

# CDC PUBLIC HEALTH GRAND ROUNDS

## Beyond the Blood Spot: Newborn Screening for Hearing Loss and Critical Congenital Heart Disease



Accessible version: <https://youtu.be/EzCy5x9Oals>

September 20, 2016



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

# Advancing the Science of Newborn Screening



**Stuart K. Shapira, MD, PhD**

*Associate Director for Science and Chief Medical Officer*

National Center on Birth Defects and Developmental Disabilities



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Health and Human Services  
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# Why Screen Newborns?

- **Newborn screening (NBS) benefits babies by detecting life-threatening diseases early**
  - Earlier diagnosis means earlier treatment, which means fewer financial and other costs
- **Criteria for selecting diseases to screen include**
  - Reliable test for NBS
  - System in operation for diagnostic testing, treatment, counseling, and follow-up



# Dried Bloodspot Screening

- **Blood collected via heel prick and spotted on filter paper cards at 24–48 hours after birth**
- **Cards shipped to NBS laboratories for testing**
- **Results reported to state health departments**
  - Follow-up on positive screens
- **Until 2005, screened conditions varied by state**



# In 2005, HHS Secretary Approved the Recommended Uniform Screening Panel (RUSP)

- **National standard panel of conditions for newborn screening**
  - In 2002, HRSA-sponsored expert review process
  - In 2005, HHS Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) recommended the RUSP, and it was approved
- **Of 29 original RUSP conditions, 28 screened by dried bloodspot test**
  - Inborn errors of metabolism (22 conditions)
  - Endocrine disorders (2 conditions)
  - Sickle hemoglobinopathies (3 conditions)
  - Cystic fibrosis
- **Congenital hearing loss screened by point-of-care test**

# Since 2005, New Conditions Added to the RUSP

## ➤ **5 new conditions approved by the ACHDNC and HHS Secretary**

- Severe combined immunodeficiency (2010)
- Critical congenital heart disease (2011)
- Pompe disease (2015)
- Mucopolysaccharidosis, type I (2016)
- Adrenoleukodystrophy (2016)

## ➤ **34 conditions currently included on the RUSP**

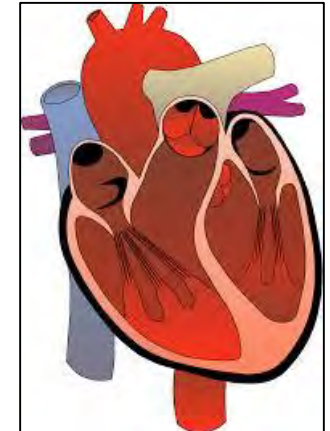
- 32 dried bloodspot tests and 2 point-of-care tests



# Same Goal for Both Types of Newborn Screening

## ➤ Two types of NBS paradigms

- Dried bloodspot screening
  - ❑ Traditional newborn screening is a heel prick
- Point-of-care screening
  - ❑ Congenital hearing loss
    - Program is Early Hearing Detection and Intervention (EHDI)
  - ❑ Critical congenital heart disease (CCHD)



## ➤ Goal is timely identification and early intervention for every baby with a condition

# Point-of-Care Screening for Congenital Hearing Loss and Critical Congenital Heart Disease

- **Typically performed at the birthing facility before discharge**
- **Newborns not passing newborn screen are referred for diagnostic testing**
- **Point-of-care screening and reporting less centralized than bloodspot screening**
  - Challenges to collecting data for evaluation and monitoring
  - Difficulty ensuring diagnostic follow-up for congenital hearing loss





# Congenital Hearing Loss is the Most Common Condition Identified Through Newborn Screening



## ➤ Congenital hearing loss

- Incidence: 1.5 per 1,000 neonates screened
- Range: 0.3–4.8 per 1,000 neonates screened
- Limitations of the incidence data
  - ▣ Infants lost to follow-up or lost to documentation
    - Rate: 32.1%
    - Range: 0.0%–86.8%

# Screening for Congenital Hearing Loss



- **Noninvasive screening conducted typically at 24–48 hours after birth using either:**
  - Automated Auditory Brainstem Response
    - ❑ Submits clicking sounds through the earphones and measures auditory nerve/lower brainstem responses through the patch on the scalp
  - Otoacoustic Emissions
    - ❑ Submits clicking sounds through a probe in the ear canal and measures “echo” responses
- **Newborns who fail the screen in one or both ears are referred to an audiologist for diagnostic hearing test**

# Screening for Congenital Hearing Loss and Diagnostic Follow-up

## ➤ Joint Committee on Infant Hearing Position Statement, 2007

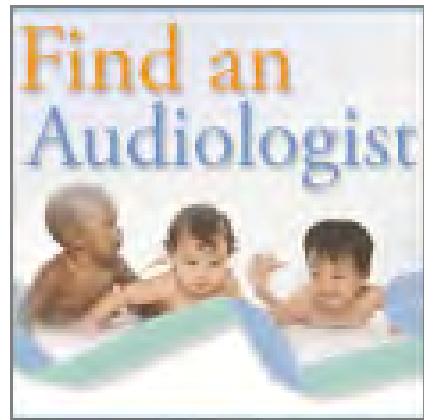
- No later than age **1 month**, all infants screened
- No later than age **3 months**, all infants not passing the screen have a comprehensive audiologic evaluation
- No later than age **6 months**, all infants with confirmed hearing loss receive appropriate intervention



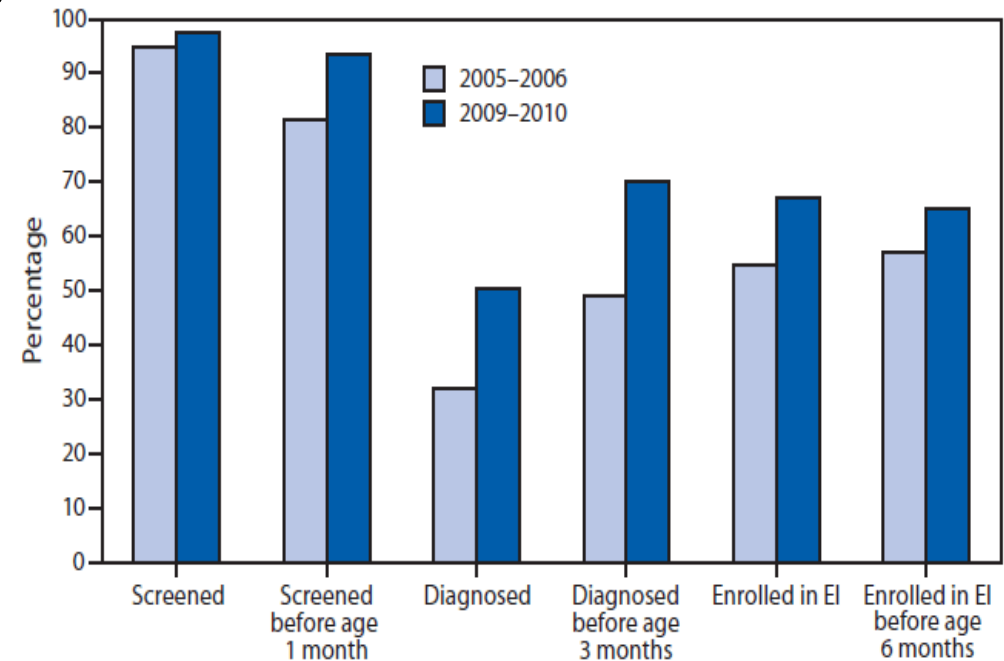
# EHDI Programs Support Families of Children Identified with Hearing Loss

## ➤ Early Hearing Detection and Intervention

- Every U.S. state, territory, and D.C. has an EHDI program
  - ▣ Supports families of children identified with hearing loss
  - ▣ Collects data on meeting the 1-3-6 month goals
  - ▣ Reports annual aggregate data to CDC



Percentage of infants screened, diagnosed, and enrolled in early intervention—United States, 2005–2006 and 2009–2010



# Incidence of CCHD and Efficacy of Screening

- **Before NBS, about 18% of babies with CCHD died during infancy**
- **Incidence of CCHD estimated at 2–3 per 1,000 live births**
  - About 70% identified in ways other than NBS
    - ❑ Prenatal diagnosis
    - ❑ Symptoms present after birth prompting echocardiogram
- **Estimated incidence potentially detected by NBS**
  - ❑ 4 per 10,000 live births
- **Limitations of the data**
  - No national data available for incidence identified by newborn screening
  - False negative rate (missed cases) unknown



Reller MD, Strickland MJ, Riehle-Colarusso T, et al. *J Pediatr*. 2008 Dec;153(6):807–13.

Ailes EC, Gilboa SM, Honein MA, et al. *Pediatrics*. 2015 Jun;135(6):1000–8.

Peterson C, Dawson A, Grosse SD, et al. *Birth Defects Res A Clin Mol Teratol*. 2013 Oct;97(10):664–72.

NBS: newborn screening

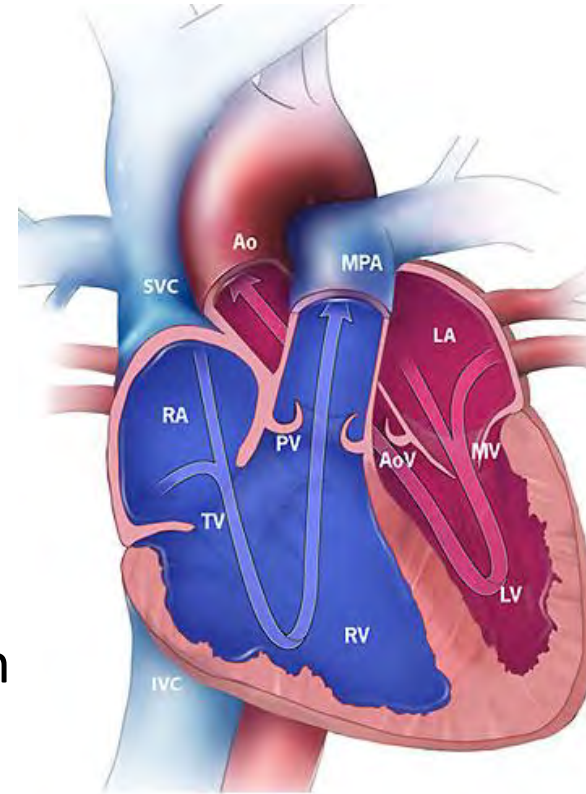
# Screening for CCHD Since 2011

- **Screens for 12 structural birth defects of the heart**
- **Noninvasive screening conducted at 24–48 hours after birth using a pulse oximeter on the right hand and one foot, which monitors oxygen saturation**
  - Typical range of normal saturation values is 95%–100%, with no more than a 3% difference between right hand and the foot
- **Algorithm evaluates saturation values to determine if**
  - Screen is passed
  - Repeat screening is needed
  - Diagnostic test is indicated

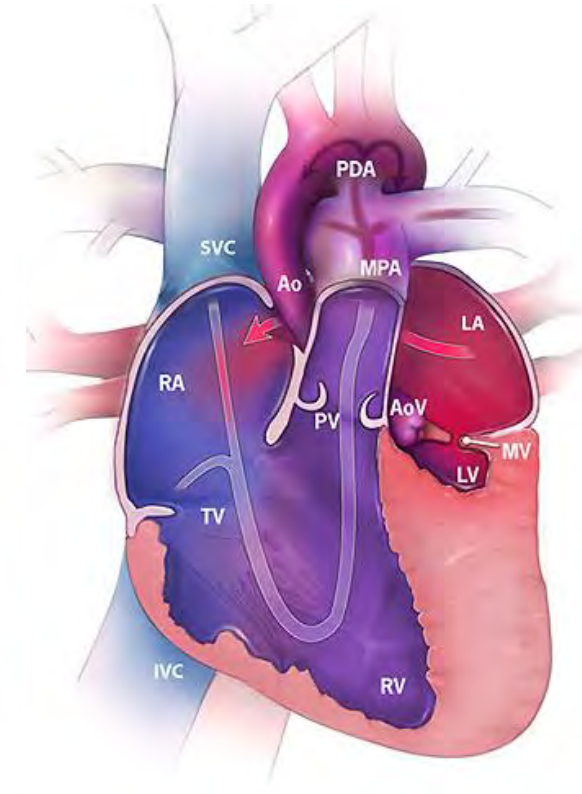


# Specific CCHD Conditions Covered by Screening

- Coarctation of the aorta
- Double outlet right ventricle
- Ebstein anomaly
- Hypoplastic left heart syndrome
- Interrupted aortic arch
- Pulmonary atresia
- Single ventricle
- Tetralogy of Fallot
- Total anomalous pulmonary venous return
- D-Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus



