How to Engage EHDI Stakeholders in Monitoring Programs for Risk Indicators

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Disclaimer

I have no relevant financial relationships with the manufacturers of any commercial products and/or provider of commercial services discussed in this CME activity

I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation

Learning Objectives

Participants will be able to identify the stakeholders involved with monitoring for delayed-onset hearing loss.

Participants will be able to explain options for risk monitoring protocols.

Participants will be able to describe opportunities to engage stakeholders within the monitoring process.

Goals of risk monitoring program

Identify infants and children at risk for delayed onset or progressive hearing loss

Timely diagnostic assessments from a pediatric audiologist

Maintain a monitoring and tracking system in the state EHDI data management system

EHDI eBook, 2015

EHDI program survey

Purpose of survey development: determine if EHDI programs across US and Canada monitor and track risk indicators for congenital or delayed-onset hearing loss

Data collected from October 2016-January 2017

Survey sent to:

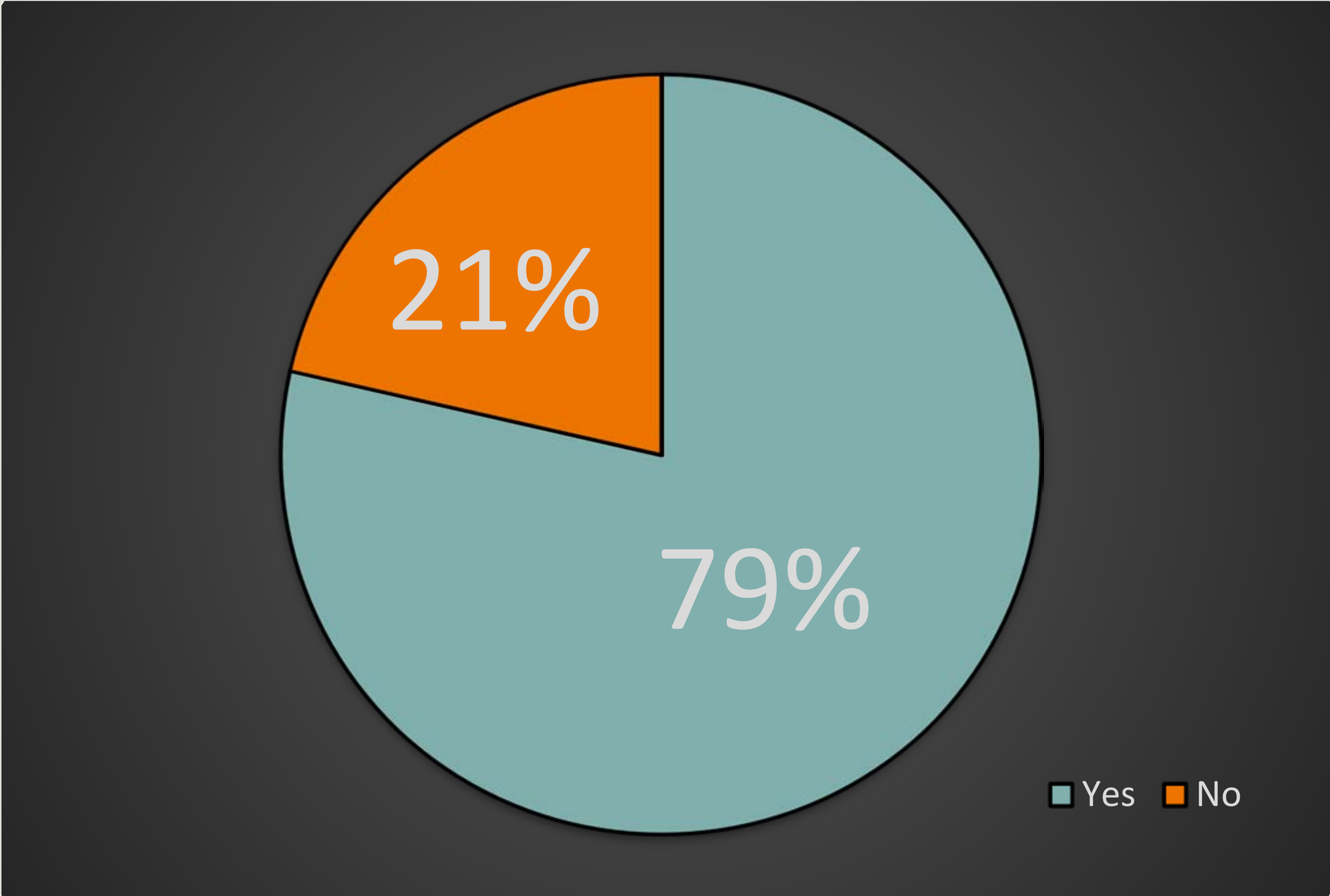
- 66 EHDI coordinators across United States
- Unknown number across Canada (*11 territories*)

