

1422 HOUSE HEALTH, EDUCATION & SOCIAL SERVICES

Sec. 08.11.120. Audiology exemptions.

(a) This chapter does not apply to an individual who practices audiology consistent with the accepted standards and code of ethics of the individual's profession as part of the individual's duties as

(1) a physician licensed under AS 08.64;

(2) an employee of the federal government who is required to practice audiology during the employment, if

(A) the employer maintains appropriate supervision of the individual's practice of audiology;

(B) the individual practices audiology as part of the duties for which the individual is employed;

(C) the individual practices audiology in the facility where the individual is employed or under the supervision of the federal governmental unit where the individual is employed; and

(D) the individual does not render or offer to render audiology services to the public for compensation in addition to the salary the individual receives from the federal governmental unit;

(3) a student, intern, or resident pursuing a course of study in audiology at an accredited college or a clinical training facility approved by the department, if the activities of the student, intern, or resident constitute part of a supervised course of study and the student, intern, or resident is designated as an "audiology intern," "audiology trainee," or other title approved by the department that clearly indicates that the person is training to be an audiologist.

(b) Notwithstanding the provisions of this chapter,

(1) a nurse licensed under AS 08.68 may perform hearing sensitivity evaluations;

(2) an individual licensed as a hearing aid dealer under AS 08.55 may deal in hearing aids;

(3) an individual holding a class A certificate issued by the Conference of Executives of American Schools of the Deaf may teach the hearing impaired;

(4) an individual may engage in the testing of hearing as part of a hearing conservation program that complies with the regulations of the Occupational Safety and Health Administration of the federal government if the individual is certified to do the testing by a state or federal agency acceptable to the Occupational Safety and Health Administration.

(c) An individual who is not an audiologist, but who is exempt under this section, may not use a title or description stating or implying that the person is an audiologist.

(d) An individual exempt under (a)(2) of this section may consult with and disseminate research findings and scientific information to accredited academic institutions or governmental agencies, and offer lectures to the public for a fee, monetary or otherwise, without being licensed under this chapter.

(e) An individual who is not licensed under this chapter but who teaches the practice of audiology in an audiologist training program at a college or university may use the title "audiologist" but may not practice audiology.

Sec. 21.42.347. Coverage for costs of birth.

(a) A health care insurer who provides coverage for the costs of childbirth shall also provide coverage for the costs of hospitalization or medical care following childbirth for a period of not less than

(1) 48 hours after a vaginal birth; and

(2) 96 hours after a caesarean birth.

(b) Except as otherwise required to provide coverage specified under (a) of this section, this section does not affect a payment arrangement entered into between a hospital or health care provider and a health care insurer.

(c) This section may not be construed to require hospitalization or medical care as described under (a)(1) or (2) of this section if the mother giving birth and the mother's health care provider agree that the mother and any newborn child of the mother should be discharged earlier than required under (a)(1) or (2) of this section.

(d) In this section,

(1) "health care insurer" has the meaning given in AS 21.54.500; "health care insurer" includes the Comprehensive Health Insurance Association as described in AS 21.55.010;

(2) "health care provider" means a person licensed in this state to provide health care services.

*Sec. 21.42.350. Exemption of proceeds, annuity contracts. [Repealed, Sec. 14 ch 62 SLA 1982. For current law see AS 09.38.025 (a)].*

AS 47.20

Sec. 47.20.060

It is the purpose of this chapter to

(1) subject to the availability of funding, provide quality learning and related early intervention family support services to eligible children under the age of three who have developmental delays or disabilities and, on a discretionary basis, to those children under the age of three who are at risk of developmental delays or disabilities;

(2) bring together and make optimal use of all available federal, state, local, and private resources for the benefit of children under the age of three with developmental delays or disabilities and their families;

(3) expand and improve existing learning and early intervention services and to provide and arrange for comprehensive services through local agencies and statewide support programs.

Sec. 47.20.070. Establishment of program.

(a) The department, with the assistance of the Governor's Council for the Handicapped and Gifted, shall establish a coordinated, comprehensive, statewide system of multidisciplinary interagency programs that provide appropriate early intervention services to eligible persons under this chapter.

(b) The department is the lead agency for purposes of federal law with respect to the administration of the early intervention services system required under (a) of this section. The department shall establish and administer the system required under (a) of this section so that the state is eligible for the maximum available funding from public and private sources.

(c) In connection with the system established under (a) of this section, the department shall

(1) develop a state plan that identifies the best methods of providing services to children under the age of three with developmental delays or disabilities and their families and report to the governor on the extent to which that plan is being implemented in the state;

(2) develop and implement an educational program concerning the nature and effects of developmental delays and disabilities;

(3) serve as a clearinghouse for educational materials and information about developmental delays and disabilities;

(4) organize and encourage training programs for persons who provide services to children under the age of three with developmental delays and disabilities and their families;

(5) establish a training program for paraprofessionals who provide services to children under the age of three with developmental delays and disabilities and their families;

(6) cooperate with other public and private agencies and individuals to facilitate the transition of children served in the early intervention system to the formal education system;

(7) identify and use all public and private resources available to the state; and

(8) monitor and evaluate the services provided to ensure the demonstrable effectiveness of the services and compliance with state and federal law and department policy regarding the provision of early intervention services.

Sec. 47.20.075. Grant authority.

The department may award grants for covered services to children and their families who are eligible under this chapter.

Sec. 47.20.080. Program eligibility.

(a) A child and the child's family are eligible for core early intervention services and additional early intervention services under this chapter if the child is under the age of three and

(1) experiencing developmental delay or disability; or

(2) at risk of experiencing developmental delay or disability if early intervention services are not provided.

(b) If the department estimates that funding available for services under this chapter will be insufficient to provide services to all persons who are eligible under (a) of this section, the department shall eliminate coverage for services in the following order:

(1) additional early intervention services for persons eligible under (a)(2) of this section;

(2) additional early intervention services for persons eligible under (a)(1) of this section;

(3) core early intervention services for persons eligible under (a)(2) of this section; and

(4) core early intervention services for persons eligible under (a)(1) of this section.

Sec. 47.20.090. Finding and evaluating eligible participants.

(a) The department shall establish a comprehensive system for finding children and their families who are eligible for services under this chapter. This child find system must

(1) include a public awareness program focusing on early identification of developmentally delayed and disabled children under three years of age;

(2) provide for participation by primary referral sources; and

(3) include procedures with timelines for referral of eligible participants to service providers.

(b) The department shall, within 45 days after a child's referral for services under (a) of this section, ensure that all affected public agencies and service providers

(1) provide for a comprehensive multidisciplinary evaluation of the functioning of the child and the needs of the child's family so that the family can appropriately assist in the development of the child;

(2) in consultation with the child's parents, develop a written individualized service plan that identifies how the needs of the child and the family could be met.

Sec. 47.20.100. Individualized family service plan.

The individualized family service plan developed under AS 47.20.090(b)(2) shall be based on the evaluation conducted under AS 47.20.090(b)(1) and must include, subject to AS 47.20.080 (b),

(1) provisions for case management services to implement the plan, including the name of the case manager from the profession most immediately

relevant to the child's or family's needs who will be responsible for the implementation of the plan and coordination with other agencies and persons;

(2) a statement of the child's present levels of physical development, cognitive development, language and speech development, psychosocial development, and self-help skills, based on appropriate objective criteria;

(3) a description of the family's concerns, priorities, and resources as they relate to the future enhancement of the child's development;

(4) a description of the specific early intervention services that will help meet the unique needs of the child and the family, including the frequency, intensity, and method with which the services should be delivered;

(5) the projected dates for initiation of services and the anticipated duration of the services;

(6) an outline of the major outcomes expected to be achieved for the child and the family along with the criteria, procedures, and timelines that will be used to determine the degree to which progress toward achieving the outcomes are being made and whether modifications or revisions of the outcomes or services are necessary; and

(7) a statement of the steps that will be taken to support the transition of the child and the family to the use of services available under other appropriate programs, including programs for children who are three years of age or older.

Sec. 47.20.110. Other duties of the department.

(a) The department shall adopt regulations necessary to implement this chapter, including regulations

(1) for personnel development, including preservice and in-service training programs for providers of early intervention services;

(2) to govern resolution of intra-agency and interagency disputes about the provision of services under this chapter and the financial responsibility of the respective parties for those services;

(3) that ensure that services are provided to children and their families in a timely manner pending the resolution of disputes among public agencies or service providers;

(4) providing for due process with respect to the rights of children and parents who are eligible for services under this chapter; the regulations must provide that during the pendency of a complaint about a change in services, the child and family shall continue to receive the prior services unless the state and the family otherwise agree, or, if the complaint relates to an application for initial services, the child and family shall receive the services that are not in dispute; and

(5) for the award of grants under this chapter.

(b) The department shall establish a system for compiling data on the numbers of children and their families in the state who need early intervention services, the numbers being served, the types of services provided, and other information as required under federal law. Personally identifiable information obtained under this chapter is confidential for purposes of AS 40.25.110 - 40.25.120.

Sec. 47.20.290. Definitions.

In this chapter,

(1) "additional early intervention services" means

- (A) family training and counseling;
- (B) speech pathology and audiology;
- (C) occupational therapy;
- (D) physical therapy;
- (E) psychological services;
- (F) medical services only for diagnostic or evaluation purposes; and
- (G) health services for the child that are necessary to enable the child to benefit from the other early intervention services;

(2) "core early intervention services" means

- (A) case management services;
- (B) special instruction, and
- (C) early identification, screening, and assessment;

(3) "department" means the Department of Health and Social Services;

(4) "developmentally delayed" means functioning at least 15 percent below a chronological or corrected age or 1.5 standard deviations below age appropriate norms in one or more of the following areas: cognitive development, gross motor development, sensory development, speech or language development, or psychosocial development, including self-help skills and behavior, as measured and verified by appropriate diagnostic instruments and procedures or through systematic observation of functional abilities in a daily routine by two professionals and a parent, developmental history, and appropriate assessment procedures;

(5) "disability" means having an identifiable physical, mental, sensory, or psychosocial condition that has a probability of resulting in developmental delay even though a developmental delay may not be exhibited at the time the condition is identified, including

(A) chromosomal abnormalities associated with delays in development, such as Down's syndrome, Turner's syndrome, Cornelia de Lange syndrome, or fragile X syndrome;

(B) other syndromes and conditions associated with delays in development, such as fetal alcohol syndrome, cocaine and other drug-related syndromes, metabolic disorders, cleft lip, or cleft palate;

(C) neurological disorders associated with delays in development, such as cerebral palsy, microcephaly, hydrocephaly, spina bifida, or periventricular leukomalacia;

(D) sensory impairment, such as hearing loss or deafness, visual loss or blindness, or a combination of hearing and visual loss, that interferes with the child's ability to respond effectively to environmental stimulus;

(E) congenital infections, such as rubella, cytomegalovirus, toxoplasmosis, or acquired immune deficiency syndrome;

(F) chronic illness or conditions that may limit learning or development, such as cystic fibrosis, bronchopulmonary dysplasia, tracheostomies, amputations, arthritis, or muscular dystrophy;

(G) psychosocial disorders, such as reactive attachment disorder, infant autism, or childhood schizophrenia; or

(H) atypical growth patterns consistent with a prognosis of developmental delay based upon parental and professional judgment, such as failure to thrive;

(6) "early intervention services" or "services" means services that are designed to help meet the developmental needs of a child under the age of three who is developmentally delayed or disabled or at risk of developmental delay or disability or the needs of the child's family so that the family can support the child's development.

# LEGAL SERVICES

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LEGISLATIVE AFFAIRS AGENCY  
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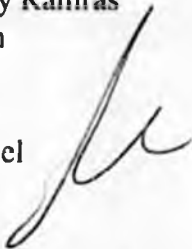
## MEMORANDUM

January 27, 2005

**SUBJECT:** HB 109, Infant Hearing Screening  
(Work Order No. 24-LS0450A)

**TO:** Representative Jay Ramras  
Attn: Jane Pierson

**FROM:** Jean M. Mischel  
Legislative Counsel



You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

**Section 1.** Describes legislative findings with respect to newborn and infant hearing loss, the value of early intervention and the relationship to language ability.

**Section 2.** Describes legislative intent to cover at least 90 percent of newborns and infants under the hearing screening and intervention program established by the act by January 1, 2007.

**Section 3.** Adds certain individuals who have been authorized by the Department of Health and Social Services to the list of individuals who may perform hearing screening tests without an audiology license.

**Section 4.** Requires the state Bureau of Vital Statistics to forward names and addresses of parents of newborns born outside of a hospital to the Department of Health and Social Services for notification of the merits of hearing screening.

**Section 5.** Requires certain minimum insurance coverage for newborn and infant screening.

**Section 6.** Establishes a newborn and infant hearing screening, tracking, and intervention program within the Department of Health and Social Services.

Representative Jay Ramras  
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**Section 7.** Authorizes the Department of Health and Social Services to promulgate regulations required to implement the act before the effective date of the act.

**Section 8.** Adds a revisor's instruction to make conforming amendments.

**Section 9.** Provides an immediate effective date for secs. 6 through 8 of the act.

**Section 10.** Provides a January 1, 2006 effective date except as stated in sec. 9.

JMM:lmb  
05-018.lmb

## Documents Attached to HB 109

1. Why is Mandatory Newborn Hearing and Screening and Reporting So Important? - This is a two-page document describes why newborn hearing screening is important.
2. Alaska Early Hearing Detection & Intervention Program Overview – A flow-chart explaining EHDI.
3. Goal of Alaska Early Hearing Detection & Intervention Program (EHDI) – Overview. – Hearing Impairment is the most common disability in newborns. Explanation of Alaska EHDI Program.
  - Ensure babies born in Alaska have newborn hearing screening prior to hospital discharge or within 30 days of birth.
  - Ensure that all newborns who fail hearing screening receive an audiological evaluation by three months of age.
  - Ensure that infants diagnosed with hearing loss are referred to and enrolled in appropriate early intervention and other needed services by six months of age.
4. Locations of Newborn Hearing and Screening Hospitals in Alaska.
5. March of Dimes Resource Center - Hearing Loss.
  - What causes hearing loss in babies and children?
  - Are there different types of hearing loss?
  - How are newborns screened for hearing loss?
  - What happens if a baby does not pass the hearing screening?
  - How are babies and children tested for hearing loss?
  - What are signs of hearing loss in infants and children?
  - How is hearing loss treated?
6. March of Dimes Resource Center – Newborn Screening Tests.
  - Which newborn screening tests are most likely to be given?
  - What other disorders can newborn screening tests detect?
  - How are the tests for inborn errors of body chemistry and hearing loss done?
  - How soon after birth should screening tests be done?
  - What does an abnormal test result mean?
  - What should you do if your child is diagnosed with one of the conditions for which they were tested?
  - If one of my children has a disorder will my other children have it?

7. March of Dimes Resource Center – Birth Defects.

- What causes birth defects?
- What are some common types of birth defects?
- Can birth defects be prevented?
- Can some birth defects be diagnosed before birth?
- Can birth defects be treated before birth?

8. The Governor's Council on Disabilities and Special Education – FY06 Legislative Priorities. – A legislative recommendation is made for Universal Newborn Hearing Screening.