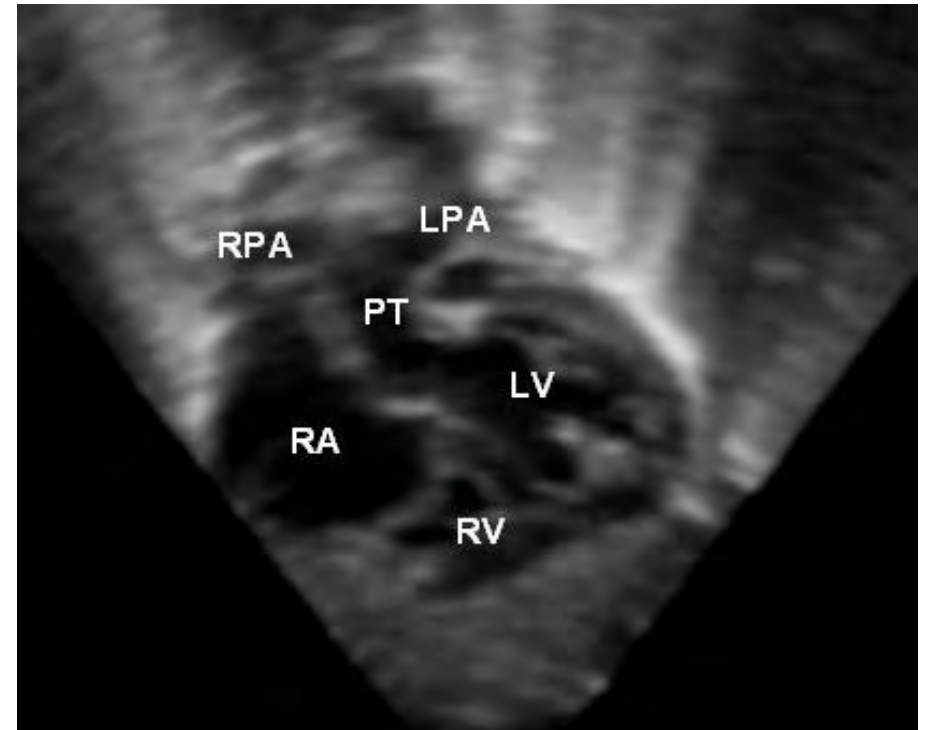
**Normal Heart**



**Hypoplastic Left Heart Syndrome**

# CCHD Screening Challenges: Individual Testing and Follow-up

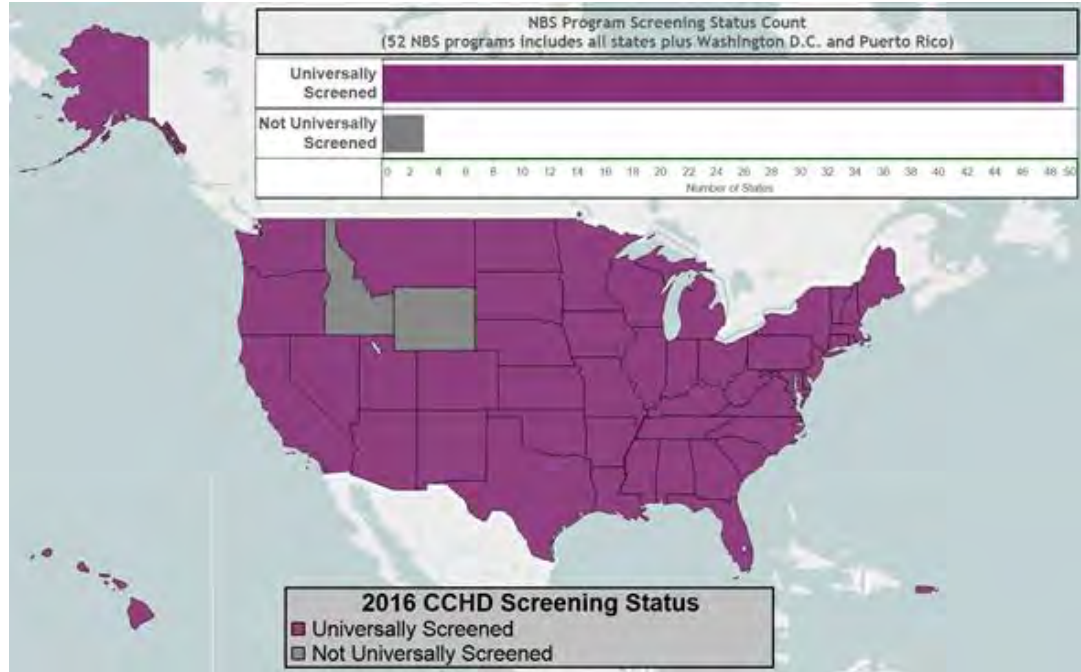
- **Newborns who fail the screen are immediately referred for an echocardiogram (ultrasound imaging of the heart)**
- **The screen-positive newborn might require transfer to another facility for diagnostic testing and interpretation**



RA: right atrium  
RV, LV: right and left ventricles  
RPA, LPA: right and left pulmonary arteries  
PT: pulmonary trunk



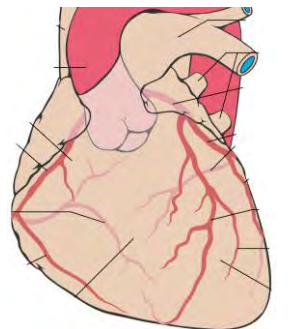
# CCHD Screening Challenges: Policy and Program



- **The program is not as mature as the one for newborn hearing screening**
  - All except 2 states currently screen every baby for CCHD
    - There is no “EHDI-like” program for CCHD
    - Some states collect data on all screened newborns, some only on those with a positive screen result

# Public Health Role in Point-of-Care Newborn Screening

- **State and territorial EHDI programs, as well as CDC and HRSA, provide support for congenital hearing loss screening**
  - Provide consultation and technical assistance
  - Organize data collection to evaluate effectiveness and quality
  - Evaluate impact of newborn screening on short-term program goals and long-term developmental outcomes
  - Provide support for families affected by hearing loss and health providers
- **For CCHD screening, public health role not yet as well defined**
  - National coordinating activities needed to accelerate the process



# The Federal Partner Perspective



**Marci K. Sontag, PhD**

*Associate Professor*

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University of Colorado Denver Anschutz Medical Campus

# Support from the Federal Level for Newborn Screening

- **Implementation**
- **Data collection and interpretation**
- **Technical assistance**
- **Quality improvement initiatives**



# Point-of-care Screening: Brief History of Implementation

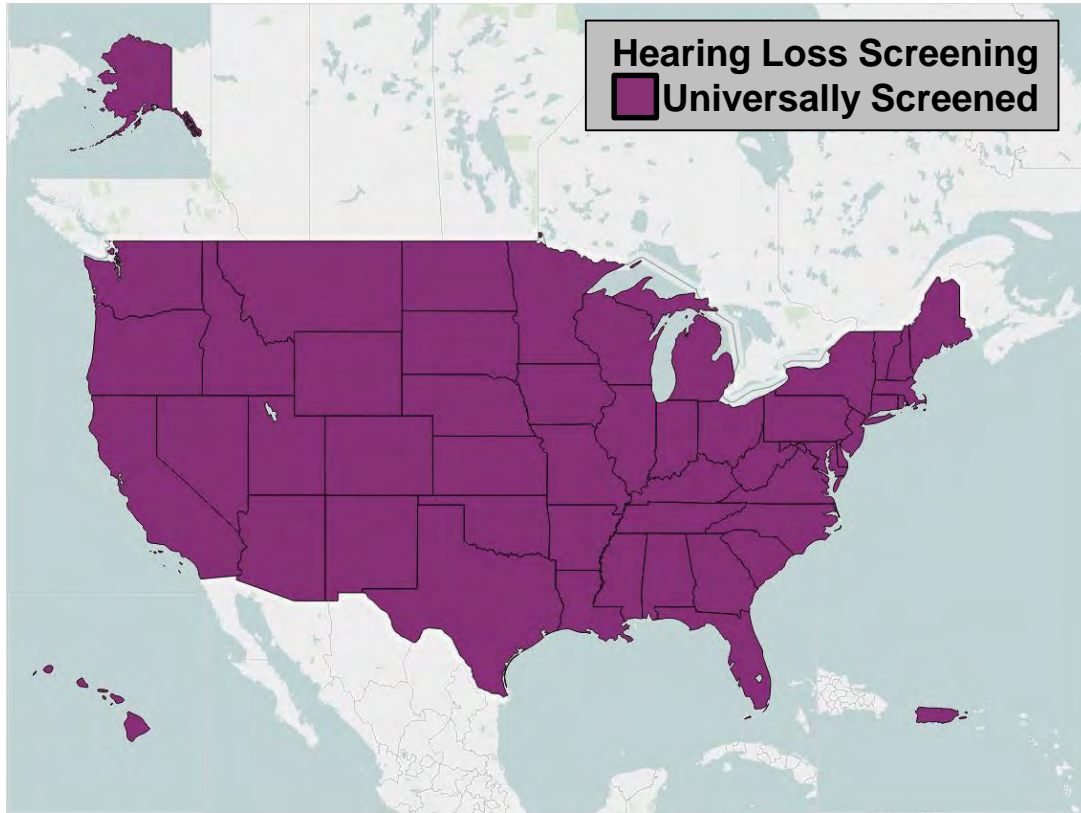
## ➤ **Hearing Loss**

- Varied implementation over many years
- Currently all states and territories have established EHDI programs

## ➤ **Critical Congenital Heart Disease**

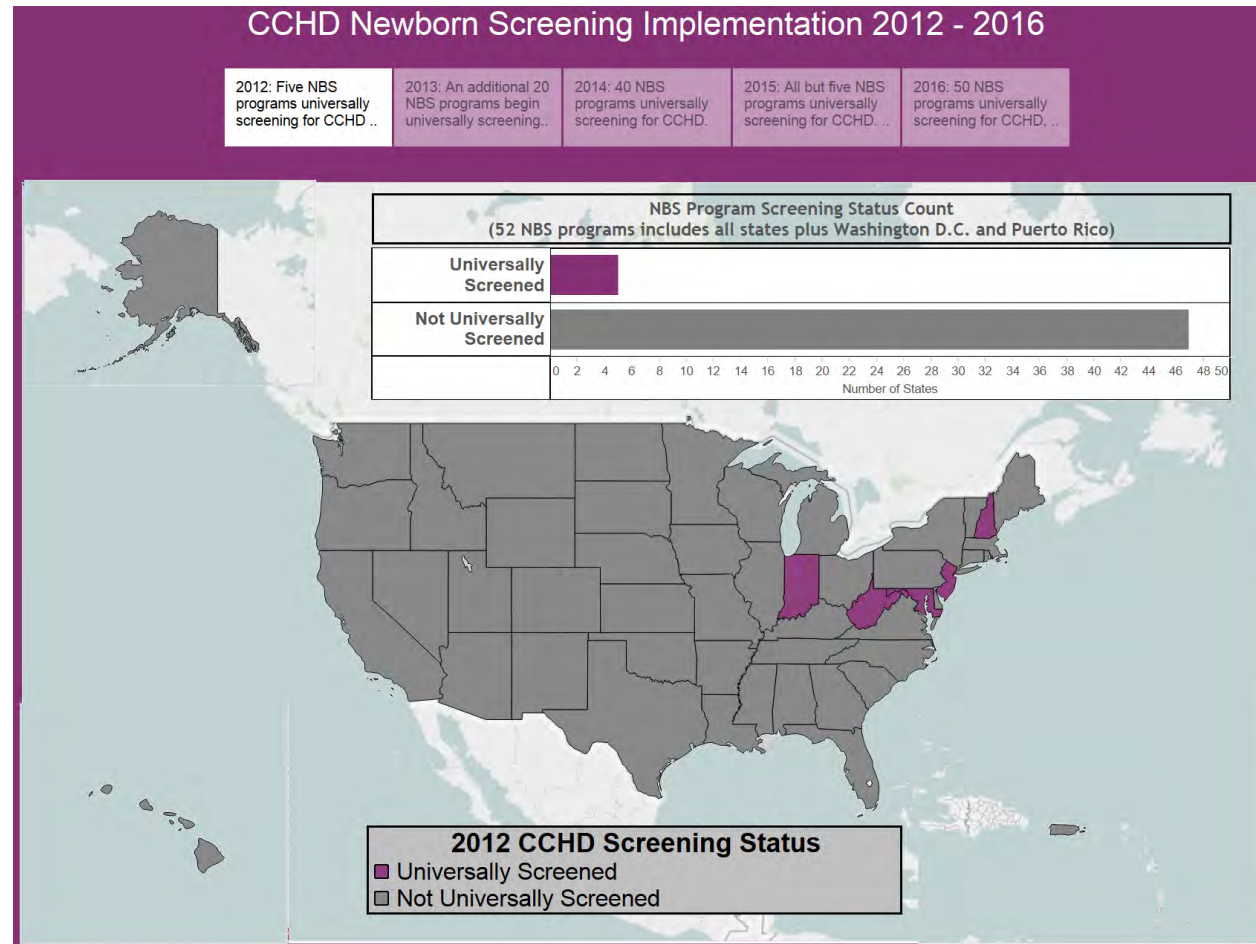
- Rapid implementation of CCHD screening has occurred since 2011
- Most states have universal screening for CCHD

