CDC PUBLIC HEALTH GRAND ROUNDS

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

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

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

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

www.isns-neoscreening.org/nl/pages/24-isns_general_guidelines_for_neonatal_screening

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**

Anderson R, Rothwell E, Botkin JR. *Annu Rev Nurs Res*. 2011;29:113–32.
NBS: newborn screening

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**

HHS: U.S. Department of Health and Human Services
HRSA: Health Resources and Services Administration

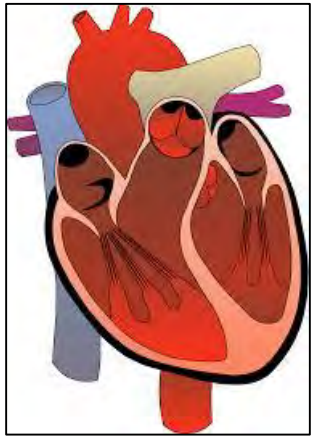
Since 2005, New Conditions Added to the RUSP

- **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

RUSP: Recommended Uniform Screening Panel
ACHDNC: Advisory Committee on Heritable Disorders in Newborns and Children
HHS: U.S. Department of Health and Human Services

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**



www.isns-neoscreening.org/nl/pages/24-isns_general_guidelines_for_neonatal_screening
NBS: newborn screening

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%

Source: cdc.gov/ncbddd/hearingloss/ehdi-data2013.html

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

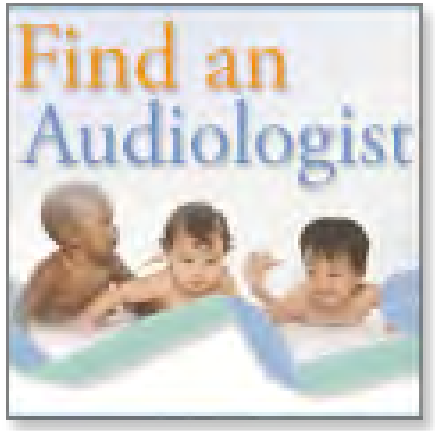
- **Joint Committee on Infant Hearing Position Statement, 2007**
  - No later than age **1 month**, all infants screened
  - No later than age **3 months**, all infants not passing the screen have a comprehensive audiologic evaluation
  - No later than age **6 months**, all infants with confirmed hearing loss receive appropriate intervention

American Academy of Pediatrics, Joint Committee on Infant Hearing. *Pediatrics* 2007;120(4):898–921.

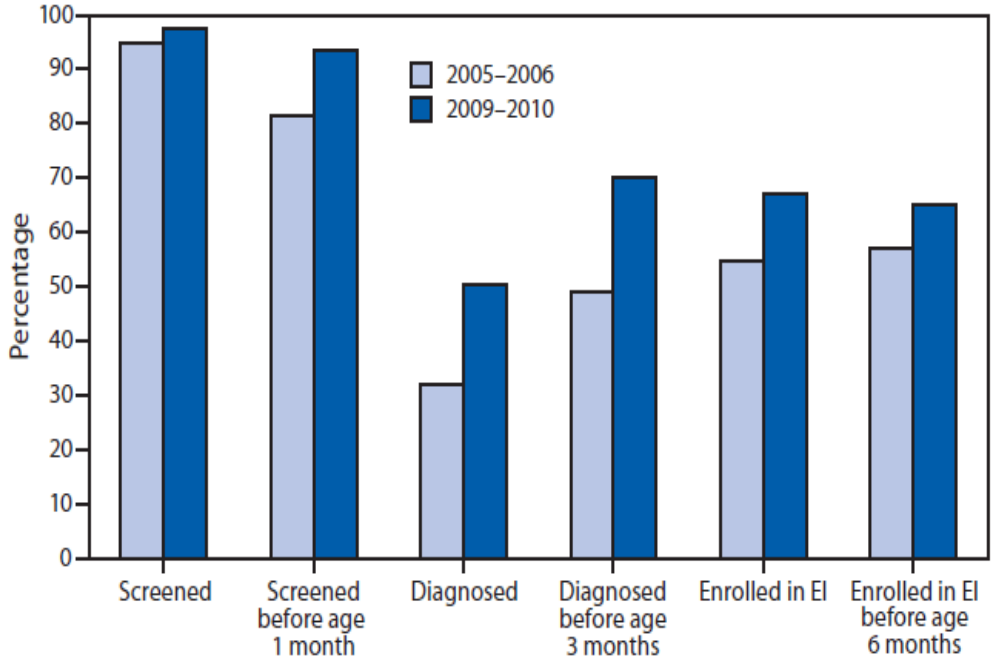
EHDI Programs Support Families of Children Identified with Hearing Loss

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



Gaffney M, Eichwald J, Gaffney C, et al. *MMWR*. 2014 Sept 12;63(02):20–26.

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

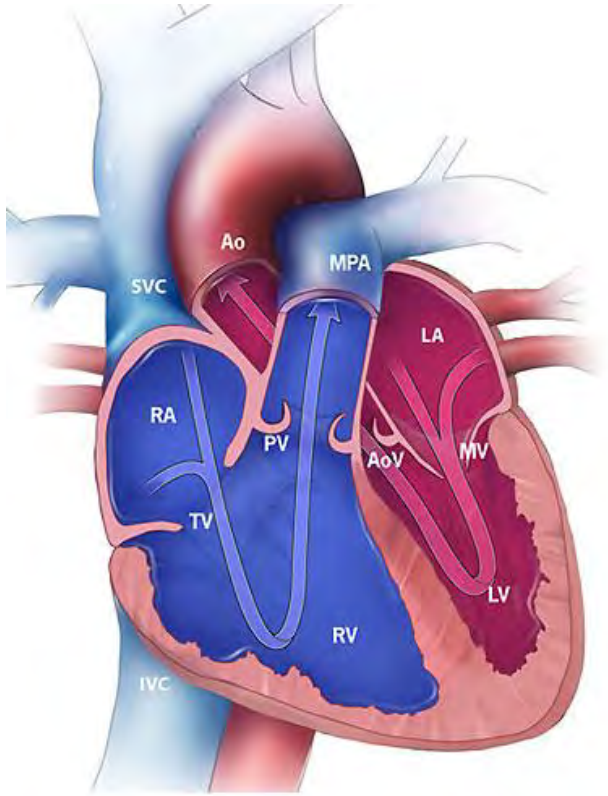
Reller MD, Strickland MJ, Riehle-Colarusso T, et al. *J Pediatr*. 2008 Dec;153(6):807–13.
Ailes EC, Gilboa SM, Honein MA, et al. *Pediatrics*. 2015 Jun;135(6):1000–8.
Peterson C, Dawson A, Grosse SD, et al. *Birth Defects Res A Clin Mol Teratol*. 2013 Oct;97(10):664–72.
NBS: newborn screening

Screening for CCHD Since 2011

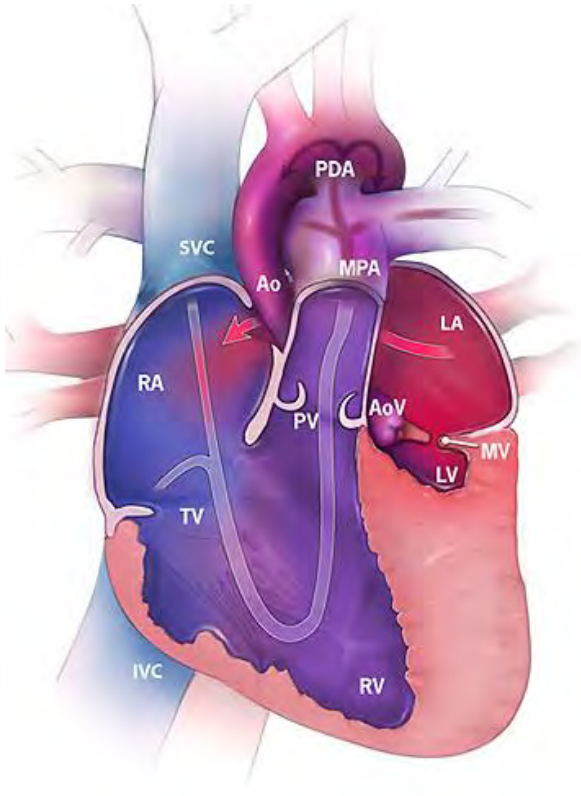
- **Screens for 12 structural birth defects of the heart**
- **Noninvasive screening conducted at 24–48 hours after birth using a pulse oximeter on the right hand and one foot, which monitors oxygen saturation**
  - Typical range of normal saturation values is 95%–100%, with no more than a 3% difference 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



