Rhode Island Department of Health Procedures for Evaluating Newborn Infants for Hearing Impairments

Revised
July 2014

Preface

The Rhode Island Department of Health Newborn Hearing Screening Program developed the following guidelines in an effort to support a comprehensive and effective statewide mechanism to screen all newborns for hearing impairments, to provide prompt audiological follow-up testing for those infants who do not pass the newborn screening and to provide timely and appropriate early intervention services for those infants who are diagnosed with a hearing loss. These guidelines are based on the Joint Committee on Infant Hearing (JCIH) position statement *Principles and Guidelines for Early Hearing Detection and Intervention Programs* **(See Appendix B**).

This document should serve as a guide for birth facility staff, midwives performing home birth, audiologists and pediatric healthcare providers in the development and implementation of the universal newborn hearing screening and follow-up. This manual is a post-training reference and not a replacement for training.

Newborn hearing screening is a mandated program per Rhode Island General Laws, Section 23-13-13. In 1994 the program was implemented at all birthing hospitals in the state. Leadership for the Newborn Hearing Screening Program is based at the Rhode Island Department of Health, in the Division of Community, Family Health and Equity. Screening, follow-up, tracking, and data management are coordinated through a contract with the Rhode Island Hearing Assessment Program (RIHAP) located at Women and Infants Hospital in Providence, Rhode Island.

Rhode Island Newborn Hearing Screening Program
Contact Information

Rhode Island Department of Health
Newborn Hearing Screening Program
3 Capitol Hill Room 302
Providence RI 02908
Tel: 401-222-6146
Fax: 401-222-1442
Website: http://www.health.ri.gov/programs/newbornscreeningandfollowup/

Rhode Island Hearing Assessment Program
134 Thurbers Ave. Suite 215
Providence, RI 02905
Tel: 401-277-3700
Fax: 401-276-7813
Website: http://www.womenandinfants.org/Services/Hearing-Assessment

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Section 1

Introduction to Hearing Screening

As of 2010, 45 US states and territories have legislation regarding newborn hearing screening and 26 states mandate universal newborn hearing screening. Rhode Island was the first state in the country to enact such legislation. Rhode Island Public Law 23-23-13 ***(See Appendix A),*** passed in 1993, requires that all babies born in the state of Rhode Island have their hearing screened by procedures approved by the state department of health for the detection of hearing impairments.

This same legislation created the Newborn Hearing Screening Advisory Committee. The members of the Newborn Hearing Screening Advisory Committee are responsible for advising the director of the department of health regarding the validity and cost of testing procedures.

Purpose of the Newborn Hearing Screening Program

Hearing loss is the most common birth disorder in the United States, occurring in approximately two to three of every 1,000 newborns. If a hearing loss is not identified at birth, it may be many months before the loss is discovered. Parents are likely unfamiliar with hearing milestones, though many may have the understanding that a child's first words should occur around one year of age. Thus it may not be until these early speech milestones are noted to be delayed that a problem is suspected. If a hearing loss is not diagnosed until one year of age, the child will very likely be significantly delayed with respect to speech and language acquisition and will be at risk of a lifetime of struggle. Prior to the inception of universal newborn hearing screening, the average age of diagnosis for childhood hearing loss was 30 months (2 ½ years).

The goal of a newborn hearing screening program is to identify all congenital hearing loss by the age of one month, allowing for appropriate intervention to occur as soon as possible. The national goals put forth by the Early Hearing Detection and Intervention (EHDI) program are to provide hearing screening for all infants by age one month, provide diagnostic audiological testing for all infants who do not pass their screening by age three months, and begin management of identified hearing loss by age six months.

Recommended Guidelines for Hearing Screening

Following the Joint Committee on Infant Hearing (JCIH) position statement *Principles and Guidelines for Early Hearing Detection and Intervention Programs* that was released in 2007, ***(See Appendix B***), the Rhode Island Newborn Hearing Screening Program set benchmarks for birth facility newborn hearing screening programs, and monitors the programs and provides technical assistance when programs fall below the desired benchmarks.

Birthing facilities should strive to achieve the following:

- Screen all newborns prior to hospital discharge.
- Document the screening date, results, and method.
- Have a percentage of infants who do not pass the initial hearing screening at birth and who get referred for audiological follow up of 4% or less.
- Offer an outpatient rescreen if an infant has been missed or fails to pass the screening in one or both ears, prior to discharge.
- Notify physicians of all screening results, including those of infants who were missed or whose parents refused the hearing screening.
- Offer newborn hearing screening to infants born at home, or those born out-of-state and transferred to a Rhode Island birthing hospital.

Physicians and hospitals are responsible to:

- Refer infants who do not pass the hearing screening at birth to a diagnostic audiologist.
    - It is important to obtain an appropriate diagnostic evaluation prior to 3 months of age in order to decrease the need for sedation of the infant, decrease parental anxiety, and identify the hearing loss within the recommended time frame.

Audiologists are responsible to:

- Notify the Rhode Island Newborn Hearing Screening Program of the diagnostic results, following confirmation of hearing loss or normal hearing.
- Provide support and care coordination services to assure the family receives early intervention services as early as possible or by 6 months of age.

Section 2

Methods of Hearing Screening

The Rhode Island Hearing Assessment Program uses two methods of hearing screening: Transient Evoked Otoacoustic Emissions testing and Automated Auditory Brainstem Response testing. These methods are based on scientifically-proven effectiveness, both in terms of accuracy and in terms of speed and ease-of-use.

Transient Evoked Otoacoustic Emissions (TEOAE)
TEOAE screening is a direct measurement of the function of the outer hair cells of the inner ear. TEOAE have been found to be very sensitive to cochlear hearing loss.