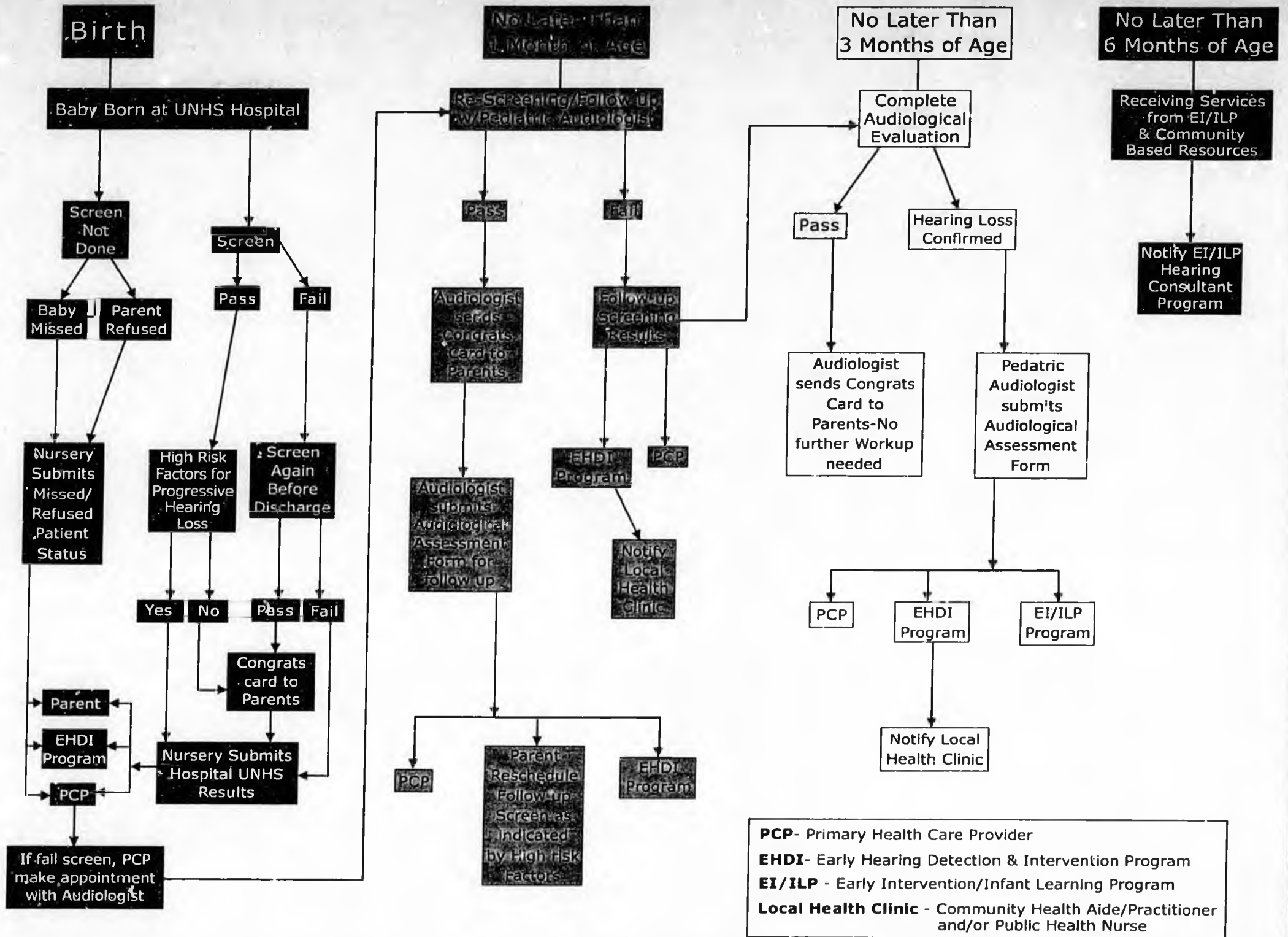
### Why Is Mandatory Newborn Hearing Screening and Reporting So Important?

1. Every day, 33 babies (or 12,000 each year) are born in the United States with permanent hearing loss, or 3 in every 1,000 births (1). In Alaska, approximately 10,000 babies are born each year and according to statistics 30-40 will likely have some type of congenital hearing loss.
2. The evidence for the benefits, practicability, and cost-efficiency of universal newborn hearing screening is so compelling that 38 other states have passed legislative mandates requiring that newborns be screened for hearing loss (2).
3. Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome, and severe mental retardation (3).
4. Hearing impairment is approximately 30 times more prevalent than PKU and hypothyroidism, screened through the metabolic disorder screening programs, and mandated by law in all 50 states. (4).
5. The cost of identifying a newborn with hearing loss is less than 1/10<sup>th</sup> the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state (5). For most birthing hospitals, the cost for newborn hearing screening per child is between \$20 - \$60 and continues to decrease (6). Many birthing facilities in Alaska, implementing newborn hearing screening voluntarily, include the cost in the total labor and delivery package cost.
6. Children not detected at birth or soon after, will not be detected, on average, until 2-3 years of age, and the most critical period for speech and language development is from birth to three years of age (7).
7. When children are not identified and served early, special education for a child with hearing loss may cost an additional \$420,000, and deafness has an estimated lifetime cost of approximately \$ 1 million per individual (8). These savings in special education costs will pay for universal newborn hearing screening many times over.
8. If left undetected, hearing loss can impair a child's language, speech, psychosocial and cognitive development. Recent research has compared children with hearing loss who receive early intervention and amplification (i.e. hearing aids) before 6 months of age versus after 6 months of age. By the time they enter first grade, children identified earlier (prior to 6 months of age) are 1-2 years ahead of their later-identified peers in language, cognitive, and social skills (9, 10, 11).
9. If it remains undetected, even mild hearing loss or hearing loss in only one ear has substantial detrimental consequences. For example, research shows that children

with hearing loss in one ear are ten times as likely to be held back at least one grade compared to a matched group of children with normal hearing (12).

10. The American Academy of Pediatrics, the National Institutes of Health, the American Academy of Audiology, the Joint Committee on Infant Hearing, and the National Association of the Deaf have recommended that all babies be screened for hearing loss before they leave the hospital (13).
11. To date, 23 of 23 communities in Alaska with birthing hospitals have voluntarily implemented universal newborn hearing screening programs. The majority of the screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screenings during home visits after hospital discharge. As of December 2003, the total number of newborns in Alaska that received hearing screening was approximately 80% (14).
12. Even though 80% sounds like a large number of Alaska's newborns, because newborn hearing screening is not mandated and the screening, reporting and follow-up is not institutionalized in facilities across the state, Alaska remains in the "unsatisfactory" category when rated nationally.
13. Due to Alaska's large geographic size, high staff turnover occurs as well as difficulty recruiting and keeping healthcare providers in many of its more rural communities. And because the screening and reporting is not mandated, it is often times not a priority at birthing facilities and among providers. As a result, it is increasingly difficult to keep nurses and other providers with the knowledge necessary to maintain a newborn hearing screening program. Gaps in screening occur in hospitals, thus babies miss their screening and are not followed for high risk factors.

# Goal Alaska Early Hearing Detection & Intervention Program (EHDI)



**PCP**- Primary Health Care Provider  
**EHDI**- Early Hearing Detection & Intervention Program  
**EI/ILP** - Early Intervention/Infant Learning Program  
**Local Health Clinic** - Community Health Aide/Practitioner and/or Public Health Nurse

# Alaska Early Hearing Detection & Intervention Program Overview

January 2005

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss.

Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome and severe mental retardation.

## **Early Identification is important because:**

- The most important period of speech and language development is from birth to age three.
- Delay in diagnosis can impair a child's language, speech, psycho-social and cognitive development.
- The average age of identification of a hearing impairment in the absence of newborn hearing screening is 2-3 years of age.
- Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

## **Alaska EHDI Program**

The Alaska Early Hearing Detection & Intervention (EHDI) Program began in April 2000. The EHDI Program is funded by two federal grants from: the Health Resources & Services Administration (HRSA) and Centers for Disease Control & Prevention (CDC).

### **Key program include the following:**

- Ensure that babies born in Alaska have newborn hearing screening prior to hospital discharge
- Ensure that all newborns who fail hearing screening receive an audiological evaluation by three months of age.
- Ensure that infants diagnosed with hearing loss are referred to and enrolled in appropriate early intervention and other needed services by six months of age.

### **Screening**

To date, 23 of 23 communities within Alaska have implemented universal newborn hearing screening programs. The majority of screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screen during home visits after hospital discharge.

### **Legislation**

Nationwide, 38 states have enacted legislation requiring hospitals to implement newborn hearing screening programs. In Alaska, newborn hearing screening was introduced and worked on during the 2001, 2002, 2003, and 2004 legislative sessions.

### **Data & Evaluation**

A primary role of the Alaska EHDI Program is to support hospitals, audiologists and other health care providers, and assist early intervention programs (Infant Learning Program) in their tracking and follow-up efforts. The EHDI Program received a grant from the Centers for Disease Control & Prevention (CDC) to develop an electronic data tracking and surveillance system to facilitate the follow-up process and ensure smooth transition occurs through services. The EHDI Program is purchasing the web-based database, Oz, and will begin implementing in communities in 2005.

### **Loaner Program**

The EHDI Loaner Program provides assistive hearing devices (i.e. hearing aids) for children (0-3 years) whose families cannot otherwise afford them. For example, these families are not eligible for Denali Kid Care and/or do not have private insurance that covers hearing aids and/or cannot afford to purchase hearing aids themselves. The Loaner Program allows these families to "borrow" money to purchase hearing aids for 6-12 months. The Loaner Program is made possible through a grant from the Mental Health Trust Authority.

### **Education & Outreach**

The EHDI Program travels to communities introducing the Alaska EHDI Program. Presentations target primary health care providers in those communities (i.e. pediatricians, public health nurses, community health aide/practitioners) regarding newborn hearing screening and early hearing detection and intervention.

To assist with this effort, educational materials were developed by EHDI Program with assistance by many dedicated providers and parents. The following materials are available from the EHDI Program: 1) general brochure regarding: universal newborn hearing screening for parents and prospective parents, 2) brochure outlining the protocol for parents to follow if their newborn does not pass the newborn hearing screening, 3) basic hearing loss information for parents and the general public, 4) parent resource manual for families of children diagnosed with hearing loss, 5) provider guide for health care providers, 6) hospital orientation manual regarding implementation of universal newborn hearing screening, and 7) video/DVD for community health aide/practitioners (CHA/Ps) in rural Alaskan communities.

For copies of the materials and/or information regarding the EHDI Program, contact:

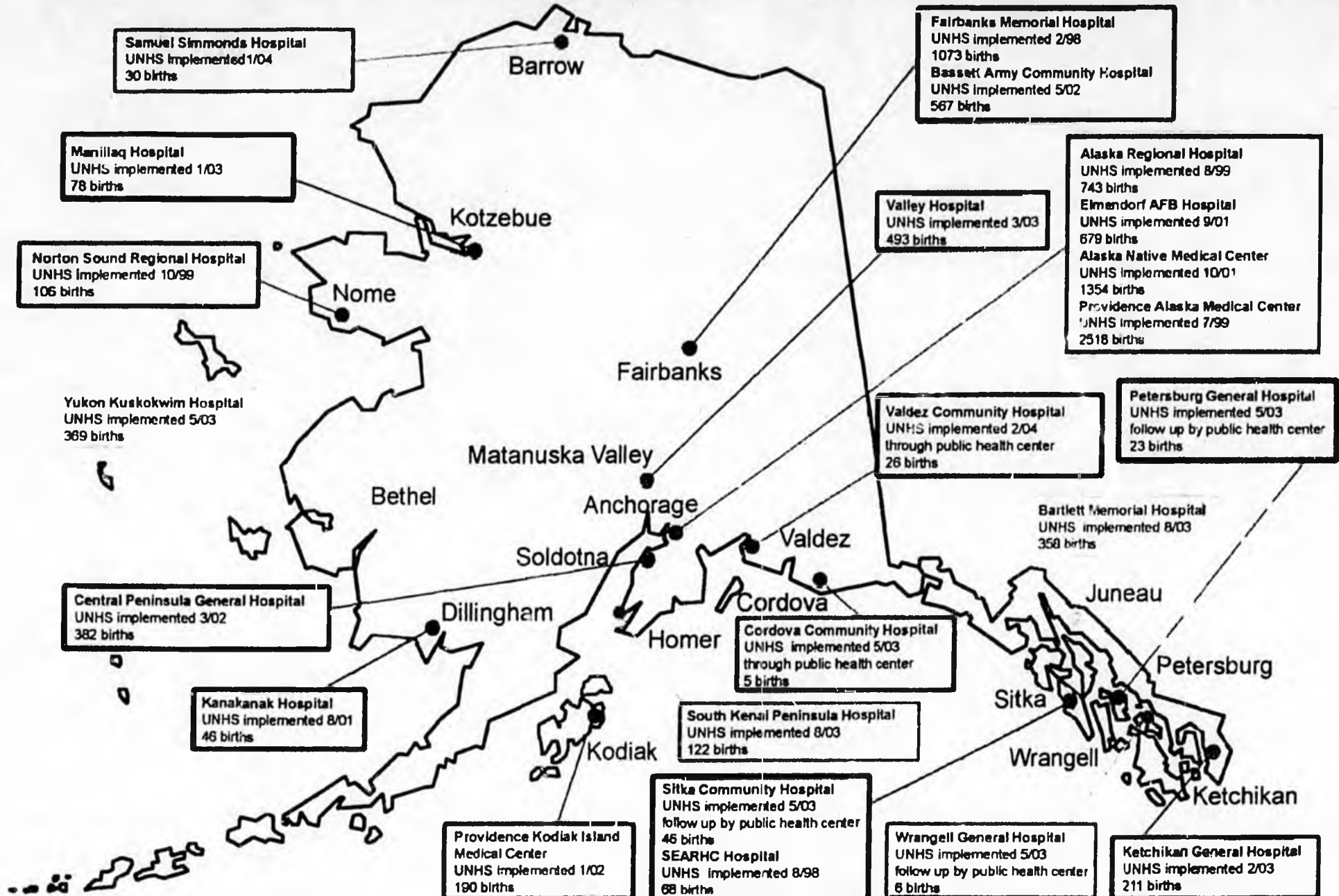
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(907) 269-3465 – fax

<http://hss.state.ak.us/dhcs/newborn>

# Locations of Newborn Hearing Screening Hospitals

2003 births



# Hearing Loss

Hearing loss is one of the most common birth defects, affecting about 3 in 1,000 babies. Hearing loss that is present at birth is called congenital hearing loss. Hearing loss also can develop later in childhood or during adulthood.

Hearing loss can have a major impact on the life of a child and his family. Because language and communication develop so rapidly during the first 3 years of life, an undetected hearing loss is likely to interfere with a child's speech, language and communication with others. Hearing loss also can result in learning problems that affect a child's performance at school. The goal of early screening, diagnosis and treatment is to help children with hearing loss to develop language and academic skills equal to their hearing peers.

