* Invited address on an Early Hearing Detection and Intervention (EHDI) Special Topics Teleconference sponsored by the Centers for Disease Control and Prevention. Transcript available online at: www.cdc.gov/ncbddd/ehdi/ddtele.htm
http://www.cdc.gov/ncbddd/ehdi/documents/JCIH_06.pdf

[4]Joint Committee on Infant Hearing (2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics, 120 (4)*, 898-921. Available online at: www.pediatrics.org
http://www.pediatrics.org/cgi/content/full/120/4/898

[5]Burton, Sarah K. MS; Blanton, Susan H. PhD; Culpepper, Brandt PhD; White, Karl R. PhD; Pandya, Arti MD; Nance, Walter E. MD, PhD; and Arnos, Kathleen S. PhD (2006). Education in the genetics of hearing loss: A survey of early hearing detection and intervention programs. *Genetics IN Medicine, 8 (8),* 510-517. Available online for purchase at: www.geneticsinmedicine.org

[6]American Speech-Language-Hearing Association (2004). Guidelines for the audiologic assessment of children from birth to 5 years of age. Available online at: www.asha.org
http://www.asha.org/NR/rdonlyres/0BB7C840-27D2-4DC6-861B-1709ADD78BAF/0/v2GLAudAssessChild.pdf

[7]National Institute on Deafness and Other Communication Disorders. Statistics about Hearing Disorders, Ear Infections, and Deafness. Retrieved January 13, 2007 from: http://www.nidcd.nih.gov/health/statistics/hearing.asp

Selected Websites

About: Deafness	http://deafness.about.com
Alexander Graham Bell Association for the Deaf and Hard of Hearing	www.agbell.org
American Academy of Audiology	www.audiology.org
American Society for Deaf Children	www.deafchildren.org
American Speech-Language- Hearing Association	www.asha.org
Boys Town National Research Hospital	www.boystownhospital.org
Hearing Loss - Centers for Disease Control and Prevention	http://www.cdc.gov/ncbddd/dd/ddhi.htm
Deaf Resource Library	www.deaflibrary.org
Hands and Voices	www.handsandvoices.org
Hawai`i Dept. of Health Newborn Hearing Screening Program	http://hawaii.gov/health/family-child-health/eis/nhsp.html
Hearing Loss Association of America	www.shhh.org
John Tracy Clinic	www.johntracyclinic.org
Laurent Clerc National Deaf Education Center of Gallaudet University	http://clerccenter.gallaudet.edu/
My Baby's Hearing	www.babyhearing.org
National Association of the Deaf	www.nad.org
National Center for Hearing Assessment and Management	www.infanthearing.org
National Institute on Deafness and Other Communication Disorders	www.nidcd.nih.gov
The Listen Up Web!	www.listen-up.org
Where do we go from Hear?	www.gohear.org

Also – Please visit the American Academy of Pediatrics "Newborn and Infant Hearing Screening Activities" webpage for documents such as:

- "Just in Time" Early Hearing Detection and Intervention Educational Kit
- Hearing Screening Coding Fact Sheet for Primary Care Providers
- Denial Management and Contract Negotiation for Hearing Screening Services
- How Medical and Other Health Professionals Can Help Increase the Number of Infants Who Return for a Follow-up Evaluation
- AAP Periodicity Schedule

at: http://www.medicalhomeinfo.org/screening/hearing.html

APPENDIX B

Selected Resources in Hawai`i

Please consult your phone book for additional resources.

ALOHA STATE ASSOCIATION OF THE DEAF (ASAD)

Website: www.asadhawaii.org

ASAD sponsors the Miss Deaf Hawai`i Pageant and Kuli Senior Citizens Club, publishes the *Ka Po'e Kuli o Hawai`i* newsletter, arranges cultural and social events for the Deaf Community, and holds a biennial statewide convention. ASAD is affiliated with the National Association of the Deaf.

AMERICAN SIGN LANGUAGE/ INTERPRETER EDUCATION PROGRAM

Kapi`olani Community College
4303 Diamond Head Road, Manono 116, Honolulu, HI 96816
Phone: 734-9154 (TTY/Voice) Fax: 734-9799
Coordinator: Jan Fried, MS, CI/CT Email: jfried@hawaii.edu
Program Assistant: Dale Peterson Email: dalep@hawaii.edu
Website: http://programs.kcc.hawaii.edu/~eia/

This program offers a variety of credit and non-credit courses in American Sign Language and the interpreting process, degree programs for Educational Interpreters and Educational Assistants, and customized inservice training for organizations employing or serving Deaf and Hard-of-Hearing individuals.

ASSISTIVE TECHNOLOGY RESOURCE CENTERS OF HAWAII (ATRC) AND CAREER EXPLORATIONS OF HAWAII

414 Kuwili Street, Suite 104, Honolulu, HI 96817
Phone: 532-7110 (Oahu) and 1-800-645-3007 (toll-free)
Fax: 532-7120 Email: atrc-info@atrc.org
Website: www.atrc.org
Executive Director: Barbara Fischlowitz-Leong

This non-profit organization provides information, training, outreach, and policy development on assistive technology for persons with disabilities. ATRC operates assistive technology equipment loan programs on four islands and provides low interest financial loans to purchase assistive technology devices and services.

DEPARTMENT OF EDUCATION (DOE)
HAWAI`I CENTER FOR THE DEAF AND THE BLIND (HCDB)

3440 Le'ahi Avenue, Honolulu, HI 96815
Phone: 733-4999 (TTY/Voice) Library Phone: 733-4831
FAX: 733-4824 Website: www.hcdb.k12.hi.us
Administrator: Sydney Dickerson

HCDB provides: 1) diagnostic and prescriptive services and monitoring of the educational progress of all students in the State who are deaf, hard-of-hearing, blind, or visually impaired; 2) technical assistance and training to DOE personnel; 3) educational programs for families; and 4) a comprehensive educational day and boarding-school program for students. Its campus library is a Captioned Video Depository.

GALLAUDET UNIVERSITY REGIONAL CENTER (GURC) & KAPI`OLANI DEAF CENTER

Kapi`olani Community College
4303 Diamond Head Road, Manono 102
Honolulu, HI 96816
Phone: 734-9210 (TTY/Voice) Fax: 734-9238
Director: Judy Coryell, Ph.D. Email: gurc.kcc@gallaudet.edu
Website: www.kcc.hawaii.edu/object/kdc.html

GURC was established in cooperation with Gallaudet University in Washington, D.C. and the University of Hawai`i. It provides continuing education programs for Deaf and Hard of Hearing adults and their families, friends, and service providers. The Kapi`olani Deaf Center maintains a lending library of books and videotapes. It also provides interpreting, note-taking and computer assisted note-taking services for Deaf and Hard of Hearing students at Kapi`olani Community College.

LIBRARY FOR THE BLIND & PHYSICALLY HANDICAPPED (LBPH)

402 Kapahulu Ave., Honolulu, HI 96815
Phone: 733-8444 (TTY/Voice) Fax: 733-8449
E-mail: olbcirc@librarieshawaii.org
Website: www.librarieshawaii.org/locations/oahu/lbph.htm
Head Librarian: Fusako Miyashiro
Public Services Section Librarian: Sue Sugimura

The library has a collection of books, periodicals and videotapes on sign language and deafness.

UNIVERSITY OF HAWAI`I SCHOOL OF MEDICINE
SPEECH AND HEARING CLINIC

1410 Lower Campus Road, Honolulu, HI 96822
Phone: 956-8279 Fax: 956-5482

This clinic is the training component of the UH Department of Speech Pathology and Audiology. Undergraduate and graduate level students provide speech/language evaluations, audiological evaluations (hearing tests), and ongoing therapy under clinical supervision.

APPENDIX C

Common Acronyms

AABR	Automated Auditory Brainstem Response screening
AAP	American Academy of Pediatrics
ABR	Auditory Brainstem Response
BAER	Brainstem Auditory Evoked Response, also called ABR
BSER	Brainstem Evoked Response, also called ABR
CI	Cochlear Implant
CSHNB	Children with Special Health Needs Branch
DOH	Hawai`i Department of Health
EHDI	Early Hearing Detection and Intervention
EI	Early Intervention
ENT	Ear, Nose and Throat Doctor
HA	Hearing Aid
HCDB	Hawai`i Center for the Deaf and the Blind
H-KISS	Hawaii Keiki Information Services System
IDEA	Individuals with Disabilities Education Act
JCIH	Joint Committee on Infant Hearing
NHSP	Newborn Hearing Screening Program
OAE	Otoacoustic Emissions, screening or diagnostic
OME	Otitis Media with Effusion
PART C	IDEA section related to early intervention services
TYMP	Tympanometry
UNHS	Universal Newborn Hearing Screening

APPENDIX D

Brochures, Handouts and Forms

Universal Newborn Hearing Screening, Diagnosis and Intervention Materials from the American Academy of Pediatrics (AAP) and the National Center for Hearing Assessment and Management (NCHAM):

1) Patient Checklist for Pediatric Medical Home Providers
www.medicalhomeinfo.org/screening/hearing.html

2) Guidelines for Pediatric Medical Home Providers
www.infanthearing.org/medicalhome/aap_gpmhp.pdf

