

Nevada Early Hearing Detection and Intervention 2018 Annual Report Of 2016 data

BUREAU OF CHILD, FAMILY AND COMMUNITY WELLNESS NEVADA DIVISION OF PUBLIC AND BEHAVIORAL HEALTH DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Table of Contents

| Introduction |
|--|
| Program Funding |
| Partners and Stakeholders |
| Statistical Overview |
| Prevalence of Hearing Loss |
| Chart 1 – EHDI Statistical Flowchart5 |
| Challenges6 |
| Map 1 – Birthing Facilities |
| Map 2 – Failed Newborn Hearing Screens7 |
| Map 3 – Audiologists Practicing in Nevada7 |
| Map 4 – Early Intervention Facilities7 |
| Map 5 – Infants with Confirmed Hearing Loss8 |
| Improvement Strategies8 |
| 2016 Statistics |
| Figure 1 - Total Hearing Screens9 |
| Figure 2 - Infants who Passed Hearing Screen9 |
| Figure 3 - Infants Screened Before One Month of Age10 |
| Figure 4 - Infants with an Audiologist's Confirmed Diagnosis10 |
| Figure 5 - Infants with a Diagnosis Before Three Months of Age11 |
| Figure 6 - Infants LTF/LTD for Hearing Diagnostic Evaluation11 |
| Figure 7 - Infants with Confirmed Hearing Loss, Enrolled in El12 |
| Figure 8 - Infants with Confirmed Hearing Loss Enrolled in EI by Six Months of Age12 |
| Figure 9 – Laterality of Hearing Loss13 |
| Figure 10 – Degree of Hearing Loss by Ear13 |
| Recommendations |
| Nevada Revised Statutes |
| Nevada Administrative Code |
| References |

Introduction

The Nevada Early Hearing Detection and Intervention (NV EHDI) Program is located within the Bureau of Child, Family and Community Wellness; Nevada Division of Public and Behavioral Health in the Nevada Department of Health and Human Services.

The purpose of the NV EHDI Program is to ensure all children born in Nevada are screened for hearing loss at birth and those identified with hearing loss receive timely and appropriate audiological, educational and medical intervention. NV EHDI follows national guidelines, and the typical infant screening procedural flow may be summarized as follows:

Following a "did-not-pass" hearing screen prior to hospital discharge, an infant should receive a second outpatient hearing screen to confirm the initial results. If the second screen is also "did-not-pass," the infant should be referred to a pediatric audiologist for a diagnostic test to confirm or rule out a hearing deficit. If a hearing deficit is ruled out, no further testing is needed. If the infant is diagnosed as being deaf or hard of hearing (D/HH), the infant is referred to early intervention services. Nevada EHDI tracks these infants throughout the process to confirm they received timely and appropriate services.

NV EHDI promotes the national EHDI goals and timelines developed by the Joint Committee on Infant Hearing (JCIH)¹ and the Centers for Disease Control and Prevention (CDC):

- 1. All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.
- 2. All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.
- 3. All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).
- 4. All infants and children with late onset, progressive or acquired hearing loss will be identified at the earliest possible time.
- 5. All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.
- 6. Every state will have a complete EHDI tracking and surveillance system that will minimize loss to follow-up.
- 7. Every state will have a comprehensive system that monitors and evaluates the progress towards the EHDI goals and objectives.

Program Funding

NV EHDI is solely funded via two federal grants: one from the CDC and the other from the Health Resources and Services Administration (HRSA). The purpose and scope of these federal grants is defined by the grantor, and the state complies with the stated purpose, goals, and accountabilities. The purpose of the HRSA grant is to develop statewide comprehensive and coordinated programs and systems of care targeted towards ensuring newborns and infants receive appropriate and timely services including screening, evaluation, diagnosis, and early intervention. The CDC cooperative agreement is to assist EHDI programs in developing and maintaining a centralized newborn hearing screening tracking and surveillance system capable of accurately identifying, matching, collecting, and reporting data on all births through the three components of the EHDI process (hearing screening, diagnosis, and early intervention).