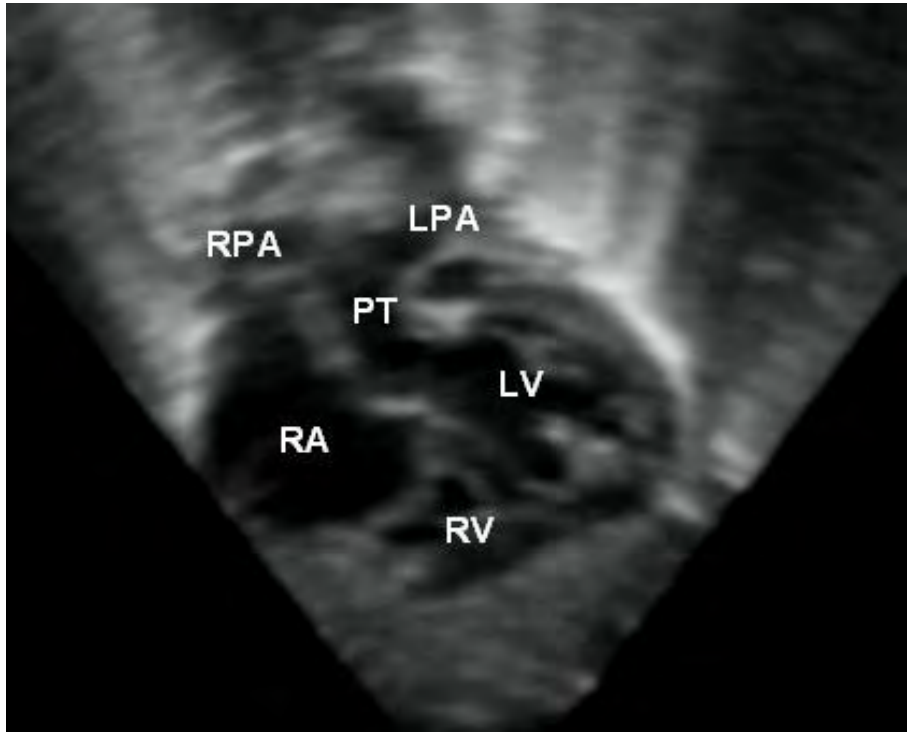
Normal Heart



Hypoplastic Left Heart Syndrome

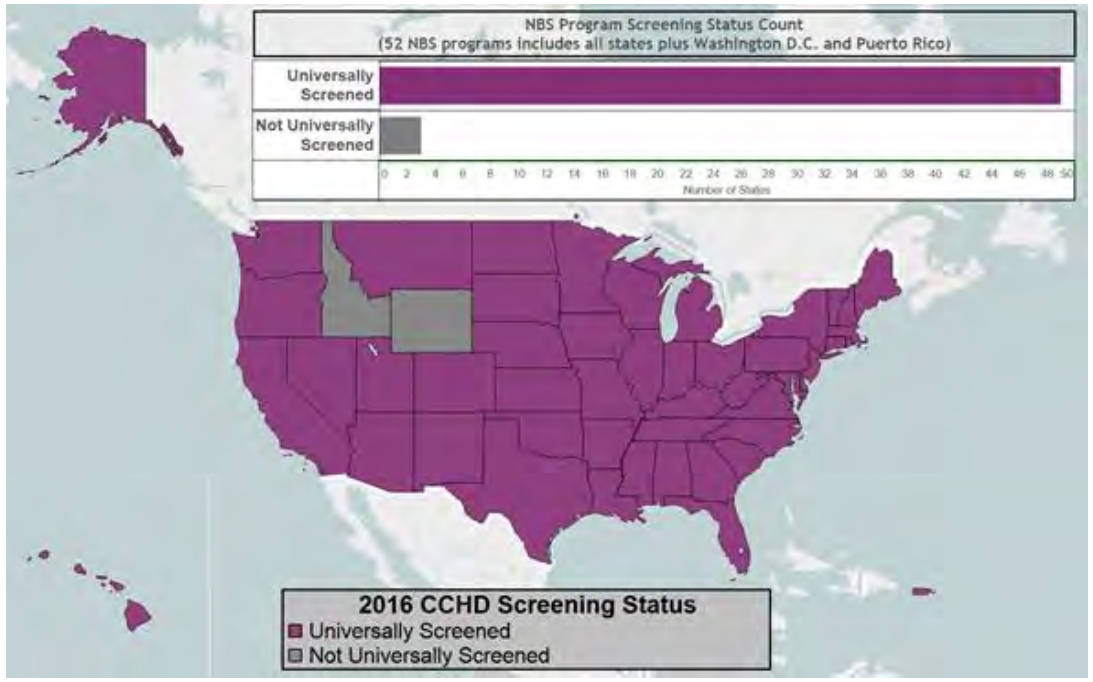
CCHD Screening Challenges: Individual Testing and Follow-up

- 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

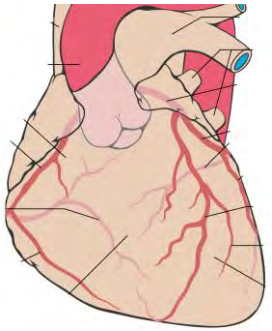
CCHD Screening Challenges: Policy and Program



- **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



HRSA: Health Resources and Services Administration

The Federal Partner Perspective

Marci K. Sontag, PhD

Associate Professor

Colorado School of Public Health

University of Colorado Denver Anschutz Medical Campus

University of Colorado Anschutz Medical Campus

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

Support from the Federal Level for Newborn Screening

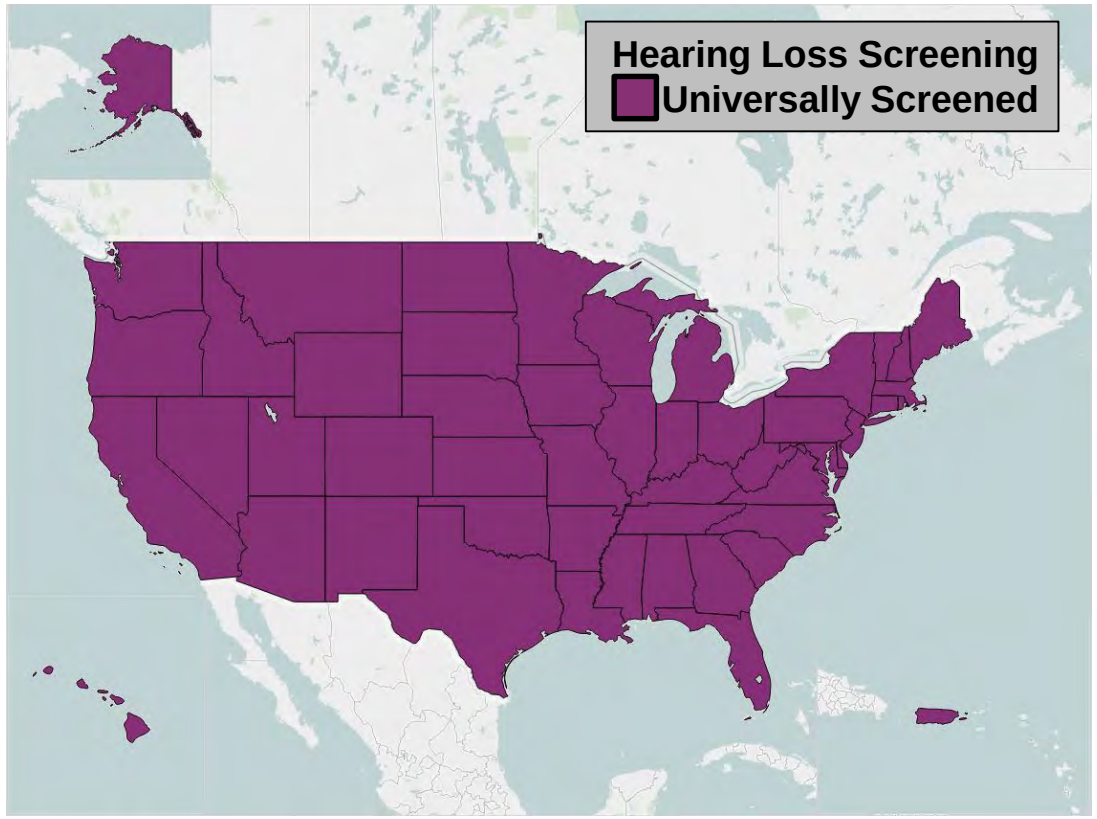
- Implementation
- Data collection and interpretation
- Technical assistance
- Quality improvement initiatives

Point-of-care Screening: Brief History of Implementation

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

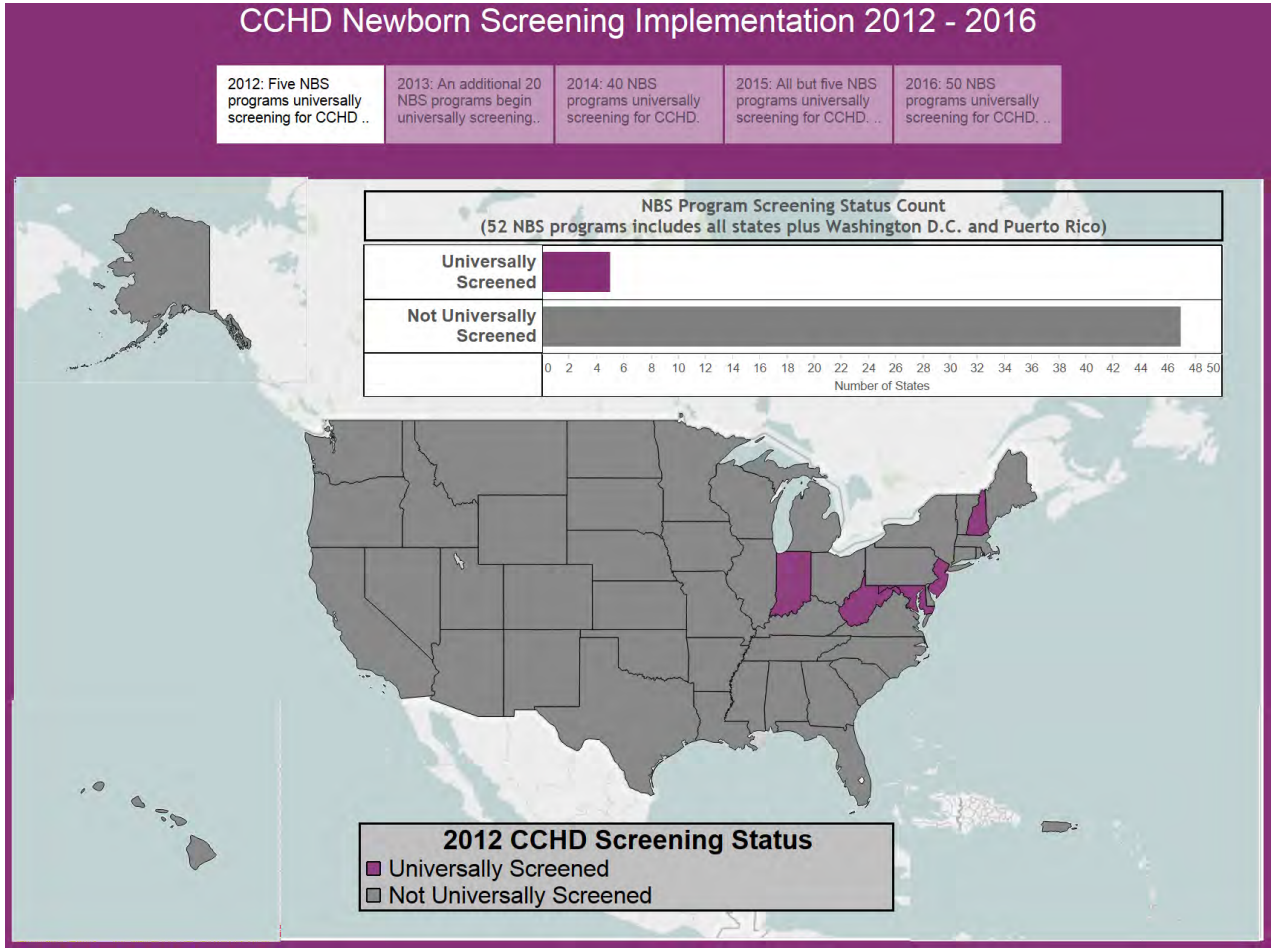
- **Critical Congenital Heart Disease**
  - Rapid implementation of CCHD screening has occurred since 2011
  - Most states have universal screening for CCHD