Materials from the Hawai`i Department of Health:

3) Newborn Hearing Screening Program (NHSP) – Fact Sheet and State Statute

4) Universal Newborn Hearing Screening: New Parent Information – Brochure (available in 12 languages)
http://hawaii.gov/health/family-child-health/eis/nhsp.html

5) Why Does My Baby Need a Hearing Test? – Handout

6) NHSP-01 Hearing Screening Status – Form
(Purpose: For screening referrals or for notifying NHSP of a child's screening status or a family's refusal of screening)

7) NHSP-02 Child Hearing Status – Form
(Purpose: For audiologists to report audiological evaluation results to NHSP)

8) *H-KISS Hawai`i Keiki Information Services System* – Brochure and Fax Referral Form
http://hawaii.gov/health/family-child-health/eis/index.html

9) Early Intervention Section – Brochure
http://hawaii.gov/health/family-child-health/eis/index.html

10) Good Hearing Helps a Baby Learn to Talk – Brochure (available in 12 languages)
http://hawaii.gov/health/family-child-health/eis/nhsp.html

11) Children with Special Health Needs Program (CSHNP) – Brochure, Referral for Service Form and Family Income Limits
http://hawaii.gov/health/family-child-health/cshcn/cshnppage.html

12) Hawaii Lions Foundation Uninsured-Underinsured Fund for Hearing and Vision Services – Brochure
http://hawaii.gov/health/family-child-health/cshcn/index.html

13) Hawaii Genetics Program – Brochure, Brochure for Parents and Fact Sheet for Healthcare Providers
http://hawaii.gov/health/family-child-health/genetics/index.html

Universal Newborn Hearing Screening, Diagnosis, and Intervention

Patient Checklist for Pediatric Medical Home Providers

Patient Name: _____

Date of Birth: ____ /___ /____

Birth

Hospital-based Inpatient Screening Results (OAE/AABR)
(also Home Births)

DATE: _____ /____/_____

Left ear:	☐ Missed	☐ Incomplete	☐ Refer[a, c]	☐ Pass
Right ear:	☐ Missed	☐ Incomplete	☐ Refer[a, c]	☐ Pass

Before 1 month

Outpatient Screening Results (OAE/AABR) _____ /____/_____

Left ear:	☐ Incomplete	☐ Refer[a, c]	☐ Pass
Right ear:	☐ Incomplete	☐ Refer[a, c]	☐ Pass

Before 3 months

☐ **Pediatric Audiologic Evaluation**[b] _____ /____/_____

☐ Hearing Loss ☐ Normal Hearing

Documented child and family auditory history _____ /____/_____

- ☐ **Report to State EHDI Program** results of diagnostic evaluation _____ /____/_____
- ☐ **Refer to Early Intervention** (IDEA, Part C) _____ /____/_____
- ☐ **Medical & Otologic Evaluations** to recommend treatment and provide clearance for hearing aid fitting _____ /____/_____
- ☐ **Pediatric Audiologic** hearing aid fitting and monitoring _____ /____/_____
- ☐ **Advise family** about assistive listening devices (hearing aids, cochlear implants, etc.) and communication options _____ /____/_____

Before 6 months

☐ **Enrollment in Early Intervention (IDEA, Part C)** _____ /____/_____
(transition to Part B at 3 years of age)

Medical Evaluations to determine etiology and identify related conditions

- ☐ Ophthalmologic (annually) _____ /____/_____
- ☐ Genetic _____ /____/_____
- ☐ Developmental pediatrics, neurology, cardiology, and nephrology (as needed) _____ /____/_____

☐ **Ongoing Pediatric Audiologic Services**

Ongoing Care of All Infants[d]

- ☐ Provide parents with information about hearing, speech, and language milestones
- ☐ Identify and aggressively treat middle ear disease
- ☐ Vision screening and referral as needed
- ☐ Ongoing developmental surveillance/referral
- ☐ Referrals to otolaryngology and genetics, as needed
- ☐ Risk indicators for late onset hearing loss: _____ (refer for audiologic monitoring)

Service Provider Contact Information

Pediatric Audiologist:
Early Intervention Provider:
Other:
Other:
Other:

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or loss to follow-up, also may be referred directly to Pediatric Audiologic Evaluation.

(b) Early Intervention (IDEA, Part C) may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.

(d) Includes infants whose parents refused initial or follow-up hearing screening.

OAE = Otoacoustic Emissions
AABR = Automated Auditory Brainstem Response
ABR = Auditory Brainstem Response
IDEA = Individuals with Disabilities Education Act
EHDI = Early Hearing Detection & Intervention

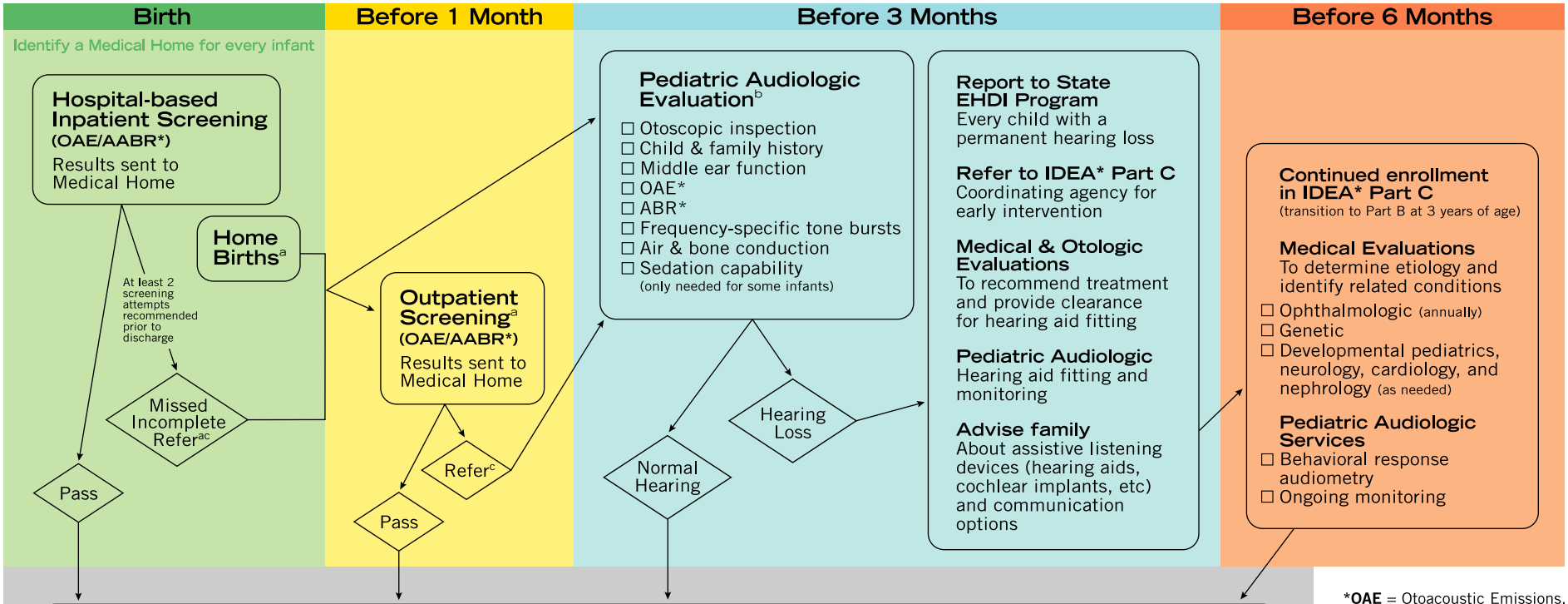
This project is funded by an educational grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.

March 2004

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

NCHAM National Center for Hearing Assessment and Management Utah State University™

Universal Newborn Hearing Screening, Diagnosis, and Intervention
Guidelines for Pediatric Medical Home Providers



Ongoing Care of All Infants[d] From the Medical Home Provider

- **Provide parents with information about hearing, speech, and language milestones**
- **Identify and aggressively treat middle ear disease**
- **Provide vision screening and referral as needed**
- **Provide ongoing developmental surveillance and referral to appropriate resources**
- **Identify and refer for audiologic monitoring infants who have the following risk indicators for late-onset hearing loss:**
  - Parental or caregiver concern regarding hearing, speech, language, and/or developmental delay
  - Family history of permanent childhood hearing loss
  - Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or eustachian tube dysfunction
  - Postnatal infections associated with sensorineural hearing loss including bacterial meningitis
  - In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
  - Neonatal indicators—specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation
  - Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, and Usher syndrome
  - Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth disease
  - Head trauma
  - Recurrent or persistent otitis media with effusion for at least 3 months

*__OAE__ = Otoacoustic Emissions, __AABR__ = Automated Auditory Brainstem Response, __ABR__ = Auditory Brainstem Response, __IDEA__ = Individuals with Disabilities Education Act

Notes:

(a) In screening programs that do not provide Outpatient Screening, infants will be referred directly from Inpatient Screening to Pediatric Audiologic Evaluation. Likewise, infants at higher risk for hearing loss, or loss to follow-up, also may be referred directly to Pediatric Audiologic Evaluation.