Because hearing loss in infancy is hard to recognize, most hospitals screen all newborns before they are discharged. Most states have an Early Hearing Detection and Intervention program to help ensure that infants who don't pass the screening receive follow-up care. The March of Dimes, the American Academy of Pediatrics, the Maternal and Child Health Bureau, the Centers for Disease Control and Prevention (CDC) and others strongly support these programs.

## What causes hearing loss in babies and children?

Hearing loss can be inherited (genetic) or can be caused by illness or injury. In some cases, the cause of hearing loss is not known. About 90 percent of babies with congenital hearing loss are born to hearing parents.

Genetic factors are believed to cause about 50 percent of cases of congenital hearing loss. About 25 genes that play a role in hearing loss have been identified.

About 30 percent of children with hearing loss also have other birth defects. In such cases, hearing loss is part of a syndrome (group of birth defects that occur together).

Illnesses that can cause congenital hearing loss include infections during pregnancy, such as rubella (German measles), cytomegalovirus, toxoplasmosis, herpes or syphilis. Babies born preterm also are at increased risk.

After birth, head injuries or childhood infections, such as meningitis, measles or chickenpox, can cause permanent hearing loss. Certain medications, such as the antibiotic streptomycin and related drugs, also can cause hearing loss. Ear infections (otitis media) may cause temporary hearing loss.

## Are there different types of hearing loss?

Hearing loss is the decreased ability to hear sounds. When sound enters the outer ear (auricle or pinna), it moves through the ear canal to the eardrum (tympanic membrane). Incoming sound causes the eardrum to vibrate, which moves three small bones (ossicles) in the middle ear. In this way, the ear canal, the eardrum and the middle ear transmit sound from the outside world to the inner ear (cochlea). Within the inner ear, thousands of tiny hair cells detect the incoming vibrations and convert them into signals that are relayed to the auditory nerves, which send neural impulses to the hearing center in the brain.

Hearing loss is often discussed in terms of where the loss occurs in the hearing pathway.

- **Conductive hearing loss** occurs when something interferes with sound passing through the outer or middle ear. A blockage in the ear canal, damage to the eardrum, or fluid or an infection in the middle ear (called otitis media) are examples of conditions that can cause a conductive hearing loss. This type of hearing loss is usually temporary and can often be corrected with medication or surgery.
- **Sensorineural hearing loss** usually occurs when the hair cells in the inner ear cannot detect all incoming vibrations or when neural impulses are not transmitted to the brain. Prenatal infections, lack of oxygen at birth, or genetic factors can cause this type of hearing loss, which is generally permanent. However, many children can be aided with devices that amplify sound. Sensorineural hearing loss also can result from damage to the brain's auditory center.
- **Mixed hearing loss** occurs when a child who has a sensorineural hearing loss also has a conductive loss (such as fluid in the middle ear). It is very important that children with

permanent hearing loss be monitored and treated for middle ear problems so hearing is not further reduced.

## How are newborns screened for hearing loss?

Newborns are screened with one of two tests, both of which measure how a baby responds to sound. Both tests take 5 to 10 minutes, are painless, and can be done when the baby is resting.

In the otoacoustic emissions (OAE) test, a small microphone is placed in the baby's ear. The microphone, connected to a computer, sends soft clicking sounds into the ear and records the inner ear's response to sound.

In the automated auditory brainstem response (AABR) test, soft clicking sounds are presented to the ear through small earphones. Sensors placed on the head and connected to a computer measure brain wave activity in response to sound.

## What happens if a baby doesn't pass the hearing screening?

If a baby does not pass the OAE or the AABR, the test should be repeated or the baby should be referred to a hearing specialist (audiologist) or an ear, nose and throat specialist (ENT or otolaryngologist) for more extensive tests to determine if the baby has a hearing loss. It is important for babies to be assessed by specialists who have experience testing very young children. Diagnostic testing should be completed by 3 months of age.

Parents must keep in mind that the screening tests cannot diagnose hearing loss. Up to 5 percent of babies will have abnormal results on their hearing screening test. However, additional tests show that only about 1 in 10 of these babies actually have hearing loss.

## How are babies and children tested for hearing loss?

The most common hearing test for infants under 6 months of age is the diagnostic auditory brainstem response test. It is similar to the automated screening test, but it provides more information and must be administered by a specialist.

Children between 6 months and 2 years of age often are tested with visual reinforcement audiometry (VRA).

During VRA testing, a series of sounds is presented to the child through earphones or speakers. The child is trained to turn toward any sound, and is then rewarded with an entertaining visual image for responding.

Children between 2 and 4 years of age are tested with conditioned play audiometry (CPA). They are asked to perform a simple play activity (like placing a ring on a peg) when they hear a sound. This is similar to the test for older children and adults, who are asked to press a button or raise their hand when they hear a sound.

These tests also may be recommended if a child was not screened as a newborn; if he has had persistent ear infections, meningitis or other illness that can cause hearing loss; has been diagnosed with a syndrome that can include hearing loss; or if a parent suspects the child is not responding normally to sounds.

#### **What are some signs of hearing loss in infants and young children?**

Parents should be alert to any signs of hearing loss and discuss them with their child's pediatrician. Some signs include: failure to startle at loud sounds; not turning toward the sound of a voice or imitating sounds after about 6 months of age; lack of babbling at 9 months; not using single words by 18 months; or using gestures instead of words to express needs. Parents should be concerned about hearing loss in older children if they develop vocabulary more slowly than their peers; have speech that is difficult to understand or that is too loud or too soft; often ask you to repeat what was said; turn the TV too loud. At school age, children with hearing loss often appear inattentive and have difficulties learning to read or perform simple mathematics, and fall behind at school.

#### **How is hearing loss treated?**

A child with a congenital hearing loss should begin receiving treatment before 6 months of age. Studies suggest that children treated this early are usually able to develop communication skills (using spoken or sign language) that are as good as those of hearing peers. Because of a federal law (the Individuals with Disabilities Education Act), children with a hearing loss between birth and 3 years of age have the right to receive interdisciplinary assessment and early intervention services at little or no cost. After age 3, early intervention and special education programs are provided through the public school system.

There are a number of treatment options available, and parents will need to decide which are most appropriate for their child. They will need to consider the child's age, developmental level and personality, the severity of the hearing loss, as well as their own preferences. Ideally a team of experts including the child's primary care provider, an otolaryngologist, a speech-language pathologist, audiologist and an educator will work closely with the parents to create an Individualized Family Service Plan. Treatment plans can be changed as the child gets older.

Children as young as 4 weeks of age can benefit from a hearing aid. These devices amplify sound, making it possible for many children to hear spoken words and develop language. However, some children with hearing loss are helped more than others by hearing aids. Some children with severe to profound hearing loss may not be able to hear enough sound, even with a hearing aid, to make speech audible. A behind-the-ear hearing aid is often recommended for young children because it is safer and more easily fitted and adjusted as the child grows as compared to one that fits within the ear.

Parents also will need to decide how their family and child are going to communicate. If the child is going to communicate orally (speech), he may need assistance learning listening skills and lip reading skills to help him understand what others are saying. Many children with hearing loss also need speech or language therapy.

A child also can learn to communicate using a form of sign language. The type preferred by most deaf adults is American Sign Language (ASL), which has rules and grammar that is distinct from English. There are also several variations of sign language that can be used along with spoken English.

Surgery may be recommended if a child has a permanent conductive hearing loss caused by malformations of the outer or middle ear, or by repeated ear infections. Although fluid in the middle ear usually results in only temporary hearing loss, chronic ear infection can cause a child to fall behind in language skills. In some cases, a doctor may suggest inserting a tube through the eardrum to allow the middle ear to drain. This procedure generally does not require an overnight hospital stay.

Surgery also may be an option for some children with severe to profound sensorineural hearing loss. A device

called a cochlear implant can be surgically inserted in the inner ear of children as young as 12 months of age to stimulate hearing. The surgery requires a hospital stay of one to several days. With additional language and speech therapy, children with cochlear implants may learn to understand speech and speak reasonably well, but the amount of improvement is variable.

#### **Does the March of Dimes support research on hearing loss?**

Several March of Dimes grantees are exploring the role that specific genes play in causing hearing loss, with the goal of developing treatments for hereditary hearing loss. Others are seeking to prevent hearing loss by preventing infections that can cause it and to improve treatment of individuals with hearing loss. One is developing improved hearing aids that amplify speech more clearly.

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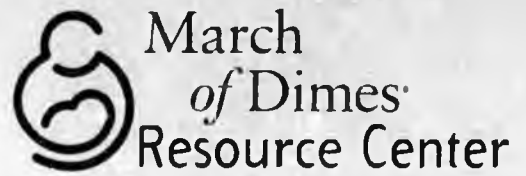
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# Newborn Screening Tests



Every state and U.S. territory now screens newborns for certain disorders of body chemistry. These birth defects have no immediate visible effects on a baby but, unless detected and treated early, can cause physical problems, mental retardation and, in some cases, death. A number of states are also screening babies for hearing loss.

Fortunately, most babies are given a clean bill of health when tested. But when test results are abnormal, early diagnosis and proper treatment can make the difference between lifelong impairment and healthy development.

Here are the answers to some common questions parents ask about newborn screening tests.

## **Which newborn screening tests are most likely to be given to my baby?**

All states and U.S. territories screen newborns for phenylketonuria (PKU). This was the nation's first newborn screening test. Developed with the help of the March of Dimes, it has been routinely administered since the 1960s. PKU affects about 1 baby in 12,000. Babies with the disorder cannot process a part of protein called phenylalanine, which is found in nearly all foods. Without treatment, phenylalanine builds up in the bloodstream and causes brain damage and mental retardation.

When PKU is detected early, mental retardation can be prevented by feeding the baby a special formula that is low in phenylalanine. This low-phenylalanine diet will need to be followed throughout adolescence and, generally, for life.

Women of childbearing age with PKU need to remain on this special diet prior to and during pregnancy. This will prevent mental retardation in their children by avoiding fetal exposure to high maternal phenylalanine levels.

Along with PKU testing, all states and U.S. territories test newborns for hypothyroidism, and most test for galactosemia. Congenital hypothyroidism is the most common disorder identified by routine screening. It affects about 1 baby in 4,000. Congenital hypothyroidism is a thyroid hormone deficiency that retards growth and brain development. If it is detected in time, a baby can be treated with oral doses of thyroid hormone to permit normal development.

Galactosemia, which affects about 1 baby in 50,000, can cause death in infancy, or blindness and mental retardation. A baby with galactosemia is unable to convert galactose, a sugar present in milk, into glucose, a sugar the body uses as an energy source. The treatment for galactosemia is to eliminate milk and all other dairy products from the baby's diet; this dietary restriction is lifelong.

You can find out which tests are routinely done in your state by asking your health care provider or state health department. You can also visit the website of the National Newborn Screening and Genetics Resource Center at <http://genes-r-us.uthscsa.edu/resources/newborn/state.htm>.

## **What other disorders can newborn screening tests detect?**

Currently, tests are available for over 30 inborn errors of body chemistry. Babies are not tested for all of these disorders for a number of reasons, including the fact that not all of these disorders are treatable. The March of Dimes would like to see all babies, in all states, screened for at least nine specific inborn errors of body chemistry including: PKU, congenital hypothyroidism, congenital adrenal hyperplasia (CAH), biotinidase deficiency, maple syrup urine disease, galactosemia, homocystinuria, sickle cell anemia, medium chain acyl-CoA dehydrogenase deficiency (MCAD), as well as hearing screening.

All of these disorders can be accurately diagnosed in newborns, and treatment is likely to improve the health of these children.

More than 40 states screen newborns for sickle cell anemia, an inherited blood disease that can cause bouts of pain, damage to vital organs such as the lungs and kidneys and, sometimes, death in childhood. Sickle cell anemia affects about 1 in 400 African-American babies and also occurs at a lower frequency among people of Hispanic, Mediterranean, Middle Eastern and South Asian descent.

Early treatment can prevent some of the complications of sickle cell anemia. Young children with the disease are especially prone to certain dangerous bacterial infections, such as pneumonia and meningitis. Studies in recent years

have shown that treatment with penicillin, beginning by 2 months of age and continuing to about 5 years, dramatically reduces the risk of these infections and the deaths that result from them. Newborn screening alerts the physician to begin antibiotic treatment before infections begin.

More than 25 states test for CAH. This group of disorders, in which there is a deficiency of certain hormones, affects genital development and, in severe cases, can disturb kidney function and cause death. Lifelong treatment with the missing hormones suppresses this disease, which occurs in about 1 in 5,000 babies.

One newborn screening test, developed by a March of Dimes grantee, detects biotinidase deficiency. About 20 states screen for this disorder. Biotinidase is an enzyme that recycles biotin, one of the B vitamins, in the body. A deficiency of this enzyme, which occurs in about 1 in 70,000 babies, may cause frequent infections, hearing loss, mental retardation and even death. If the deficiency is detected in time, problems can be prevented by giving the baby extra biotin.

Maple syrup urine disease and homocystinuria are rare life-threatening disorders that affect fewer than 1 baby in 250,000. About 20 states screen for maple syrup urine disease, and 15 for homocystinuria.

At least eight states are now testing for MCAD, a disorder that can cause sudden death in infancy and serious disabilities in survivors, such as mental retardation. MCAD affects about 1 baby in 15,000. Normally the body burns fat for energy when it runs out of stored sugar (glucose). Babies with MCAD cannot make this switch, so they may suddenly develop seizures, respiratory failure, cardiac arrest or go into a coma or get infections or other illnesses if they do not eat regularly. When diagnosed early, the disorder can be successfully treated with a steady food intake and avoidance of fasting.

About half of all states now screen newborns for hearing loss. Approximately 1 to 3 in 1,000 babies in well-baby nurseries and 2 to 4 in 100 in intensive care nurseries have significant hearing loss. Without testing, most babies with hearing loss are not

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diagnosed until 2 to 3 years of age. By this time, they often have delayed speech and language development. Detection of hearing loss in the neonatal period allows the baby to be fitted with hearing aids before 6 months of age. Recent studies show that this early intervention helps prevent serious speech and language problems.

#### **How are the tests for inborn errors of body chemistry and hearing loss done?**

Inborn errors of body chemistry are detected by a blood test. The baby's heel is pricked to obtain a few drops of blood for laboratory analysis. The same blood sample can be used to screen for a number of disorders. Usually, the baby's blood specimen is sent to a state public health laboratory for testing, and findings are sent to the health care professional responsible for the infant's care.

Babies are tested for hearing loss with one of two tests that measure how the baby responds to sounds. The tests use either a tiny soft earphone or microphone that is placed in the baby's ear. If either of these tests shows abnormal results, the baby may need more extensive hearing testing to see if he or she does have hearing loss.

#### **How soon after birth should screening tests be done?**

A blood specimen should be taken from every newborn prior to hospital release. Some of the tests (such as the one for PKU) may not give accurate results, however, if they are done too soon after birth. Because of early hospital discharge, some babies are tested within the first 24 hours of life. Because some cases of PKU can be missed when the test is performed this early, the American Academy of Pediatrics recommends that a repeat specimen be taken 1 to 2 weeks later from infants whose initial test was taken within the first 24 hours of life. Hearing tests are also usually performed before the baby is discharged from the hospital. Babies born outside the hospital should have newborn screening tests done before the 7th day of life.