Current National Screening Status for Early Hearing Loss

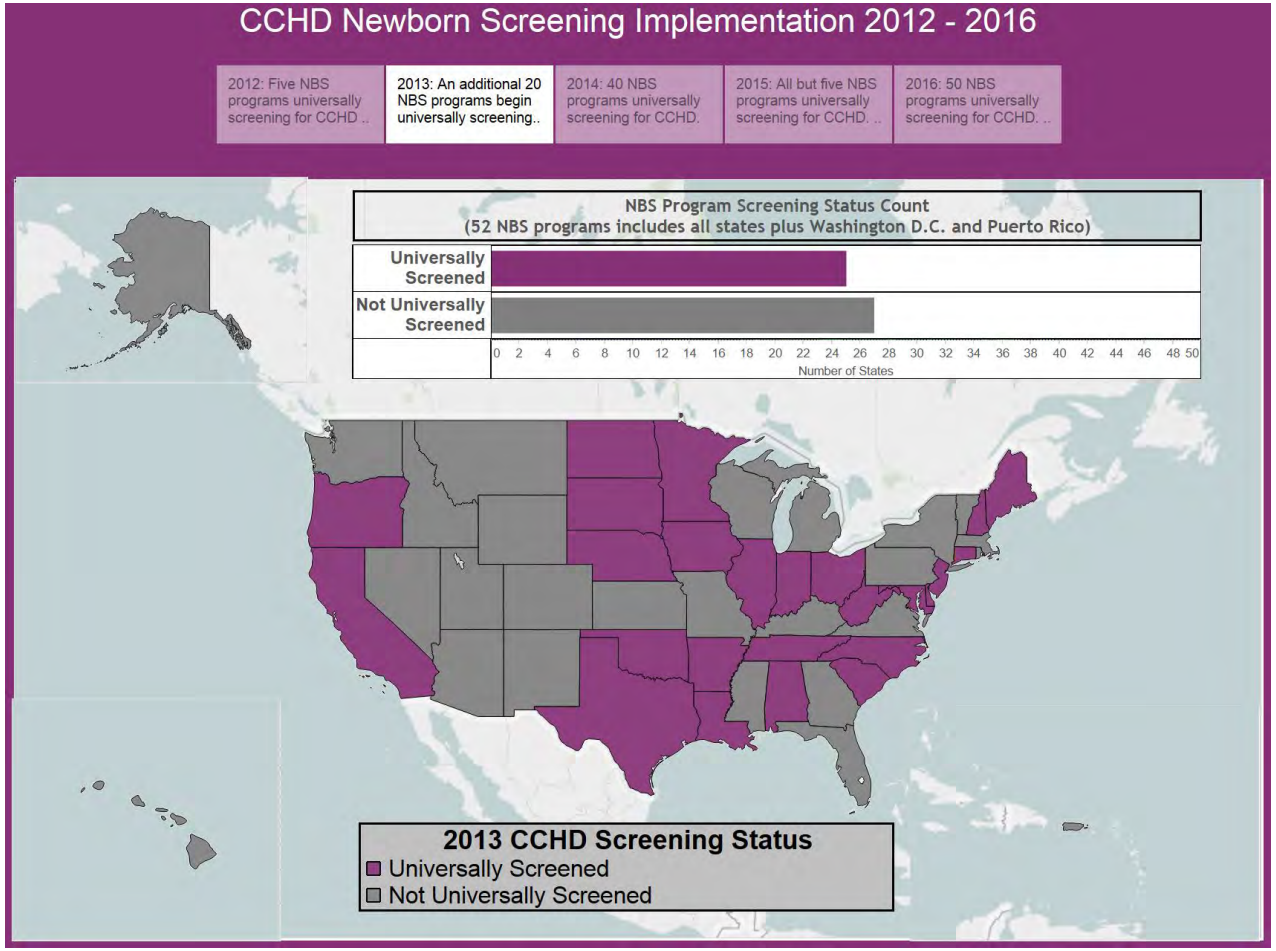


- Screening for hearing loss began in select states in 1990
- By 2003 all states had begun screening for hearing loss
- All states have implemented EHDI programs