TEOAE are measured by placing a small probe in the external ear of the patient. This probe contains two ports: a speaker and a microphone. Once the probe is placed and the test is started, the speaker emits a buzzing noise. This noise travels through the outer ear and middle ear to the inner ear, where the outer hair cells are stimulated. These hair cells move, stimulating the auditory nerve, but in the process they generate a small amount of noise. This noise is known as an "otoacoustic emission (OAE)." The OAE travels back through the middle ear and outer ear, where it is detected by the microphone portion of the probe. The computer measures this sound over a fairly short period of time and if the sound is of normal intensity, the test is passed. If the OAE is absent or of insufficient intensity, the test is not passed (failed).

TEOAE testing can be performed on a patient who is asleep or awake. Because the test measures very soft noises coming from the inner ear, excessive patient or room noise can undercut the ability to perform the test. Sometimes even minimal patient noise (sucking on a pacifier, feeding, and labored breathing) can interfere with testing.

Additionally, because both the stimulus sound and the otoacoustic emissions are traveling through the outer and middle ear, any problem in these areas can interfere with the test. Examples of this are birthing debris (vernix caseosa) or other material present in the outer ear canal or fluid in the middle ear. Thus, a failed TEOAE screening indicates that there is something reducing the sound of the response of the cochlear hair cells, measured in the external ear canal, but not specifically what area of the ear is causing this problem or whether this is a permanent situation. A failed screening only indicates that further testing is necessary.

Automated Auditory Brainstem Response (AABR)
The Automated Auditory Brainstem Response (AABR) is a measurement of the function of the auditory nerve and components of the auditory nervous system to the level of the midbrain in the brainstem. Also know as (ALGO). When the hair cells in the cochlea respond to sound, they send a signal to the auditory nerve. The auditory nerve generates an action potential, or nerve impulse. This electrical signal travels along the auditory nerve into the brainstem. The electrical (neurological) energy passes through the brainstem where different anatomical structures are stimulated. The AABR measures the electrical energy along the auditory nerve and other structures within the brainstem. This electrical energy is measured graphically, with the energy being viewed as a waveform.

This test is called the "automated" auditory brainstem response because the interpretation of the waveform is performed automatically by the computer. By contrast, a "diagnostic" ABR is interpreted by a trained professional, most commonly an audiologist or otologist.

The AABR is used for hearing screening; the diagnostic ABR is used for final diagnosis of hearing loss and for testing of other problems of the auditory system.

While the AABR is a measurement of auditory nerve and auditory central nervous system function, the stimulus is presented to the auditory system through the outer ear and middle ear. A problem in either or both of these areas can interfere with the test results. For example, if there is some debris blocking the external ear canal, the stimulus will not get to the inner ear at an adequate intensity, resulting in a reduced response from the auditory nerve, which will cause the screening to be failed. Thus, a failed AABR screening indicates that there is something reducing the response of the auditory nerve, but not specifically what area of the ear is causing this problem and whether this is a permanent situation. A failed screening only indicates that further testing is necessary.

Section 3

Hearing Screening Protocols and Procedures

Infants Eligible for Screening
In general, infants in the newborn nurseries can be screened once they are 12 hours old. The reason for this delay is that the infant may still have birthing debris (vernix caseosa) in his or her ears for several hours after birth.

In the NICU the determination of screening candidacy is a little more complicated. First, the infant needs to be at least 34 weeks gestation before he or she is eligible to be screened. Second, the infant needs to be medically stable. The best way to obtain information on this is to talk to the bedside nurse or the medical care provider responsible for the infant. Third, the infant needs to be out of an isolette (warmer) and in a regular crib or pram. Often it is difficult to screen infants who are on ventilation, but if the infant is otherwise eligible, the screening should be attempted.

Patient Preparation
Hearing screening is most likely to be successful when performed on an infant who is quiet and calm, preferably sleeping. If at all possible try to screen each baby when he or she is asleep. Perform a gross inspection of the external ear to assure that the ear appears normally-formed and that the ear canal is open and free of obvious debris. Any noticeable malformations of the ear should be noted. If there is visible debris at the opening of the ear, this material should be wiped away with a clean tissue or gauze pad. Do not attempt to remove any debris that is inside the patient's ear canal.

Protocols
Separate protocols have been designed for use with babies in the Well Baby Nurseries, for babies in the Neonatal Intensive Care Unit (NICU), and for babies born at home.

Well Baby Newborn Nursery - Hearing Screening protocol

- Initial screening - performed using Otoacoustic Emissions (OAE)
  - If this screening is passed, baby is done with screening
  - If this screening is failed, proceed to a secondary screening using Automated Auditory Brainstem Response (ALGO or AABR).

- Secondary screening - performed using automated auditory brainstem response (ALGO or AABR).
  - If infant fails initial (OAE) screening, the AABR screening is performed immediately
  - AABR screening performed on both ears regardless of whether one or both ears failed initial screening
  - If this screening is passed, baby is done with screening
  - If this screening is failed, proceed to a **Re-screen**

- Re-screen – performed if infant failed initial (OAE) and secondary (AABR) screenings.
  ** This will be performed on the day after the infant failed the first two screenings.*
  Re-screen using automated auditory brainstem response (ALGO or AABR)
  - Screening performed on both ears regardless of whether one or both ears failed previous screenings.
  - If this screening is passed, infant is done with screening
  - If this screening is failed, proceed to Outpatient re-screen

- Outpatient re-screen – performed if infant failed initial (OAE) and secondary (AABR) screenings and AABR re-screen.
  Re-screen using automated auditory brainstem response (ALGO or AABR).
  - If this screening is passed, baby is done with screening
  - If this screening is failed, proceed to Diagnostic Auditory Brainstem Response (ABR)

- Diagnostic Auditory Brainstem Response (ABR)
  - This will be done on an outpatient basis
  - This will be performed by approved ABR sites.
  - Schedule ABR prior to discharge
  - For infants who refer on the weekend and for whom follow up care is necessary, the outpatient facility should be contacted the next business day.