#### **What does an abnormal test result mean?**

Parents should not be overly alarmed by abnormal test results, as the initial screening tests give only preliminary information that must be followed up by more precise testing. Most babies with abnormal thyroid screening test results, for example, prove normal in further testing, as do many with abnormal hearing test results.

#### **What should I do if my child is diagnosed with one of the conditions for which he was tested?**

Your child may need follow-up treatment at a pediatric center that specializes in children with inborn errors of body chemistry. It is essential for your child's healthy development that you follow the recommendations of his or her doctor. As your child grows, he or she will need careful, continued evaluations and monitoring.

#### **If one of my children has a disorder, will my other children also have it?**

When one child in a family has PKU, galactosemia, biotinidase deficiency, sickle cell anemia, CAH or MCAD, the chance of the same birth defect occurring in a sibling is 1 in 4. The chances remain the same with each pregnancy. Parents who have a baby with one of these disorders can discuss their risk of having another affected child with their health care provider or a genetic counselor.

These disorders are inherited when both parents have the same abnormal gene and pass it on to their baby. A parent who has the abnormal gene, but not the disease, is called a carrier. The health of a carrier is rarely affected.

Congenital hypothyroidism usually is not passed on through parents' genes. The siblings of those who have this disorder are seldom affected.

Hearing loss can be passed on through parents' genes. However, other causes of hearing loss, such as infections that are passed on to the baby during pregnancy or birth, are unlikely to recur in another pregnancy.

You also may wish to read these other March of Dimes Fact Sheets:

Hearing Loss  
PKU  
Sickle Cell Disease

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*Saving babies, together*

# Birth Defects

About 150,000 babies are born each year with birth defects. The parents of one out of every 28 babies receive the frightening news that their baby has a birth defect.

A birth defect is an abnormality of structure, function or metabolism (body chemistry) present at birth that results in physical or mental disability, or is fatal. Several thousand different birth defects have been identified. Birth defects are the leading cause of death in the first year of life.

## What causes birth defects?

Both genetic and environmental factors can cause birth defects. However, the causes of about 60 to 70 percent of birth defects currently are unknown.

A single abnormal gene can cause birth defects. Every human being has at least 30,000 to 35,000 genes that determine traits like eye and hair color, as well as direct the growth and development of every part of our physical and biochemical systems. Genes are packaged into each of the 46 chromosomes inside our cells.

Each child gets half its genes from each parent. A person can inherit a genetic disease when one parent (who may or may not have the disease) passes along a single faulty gene. This is called dominant inheritance. Examples include achondroplasia (a form of dwarfism) and Marfan syndrome (a connective tissue disease). Many other genetic diseases are inherited only when both parents (who do not have those diseases) happen to carry the same abnormal gene and pass it on to a child. This is called recessive inheritance. Examples include Tay-Sachs disease (a fatal disorder seen mainly in people of European Jewish heritage) and cystic fibrosis (a fatal disorder of lungs and other organs, affecting mainly Caucasians). There also is a form of inheritance (X-linked) where sons can inherit a genetic disease from a mother who carries the gene (usually with no effect on her own health). Examples include hemophilia (a blood-clotting disorder) and Duchenne muscular dystrophy (progressive muscle weakness).

Abnormalities in the number or structure of chromosomes can cause numerous birth defects. Due to an error that occurred when an egg or sperm cell was

developing, a baby can be born with too many or too few chromosomes, or with one or more chromosomes that are broken or rearranged. Down syndrome, in which a baby is born with an extra chromosome 21, is one of the most common chromosomal abnormalities. Affected children have varying degrees of mental retardation, characteristic facial features and, often, heart defects and other problems. Babies born with extra copies of chromosome 18 or 13 have multiple birth defects and usually die in the first months of life.

Missing or extra sex chromosomes (X and Y) affect sexual development and may cause infertility, growth abnormalities, and behavioral and learning problems. However, most affected individuals have essentially normal lives.

Birth defects also may result from environmental factors such as drug or alcohol abuse, infections, or exposure to certain medications (such as the acne drug Accutane) or other chemicals. Many birth defects appear to be caused by a combination of one or more genes and environmental factors (called multifactorial inheritance). Some examples include cleft lip/palate, clubfoot and some heart defects.

## What are some common types of birth defects?

Birth defects generally are grouped into three major categories: structural/metabolic, congenital infections, and other conditions.

### • Structural/metabolic abnormalities

When a baby has a structural birth defect, some part of the body (internal or external) is missing or malformed. Heart defects are the most common type of structural birth defect, affecting one baby in 125. While advances in surgery have dramatically improved the outlook for affected babies, these remain the leading cause of birth defect-related infant deaths. Doctors usually do not know what causes a baby's heart to form abnormally, although genetic and environmental factors are believed to play a role.

Spina bifida (open spine, in which the backbone never completely closes and the spinal cord is usually malformed) affects one in 2,000 babies. Affected babies suffer varying degrees of paralysis, and bladder and bowel problems.

Both genetic and nutritional factors appear to play a role.

About one baby in 135 has a structural defect involving the genitals or urinary tract. These vary greatly in severity, ranging from abnormal placement of the urinary opening in males (hypospadias) to absence of both kidneys. The cause of hypospadias, which is surgically correctable, is unknown. Babies who lack both kidneys die in the first hours or days of life. This tragic defect is sometimes inherited.

Metabolic disorders affect one in 3,500 babies. These disorders are not visible, but can be harmful or even fatal. Most are recessive genetic diseases. These diseases result from the inability of cells to produce an enzyme (protein) needed to change certain chemicals into others, or to carry substances from one place to another. An example is Tay-Sachs disease. Affected babies lack an enzyme needed to break down certain fatty substances in brain cells. These substances build up and destroy brain cells, resulting in blindness, paralysis and death by age five. Phenylketonuria (PKU) is another metabolic disorder, in which affected babies cannot process a part of protein, which builds up in blood and causes brain damage. PKU is routinely detected with newborn screening tests, so affected babies can be placed on a special diet that prevents mental retardation.

### • Congenital infections

Rubella (German measles) probably is the best known congenital infection that can cause birth defects. If a pregnant woman is infected in the first trimester, her baby has a one-in-four chance of being born with one or more features of congenital rubella syndrome (deafness, mental retardation, heart defects, blindness). Fortunately, with widespread vaccination, this syndrome is now rare in this country.

The most common congenital viral infection is cytomegalovirus (CMV). About 1 percent (40,000 babies a year) of all newborns in this country are infected, although only about 10 percent of them (3,000-4,000) have serious consequences, including mental retardation, and loss of vision and hearing. Pregnant women often acquire CMV from young children, who usually have few or no symptoms.

Sexually transmitted infections in the mother also can endanger the fetus and newborn. For example, untreated syphilis can result in stillbirth, newborn death, or bone defects. About one baby in 2,000 is affected.

• *Other causes*

Other causes of birth defects include fetal alcohol syndrome, which affects one baby in 1,000. This pattern of mental and physical birth defects is common in babies of mothers who drink heavily during pregnancy. Even moderate or light drinking during pregnancy can pose a risk to the baby.

Rh disease of the newborn, which is caused by an incompatibility between the blood of a mother and her fetus, affects about 4,000 infants a year. It can result in jaundice (yellowing of the skin), anemia, brain damage and death. Rh disease usually can be prevented by giving an Rh-negative woman an injection of a blood product called immunoglobulin at 28 weeks of pregnancy and after the delivery of an Rh-positive baby.

Babies of mothers who use cocaine early in pregnancy may be at increased risk of birth defects. A large study has suggested that these babies are five times more likely to be born with urinary tract defects than babies of women who don't use cocaine.

### **Can birth defects be prevented?**

While the causes of most birth defects are not known, there are a number of steps a woman can take to reduce her risk of having a baby with a birth defect. One important step is a pre-pregnancy visit with her health care provider. During this visit, the provider can obtain valuable information about a woman or couple's family history, which may help identify risk factors for birth defects or inherited genetic conditions. This information allows for appropriate testing and screening to be offered prior to or during pregnancy. During a pre-pregnancy visit, providers also can take a good look at a woman's health and lifestyle, and guide her in any changes that could improve her chances of having a healthy baby.

A pre-pregnancy visit is especially crucial for women with medical problems like diabetes, high blood pressure, and epilepsy, which can affect pregnancy. For example, women with poorly controlled diabetes are several times more likely than women without diabetes to have a baby with a serious birth defect. However, if their blood sugar levels are well controlled starting before pregnan-

cy, they are almost as likely to have a healthy baby as women without diabetes.

If a woman has never had chickenpox (and has not been vaccinated), a pre-pregnancy visit is a good time to check whether she should be vaccinated prior to pregnancy. Like rubella, chickenpox can cause birth defects when contracted by the pregnant woman, although the risk is low. If she has not been vaccinated against rubella since childhood, she should ask her doctor about the rubella vaccine or a combination vaccine such as measles-mumps-rubella (MMR). She should avoid pregnancy for one month after chickenpox, rubella or MMR vaccination.

All women who could become pregnant should take a daily multivitamin containing 400 micrograms of the B-vitamin folic acid. Studies show that taking this vitamin prior to and in the early weeks of pregnancy reduces the risk of having a baby with certain birth defects of the brain and spine, including spina bifida. If a woman already has had a baby with one of these birth defects, she should consult her doctor prior to pregnancy about how much folic acid to take. Generally, a higher dose, 4 milligrams, is recommended.

A woman who is pregnant or planning pregnancy should avoid alcohol, smoking, and street drugs — these can cause birth defects and other pregnancy complications. She should not take any medication — prescription, over-the-counter, or herbal — without first checking with her health care provider.

### **Can some birth defects be diagnosed before birth?**

Some birth defects can be diagnosed before birth, using one or more prenatal tests including ultrasound, amniocentesis and chorionic villus sampling (CVS). Ultrasound can help diagnose structural birth defects, such as spina bifida, heart and urinary tract defects. Amniocentesis and CVS are used to diagnose chromosomal abnormalities, such as Down syndrome. They also can detect, or rule out, numerous genetic birth defects that may be suspected because of family history or ethnic background.

### **Can birth defects be treated before birth?**

A small percentage of couples will learn through prenatal diagnosis that their baby has a birth defect. While this news can be devastating, prenatal diagnosis sometimes can improve the outlook for the baby. Advances in prenatal therapy now make it possible to treat some birth defects before birth. For example,

biotin dependence and methylmalonic acidemia — two life-threatening inherited disorders of body chemistry — have been diagnosed by amniocentesis and treated in the womb, resulting in the births of healthy babies.

Prenatal surgery has saved babies with urinary-tract blockages, rare tumors of the lung, and congenital diaphragmatic hernia (a hole in the muscle that separates the chest from the abdomen). More than 100 babies have undergone experimental prenatal surgery to repair spina bifida before birth. Preliminary results appear promising: fewer babies who have had surgery for spina bifida require shunts to drain fluid from their brain. However, it is too soon to know how well most of these babies will walk, and the procedure leads to preterm birth. Prenatal blood transfusions have saved numerous babies with severe Rh disease, and heart medications given to the pregnant woman have saved babies with serious heart rhythm disturbances. However, even when a fetus has a condition for which prenatal treatment is not yet possible, prenatal diagnosis permits parents to prepare themselves emotionally, and to plan with their provider the safest timing, location and method of delivery.

Couples who have had a baby with a birth defect, or who have a family history of birth defects, should consider consulting a genetic counselor. These health professionals help families understand what is known about the causes of a birth defect, and the chances of the birth defect recurring in another pregnancy. Genetic counselors also can provide referrals to medical experts as well as to appropriate support groups.

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*Disability & Special Ed.  
Benarsi Lal.*

**FY06 Legislative Priorities**

**Fiscal Plan**

Home and community-based services funded by Medicaid and state grants enable Alaskans with severe disabilities to live independently and become productive, gainful members of their communities. In an economy where the source of revenues is unpredictable, Alaskans with severe disabilities, whose independence and productivity is linked to government supports, are at risk for negative, unpredictable life changes.

Recommendation: The Council urges the Legislature to meet the needs of Alaskans with disabilities by developing a consistent revenue stream for supports and services as a part of a long range fiscal plan.

**Dental Services**

Governor Murkowski will introduce legislation to expand Medicaid coverage for adult recipients that will include preventive and restorative dental services. Proposed coverage will be capped at \$1,150 annually. The Alaska Mental Health Trust Authority has agreed to contribute \$5.4 million over five years toward the costs of dental services for Trust beneficiaries. In FY03, costs of emergency dental care totaled \$2.2 million. Over time, the State's investment, coupled with the Trust funded donated dental and dental training programs, will significantly reduce the cost for emergency dental services.

Recommendation: The Council urges adoption of the Governor's legislation to include adult preventive dental coverage under Medicaid.

**Bring the Kids Home**

At any given time approximately 400 children are served in costly out-of-state placements. Governor Murkowski's initiative will develop a support system within the state to allow Alaskan children to receive services near their homes and families. State expenditures will decrease as children are moved home and supported in their communities. The Council recommends that all cost savings realized in this initiative be reinvested in Keeping Kids Home.

Recommendation: The Council urges the legislature to support the Governor's Bring the Kids Home Initiative.

Disability & Specialty Ed  
Banarsi Lal.

## **Additional Legislative Recommendations**

### **Grant dollars for DD services**

Investing general fund dollars in DD community grants will save the state money. Grant-funded services are generally low-cost and if provided at the right time, help keep families together and avert high-cost crisis situations. Although some services were one-time services or did not completely meet people's needs, in FY02 the average cost of grant-funded services was \$6,683 compared to the State's share (\$32,500) of a waiver.

Recommendation: The Council urges that the legislature increase general fund dollars for DD community grants.

### **Capital Funding for Assistive Technology and Home Modifications**

The Governor's budget includes \$300,000 for assistive technology and home modifications that will enable the Division of Vocational Rehabilitation to get more Alaskans to work.

Recommendation: The Council urges that this capital request be funded.

### **→ Universal Newborn Hearing Screening**

Using national incidence rates, the Department of Health & Social Services estimates that congenital hearing loss is likely to be present in 30 of the 10,000 babies born annually. Thirty-eight (38) states have passed UNHS legislation. The average lifetime costs in present dollars for persons with hearing loss are estimated to be \$417,000 (CDC 2004). With appropriate early intervention, children with hearing loss can learn and progress at a rate similar to children with normal hearing, underscoring the importance of early diagnosis and intervention (Yoshinaga-Itano, 2003). In addition, early intervention for children with hearing loss has been associated with higher language development scores and newborn hearing screening is projected to be cost-effective because of anticipated gains in lifetime earnings. (CDC, 2004)

Recommendation: The Council urges passage of UNHS legislation.

### **Increase in Formula Funding and Two-Year Funding Cycle for Education**

This initiative will allow school districts to know how much funding they can rely on, which will help them retain staff. The increase in formula funding will allow them to better address student needs throughout Alaska.

Recommendation: The Council urges that school formula funding be increased and that education be funded on a two-year cycle.