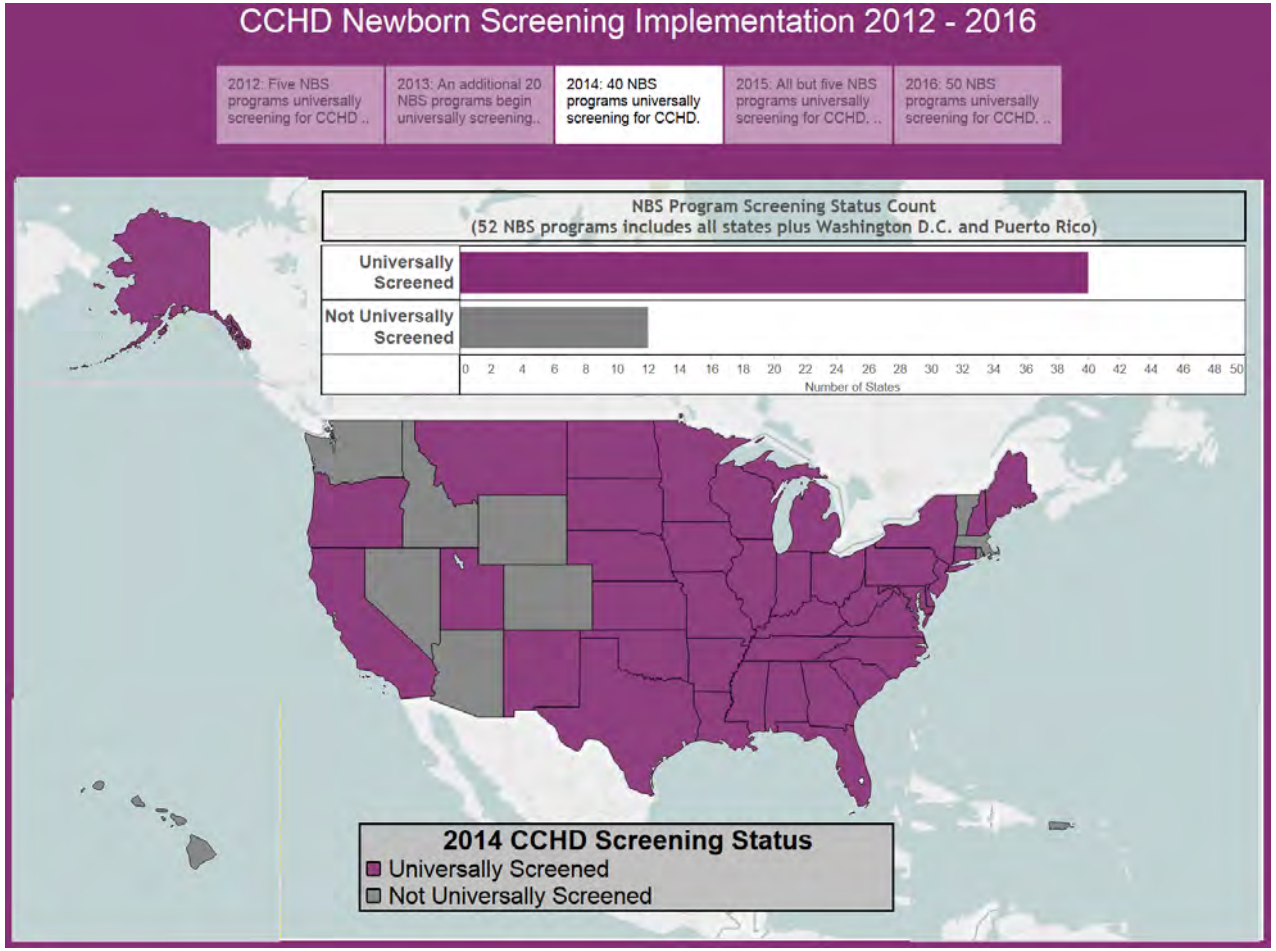
CCHD Screening: 2012



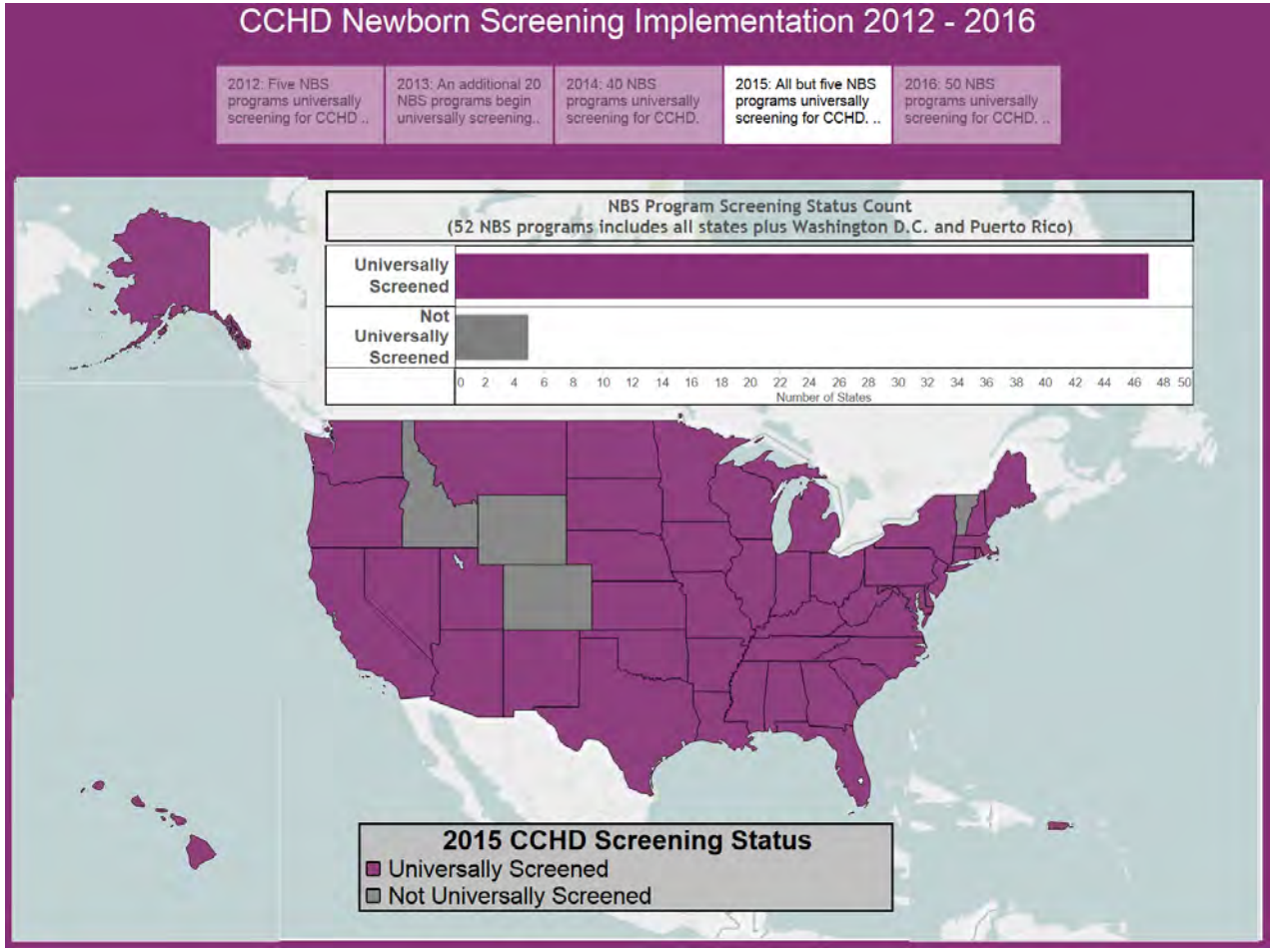
CCHD Screening: 2013



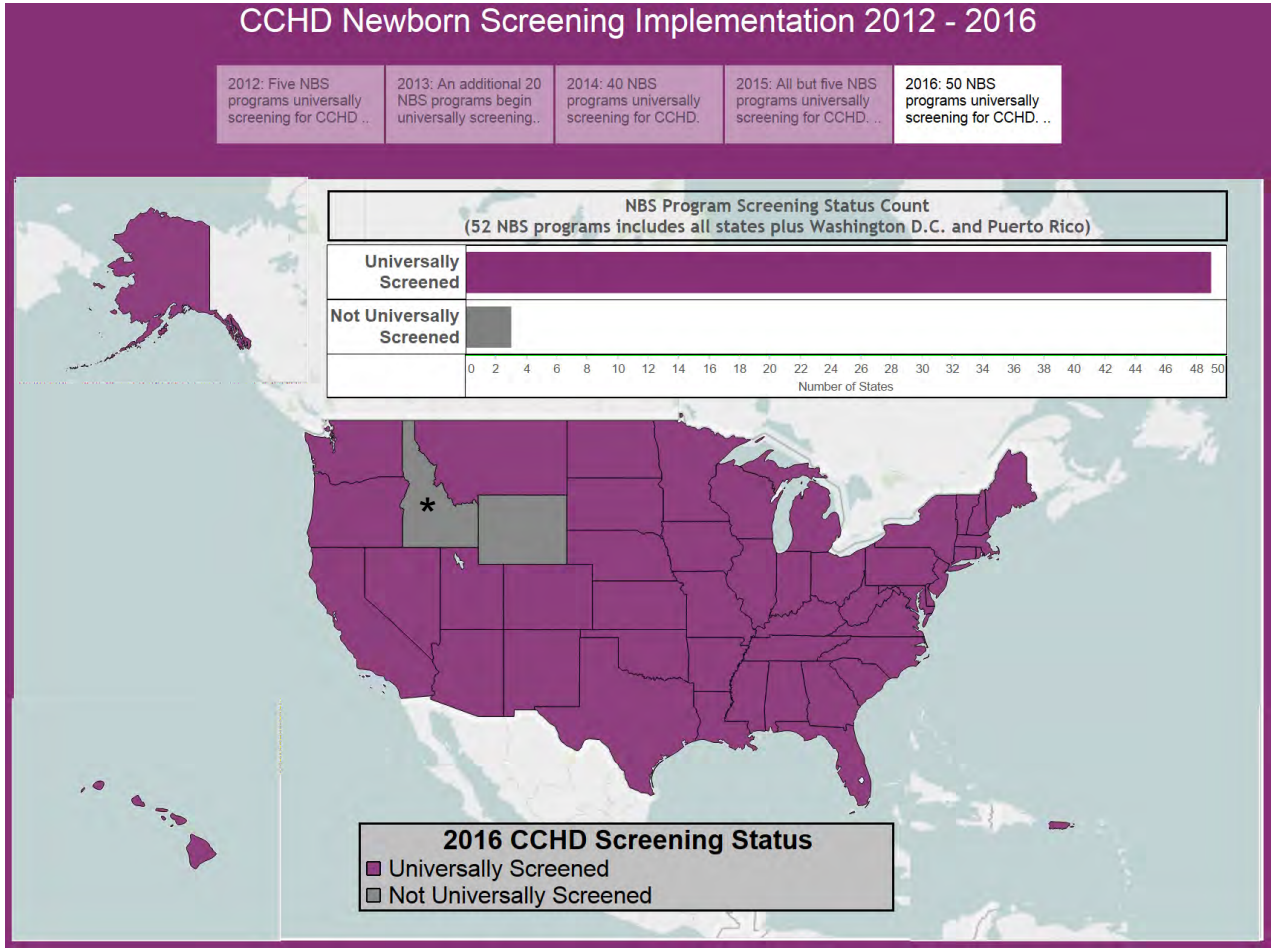
CCHD Screening: 2014



CCHD Screening: 2015



CCHD Screening: 2016

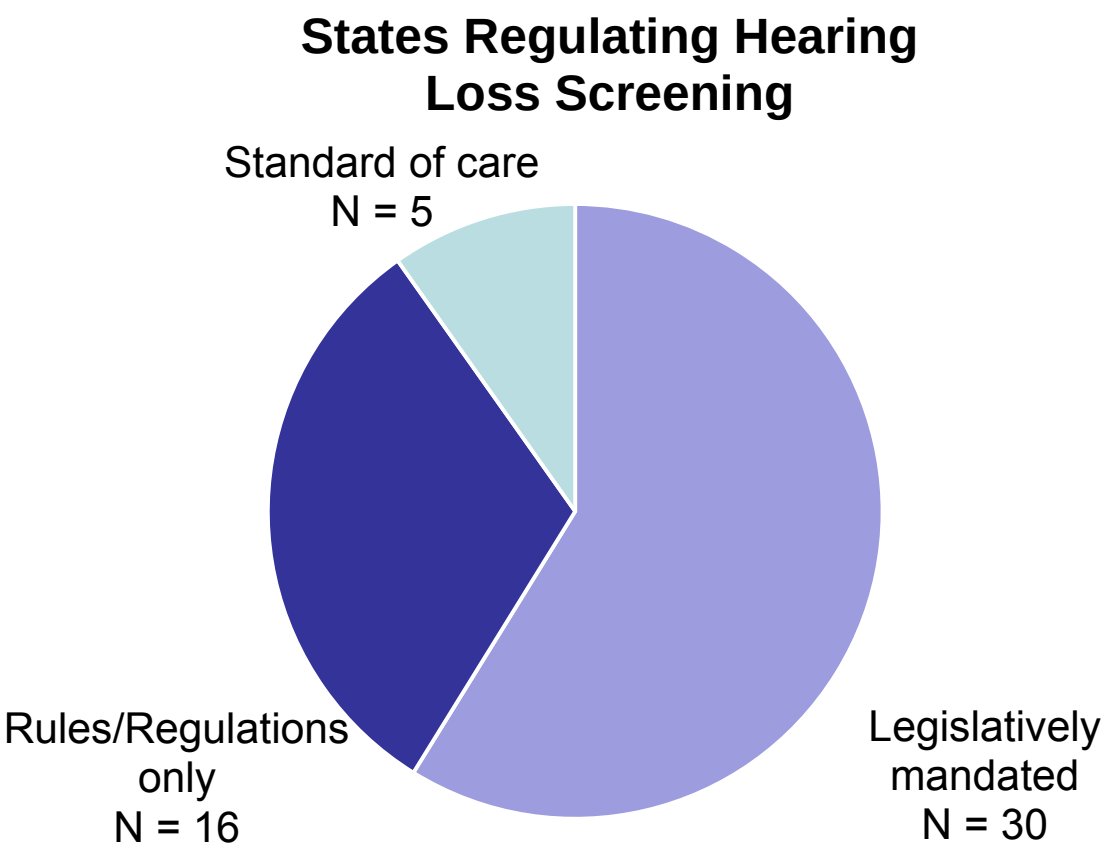


newsteps.org

*Discussions with partners related to legislation for CCHD screening are occurring in Idaho