Partners and Stakeholders

Meeting the goals and purposes of federal funding requires a coordinated effort of multiple partners within the national, state, public, and private sectors. The following entities assist in this endeavor:

The National Center for Hearing Assessment and Management (NCHAM) serves as the technical resource center for the implementation and improvement of comprehensive and effective early hearing detection and intervention with all state and territory EHDI programs. NCHAM works closely with both federal funders and each state to provide ongoing training, research, and resources.²

The American Academy of Pediatrics (AAP) also works with both federal funders to provide assistance to physicians, hospitals, state EHDI programs, and parents to meet national EHDI goals. The AAP promotes the medical home concept and has established physician practice guidelines for infant hearing screening and follow-up. Each state AAP chapter designates an EHDI chapter champion to work with state EHDI programs.³

Nevada audiologists assist NV EHDI by providing screenings and diagnostic testing to all infants suspected of hearing loss and reporting those findings to the state.

All birthing facilities/hospitals in Nevada provide hearing screenings to infants prior to discharge and report this data to the state. The Federal Hospital at Nellis Air Force Base which reports birth data to the state, consistently screens their infants but during the timeframe covered in this report, were not consistently reporting hearing screening data. Beginning in 2018 their reporting of hearing screening data has become more reliable.

Nevada midwives are currently participating in a pilot project to place hearing screening equipment in midwife practices.

University of Nevada Reno – Center for Program Evaluation who assists with evaluation and quality improvement development and implementation.

NV EHDI works closely with Nevada Hands & Voices (H&V), a statewide non-profit, to assist with reducing the number of infants lost to documentation and/or follow-up. Nevada H&V also provides parent mentors who assist families who have a newly diagnosed infant with a confirmed hearing deficit.⁴

As a program within the Nevada Division of Public and Behavioral Health, NV EHDI works closely and collaboratively with a variety of public programs and agencies providing support services to a similar population of infants and children. These programs include, but are not limited to:

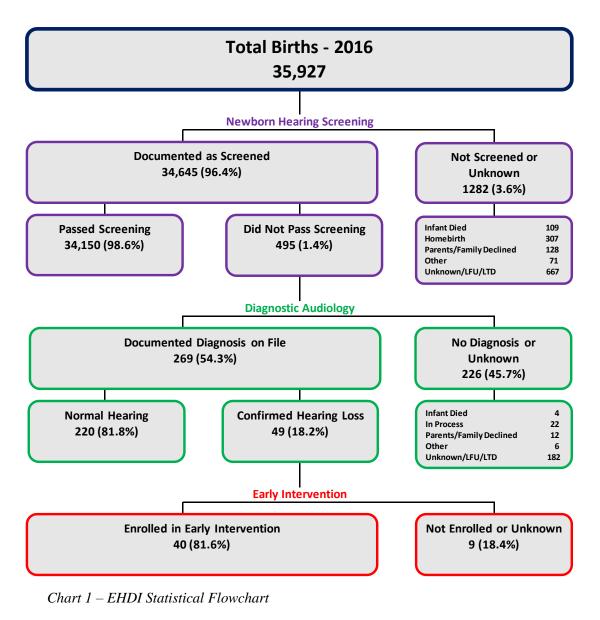
- Maternal and Child Health Title V Block Grant Program, including the Children and Youth with Special Health Care Needs Program
- Nevada Home Visiting Program
- Nevada Individuals with Disabilities Education Act (IDEA) Part C Office
- Nevada Early Intervention Services
- Nevada Office of Vital Records
- Nevada Office of Public Health Investigations and Epidemiology
- Nevada Department of Education
- Nevada Head Start Collaboration and Early Childhood Systems Office

Statistical Overview

Prevalence of Hearing Loss

Hearing loss is one of the most common birth defects, affecting approximately 1.4 out of every thousand infants.⁵ The number is estimated to increase to 9-10 per thousand in the school-age population.⁶

For 2016, Nevada observed a rate of 1.36 infants per thousand with documented confirmed hearing loss. With a total of 35,927 births in 2016, 34,645 (96.4%) were documented as receiving a hearing screening. Of those infants without documentation of a hearing screen, 109 died, parents or family members declined services for another 128, and 307 were planned homebirths. The 71 infants in the "Other" category were either unable to be screened due to medical reasons, or they were transferred to another hospital with no record of a screening.