Neonatal Intensive Care Unit (NICU) Level II

- Initial Screening – performed using automated auditory brainstem response (ALGO or AABR)
  - If screening is passed, infant is done with screening
  - If screening is failed, patient needs to have diagnostic auditory brainstem response (ABR) testing.
  - Diagnostic ABR testing can be performed by sites provided on the approved ABR site list.
- Diagnostic Auditory Brainstem Response (ABR)
  - This will be done on an outpatient basis
  - This will be performed by approved ABR sites.
  - Schedule ABR prior to discharge
  - For infants who refer on the weekend and for whom follow up care is necessary, the outpatient facility should be contacted the next business day.

Out of Hospital Birth - Home Birth

- Initial screening - performed using a portable Otoacoustic Emissions (OAE) machine.
  - If this screening is passed, baby is done with screening.
  - If this screening is failed, schedule an outpatient re-screen

(See Appendix G - Hearing Screening Policy for Home Births)

Transferred Infants

In-State Transfers

If a newborn is transferred to another Rhode Island birthing hospital and was not screened prior to discharge because of an acute medical condition or other factor, it is the responsibility of the hospital of birth to assure that the hearing screen is conducted.

Adoption or Foster Care

Newborns that will be placed for adoption will have the hearing screening and any repeat screenings conducted prior to discharge. If a referral for diagnostic follow-up is indicated, the follow-up information will be given to the representative of the adoption agency at the time the newborn is discharged, as well as to the birthing facility social worker and/or discharge planner, as per facility policy.

Non-Resident Births

Infants born in a Rhode Island birthing hospital should have the hearing screen conducted, regardless of the state of residence.

Out-of-State Births

Infants that are born out of state and transferred to a Rhode Island hospital should have a hearing screening conducted before discharge. The results will be sent to the EHDI Coordinator for the Department of Public Health in the infant's state of birth ***(see Appendix D - Border Interstate Agreement).***

Transfers out of state
When a Rhode Island-born infant is transferred to an out-of-state hospital and in the event the hearing screen has not been conducted prior to transfer due to the infant's medical condition, screening still needs to occur. Since all states bordering Rhode Island have hearing screening programs, the hospital of transfer should conduct the hearing screening on the infant prior to discharge

Hearing Screening Refusal

In accordance with the Rhode Island General Statute, 23-23-23, a newborn's parent/responsible party has the right to oppose having the hearing screening conducted if it is in conflict with their religious tenets and practice. Should the parents refuse to have the baby's hearing screened, have the parent sign a hearing screening refusal form prior to discharge ***(see Appendix E, Refusal Form*)**. The Hearing Screening Refusal Form can be accessed electronically at:
www.health.ri.gov/forms/refusalofconsent/NewbornHearingScreening.pdf

Remember to:

- Encourage parents to sign the form.
- Healthcare providers should sign the form on the line marked for healthcare providers.
- Send the original form to the Rhode Island Hearing Assessment Program, c/o Women & Infants Hospital 101 Dudley Street, Providence, RI 02905.
- Provide a copy of the form to the parents and send a copy to the baby's primary care provider. Keep a copy for your records.

Section 4

Risk Factors for Hearing Loss

Prior to the inception of newborn hearing screening, the only indicator that an infant may have had a hearing loss was the presence of risk factors. Unfortunately, risk factors are only present in about 50% of infants with hearing loss and thus are inefficient as a method of determining hearing loss. Still, the presence of risk factors should be noted and considered significant, even if the baby passes his or her newborn hearing screening. In many cases, children may have normal hearing at birth but have a condition that results in a progressive or later-onset hearing loss.

The following is a review of conditions considered to be risk factors for hearing loss.

Low Birth Weight (less than 1500 grams)

Infants who are born with low birth weight may not have developed completely before being born. This is the case with infants born prematurely. Though many of the auditory structures develop early on in gestation, the auditory system continues to develop throughout gestation.

A premature birth or low birth weight may result in an incompletely developed and possibly dysfunctional auditory system.

Use of a mechanical vent for more than 5 days

Infants with respiratory problems are considered to be at increased risk for hearing loss, because it is possible that the very delicate organs of the inner ear may not have received sufficient oxygen to thrive.

Multiple courses of ototoxic medication

Certain medications, notably an antibiotic called gentamicin, can be poisonous to the structures of the inner ear. Though the dosages of these medications are carefully monitored, if a baby is on these drugs for extended periods, he or she is at increased risk of permanent hearing loss.

Hyperbilirubinemia

Bilirubin is a substance generated during the normal cell life-cycle. It is normally processed by the liver and excreted in feces and urine. When excessive bilirubin levels build up in the blood it can cause significant neurological damage, including permanent damage to the auditory nerve.

Cranio-facial anomalies

The presence of noticeable abnormalities on the head or face may indicate abnormal development of non-visible areas of the head or face, such as the middle or inner ear or the auditory nerve. These conditions include the following:

- pre-auricular skin tags
- pre-auricular pits
- cleft lip
- cleft palate

Certain congenital infections

Some infections that a baby is born with, acquires shortly after birth, or that were experienced by the mother during pregnancy are associated with permanent hearing loss. These infections include the following:

- toxoplasmosis
- cytomegalovirus
- herpes
- rubella
- syphilis

Family history of hearing loss

In many cases, hearing loss is hereditary. A history of hearing loss in the baby's parents, siblings, grandparents, or aunts or uncles is considered to put the baby at an increased risk for hearing loss.

Syndromes associated with hearing loss

There are hundreds of syndromes associated with hearing loss. Some of the more common include the following:

- Down Syndrome (Trisomy 21)
- Treacher-Collins Syndrome
- Usher Syndrome
- CHARGE Syndrome
- Waardenberg Syndrome
- Pendred Syndrome
- Brancio-Oto-Renal (BOR) Syndrome

Post-natal Infection

Some infections that occur after an infant is born are associated with hearing loss. These include bacterial and viral meningitis.

More than 5 days spent in the NICU

In general, children who spend a longer period of time in the neonatal intensive care unit (NICU) tend to have health conditions that put them at increased risk for hearing loss. Whether it is the condition itself, medications used to treat the condition, or other factors, children with NICU stays longer than 5 days are considered at risk of hearing loss.