(b) Part C of IDEA* may provide diagnostic audiologic evaluation services as part of Child Find activities.

(c) Infants who fail the screening in one or both ears should be referred for further screening or Pediatric Audiologic Evaluation.

(d) Includes infants whose parents refused initial or follow-up hearing screening.

January 2003

Appropriate Referrals

1. Audiologist knowledgeable in pediatric screening and amplification

Name:
Telephone number:
Fax:
Date of referral:

2. Otolaryngologist knowledgeable in pediatric hearing loss

Name:
Telephone number:
Fax:
Date of referral:

3. Local early intervention system

Name:
Telephone number:
Fax:
Date of referral:

4. Family support resources, financial resources

Name:
Telephone number:
Fax:
Date of referral:

5. Speech/language therapy and/or aural rehabilitation therapy

Name:
Telephone number:
Fax:
Date of referral:

6. Sign language classes if parents choose manual approach

Name:
Telephone number:
Fax:
Date of referral:

7. Ophthalmologist knowledgeable in co-morbid conditions in children with hearing loss

Name:
Telephone number:
Fax:
Date of referral:

8. Clinical geneticist knowledgeable in hearing impairment

Name:
Telephone number:
Fax:
Date of referral:

9. Equipment vendor(s)

Name:
Telephone number:
Fax:
Date of referral:

10. State EHDI coordinator
http://www.infanthearing.org/status/cnhs.html

Name:
Telephone number:
Fax:
Date of referral:

11. AAP Chapter champion
http://www.medicalhomeinfo.org/screening/Champions%20Roster.pdf

Name:
Telephone number:
Fax:
Date of referral:

12. Family physician(s)

Name:
Telephone number:
Fax:
Date of referral:

National Resources

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)
202/337-5220
www.agbell.org

American Academy of Audiology (AAA)
800/AAA-2336
www.audiology.org

American Academy of Pediatrics
www.aap.org

American Society for Deaf Children
717/334-7922
www.deafchildren.org

American Speech-Language-Hearing Association (ASHA)
800/498-2071
www.asha.org

Boys Town Center for Childhood Deafness
www.babyhearing.org

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/ehdi

Cochlear Implant Association, Inc.
202/895-2781
www.cici.org

Families for Hands and Voices
303/300-9763
www.handsandvoices.org

Laurent Clerc National Deaf Education Center and Clearinghouse at Gallaudet University
www.clerccenter.gallaudet.edu/InfoToGo

National Association of the Deaf (NAD)
301/587-1788
www.nad.org

National Center on Hearing Assessment and Management (NCHAM)
www.infanthearing.org

National Institute on Deafness and Other Communication Disorders
www.nidcd.nih.gov

Oberkotter Foundation
www.oraldeafed.org

The recommendations in this document do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

This project is funded by an educational grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services.

American Academy of Pediatrics
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NCHAM National Center for Hearing Assessment and Management Utah State University™

Newborn Hearing Screening Program

Early Intervention Section
Children with Special Health Needs Branch
Department of Health – State of Hawai`i

The **Newborn Hearing Screening Program** (NHSP) oversees statewide efforts to identify babies who are deaf or hard of hearing and refer them for appropriate follow-up. In addition, NHSP helps families get hearing tests for children who:

- ☐ Are under 3 years of age;
- ☐ Are not eligible for Part C early intervention; and
- ☐ Need a hearing test to find out if they have permanent hearing loss.

Services include:

- ☐ ***Information about resources:*** We provide information to help families set up hearing tests for their children. If permanent hearing loss is found, we refer children for early intervention services. We work with physicians, hospitals and other people, programs, or agencies that are helping the family.
- ☐ ***Financial assistance for children who are eligible:*** We arrange financial assistance through the Early Intervention Section to help pay for hearing tests. Some travel costs may also be covered.
  - NHSP pre-authorization is required.
  - Department of Health participating audiologists must be used.
  - Audiologists must bill Medicaid, QUEST and private health insurance first if the child has coverage. Families are not billed.

Services not covered include, but are not limited to: primary care services, hospitalization, surgery/anesthesia, out-of-state services, emergency department or transport services, DNA/chromosomal testing, durable medical equipment, hearing aids, and hearing aid related services. NHSP cannot arrange payment for health insurance premiums or medicine.

For more information, please contact us at:

Statewide and on O`ahu (area code 808):

Phone:	594-0042
Voice/TTY:	1-800-235-5477

Toll-Free calls from Neighbor Islands:

From Hawai`i	974-4000 ext. 40042
From Kaua`i	274-3141 ext. 40042
From Maui	984-2400 ext. 40042
From Moloka`i/Lana`i	1-800-468-4644 ext. 40042

Or visit our website at:

http://hawaii.gov/health/family-child-health/eis/nhsp.html

DOH-NHSP
Rev. 3/2008

HAWAII REVISED STATUTES

[PART XXIX.] STATEWIDE NEWBORN HEARING SCREENING PROGRAM

Revision Note

In this part, "part" substituted for "chapter".

[§321-361] Definitions. As used in this part, unless the context clearly indicates otherwise:

"Department" means the department of health.

"Hearing-impaired infant" means an infant who has an impairment that is a dysfunction of the auditory system of any type or degree sufficient to interfere with the acquisition and development of speech and language skills.

"Infant" means a child from birth to thirty-six months of age.

"Management" means the habilitation of the hearing-impaired infant.

"Screening" means a test or battery of tests administered to determine the need for a professional examination. [L 1990, c 85, pt of §3]

§321-362 Duties. It shall be the duty and responsibility of the department to:

(1) Establish, implement, and evaluate a statewide program for early identification of, and intervention for, hearing impairment in infants;

(2) Establish standards and guidelines for the screening, identification, diagnosis, intervention, and monitoring of infants with hearing impairment and infants at risk for delayed onset of hearing impairment;

(3) Develop a plan in conjunction with the department of education's statewide center for students with hearing or visual impairments to involve the parents or guardians with the medical and educational follow-up and management of infants who have been identified as hearing-impaired or at risk of delayed onset of hearing impairments; and

(4) Collect and analyze program data in relation to the duties and responsibilities of the department. [L 1990, c 85, pt of §3; am L 2001, c 42, pt of §2]

[§321-362.5] Screening for hearing impairment. (a) All newborn infants shall be screened for hearing impairment for early identification of children with hearing loss and for the promotion of their development of language and communication.

(b) The person in charge of each birthing facility caring for newborn infants and the responsible physician attending the birth of a newborn or the person assisting the birth of a child not attended by a physician shall ensure that every infant in the person's care be screened for hearing impairment. This section shall not apply if the parent, guardian, or other person having custody or control of the child objects to the screening in writing on the grounds that the screening conflicts with their religious beliefs. The written objection shall be made a part of the infant's medical record.

(c) Birthing facilities screening newborn infants for hearing impairment shall report screening results to the department, for the purpose of the department ensuring a statewide system for the screening, diagnostic evaluation, and intervention for all newborn infants with hearing impairment. [L 2001, c 42, §1]

§321-363 Rules. The department shall adopt rules, pursuant to chapter 91, necessary for the purposes of this part, including but not limited to administration and quality of newborn hearing screening; retention of records and related data; reporting of positive screening results; diagnostic evaluation and intervention for infants with hearing impairment; informing parents about the purpose of screening; and maintaining the confidentiality of affected families. [L 1990, c 85, pt of §3; am L 2001, c 42, pt of §2]

Sometimes babies do not pass initial screenings. Try not to worry if this happens. Your baby may not pass because:

- ✓There is birthing fluid in the ear; or
- ✓The ear canal is still narrow.

If your baby does not pass initially, another screening or further testing may be needed in 2 to 4 weeks.

Further Testing

For babies who do not pass their hearing screenings, an ***Auditory Brainstem Response Diagnostic Test*** is used to determine if there is a hearing loss.

If Hearing Loss is Found

If a hearing loss is found, the audiologist or your baby's doctor will talk to you about what do next and may refer you to the Department of Health for early intervention services.

You may also call the Hawaii Keiki Information Services System (H-KISS) to receive information about services and support. The H-KISS number is 808-594-0066 on Oahu or toll-free at 800-235-5477 on Neighbor Islands.

Other Information

As required by state law, information about your baby's hearing screening and diagnostic tests will be sent to the Department of Health. This information represents the minimum necessary to carry out the public health purposes of the Newborn Hearing Screening Program, pursuant to 45 CFR § 164.514(d) of the Privacy Rule.

Linda Lingle, Governor
Chiyome Leinaala Fukino, M.D., Director of Health

Supported in part by project H61 MC 00038 from the Maternal Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Rev. 01/08; Phone List Updated 01/08 (Language: English)

UNIVERSAL NEWBORN HEARING SCREENING

NEW PARENT INFORMATION

Congratulations! As you welcome your baby's birth and look forward to the future, remember it's important to get your baby off to a good start.

Begin with Good Hearing

Good hearing helps your baby learn to talk. Babies begin to listen from birth. They learn to speak by listening to their families talk.

All babies born in Hawaii have their hearing screened soon after birth. If hearing screening is against your religious beliefs, you may sign a written refusal. If your baby hasn't been screened yet, please look inside to find out where to call for an appointment.