Of all infants screened, 495 (1.4%) did not pass the screening. Further audiologic testing identified 220 of the 495 with normal hearing, 49 with confirmed hearing loss, and the remainder do not have documentation of audiologic testing.

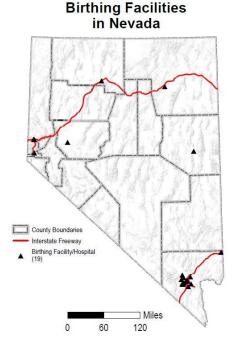
Of the 49 infants with confirmed hearing loss, 40 (81.6%) are documented as being enrolled in Early Intervention Services.

Challenges

Hearing loss is one of the most common congenital birth defects; if left undetected, hearing impairment in infants can negatively impact speech and language acquisition, academic achievement, and social and emotional development. When diagnosed early however, these negative impacts can be diminished or even eliminated through early intervention.

Ensuring provision of health care services to those affected with hearing loss is challenging due to unique Nevada characteristics such as geography, the distribution of population and infrastructure, and the distribution of medical and support services. The following maps illustrate some of the challenges faced by parents, physicians, hospitals, audiologists, and early intervention staff.

The location and distribution of all birthing hospitals in Nevada are detailed in Map 1.

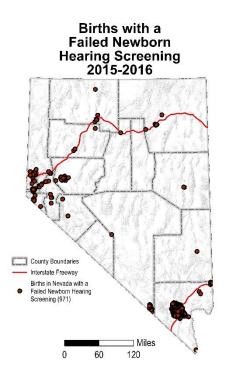


Nevada Birthing Facilities:

- Banner Churchill Community Hospital
- Carson Tahoe Regional Medical Center
- Centennial Hills Hospital
- Henderson Hospital
- Humboldt General Hospital
- Mesa View Regional Hospital
- Mike O'Callaghan Federal Hospital
- Mountain View Hospital
- Northeastern Nevada Regional Hospital
- Renown Health
- Saint Mary's Regional Medical Center
- St. Rose Dominican Hospital San Martin
- St. Rose Dominican Hospital Siena
- Southern Hills Hospital and Medical Center
- Spring Valley Hospital
- Summerlin Hospital
- Sunrise Hospital & Medical Center
- University Medical Center
- William Bee Ririe Hospital

Map 1 – Birthing Facilities

When the birthing facility locations (Map 1) and distribution of failed newborn hearing screens (Map 2) are compared, it becomes clear many parents are required to travel many hours back to the hospital if their infant requires a hearing rescreen.



The parental travel distance and time burden is accentuated further when observing the location of audiologists (*Map 3*) in relation to the distribution of failed newborn hearing screens (*Map 2*).

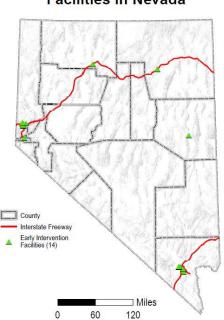
Nevada currently has only six pediatric audiology facilities which have both a trained audiologist who works with infants and with the appropriate pediatric equipment. With so few resources comes limited capacity and long wait times for timesensitive diagnostic appointments.

Communities with Pediatric Audiology Facilities:

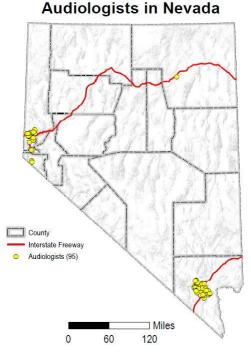
- Elko
- Las Vegas
- Mesquite
- Reno

Map 2 – Failed Newborn Hearing Screens

It is not uncommon for an infant to need more than one visit to an audiologist and multiple ongoing visits to early intervention services (*Map 4*).