Section 5

Screening Protocols for Hospital Readmission

The JCIH Year 2007 Position Statement: *Principles and Guidelines for Early Hearing Detection and Intervention Programs* ***(See Appendix B)*** recommends that an ABR screening should be performed before discharge when an infant is readmitted to a hospital in the first month of life when there are conditions associated with potential hearing loss (eg. hyperbilirubinemia that requires exchange transfusion or culture-positive sepsis).

Section 6

Interpreting the results

When the screen result is a "Pass"

Infants who "*Pass"* the first hearing screen, or any subsequent screenings can be assumed to have adequate hearing function for speech/language development, at that point in time. It is important to note that a "*Pass"* result on the newborn screen does not guarantee normal hearing for the rest of the child's life. Infants and children can "*Pass"* the hearing screen at birth and develop a delayed onset or progressive hearing loss at a later time. Therefore, primary care providers have the responsibility for surveillance of all infants to

monitor for delayed onset or progressive hearing loss. Parental concern at any age should prompt a referral for an audiological evaluation.

- If the infant passes the hearing screen at birth and has one or more risk factors present, the child should be referred for follow-up audiological monitoring. Infants with one or more risk factors should have an audiological evaluation **every six months**, up until age three.
- The infant's parent/responsible party will be notified by screener of the hearing screen result and of the recommendation for follow-up audiological monitoring, both verbally and in writing.
- The newborn's pediatric healthcare provider will be notified of the screening results and any identified risk factors associated with the potential for hearing impairment, which may warrant the need for audiological follow-up.
- Any recommendations for audiological follow-up should be documented on the discharge summary and be explained to the parent/responsible party, prior to discharge. The screener will document that the infant has been screened and will record the results on the Sound Beginnings form (Appendix C). Documentation that infant has been screened must be made in the infant's medical record as well as electronically through RITRACK the Newborn Hearing Screening Data System**.**
- If the infant passed the hearing screen at birth and has NO risk factors, the child should receive ongoing surveillance of communicative development beginning at 2 months of age, during well-child visits in the medical home.

When the baby "Does Not Pass" the screen

Any infant who does not pass the first hearing screening in one or both ears, must have, at a minimum, a second hearing screening performed prior to discharge. The second, or repeat screening, should be conducted using the (ALGO-AABR) equipment.

- If the baby does not pass the 2nd AABR screen, the child should be referred for a Re-screen using automated auditory brainstem response (ALGO or AABR)
- A list of Testing Centers for a rescreening, and, when indicated, comprehensive evaluation, including diagnostic ABR testing is available. For rescreening, a complete screening on both ears is recommended, even if only one ear failed the initial screening.
- The birth hospital should ensure that parents and primary healthcare professionals receive and understand the hearing screening results, that parents are provided with appropriate follow-up and resource information, and that each infant is linked to a medical home.
- The birth facility should ensure that hearing screening information is transmitted promptly to the state Newborn Hearing Assessment Program.

Explaining results to parents

Hearing screening results are to be presented to parents of infants in the Well Baby newborn Nurseries by the hearing screeners. Results of hearing screenings performed on infants in the Neonatal Intensive Care Unit (NICU) will be discussed with the parents by the NICU medical care team.

Infants screened while in the nursery

When an infant is screened in the nursery, results are to be recorded as is typically done. The screener is not responsible for giving the results to the parents at that time. The results may be given to the parents both verbally and in writing at the end of the screener's shift. Additionally, at the time that the results are given verbally and in writing to the parent(s), the parents should also be given the CDC milestones card and the Frequently Asked Questions sheet with results in writing.

Infants screened in a Mother/Baby room

When an infant is screened in a Mother/Baby (M/B) room, or taken from the M/B room for screening in the nursery, the parent(s) should be given the results of the screening verbally at the completion of the screening. Additionally, at the time that the results are given verbally and in writing to the parent(s), the parents should also be given the CDC milestones card and the Frequently Asked Questions sheet with results in writing.

Example scripts:

"Passing" script

Congratulations on the birth of your baby. The hearing screen was a pass. It is important to monitor his/her speech and language development because his/her hearing can change. Here's a brochure that talks about speech and language development. If you are ever worried about your baby's hearing, talk to his/her doctor and ask for a referral to an audiologist who is skilled at testing infants and young children.

"Initial not passing" script

Congratulations on the birth of your baby. The hearing screen was just completed and the result was not a pass. This does not necessarily mean that your baby has a permanent hearing loss, but without additional testing we can't be sure. The screening result will be sent to your baby's doctor. It is important to repeat the screening. Please be sure to keep this appointment for the re-screen.

"Re-screen not passing" script

Your baby did not pass the 2nd screen. The screening does not tell us whether your baby has a permanent hearing loss. It just tells us that further testing should be done as soon

as possible. The next step is to get a diagnostic test. This test should be discussed immediately with your baby's doctor who may need to help you with obtaining a referral to a pediatric audiologist.

"Pass with risk factor" script

Congratulations on the birth of your baby. The hearing screen was a pass. We have identified that your baby has a risk factor for hearing loss. This means that your baby may be at increased risk of developing a hearing loss. A follow up hearing test is recommended at about 6 months of age. A reminder will be sent to you and the pediatrician. Here's a brochure that talks about speech and language development.

"Missed screen" script

A hearing screening was not done on your baby. It is important that your baby be screened as soon as possible. Please be sure to keep this appointment for the hearing screen.

Section 7

Scheduling Procedures for Outpatient Tests

Outpatient Procedures:

Patients are to be scheduled for outpatient testing under the following conditions:

1. Screening performed when infant was an inpatient was not a pass or was incomplete.
    - Schedule patient for "Outpatient Re-screen" at birthing hospital with hearing screener prior to discharge
2. Screening was not performed on patient in the hospital (patient was a "miss").
    - Schedule patient for "Outpatient Initial Screening" at hospital with hearing screener prior to discharge
3. Patient did not pass all hearing screenings
    - Schedule patient for "Diagnostic Auditory Brainstem Response (ABR)" at an ABR site with an audiologist prior to discharge

Outpatient Initial Screening

- Appropriate for infants who did not receive hearing screening as inpatients (are a "miss")
- If an infant was missed for hearing screening as an inpatient the parents will be contacted by the Birthing hospital. The Birthing hospital will schedule the infant for an Outpatient Initial Screening with a hearing screener.
- Birthing hospital will send Sound Beginnings Form to RIHAP.
- Make sure you fill out the five questions on the back of the Sound Beginnings Forms for all re-screens.