# Current National Screening Status for Early Hearing Loss

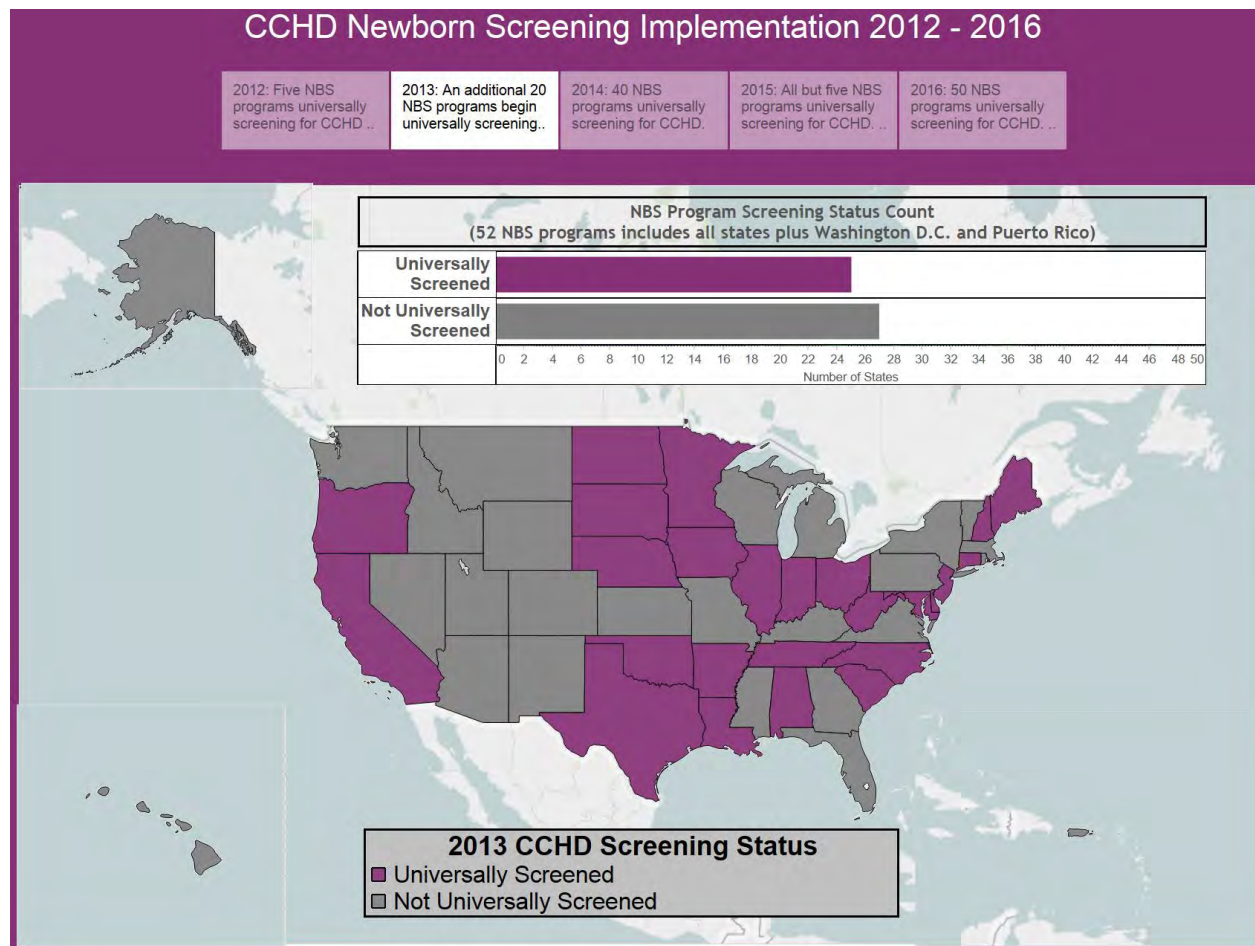


- Screening for hearing loss began in select states in 1990
- By 2003 all states had begun screening for hearing loss
- All states have implemented EHDI programs