Early Intervention Facilities in Nevada

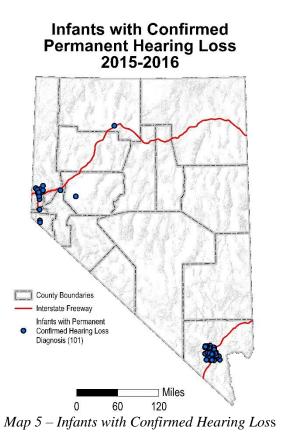


Map 3 – Audiologists Practicing in Nevada

Map 4 – Early Intervention Facilities

Early Intervention (EI) Services are also limited with only six communities having trained staff to work with deaf or hard of hearing clients. EI services often entail multiple visits per week for infants ages 1-2 months through 3 years of age, and in the years 2015 and 2016 combined, 101 infants were diagnosed as deaf or hard of hearing (*Map 5*).

The cost to travel long distances, multiple times, can be a significant impediment to receiving needed medical or developmental support services not provided locally. The lack of readily accessible services has caused families to move from their homes in rural and frontier locations to in-state metropolitan areas or other states. These unique barriers pose a challenge to parents, physicians, audiologists, early intervention staff, and the NV EHDI program to ensure all infants are screened, receive timely diagnostic audiology services, and are enrolled in early intervention before six months of age.



Improvement Strategies

Nevada EHDI is meeting these challenges by forming strong collaborative relationships with each of the previously mentioned partners and stakeholders. This collaborative bond is strengthened through regular in-person communication, training opportunities, contractual agreements, and formal data-sharing agreements.

To ensure the JCIH processes and associated timeframes are followed with fidelity, the following strategies have been incorporated:

- Facilitate timely and accurate reporting of data to NV EHDI by hospitals, audiologists and early intervention facilities;
- Facilitate appropriate training to all providers (hospital screeners, audiologists, primary care providers, developmental specialists within early intervention facilities);
- Educate and encourage all professionals to incorporate current practice guidelines in their practices;
- Facilitate open communication among all partners;
- Work with the Office of Vital Records to improve the functionality of the NV EHDI information system;
- Provide accurate and consistent education to parents and families throughout all stages of the hearing detection and intervention process;
- Advocate for and financially assist family-based D/HH organizations.

2016 Statistics

Data presented in this annual report are for the years 2011 through 2016, unless otherwise specified. Each year's EHDI data is considered preliminary until it is reported to the CDC in the annual EHDI Hearing Screening and Follow-up Survey. In 2018, the CDC requested 2016 data. This delay in reporting allows sufficient time for infants to move through the EHDI continuum (screening, diagnosis, and intervention) prior to data being released.

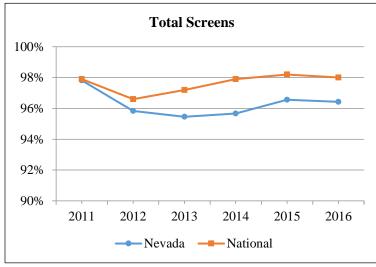


Figure 1 - Total Hearing Screens

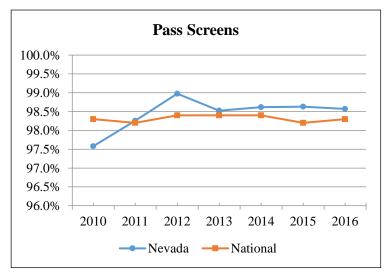


Figure 2 - Infants who Passed Hearing Screen

Figure 1 – Total Hearing Screens

Nevada's percent screened is slightly below the national average. Chart 1 (page 5) categorizes results and describes reasons for the lack of screen documentation for some infants.