42 responses received

- 37 from US (response rate of 56.1%)
- 5 from Canada (response rate of 45.5%)

Stich-Hennen & Bargen, 2017

EHDI program monitor risk indicators for delayed-onset and/or progressive hearing loss



Stich-Hennen & Bargen, 2017

Barriers to monitoring risk indicators for EHDI programs

Accurate reporting by hospital staff

Accurate reporting by families (i.e. family history)

Accurate and timely reporting by audiologists

Shortage of pediatric audiologists

High lost-to follow-up rates

Lack of support by medical homes

Lack of funding

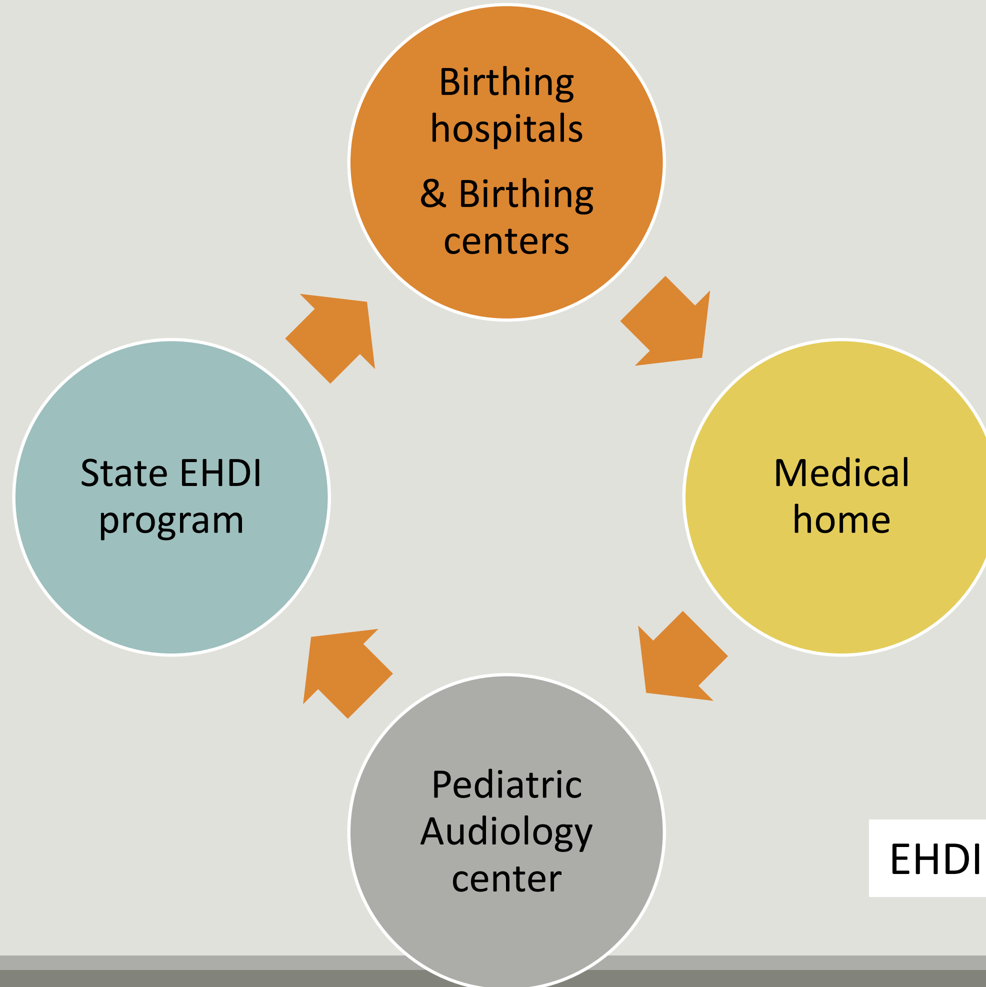
No standard protocol for audiological monitoring of risk indicators

- What age to start/stop monitoring
- What tests to use for evaluation

Stich-Hennen & Bargen, 2017

Identify the stakeholders

Risk Monitoring Program



EHDI eBook, 2015

Birthing Hospital/Birthing Center roles:

Identify infants who have 1 or more risk indicators

Provide family with referral to pediatric audiology clinic

Provide family with information about risk indicators

Provide medical home information regarding risk indicator referral

Report infants with risk indicators to state EHDI program

EHDI eBook, 2015

Medical home roles:

Being familiar with risk factors for delayed onset hearing loss

Explaining screening results and answer questions for the family

Encourage risk monitoring follow-up

Providing family with referral to pediatric audiology clinic

EHDI eBook, 2015

Pediatric audiology center roles:

Providing appropriate comprehensive diagnostic testing for children with risk factors

Knowledge of risk factors that have high prevalence of delayed onset hearing loss and require early and more frequent assessments