# CCHD Screening: 2012

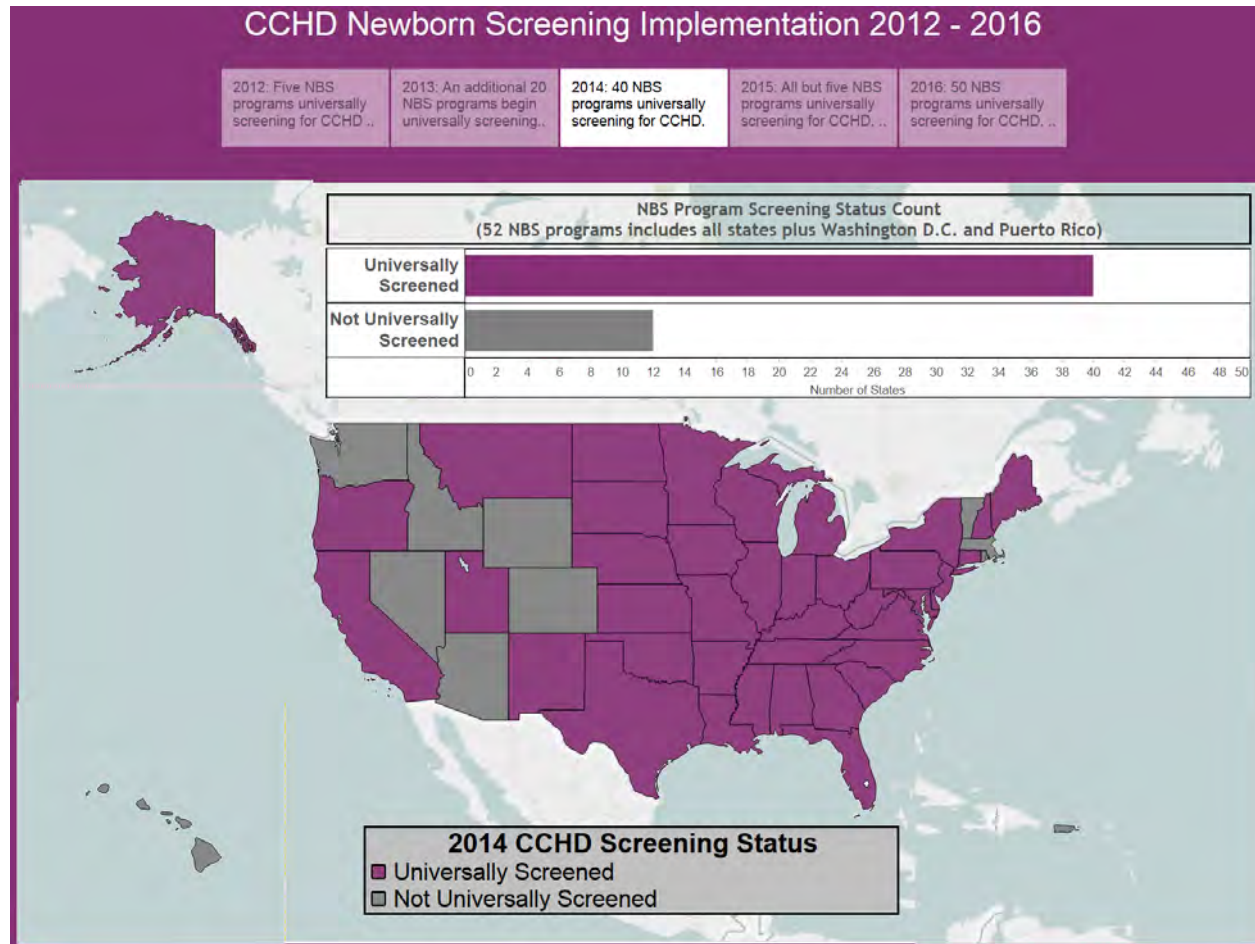


# CCHD Screening: 2013

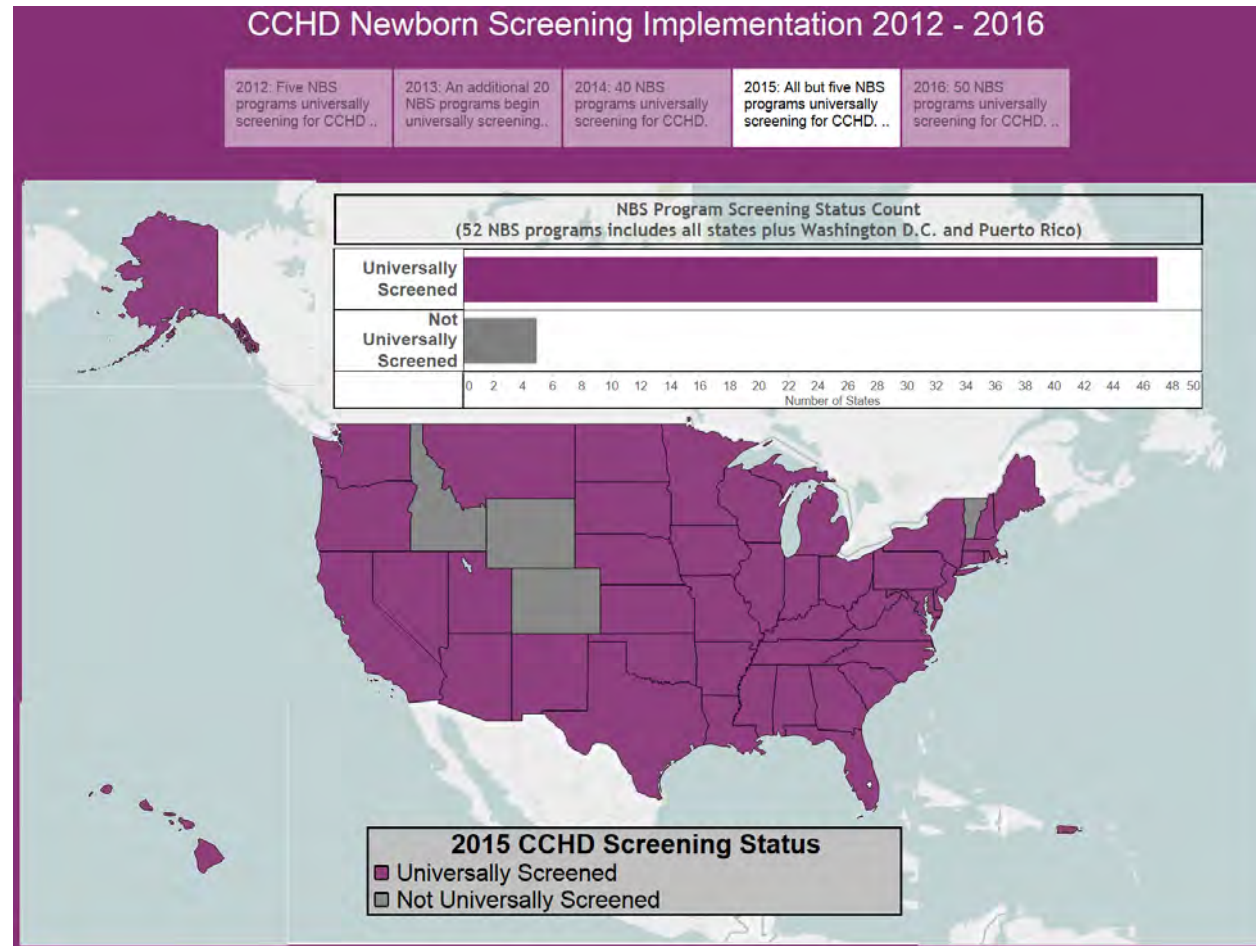




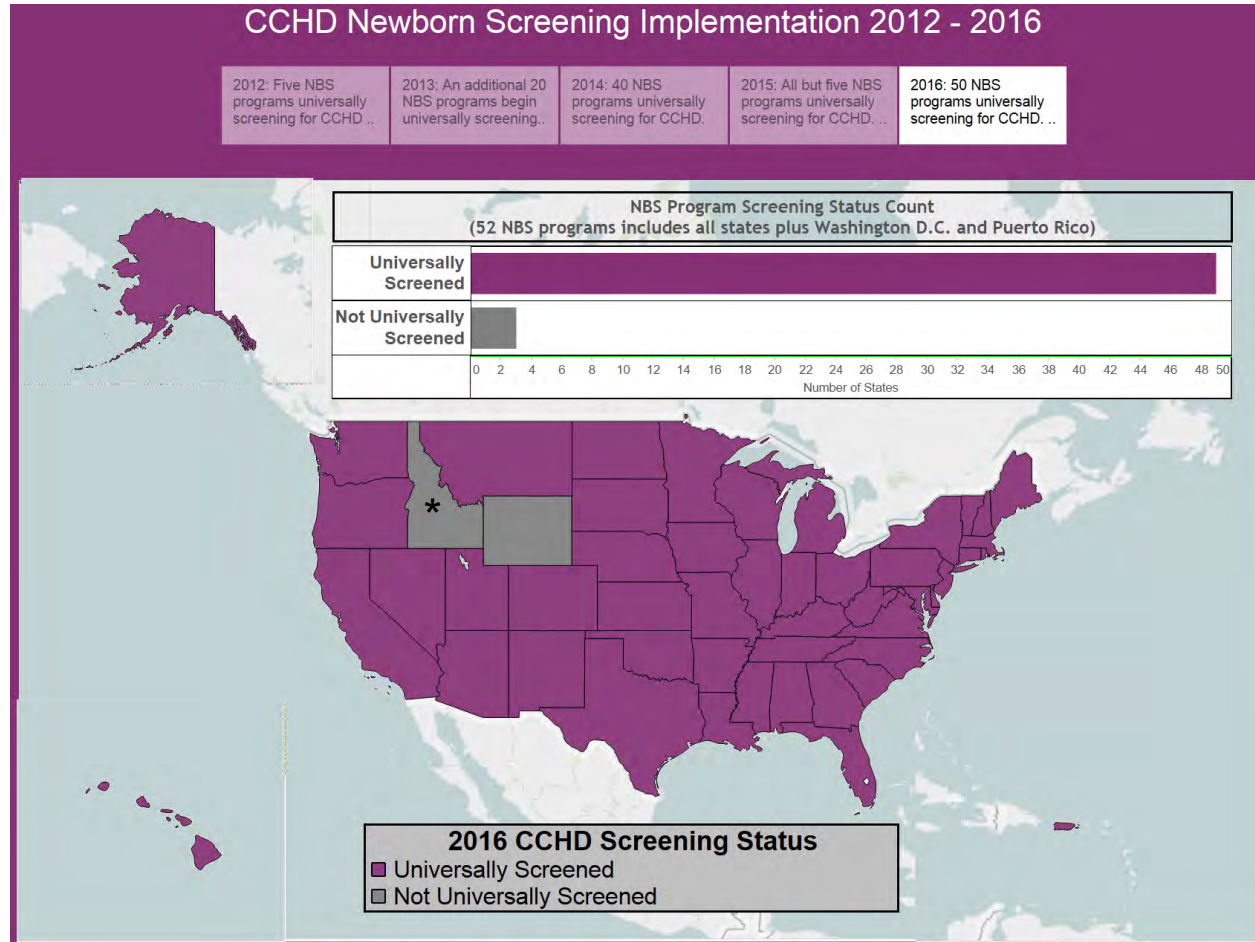
# CCHD Screening: 2014



# CCHD Screening: 2015

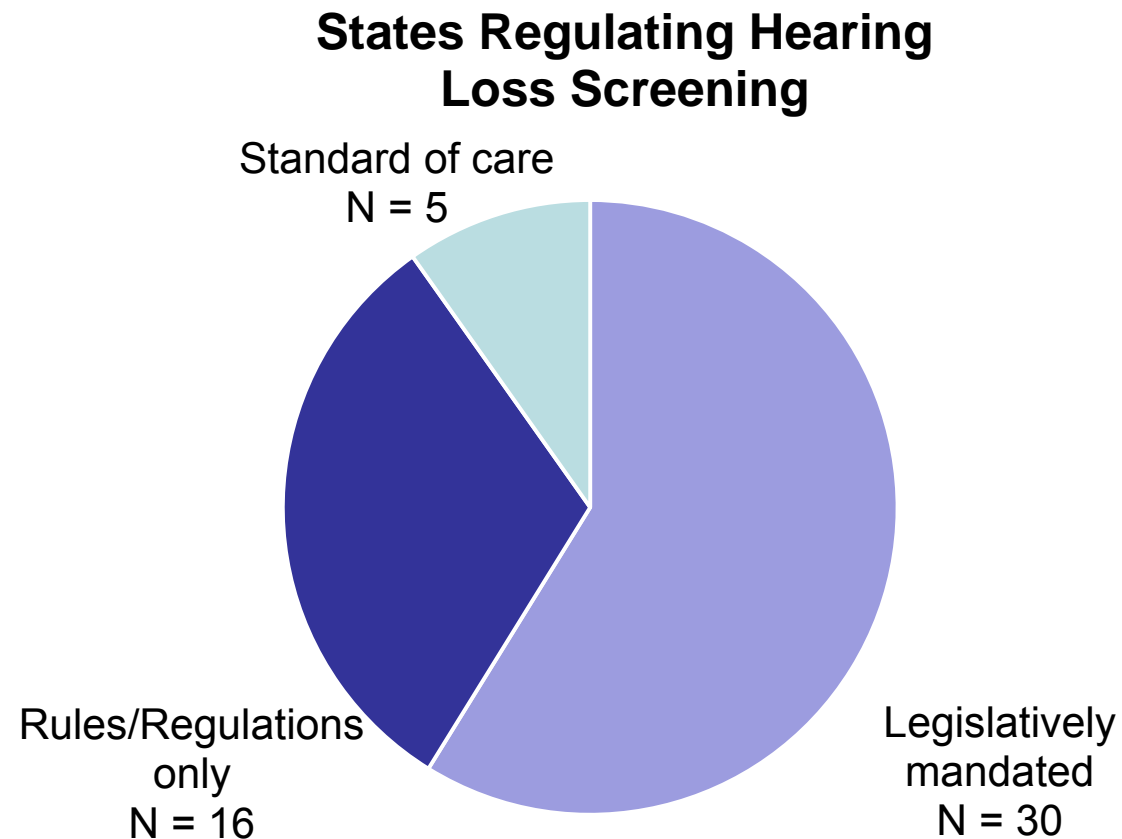


# CCHD Screening: 2016



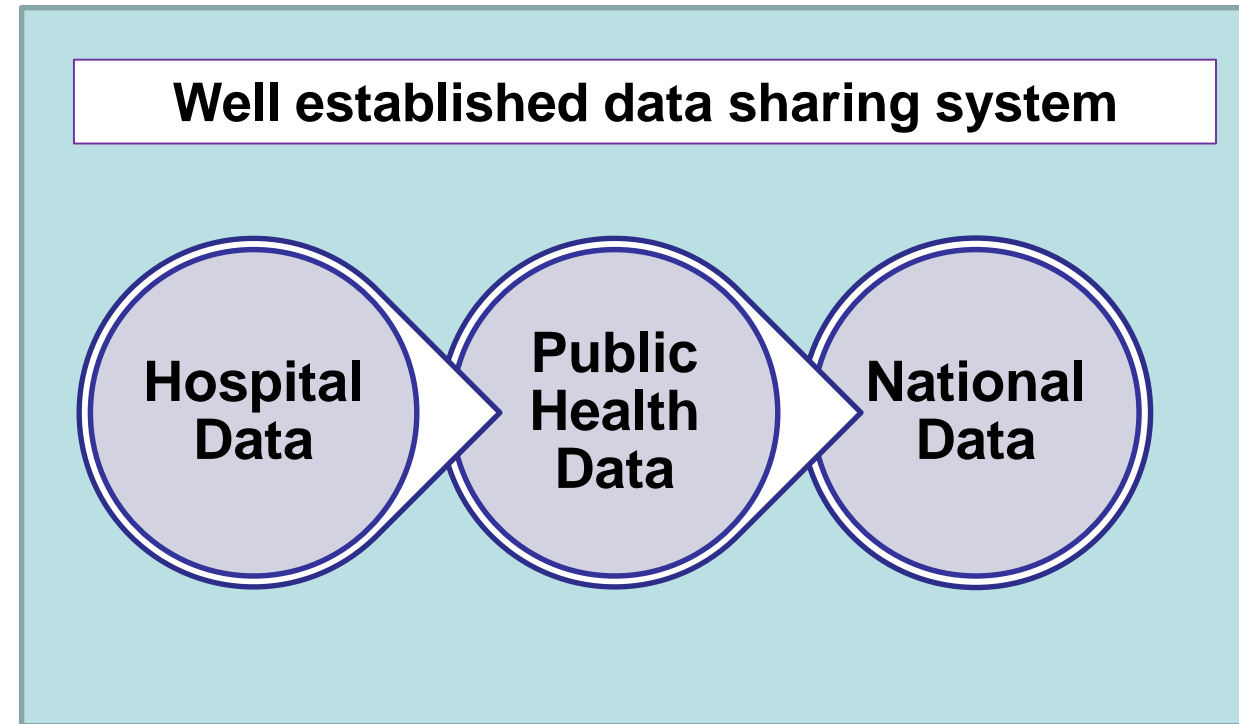
# Newborn Hearing Screening Implementation

- **Required in 46/51 programs  
(50 states and Washington, D.C.)**



# Early Hearing Loss Data Reporting at Public Health Level

- **Data reporting is required in 36 states**
- **All state programs collect some type of data**
  - E.g., electronic birth certificate or other automated systems