- Diagnostic ABR
- Appropriate for former Well Baby Newborn Nursery infants who have failed their inpatient screens and outpatient re-screen.
- If an infant has returned for an outpatient screening and the screening was not passed, this infant should be scheduled for a diagnostic ABR prior to leaving the re-screen appointment. ***(See Appendix I - for approved ABR site list.)***
- If the parent is concerned about the results of the hearing screening and wishes to speak to an audiologist, the screener may contact RIHAP and the audiologist will discuss the test results with the parent.

Section 8

Guidelines for Rhode Island Pediatric Medical Home Providers

Coordination with Medical Homes is essential to reducing loss to follow-up. When recommendations for follow-up are sent, primary care providers also receive the RI EHDI Algorithm ***(Please see Appendix F)***, which guides them through the follow-up process and improves coordination of care. RIHAP also sends the EHDI family algorithm to all patients in a practice who were referred from newborn screening and reminder letters for follow-up.

Section 9

Data Reporting to the Rhode Island Department of Health

Newborn Hearing Screening Reporting

The hearing screening facility (i.e., birthing hospital, midwife) must provide the Department of Health with data concerning the number of newborns screened or not screened. Demographic information is downloaded daily from the Rhode Island child health information system (KIDSNET). Screening results are transferred electronically from OAE screening equipment to RITRACK. Individual-level AABR screening results are received by paper form. All OAE results are submitted on the Sound Beginnings form ***(See Appendix C)***, as back up to the electronic transfer.

Diagnostic Reporting

Hearing loss is a reportable birth defect by law and regulation. State law *23-12.3-BD* ***(See Appendix H)*** of the General Laws of Rhode Island mandates that audiologists send data to the Department of Health concerning the result of diagnostic testing for all infants who did not pass an audiological assessment and who were identified with a hearing impairment. Data and information should be reported electronically into KIDSNET or by US postal mail to RIHAP.

Section 10

Early Intervention – Part C

All children diagnosed with established conditions that have a high probability of resulting in developmental delay, are eligible for Early Intervention (EI) services until the child's third birthday. Diagnostic must be made by a physician or other appropriately licensed professional and documentation of medical diagnostic is required ***(See Appendix K).***

Once any degree of hearing loss is confirmed in a child, a referral should be initiated to the Early Intervention Part C system within 2 days of confirmation of hearing loss.
A supplement to the JCIH 2007 Position Statement advocates for the implementation of a coordinated statewide system with the expertise to provide individualized, high-fidelity EI programs for children who are Deaf and Hard of Hearing and their families. "Principles and Guidelines for Early Intervention after Confirmation That a Child Is Deaf or Hard of Hearing" can be referenced ***(See Appendix J).***

Appendices

Appendix A: RIGL 23-13-13 http://webserver.rilin.state.ri.us/
Appendix B: Joint Committee on Infant Hearing (JCIH) in 2007
http://www.jcih.org/ExecSummFINAL.pdf
Appendix C: Sound Beginnings Form
Appendix D: Newborn Hearing Screening Interstate Exchange Agreement
Appendix E: Parent Refusal Form
http://www.health.ri.gov/forms/refusalofconsent/NewbornHearingScreening.pdf
Appendix F: Guidelines for Rhode Island Pediatric Medical Home
http://www.health.ri.gov/publications/guidelines/UniversalNewbornHearing.pdf
Appendix G: Hearing Screening Policy for Home Birth
Appendix H: RIGL 23-13.3-BD http://webserver.rilin.state.ri.us/Statutes/TITLE23/23-13.3/23-13.3-3.HTM
Appendix I: Diagnostic approved ABR site list
http://www.health.ri.gov/find/pediatricaudiologists/
Appendix J: Supplement to the JCIH 2007 Position Statement
http://pediatrics.aappublications.org/content/131/4/e1324.full.pdf+html
Appendix K: Rhode Island Early Intervention established conditions and significant developmental delays
http://www.eohhs.ri.gov/Portals/0/Uploads/Documents/EI%20Policies%20and%20Procedures%202.Eligibility%20November%202013.pdf

RIHAP Rhode Island Hearing Assessment Program

Sound Beginnings Form

Birth Facility:_____

All sections of form MUST be complete per JCAHO standards.

Room Assignment:_____

Infant Demographic Data – Completed by screener

Screener ID:

**Hospital registration label may be used to document Infant's Medical Record Number, Mother's Name and Infant's Last Name.

Date of Birth	Gestational Age	Gender	Birth Weight	C-Section
___/___/___	_____ wks	_____	_____g	□ Yes □ No

Medical Record Number** _____

Private Ped./ Clinic/Other _____ □ Unknown

NEO Admission _____

Mother's Name** _____

NICU admission □ Yes □ N/A Reason_____ Date ___/___/___

Infant's Last Name** _____

Re-Admit □ Yes □ N/A Reason_____ Date ___/___/___

Infant's First Name _____ □ Unknown

Transfer □ Yes □ N/A Reason_____ Date ___/___/___

Hearing Screening Information – Completed by screener

Screener ID:

			OAE Left	OAE Right	AABR Left	AABR Right
Initial Screen Date___/___/___	Screener ID: _____ AABR Protocol □ Yes □ N/A	Results Attached	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT
		Coded Result	Left_____	Right_____	Left_____	Right_____
Child Will Receive a Re-do In-Patient Screen on Date ___/___/___ □ N/A						
Redo Screen Date___/___/___	Screener ID: _____ AABR Protocol □ Yes □ N/A	Results Attached	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT
		Coded Result	Left_____	Right_____	Left_____	Right_____
Outpatient Screen * ** Date___/___/___	Screener ID: _____ AABR Protocol □ Yes □ N/A	Results Attached	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT	□ Yes □ DNT □CNT
		Coded Result	Left_____	Right_____	Left_____	Right_____