Providing documentation regarding evaluation outcomes to state EHDI program

EHDI eBook, 2015

State EHDI program roles:

Providing training and support for hospitals, birthing center, physicians, and pediatric audiologists on risk factor

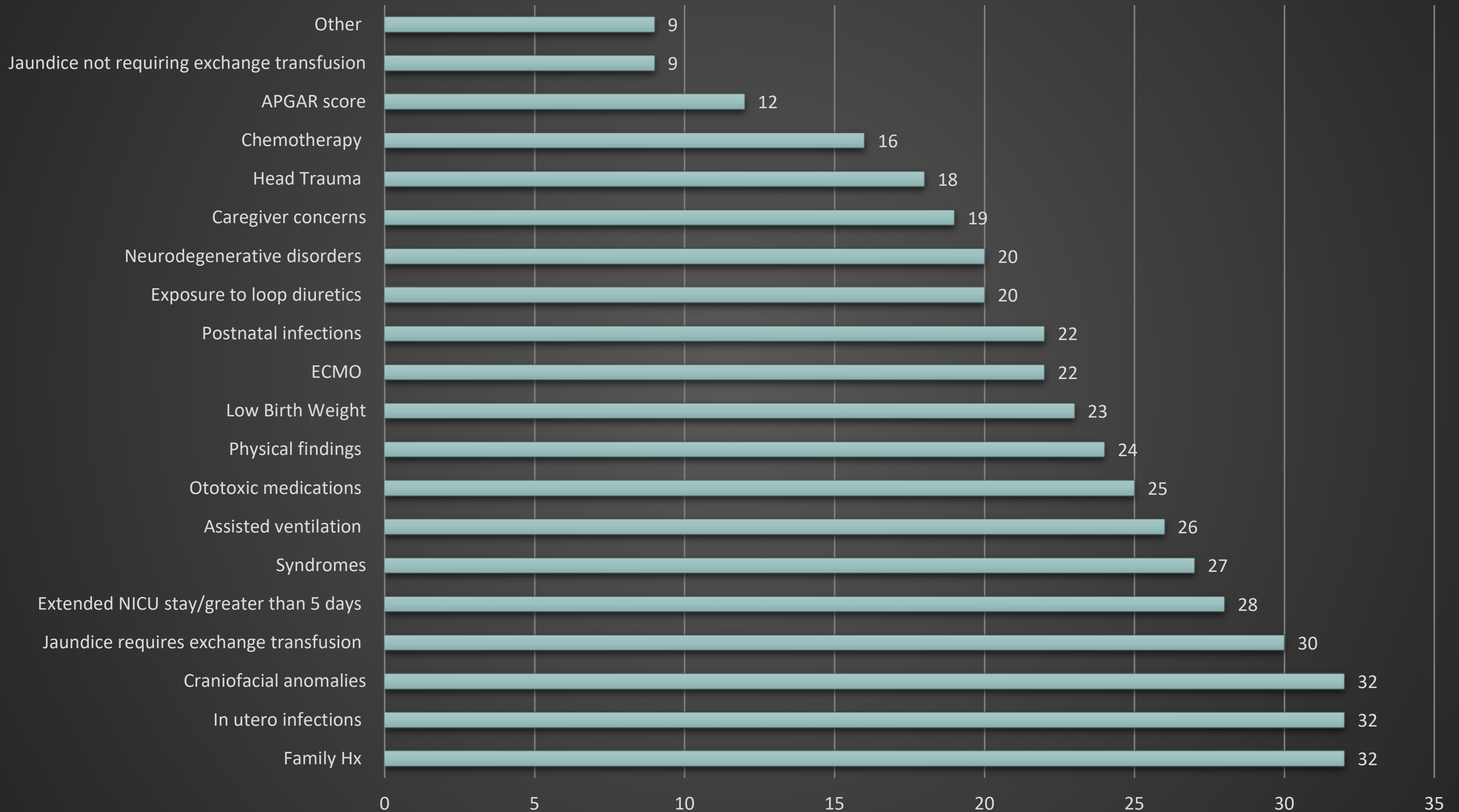
Providing a method for hospitals, birthing centers and pediatric audiologists to report information regarding infants with risk indicators to the state EHDI program

Tracking and surveillance of infants with risk factors

EHDI eBook, 2015

Risk monitoring protocols

Which risk indicators does your EHDI program monitor?