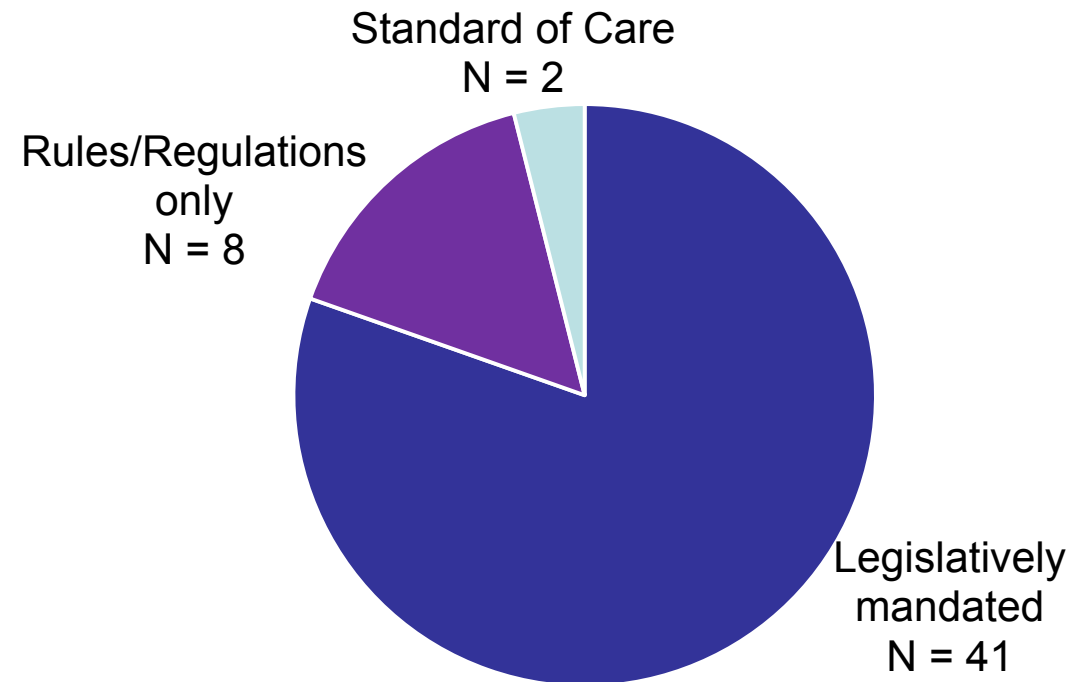


# CCHD Regulatory Requirements for Screening and Data Collection

## ➤ Required in 49/51 programs

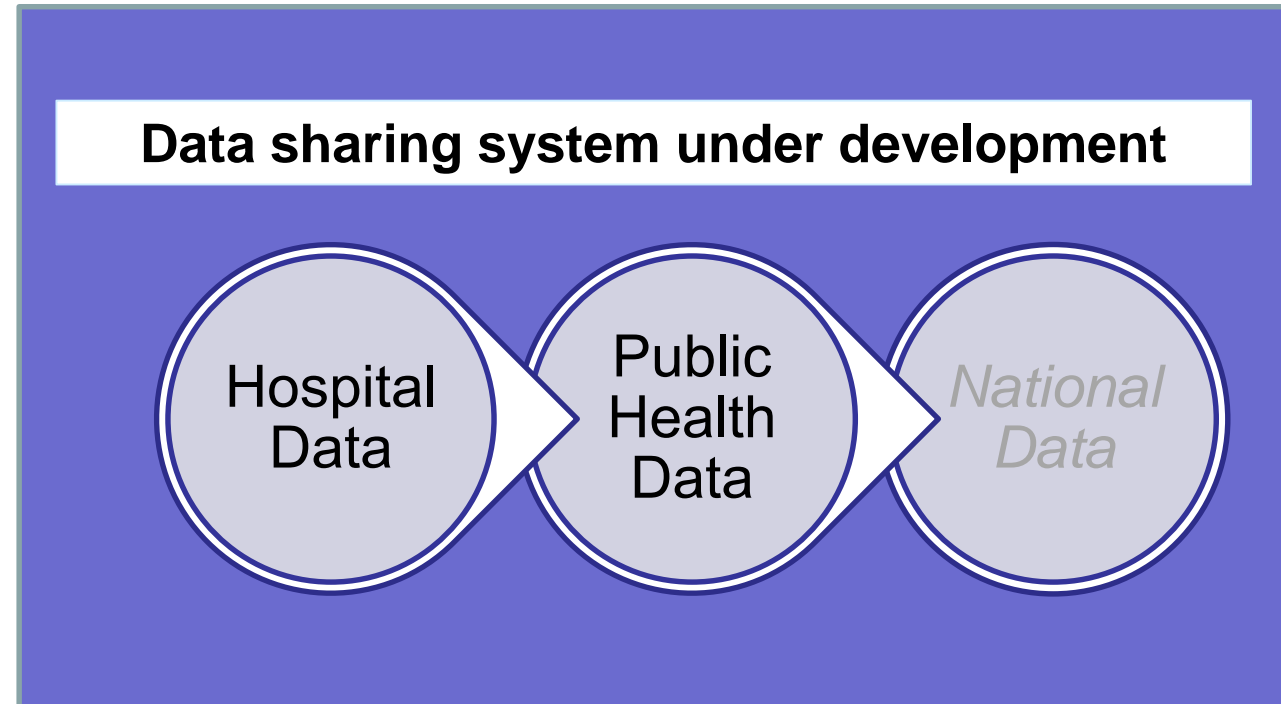
- Legislatively mandated in 41 states
- Required only through rules or regulations in 8 states
- Two programs support CCHD screening as a standard of care

## Regulations Guiding CCHD Screening



# CCHD Screening Data Reporting at Public Health Level

- **36 programs collect screening data from hospitals data at public health level**
- **No national data system**



# Technical Assistance at the Federal Level

## ➤ **CDC National Center on Birth Defects and Developmental Disabilities**

- National Birth Defects Prevention Network
- Technical assistance and state-level funding to support high-quality hearing screening, data systems, and follow-up

## ➤ **Health Resources and Services Administration**

- Technical assistance and state-level funding to support high-quality hearing and CCHD screening, data systems, and follow-up



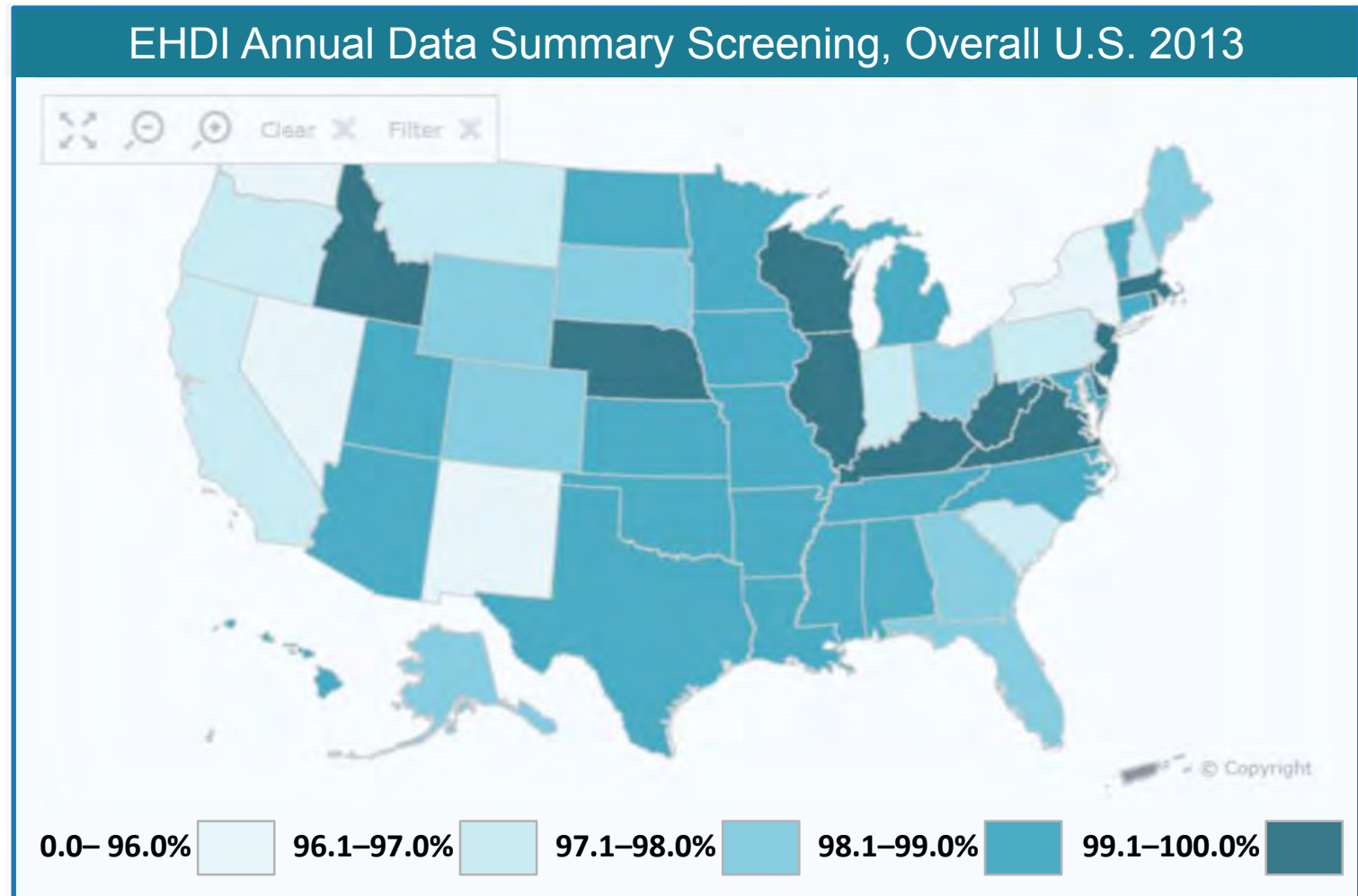
# CDC's Role in Supporting EHDI

## ➤ Provide assistance to state EHDI programs

- Funding
- Data management protocols
- EHDI-Information Systems

## ➤ Other program activities

- Develop data management procedures and assess program costs and effectiveness
- Support research related to screening, evaluation, and early education



# HRSA: Technical Assistance Resource for EHDI

## ➤ **National Center for Hearing Assessment and Management**

- Develop and coordinate educational activities and information
- Provide a forum for communication among key stakeholders
- Maintain a newborn hearing screening expert network
- Support training opportunities for families and public health practitioners
- Coordinate with other infant and toddler screening programs
- Long-term outcome and impact evaluation



# Critical Congenital Heart Disease

- **Major differences in overall picture of state-level screening**
  - Data collection
  - Sources and types of federal assistance
  - Resource allocation



# CCHD Lessons Learned: American Academy of Pediatrics

- **Screening implemented widely in the U.S.**
- **Common challenge: lack of funding**
  - Cost of screening (\$5–\$14 per infant) is responsibility of birthing facilities
  - Funding required for essential activities
- **Need a national data collection system to assess the true impact of CCHD screening on outcomes for infants with CCHD or secondary conditions**



# CCHD Newborn Screening Technical Assistance

## ➤ **NewSTEPs: Newborn Screening Technical assistance and Evaluation Program**

- National resource center for newborn screening, including CCHD screening
- Support training opportunities
- Ongoing collaboration and networking
- Quality practice resources and data repository
  - ❑ To assess frequency of disorders
  - ❑ To assess time elapsed until screening and diagnosis



# CCHD Newborn Screening Funding Support



- **CCHD surveillance and quality assurance is funded at the local level**
  - Hospitals
  - Public health programs
- **There are no current congressional appropriations for CCHD newborn screening or follow-up**
- **EHDI can serve as a model**

# Follow-up and Impact Evaluation: Differences between EHDI and CCHD



## Connecting Networks

### Early Hearing Loss

- Audiologists
- Established public health programs

### CCHD

- Cardiologists
- Public health programs still developing



## Ensuring Follow-up

### Early Hearing Loss

- Occurs after discharge

### CCHD

- Occurs in birthing facility
- Limited access echocardiogram



## Evaluating Programs

### Early Hearing Loss

- Some success in tracking outcomes

### CCHD

- Limited ability to measure and track success



## Measuring Impact

### Early Hearing Loss

- National programs and funding
- Developmental outcomes

### CCHD

- Limited data and support

# Conclusion



- **Implementation of early hearing loss and CCHD newborn screening has been widespread**
  - Local and national efforts are in place to collect data
  - Funding and resource allocation varies by state
- **Both programs face resource challenges for data collection and impact evaluation**



# Implementing and Evaluating CCHD Screening in New Jersey



**Kim Van Naarden Braun, PhD**

*Epidemiologist*

Division of Family Health Services, New Jersey Department of Health  
National Center on Birth Defects and Developmental Disabilities



# Evolution of CCHD Screening in New Jersey

- **Implementation and evaluation of statewide CCHD screening**
- **Lessons learned**
- **Questions remaining**



# New Jersey CCHD Screening Legislation

- **NJ first state to implement a mandate for pulse oximetry screening**
- **Legislation signed into law June 2, 2011**
- **Screening began August 31, 2011**



# Dylan's Story

## First-in-the-Nation New Jersey Newborn Heart Defect Screening Law Already Saving Lives

Wednesday, November 9, 2011 • Tags: [Other](#)

Governor Christie Travels to Sussex County to Meet Baby Dylan Who was Diagnosed and Treated as a Result of Landmark Law



# Identifying Mechanisms for Ongoing Surveillance

- **Options for rapid data collection**
  - Newborn bloodspot card
  - Electronic birth record
  - Immunization registry
  - State birth defects registry
- **Crucial component was linking newborn screening with ongoing birth defects surveillance**



# Rapid Implementation and Tracking Screening Coverage: New Jersey's Plan of Action in 2011

- **New electronic birth record system**
  - Quarterly aggregate data
- **Building on existing birth defects surveillance infrastructure**
  - Collect additional information through NJ Birth Defects Registry (BDR)
  - Include all children who fail CCHD screening
  - Include relevant clinical information to evaluate contribution of screening to detection



# Quarterly Submission and Aggregate Data Used to Assess Screening Coverage

## Data from August 31, 2011–December 31, 2014

<b>Live births</b>	<b>338,124</b>
<b>Live births eligible to be screened*</b>	<b>328,591</b>
<b>Live births screened</b>	<b>327,447</b>
<b>Eligible live births screened</b>	<b>99.7%</b>

\*Excludes deaths, infants <24 hours old, infants for whom screening deemed not medically appropriate

# High Proportion of Newborns Screened for CCHD





# New Jersey Birth Defects Registry (NJ BDR)

- Birthing facilities report all failed CCHD screens to the NJ BDR
- Health care professionals required to register infants with CCHD who are NJ residents
- Core CCHD team and BDR staff investigate CCHD screen failures

## NJ Birth Defects Registry - Child Information Summary

[Home](#) [Create New Registration](#) [Search](#) [Reports](#) [Submissions](#) [Print Letters](#) [Merge Records](#) [Change Password](#) [Manage Users](#)

**Summary Page for Aire Test - Unique ID: 19**  
[View Registration Notes](#)  
[Edit](#) this Registration  
[Add](#) Pulse Oximetry  
Child Record is currently incomplete. Please Edit and Complete this Registration

