

R398. Health, Family Health and Preparedness, Children with Special Health Care Needs.

R398-2. Newborn Hearing Screening: Early Hearing Detection and Intervention (EHDI) Program.

R398-2-1. Authority and Purpose.

- (1) Authority for this rule is found in Section 26-10-6, Testing of newborn infants.
- (2) The purpose of this rule is to facilitate early detection, prompt referral, and early intervention of infants who are deaf or hard of hearing.

R398-2-2. Definitions.

- (1) "Audiologist" means a person who is licensed by the state where services are provided and has expertise in infant and pediatric audiology.
- (2) "Birth attendant" means the person or provider that assists with an infant's birth.
- (3) "Deaf or Hard of Hearing" means a dysfunction of the auditory system of any type or degree that is sufficient to interfere with the acquisition and development of speech and language skills.
- (4) "Department" means the Utah Department of Health, Newborn Hearing Screening: Early Hearing Detection and Intervention (EHDI) program.
- (5) "Diagnostic procedures" means audiometric and medical procedures required to diagnose an infant as deaf or hard of hearing.
- (6) "Early intervention" means auditory habilitation, enrollment into a formal early intervention program or both.
- (7) "Follow-up" means appropriate services and procedures relating to the confirmation of hearing status and appropriate referrals for infants with abnormal or inconclusive screening or diagnostic results.
- (8) "Institution" means a facility licensed by this state for birthing babies.
- (9) "Lost to follow-up" means infants who cannot be identified through tracking, and who have not completed the screening, diagnostic or early intervention referral processes.
- (10) "Newborn hearing screening" means the completion of an objective, physiological test or battery of tests administered to determine the infant's hearing status and the need for further diagnostic testing by an audiologist with expertise in infant and pediatric audiology or physician with the Department approved instrumentation, protocols and pass-fail criteria. Newborn hearing screening includes both the initial screening and follow-up screening as required after a fail result; this would include outpatient rescreening if born in hospital.
- (11) "Parent" means a natural biological parent, a stepparent, adoptive parent, legal guardian, or other legal custodian of a child.
- (12) "Primary care provider" means the infant's primary medical caregiver.
- (13) "Referral" means to direct an infant to an audiologist or physician for appropriate diagnostic procedures to diagnose and determine hearing status and for appropriate early intervention.
- (14) "Tracking" means the use of information about the infant's newborn hearing screening status to ensure the infant receives timely and appropriate services to complete the screening, diagnostic and early intervention referral processes.

R398-2-3. Implementation.

Each newborn in this state shall submit to the newborn hearing screening testing, except as provided in Subsection 26-10-6(1), Testing of newborn infants.

R398-2-4. Responsibility for Screening.

- (1) Each institution shall designate a person to be responsible for the newborn hearing screening program in that institution.
- (2) An audiologist who is licensed by the state shall oversee each newborn hearing screening program. This audiologist may be full or part time, on or off site, an employee of the institution, or under contract or other arrangement that allows them to oversee the newborn hearing screening program. The audiologist shall advise the institution about each aspect of the newborn hearing screening program, including screening, tracking, follow-up, and referral for diagnosis.
- (3) The institution must provide inpatient newborn hearing screening services as required by this rule before discharge, unless the infant is transferred to another institution before screening is completed. For infants who need additional procedures to complete the screening process due to a missed test, inconclusive results, or a failure to pass, the institution shall provide outpatient screening.
- (4) If the infant is transferred to another institution before screening is completed, the receiving institution must provide inpatient hearing screening services as required by this rule before discharge. For infants who need additional procedures to complete the screening process due to a missed test, inconclusive results, or a failure to pass, the institution shall provide outpatient screening.
- (5) If the infant is born outside of an institution, the birth attendant must perform or arrange for the infant's hearing screening before ten days of age as required by this rule. This shall include follow-up screening as required after a fail result.
- (6) If there is no birth attendant, a parent must have the infant's hearing screened, according to Department protocols, before the infant is ten days of age. This shall include follow-up screening as required after a fail result.
- (7) Newborn hearing screening shall be performed by a person who is appropriately trained and supervised, according to protocols as established by the Department with input from the Newborn Hearing Screening Committee, as described in Subsection 26-10-6(5).

R398-2-5. Information to Parents and Primary Care Providers.

