

#### How to Engage EHDI Stakeholders in Monitoring Programs for Risk Indicators

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**ELKS** Hearing and Balance Center

Services provided by St. Luke's





### 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 program survey

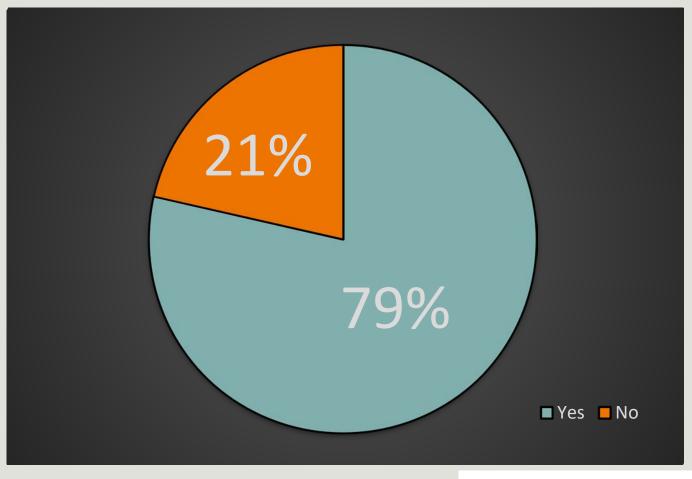
Purpose of survey development: determine if EHDI programs across US and Canada monitor and track risk indicators for congenital or delayed-onset hearing loss

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%)

EHDI program monitor risk indicators for delayedonset and/or progressive hearing loss



# 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

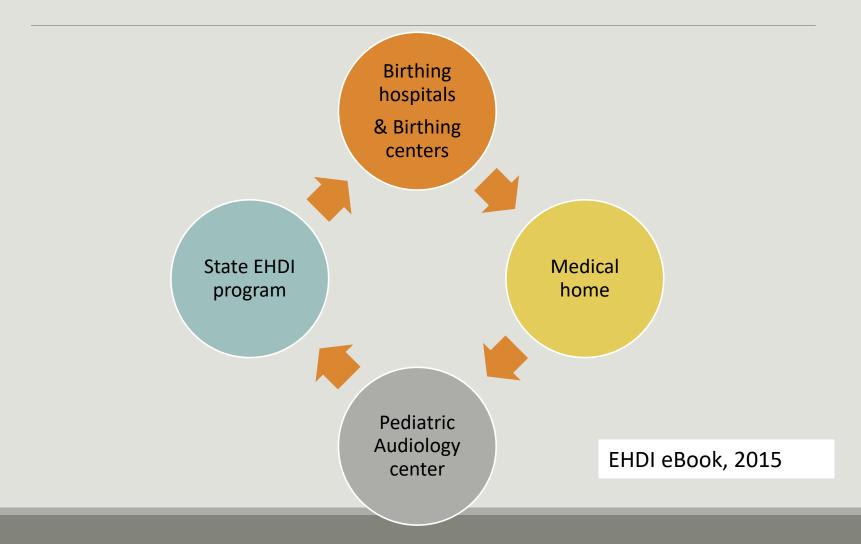
Lack of funding

No standard protocol for audiological monitoring of risk indicators

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

#### Identify the stakeholders

#### **Risk Monitoring Program**



# 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

### 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

## 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

## State EHDI program roles:

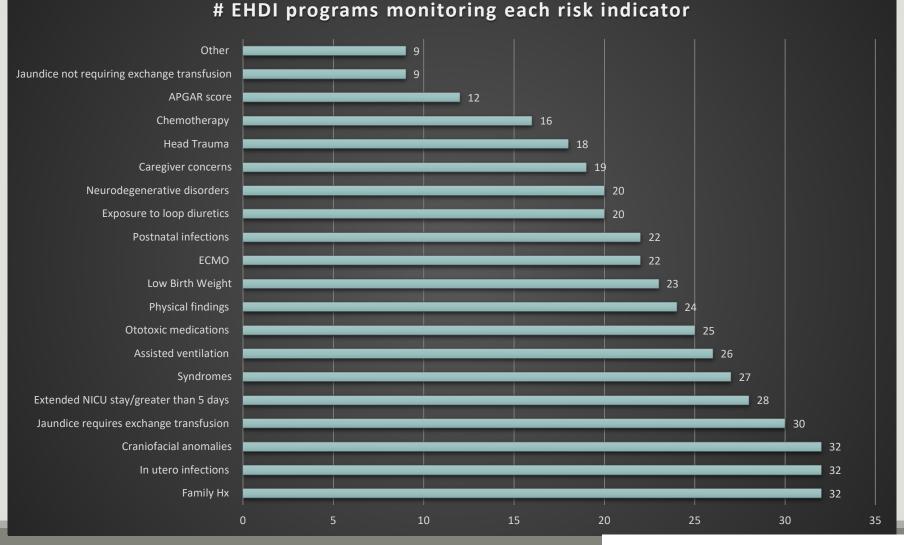
Providing training and support for hospitals, birthing center, physicians, and pediatric audiologists on risk factor