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**Representative Tom Anderson**  
**Chairman, House Labor and Commerce**  
**19th House District**

**Fax: (907) 465-2418**

**Re: House Bill 109**

February 1, 2005

Dear Representative Anderson:

I am writing to ask for your support of House Bill 109 ("related to screening Newborns for Hearing Ability"), sponsored by Rep. Jay Ramras. This bill will be coming before your Labor and Commerce committee on Friday, February 4 and I will be offering testimony by telephone. I am a pediatrician in private practice in Anchorage with 26 years of experience. I also serve as the Alaska Chapter Champion for the Early Hearing Detection and Intervention Program for the American Academy of Pediatrics. The American Academy of Pediatrics supports the development of programs in each state for universal screening of all infants for hearing deficits at or soon after birth in order to allow for early identification and intervention of hearing impaired children in order to maximize their potential. There are several reasons that this program is important:

1. Hearing loss is one of the most common birth defects. One in 3000 infants are born in Alaska with permanent congenital hearing loss. Without universal newborn hearing programs, the average age of detection of even severe hearing loss is 2-3 years old
2. Hearing loss has a significant negative effect on children. This would seem obvious but many studies indicate the negative impact of hearing loss on a child's emotional and social development as well as language delays that do not seem to progress even after diagnosis, in some children, when that diagnosis is delayed. Even mild and unilateral hearing loss - problems that often defy detection much longer without an objective early hearing screen - may have long lasting negative effects to the child.
3. Early detection and intervention of hearing deficits significantly helps children. Numerous studies show that when children are diagnosed with hearing loss and appropriate intervention to augment hearing and provide appropriate communication options are started early in life, preferably before 6 months of age, significant and long lasting benefits are achieved by the children in language skills, emotional development, social and familial adjustment.

In order to achieve these benefits for children and their families, there are several steps that must occur that are benchmarks for a successful early hearing detection and intervention program and each of these can be greatly aided by HB 109 as written:

1. Universal hearing screen for all newborns - This first step is already nearly achieved in Alaska. Due to new advancement in screening technology almost all birthing hospitals either are or soon will be screening newborns for hearing loss. By allowing non-audiologists to administer the screen and bill appropriately for this service, and asking insurance companies to cover this "standard of care" evaluation, all infants in the state can have this evaluation before they leave the hospital or birthing facility.
2. When a hearing screen is failed, they are referred for evaluation - This step may have one or two parts. A child who fails the initial screen is referred for re-screen and if still abnormal, diagnostic intervention is performed by 3 month of age. Each institution and/or the infant's medical provider

● Page 2

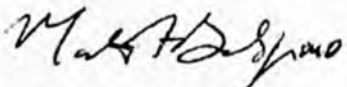
February 1, 2005

are responsible for this step. The failure to return for re-screening or for diagnostic testing markedly reduces the effectiveness of the entire program. With the tracking provision of your bill, information will be shared with a state program that can make sure that each infant that needs further intervention have this option provided for them. Without a state mandate, this information will have to be shared voluntarily between institutions, which will allow for some institutions to ignore this critical step. Diagnostic intervention involves testing called auditory brainstem response testing (ABR) which is only done by audiologists trained in this procedure.

3. Once diagnosed, in order to receive maximum benefit, parents should be presented with communication options and intervention should begin before 6 months of age. These options may include hearing aids (which are accepted by infants much better if started in early infancy), and various communication options including sign language and other visual cues. The parents and the infant's medical provider must serve as a medical home and have information to make appropriate referrals for subspecialty evaluation and community based resources in accordance with the Individuals with Disabilities Education Act.

I would appreciate your support for HB 109 which will assure that our youngest Alaskans have the opportunity to have this most common, but invisible, birth defect diagnosed early with appropriate intervention that will offer long term benefits for their future. If I can be of any assistance, please let me know.

Sincerely,



Martin F. Beals, Jr., M. D., FAAP  
Alaska AAP Chapter Champion, EHDI program

Suzanne Rust  
7930 Ingram Street  
Anchorage, Alaska 99502  
907-243-3160

February 1, 2005

Representative Tom Anderson  
Special Assistant Health and Human Services  
State Capitol  
Juneau, Alaska 99801-1182

Dear Representative Anderson:

I want to take this opportunity to tell you about Lauren, my 12-month-old daughter. Besides being a marvelous girl, she happens to be hard of hearing. Providence Hospital's New-Born Screening identified Lauren's condition at birth. Although it took us 13 weeks of hard work to verify that she has a hearing loss, the screening was essential. Since she is hard of hearing, we may not have detected her loss until her language was affected. We would have lost the opportunity for laying a solid foundation of speech and language development.

I am contacting you today because I would like you to support House Bill 109 which requires universal hearing screening for new-born infants and mandatory reporting by birthing facilities of the hearing screening results to the State of Alaska's Early Hearing Detection and Intervention Program. This will ensure that children with possible hearing loss receive a timely diagnostic evaluation and, if necessary, are enrolled in early intervention services at the earliest possible time. The reasons I believe this bill should be whole-heartedly supported are many but I will list a few:

- Hearing impairment is the most common disability in newborns.
- The low cost of screening is minimal when compared to the additional hundreds of thousands of dollars the state may have to spend in special education.
- The most important period of speech and language development is from birth to age three. The average age of identification in the absence of the newborn hearing screening is 2-3 years.
- Children with hearing loss can develop and progress like those without hearing loss if they are identified early.

Because Lauren was identified in the screening process, she has had hearing aids since she was three months old. Her language and speech seem to be on track and, thankfully, she has been able to hear my voice. Please join me in assuring that everyone's child gets the same chance for success Lauren received. Thank you in advance for your support.

Sincerely,

Suzanne Rust

## **FACT SHEET:**

### **Universal Newborn Hearing Screening (UNHS)/Early Hearing Detection & Intervention (EHDI)**

1. Every day, 33 babies (or 12,000 each year) are born in the United States with permanent hearing loss, or 3 in every 1,000 births (1). In Alaska, approximately 10,000 babies are born each year and according to statistics 30-40 will likely have some type of congenital hearing loss.
2. The evidence for the benefits, practicability, and cost-efficiency of universal newborn hearing screening is so compelling that 37 states have passed legislative mandates requiring that newborns be screened for hearing loss (2).
3. Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome, and severe mental retardation (3).
4. Hearing impairment is approximately 30 times more prevalent than PKU and hypothyroidism, screened through the metabolic disorder screening programs, and mandated by law in all 50 states. (4).
5. The cost of identifying a newborn with hearing loss is less than 1/10<sup>th</sup> the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state (5). For most birthing hospitals, the cost for newborn hearing screening per child is between \$20 - \$60 and continues to decrease (6). Many birthing facilities in Alaska implementing newborn hearing screening voluntarily include it in the total labor and delivery package cost.
6. Children not detected at birth or soon after, will on average not be detected until 2-3 years of age, and the most critical period for speech and language development is from birth to three years of age (7).
7. When children are not identified and served early, special education for a child with hearing loss may cost an additional \$420,000, and deafness has an estimated lifetime cost of approximately \$ 1 million per individual (8). These savings in special education costs will pay for universal newborn hearing screening many times over.
8. If left undetected, hearing loss can impair a child's language, speech, psychosocial and cognitive development. Recent research has compared children with hearing loss who receive early intervention and amplification (i.e. hearing aids) before 6 months of age versus after 6 months of age. By the time they enter first grade, children identified earlier (prior to 6 months of age) are 1-2 years ahead of their later-identified peers in language, cognitive, and social skills (9, 10, 11).

9. If it remains undetected, even mild hearing loss or hearing loss in only one ear has substantial detrimental consequences. For example, research shows that children with hearing loss in one ear are ten times as likely to be held back at least one grade compared to a matched group of children with normal hearing (12).
10. The American Academy of Pediatrics, the National Institutes of Health, the American Academy of Audiology, the Joint Committee on Infant Hearing, and the National Association of the Deaf have recommended that all babies be screened for hearing loss before they leave the hospital (13).
11. To date, 23 of 23 communities within Alaska have implemented universal newborn hearing screening programs. The majority of screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screen during home visits after hospital discharge (14).

**Representative Jay Ramras**  
**Co-Chair, House Resources**  
**V-Chair, Economic Develop.**  
**Tourism & Trade**

**House State Affairs**  
119 N. Cushman St. Suite 207  
Fairbanks, Alaska 99701  
Phone: (907) 452-1088  
Fax: (907) 452-1146

## Alaska State Legislature



While in Session  
**State Capitol, Room 104**  
**Juneau, Alaska 99801-1182**  
(907) 465- 3004  
Fax: 465-2070  
Toll Free: (877) 465-3004

**House District 10**

### House of Representatives

## MEMO

To: Representative Tom Anderson, Chair Labor & Commerce

Fm: Jane Pierson *JWP*

Cc:

Date: January 26, 2005

Re:

---

Please accept this Memo as a request for the House Labor & Commerce Committee to hear HB 109. "An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening tests; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date." HB 109 will protect newborns in Alaska by mandating that infants receive hearing screening at birth, and that follow-up is provided for at risk infants.

Thank you in advance for scheduling HB 109 before the House Labor & commerce Committee.

Attachments: Sponsor Statement, HB 109, AS 08.11.120(b), AS 21.42, AS 47.20, Why is Mandatory Newborn Hearing and Screening and Reporting So Important?, Alaska Early Hearing Detection & Intervention Program Overview, Goal of Alaska Early Hearing Detection & Intervention Program (EHDI) – Overview, Locations of Newborn Hearing and Screening Hospitals, March of Dimes - Hearing Loss, March of Dimes – Newborn Screening Tests, March of Dimes – Birth Defects, and The Governor's Council on Disabilities and Special Education – FY06 Legislative Priorities.

**Representative Jay Ramras**  
**Co-Chair, House Resources**  
**V-Chair, Economic Develop.**  
**Tourism & Trade**

**House State Affairs**  
119 N. Cushman St. Suite 207  
Fairbanks, Alaska 99701  
Phone: (907) 452-1088  
Fax: (907) 452-1146

# Alaska State Legislature



While in Session  
**State Capitol, Room 104**  
**Juneau, Alaska 99801-1182**  
(907) 465-3004  
Fax: 465-2070  
Toll Free: (877) 465-3004

**House District 10**

## House of Representatives

### MEMO

To: Josh Applebee

Fm: Jane Pierson

Cc: LIO

Date: January 31, 2005

Re: L&C Testimony on HB 109

The following people are expected to testify concerning HB 109 before the Labor & Commerce Committee on February 4, 2005.

- Millie Ryan, The Governor's Council on Disabilities – in person
- Martin Beals, Jr., M.D., Pediatrician – LIO in Anchorage
- Debbie Golden, March of Dimes – LIO in Anchorage
- Lisa Owens, Audiologist – LIO in Anchorage
- Susan Walker, Parent - LIO in Anchorage

The information contained in this memo is **CONFIDENTIAL** and/or privileged. This memo is intended to be reviewed initially by only the individual named above. If the reader of this page is not the intended recipient or a representative of the intended recipient, you are hereby notified that any review, dissemination, or copying of this memo or the information contained herein is prohibited. If you have received this memo in error, please immediately notify the sender by telephone and return this memo to the sender at the above address.

**Thank you**

**Testifiers for the 2/4/05 House Labor & Commerce Meeting for the HB 102 Hearing**

- Jim Jordan, Executive Director of the Alaska State Medical Board
- Dr. George Stewart

Both these gentleman will be testifying via teleconference from Anchorage.

Jean Michel  
IPG  
2/16/05, 4:07 p.m.

CSHB 109(L&C) Version "F" page 3, lines 9-24:

Sec. 5. AS 21.42 is amended by adding a new section to read:

**Sec. 21.42.349. Coverage for newborn and infant hearing screening.** (a) If a health care insurer offers, issues for delivery, delivers, or renews in this state a health care insurance plan that covers services provided to women during pregnancy and childbirth and the dependents of a covered individual, including routine newborn care, the health care insurer ~~must~~ <sup>shall</sup> comply with the requirements of this subsection.

(1) <sup>Provide</sup> ~~The health care insurer may not deny~~ coverage for a newborn or infant screening to be performed within 30 days after the child's birth; and

(2) If the initial screening under (1) of this section determines that the child may have a hearing impairment, the plan <sup>shall provide</sup> ~~may not deny~~ coverage for a confirmatory hearing diagnostic evaluation.

(b) The coverage required by this section may be subject to standard policy provisions, such as deductible or copayment provisions.

<+it are applicable to other benefits>

**Rationale:** (a): Deletes exception for fraternal benefit societies. Because the intent of the bill is to assure that 100% of newborns are screened, no sources of payment should be excluded from the requirements. (a)(1) through (b): Under current practice, any costs for the initial screening are typically included in the hospital or other facility's charge for newborn care or in the physician or other practitioner's charge for routine follow-up care. Diagnostic tests, including hearing examinations, are covered under existing medical benefits. The amendment changes the bill language to reflect standard practice and health plan design.

# FISCAL NOTE

**STATE OF ALASKA**  
**2005 LEGISLATIVE SESSION**

Fiscal Note Number: \_\_\_\_\_  
 Bill Version: HB109-DHSS-DPH-02-04-05  
 ( ) Publish Date: \_\_\_\_\_

Revision Date/Time (Note if correction): 02/04/05 8:00 AM Dept. Affected: Health & Social Services

Title: RELATING TO NEWBORN HEARING SCREENING, AUDIOLOGISTS, AND INSURANCE RDU Public Health  
 Component: Women, Children and Family Health

Sponsor: RAMRAS

Requester: HOUSE (L&C) Component No. 2788

**Expenditures/Revenues (Thousands of Dollars)**

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims	31.9	39.4	47.4	55.8	64.6	64.6
Miscellaneous						
<b>TOTAL OPERATING</b>	<b>31.9</b>	<b>39.4</b>	<b>47.4</b>	<b>55.8</b>	<b>64.6</b>	<b>64.6</b>

<b>CAPITAL EXPENDITURES</b>						
-----------------------------	--	--	--	--	--	--

<b>CHANGE IN REVENUES (0)</b>						
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**FUND SOURCE (Thousands of Dollars)**

1002 Federal Receipts			( 29.7)	( 111.6)	( 115.9)	( 119.8)
1003 GF Match						
1004 GF	31.9	39.4	77.1	167.4	180.5	184.4
1037 GF/Mental Health						
Other(Specify Type-do not abbreviate)						
Other(Specify Type-do not abbreviate)						
<b>TOTAL</b>	<b>31.9</b>	<b>39.4</b>	<b>47.4</b>	<b>55.8</b>	<b>64.6</b>	<b>64.6</b>

Estimate of any current year (FY2005) cost: \_\_\_\_\_

Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

**POSITIONS**

Full-time						
Part-time						
Temporary						

**ANALYSIS:** (Attach a separate page if necessary)

The intent of this bill is to ensure all newborns are provided with hearing screening within 30 days of their birth, and that those identified with a positive screen or high risk factors receive a second screen or diagnostic work-up, are enrolled in early intervention and receive treatment as needed. Projected costs associated with maintenance of the Early Hearing Detection and Intervention program (EHDI) are based on the following assumptions: 1) The number of newborns screened is based on the average number of births currently at 10,000 per year. 2) The diagnostic rate of hearing loss is estimated to be at 0.3% of the 10,000 births=30 newly diagnosed infants per year, however, not all newborns with hearing loss will be immediately identified. 3) 90% of newborns would be screened by FY 06; 95% by FY 07; and 100% by FY 08 and beyond. (Continued on P.2)

Prepared by: Richard Mandsager, M.D.  
 Division: Public Health  
 Approved by: Joel S. Gilbertson, Commissioner  
 Agency: Department of Health and Social Services

Phone 465-3090  
 Date/Time 02/02/2005  
 Date 02/04/2005

FISCAL NOTE

FN #

STATE OF ALASKA  
2005 LEGISLATIVE SESSION

BILL NO. HB109-DHSS-DPH-02-04-05

**ANALYSIS CONTINUATION**

4) There is a need to follow an additional 10% of all newborns each year who are at high risk for later onset hearing loss during their first three years of life. Thus, the program requires a reporting and surveillance system for tracking all newborns and assisting them with ongoing hearing screening, diagnostic and intervention services. 5) The department is proposing elimination of Sec. 47.20.310 (g). It is not possible on this short notice to determine the increased cost to the department of the mandate included in (g), and therefore this fiscal note assumes that subsection (g) is deleted.