Hearing screening is simple and safe for your baby. If not found early, hearing loss may cause delays in your baby's development.

What to Expect

Your baby's hearing will be screened in one or more ways.

*If an **Otoacoustic Emission Screening** is used, tiny earphones will be placed in your baby's ears to pick up responses as sounds are played.*

*If an **Auditory Brainstem Response Screening** is used, tiny electrodes will be taped to your baby's head to pick up responses as sounds are played.*

DID YOUR BABY HAVE A HEARING SCREENING?

If not, please call the hospital where your baby was born or the Department of Health's Newborn Hearing Screening Program to make an appointment today.

WHERE TO CALL FOR AN APPOINTMENT

Castle Medical Center	808-263-5270
Hilo Medical Center	808-974-4715
Kahuku Medical Center	808-293-9221, ext 369
Kaiser Permanente Moanalua Medical Center (Kaiser members only)	808-432-8292
Kapiolani Medical Center for Women & Children	808-983-8230
Kona Community Hospital	808-322-4416
Maui Memorial Medical Center (Screening by Imua Family Services)	808-244-7467
Molokai General Hospital (Women's Health Center)	808-553-3145
North Hawaii Community Hospital	808-881-4771
The Queen's Medical Center	808-547-4213
Tripler Army Medical Center (Audiology Clinic)	808-433-3197
West Kauai Medical Center/ Kauai Veterans Memorial Hospital	808-338-9431
Wilcox Memorial Hospital	808-245-1433
Department of Health Newborn Hearing Screening Program	808-594-0042

Updated 01/08

You Can Help Your Baby if a Hearing Loss is Found

- ✓You can get early intervention services to help your baby build strong language, communication and listening skills.
- ✓You can talk to an audiologist (hearing specialist) about ways to help your baby hear better.
- ✓You can watch for changes in how your baby responds to sound.

Hearing Can Change Over Time

If you think your child is having trouble hearing or talking, please call your health care provider right away.

You can also call the Hawaii Keiki Information Services System (H-KISS) for information about services and support. The H-KISS number is 594-0066 on Oahu or toll-free from Neighbor Islands at 1-800-235-5477.

Help Protect Your Baby's Hearing!

For more information, please visit the Hawai`i Department of Health's Newborn Hearing Screening Program website at: http://hawaii.gov/health/family-child-health/eis/nhsp.html

03/08 Handout (Language: English)

Why Does My Baby Need a Hearing Test?

Because 3 Babies per 1000 are Born with Hearing Loss

Hearing loss is common and easy to miss without testing. Your baby may hear some sounds, but not hear clearly enough to learn to talk.

Because Babies are Born with Brains that are Ready to Hear

The ears are just a way to get sound to the brain. Without sound, babies begin using the part of the brain that hears for other things.

And Because Earlier is Better if Your Baby has a Hearing Loss

Children with hearing loss often have trouble talking and learning if they don't get help early. The outlook is best if they receive help before six months of age.

Every Baby Needs a Hearing Test!

Hearing screening tests are simple and safe. Most babies receive a hearing screening test before one month of age.

HAS YOUR BABY HAD A HEARING SCREENING TEST?

Call the Newborn Hearing Screening Program before scheduling if you have questions or need help with costs not covered by insurance.

We can have a participating audiologist (hearing specialist) see your baby on the Big Island, Kaua`i, Maui or Oahu.

Or you can call one of these hospitals to set up your baby's hearing screening test.

WHERE TO CALL FOR AN APPOINTMENT

Hospitals -

Castle Medical Center..... 263-5270

Hilo Medical Center..... 974-4715

Kaiser Permanente Moanalua Medical Center..... 432-8292
(Kaiser members only)

Kapiolani Medical Center for Women & Children..... 983-8230

Kona Community Hospital..... 322-4416

Maui Memorial Medical Center..... 244-7467
(Screening by Imua Family Services)

Molokai General Hospital..... 553-3145
(Women's Health Center)

North Hawaii Community Hospital..... 881-4771

The Queen's Medical Center..... 547-4213

Tripler Army Medical Center..... 433-3197
(Audiology Clinic)

West Kauai Medical Center/..... 338-9431
Kauai Veterans Memorial Hospital

Wilcox Memorial Hospital..... 245-1433

Department of Health
Newborn Hearing Screening Program

Hawai`i (toll-free)..... 974-4000, ext. 40042

Kaua`i (toll-free)..... 274-3141, ext. 40042

Maui (toll-free)..... 984-2400, ext. 40042

Moloka`i and Lana`i (toll-free)..... 1-800-468-4644, ext. 40042

Oahu and Nationwide (Area Code: 808)..... 594-0042

Updated 03/08

HEARING SCREENING STATUS

Hawai`i Department of Health
Newborn Hearing Screening Program (NHSP)
1350 South King Street, Suite 200
Honolulu, HI 96814
Ph: 808-594-0042 Fax: 808-594-0015

Instructions: Please send to NHSP if baby was transferred or if family refused screening.
This confidential information is used only for screening follow-up and statistical purposes.

Submitted by:		Phone #:	
Child's Name:		Date of Birth:	
Birth Location:		Birth Weight:	
Mother's Name:		Gender:	☐ Boy ☐ Girl
Baby's Doctor:		Birth Order:	☐ Single Birth
Insurance Co:		or Twin, etc.	☐ A ☐ B ☐____

Screen Result:	Left: ☐ Passed ☐ Referred ☐ Missed Date:	☐ OAE ☐ ABR
	Right: ☐ Passed ☐ Referred ☐ Missed Date:	☐ OAE ☐ ABR

Transferred: To be completed if transferred to another hospital or health care provider before passing hearing screening in both ears.

Transferred to: _____ City/State: _____

Family Refusal: To be signed by family if newborn hearing screening is refused.

I understand that:

- Hearing loss can cause a baby to have delays in talking and learning.
- Babies with hearing loss do best if they receive help before six months of age.
- A simple screening test can show if my baby hears clearly enough to learn to talk.
- State law allows me to refuse hearing screening if it conflicts with my religious beliefs.

My decision to refuse hearing screening was made freely, without force or encouragement from my health care provider, birth attendant, hospital staff or any State official.

Mother, Father, or Legal Guardian Signature	Date Signed

CHILD HEARING STATUS

Hawai`i Department of Health
Newborn Hearing Screening Program (NHSP)
1350 South King Street, Suite 200
Honolulu, HI 96814
Ph: 808-594-0042 Fax: 808-594-0015

Instructions: Please fax this information to NHSP with the child's audiogram/evaluation report.
This confidential information is used only for follow-up and statistical purposes. Thank you.

Child's Name: _____ Birthdate: _____
Birth Location: _____ Gender: ☐ Boy ☐ Girl
Mother's Name: _____

AUDIOLOGIST: _____ **TEST DATE:** _____

Right Ear Status (Estimated Type):		**Degree (Estimated Range):**		
Normal	☐	Normal	(0-20dB)	☐
Conductive (Cond)	☐	Mild	(21-40dB)	☐
Sensorineural (SNHL)	☐	Moderate	(41-70dB)	☐
Mixed (SNHL & Cond)	☐	Severe	(71-90dB)	☐
Permanent Conductive	☐	Profound	(Above 90dB)	☐
Auditory Neuropathy	☐			

Other - DXOAE: ☐ Pass ☐ Refer ☐ **226 Hz** ☐ **1000 Hz TYMP:** ☐ Normal ☐ Abnormal

Left Ear Status (Estimated Type):		**Degree (Estimated Range):**		
Normal	☐	Normal	(0-20dB)	☐
Conductive (Cond)	☐	Mild	(21-40dB)	☐
Sensorineural (SNHL)	☐	Moderate	(41-70dB)	☐
Mixed (SNHL & Cond)	☐	Severe	(71-90dB)	☐
Permanent Conductive	☐	Profound	(Above 90dB)	☐
Auditory Neuropathy	☐			

Other - DXOAE: ☐ Pass ☐ Refer ☐ **226 Hz** ☐ **1000 Hz TYMP:** ☐ Normal ☐ Abnormal

Needs Diagnostic ABR: ☐ Refer for dxABR ☐ Not needed yet ☐ Already completed
Early Intervention Status: ☐ Refer for EI ☐ Not needed yet ☐ Already referred to EI
Amplification Status: ☐ Recommended ☐ Not needed yet ☐ Fitted on: _____
Notes: _____

_____

WHAT IS H-KISS?

A FREE information and referral service

Your connection to a "care coordinator" who can help answer your questions and get your child evaluated for developmental delays or other special needs

A way to get needed services like speech therapy and physical therapy at no cost to your family

A link to other parents and services such as child care, family support, respite, and community services

CALL H-KISS

On Oahu:

594-0066

Neighbor Islands Call Toll Free:

1-800-235-5477

(Voice & TTY available)

Early Intervention Section
1350 South King Street Suite 200
Honolulu, Hawaii 96814
PH: 594-0000
Fax: 594-0015

3/04

H-KISS

Hawaii Keiki Information Service System

For families with young children

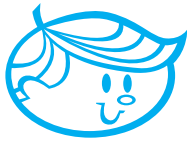
A service of the
EARLY INTERVENTION SECTION
Hawaii Department of Health

What are your concerns?