**Add Failed Pulse Oximetry Registration**

**Revisions**  
No Revisions Yet  
Currently viewing most recent revision.

**Registration Information**

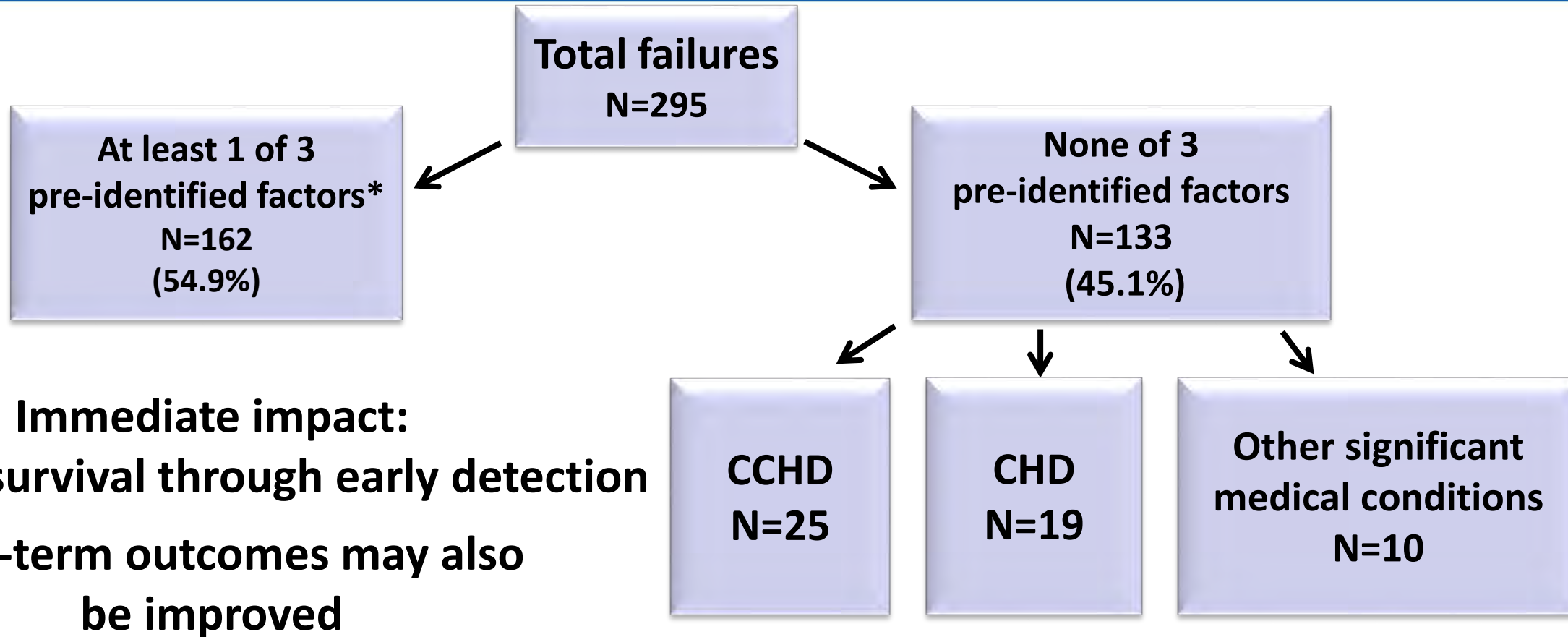
Registration File Type: BDR Only  
Audit: False  
Registration Status: New  
Reporting Facility Type: ACH  
Family Informed: None  
Registering Agency: Monmouth Medical Center  
Registration Date: 02/13/2013

# Evaluating the Unique Contribution of CCHD Screening

- **Some CCHD may be detected through**
  - Prenatal diagnosis of congenital heart defect
  - Echocardiogram or cardiac consultation performed or planned before the screening
  - Signs or symptoms detected prior to screening
- **Using these 3 factors we evaluated how many CCHD were detected through CCHD screening**



# Failed Screens Registered to NJ BDR August 31, 2011–June 30, 2016



\*Factors include: 1. Prenatal diagnosis of CHD, 2. Signs or symptoms at the time of the screen, 3. Cardiac consult or echocardiogram prior to the screen  
CHD: Non-Critical Congenital Heart Disease

# Public Health Cost Assessment

## ➤ Hospital-based screening costs assessed

- CDC study in 7 NJ birthing facilities
- Mean screening time per newborn was 9.1 minutes (standard deviation: 3.4 minutes)
- Mean estimated cost per newborn screened was \$14.19
  - ▣ \$7.36 in labor costs and \$6.83 in equipment and supply costs
- Subsequent clinical examinations


## ➤ Public health costs at state level

- Administrative oversight, technical support
- Data systems and monitoring

# Importance of Ongoing Education and Training

## ➤ NJ screening resources include

- NJ Recommended Screening Algorithm
- Quick Reference Guide
- Parent Information (6 languages)
- Pulse oximetry worksheet
- Online course for nurses
- NJ CCHD Screening Reference Guide



The screenshot shows the NJ Department of Health website. At the top, there is a navigation bar with links for 'NJ Home', 'Services A to Z', 'Departments/Agencies', and 'FAQs'. A search bar is also present. The main header features the State of New Jersey Department of Health logo and the 'NJ Health' logo. Below the header, the page is titled 'DOH Home >> Family Health Services'. A left-hand navigation menu lists various services, with 'Critical Congenital Heart Defects Screening Resources (CCHD)' highlighted. The main content area is titled 'Critical Congenital Heart Defects (CCHD) Screening Resources'. It includes a section for a 'Newborn Screening for Critical Congenital Heart Defects (CCHD) Using Pulse Oximetry Course' for nurses, with a link to the course information. Below this, there is a section for 'Course Information and How to Register' and a paragraph stating that resources for CCHD screening are available for printing and distribution. A list of resources follows, including the 'New Jersey Recommended Screening Algorithm', 'Quick Reference Guide', 'Birth Defects Registry (BDR) Worksheet', and a study published in Pediatrics. At the bottom, there is a section for 'Newborn Screening for Congenital Heart Defects: Information for Parents' with links for Arabic, English, Hindi, Korean, Polish, and Spanish versions, as well as a 'Screening results by year' link.

# Collaboration Between Birth Defects Surveillance, Hospitals, Community Partners, and Vital Statistics is Important

## ➤ **Impact on data collection and evaluation**

- Screening successfully built upon NJ Birth Defects Registry's existing infrastructure
- Aggregate reporting enabled timely evaluation
- Distribution of a standardized tool led to internal quality assurance and accountability measures

## ➤ **Relationships and strong communication with birthing facilities are essential**

# Progress in CCHD Screening, But Some Questions Remain Unanswered

- **Screening is moving toward becoming universal in the U.S.**
- **Screening in special sub-populations**
  - Neonatal intensive care unit (NICU)
  - Out-of-hospital births
  - High-altitude births

# Additional Questions

## ➤ **Quantifying false negatives**

- Linkage of NJ BDR to VIP birth certificate data addresses one aspect
- Other data sources include out-of-state surgery centers or emergency rooms

## ➤ **Cost effectiveness**

- No studies specifically examine the cost and burden of universal screening

## ➤ **Defining and measuring follow-up**



# From Data to Action: The EHDI Experience



**Craig A. Mason, PhD**

*Professor*

Education and Applied Quantitative Methods

University of Maine



**U.S. Department of  
Health and Human Services**  
Centers for Disease  
Control and Prevention

# EHDI: Early Hearing Detection and Intervention

## ➤ **Newborn screening expanded into long-term diagnosis and follow-up**

- Joint Committee on Infant Hearing (JCIH)
  - 1:3:6 process
- Other partners: HRSA, AAP, Hands & Voices
- National Data Committee

## ➤ **Public health role of EHDI**

- Surveillance: complete, accurate data to reduce loss to follow-up and loss to documentation
- Quality assurance: quality of data leads to quality of care and practice and accuracy of estimates for public health planning

# Success in Surveillance and Follow-up

	Change from 2000 to 2014	
<b>Screening</b>	<b>52%</b> of newborns	<b>98%</b> of newborns
<b>Diagnostic evaluation</b>	<b>855</b> infants diagnosed	<b>6,163</b> infants diagnosed
<b>Early intervention (EI)</b>	<b>446</b> receive EI	<b>4,000</b> receive EI

# EHDI Data: State and National Data

## ➤ State EHDI data systems

- Individual child-level data
- Multiple sources

## ➤ National data systems

- CDC Hearing Screening and Follow-up Survey (HSFS)
  - ❑ States report annual child-level aggregate data
- iEHDI pilot project
  - ❑ Quarterly child-level data
  - ❑ CDC developed a data validation tool



# Challenges

## ➤ Structural factors leading to loss to follow-up

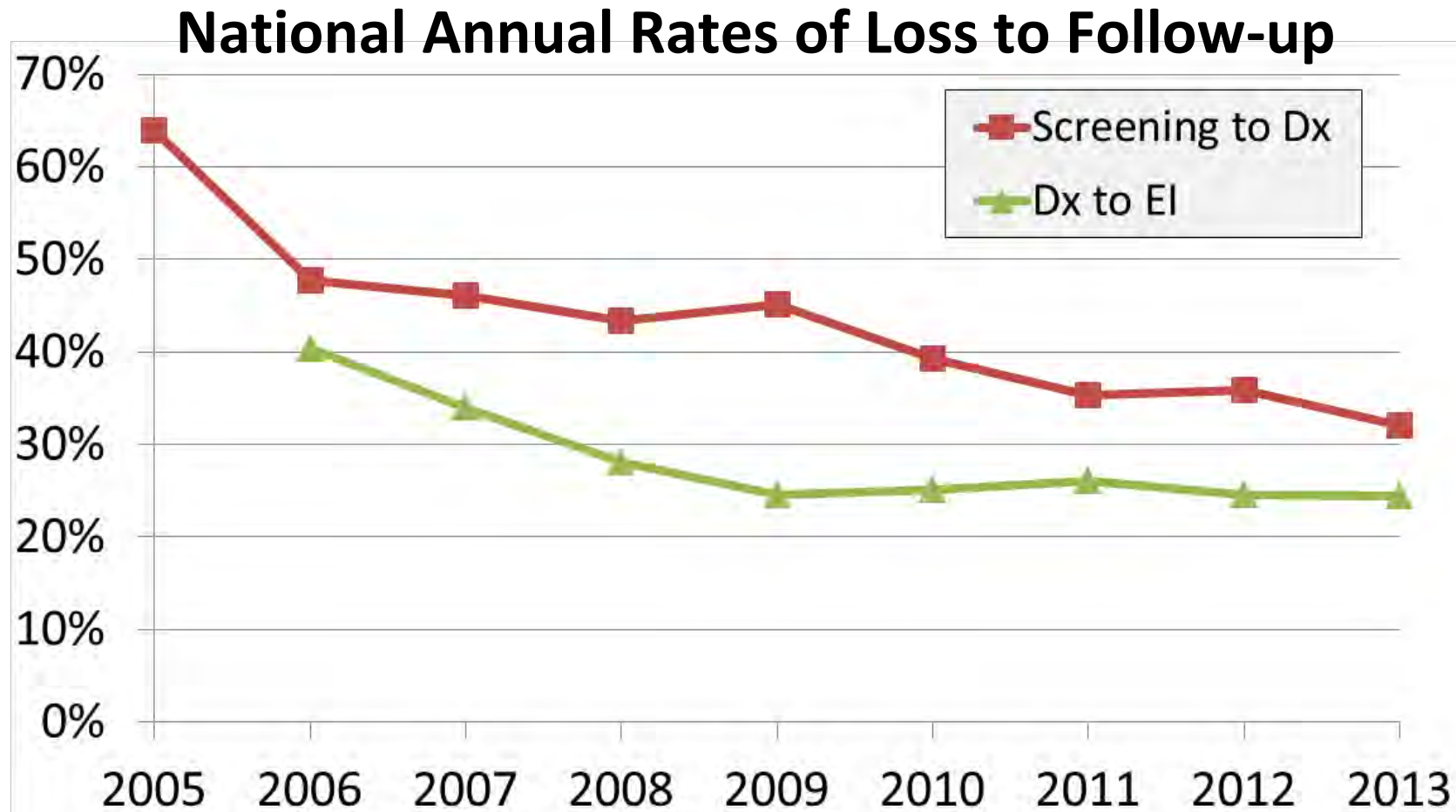
- Data access
- NICU births, border babies, out-of-hospital births