Newborn Hearing Screening Implementation

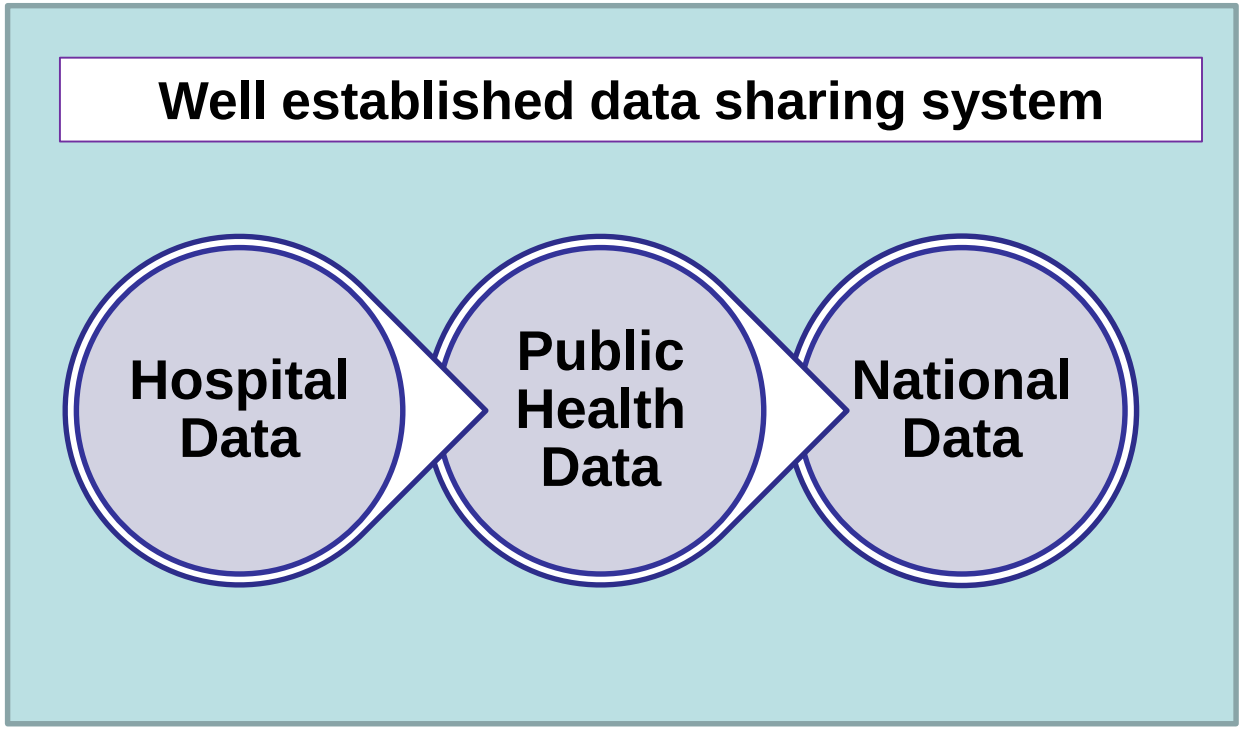
- **Required in 46/51 programs (50 states and Washington, D.C.)**



American Academy of Pediatrics. 2014 State EHDI Laws and Regulations Report. infanthearing.org/legislative/summary/index.html

Early Hearing Loss Data Reporting at Public Health Level

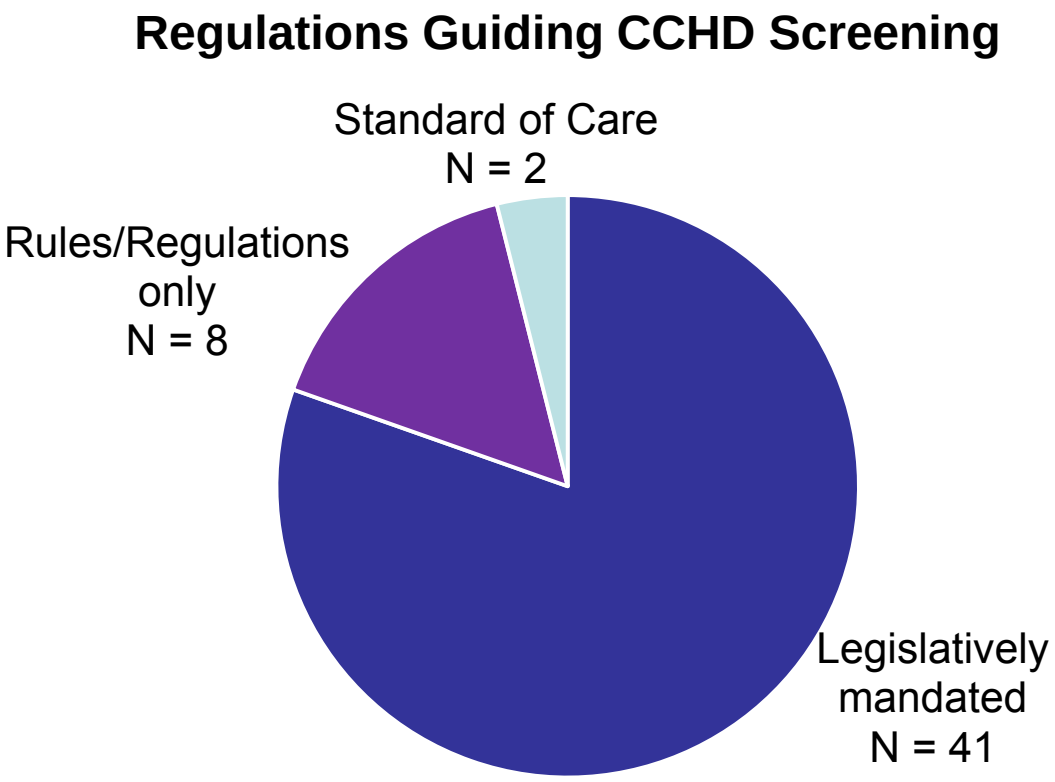
- **Data reporting is required in 36 states**
- **All state programs collect some type of data**
  - E.g., electronic birth certificate or other automated systems



American Academy of Pediatrics. 2014 State EHDI Laws and Regulations Report. infanthearing.org/legislative/summary/index.html

CCHD Regulatory Requirements for Screening and Data Collection

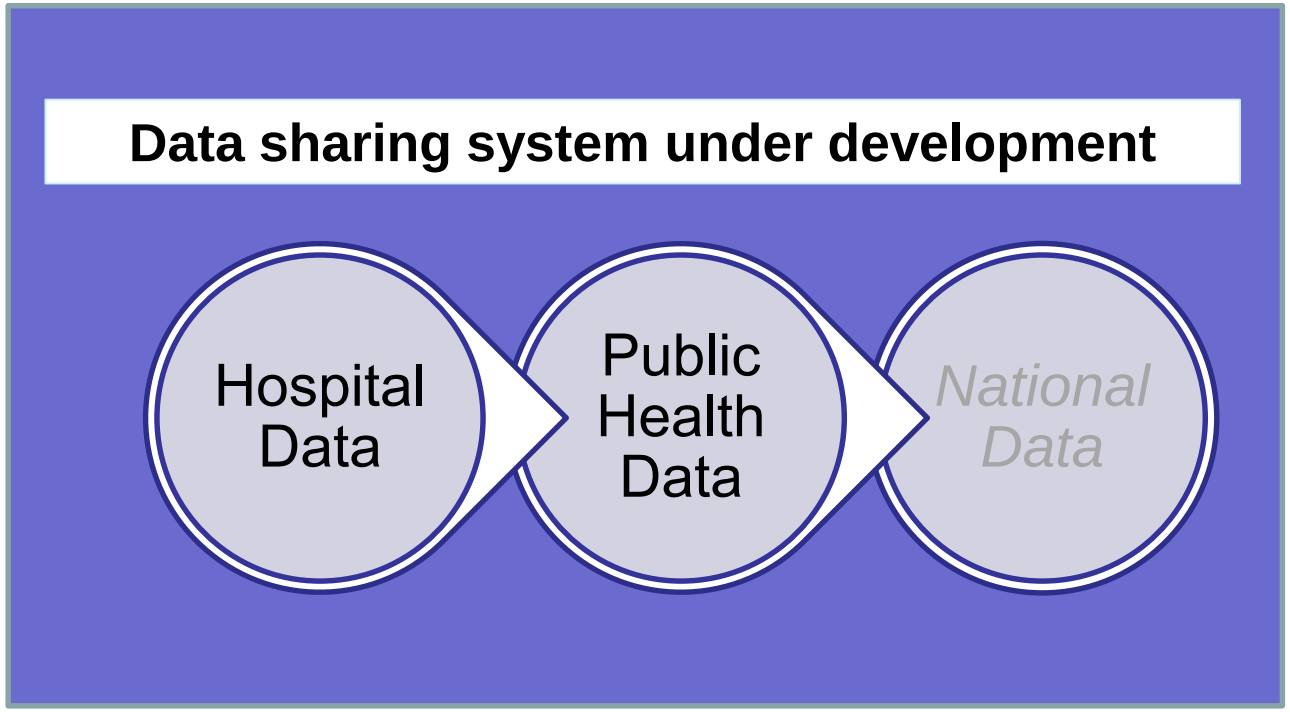
- **Required in 49/51 programs**
  - Legislatively mandated in 41 states
  - Required only through rules or regulations in 8 states
  - Two programs support CCHD screening as a standard of care



Glidewell J, Olney RS, Hinton C, et al. *MMWR*. 2015 Jun 19;64(23):625–30.

CCHD Screening Data Reporting at Public Health Level

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



American Academy of Pediatrics. 2014 State EHDI Laws and Regulations Report. infanthearing.org/legislative/summary/index.html

Technical Assistance at the Federal Level

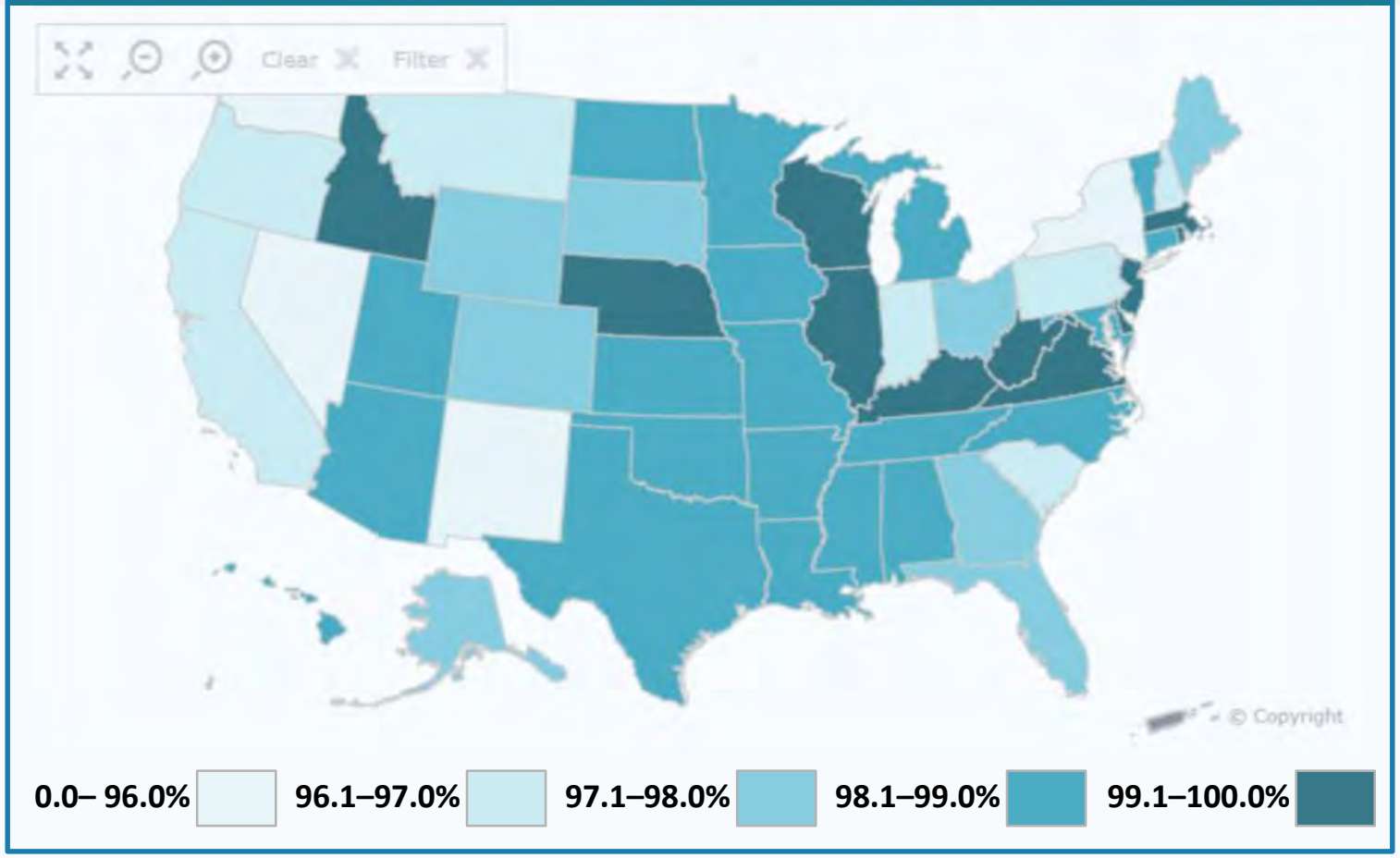
- **CDC National Center on Birth Defects and Developmental Disabilities**
  - National Birth Defects Prevention Network
  - Technical assistance and state-level funding to support high-quality hearing screening, data systems, and follow-up