Figure 2 – Infants who Passed the Hearing Screen

Acceptable hospital screening pass percentages are estimated to be between 96% and 98.5%. A less than 96% pass percentage may indicate a high number of false positives (infants screened as not passing when in reality they have normal hearing). Percentages above 98.5% may indicate a high number of false negatives (infants screened as passing when in reality they have a hearing deficit).

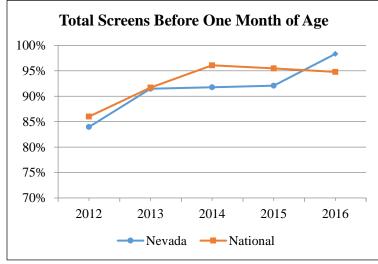


Figure 3 - Infants Screened Before One Month of Age

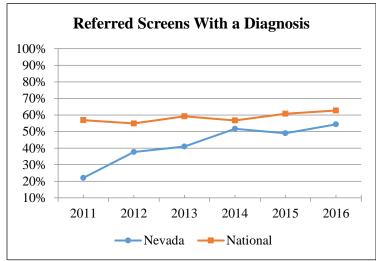


Figure 4 - Infants with an Audiologist's Confirmed Diagnosis

Figure 3 – Infants Screened Before One Month of Age

The national goal is to screen infants prior to one month of age and those who do not pass the screen, refer for audiologic testing. This figure reflects how well Nevada screens and refers within the one-month benchmark.

Figure 4 – Infants with an Audiologist's Confirmed Diagnosis

This figure represents those infants who did not pass the hearing screen and whose audiological diagnosis has been reported to Nevada EHDI. Infants whose diagnostic results have not been reported are included in Figure 6 - Lost to Follow-up/Lost to Documentation (LTF/LTD).

Figure 5 – Infants with a Diagnosis before Three Months of Age

The JCIH benchmark for infants to receive an audiologic diagnosis is before three months of age. The progress being made towards the occurrence of diagnostic evaluations is demonstrated in Figures 4 and 6, while Figure 5 shows the need to have these diagnostic evaluations occur before the 3-month goal.

Figure 6 – Infants LTF/LTD for Hearing **Diagnostic Evaluation**

Nevada EHDI has made huge strides in reducing the number of infants lost to follow-up (LTF) or lost to documentation (LTD). This improvement is the result of close collaboration with hospitals, parents, audiologists, state non-profits, and infants' primary care physicians.

Page 11

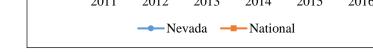
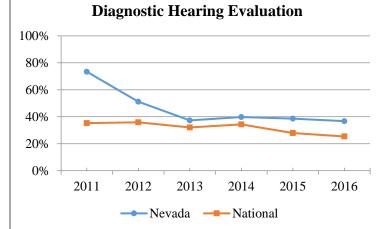
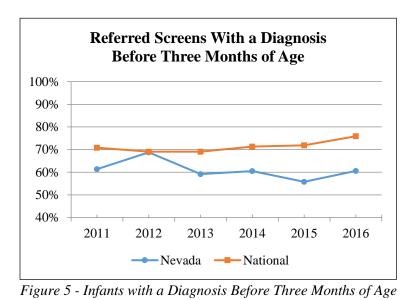
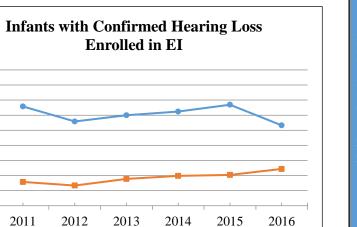


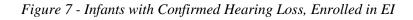
Figure 6 - Infants LTF/LTD for Hearing Diagnostic Evaluation