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

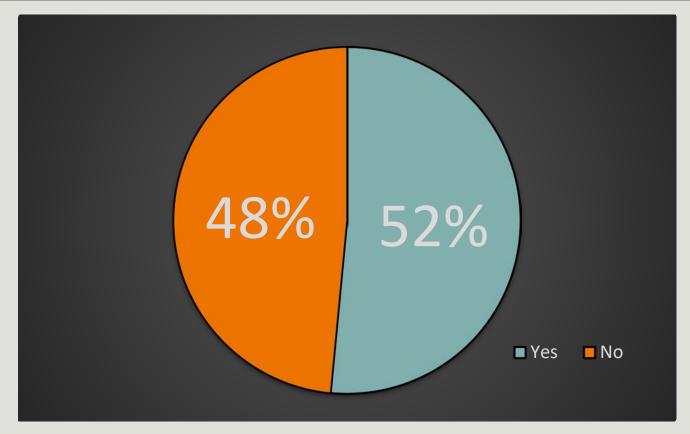
Tracking and surveillance of infants with risk factors

#### Risk monitoring protocols

# Which risk indicators does your EHDI program monitor?



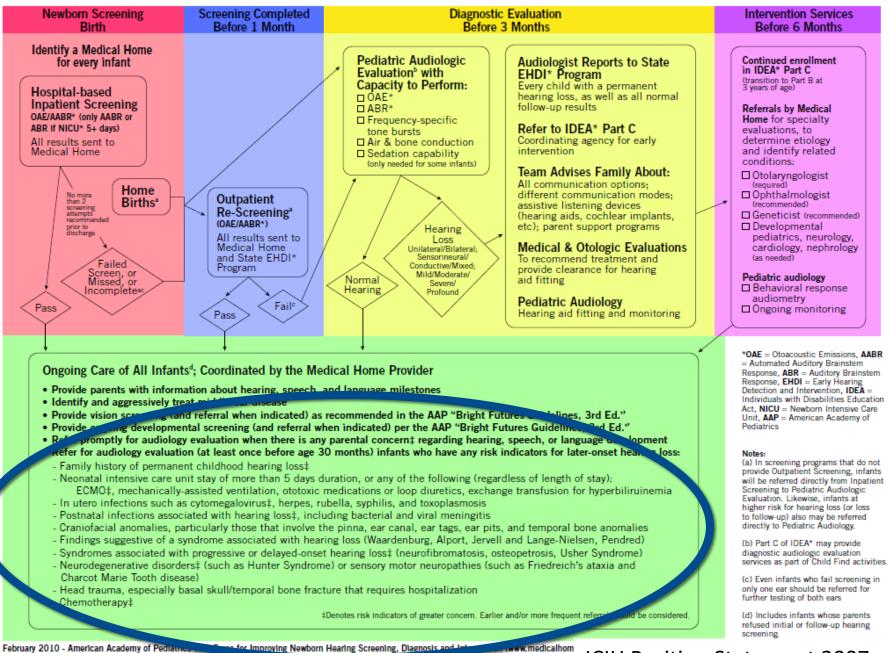
Do you provide state audiology clinics with guidelines for monitoring risk indicators for delayed-onset and/or progressive hearing loss (i.e. when to test, which risk indicators to monitor, how long to monitor)?