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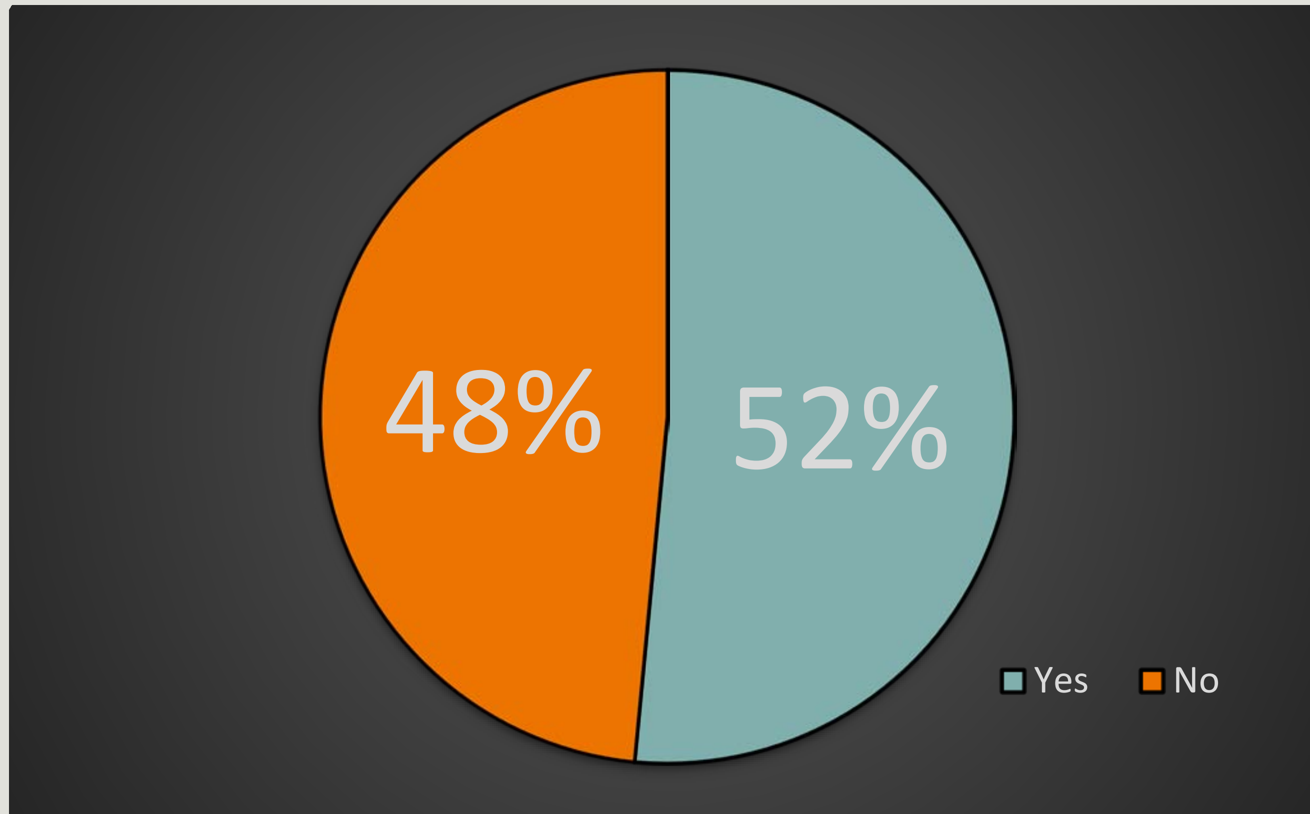
Do you **provide state audiology clinics with guidelines for monitoring risk indicators** for delayed-onset and/or progressive hearing loss (i.e. when to test, which risk indicators to monitor, how long to monitor)?