Do you have concerns about how your child is growing and learning?

Do you need information or help finding services that will assist you and your child?

Do you know of other families who have concerns about their children?



Do you want to speak with another parent?

CALL H-KISS

On Oahu:

594-0066

Neighbor Islands Call Toll Free:

1-800-235-5477

(Voice & TTY available)

Telephone Hours:

Monday – Friday

8:30 a.m. – 3:00 p.m.

(After hours, please leave a message and your call will be returned as soon as possible.)

When to call H-KISS

If you have concerns about your child...

Under the age of 3

Developmental delays such as difficulty walking, talking or learning

Special health care needs such as Downs Syndrome, very low birthweight, or drug exposure during pregnancy

Age 3 – 5

Information on how to access the Department of Education special education preschool

Options for services in the community

H-KISS FAX REFERRAL FORM

Please complete all areas. If information is not available for some areas, you may skip these sections and H-KISS will follow up.

Call Date to H-KISS: ___/___/___ **Referral Source Name:** _____ **Ph #:** _____

Relationship to Child: ☐ Parent ☐ Pediatrician ☐ Other: _____

Address (if not parent): _____

How Referral Source Became Aware of H-KISS: _____

Child Name: _____ **Date of Birth:** _____

Gender: ☐ M ☐ F **Age:** _____ years _____ months_____weeks

Area(s) of Concern:

☐ **Developmental Delay**	☐ Cognitive	☐ Physical	☐ Communication	☐ Social/Emotional	☐ Adaptive
☐ **Biological Risk**	☐ Gestational Age < 32 wks ☐ Birth weight < 1500gm/3.3 lbs. ☐ Technologically Dependent/Skilled Nursing Needed		☐ In hospital ☐ Estimated date of discharge _____/_____/_____		
☐ **Environmental Risk**	☐ Child Welfare Services Involvement		Authority to Consent ☐ CWS ☐ Other _____		

Developmental, Medical, and/or Environmental Concerns: _____

_____

_____

_____

_____

_____

Screenings Done:

☐ ASQ	☐ DIAL-R	☐ Denver	☐ CBCL	☐ ASQ-SE	☐ HELP	☐ PEDS
☐ Audiological (Include Newborn Hearing Screening)			☐ Other: _____			
Significant Results: _____						

Pediatrician: _____ Ph #: _____

MD Specialist(s): _____

Agencies Working w/Child:	☐ Child Welfare Services	☐ Children w/Special Health Needs Branch	☐ Early Intervention Section	
☐ Public Health Nursing Branch	☐ Healthy Start Prgm.	☐ Guardian Ad-Litem	☐ Early Head Start Prgm.	☐ Kaiser Hospital
☐ Kapi'olani Medical Center	☐ Tripler Army Medical Center	☐ Other: _____		
☐ EPSDT Medically Fragile CM Agency (Specify Agency): _____				

Primary Caregiver Name(s): _____

Relationship to Child: ☐ mother ☐ father ☐ foster parent ☐ guardian ☐ other: _____

Residence Address: _____

Mailing/Other Address: _____

Ph # (h): _____ (w): _____ (other): _____ **Best call time**: _____

WHERE TO FIND US

Services are available on all islands. Please call Hawaii Keiki Information Service System (H-KISS) information and referral line to learn more about our program or to have your child evaluated for eligibility. Call H-KISS (Voice and TTY available):

Oahu	**Neighbor Islands Toll-Free**
(808) 594-0066	1-800-235-5477

Telephone hours: Monday – Friday, 8:30 a.m. – 3:00 p.m. If calling after hours, please leave a message and your call will be returned as soon as possible.

OTHER CONTACT OPTIONS FOR NEIGHBOR ISLANDS

For families on the neighbor islands, services are also available at:

Kauai Easter Seals	245-7141
Imua Family Services (Maui & Lanai)	244-7467
Ikaika for Molokai	553-3276
Hilo Easter Seals	961-3081
Kona Early Childhood Services Program	322-4880
North Hawaii Child Development Program	326-7778

Early Intervention Section

1350 South King Street Suite 200

Honolulu, Hawaii 96814

Ph: 594-0000

FAX: 594-0015

For information about other children's services, please call:

SPIN (Special Parent Information Network)
Oahu: (808) 586-8126
Enterprise: 5270

The Parent Line
Oahu: (808) 526-1222
Neighbor Islands (*toll-free*): 1-800-816-1222

Department of Education, Operation Search
(for children 3 or older)
Oahu: (808) 733-4403
Neighbor Islands (*toll-free*): 1-800-297-2070

Project AWARE *(Assisting with Appropriate Rights in Education)*
Oahu: (808) 536-9684
Neighbor Islands (*toll-free*): 1-800-533-9684

Linda Lingle, Governor
Chiyome Fukino, M.D., Director of Health

STATE OF HAWAII
DEPARTMENT OF HEALTH

E I S

Early Intervention Section

Providing services for 0–3

WHAT WE DO

The Early Intervention Section of the State Department of Health provides services for children from birth to three years of age with special needs. Services assist your child in five developmental areas:

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

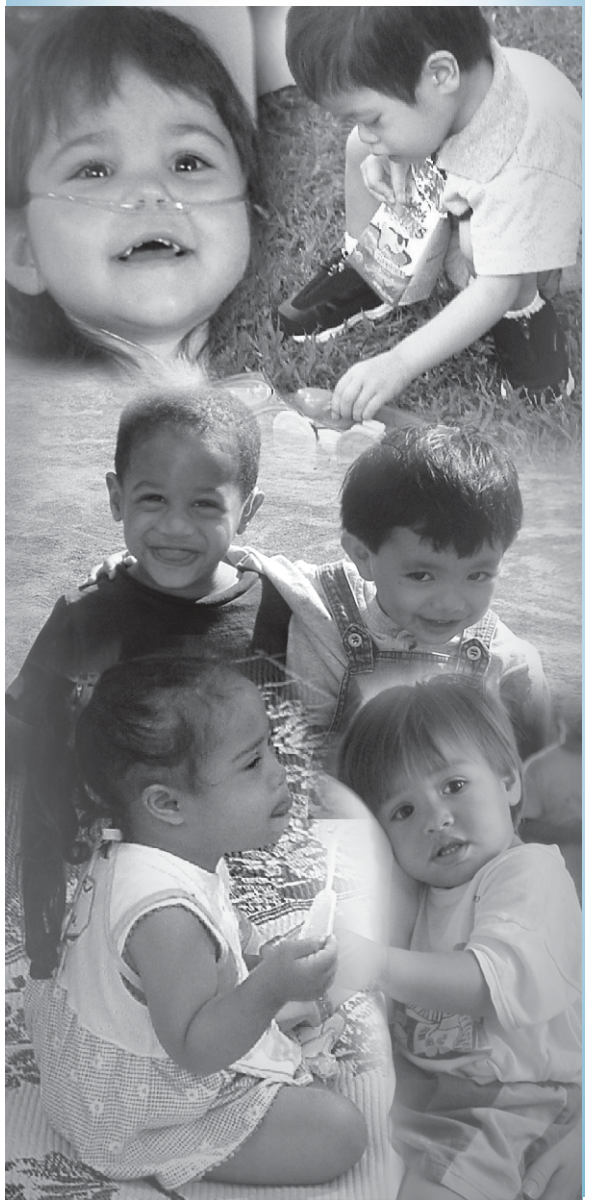
WHEN YOUR CHILD IS ELIGIBLE FOR SERVICES

Your child is eligible for services if your child:

- Has a delay in development; or
- Is at-risk of developing a delay

Having a delay means that your child's development may be somewhat slower than expected. Being at-risk for a delay means that your child has a diagnosed condition (e.g., cerebral palsy, Downs Syndrome) that often causes a developmental delay. Your child may also be at-risk if your family lives in a stressful situation that may affect your child's development (e.g., low income, teenage parents).

Do *you* have concerns about how your child is *growing* & *learning*?



A CHILD CARE COORDINATOR FOR YOU

All eligible children will have a care coordinator. Your care coordinator will assist in having your child evaluated. Services are delivered based on an Individualized Family Support Plan (IFSP) which is developed by a team that includes your family and care coordinator. Services are provided in a variety of locations to support your child and family.

NO COST TO YOUR FAMILY

There is no cost to your family for services and support

MANY SERVICES PROVIDED

- Assistive technology (special equipment)
- Audiology
- Care coordination
- Family support and education
- Health services
- Nursing services
- Nutrition services
- Occupational therapy (self-help, small muscles)
- Parent-to-parent support
- Physical therapy
- Psychological support services
- Speech & language therapy
- Social work (counseling)
- Specialized teaching
- Transportation to early intervention services
- Vision services

Hearing can change over time

Your child may need hearing tests twice a year until age 3 if there was:

- Infection at birth (German Measles, Toxoplasmosis, Cytomegalovirus)
- Infection after birth (Meningitis)
- Low birthweight (1500 grams or less)
- Jaundice requiring blood transfusion
- Differently shaped head or face (cleft lip or palate)
- Breathing difficulty at birth
- Head injury
- Medicine that can damage the ear
- Two or more days in the neonatal intensive care unit
- Family history of permanent or progressive hearing loss

To find out more information call our:

Hawaii Keiki Information Services System (H-KISS) information and referral line

H-KISS Oahu
594-0066
(Voice & TDD)

or
H-KISS Neighbor Islands
Call toll-free:
1-800-235-5477
(Voice & TDD)

Linda Lingle, Governor
Chiyome Leinaala Fukino, M.D., Director of Health

The Hawaii Department of Health provides access to activities without regard to race, color, national origin (including language), age, sex, religion, or disability. Write or call our Affirmative Action Officer at Box 3378, Honolulu, HI 96801-3378 at (808) 586-4616 (voice/tty) within 180 days of a problem.