At present the Division of Health Care Services is receiving two federal grants to support the development of this program. One grant, scheduled to be completed in March of FY 05, covers the expenses associated with development of the newborn hearing program, including assisting hospitals with implementation and education, and professional and public educational information. The second grant will end in August of 2005 and covers start up costs associated with the statewide early detection/intervention surveillance and tracking system. Both grants have been submitted for continuation funding for three additional years. This would provide funds for infrastructure costs through FY 08 if awarded.

The increased line item expenditures shown on page 1 will be utilized for:

GRANTS AND CLAIMS (\$31.9 in FY 06): Additional funds for special hearing resources would be needed for the existing Early Prevention/ILP programs to work with the anticipated increased volume as children are identified earlier and thus require services during the 0-3 period. The additional grant funds would be awarded incrementally over the next five fiscal years to allow for increased capacity-building to support special hearing services for children identified with hearing loss in preparation for school readiness and learning. The dollar figure is based on:

1) An average FY 05 cost of \$3,100 per newly enrolled infant, with a 3% inflation factor built in annually. 2) Only assumes about 50% of the newly diagnosed infants would enroll in the early intervention hearing resources program (10 new infants in FY 06; 12 in FY 07; 14 in FY 08; 16 in FY 09; and 18 in FY 10 and FY 11).

The General Funds replacing Federal Funds (and so not shown as line item expenditures on page 1) will be allocated by cost category as follows:

PERSONAL SERVICES (\$72.0 in FY 09, assumes a 3.5 percent annual merit increase thereafter):

a) 0.5 FTE - EHDI Health Program Manager II (R/19). This position oversees the maintenance of the reporting and surveillance activities of the program, assures early intervention referrals, tracks high-risk infants through the age of 3, provides outreach education to providers, and technical assistance to health care facilities throughout the state.

b) 0.5 FTE - Administrative Clerk III (R/10). This position provides administrative support and data entry for the activities required for maintenance of a statewide newborn hearing screening program.

TRAVEL (\$1.0 in FY 08): Travel costs are included for the EHDI manager to visit screening sites for TA and program compliance. Additional travel funds would be required in FY 09 with the termination of federal funding.

SUPPLIES (\$1.0 in FY 08): This includes the cost of postage to mail brochures and technical assistance resources.

CONTRACTUAL (\$27.7 in FY 08): Includes the actual cost of supporting web-based data and surveillance system. Cost averages at \$3.00 per newborn. Costs also include those needed for the reprinting of educational materials for parents and providers.

Hello my name is Pam Mueller-Guy. I was born as a hearing child. However, I had to have a blood transfusion from a stranger when I was five days old, due to my rare blood type. Due to this blood transfusion, I became deaf, but no one realized it till I was about 2 years old.

Even as a toddler, I could speak a little bit and mimicked by brother while playing with toys. My grandmother finally figured out that I could not hear, realizing I never responded when they called my name. Only when a loud noise occurred, such as a stomp on the floor, did I look their way.

They finally took me to have a hearing test and I was diagnosed with severe profound nerve deafness. They were in shock and wept for me because they didn't know what to do. They asked, "How can she can hear music?" My whole family is musical! They had grief until they realized I could experience music.

My mother wrote letters to all the important people that know about deafness and to the John Tracy clinic in California. They gave a lot of info and said it was needed for parent to work with me and go to school half-day to learn how to work with me.

I started speech classes at 2 1/2 years old then started wearing hearing aids at 3 1/2 years old and started half days till four years old to stay at boarding parents house during the week because deaf school was 25 miles away from my home.

I hope for the new generation that they can be diagnosed early and begin to learn early so they may be capable of writing English easy instead of the hard way. I see most deaf and hard of hearing have a hard time in alaska for jobs. Schools also should have programs specifically for children who are deaf so they won't be isolated. I am hopeful children who are deaf will be able to communicate in both the hearing world and the deaf world.

The newborn hearing screen would be best for all needs so the parents of the baby can start early to learn to cope with the child and their lives would be easier!

one hearing aid  
3 1/2 - 6th grade  
two hearing aids

6 grade to 9th grade  
Then behind (BTE)  
the ear rest of life present

Reason hold me back other deaf students  
to be w/ other deaf students  
hard to make friends  
all over again back when hold me back

They hold me back 4th grade

Also hold me back in 7th grade half time half time in deaf school then 7-8-8-9 full 9th



# Alaska State Legislature

Please enter into the record my testimony to the House HESS Committee  
Committee name

Committee on HB 109 dated 17 February 2005  
Bill/Subject

I would like to write in support of HB 109. The Grange, the organization I belong to, has supported mandatory infant hearing screening since 1999. I have 2 children of my own and know firsthand how important the first years of life are in language development.

Early identification and intervention of hearing loss is so very important. I consulted the National Center for Hearing Assessment and Management website, infanthearing.org, and learned that 2-4 babies per 1000 screened at birth had permanent congenital hearing loss. Alaska's babies deserve early identification and care. Please help Alaska join the 32 other states that have enacted legislation for Newborn Hearing Screening.

Signed: Lou Bisset  
Testifier

Northland Pioneer Grange No. 1  
Representing (Optional)

P.O. Box 2304 Palmer  
Address

746-4900  
Phone number



# ALASKA PUBLIC HEALTH ASSOCIATION

Committed To Advancing Alaska's Public Health Since 1978

February 17, 2005  
(H) HESS HB 109

## IN SUPPORT OF HB 109 "SCREENING NEWBORNS FOR HEARING ABILITY"

Dear members of the (H)HESS Committee:

On behalf of the Alaska Public Health Association, representing two hundred and twenty public health professionals who are deeply committed to developing sound public health policy to improve the health of all Alaskans, we encourage you to vote yes on HB 109 and move it out of Committee today.

Recognizing the importance of universal hearing screening of newborns as a critical public health intervention, the Alaska Public Health Association encourages you to support HB 109. Hearing impairment is the most common disability in newborns, impacting 2-3 children out of every thousand. Identified early, these children will not be left behind during the most critical period for speech and language development: birth to 3 years.

Late identification of infant hearing loss presents a significant public health problem. Without screening, children with hearing loss are usually not identified until two years of age or later, which results in significant delays in speech, language, social, cognitive, and emotional development -- and a greater cost for services.

Research has shown that children identified at birth with mild-to-severe hearing loss who receive intervention before they are 6 months of age fall within a normal range of language comprehension and expression as well as social development by the time they are ready to begin school. By contrast, children with hearing loss diagnosed after six months of age experience significant delays in both language and social development. The cost savings of early intervention is significant.

HB 109 offers an important first step in providing newborn hearing loss screening. Yet we urge you to not stop at the hospital or birth center, as what happens after screening is also important. Families need to receive appropriate information and services following newborn hearing screening and to have their children begin receiving intervention services by six months of age. It is also critical the team working with the child measure the impact of early identification of hearing loss on development, tracking gains made and areas to develop. The public health surveillance system must be in place for the Early Hearing Detection Program to be effective.

To quote from Dr. Marion Downs, the world-renowned pioneer in pediatric audiology, "If a child can be identified at birth and receive immediate intervention, we have done our jobs," she said. "On the other hand, if we don't detect the hearing loss until the child reaches 2 years of age or later, that child has, in most cases, lost the opportunity to catch up with others his or her own age. *Why, with all the tools we have, would we not speed the time to establish a model for screening and early intervention in our nation's hospitals?*" That is the challenge before us in Alaska.

HB 109 takes an important step in bringing forth universal hearing, building on the success of Alaska's hospitals and birthing centers who are already voluntarily screening, to assure all newborns will be screened. With appropriate screening and follow up services, HB 109 will assure our children who are deaf or hearing impaired receive the early intervention services they need to develop their fullest potential. Thank you.

Marie J. Lavigne, Executive Director Alaska Public Health Association

**Josh Applebee**

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**From:** Hilary Hardwick [hilaryh52@gci.net]  
**Sent:** Monday, February 07, 2005 12:20 PM  
**To:** Rep. Tom Anderson  
**Subject:** Pleas pass HB 109 - it is critical

Dear Rep Anderson,

It is critical to communication developed and early intervention that newborns be screened for hearing. So much can be done if caught early and the benefits for early intervention are significant - both to the child's development of communication skills but also in cost savings - much less is spent in remediation of problems when caught at birth than if one waits. You can consider a double or triple cost per year for every year intervention is delayed. Please pass this bill.

Hilary Hardwick, Speech-Language Pathologist - Anchorage

### **Mandated Benefits Added by the Legislature in the Last Ten Years**

- 42.345 Coverage of newly born children (federal requirement) (1975, amended in 1992, 1995, 1996, 1997)
- 42.347 Postpartum hospital stay coverage (federal requirement) (1996, amended in 1997)
- 42.353 Acupuncture coverage (offer only, does not mandate coverage) (1990, amended in 1995, 1996, 1997)
- 42.355 Coverage for services of midwives (1981, amended in 1995, 1996, 1997)
- 42.365 Substance abuse treatment coverage (1988, amended in 1996, 1997, 2002)
- 42.375 Mammography coverage (1991, amended in 1995, 1996, 1997)
- 42.380 Phenylketonuria (1992, amended in 1995, 1996, 1997)
- 42.385 Dental, Vision, Health coverage (offer only, does not mandate coverage) (1992, amended in 1996, 1997)
- 42.390 Coverage for diabetes treatment (2000, amended in 2002)
- 42.395 Prostate and cervical cancer screening (1996, amended in 1997, 2000)
- 42.400 Reconstructive surgery following mastectomies (federal requirement) (2000)

**Josh Applebee**

---

**From:** Kathleen Pampusch [askmp11@uaa.alaska.edu]  
**Sent:** Sunday, February 06, 2005 6:22 PM  
**To:** Rep. Tom Anderson  
**Cc:** Rep. Gabrielle LeDoux; Rep. Norman Rokeberg; Rep. Harry Crawford; Rep. David Guttenberg  
**Subject:** Newborn Screening Bill

Dear House Labor and Commerce Committee Member:

I am writing to urge you to support HB 109, the Newborn Hearing Screening Bill. In my former career, I was a service provider for individuals with developmental disabilities. Through this experience I learned that early diagnosis is vital. Once a disability is diagnosed, the child benefits from early intervention. The sooner the diagnosis, the better the benefit for the child.

I am counting on your support of Alaska's children!

Thank You,

Kathleen Pampusch  
Anchorage

Hello my name is Pam Mueller-Guy. I work for Southeast Alaska Independent Living as the Deaf Services & Interpreter Referral Coordinator. I am representing for SAIL in support for the Newborn Hearing Screening test, House Bill 109 and Senate Bill 68.

I was born as a hearing child. However, I had to have a blood transfusion from a stranger when I was five days old, due to my rare blood type. Due to this blood transfusion, I became deaf, but no one realized it till I was about 2 years old.

Even as a toddler, I could speak a little bit and mimicked by brother while playing with toys. My grandmother finally figured out that I could not hear, realizing I never responded when they called my name. Only when a loud noise occurred, such as a stomp on the floor, did I look their way.

They finally took me to have a hearing test and I was diagnosed with severe profound nerve deafness. They were in shock and wept for me because they didn't know what to do. They asked, "How can she can hear music?" My whole family is musical! They had grief until they realized I could experience music.

I started speech classes at 2 ½ years old then started wearing hearing aids at 3 1/2 years old and started half days till four years old to stay at boarding parents house during the week because deaf school was 25 miles away from my home.

I was held back in school twice due to my hearing disability. One time, just because they wanted to keep all the students who were deaf together in one grade. I had to make friends all over again.

If this bill is passed, it will also allow parents of newborn babies with hearing loss to get information immediately and begin preparing for life with a child who is deaf. It is difficult for organizations like SAIL to identify and assist persons who have hearing loss; a much better way to do this is to catch the baby and family at the beginning of life. I do not want to see people with hearing loss have to go the hard way like me.

I hope for the new generation that they can be diagnosed early and begin to learn early so they may be capable of writing English easy instead of the hard way. I see most deaf and hard of hearing have a hard time in Alaska for jobs. Schools also should have programs specifically for children who are deaf so they won't be isolated. I am hopeful children who are deaf will be able to communicate in both the hearing world and the deaf world.

The newborn hearing screen would be best for all needs so the parents of the baby can start early to learn to cope with the child and their lives would be easier! This bill will

save a lot of money for the government, schools, and insurance, including Medicaid, in the long run. Thank you for taking your time to listen to me. Keep passing those bills for better lives in Alaska!

## Josh Applebee

---

**From:** Phyllis Kiehl [pkiehl@pol.net]  
**Sent:** Friday, February 04, 2005 8:45 AM  
**To:** Rep. Tom Anderson  
**Subject:** HB 109, Hearing screening

Dear Rep. Anderson,

I am writing to ask you to support and vote for House Bill 109 ("related to screening Newborns for Hearing Ability. I am a pediatrician who has been in private practice in Anchorage for 30 years. The American Academy of Pediatrics supports the development of programs for universal screening of all infants for hearing deficits at or soon after birth. This enables early identification of hearing impaired children in order to be able to intervene to maximize their potential. This program is important because:

1. Hearing loss is one of the most common birth defects. One in 3000 infants are born in Alaska with permanent congenital hearing loss. Without universal newborn hearing programs, the average age of detection of even severe hearing loss is 2-3 years old. Hearing loss has a significant negative effect on children. This would seem obvious, but many studies indicate the negative impact of hearing loss on a child's emotional and social development as well as language delays (that do not seem to progress even after diagnosis in some children, when that diagnosis is delayed).

Even mild hearing loss or even when only one side is affected may have long lasting negative effects to the child. It affects interactions in the family, too.

3. Early detection and intervention of hearing deficits significantly helps children. Numerous studies show that when children are diagnosed with hearing loss and appropriate intervention to augment hearing and provide appropriate communication options are started early in life, preferably before 6 months of age, significant and long lasting benefits are achieved by the children in language skills, emotional development, social and familial adjustment.