*** If Outpatient screen: please answer questions on back of form

Hearing screening results (circle one) PASS NOT A PASS

Abbreviations
CNT - Could Not Test DNT - Did Not Test
OAE - Otoacoustic Emissions AABR - Automated Auditory Brainstem Response

Screening Result codes
OAE Codes 1 - Pass 3 - Fail 4 Invalid 7 - CNT 8 - DNT
AABR Codes 1 - Pass 2 - Fail 7 - CNT 8 - DNT

If child did NOT receive a screening indicate the following below. – Completed by screener

1) Date of missed screening Date____/____/____

2) Reason for the missed screening (indictate reason from the list below)

Transfer to (please specify hospital): Expired

Discharged to Home Parent Refused Other(please specify):

Risk factors for hearing loss (Check all that apply)

Completed by **medical provider** signature: date___/___/___

- □ None Identified
- □ Birth Weight less than 1500grams
- □ Mechanical Vent more than 5 days
- □ Multiple Courses of Ototoxic Medication
- □ Exchange for Hyperbilirubinemia
- □ Skin Tag(s) right / left (please indicate)
- □ Pre-auricular Pit right / Left (please indicate)
- □ Cleft Palate
- □ Cleft Lip
- □ Toxoplasmosis
- □ Cytomegalovirus (CMV)
- □ Herpes
- □ Rubella
- □ > 5 Days in NICU
- □ Family History or Hearing Loss since childhood (Please Specify Relationship)
- □ Syndrome or Aneuploidy Associated with Hearing Loss (Please Specify)
- □ Other (Please specify)

Audiological recommendation (check one) completed By Screeners Screener: Date:___/___/___

□ **Discharge -** No audiological follow-up indicated at this time. Primary care provider should perform routine surveillance as some children may have late onset hearing loss.

□ **Outpatient Initial Screen -** Outpatient initial screening needed due to missed, incomplete or invalid screening. **Your Birthing Hospital will contact family to schedule outpatient screening in 1 – 3 weeks.**

□ **Rescreen -** In-patient screening results not a pass. Outpatient repeat screening needed. **Your Birthing Hospital will contact family to schedule outpatient screening in 1 – 3 weeks.**

For More Information
Contact the Rhode Island Hearing Assessment Program (RIHAP) at 401-277-3700.

□ **Medical Monitor -** Periodic hearing tests starting at 6 months corrected age due to risk factors associated with late onset or progressive hearing loss. **RIHAP will mail information about recommended audiological follow-up testing to family and primary care physician.**

□ **Diagnostic ABR** – In-patient screening results were not a pass, due to risk factors for hearing loss, diagnostic testing necessary. RIHAP audiologist will contact family to discuss screening results and help schedule outpatient diagnostic testing. **For inpatient W&I NICU babies, medical provider should order DXABR to be completed prior to discharge, by contacting the RIHAP/W&I Audiologist at 401-277-3700.**

***These results are for a screening and should NOT be considered a permanent diagnosis.**

Newborn Hearing Screening
Interstate Exchange Agreement

I. PURPOSE OF THE AGREEMENT

The purpose of this Agreement is to facilitate the sharing of newborn hearing screening results and demographic tracking information concerning residents of one state who were born in a different state among Newborn Hearing Screening Programs in the six New England States and New York. This will enable each state signing this Newborn Hearing Screening Interstate Exchange Agreement to collect information about its residents in order to provide appropriate and timely follow-up services, and to maintain more accurate and complete information on newborn hearing screening results for its residents.

II. DEFINITIONS

The following terms when used in this Agreement shall have the meanings ascribed below:

"Confidential Data" means any individually identifiable information, including, but not limited to, medical and demographic information, that:

1) Reveals the identity of a person or is readily identified with that person, such as name, address, telephone number, or date of birth; or
2) Provides a reasonable basis to believe that the information could be used, either alone or in combination with other information, to identify a person.

"Data Owner" means the state Newborn Hearing Screening Program that collects newborn hearing screening data on children born and/or screened in that state.

"Newborn Hearing Screening Data" or "the Data" means the screening results and demographic information collected by a Newborn Hearing Screening Program.

"Newborn Hearing Screening Program" means the office or program in any of the six New England States and New York that is authorized by law to collect information related to hearing screening results and demographics for any child born and/or screened in that state and whose duly authorized representative has signed this Agreement.

"Recipient" means the state Newborn Hearing Screening Program that receives newborn hearing screening data on its residents sent to it by the Data Owner.

III. AGREEMENT

The undersigned Data Owners hereby agree to:

A. Provide Newborn Hearing Screening Data to the Newborn Hearing Screening Program of the state of residence of the infant to whom the data applies. The Data Owner agrees to provide all data elements specified in Attachment A except those that the Data Owner specifically excludes in Attachment A.

B. Provide Newborn Hearing Screening Data on a Newborn Hearing Screening Data form (Attachment A) in a mutually agreed upon method of data transfer that complies with Section IV below.

C. Provide the Data on a monthly basis and/or upon request, unless the Data Owner and the Recipient mutually agree upon and document in writing a different schedule.

D. Protect the confidentiality of any Newborn Hearing Screening Data it receives from a Data Owner in accordance with Section IV of this Agreement.

IV. CONFIDENTIALITY AND SECURITY PROVISIONS

When receiving Newborn Hearing Screening Data from a Data Owner, the Recipient will:

A. Only use the Data (1) for providing follow-up services to its residents; (2) for maintaining more accurate and complete information on its residents' newborn hearing screening results; (3) as required by law; and (4) for statistical, program evaluation, and administrative purposes provided that any use of the Data by the Recipient would not violate HIPAA, other federal law, and the state law of the Data Owner. When using the Data for statistical, program evaluation and administrative purposes, the Recipient agrees to use only the minimum necessary amount of the Data needed to accomplish the purpose for which it is being used. The Recipient must obtain the written permission from the Data Owner to use the Data for any other purpose.