Supported in part by project H61 MC 00038 from the Maternal Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Rev. 10/04 (Language: English); Phone Number Updated 12/06

GOOD HEARING HELPS A BABY LEARN TO TALK

A hearing test can be done at any age

NEWBORN HEARING SCREENING PROGRAM

Early Intervention Section
Hawaii Department of Health

Is your child learning language?

Birth to 3 months
- ☐ Startle at loud sounds (about 6 feet away)
- ☐ Make squealing sounds
- ☐ Feel comforted by mother's voice

3 to 6 months
- ☐ Turn head or eyes to an interesting sound (toys)
- ☐ Make several sounds (ooh, ba-ba, ma-ma)
- ☐ Respond to his/her name with a smile

6 to 9 months
- ☐ Listen to music or singing
- ☐ Imitate speech and non speech
- ☐ Understand "no" and "bye-bye"

9 to 12 months
- ☐ Turn head toward sound
- ☐ Produce these sounds in babbling: b,m,p,d,t,n,g,k,w,f,v,th,s,z,l
- ☐ Say "mama" or "dada" with meaning

12 to 18 months
- ☐ Point to body parts, people, and toys
- ☐ Omit final and some initial consonant sounds ("ca" for "cat")
- ☐ Understand 50-75 words

18 to 24 months
- ☐ Comprehend about 300 words
- ☐ Use about 50 recognizable words
- ☐ Follow simple commands

24 to 36 months
- ☐ Learn new words everyday
- ☐ Make about half of speech sounds correctly
- ☐ Ask questions and answers "wh" questions (like why and what)

The *critical time* for learning speech and language is the first 3 years of life.

Babies need good hearing to learn language quickly during this time.

Help your child learn to listen

Limit background noise by turning off noisy appliances such as the AC, radio, or fans. Use the most quiet room in the house to be your child's room so you talk, talk, and talk.

Follow what interests your child. Talk about what your child is looking at and doing. Let your child lead during play time.

When you talk, ***sit in front of your child*** so he/she can see the expressions on your face. Sit and speak on the side of the better ear.

Speak at a ***regular volume*** (not too loud and not too soft). Communicate naturally!

Imitate your child. Children love hearing you talk like them. Focus on vowels sounds while using one or two words at a time.

Help your child listen to your voice. Speak with ***different pitches, loudness, and rhythms.*** Use lots of repetition.

Praise your child's communication attempts! Applaud when your child listens and responds to sound (for example, stopping movement, making eye contact, pointing at an object, imitating a sound, or changing body position).

For more information

Oahu
Children with Special Health Needs Program

(main office)
Phone (or TTY): (808) 733-9055
Fax: (808) 733-9068
741 Sunset Avenue
Honolulu, HI 96816

Toll-free calls
From Kauai: 274-3141 ext. 39055#
From Maui: 984-2400 ext. 39055#
From Hawaii 974-4000 ext. 39055#
From Molokai/Lanai: 1-800-468-4644 ext. 39055#

Kauai
Children with Special Health Needs
Phone: (808) 241-3376
3040 Umi Street ⊄ Lihue, HI 96766

Maui
Children with Special Health Needs
Phone: (808) 984-2130
54 High Street ⊄ Wailuku, HI 96793

East Hawaii
Children with Special Health Needs
Phone: (808) 974-4288
46 Keawe Street#⊄ Hilo, HI 96720

West Hawaii
Children with Special Health Needs
Phone: (808) 322-4880
81-980 Halekii St. #103#⊄ Kealakekua, HI 96750

Linda Lingle, Governor
Chiyome Leinaala Fukino, M.D., Director of Health

August 2004

Children with Special Health Needs Branch
Family Health Services Division
Hawaii Department of Health

Children with Special Health Needs Program

Assisting families with coordinating and obtaining services for their children with special health needs

Children with Special Health Needs Program

Who are children with special health needs?

Children with special health needs are children who have or may have long-term or chronic health conditions that require specialized medical care.

Examples of conditions include cleft lip and palate, seizure disorder, hearing loss, diabetes, heart conditions, arthritis, and metabolic disorders.

How may we help you?

We help families with children with special health care needs:

- who are having difficulty in coordinating or obtaining health care services.
- who cannot get services elsewhere, such as nutrition therapy for metabolic disorders.
- who cannot get medical services on their island. We arrange Neighbor Island pediatric specialty clinics, or arrange travel to another island for services.
- who are uninsured or whose insurance does not pay for needed services, and/or having difficulty affording services.

What services may children and their families receive?

- Coordination of health and other services. Follow-up with family, physicians, specialists, and other providers.
- Information about community services and resources. Help in obtaining services.
- Social work services.
- Neighbor Island clinics - pediatric neurology, cardiology, and nutrition.
- Limited financial assistance* for services related to the childs chronic condition, for families who meet financial requirements:
  - Medical specialist office visits
  - Laboratory tests
  - X-rays, EKG, EEG
  - Travel and lodging expenses for Neighbor Island children requiring medical services on another island
  - Prescription medications
  - Hearing aids and related services
  - Prescription eye glasses

**Restrictions may apply. Financial assistance depends on available program funds. Services must be pre-authorized. Health care providers must be willing to accept program payment.*

Who are eligible?

Children and youth with special health needs who are eligible for program services must:

- Be under the age of 21 years.
- Have a chronic health condition that has lasted (or may last) at least 1 year, and needs specialized medical care.
- Reside in Hawaii.

Assistance with service coordination is provided to families without regard to income.

To receive financial assistance, families must meet program financial requirements.

Children with Special Health Needs Program
REFERRAL FOR SERVICE

Date _____

Child's Name_____
LAST FIRST MIDDLE

Date of Birth _____ **Sex/Gender:** **Male** _____ **Female** _____

Address _____ **Home Phone** _____

Mailing Address (if different from above) _____

Mother's Name _____ **Work/Cell Phone** _____
LAST FIRST M.I.

Father's Name _____ **Work/Cell Phone** _____
LAST FIRST M.I.

Legal Guardian/Other Contact Person _____
LAST FIRST M.I.

Relationship to Child _____ **Home Phone** _____ **Work/Cell** Phone _____

Child's Health Insurance Plan _____ **Member Number** _____
IF QUEST, SPECIFY PLAN

Physician/Primary Care Provider _____ **Phone** _____

Dentist/Dental Provider _____ **Phone** _____

Reason for Referral _____

_____

_____

_____

_____

Significant Information (i.e. hospitalizations, conditions/diagnoses, discharge date, evaluations conducted)

_____

_____

_____

_____

Other Agencies Involved with Contact Numbers (if additional, please attach or use other side of referral)

1. _____ _____ **4.** _____ _____

2. _____ _____ **5.** _____ _____

3. _____ _____ **6.** _____ _____

Referred By _____ _____ _____
NAME **TITLE** **AGENCY** **PHONE** **FAX**

PLEASE MAIL OR FAX REFERRAL TO (808)733-9068

Call the numbers listed below for more information

Children with Special Health Needs Program
State of Hawaii / Department of Health
741 Sunset Avenue ▪ Honolulu, Hawaii 96816

Oahu 733-9066
Kona 322-4880
Hilo 974-4288

Maui 984-2130
Kauai 241-3376
Molokai & Lanai 733-9066 *(call collect)*

Children with Special Health Needs Branch

CHILDREN WITH SPECIAL HEALTH NEEDS PROGRAM

February 1, 2007

There are no income criteria for Children with Special Health Needs Program (CSHNP) services, except for financial assistance with medical specialty services. Medical specialty services include CSHNP neighbor island Cardiac and Neurology Clinics. The family income criteria are 300 percent of the current poverty level or below.

2007 CSHNP FINANCIAL ELIGIBILITY GUIDELINES
300% of DHHS* Poverty Guidelines for Hawaii

Size of Family Unit	Monthly Gross Income	Annual Gross Income
1	**$2,938**	**$35,250**
2	**$3,938**	**$47,250**
3	**$4,938**	**$59,250**
4	**$5,938**	**$71,250**
5	**$6,938**	**$83,250**
6	**$7,938**	**$95,250**
7	**$8,938**	**$107,250**
8	**$9,938**	**$119,250**
For each additional person, add	**$1,000**	**$12,000**

* DHHS - United States Department of Health and Human Services

Revised 1/25/07

❖

The Hawaii Lions Foundation has very generously established a fund to assist eligible uninsured and under-insured Department of Education students in receiving needed vision and hearing testing and services.