- **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

EHDI Annual Data Summary Screening, Overall U.S. 2013



cdc.gov/ncbddd/hearingloss/ehdi-data.html

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

NCHAM
National Center for Hearing Assessment and Management
Utah State University™

HRSA: Health Resources and Services Administration
infanthearing.org/

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**

Oster ME, Aucott SW, Glidewell J, et al. *Pediatrics*. 2016 May;137(5).

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

NewSTEPs
A Program of the Association of Public Health Laboratories™

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

VIP vital information platform
STATE OF NEW JERSEY DEPARTMENT OF HEALTH

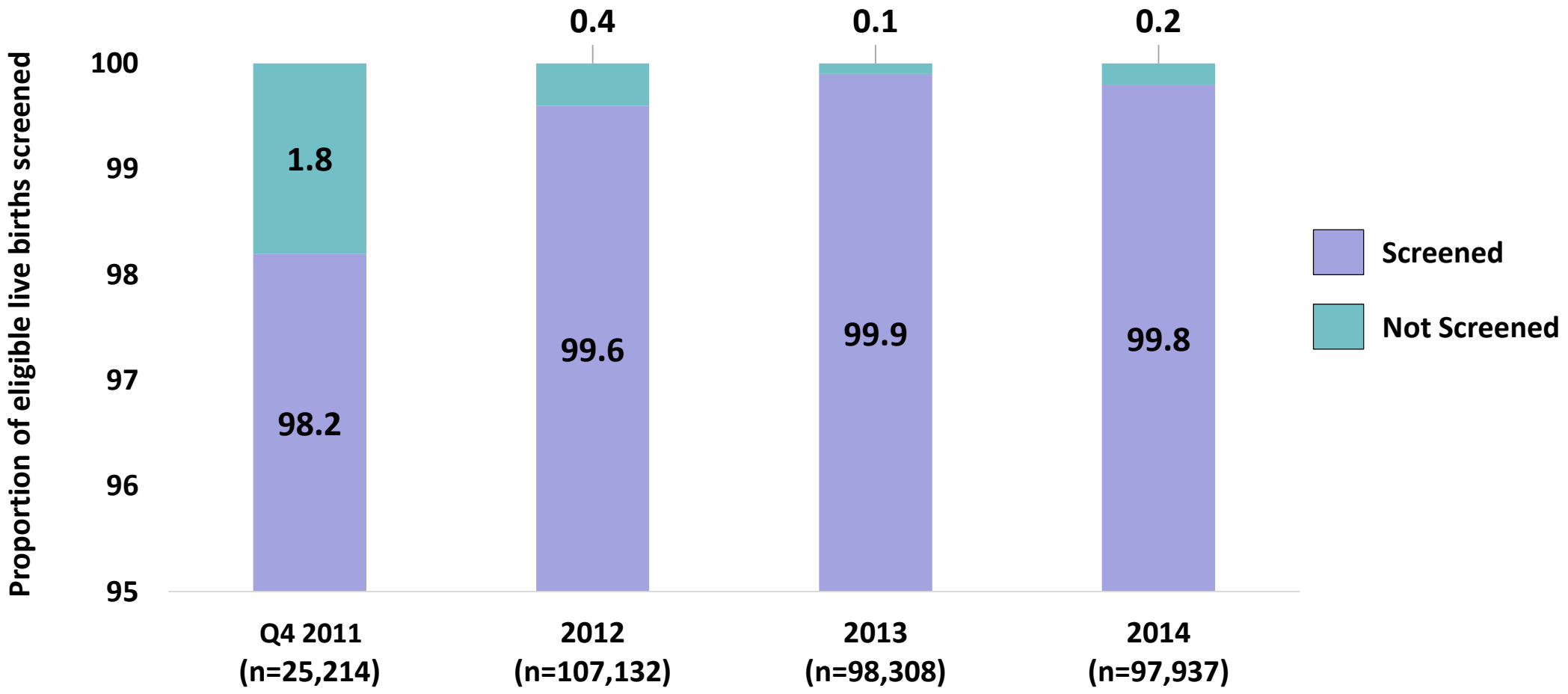
Quarterly Submission and Aggregate Data Used to Assess Screening Coverage

Data from August 31, 2011–December 31, 2014

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

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

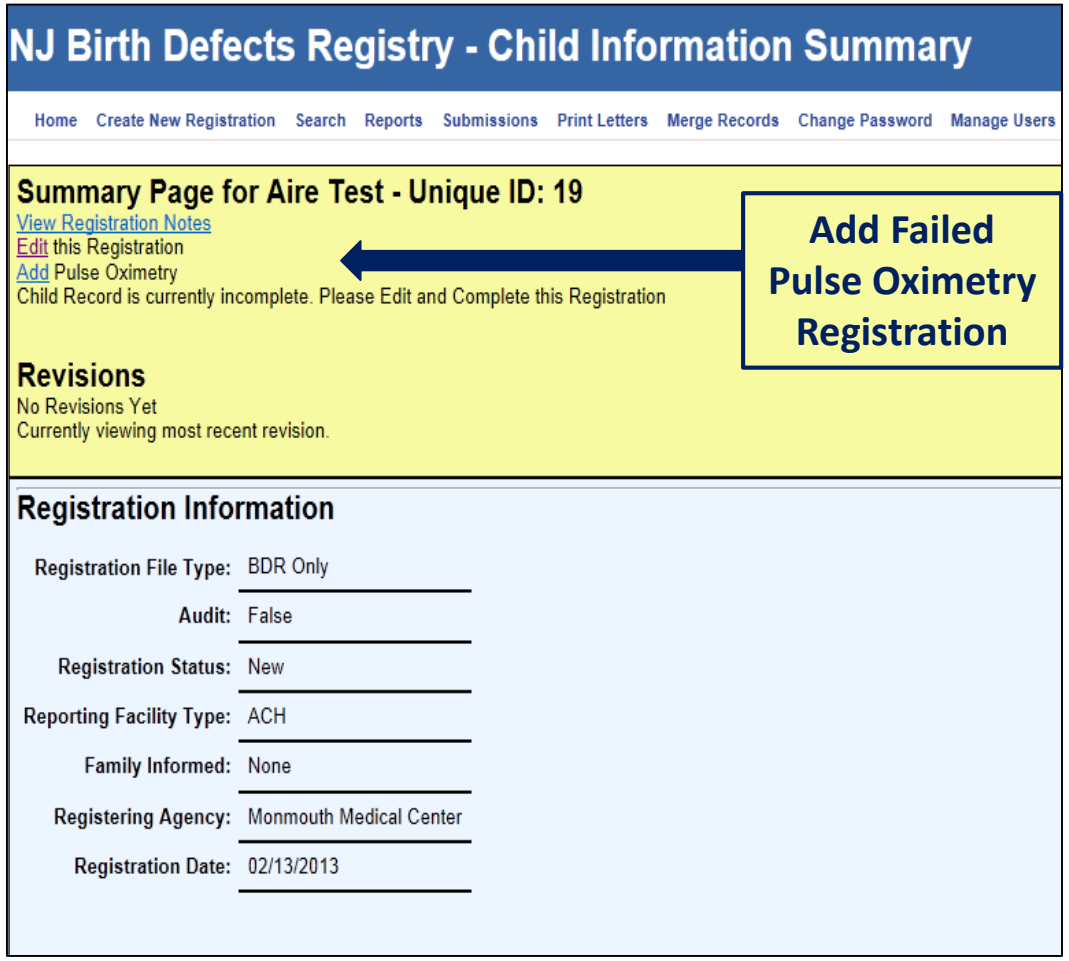
High Proportion of Newborns Screened for CCHD



Q4: Fourth quarter
Unpublished data

New Jersey Birth Defects Registry (NJ BDR)