B. Establish with the Data Owner a secure mechanism for transfer and receipt of the Data to prevent unauthorized access to the Data. This mechanism shall be agreed to and documented in writing by the Data Owner and the Recipient.

C. Limit access to the data to only those staff that are authorized to have access. Data may also be accessed by the Recipient's agents or contractors who have agreed in writing to not further disclose this Data and to abide by the terms of this Agreement. Re-release of Newborn Hearing Screening Data is strictly prohibited except for aggregate data or other releases that are approved in writing by the Data Owner or the data subject.

D. Provide appropriate administrative, physical, and technical safeguards to ensure the confidentiality and security of the Data and prevent unauthorized use or access to it. Upon request from the Data Owner, the Recipient will identify in writing all of the safeguards that it uses to prevent unauthorized use or access. Safeguards shall include, but are not limited to, storing the Data, if in paper format, in locked files with access limited to authorized individuals only and storing the Data, if in electronic format, by password protecting, encrypting, or otherwise securing all electronic copies of the Data to permit access only by authorized individuals.

E. Place an electronic flag or other equivalent marker on any records in any electronic databases that contain the Data in order to maintain a record of the Data and the Data Owner received pursuant to this Agreement.

F. Obtain permission from the Data Owner before publishing or otherwise publicly releasing any information derived from the Data so that the Data Owner may ensure that the conditions specified in this Agreement have been met, except that aggregate statistical data may be released without prior approval of the Data Owner provided that cell sizes less than 5 are suppressed and any complimentary cells that could lead to the calculation of a suppressed cell are also suppressed.

G. Provide telephone and written notice to the Data Owner as soon as possible, but no longer than 48 hours, after becoming aware of a violation of this Agreement or any unauthorized access to the Data. The notification must provide a full description of the breach and corrective action taken or to be taken. The Recipient shall take corrective action, to the extent practicable, to mitigate any harmful effect that is known to it.

H. Notify the Data Owner if the Recipient receives a subpoena or other compulsory legal process that requires disclosure of any of the Data. The Recipient agrees to provide such notification as soon as possible, but no later than 48 hours, after receipt of such subpoena or other compulsory legal process or prior to the return date specified in the subpoena or other compulsory legal process, which ever is sooner, and agrees to take all legal steps reasonably necessary to oppose the disclosure of the Data Owner's Newborn Hearing Screening Data.

V. TERMS OF AGREEMENT

A. Any Newborn Hearing Screening Program may terminate its participation in this Agreement by providing 30 days advance written notice to all other Newborn Hearing Screening Programs of its intent to terminate its participation.

B. Any Newborn Hearing Screening Program may terminate its participation with respect to any particular state by providing 30 days advance written notice to that state and notifying in writing all other participating Newborn Hearing Screening Programs.

C. The requirements of Section IV of this Agreement remain in effect as long as the Data are held by the Newborn Hearing Screening Program and survive the termination of this Agreement.

D. The laws of the state of the Data Owner shall govern disputes related to the Data. Any ambiguity in this Agreement shall be resolved to permit the Data Owner to comply with the federal and state laws applicable to it.

Approval of Newborn Hearing Screening Programs:

State: Vermont

Name of Program: Vermont Early Hearing Detection and Intervention Program

Signed by: Wendy S. Davis, MD

Print Name and Title: Wendy S. Davis, MD, Commissioner

Primary Data Contact (if different): Stacy M Jordan

Date: 9/2/08

State: Massachusetts

Name of Program: Universal Newborn Hearing Screening Program

Signed by: X Ron Benham

Print Name and Title: Ronald Benham, Acting Director, Bureau of Family Health and Nutrition

Primary Data Contact (if different): Janet M. Farrell

Date: 11/14/08

State: Rhode Island

Name of Program: Rhode Island Newborn Hearing Screening Program/KIDSNET

Signed by:

Print Name and Title: David R. Gifford, MD, MPH Director of Health

Primary Data Contact (if different): Ellen Amore

Date:

Approval of Newborn Hearing Screening Programs (cont.):

State: _____

Name of Program: _____

Signed by: _____

Print Name and Title: _____

Primary Data Contact (if different): _____

Date: _____

State: _____

Name of Program: _____

Signed by: _____

Print Name and Title: _____

Primary Data Contact (if different): _____

Date: _____

State: _____

Name of Program: _____

Signed by: _____

Print Name and Title: _____

Primary Data Contact (if different): _____

Date: _____

VERMONT

Department of Health
Children with Special Health Needs
Newborn Hearing Screening Program
108 Cherry Street, PO Box 70, Drawer 28
Burlington, VT 05402

[phone] 802-865-1330
[fax] 802-951-1218

Agency of Human Services

Attachment A

The Vermont Early Hearing Detection and Intervention (EHDI)/Universal Newborn Hearing Screening (UNHS) Program will share information with other states on newborns and infants who have a hearing screening conducted in Vermont but reside in another state.