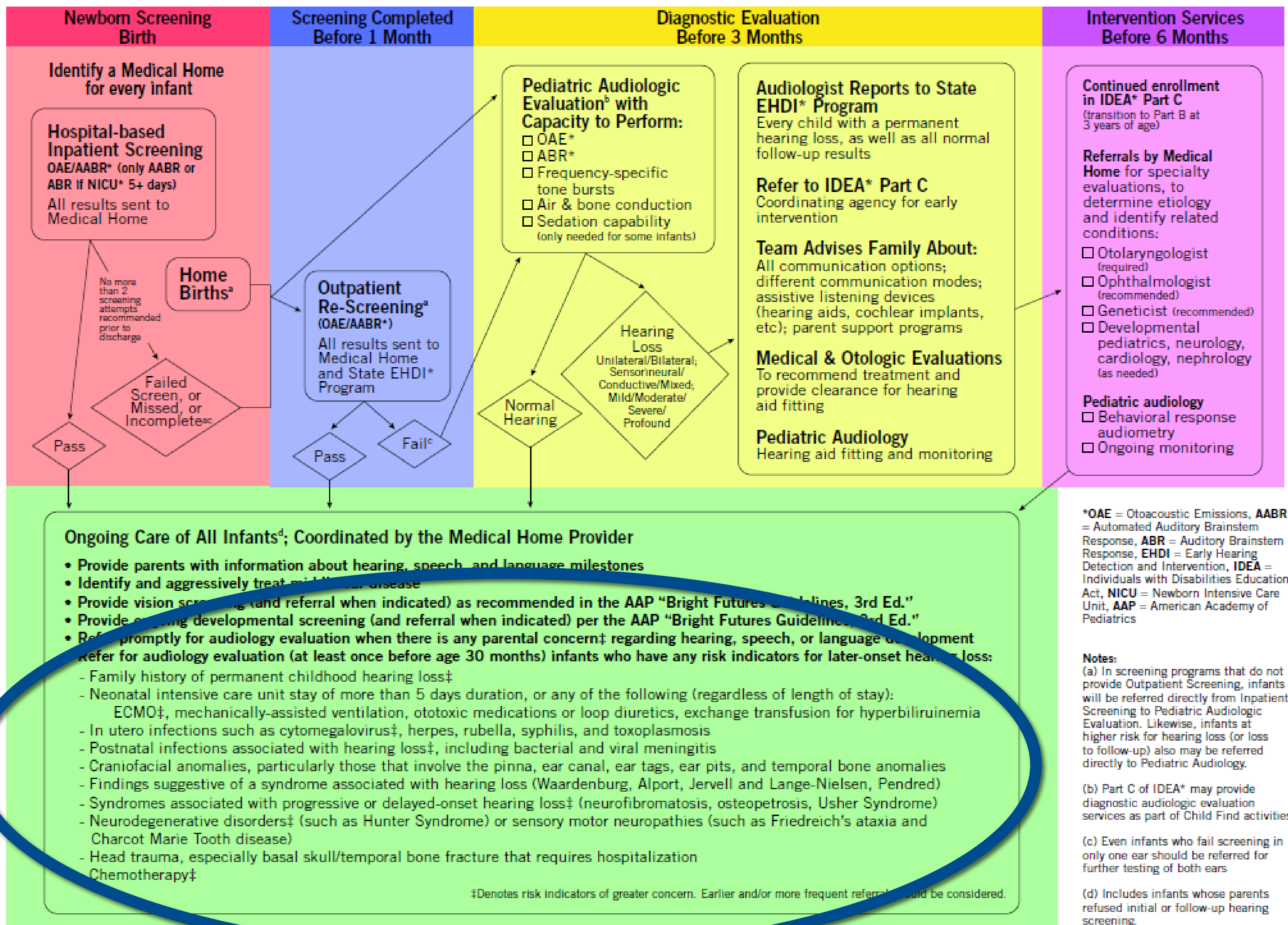
Stich-Hennen & Bargen, 2017

2007 JCIH Position Statement

"Infants with risk factors for hearing loss should be referred for an audiological assessment "at least once by 24-30 months of age."

Children with risk indicators that are "highly associated with delayed onset hearing loss, such as having received ECMO or having CMV infection, should have more frequent audiological assessments."

JCIH Position Statement 2007



JCIH Position Statement 2007

Opportunities to engage stakeholders

Ideas to engage stakeholders

Provide education opportunities

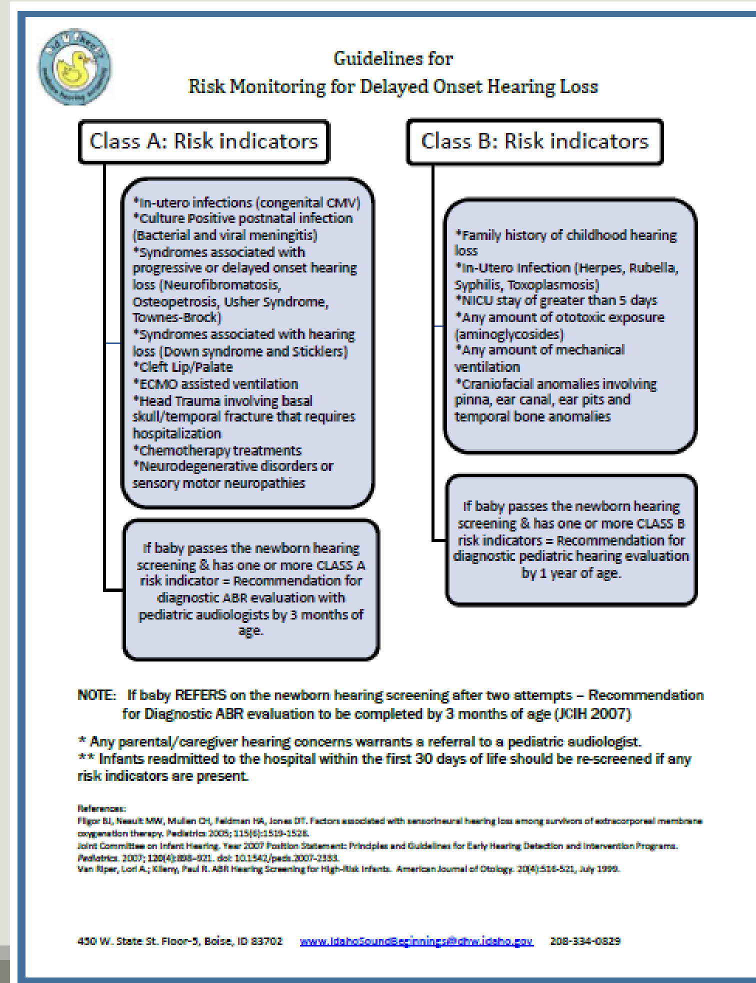
- Families
- Medical professionals

Provide reporting tools

- Birthing Hospitals/Birthing Center
- Audiologists

Provide program feedback

Who needs referral??