(1) Institutions or birth attendants shall provide information about newborn hearing screening to parents and primary care providers of infants. This shall include:

(a) information, which shall be available to parents at the time of birth, about the purpose of newborn hearing screening, the procedures used for screening, the benefits of newborn hearing screening;

(b) whether each live birth was screened before discharge from the institution;

(c) the results of the completed newborn hearing screening;

(d) what follow-up screening procedures, if any, are recommended and where those procedures can be obtained; and

(e) cytomegalovirus (CMV) testing, as described in Section 26-10-10, when appropriate.

(2) For infants who require additional procedures to complete the screening process after being discharged from the birthing institution, the institution shall provide parents and the primary care providers with written notice about the availability and importance of the additional screening procedures along with when to return to the institution for outpatient rescreening. For infants who do not complete additional hearing screening procedures, the institution shall send a second written notice to the parents and the primary care provider.

(3) For infants who fail the complete newborn hearing screening procedure, the institution or the provider who completes the newborn hearing screening procedure shall provide the parents and the primary care provider with written notice about the results of the screening, recommended diagnostic procedures, where those procedures can be obtained.

(4) For infants who need additional procedures to complete the screening due to a missed test, inconclusive results, or a failure to pass, and who do not return for the needed newborn hearing screening procedures before ten days of age, or for infants who are lost to follow-up, the institution or birth attendant shall make reasonable efforts to locate the parents and inform them of the need for testing. To be considered a reasonable effort, the institution or birth attendant must have documentation of at least two attempts to contact the infant's parents, and at least one attempt to contact the infant's primary care provider. If necessary, the institution or birth attendant must use information available from its own records, adoption agencies, and the infant's primary care provider. Contact with the parent may be made by mail, email, telephone, text, primary care provider, or public health worker.

R398-2-6. Reporting to Utah Department of Health.

(1) Each institution or birth attendant shall submit information to the Department about the newborn hearing screening procedures being used, the results of the screening, and other information necessary to ensure timely referral where necessary. This information shall be provided to the Department at least weekly. This information shall include:

(a) for each live birth, identifying information for the infant, last name, date of birth, newborn screening kit number, birth mother's first and last name and/or other information as determined by the Department, and the hearing screening status, including passed, failed, inconclusive, refused, missed, transferred, deceased;

(b) for infants who did not pass the newborn hearing screening or who were not screened, this additional information is required: primary contact's first and last name, address, telephone number, and primary care provider's first and last name, and/or other information as determined by the Department;

(c) any information the institution or provider has about the results of follow-up screening, diagnostic procedures, and cytomegalovirus lab results; including whether the infant has been lost to follow-up.

(2) Each institution shall submit information to the Department a summary of the procedures used by the institution or screening program to do newborn hearing screening, including the name of the program director, overseeing audiologist, equipment, screening protocols, pass-fail criteria, and parent education materials and other information as determined by the Department. This information shall be provided to the Department bi-annually and within 30 days of any changes to the existing procedures.

(3) Persons who conduct any procedure necessary to complete an infant's hearing screening or audiological diagnostic assessment, shall report the results of these procedures to the institution where the infant was born and to the Department within seven days.

(4) The Department shall have access to infants' medical, diagnostic, amplification, implantation, and early intervention records to obtain information necessary to ensure the provision of timely and appropriate followup diagnostic and intervention services, including CMV testing results and follow-up, congenital CMV sequelae, treatments, and anything else deemed necessary to determine long-term outcomes.

(5) Providers who diagnose an infant or child as deaf or hard of hearing shall refer the families to early intervention and family to family support services. To facilitate timely intervention services, the provider shall:

(a) Send each necessary diagnostic result and recommendation to the early intervention program; and

(b) Advise families on the benefits of early intervention services for any permanent atypical hearing levels or chronic middle ear effusion.

R398-2-7. Confidentiality of Reported Information.

(1) The confidentiality of personal information obtained under this rule shall be maintained pursuant to Title 26, Chapter 3, Health Statistics. The reports are confidential and are not open to public inspection.

(2) Pursuant to Title 26, Chapter 25, Confidential Information Release, persons who report information covered by this rule may not be held liable for reporting the information to the Department of Health.

R398-2-8. Penalty for Violation of Rule.

Any person who violates any provision of this rule may be assessed a penalty as provided in Section 26-23-6.

KEY: newborn hearing screening

Date of Last Change: February 14, 2022

Notice of Continuation: June 19, 2018

Authorizing, and Implemented or Interpreted Law: 26-10-6