❖

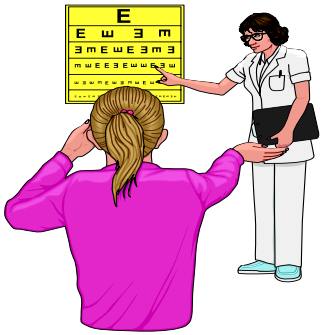
The State of Hawaii, Department of Health's Children with Special Health Needs Branch (CSHNB) is assisting in this project.

❖

Children with Special Health Needs Branch
Department of Health
State of Hawaii
741 Sunset Avenue
Honolulu, HI 96816
(808) 733-9055

Linda Lingle, Governor of Hawaii
Chiyome Leinaala Fukino, M.D., Director of Health

revised 02/2006



Hawaii Lions Foundation Uninsured-Under-insured Fund for Hearing and Vision Services

❖

Do you think your child needs to have his/her vision or hearing checked but cannot afford to see a doctor or an audiologist?

❖

Does your child need glasses or hearing aids but you cannot afford them?

❖

The requirements for help from the
Hawaii Lions Foundation's Uninsured/Under-insured Fund
for Hearing and Vision Services are:

Your child must meet **all three** conditions:

1. Your child seems to have a hard time seeing or hearing, **AND**

2. Your child does not have health insurance, **or**
   Has an insurance plan that does not cover vision or hearing testing, glasses or hearing aids, **AND**

3. Your gross family monthly income is not more than the levels listed below.

Family size	Monthly income cannot exceed:
1	$2,818
2	$3,795
3	$4,773
4	$5,750
5	$6,728
6	$7,705

for each additional family member add: $978

If you feel your child may benefit from this fund, please call the CSHNB Audiologist or neighbor island social worker for more information.

On Oahu: 733-9067

Neighbor island **toll-free**: Hawaii: 974-4000, ext. 39067
Kauai: 274-3141, ext. 39067
Maui: 984-2400, ext. 39067
Molokai/Lanai: 1-800-468-4644, ext. 39067

COMMON REASONS TO SEEK GENETIC SERVICES

- Medical problems of the developing baby detected by prenatal screening or testing.
- Harmful exposures during pregnancy such as alcohol or prescription or recreational drugs.
- Birth defects such as heart problems, structural brain abnormalities, and physical differences like cleft lip and palate.
- Mental retardation or developmental delays where the person does not reach developmental milestones on time or they do not function developmentally, intellectually, socially or behaviorally as expected for their age.
- Changes in body chemistry such as extremely high and low protein, fat or sugar levels in the blood.
- Sensory impairments like vision or hearing problems.
- Family history of a hereditary disease or cancer.

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Hawai'i Genetics Program

Hawai'i Department of Health Genetics Program

HAWAII STATE DEPARTMENT OF HEALTH

741 Sunset Avenue, Honolulu, HI 96816
Phone: (808) 733-9055 Fax: (808) 733-9068
www.hawaiigenetics.org

HAWAIʻI DEPARTMENT OF HEALTH GENETICS PROGRAM

The **Department of Health Genetics Program** is within the **Children with Special Health Needs Branch**.

The Program aims to:

- Provide information and education about topics in genetics.
- Obtain and administer funding related to genetics.
- Coordinate and support genetics related programs and activities.
- Support clinical genetic services.
- Research clinical and public health genetics topics.
- Develop public policy surrounding genetics.
- Provide technical assistance to other programs.

The **Genetics Program** also administers and participates in local, regional, and national projects. Some projects that may be of interest to families and providers are:

Western States Genetic Services Collaborative
This is a HRSA funded multi-state project that seeks to improve access to genetic services and education. One of the project's major activities in Hawaii is to increase statewide clinical genetic services by offering neighbor island clinics and telehealth visits.

Sickle Cell Disease Project
This HRSA funded project seeks to develop policies and activities to ensure that newborns and families with Sickle Cell Disease or Trait receive comprehensive care and education.

Tandem Mass Spectrometry Project
This was a HRSA multi-state collaborative project, led by the Hawai`i Department of Health, to obtain research data, identify strategies and develop materials for addressing the financial, ethical, legal and social issues (FELSI) surrounding the use of MS/MS for neonatal metabolic screening of culturally and ethnically diverse populations.

Etiology of Hearing Loss
This was a CDC multi-state collaborative project to determine the cause of congenital hearing loss in children identified through the statewide Newborn Hearing Screening (NBHS) program by offering a genetic evaluation to children with hearing loss.

OTHER RELATED PROGRAMS

Newborn Metabolic Screening (NBMS)
The NBMS Program ensures that newborns in the state of Hawaii receive screening for certain genetic/metabolic disorders. If found and treated before symptoms appear, babies born with these disorders may lead a normal, healthy life.

Newborn Hearing Screening (NBHS)
The NBHS Program ensures that newborns in the state of Hawaii receive screening for hearing loss. If intervention services begin before six months of age, babies with hearing loss have a better chance of learning to communicate as well as babies without hearing loss.

Hawaii Birth Defects (HBD)
The HBD Program collects statewide birth defects information. The information is used to monitor the incidence of birth defects to find any trends or changes over time in our state. The data is also used to develop public health activities to prevent birth defects.

Children with Special Health Needs (CSHN)
The CSHN Program provides medical services, care coordination and support services for children who have or may have long-term or chronic health conditions that require specialized medical care, and their families.

How can I find out more about the cause of my child's hearing loss?

One step a family can take to identify the cause of their child's hearing loss is to have a genetics evaluation performed by a genetics team. It will usually consist of:

- A physical exam
- Taking a medical and family history
- Education about genetics and hearing loss
- Discussion of options for your family, which may include clinical and genetic testing

Genetic testing is a personal decision for each family. Meeting with a genetics team can provide your family with the information you need to help make an informed decision.

Where can I find more information?

You can find a more detailed fact sheet about the genetics of hearing loss at the Hawai'i Genetics Program website:

www.hawaii.gov/health/family-child-health/genetics/program.html

Who can I contact for more information?

The Hawai'i Genetics Program genetic counselors would be happy to answer your questions.

Hawai'i Genetics Program
741 Sunset Avenue
Honolulu, HI 96816
Tel: 808-733-9055
Fax: 808-733-9068

Hawai'i Genetics Program

Who can I contact to schedule a genetics evaluation?

Hawai'i Community Genetics provides pediatric genetic clinical services across the state of Hawai'i. Services include genetics evaluation for hearing loss.

Hawai'i Community Genetics
1441 Kapi'olani Blvd., #1800
Honolulu, HI 96814
Tel: 808-973-3403
Fax: 808-973-3401

Your medical care providers at Kaiser Permanente or Tripler Army Medical Center may also provide genetic evaluations for hearing loss.

WHAT CAUSED MY CHILD'S HEARING LOSS?

Hawai'i State Department of Health

Linda Lingle
Governor of Hawai'i

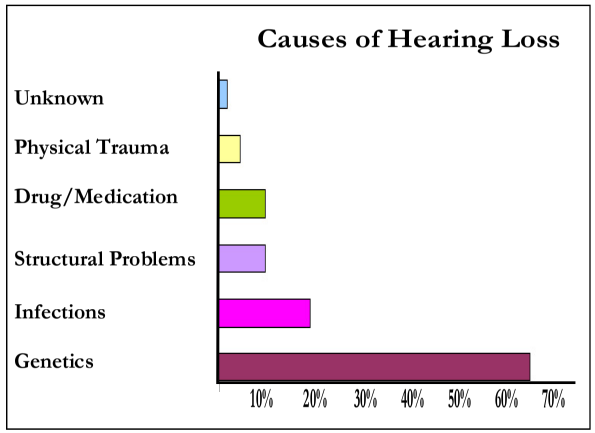
Chiyome Leinaala Fukino, M.D.
Director of Health

Hawai'i Department of Health
Family Health Services Division
Children with Special Health Needs Branch
Newborn Hearing Screening and Genetics Programs
December 2007

What are the causes of permanent childhood hearing loss?

Permanent hearing loss can have many causes. These include genetics, drugs or medications, infections, physical trauma and structural problems.

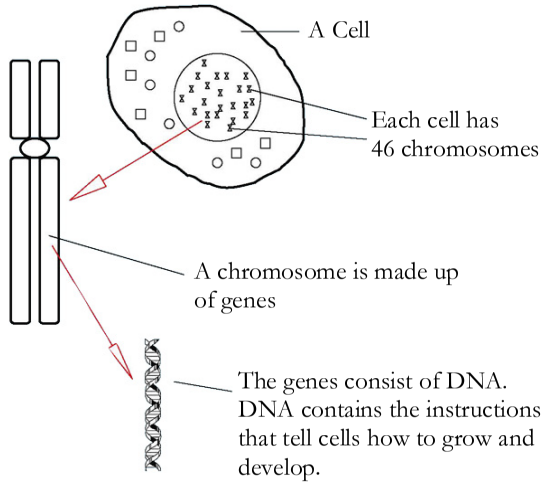
These causes are shown in the chart below:



As you can see from the diagram above, **over 50%** of hearing loss has a genetic cause.

What do you mean by genetic causes?

Genes are the structures in our bodies that determine how we grow and develop. We all have genes in our body that are responsible for hearing. Over 400 genes are known to be involved in the hearing process. When these genes are changed, this can lead to hearing loss.