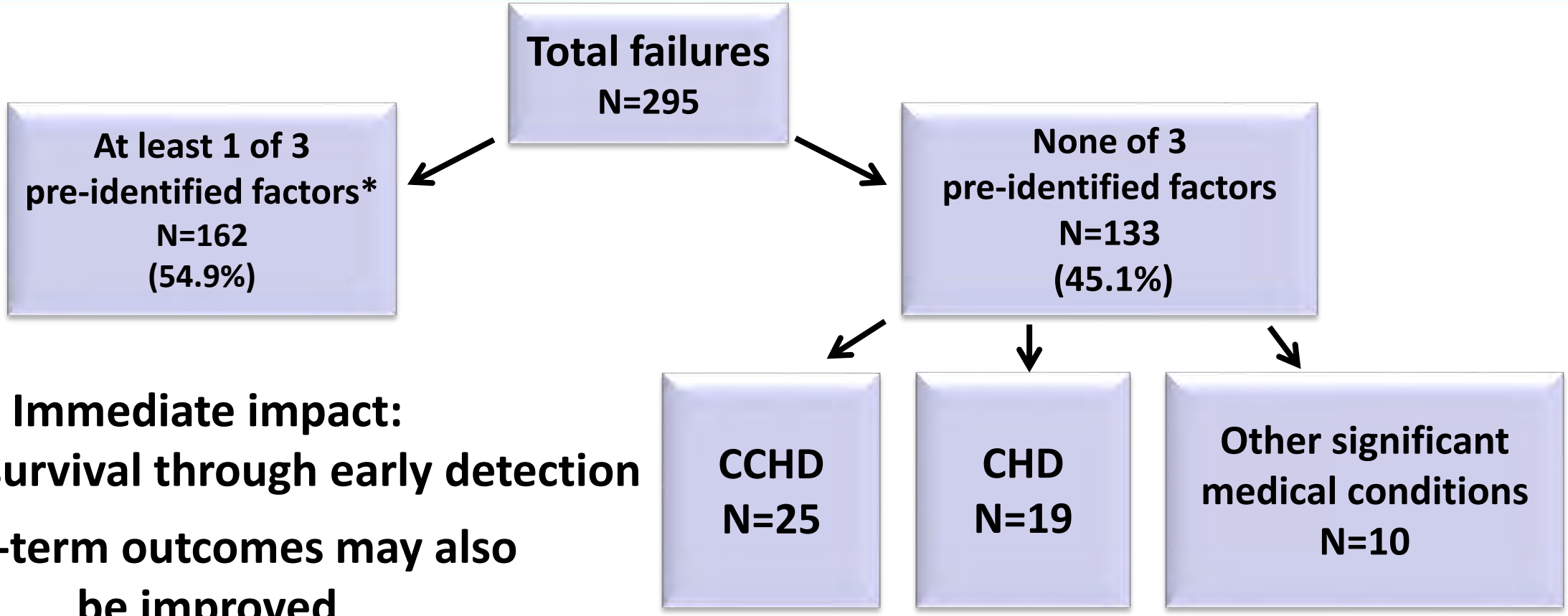
- Birthing facilities report all failed CCHD screens to the NJ BDR
- Health care professionals required to register infants with CCHD who are NJ residents
- Core CCHD team and BDR staff investigate CCHD screen failures



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



Immediate impact:
improved survival through early detection

Long-term outcomes may also be improved

*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

Peterson C, Grosse SD, Glidewell J, et al. *Public Health Rep*. 2014 Jan-Feb;129(1):86–93.

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

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State of New Jersey Department of Health

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- For Health Care Providers
- National Resources
- Critical Congenital Heart Defects Screening Resources (CCHD)
- Publications
- Statistics
- Sickle Cell Disease Testing and Counseling
- Pediatric Specialists
- Family Health Home

Critical Congenital Heart Defects (CCHD) Screening Resources

Newborn Screening for Critical Congenital Heart Defects (CCHD) Using Pulse Oximetry Course for nurses on New Jersey Learning Management Network (NJLMN). Go directly to course if already registered. https://njlmn.rutgers.edu

Course Information and How to Register [pdf 23k]

These resources for CCHD screening of newborns using pulse oximetry are available for printing and distribution.

- New Jersey Recommended Screening Algorithm [pdf 65k]
- Quick Reference Guide [pdf 157k]
- Birth Defects Registry (BDR) Worksheet [pdf 77k]
- Results From the New Jersey Statewide Critical Congenital Heart Defects Screening Program - Study Published in Pediatrics Read the abstract/report and a summary of the key findings.
- Centers for Disease Control and Prevention. Rapid Implementation of Pulse Oximetry Newborn Screening to Detect Critical Congenital Heart Defects — New Jersey, 2011. MMWR 2013;62(15); 292-294.

Newborn Screening for Congenital Heart Defects: Information for Parents

- Arabic [pdf 360k]
- English [pdf 197k]
- Hindi [pdf 579k]
- Korean [pdf 525k]
- Polish [pdf 348k]
- Spanish [pdf 200k]

- **Screening results by year** [pdf 67k]

state.nj.us/health/fhs/nbs/cchd_resources.shtml

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

American Academy of Pediatrics. Newborn screening for CCHD 2016—State Actions.

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**

BDR : Birth Defects Registry
VIP: Vital Information Platform

From Data to Action: The EHDI Experience

Craig A. Mason, PhD

Professor

Education and Applied Quantitative Methods
University of Maine

THE 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

HRSA: Health Resources and Services Administration
AAP: American Academy of Pediatrics
jcih.org/default.htm