### 2007 JCIH Position Statement

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

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



JCIH Position Statement 2007

#### Opportunities to engage stakeholders

### Ideas to engage stakeholders

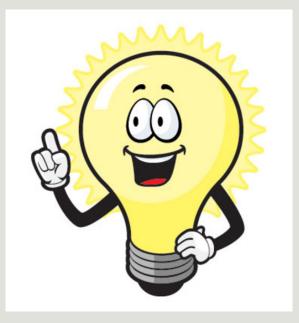
#### Provide education opportunities

- 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 Class B: Risk indicators
<ul> <li>*In-utero infections (congenital CMV)</li> <li>*Culture Positive postnatal infection (Bacterial and viral meningitis)</li> <li>*Syndromes associated with progressive or delayed onset hearing loss (Neurofibromatosis, Osteopetrosis, Usher Syndrome, Townes-Brock)</li> <li>*Syndromes associated with hearing loss (Down syndrome and Sticklers)</li> <li>*Cleft LipPalate</li> <li>*ECMO assisted ventilation</li> <li>*Head Trauma involving basal skull/temporal fracture that requires hospitalization</li> <li>*Chemotherapy treatments</li> <li>*Neurodegenerative disorders or sensory motor neuropathies</li> <li>If baby passes the newborn hearing screening &amp; has one or more CLASS A risk indicator = Recommendation for diagnostic ABR evaluation with pediatric audiologists by 3 months of age.</li> </ul>
<ul> <li>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)</li> <li>* Any parental/caregiver hearing concerns warrants a referral to a pediatric audiologist.</li> <li>** Infants readmitted to the hospital within the first 30 days of life should be re-screened if any risk indicators are present.</li> </ul>
References: Fligor bi, Newit MW, Mullen CH, Feldman HA, Jones DT. Factors associated with sensorineural hearing loss among survivors of estracorporeal membrane congrenation thrancy. Prediation 2005;131(6):353-3523. Joint Committee on Inferent Hearing, Year 2007 Pation Datament: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Prediotics. 2007;120(4):858-923. doi: 10.1542/pade.2007.2333. Ven Riper, Lof A.; Klieny, Paul R. ABR Hearing Screening for High-Filial Infents. American Journal of Otology. 20(4):516-523, July 1999.
430 W. State St. Floor-3, Boise, ID 83702 www.ldahoioundBeginnings/Hshwidaho.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**

		Family History of Permanent He	aring Loss <
Every teams of textures and information a		Family History of Permanent He NICU stay >5 days Syndrome Associated with HL Congenital infection (e.g. T-O-R Postnatal infection (e.g. Mening) Craniofacial Anomalies Cototoxic Medications - any amou Cototoxic Medications - any amou Nechanical Ventilation - any amou Parent or Physician Concern Head TraumaOther (monitoring through age 3 is recomme	(e.g. Down -C-H) tts) unt tount
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fore baby is <u>3</u> language dev D Your bab Imately <u>8 mor</u>	months old. If bab elopment early iden y is <u>at risk for late</u> ths of age is recom	hearing screen. Hearing testing should be only is not hearing all the sounds necessary for titleation can minimize any communication de r-onset ohildhood hearing loss. Hearing te mended for most risk factors. A Pediatric Au- ring schedule for your baby.	speech and elays.

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)

Audiologist: Phone: \_\_\_\_\_ idhood hearing loss. Hearing testing at approx-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

«Recipient\_Address»

«Today» 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 <u>www.EHDI-PALS.org</u> 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 IdahoSoundBeainnings/ddhwidaho.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 <u>www.EHDI-Pals.org</u> Idaho Infant and Toddler Brochure Idaho Sound Beginnings Early Hearing Detection and Intervention Program (EHDI) Idaho Infant Toddler Program – 450 W State St. Boise, ID 83720-(208) 334-0829

«Recipient\_Address»

«Today» 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 <u>www EHDI-PALS org</u> 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 <u>www.EHDI-Pals.org</u> Developmental Milestones Brochure

### How do we find audiologists?

EH PA Early Hearing D	Petection & Intervention - Pediatric Audiol	logy Links to Services (EHDI-PALS)
Welcome to EHDI-PALS!  Home Find Audiology Facilities	Welcome to EHDI-PALS, Early Hearing Detection & Ir web-based link to information, resources, and service PALS is a national web-based directory of facilities th who are younger than five years of age.	es for children with hearing loss. At the heart of EHE at offer pediatric audiology services to young childre
<ul> <li>Resources about hearing</li> <li>Resources about early intervention</li> </ul>	LEARN MORE about childhood hearing loss, hearing when making appointments. This contains great web to Find OTHER HELPFUL WEBSITES, including nation resources. You can also find out more about the EHDI-PALS Advi	resources for parents and professionals. al and state parent support organizations and oth
<ul> <li>Other Helpful Websites</li> <li>Audiologists:</li> <li>Create/Update Facility Profile</li> <li>Professional</li> </ul>	Looking For A Facility? Find a Facility for hearing services for children from birth to 5 years old:	List Or Update Your Facility Are you a provider interested in listing your facility in the EHDI-PALS directory? If so, enter here:
<ul> <li>Professional Resources</li> <li>EHDI-PALS Advisory Group</li> <li>EHDI Program Log-in</li> </ul>	Find An Audiology Facility	List or Update Your Facility
Gontact us		

#### 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-ouset hearing loss." (CLH 2007 pointion 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 (CH 2008 christication

#### 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.

#### Idaho Sound Beginnings (EHDI)

Infant Toddler Program, 450 W. State St.FI-5, Boise, ID 83720-0036 (208) 334-0829 (208) 332-7331 FAX Cynthia Carlin. EHDI Project Coordinator – carline@dhw.idaho.gov Risk Indicators Associated with Permanent Congenital, Delayed-onset, or Progressive Hearing Loss in Childhood