Due to new advancements in screening technology, non-audiologists can administer the screen (and bill appropriately for this service). By asking insurance companies to cover this "standard of care" evaluation, all infants in the state can have this evaluation before they leave the hospital or birthing facility.

Universal hearing screen for all newborns is essential for Alaskan children.  
Please support HB 109.

Thank you.  
Sincerely,  
Phyllis Kiehl, M.D.

--  
Phyllis' numbers:  
Home: 907/345-3394  
Office: 907/562-2120  
Beeper: 907/275-2030

# LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES  
LEGISLATIVE AFFAIRS AGENCY  
STATE OF ALASKA

(907) 465-3867 or 465-2450  
FAX (907) 465-2029  
Mail Stop 3101

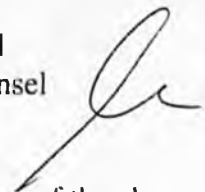
State Capitol  
Juneau, Alaska 99801-1182  
Deliveries to: 129 6th St., Rm. 329

## MEMORANDUM

February 4, 2005

**SUBJECT:** CSHB 109( ), Infant Hearing Screening  
(Work Order No. 24-LS0450\G)

**TO:** Representative Jay Ramras  
Attn: Jane Pierson

**FROM:** Jean M. Mischel  
Legislative Counsel 

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

**Section 1.** Describes legislative findings with respect to newborn and infant hearing loss, the value of early intervention and the relationship to language ability.

**Section 2.** Describes legislative intent to cover 100 percent of newborns and infants under the hearing screening and intervention program established by the act by January 1, 2008.

**Section 3.** Adds certain individuals who have been authorized by the Department of Health and Social Services to the list of individuals who may perform hearing screening tests without an audiology license.

**Section 4.** Requires the state Bureau of Vital Statistics to forward names and addresses of parents of newborns born outside of a hospital to the Department of Health and Social Services for notification of the merits of hearing screening.

**Section 5.** Requires certain minimum insurance coverage for newborn and infant screening.

**Section 6.** Establishes a newborn and infant hearing screening, tracking, and intervention program within the Department of Health and Social Services.

Representative Jay Ramras  
February 4, 2005  
Page 2

**Section 7.** Authorizes the Department of Health and Social Services to promulgate regulations required to implement the act before the effective date of the act.

**Section 8.** Adds a revisor's instruction to make conforming amendments.

**Section 9.** Provides an immediate effective date for secs. 6 through 8 of the act.

**Section 10.** Provides a January 1, 2006 effective date except as stated in sec. 9.

JMM:lmb  
05-031.lmb

Susan Walker  
P.O. Box 770658  
Eagle River, Alaska  
Ph. 907-696-1995 Email:jsjk@mtaonline.net

February 3, 2005

Representative Jay Ramras  
State Capitol  
Juneau, Alaska 99801-1182

Subject: Letter in Support of House Bill 109  
"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants..."

Dear Representative Jay Ramras:

I am writing to thank you for your sponsorship of HB 109. I am a parent of two children with hearing loss. I serve as a parent representative on the State's Early Hearing Detection and Intervention (EHDI) Programs' advisory group and am on the March of Dimes steering committee to introduce newborn and infant screening legislation.

My son Jack has a bilateral profound loss and my daughter Kate has a unilateral mild/moderate loss. Their hearing loss was not identified until six months of age and four years respectively. Identification of my son's loss at 6 months, appropriate intervention from highly skilled professionals, and technology have all been instrumental in providing him access to sound – a critical element in his language, social, and emotional development. Our family goal for Jack was that he will be oral and just prior to his second birthday he received a cochlear implant. His language and speech skills are on par with hearing children his age. Jack is now 5 years old, a phenomenal reader, and mainstreamed in kindergarten at his local elementary school. He receives support services but does not require an interpreter or full-time assistance. The degree of Kate's hearing loss is minor compared with her brother but a unilateral loss can still affect a child's ability to receive clear information. And it is harder to detect because they are obviously hearing.

HB 109 is one of two bills before the Legislature relating to newborn hearing screening. The other is SB 68. HB 109 contains the elements that are needed to successfully implement a screening, tracking, and intervention program for newborns and infants in the State of Alaska. Hearing loss is invisible – it cannot be seen at birth. For many toddlers, the possibility that there may be a problem only begins to emerge when they should be talking but seem to be delayed. By then, it is very hard to make up lost time. Early detection is the first critical step, but the other elements are extremely important and part of the process that will allow newborns and infants with hearing loss to maximize the critical brain development window (0 to 3 years) for language acquisition.

I have testified for previous versions of this bill at an earlier time and stage in my son's speech and language development when we (the family) were still hoping it was all going to work. Now we have no doubts – he is cruising! I make no attempt to quantify or reduce his progress to a dollar value or to predict what he will be when he moves on into the world of work. But I know

Susan Walker  
P.O. Box 770658  
Eagle River, Alaska  
Ph. 907-696-1993 Email:jsjk@mtaonline.net

one thing for certain - he will not be limited by his hearing loss. At 5 years old he can have telephone conversations with family and friends, communicate with them directly when visiting, advocate for himself in the classroom, and in the recreational and cultural activities in which he participates.

How often do you think about the importance of good language and writing skills to your success and effectiveness as a legislator? Communication is key to your job. Early detection and intervention works. Early detection and intervention opens doors that have been closed to many: children with hearing loss deserve that key to open up their world to language and sound.

Sincerely,

Susan Walker

Distribution:

Sponsor and Co-Sponsors

Representative Jay Ramras  
Representative Les Gara  
Representative Jim Elkins  
Representative Peggy Wilson  
Representative Max Gruenberg  
Representative Lesil McGuire

Labor and Commerce Committee

Representative Pete Kott  
Representative Gabrielle LeDoux  
Representative Bob Lynn  
Representative Norman Rokeberg  
Representative Harry Crawford  
Representative David Guttenberg

House Leaders

Representative Ethan Berkowitz  
Representative John Coghill



February 3, 2005

The Honorable Tom Anderson, Chair  
House Labor and Commerce Committee  
Alaska State Capitol, Room 408  
Juneau, AK 99801-1182

RE: HB 109 (Ramras)--Support

Dear Chair Anderson:

On behalf of the members of AARP in Alaska, we encourage you and your colleagues on the House Labor and Commerce Committee to support HB 109, authored by Representative Jay Ramras and co-sponsored by Representatives Gara, Elkins, Wilson, Gruenberg and McGuire.

AARP is not only a "senior organization." We are also an organization of grandparents concerned about the quality of health of all Alaskans of all ages.

The goal of HB 109 is to have all children born in Alaska screened for hearing problems soon after birth. If screening is not done early, very often hearing losses or problems will not be detected until a child is two or three years of age. The most important period for speech and language development is from birth to three. Most of our newborns are offered this screening. AARP hopes you will enable us to have 100% of them screened at birth. We are pleased to join the March of Dimes in support of this bill.

We urge an "AYE" vote on HB 109.

Should you have any questions about our position, please feel free to contact me (586-3637) or Patrick Luby, AARP Advocacy Director (907-762-3314).

Thank you for your consideration.

Sincerely,

*Marie Darlin*

Marie Darlin, Coordinator  
AARP Capital City Task Force  
415 Willoughby Avenue, Apt. 506  
Juneau, AK 99801  
586-3637 (voice)  
463-3580 (fax)

CC: Vice-Chair Pete Kott  
Representative Gabrielle LeDoux  
Representative Bob Lynn  
Representative Norman Rokeberg  
Representative Harry Crawford  
Representative David Guttenberg  
Representative Jay Ramras

# STATE OF ALASKA

DEPARTMENT of HEALTH & SOCIAL SERVICES  
DIVISION of PUBLIC HEALTH

FRANK H. MURKOWSKI, GOVERNOR

OFFICE OF THE DIRECTOR  
P.O. BOX 110610  
JUNEAU, AK 99811-0610  
PHONE: (907) 465-3090  
FAX: (907) 465-4632

February 3, 2005

The Honorable Jay Ramras  
Alaska State Legislature  
State Capitol Room 104  
Juneau, AK 99801

Dear Representative Ramras:

Thank you for your support of newborn hearing screening. I write to offer some suggested amendments to HB 109 on behalf of the Administration. We believe these changes, mostly technical amendments to update language and programmatic information but a couple more substantive, will help make the bill more supportable. Our proposed amendments are as follows:

1. Page 2:
  - Line 15: Change the "90 percent" to 100%."
  - Line 16: Change the date of "January 1, 2007" to "January 1, 2008."
2. Page 3:
  - Line 19: change the word "test" to "screen."
  - Line 20 change the word "test" to "evaluation."
3. Page 4:
  - Line 3: change the word "tested" to "screened."
  - Line 11: add the following: "Results of all newborns screened will be reported to the state early hearing, detection and intervention (EHDI) program on a regular basis to ensure appropriate tracking, surveillance and intervention."
  - Line 14: Change the number of births from 50 to 20.  
(Rationale: We currently have screening programs and equipment in place in all 23 of the communities where birthing centers exist (either hospital based or free standing birthing centers). The screening equipment is either owned by the hospital and the hospital administers the program or the equipment is owned by the state program and in place at the public health nursing centers. Additional equipment could possibly be purchased and placed in other public health nursing centers as needed if the number of out of hospital births in the community warranted its placement.)
  - Line 18: Change the word "testing" to "screening."
  - Line 20: Change the word "tested" to "screened."
  - Line 24: after the words "speech and language skills" include the words "psychosocial

and cognitive development.”

Line 25: add “(3): notify the state early hearing, detection and intervention (EHDI) program of the newborn’s screening results.”

Line 30: Change the word “testing” to “screening.”

4. Page 5:

Line 1: Change the word “testing” to “screening”

Line 10: Change the word “testing” to “screening”

Line 14: Add the following: “Signed refusals by the parent(s) will be sent to the state program for tracking”.

Lines 15-19: Delete this entire section.

Rationale: Payment methodologies for screening both during the hospital stay have been established with the recent revision of Medicaid regulations and the accompanying provider billing manuals. It is not feasible for the department to take on the costs and reimbursement processes that would need to be established in order to reimburse the hospitals for non-paying patients.

Line 22: Change the word “tested” to “screened”

5. Page 6: Section 47.20.320:

Line 12: include the words: “certified nurse midwife, direct entry midwife,....”

6. Page 7:

Line 6: change “and the value of early hearing testing” to “and the value of early hearing screening, tracking and intervention.”

Line 10: change the word “testing” to “early hearing screening, detection, and intervention.”

Line 13: add a new section:

Section: 47.20.360. Performance Evaluation. The Department will collect and compile performance data to ensure that the Early Hearing Detection and Intervention (EHDI) program is in compliance with this section, including the number of infants born, the proportion of all infants screened, the referral rate, the follow-up rate, the false-positive rate, and the false-negative rate.

(a) Testing Performance Standards.

(1) Each newborn hearing screening program should have a false-positive rate of 3% or less.

(2) Each newborn hearing screening program should have a false-negative rate of 3% or less.

(b) Oversight Responsibility. The Department shall exercise oversight responsibility for EHDI programs, including establishing a performance data set and reviewing performance data collected pursuant thereto by each hospital, birthing center or public health nursing center.

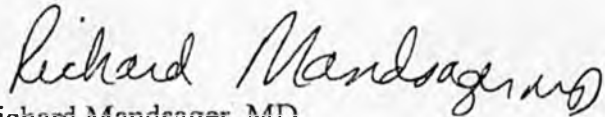
Line 25: Change “30 decibels” to “40 decibels.”

7. Page 8: After line 2, add the following definitions:

9. "Health Care Insurer" means any entity regulated by the Insurance Commissioner, including, but not limited to, health care insurers; health, hospital or medical service plan corporations; or health maintenance organizations.

10. "Hearing screening test" means automated auditory brain stem response, otoacoustic emissions, or another appropriate screening test approved by the state Department of Health and Social Services.

Sincerely,

A handwritten signature in cursive script that reads "Richard Mandsager MD".

Richard Mandsager, MD  
Director, Division of Public Health

Mary Weymiller  
907-479-4395  
907-479-7432 fax

Testimony for House Labor & Commerce Committee  
February 4, 2005 1:30 p.m.

**HB 109** "An act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening test; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date."

Thank you Representative Anderson and committee members for hearing my testimony today.

**National Institute for Health**

- Approximately 3 out of every 1,000 children in the United States are born deaf or hard-of-hearing.
- Children begin learning speech and language in the first 6 months of life.
- Congenital hearing loss should be identified early enough that intervention could start before 6 months of age.
- The earlier deafness and hearing loss is diagnosed, the sooner the child can benefit from strategies that will help them learn to communicate.

**Healthy Alaskans for 2010**

- One of the stated goals to improve the hearing health of Alaskans through prevention, early detection, treatment and rehabilitation, is to increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months and are enrolled in appropriate intervention services by 6 months of age.
- Executive Summary states four hospitals in Alaska now perform routine hearing screening of newborns. Forty-six percent of the babies born in Alaska in 2000 were screened. With approximately 10,000 births annually, 30 to 40 infants would be expected to have congenital hearing impairments.

**Quota International of Fairbanks**

- Service organization serving the speech and hearing impaired
- Each year grants approximately \$4,000 for equipment to assist children with speech and hearing problems in the Fairbanks area alone.
- Over 600 school age children receiving therapy in the North Star Borough School District.

Please pass this bill and make a difference for the 30-40 babies born with hearing deficits in Alaska each year.

*Mary Weymiller*

*Quota International of Fairbanks*  
P.O. Box 74850  
Fairbanks, AK. 99707  
[www.quotaofairbanks.org](http://www.quotaofairbanks.org)

**Resolution in support of establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants**

Whereas thirty to forty babies born annually in Alaska are likely to have some type of congenital hearing loss; and

Whereas approximately 50% of newborns with hearing loss are not identified and will not be identified until 18 mos. to 3 years of age; and

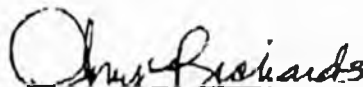
Whereas undetected hearing loss can result in lifelong delays in language, cognitive, socio-emotional and academic development; and

Whereas over the educational lifetime of a child, substantial amounts of money would be saved if, as a result of early identification and intervention, the most appropriate educational setting for the child is a regular mainstream classroom instead of a self-contained classroom or a self-contained program; and

Whereas the prevalence of congenital hearing loss at 3 per 1000 births nation wide is substantially higher than the prevalence of phenylketonuria (PKU), hyperthyroidism, or sickle cell anemia, which are required for screening in every state;

Now therefore be it resolved that Quota International of Fairbanks, a service organization focused on the speech and hearing impaired, wholeheartedly supports IJR 109 "an act to establish a screening, tracking, and intervention program related to the hearing ability of newborns and infants....."

Resolution #1 Adopted unanimously by the general membership on February 1, 2005, 6 p.m. Regency Hotel, Fairbanks, Alaska.