Infants LTF/LTD for







---- Nevada ---- National

100% 95%

90%

85%

80%

75%

70%

65% 60% 55%

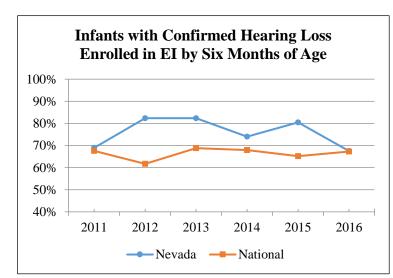


Figure 8 - Infants with Confirmed Hearing Loss Enrolled in EI by Six Months of Age

Figure 7 – Infants with Confirmed Hearing Loss Enrolled in Early Intervention

Nevada surpasses national levels on enrolling deaf and hard of hearing infants into early intervention services (EI). This data are reflective of the close collaborative relationship with pediatric audiologists, EI services, and Nevada EHDI.

Figure 8 – Infants with Confirmed Hearing Loss Enrolled in EI by Six Months of Age

Nevada tends to meet or surpass national levels on enrolling deaf and hard of hearing infants into early intervention services within the six-month benchmark.

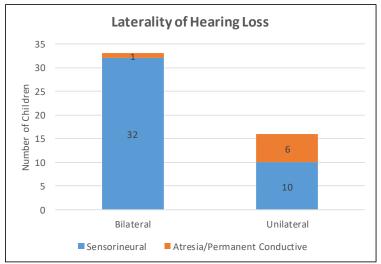


Figure 9 – Laterality of Hearing Loss

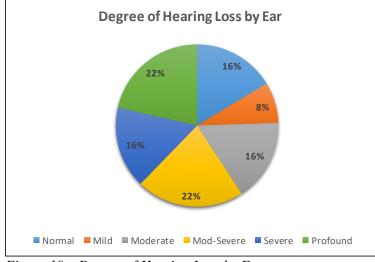


Figure 10 – Degree of Hearing Loss by Ear

Figures 9 and 10 represent the 49 children with documented hearing loss.

Figure 9 – Laterality and type of Hearing Loss

Hearing loss may be bilateral (both ears) or unilateral (one ear) and diagnostically classified as sensorineural, conductive, or mixed

67% of hearing loss was bilateral33% of hearing loss was unilateral85% of hearing loss was sensorineural15% of hearing loss was conductive

Figure 10 – Degree of Hearing Loss by Ear

This figure breaks down the degree of hearing loss for each of the 98 ears tested. It must be noted these children often have a different degree of hearing loss for each ear.

Recommendations

As a requirement of Nevada Revised Statutes (NRS) 442.550(5), the Nevada EHDI program shall provide an annual report to the Governor which addresses the effectiveness of the EHDI NRS provisions and related recommendations.

Current "Screening of Hearing of Newborn Children" statutes were initially adopted in 2001 and have not been amended since that time. Over the last 15 years, infant hearing screening and early hearing detection and intervention concepts have evolved and expanded to encompass much more than the intent of the original legislation. Nationally and at the individual level, states have demonstrated a great public health success in the provision of hearing screens at the hospital/birthing facility level. States are consistently screening 96% to 97% of infants. It is now recognized hearing screening is not a suitable end goal, but only the first step in the process of ensuring deaf and hard of hearing infants receive a timely diagnosis and appropriate intervention.

CDC and HRSA now direct state programs to move beyond simply tracking infants to ensure they are receiving appropriate and timely hearing screens. The current national guidelines direct states to also track and ensure timely and appropriate diagnostic follow-up and intervention services, as well as collaborate with community family-based organizations. Screening, diagnostic, and early intervention enrollment data is submitted annually to the CDC.⁷

In accordance with current national standards, modification recommendations to Nevada's EHDI Program, will address the following:

- Establish best practice standards related to consistent, accurate, and timely data submission to the state by hospitals, midwives, physicians, audiologists, and early intervention providers;
- Update current pediatric audiology practice guidelines;
- Establish midwife responsibilities related to hearing screening and reporting; and
- Establish responsibilities of all EHDI partners related to timely and appropriate referral practices for audiologic testing and early intervention services.