Guidelines for
Risk Monitoring for Delayed Onset Hearing Loss

Class A: Risk indicators

*In-utero infections (congenital CMV)
*Culture Positive postnatal infection (Bacterial and viral meningitis)
*Syndromes associated with progressive or delayed onset hearing loss (Neurofibromatosis, Osteopetrosis, Usher Syndrome, Townes-Brock)
*Syndromes associated with hearing loss (Down syndrome and Sticklers)
*Cleft Lip/Palate
*ECMO assisted ventilation
*Head Trauma involving basal skull/temporal fracture that requires hospitalization
*Chemotherapy treatments
*Neurodegenerative disorders or sensory motor neuropathies

If baby passes the newborn hearing screening & has one or more CLASS A risk indicator = Recommendation for diagnostic ABR evaluation with pediatric audiologists by 3 months of age.

Class B: Risk indicators

*Family history of childhood hearing loss
*In-Utero Infection (Herpes, Rubella, Syphilis, Toxoplasmosis)
*NICU stay of greater than 5 days
*Any amount of ototoxic exposure (aminoglycosides)
*Any amount of mechanical ventilation
*Craniofacial anomalies involving pinna, ear canal, ear pits and temporal bone anomalies

If baby passes the newborn hearing screening & has one or more CLASS B risk indicators = Recommendation for diagnostic pediatric hearing evaluation by 1 year of age.

NOTE: If baby REFERS on the newborn hearing screening after two attempts – Recommendation for Diagnostic ABR evaluation to be completed by 3 months of age (JCIH 2007)

* Any parental/caregiver hearing concerns warrants a referral to a pediatric audiologist.
** Infants readmitted to the hospital within the first 30 days of life should be re-screened if any risk indicators are present.

References:
Fligor BJ, Neault MW, Mullen CH, Feldman HA, Jones DT. Factors associated with sensorineural hearing loss among survivors of extracorporeal membrane oxygenation therapy. Pediatrics 2005; 115(6):1519-1528.
Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*. 2007; 120(4):898–921. doi: 10.1542/peds.2007-2333.
Van Riper, Lori A.; Kileny, Paul R. ABR Hearing Screening for High-Risk Infants. American Journal of Otology. 20(4):516-521, July 1999.

450 W. State St. Floor-5, Boise, ID 83702 www.IdahoSoundBeginnings@dhw.idaho.gov 208-334-0829

What do we tell the family??

“Your baby has been identified as having a risk indicator (________) for delayed-onset or progressive hearing loss. It is recommended that any baby with (_______) risk indicator has an audiological evaluation (_____) months of age. We will provide a copy of this referral form to the pediatric audiology center and they will contact you for an appointment.”

Referral forms

4. RISK ASSESSMENT (check all that apply)

FOR LATER-ONSET CHILDHOOD HEARING LOSS:

____Family History of Permanent Hearing Loss <18 yrs of age

____NICU stay >5 days

____Syndrome Associated with HL (e.g. Downs)

____Congenital Infection (e.g. T-O-R-C-H)

____Postnatal Infection (e.g. Meningitis)

____Craniofacial Anomalies-____________________

____Ototoxic Medications - any amount

____Mechanical Ventilation - any amount

____Parent or Physician Concern

____Head Trauma ___ Other ____________________

(monitoring through age 3 is recommended for most risk factors)

☐ Your baby **did not pass** the hearing screen. Hearing testing should be completed before baby is **3 months** old. If baby is not hearing all the sounds necessary for speech and language development early identification can minimize any communication delays.

☐ Your baby is **at risk for later-onset childhood hearing loss.** Hearing testing at approximately **8 months** of age is recommended for most risk factors. A Pediatric Audiologist can advise on the appropriate monitoring schedule for your baby.

Audiologist: ____________________

Phone: ____________________

Address: ____________________

Appt. date/time:

Risk indicator letters

Idaho Sound Beginnings
Early Hearing Detection and Intervention Program (EHDI)
Idaho Infant Toddler Program – 450 W State St. Boise, ID 83720-(208) 334-0829

«Today»

«Recipient_Address»

Child's Name: «Baby_Name»
Date of Birth: «Birth_Datetime»
Hospital «Birth_Hospital»

Dear Mr./Ms. «Contact_Lastname»:

Congratulations! We hope you are enjoying the exciting first days of your baby's life.