## ➤ Data gaps or limitations impact surveillance, quality, and support

- Standardization
- Quality
- Timeliness



# Reducing EHDl Loss to Follow-up: It's a Good Thing



# EHDI Data Improvement Strategies: Standardization and Interoperability

- **EHDI functional standards**
  - Identifies recommended data items
  - Provides system design guidance
- **Data committee**
  - Promotes standard operational definitions
  - Collects additional detail on EHDI activities
- **HSFS documentation**
  - Expanded data collection and reporting
  - Includes example survey items



# Supporting Electronic Data Transfer

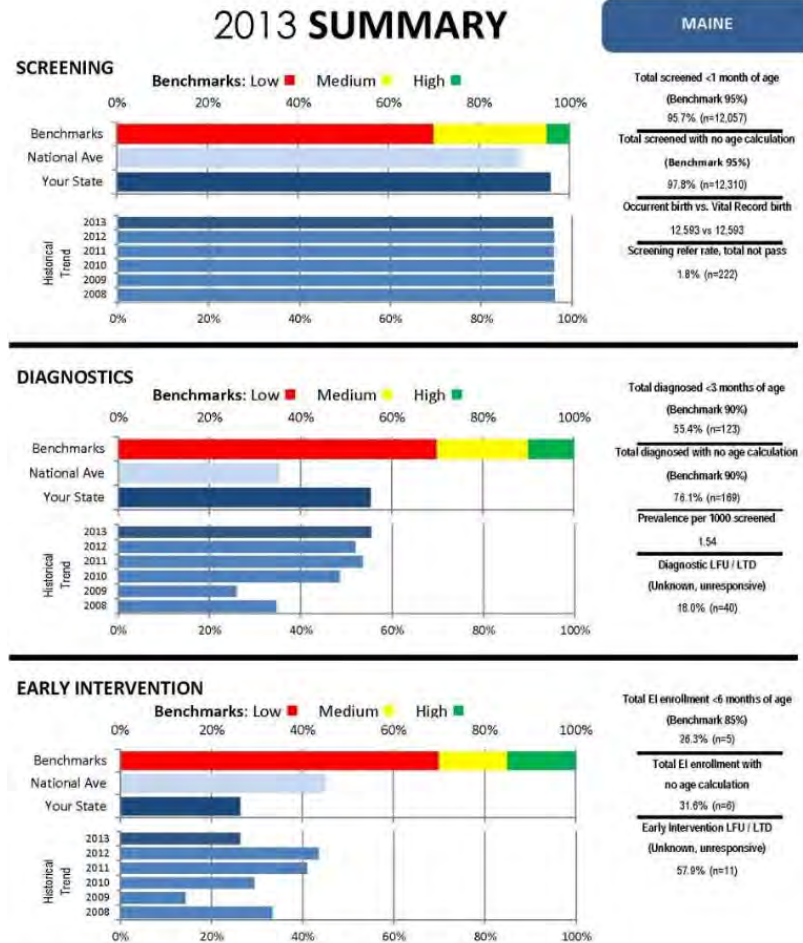
## ➤ IHE Newborn Admission and Notification Information (NANI)

- Automates data transfers from a birthing hospital electronic health record to a state's EHDl program
- Improves the completeness and quality of data
- Increases accuracy of data used in quality indicators
- Can be used as a framework for other programs





# Making Data Usable

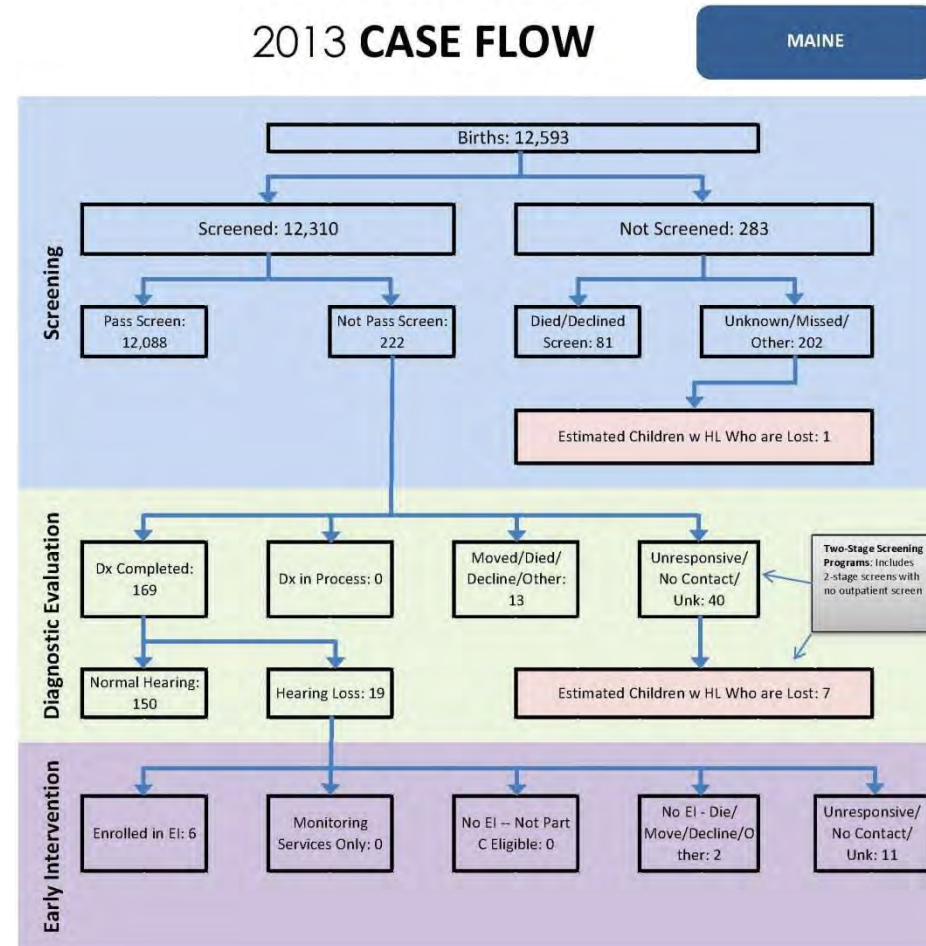


Total screened by 1 month of age

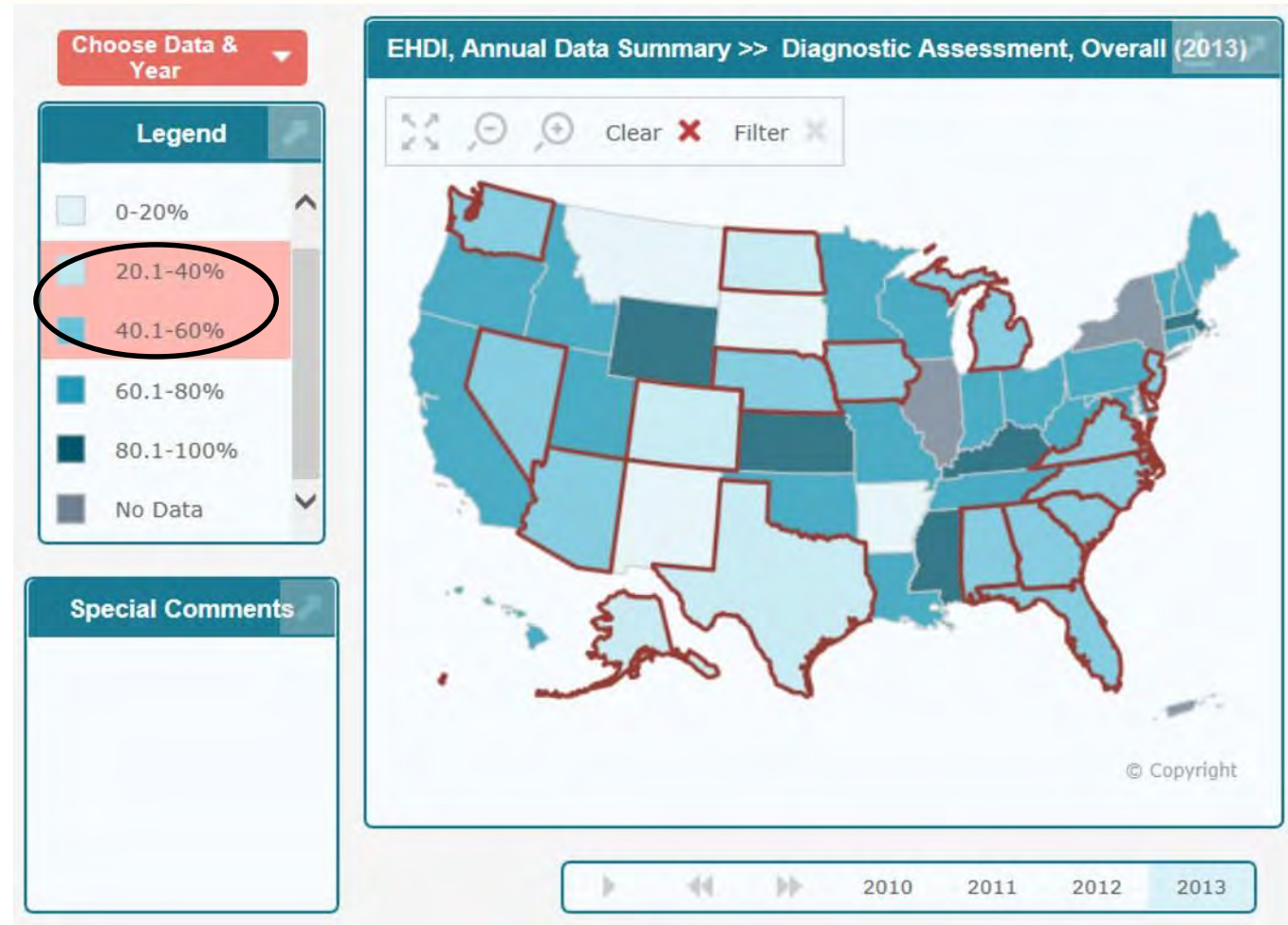
Total diagnosed by 3 months of age

Total EI-enrollment by 6 months of age

# Making Data Usable for States: Annual Reports



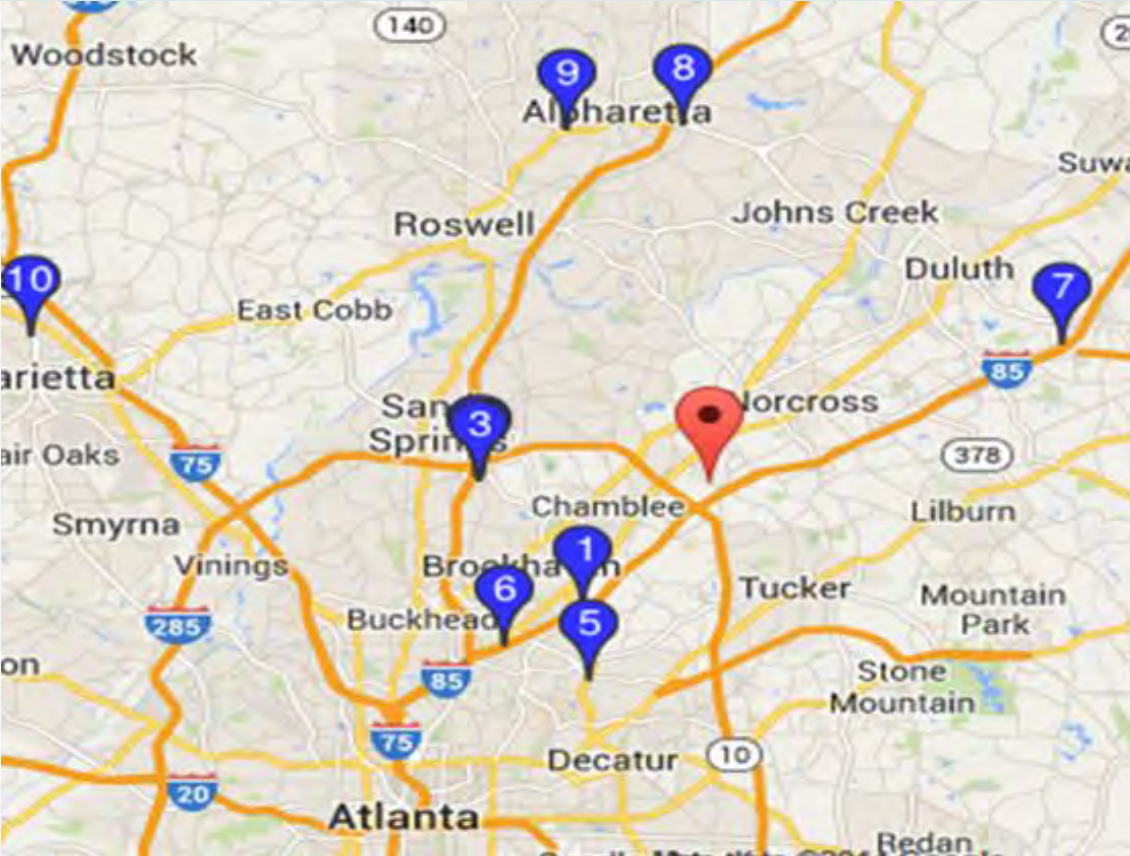
# Making Data Usable Nationally: EHDI-DASH