Gene changes can occur in the egg or the sperm. Sometimes one or both parents will also have hearing loss, but it is common that the child is the first one in the family with childhood hearing loss.

Why would it be helpful to know if my child's hearing loss is genetic?

Some gene changes that cause hearing loss also cause other health conditions. Determining the cause of hearing loss may help with your child's medical care.

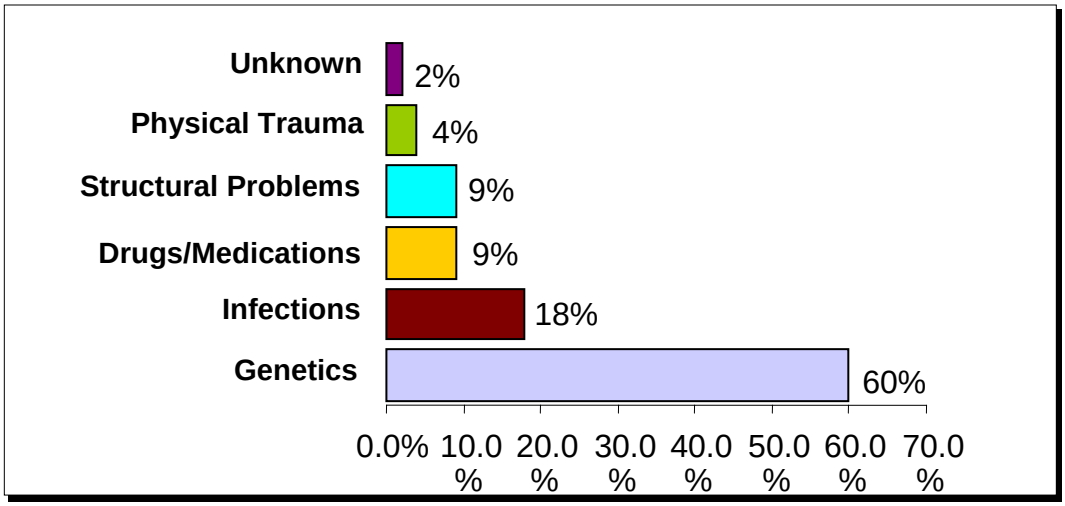
If a child has genetic hearing loss, future children in the family might also have hearing loss. Some families are interested in finding out their chances of having another child with hearing loss.

Fact Sheet for Parents: Why Does My Child Have a Hearing Loss?

This fact sheet gives general information about genetic evaluations and the causes of hearing loss. It is not intended to replace the clinical judgment of a healthcare provider.

What causes permanent childhood hearing loss?

Permanent childhood hearing loss can have many causes. The most common are:



As you can see from this chart, over half of permanent childhood hearing loss has a genetic cause.

What do you mean by a genetic cause?

Genes are the structures in our bodies that determine how we grow and develop. Some of our genes are responsible for hearing. A change in one or more of these genes may cause a person to have hearing loss. Genetic causes of hearing loss are mainly divided into two types: syndromic and nonsyndromic.

Syndromic hearing loss means that the gene change which causes hearing loss also causes other health problems. About 30% of people who have genetic hearing loss are found to have a syndrome. Examples of syndromic forms of hearing loss include:

NAME OF SYNDROME	OTHER FEATURES (besides hearing loss)
Alport	Kidney problems
Pendred	Thyroid gland enlargement
Usher	Vision impairment
Jervell and Lange-Nielsen	Heart problems

Most people with genetic hearing loss have no other health problems. This type of genetic hearing loss is called ***nonsyndromic hearing loss,*** or isolated hearing loss. About half of ***nonsyndromic hearing loss*** is caused by a change in the gene Connexin 26. Three of the most common Connexin 26 changes linked to hearing loss are:

- 35delG, found mostly in Northern European families
- 167delG, found mostly in Ashkenazi Jewish families
- 235delC, found mostly in Japanese and Chinese families

How can I find out what caused my child's hearing loss?

One option is to have an evaluation by a genetics team. This will likely consist of:

- A physical exam
- Providing a medical and family history
- Education about genetics and hearing loss
- Discussion of options such as clinical evaluation and genetic testing

Sometimes what caused a hearing loss can be discovered without genetic testing. Genetic testing is not necessary for every child and may not be offered as part of the genetics evaluation. If genetic testing is offered, meeting with the genetics team to discuss the possible benefits and limitations of genetic testing can provide you with the information needed to help make an informed decision. Genetic testing is a personal decision for each family.

What are some possible benefits of genetic testing as part of a genetics evaluation?

Here are a few of the possible benefits. Genetic testing can help confirm the cause of a hearing loss. Finding out if your child has syndromic or non-syndromic hearing loss may have an impact on your child's health care. Your child may be able to avoid the need for further diagnostic tests if a genetic cause is found. Finally, genetic testing may help you and other relatives find out the chances of having more children with hearing loss.

Will genetic testing tell me why my child has a hearing loss?

Genetic testing is only one part of the evaluation process. There is a chance that genetic testing will not identify the cause of your child's hearing loss. Over 400 genes that are linked to hearing have been identified. However, not all gene changes that cause childhood deafness are known.

Sometimes we receive a genetic test result that has not been reported before in people with hearing loss. Everyone has some natural differences in their genes. We may not be able to determine whether a specific gene change causes hearing loss or is just a natural difference.

In addition, current testing technology may not be able to detect all gene changes. This means that we cannot be sure there isn't a genetic cause even if the test results do not show a gene change.

Will non-genetic causes be considered during a genetics evaluation?

Yes, a genetics team also looks for other known causes of hearing loss during a genetics evaluation. They consider such possible causes as infections before or after birth, exposure to certain drugs and medications, physical trauma and structural differences inside or outside the ear.

Several additional factors seem to increase a child's chances for hearing loss. For example, children seem more likely to have a hearing loss if they have had:

- Conditions requiring more than 5 days in a neonatal intensive care unit
- Low oxygen levels
- High bilirubin levels
- Very premature birth

Hearing can change over time. You and your child's healthcare provider should pay extra attention to your child's hearing and speech-language development and watch for changes in how your child responds to sound.

What else can I do to help my child while I wait for the genetic evaluation to be completed?

First, if your child is under three years of age, you can arrange for your child to receive early intervention (EI) services. Children with hearing loss do best if they begin EI services before six months of age. The lead agency for EI in Hawai`i is the Department of Health.

Services such as audiology, speech therapy, family support, and information sharing can begin even before all the exams are completed and before hearing aids are obtained. EI services are available at no cost to families, although use of insurance is encouraged. To contact the Hawaii Keiki Information Services System (H-KISS) for more information about enrolling your child for EI services, call 594-0066 from Oahu or toll-free from Neighbor Islands at 1-800-235-5477.

Second, you can obtain hearing aids for your child as soon as possible if the audiologist recommends them. Hearing aids can be fitted as early as one month of age to help get sound to the brain.

Babies are born with brains that are ready to hear. The ears are just a way to get sound to the brain. Without sound, children begin using the part of the brain that hears for other things. Obtaining hearing aids as soon as you can and helping your child learn to wear them can protect your child's long-term hearing potential.

Third, you can work closely with your child's healthcare provider to monitor your child's health and obtain medical treatment whenever needed. Ear infections can flare up and make your child's hearing loss worse. It's important to contact your child's healthcare provider as soon as possible if you think your child is having more trouble hearing than usual or isn't feeling well.

Sometimes, the cause of your child's hearing loss will remain unknown after all the exams are completed. Not knowing why your child has a hearing loss doesn't mean you can't get help for your child. Beginning intervention services as early as possible, helping your child learn to wear hearing aids if recommended, and taking your child to see a healthcare provider and audiologist regularly will provide the best chances for your child to stay healthy and build strong language, communication and listening skills that will last a lifetime.

Who can I contact for a genetics evaluation?

Hawai'i Community Genetics provides pediatric and adult genetics clinical services across the state of Hawai'i.

Hawai'i Community Genetics
1441 Kapi'olani Blvd, #1800
Honolulu, HI 96814
Tel: 808-973-3403
Fax: 808-973-3401

Your medical care provider at Kaiser Permanente or Tripler Army Medical Center may also provide genetic evaluations for hearing loss.

Where can I find more information about hearing loss?

Here is a list of websites you may find helpful:

National Center for Hearing Assessment and Management
http://www.infanthearing.org/

My Baby's Hearing
http://www.babyhearing.org/

Hands and Voices
http://www.handsandvoices.org/

U.S. National Library of Medicine Genetics Home Reference on non-syndromic deafness.
http://ghr.nlm.nih.gov/condition=nonsyndromicdeafness

Center for Disease Control and Prevention on the genetics or deafness
http://www.cdc.gov/ncbddd/ehdi/genetics.htm

National Institute on Deafness and Other Communication Disorders
http://www.nidcd.nih.gov/health/hearing/

Orphanet is a database dedicated to information on rare genetic diseases. Go to "see alphabetical listing of diseases" to read more about deafness.
http://www.orpha.net/consor/cgi-bin/index.php

Hawai'i Genetics Program
http://www.hawaiigenetics.org/

Hawai'i Newborn Hearing Screening Program
http://hawaii.gov/health/family-child-health/eis/nhsp.html

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