Your baby had their hearing screened shortly after birth. While your baby may have passed their screening there is a possibility that hearing loss could develop later on due to the risk factor(s) that were identified:

- «Risk_Indicators»

We recommend at least one diagnostic hearing test before 3 months of age by a pediatric audiologist based on your child's risks. Please talk to your baby's physician about obtaining a referral for a hearing evaluation.

If you need help finding a pediatric audiologist in your area, please visit www.EHDI-PALS.org or you can call us at (208) 334-0829 if you do not have internet access. We encourage you to make an appointment for your child as soon as possible. If you have any questions or concerns, please call (208) 334-0829 or email us at IdahoSoundBeginnings@dhw.idaho.gov .

Included is a brochure on the Idaho Infant and Toddler Program, a free program to help you understand your child's development.

Warmest regards,

Brian Shakespeare
Idaho Sound Beginnings Program Coordinator

Andrea Amestoy, R.N.
Parent Outreach Consultant

Enclosure:
Your Baby's Hearing Test
Information on www.EHDI-Pals.org
Idaho Infant and Toddler Brochure

Because babies can't tell us if they can't hear…

Idaho Sound Beginnings
Early Hearing Detection and Intervention Program (EHDI)
Idaho Infant Toddler Program – 450 W State St. Boise, ID 83720-(208) 334-0829

«Today»

«Recipient_Address»

Child's Name: «Baby_Name»
Date of Birth: «Birth_Datetime»
Hospital «Birth_Hospital»

Dear Mr./Ms. «Contact_Lastname»:

Congratulations! We hope you are enjoying the exciting first year of your baby's life.

Your baby had their hearing screened shortly after birth. While your baby may have passed their screening there is a possibility that hearing loss could develop later on due to the risk factor(s) that were identified:

- «Risk_Indicators»

We recommend at least one diagnostic hearing test at approximately 9-12 months of age by a pediatric audiologist. Please talk to your baby's physician about obtaining a referral for a hearing evaluation.

If you need help finding a pediatric audiologist in your area, please visit www.EHDI-PALS.org or you can call us at (208) 334-0829 if you do not have internet access. We encourage you to make an appointment for your child as soon as possible. If you have any questions or concerns, please call (208) 334-0829 or email us at IdahoSoundBeginnings@dhw.idaho.gov .

Included is a brochure on Developmental Milestones, a free program to help you understand your child's development.

Warmest regards,

Brian Shakespeare
Idaho Sound Beginnings Program Coordinator

Andrea Amestoy, R.N.
Parent Outreach Consultant

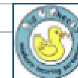
Enclosure:
How to Prepare for Your Child's Hearing Test
Information on www.EHDI-Pals.org
Developmental Milestones Brochure

Because babies can't tell us if they can't hear…

How do we find audiologists?

Provide guidance for testing

Idaho Sound Beginnings Best Practice Protocol



Audiology Assessment for Risk Factor Follow- up

"The timing and number of hearing re-evaluations for children with risk factors should be **customized and individualized depending on the relative likelihood of a subsequent delayed-onset hearing loss.**" (JCIH 2007 Position Statement)

Early and more frequent assessment may be indicated for children with: cytomegalovirus (**CMV**) infection, **syndromes** associated with progressive hearing loss, **neurodegenerative** disorders, trauma, culture-positive **postnatal infections** in association with sensorineural hearing loss; for children who have received **ECMO** or **chemotherapy**; and when there is a **caregiver concern** or a **family history** of hearing loss (JCIH 2008 clarification)

Recommended *Minimum* Standards:

Behavioral testing at 9 months of age**

All testing should be ear-specific

Tests included in this evaluation are:

- ☑ Family/child history
- ☑ Otoscopy
- ☑ Visual Reinforcement Audiometry for each ear:
  - Minimal Response levels for air conduction: 500, 2000 and 4000 Hz
  - Bone conduction as needed to rule out conductive pathology
  - Speech Awareness Thresholds (SAT)
- ☑ Limited Otoacoustic Emissions, DPOAE and/or TEOAE
- ☑ Immittance battery:
  - 226 Hz probe tone tympanometry-each ear.
  - Ipsilateral acoustic reflexes at 500, 1000 and 2000 Hz;(can also use broadband noise reflex – normal is less than 80 dB HL)
- ☑ ABR testing is indicated, if hearing loss is diagnosed, or if responses to behavioral audiometry are not reliable.

Based on: American Speech-Language-Hearing Association. (2004). *Guidelines for the Audiologic Assessment of Children from Birth to 5 Years of Age*. [Guideline]. www.asha.org/policy

The recommendation for the initial risk factor evaluation to be done at 9 **months of age is based on the following factors:

The ease of testing using Visual Reinforcement Audiometry for the child and family. and

The ability to gather the greatest amount of information quickly with minimal repeat visits, balanced with…

The ability to identify and address hearing losses and caregiver concerns early enough during the critical "language learning period" to maximize communication skills and minimize speech and language delays. Testing of a 2 year old can also be difficult, time consuming and delays identification.