The following data elements will be provided:

Baby Information:
Last Name
First Name
Date of Birth
Birth Facility
Gender

Guardian Information:
Last Name
First Name
Telephone Number
Mailing Address

Screening Information:
Right Ear:
Place Screening was conducted
Date
Final Results
Technology Used

Left Ear:
Place Screening was conducted
Date
Final Results
Technology Used

Massachusetts ATTACHMENT A
EHDI Border Baby Data Reporting Form

Today's Date: ___ / ___ / _____

Resident State: ____

Reporting State: **Program Contact:** **Phone Number:**

Birth Information:

1) Infant First Name: _____ Last Name: _____
2) Infant's Date of Birth (mm/dd/yyyy): ___ / ___ / _____
3) Sex of Infant: Male / Female / Undetermined
4) Birth Hospital: _____
5) Infant Death: Yes / No
6) Birth Order (if multiple births occurred): _____

Parent / Guardian Information:

7) Mother First Name: _____ Mother Last Name: _____
8) Mother Primary Language: _____
9) Mother Address:
   Street: _____ Apt. #: _____
   City: _____ State: _____ Zip Code: _____
10) Mother Phone Number: _____

Hearing Screening Information:

11) Screening Hospital: _____
12) Date of Screening: ___ / ___ / _____

BABY WAS SCREENED:

- ☐ Passed Both Ears
- ☐ Both Ears Did Not Pass
- ☐ Left Ear Did Not Pass
- ☐ Right Ear Did Not Pass
- ☐ Screened, missing information

BABY WAS NOT SCREENED, because:

- ☐ Missed
- ☐ Parents Refused Test
- ☐ Child is deceased
- ☐ Child was transferred
- ☐ Other reason (specify):

Infant's Primary Care Provider:

13) Name: _____
14) Address:
   Street: _____ Apt. #: _____
   City: _____ State: _____ Zip Code: _____

Additional Information, Restrictions, and/or Data Exclusions (specify if applicable):

_____

_____

_____

_____

_____

Rhode Island ATTACHMENT A
EHDI Border Baby Data Reporting Form

Today's Date: ____ / ____ / _____

Residence State: _____ **Program Contact:** _____ **Phone #:**_____

Infant's Birth Information:

1) First Name:_____ Last Name:_____
2) Date of Birth (mm/dd/yyyy): ____ / ____ / _____
3) Sex: Male / Female / Unknown
4) Birth Hospital: _____
5) Deceased? Yes / No
6) Birth Order (if multiple births occurred): _____

Parent / Guardian Information:

7) Mother First Name: _____ Mother Last Name:_____
8) Primary Language: _____
9) Mother Address:
   Street: _____ Apt #: _____
   City: _____ State: _____ Zip Code: _____
10) Mother Phone #: _____

Hearing Screening and Diagnostic Information:

11) Screening Hospital: _____
12) Newborn Hearing Screening Results

Date Tested	Screen Type	Result

Screening Result:
Audiological Recommendation:
Risk Factors:

13) Diagnostic Information:

Date Tested: Audiologist:
Diagnosis Left: Diagnosis Right:
Degree Left: Degree Right:
Tests performed:

Infant's Primary Care Provider:

14) Name: _____
15) Address: Street: _____
    City: _____ State: _____ Zip Code: _____

Additional Information / comments:

_____

_____

_____

RIHAP RHODE ISLAND HEARING ASSESSMENT PROGRAM

PROGRESS NOTES

NOTE: ALL REMARKS MUST INCLUDE THE SIGNATURE OF PROVIDER, DATE AND TIME.

Questions for caregiver at time of outpatient screening.

1. At how many weeks did you deliver? _____ Weeks
2. What was your child's birth weight? _____ g
3. Did your child, at any time, go to the Special Care Nursery/NICU? ☐ Yes ☐ No *Reason*_____
4. Has your child had any ear infections? ☐ Yes ☐ No
5. Is there a family history of hearing loss since childhood? ☐ Yes ☐ No *If Yes, what is family relation?*_____

Date	*Time*	*Comments and Remarks*

AABR Results Attached Here

Newborn Hearing Screening

You play an important role in ensuring that all babies born at home are screened for hearing loss. Rhode Island General Law §23-13-13 requires hospitals to offer hearing screening for all newborns. Babies born at home have access to hearing screening services through the Rhode Island Hearing Assessment Program (RIHAP). National hearing screening goals are to screen all babies by one month of age, to diagnose referred babies by three months of age, and to initiate Early Intervention for babies diagnosed with hearing loss by six months of age.

What you should do

1. Inform the parents of the newborn hearing screening requirement and talk with them about the benefits of hearing screening.

- Use the Newborn Screening and Services brochure, Frequently Asked Questions sheet, and as a resource when answering questions.

2. Complete the hearing screening.

- Equipment, manual, scripts to explain results, Sound Beginnings forms to record results, list of birthing hospitals, and step by step screening instructions provided by RIHAP.
- Contact RIHAP at (401)277-3700 with any questions about equipment and/or screening protocol.

Explain results to families.

- If the child passes, discuss the importance of ongoing surveillance.
- If the child does not pass, discuss the need for follow-up and assist with arranging a rescreening appointment at any of the birthing hospitals. (See list of Birthing Hospitals)
- See Scripts to give results to parents.
- Follow-up Rescreen appointments should be made for one to two weeks after the initial screen.
- Complete the Hearing Screening Results and Recommendation form and give it to the family for their records.

Record Demographic Information and Screening Results on Sound Beginnings Form

- Complete all of the information on the Sound Beginnings Form
- Print screening results from the equipment.
- Fax a copy of the screening results and completed Sound Beginnings form to RIHAP at (401)276-7813.
- Keep a copy for your records.

Review

- There will be annual visits by the Department of Health, where screening data will be reviewed.
- An internal policy and procedure must be created for Newborn Hearing Screening to be submitted to the Department of Health for review.
- Annual skills checks will also be performed by RIHAP.

Equipment

- To replenish supplies such as disposable ear tips or if any equipment issues arise please contact RIHAP immediately at (401)277-3700.

- The hearing screening equipment must be completed annually. RIHAP will contact you and a date and time will be coordinated for this to take place.

3. Should the parents refuse to have the baby's hearing screened, have the mother sign a refusal of consent form.

- Encourage parents to sign the form.
- Sign the form yourself on the line marked for healthcare providers.
- Send the original form to the Rhode Island Hearing Assessment Program, c/o Women & Infants Hospital 101 Dudley Street, Providence, RI 02905.
- Provide a copy of the form to the parents and send a copy to the baby's primary care provider. Keep a copy for your records.
- Find extra forms in this binder. Order additional forms at www.health.ri.gov/forms/onlineordering/form_maternal.php
- For refusal forms go to www.health.ri.gov/forms/refusalofconsent/NewbornHearingScreening.pdf