---

Amy Richards, President  
907-452-1751 wk.  
907-456-5982 fax

A	B	C	D	E	F	G	H	I	J	K
Name	Address	Profession	Home Phone	Work Phone	Fax	Cell	Sponsor	Entry	B-Day	E-Mail
1	1420 Kelton Street Fairbanks, AK 99701	GD&A, Inc. Chief Fr. Oilier	456-5833	452-1213	452-2266		Corz K	12/7/1982	24-Jun	lennycollidge@fairbanks.net
2	P.O. Box 85281 Fairbanks, AK 99708	Admittans Resources Agency	474-0722	452-2277			Leslie G.	5/3/2003	6-Jan	lennycollidge@fairbanks.net
3	P.O. Box 71559 Fairbanks, AK 99707	MB MfgL Services, Inc. KMI Realty	439-2118	479-0265	479-5223	322-9872	Chdy Suller	12/7/1986	29-Jun	lennycollidge@fairbanks.net
4	P.O. Box 74746 Fairbanks, AK 99707	MacKenzie Financial Consultant	452-6238	461-7767	45-8065		Barbara Hempesch	4/2/2002	18-Aug	lennycollidge@fairbanks.net
5	PO Box 63223 Fairbanks, AK 99708	Director-Port Star Volut Coast	478-5385	457-6792	457-6791	322-7869	Buzzy	11/4/2003	30-Aug	lennycollidge@fairbanks.net
6	1616 Vall View Dr Fairbanks, AK 99712	Regency Fairbanks Hotel	455-8628	452-5600	452-6505	590-1166	Malissa Birkwell	12/22/2003	2-Apr	
7	2006 Carr St. Fairbanks, AK 99709	Refrec Fountainhead Dev Bridgwal	456-7285	N/A				4/3/1981	12-Nov	
8	P.O. Box 71045 Fairbanks, AK 99707	Manager State Farm Insurance	479-8172	452-6661	452-6128			12/7/1999	12-Mar	lennycollidge@fairbanks.net
9	450 S. Santa Cruz L.N. North Pole, AK	Agent-Owner FBKS Day Care Food-	488-5017	488-7082	488-7143	480-2915		5/6/1997	13-Jul	lennycollidge@fairbanks.net
10	784 Quasar Drive Fairbanks, AK 99712	Exec. Dir. Frontier Bus. MacClas-	457-3562	451-7223	451-7228		Rionda Carpin	3/5/1988	25-Jun	lennycollidge@fairbanks.net
11	3321 Cheana Dr. Fairbanks, AK 99709	Manager/Cliber Owner & Assoc. White Spruce	457-3869	451-4155	451-8380	322-1445		2/3/1992	10-Apr	lennycollidge@fairbanks.net
12	10293 Old Valdez Trail Selditz, AK 99714	Enterpnas. Inc-Owner	489-2073	498-3034	488-2551	388-4541	Beth Rausch	1/27/1988	25-Dec	lennycollidge@fairbanks.net

Chico of Fairbanks Roster (3-25-04)

Page 2

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Name	Address	Profession	Phone	Phone	Fax	Cell	Spone	Entry	B-Day	E-Mail
14	Hai Bairie 16 Trinidad Dr. Fairbanks, AK 99709	Guess & Recd- ParaegalBNH Paraegal Services- Owner Audit Office	457-4257	452-8986	452-7015	347-7211	Wendy Haider	6/5/2000	13-Dec	haig@guess.aiki.com
15	Janet Wendy P.O. Box 70622 Fairbanks, AK 99707	Products- Commercial Designer K&K Recycling Inc.	457-7442	459-0303	459-0304	590-3612	Charal Vansant	1/17/1976	27-Jul	charal@kandk.com
16	Jaskaia Diga Fairbanks, AK 99710	Account- Hornesch & Evens PC Tax Accountant	452-210	489-1609	489-4053		Chris McLean	6/7/1934	4-Nov	cdiga@alaska.com
17	Hornesch, Barbara P.O. Box 81534 Fairbanks, AK 99708	Accountant	475-9216	452-1700	456-5693			1/2/2001	4-Jul	barbhornesch@comcast.net
18	Hevda Ann 1560 Tardak Dr Fairbanks, AK 99708	Tupperware Photo- Photography	452-8475				Rita Vaentno	10/7/2003	19-Feb	annhevda@hotmail.com annhevda@comcast.net
19	Kelsey, Cora P.O. Box 7-923 Fairbanks, AK 99707	State of AK DOT	456-7133	474-2548	474-2570	978-4087	Melissa Biswell	4/6/1997	14-Aug	melissa@dot.state.ak.us melissa@dot.state.ak.us
20	Kirkcaldy, Kaye P.O. Box 58179 Fairbanks, AK 99711	Mc McKinley Bank Manager Gold Coast Mortgage-Long Rentals	488-1610	474-1770	474-771	322-4110	Amy Richards	5/1/2000	21-Jul	kkirkcaldy@comcast.net
21	Loth, Victoria P.O. Box 70143 Fairbanks, AK 99707	World Traveler Princess River-side Lodge-Sales Manager	489-0389	451-7975	451-7381	322-0362	Rita Valentire	11/7/2003	2-May	lothvictoria@alaska.net
22	Phipps, Becki 4477 Pike's Landing Rd. Fairbanks, AK 99709	World Traveler Princess River-side Lodge-Sales Manager	451-6821	451-8543	327-3478			2/2/1988	28-Mar	becki@worldtraveler.com
23	Rentz, Helen 2406 Englewood Fairbanks, AK 99709	MC McKinley Bank VP Operations	907-522- 0082	455-5022	455-5085	5466	Rita Valeriana	11/3/1988	30-Jul	hrentz@comcast.net
24	Richards, Amy 4430 Dardmore 99709	Bank VP Operations	479-721E	452-1751	456-5982	578-1858	Becki Phipps	5/1/2004	2-Jan	amrichards@comcast.net

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9-7-04 12-11-57 Miller@mta.ky.gov  
Amy  
Huge  
474-3754

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Name	Address	Profession	Phone	W/A Phone	Fax	Cell	Sponsor	Entry	B-Day	E-Mail
25	Roderick, Sheri 452 Shannon Dr. Fairbanks, AK 99701	Power Fuel Owner	456-6772	451-9255	461-9301	590-3890	Patty W. Margusilla	2/4/2005	11-Feb	sherid@adventure.com sherid@adventure.com
26	Sator, Elizabeth 1107 Nanana St. Fairbanks, AK 99709	FBKS Korlassoff School Director	474-4071	451-8485	462-4872	322-8198		5/6/1997	13-Nov	elizabethsator@alaska.net
27	Shilling, Cincy P.O. Box 63744 Fairbanks, AK 99703	Shilling CFP Owner	479-8214	ext. 2	474-1632			4/21/1985	10-Sep	cshilling@alaska.net
28	Shoemaker, Diane 1640 Chena Ridge Fairbanks, AK 99709	Coordinator Der. Sales	457-8340	459-6117	451-3376	378-3927	Melissa Beech	12/4/2001	3-Jan	diane@shoemaker.com
29	Simon, Lisa 2851 Gold Street North Pole, AK 99705	Owner Cowboy Carpolitecn	490-5935		490-5935	322-7821	Wendy Scully	12/5/2000	26-Oct	lisa@simon.com
30	Svensson, Syd 2005 Richardson Hwy. North Pole, AK 99705	M. Richards Owner	488-4125	488-9407	484-9504	388-3322	Jeff Wagner	5/31/1994	23-Jun	syd@svensson.com
31	Thonia, Kris 3111 Pangolin Lane Fairbanks, AK 99712	State Farm Marketing Relations	493-2325	452-1881	456-0059	317-898	Tammy Collage	12/4/2001	20-Nov	kris@thonia.com
32	Valentine, Rita 2171 Peimeler Dr. North Pole, AK 99705	Able Rent-A- Car Manager	488-7138	474-0800	474-2013	322-3820		2/1/1988	29-Jul	rita@valentine.com
33	Weaver, Patsy 1704 CAT Ave. Fairbanks, AK 99709	Manager Plikes On The River	478-7288	456-5200	456-5214	378-6005		5/31/1994	5-May	patsy@weaver.com
34	Weedercall, Fern P.O. Box 73032 Fairbanks, AK 99707	President/Dom er - Diamond Fence Co.	452-2570	458-0087	452-2259	322-3224	Becky Fritpps	11/4/2005	29-Sep	fern@weedercall.com
35	Waymil, Nancy 686 11th Ave. #302 Fairbanks, AK 99701	Nurses Nurses	479-4395		478-7432	322-0111	Nancy Heller	5/6/1987	5-Oct	nancy@waymil.com

# American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



February 4, 2005

## Alaska Chapter

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907/348-5911

### Chapter Vice-President

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### Chapter Secretary-Treasurer

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### Chapter Executive Director

Janice T Tower  
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Fax: 907/348-8028  
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Representatives: Tom Anderson, Chair, House Labor and Commerce  
Pete Kott, Vice-Chair  
Gabrielle LeDoux  
Bob Lynn  
Norm Rokeberg  
Harry Crawford  
David Guttenberg

Dear Representative Anderson and Members of the House L&C Committee:

On behalf of the pediatricians of the Alaska Chapter of the American Academy of Pediatrics I am writing to encourage your support of HB 109: Newborn Hearing Screening, Tracking and Intervention. We recommend that all babies be screened for hearing loss before they leave the hospital.

The cost of identifying a newborn with hearing loss is less than 1/10<sup>th</sup> the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state. For most birthing hospitals, the cost for newborn hearing screening per child is between \$20 and \$60 and continues to decrease. The evidence for the benefits, practicability and cost-efficiency of universal newborn hearing screening is so compelling that 37 states have passed legislation requiring that newborns be screened for hearing loss. Most importantly, children not detected at birth or soon after, will on average not be detected until 2-3 years of age. The most critical period for speech and language development is from birth to three years of age.

Thank you for supporting HB 109.

Sincerely,

Thomas J. Porter, MD FAAP  
President  
American Academy of Pediatrics, Alaska Chapter

**HB**

**1 1 1**





**State of Alaska  
Representative Peggy Wilson  
House District 2**

State Capitol, Room 108  
Juneau AK 99801  
Representative.Peggy.Wilson@legis.state.ak.us

Phone 907-465-3824  
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**Fax transmittal sheet**

To Leg Legal  
Fax # 465-2029

Date March 31, 2005  
1 page

From: Kathy Hope Erickson for Representative Peggy Wilson  
Re: HB 111, Medicaid Coverage for Birthing Centers

Comments: HESS Committee has passed HB 111 out of committee, and has made this conceptual amendment - on page 1 line 9 of HB 111 (A) ADD "Section 2. That the provisions of Section 1 are contingent upon approval of matching funding from the federal Medicaid program."

I am also requesting a final. Thank you very much.



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**Fax transmittal sheet**

To Leg Legal  
Fax # 465-2029

Date March 31, 2005  
1 page

From: Kathy Hope Erickson for Representative Peggy Wilson  
Re: HB 111, Medicaid Coverage for Birthing Centers

Comments: HESS Committee has passed CSHB 220 (Y) out of committee, and has made two conceptual amendments

- 1) On page 1 line beginning on 11, DELETE section (b).
- 2) On page 2, line 3, DELETE "in patient rooms"

I am also requesting a final. Thank you for everything.

# FISCAL NOTE

**STATE OF ALASKA**  
**2005 LEGISLATIVE SESSION**

Fiscal Note Number: \_\_\_\_\_  
 Bill Version: HB111-DHSS-HCS-03-30-05

Revision Date/Time (Note if correction): 3/30/05p  
 Title ADDING BIRTH CENTERS TO FACILITIES  
PAID BY MEDICAID

( ) Publish Date: \_\_\_\_\_  
 Dept. Affected: Health & Social Services

Sponsor CRAWFORD  
 Requester \_\_\_\_\_

RDU Health Care Services  
 Component Medicaid Services

Component No. 2077

**Expenditures/Revenues** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims						
Miscellaneous						
<b>TOTAL OPERATING</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

<b>CAPITAL EXPENDITURES</b>						
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<b>CHANGE IN REVENUES (0)</b>						
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FUND SOURCE	(Thousands of Dollars)					
1002 Federal Receipts						
1003 GF Match						
1004 GF						
1037 GF/Mental Health						
Other(Specify Type-do not abbreviate)						
Other(Specify Type-do not abbreviate)						
<b>TOTAL</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

Estimate of any current year (FY2005) cost: \_\_\_\_\_  
 Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

**POSITIONS**

Full-time						
Part-time						
Temporary						

**ANALYSIS:** *(Attach a separate page if necessary)*

There is a great deal of uncertainty in calculating the cost differential between birth center and hospital births. There are potential savings and costs, but with the large number of variables involved, we cannot determine the net amount. Therefore, the fiscal note is for zero dollars. The number of Medicaid eligible women who might choose a birthing center instead of a hospital is unknown. In Alaska, about 2% of all births occur in a birthing center compared to less than 1% nationally. Medicaid babies are generally the most at-risk because of their circumstances. One birthing center delivery with serious complications could easily offset any cost savings. The rate of Medicaid deliveries in birthing centers would probably be lower than the statewide rate since birthing centers do not provide adequate care for high-risk pregnancies. An independent study found that the facility cost for a birthing center delivery is about 22% less than a hospital. The cost savings for 100 births is approximately \$40,000.00. There is a question whether birthing centers are an allowable federal Medicaid service. If birthing centers do not qualify for Medicaid reimbursement, the cost would be all GF. If they do qualify, the regular matching rate would apply.

Prepared by: Dwayne Peoples, Director Phone 465-5830  
 Division Health Care Services Date/Time 03/30/2005  
 Approved by: Joel S. Gilbertson, Commissioner Date 03/30/2005  
 Agency Department of Health and Social Services

**Alaska State Legislature**  
**House of Representatives**



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**Representative Harry Crawford**  
District 21

**MEMORANDUM**

**TO:** Representative Peggy Wilson, Chair  
House Health, Education & Social Services Committee

**FROM:** Representative Harry Crawford

**DATE:** March 17, 2005

**RE:** House Bill 111

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I respectfully request that House Bill 111, "An Act adding birthing centers to the list of health facilities eligible for payment of medical assistance for needy persons," be scheduled for a hearing in the House Health, Education & Social Services Committee at your earliest possible convenience. I have attached a sponsor statement, sectional analysis and copy of HB 111. Additional backup information, including letters of support, will be provided to your office as it becomes available.

**Alaska State Legislature**  
House of Representatives

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Representative Harry Crawford  
District 21

**SPONSOR STATEMENT FOR HB 111**

In Alaska, Medicaid does not cover licensed birthing center facility fees. House Bill 111 adds birthing centers to the list of health facilities eligible for medical assistance purposes.

Cost savings could be realized by adding birthing centers to the list of covered facilities. The cost of a hospital birth is significantly greater than those at a birthing center. Licensed birthing centers in Alaska often charge less than half the price of a hospital stay for a "normal" delivery.

House Bill 111 not only gives Medicaid recipients more freedom in choosing their preferred birthing location, it also provides them with an option that could save the state money.

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Representative Harry Crawford  
District 21

**SECTIONAL ANALYSIS HB 111**

**Section 1:** Adds birthing centers to the definition of "health facility" for medical assistance purposes.