Risk Indicators Associated with Permanent Congenital, **Delayed-onset**, or **Progressive** Hearing Loss in Childhood

1. **Caregiver concerns** regarding hearing, speech, language or developmental delay
2. **Family history** of permanent childhood hearing loss.
3. Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: **ECMO**, assisted ventilation, exposure to ototoxic medications (gentamycin/tobramycin) or loop diuretics (furosemide/Lasix) and hyperbilirubinemia requiring exchange transfusion.
4. In utero infections: CMV, herpes, rubella, syphilis, and toxoplasmosis.
5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.
6. Physical finding, such as a white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
7. **Syndromes associated with hearing loss** or progressive or late onset hearing loss such as neurofibromatosis, osteopetrosis and Usher syndrome; other frequently identified syndromes including Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.
8. **Neurodegenerative disorders**, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.
9. **Culture-positive postnatal infections associated with sensorineural hearing loss**, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
10. Head trauma, especially basal skull/temporal bone fractures that requires hospitalization.
11. **Chemotherapy**

Risk factors **bolded** are considered to have a greater concern for delayed onset hearing loss and monitoring of those children should be **more frequent** than once following the neonatal period.

Principles and Guidelines for Early Hearing Detection and Intervention Programs: Appendix 2. Joint Committee on Infant Hearing 2007 Position Statement (www.jcih.org)

Idaho Sound Beginnings (EHDI)
Infant Toddler Program, 450 W. State St.Fl-5, Boise, ID 83720-0036
(208) 334-0829 (208) 332-7331 FAX
Cynthia Carlin, EHDI Project Coordinator – carlinc@dhw.idaho.gov

Funding Provided By Maternal & Child Health Bureau (MCHB), Health Resources And Services Administration (HRSA)

Quick and easy reporting opportunities

Paper forms

IDAHO SOUND BEGINNINGS
Early Hearing Detection and Intervention (EHDI)
Department of Health and Welfare, Infant Toddler Program

AUDIOLOGY RESULTS FORM
BIRTH TO 3 YEARS

FAX completed form to 208-332-7331 within 5 days of evaluation.

Online reporting

On-Line Hearing Evaluation Submission Form

Contact Idaho Sound Beginnings (ISB) for your "State HT Code" before using this form.

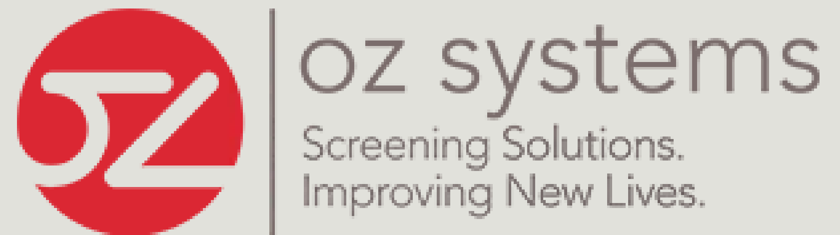
The form is accessed at the following link:
https://htweb.dhw.idaho.gov/HiTrack_4/HiTrack_4_Web_PL/SubmitHearingEvaluation.aspx

Hearing Disposition: Select the Degree of Loss from the drop-down list for each ear. If there is a loss, select the Type of Loss and Configuration of Loss for each ear. If there is a permanent hearing loss, or if hearing has been confirmed as Normal, check the "Confirmed" box.

DxABR: Select the appropriate info from each of the drop-down boxes in each section where values are to be entered. Values entered must be a whole number or integer, with no decimal point, and divisible by 5 (5, 10, 15, 20...).

OAE: Select the appropriate info from each of the drop-down boxes as needed.

Use of data management system



Did U Check?
newborn hearing screening

Prevalence of infants WITH risk indicators in Idaho (2007-2017)

Year	% infants WITH risk indicators	% infants WITHOUT risk indicators
2007	3.1	96.9
2008	4.1	95.9
2009	7.3	92.7
2010	9.3	90.7
2011	9.8	90.2
2012	10.2	89.8
2013	11.4	88.6
2014	11.6	88.4
2015	11.5	88.5
2016	10.7	89.3
2017	10	90

Childhood hearing loss in Idaho (2007-2015)

13% PASSED newborn hearing screening and had risk indicators

13%

41% FAILED newborn hearing screening and had NO risk indicators

41%

43% FAILED newborn hearing screening and had risk indicators

43%

3%

3% PASSED newborn hearing screening and had NO risk indicators

REFERENCES

Hi-Track data from Idaho Sound Beginnings Program (2007-2017).

Joint Committee on Infant Hearing (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Invention Programs. *Pediatrics*, *120*: 898-921.

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