- Caregiver concerns regarding hearing, speech, language or developmental delay
   Family history of permanent childhood hearing
- Neonatal intensive care of more than 5 days or any of the following regardless of length of stays ECMO, assisted ventilation, exposure to ottoxic medications (gentamycin/kohramycin) or loop disturtiss ((trosende/Lasis) and hyperbilinubinenia requiring exchange transfusion.
- In utero infections: CMV, herpes, rubella, syphilis, and toxoplasmosis.
- Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.
- Physical finding, such as a white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
- Syndromes associated with hearing loss or progressive or late onset hearing loss such as neurofibromatosis, osciopetrosis and Usher syndrome; other frequently identified syndrome including Waardenburg, Alport, Pendred, and Jervell and Lange-Nielsion.
- Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charoot-Marie-Tooth syndrome.
- Culture-positive postnatal infections associated with sensorineural hearing loss, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
- Head trauma, especially basal skull/temporal bone fractures that requires hospitalization.
   Chemotherapy

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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)

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

#### Family history of permanent childhood hearing loss. Neonatal intensive care of more than 5 does or

#### Quick and easy reporting opportunities

#### Paper forms

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Note			
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#### Online reporting

Ear	Right			Ear Left								
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<ul> <li>DxABR</li> <li>OAE</li> <li>Tympanometry</li> <li>Behavioral</li> <li>Screening</li> </ul>												

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 fhearing has been confirmed as Normal, check the 'Confirmed' box.

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<u>DxABR</u>: 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...).

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

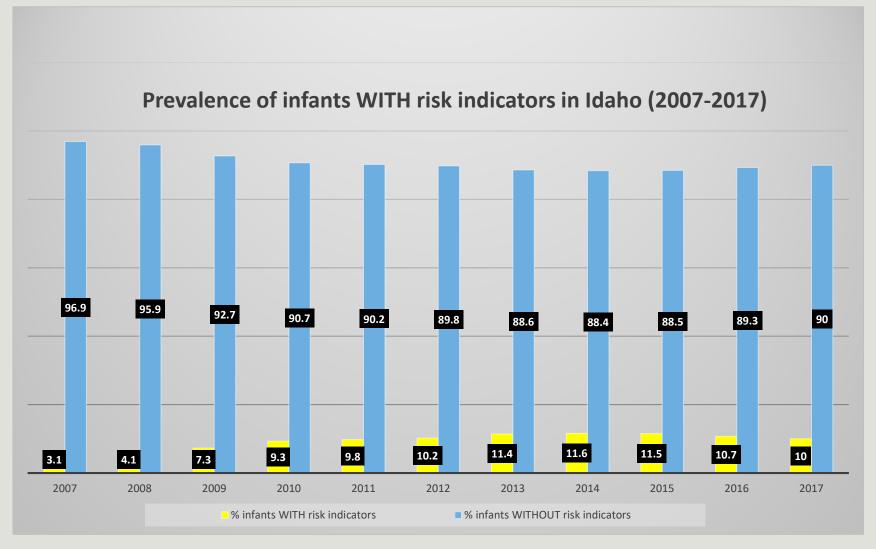
# Use of data management system



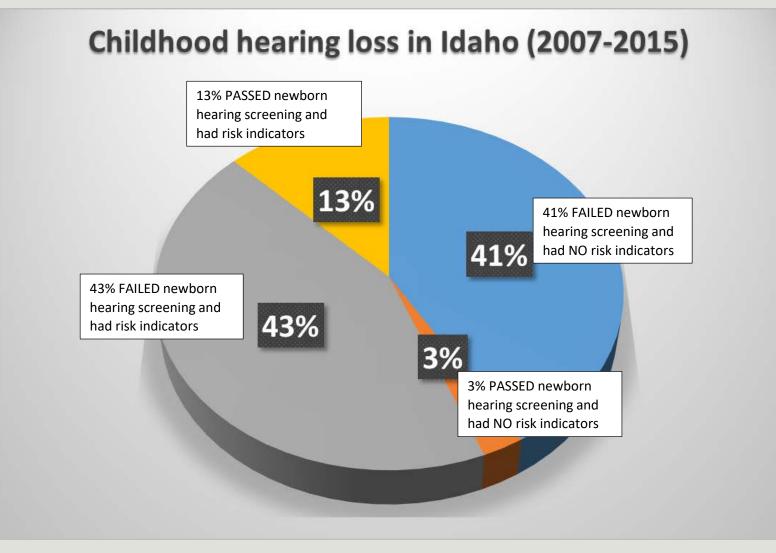














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