SCREENING OF HEARING OF NEWBORN CHILDREN

NRS 442.500 Definitions. As used in <u>NRS 442.500</u> to <u>442.590</u>, inclusive, unless the context otherwise requires, the words and terms defined in <u>NRS 442.510</u>, <u>442.520</u> and <u>442.530</u> have the meanings ascribed to them in those sections.

(Added to NRS by <u>2001, 2460</u>)

NRS 442.510 "Hearing screening" defined. "Hearing screening" means a test or battery of tests administered to determine the need for an in-depth hearing diagnostic evaluation.

(Added to NRS by 2001, 2460)

NRS 442.520 "Hospital" defined. "Hospital" has the meaning ascribed to it in <u>NRS 449.012</u>. (Added to NRS by <u>2001, 2460</u>)

NRS 442.530 "Provider of hearing screenings" defined. "Provider of hearing screenings" means a health care provider who, within the scope of his or her license or certificate, provides for hearing screenings of newborn children in accordance with <u>NRS 442.500</u> to <u>442.590</u>, inclusive. The term includes a licensed audiologist, a licensed physician or an appropriately supervised person who has documentation that demonstrates to the State Board of Health that he or she has completed training specifically for conducting hearing screenings of newborn children.

(Added to NRS by 2001, 2460)

NRS 442.540 Certain medical facilities prohibited from discharging newborn child born in facility until child has undergone or been referred for hearing screening; exception; regulations.

1. Except as otherwise provided in this section and <u>NRS 442.560</u>, a licensed hospital in this state that provides services for maternity care and the care of newborn children and a licensed obstetric center in this state shall not discharge a newborn child who was born in the facility until the newborn child has undergone a hearing screening for the detection of hearing loss to prevent the consequences of unidentified disorders, or has been referred for such a hearing screening.

2. The requirements of subsection 1 do not apply to a hospital in which fewer than 500 childbirths occur annually.

3. The State Board of Health shall adopt such regulations as are necessary to carry out the provisions of <u>NRS 442.500</u> to $\underline{442.590}$, inclusive.

(Added to NRS by <u>2001, 2461</u>)

NRS 442.550 Hearing screenings: Persons authorized to conduct; certain medical facilities to hire or enter into written agreement with provider of hearing screenings; documentation to be placed in medical file of newborn child; written reports.

1. A hearing screening required by <u>NRS 442.540</u> must be conducted by a provider of hearing screenings.

2. A licensed hospital and a licensed obstetric center shall hire, contract with or enter into a written memorandum of understanding with a provider of hearing screenings to:

(a) Conduct a program for hearing screenings on newborn children in accordance with <u>NRS 442.500</u> to 442.590, inclusive;

(b) Provide appropriate training for the staff of the hospital or obstetric center;

(c) Render appropriate recommendations concerning the program for hearing screenings; and

(d) Coordinate appropriate follow-up services.

3. Not later than 24 hours after a hearing screening is conducted on a newborn child, appropriate

documentation concerning the hearing screening, including, without limitation, results, interpretations and recommendations, must be placed in the medical file of the newborn child.

4. A licensed hospital and a licensed obstetric center shall annually prepare and submit to the Division a written report concerning hearing screenings of newborn children in accordance with regulations adopted by the State Board of Health. The report must include, without limitation, the number of newborn children screened and the results of the screenings.

5. The Division shall annually prepare and submit to the Governor a written report relating to hearing tests for newborn children. The written report must include, without limitation:

(a) A summary of the results of hearing screenings administered to newborn children and any other related information submitted in accordance with the regulations of the State Board of Health;

(b) An analysis of the effectiveness of the provisions of <u>NRS 442.500</u> to $\underline{442.590}$, inclusive, in identifying loss of hearing in newborn children; and

(c) Any related recommendations for legislation.

(Added to NRS by 2001, 2461)

NRS 442.560 Hearing screening not required if parent or legal guardian of newborn child objects in writing; written objection to be placed in medical file of newborn child. A newborn child may be discharged from the licensed hospital or obstetric center in which he or she was born without having undergone a required hearing screening or having been referred for a hearing screening if a parent or legal guardian of the newborn child objects in writing to the hearing screening. The hospital or obstetric center shall place the written objection of the parent or legal guardian to the hearing screening in the medical file of the newborn child.