# Making Data Usable for Parents: EHDI-PALS

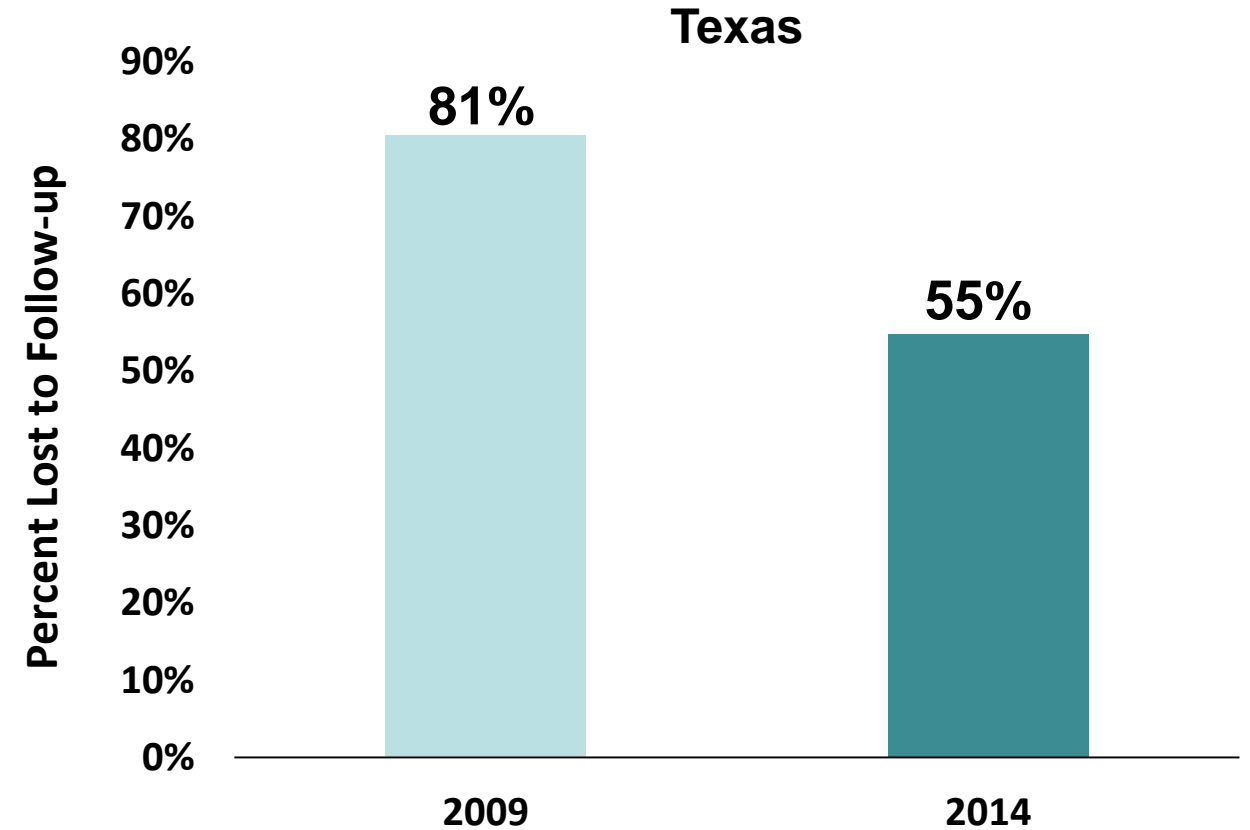
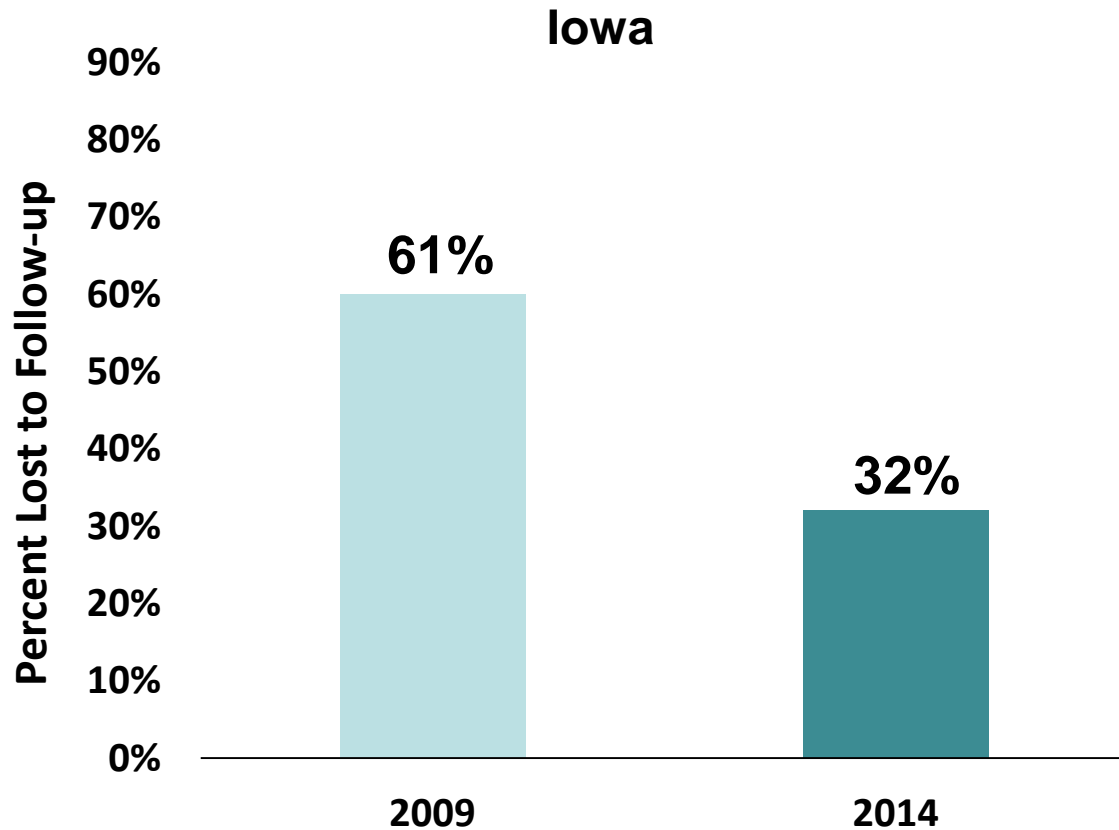
## EHDI-PALS Facility Locator

- Home
- Find Audiology Facilities
- Parent Resources
- Professional Resources
- Other Helpful Websites
- Providers Enter Here
- EHDI-PALS Program Log-in
- EHDI-PALS Advisory Group



The map displays the Atlanta metropolitan area with 10 numbered blue location pins and one red location pin. The numbered pins are located in the following areas: 1. Chamblee, 2. Brookhaven, 3. Sandy Springs, 4. Buckhead, 5. Decatur, 6. Buckhead, 7. Duluth, 8. Alpharetta, 9. Alpharetta, and 10. Marietta. The red pin is located in the area between Sandy Springs and Dorcross. Major highways like I-75, I-85, and I-285 are visible.

# Increasing Quality and Timeliness of Reporting Leads to Fewer Infants Lost to Follow-up



# Increasing Number of Children Identified and Supported in States with Large Birth Cohorts

- **CDC-EHDI large state loss to follow-up project**
  - Formal partnership
  - States with  $\geq 150,000$  births per year
    - California
    - Florida
    - Illinois
    - New York
    - Texas



# Challenges to Evaluating Impact

## ➤ **Accessing educational data**

- Family Educational Rights and Privacy Act
- Part C regulations of Individuals with Disabilities Education Act
- Neither includes public health exemptions

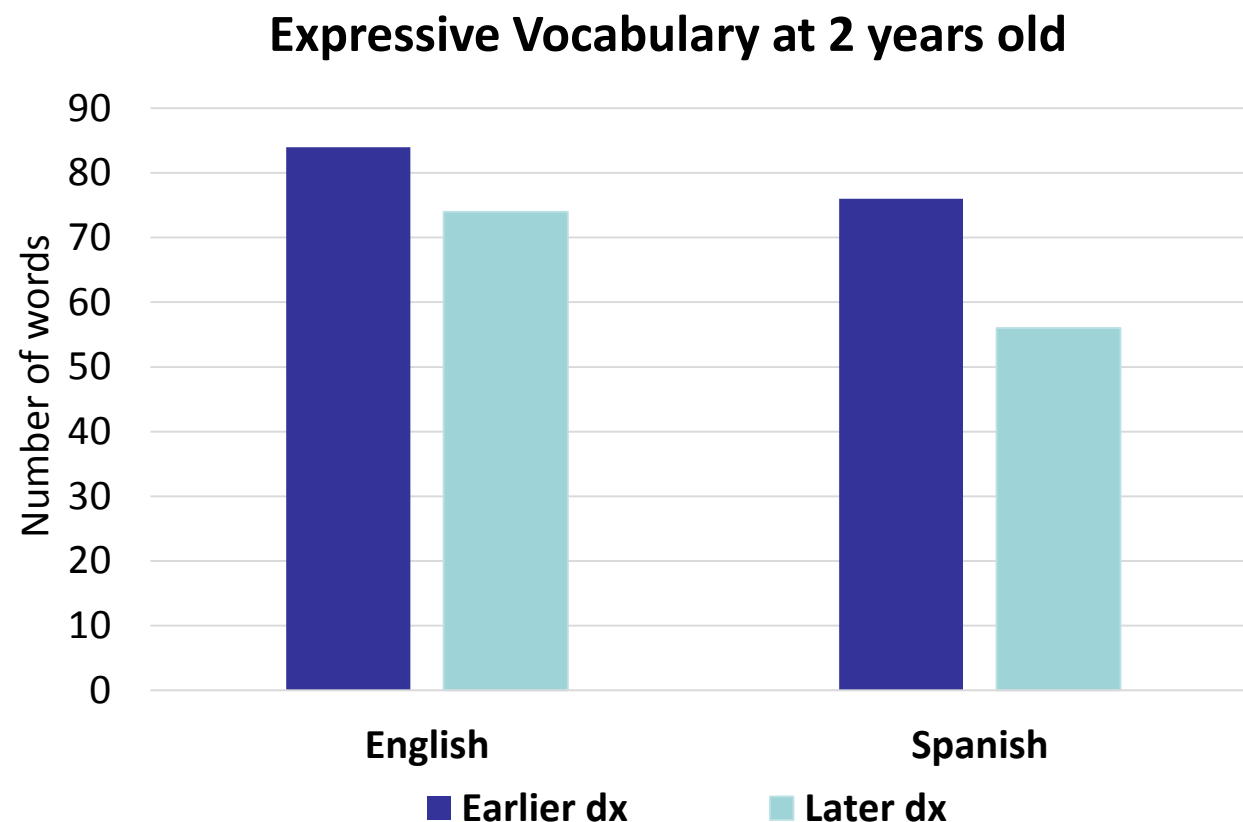
## ➤ **State policies may change over time**

## ➤ **Permissions, coordination, and management change**

# Evaluating Impact: Outcomes, Evidence, and Insights

## ➤ EHDI Developmental Outcomes Study

- Language outcomes for children with hearing loss
- Higher expressive vocabulary with earlier diagnosis
  - Earlier diagnosis defined as under 6 months of age



dx: Diagnosis



# Evaluating Longer-Term Impact of EHDI: Evidence of Improved Outcomes

## ➤ Third grade academic achievement improved when hearing loss detected by EHDI

- Maine EHDI data linked to standardized test data
- Assessed reading and math proficiency
- More children with hearing loss met math standards if identified through EHDI

Academic Achievement Among Students With Hearing Loss		
Source of Hearing Loss Detection	Met Standards	
	Math	Reading
<b>EHDI</b>	<b>82%</b>	<b>82%</b>
<b>Other</b>	<b>63%</b>	<b>76%</b>

# Conclusion

- **Expanding tracking and surveillance into longer-term follow-up and monitoring involves a range of challenges**
  - Data and technology barriers
  - Increased policy barriers
- **Leads to meaningful benefits**
  - Creates value for families, health policy makers, and providers
  - Creates opportunity for deeper understanding and improved programming in the future