(Added to NRS by <u>2001, 2461</u>)

NRS 442.570 Physician to recommend diagnostic evaluation if hearing screening indicates possibility of hearing loss. If a hearing screening conducted pursuant to <u>NRS 442.540</u> indicates that a newborn child may have a hearing loss, the physician attending to the newborn child shall recommend to the parent or legal guardian of the newborn child that the newborn child receive an in-depth hearing diagnostic evaluation.

(Added to NRS by 2001, 2462)

NRS 442.580 Lead physician or audiologist: Designation; responsibilities. A licensed hospital and a licensed obstetric center shall formally designate a lead physician or audiologist to be responsible for:

1. The administration of the Program for conducting hearing screenings of newborn children; and

2. Monitoring the scoring and interpretation of the test results of the hearing screenings. (Added to NRS by 2001, 2462)

NRS 442.590 Written brochures: Creation by Division; required contents; distribution.

1. The Division shall create written brochures that use terms which are easily understandable to a parent or legal guardian of a newborn child and include, without limitation:

(a) Information concerning the importance of screening the hearing of a newborn child; and

(b) A description of the normal development of auditory processes, speech and language in children.

2. The Division shall provide the brochures created pursuant to subsection 1 to each licensed hospital and each licensed obstetric center in this state. These facilities shall provide the brochures to the parents or legal guardians of a newborn child.

(Added to NRS by 2001, 2462)

SCREENING OF HEARING OF NEWBORN CHILDREN

NAC 442.850 Annual reports to Division of Public and Behavioral Health: Contents. (NRS 442.540, 442.550) The annual written report required to be submitted to the Division of Public and Behavioral Health of the Department of Health and Human Services pursuant to NRS 442.550 by licensed hospitals and licensed obstetric centers must include the following information concerning hearing screenings of newborn children conducted at the licensed hospital or licensed obstetric center during the period covered by the report:

- 1. The name of the licensed hospital or licensed obstetric center.
- 2. The number of newborn children screened.

3. The number of newborn children who required follow-up services and for each of those newborn children:

- (a) The age of the newborn child at the time the hearing screening was conducted;
- (b) The gestational age of the newborn child at birth;
- (c) The type of hearing screening that was conducted on the newborn child;
- (d) The results of the hearing screening;
- (e) Any recommendations made for the newborn child as a result of the hearing screening;
- (f) Any referrals made for the newborn child as a result of the hearing screening;
- (g) The county of residence of the newborn child;
- (h) The name and date of birth of the mother of the newborn child; and
- (i) The name of the attending physician of the newborn child.
- (Added to NAC by Bd. of Health by R191-01, eff. 5-23-2002)

NAC 442.860 Referral of child for certain services: Notification of Division of Public and Behavioral Health. (NRS 442.540) If a licensed hospital or licensed obstetric center makes a referral for a newborn child because the newborn child needs assistance with accessing diagnostic and treatment services, the licensed hospital or licensed obstetric center shall notify the Division of Public and Behavioral Health of the Department of Health and Human Services of the referral at the time the referral is made.

(Added to NAC by Bd. of Health by R191-01, eff. 5-23-2002)

References

- ¹ <u>http://www.jcih.org</u>
- ² <u>http://www.infanthearing.org</u>
- ³ <u>http://www.aap.org</u>
- ⁴ <u>http://nvhandsandvoices.org</u>
- ⁵ <u>http://www.cdc.gov/ncbddd/hearingloss/data.html</u>

⁶ White, K. (October, 2010). *Twenty years of early hearing detection and intervention (EHDI): Where we've been and what we've learned*. ASHA Audiology Virtual Conference.

⁷ <u>http://www.cdc.gov/ncbddd/hearingloss/data.html</u>