Success in Surveillance and Follow-up

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

cdc.gov/ncbddd/hearingloss/ehdi-data.html

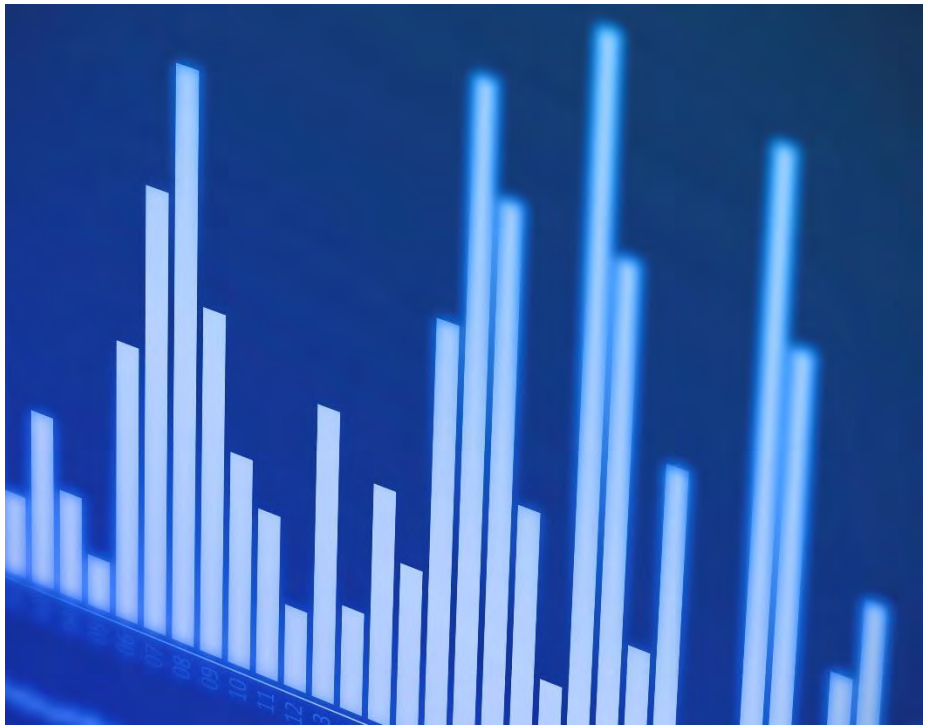
EHDI Data: State and National Data

- **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

iEHDI: individual Early Hearing Detection and Intervention

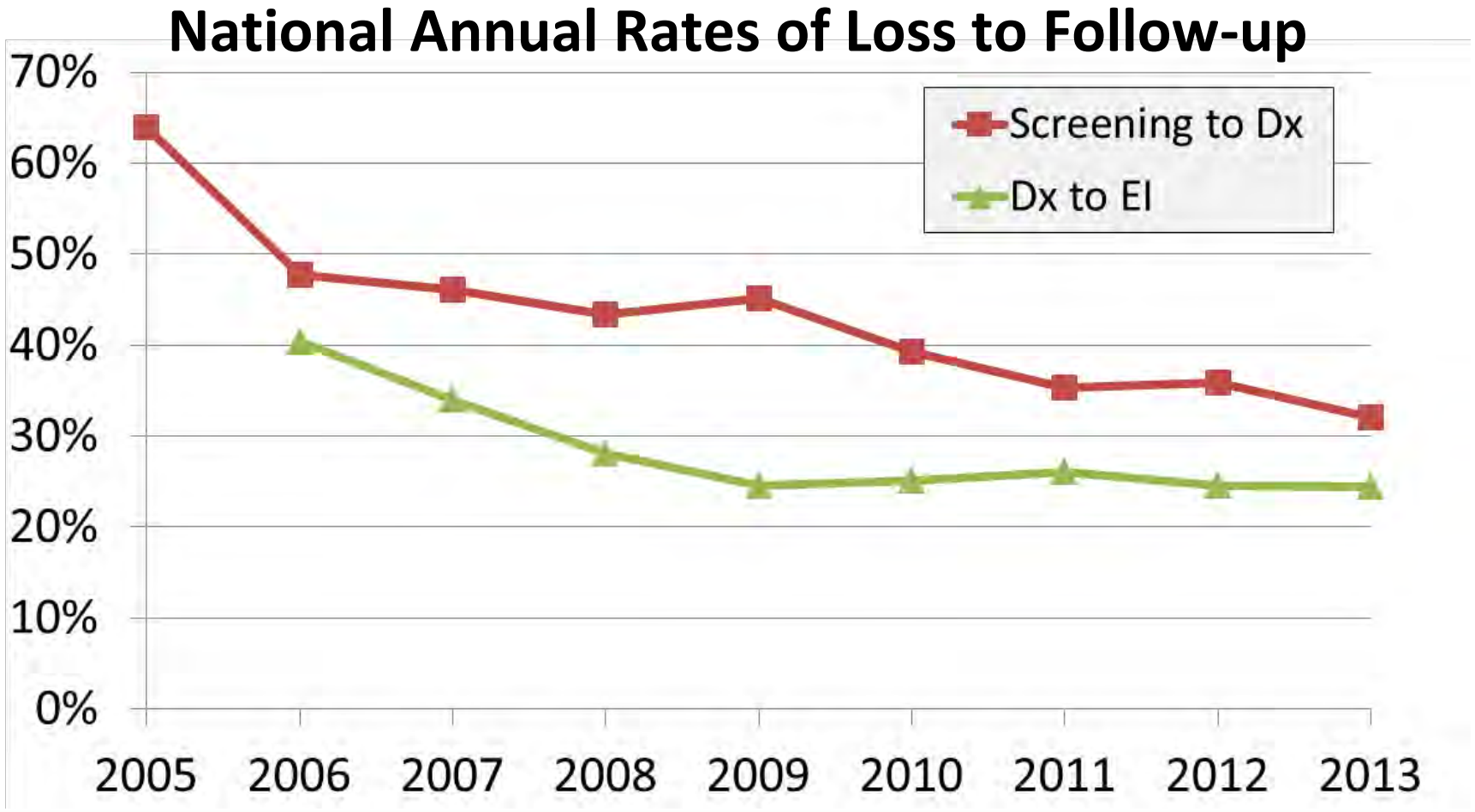
Challenges

- **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



NICU: Neonatal intensive care unit

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



Dx: Diagnosis
EI: Early intervention

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

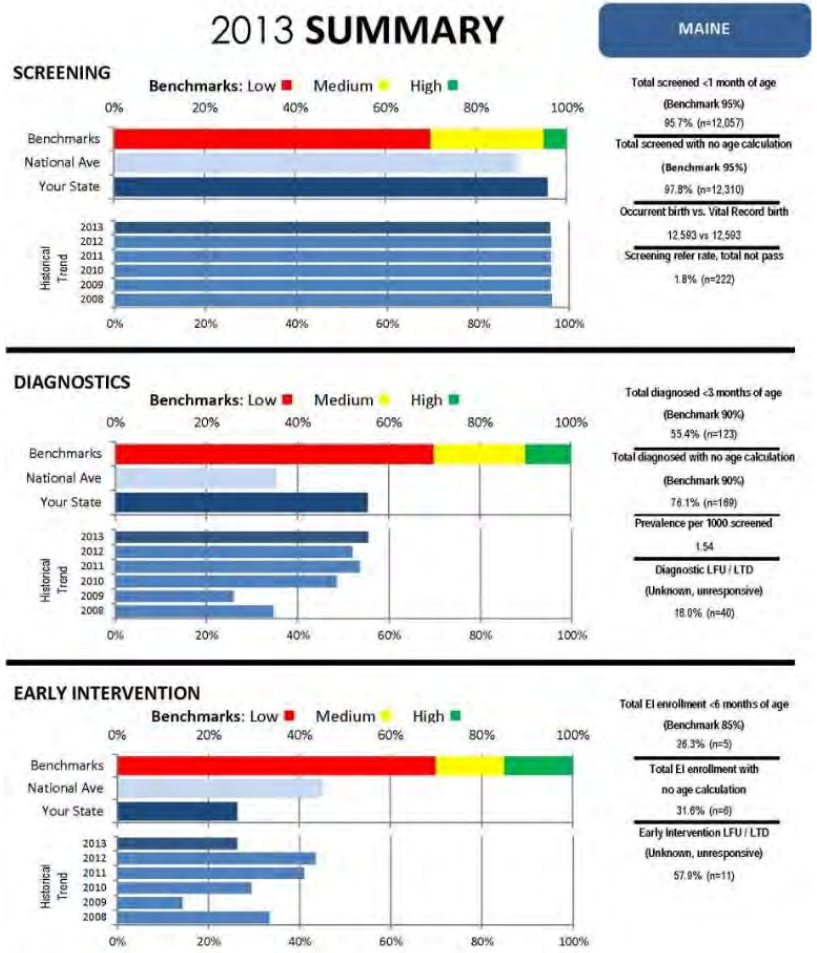
HSFS: Hearing Screening and Follow-up Survey
cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html

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 EHDI 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

IHE: Integrating the Healthcare Enterprise
ihe.net/uploadedFiles/Documents/QRPH/IHE_QRPH_Suppl_NANI.pdf

Making Data Usable



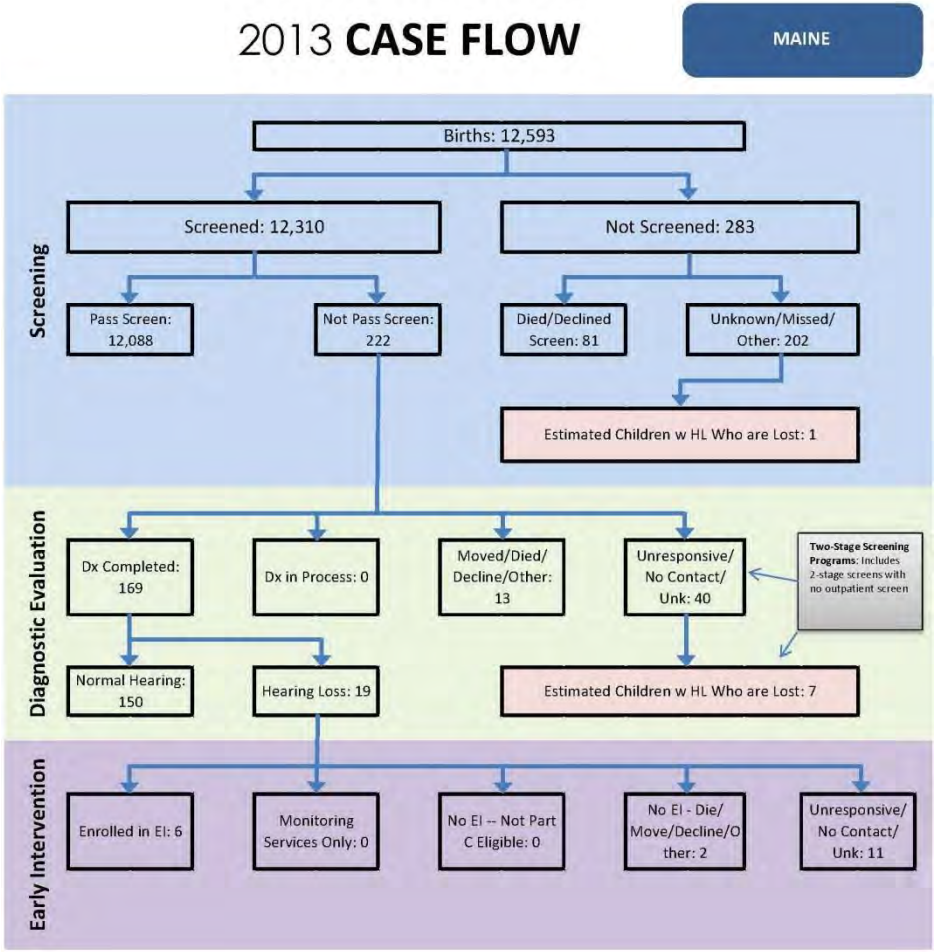
Total screened by 1 month of age

Total diagnosed by 3 months of age

Total EI-enrollment by 6 months of age

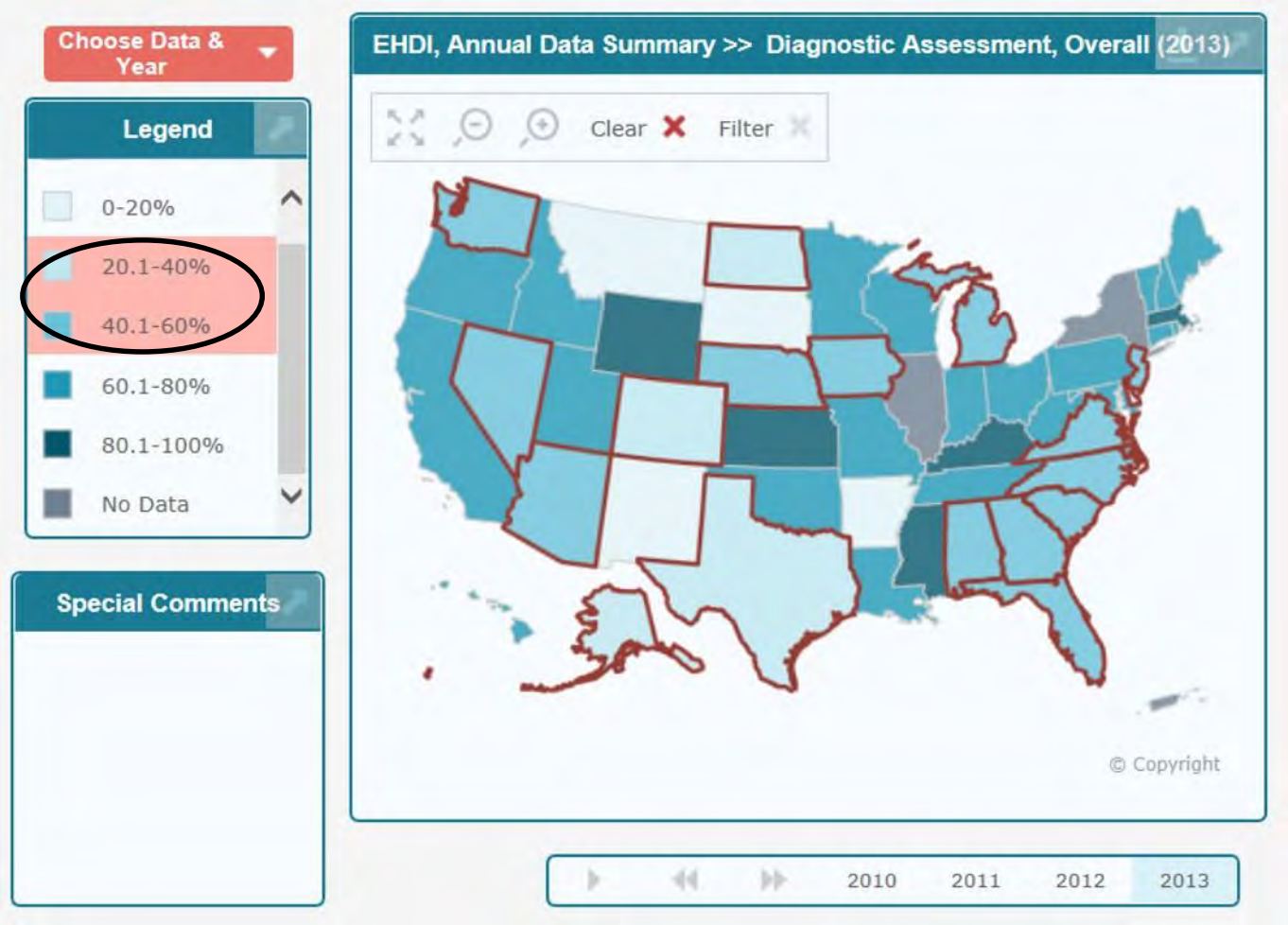
EI: Early intervention
cdc.gov/ncbddd/hearingloss/ehdi-data.html

Making Data Usable for States: Annual Reports



cdc.gov/ncbddd/hearingloss/ehdi-data.html

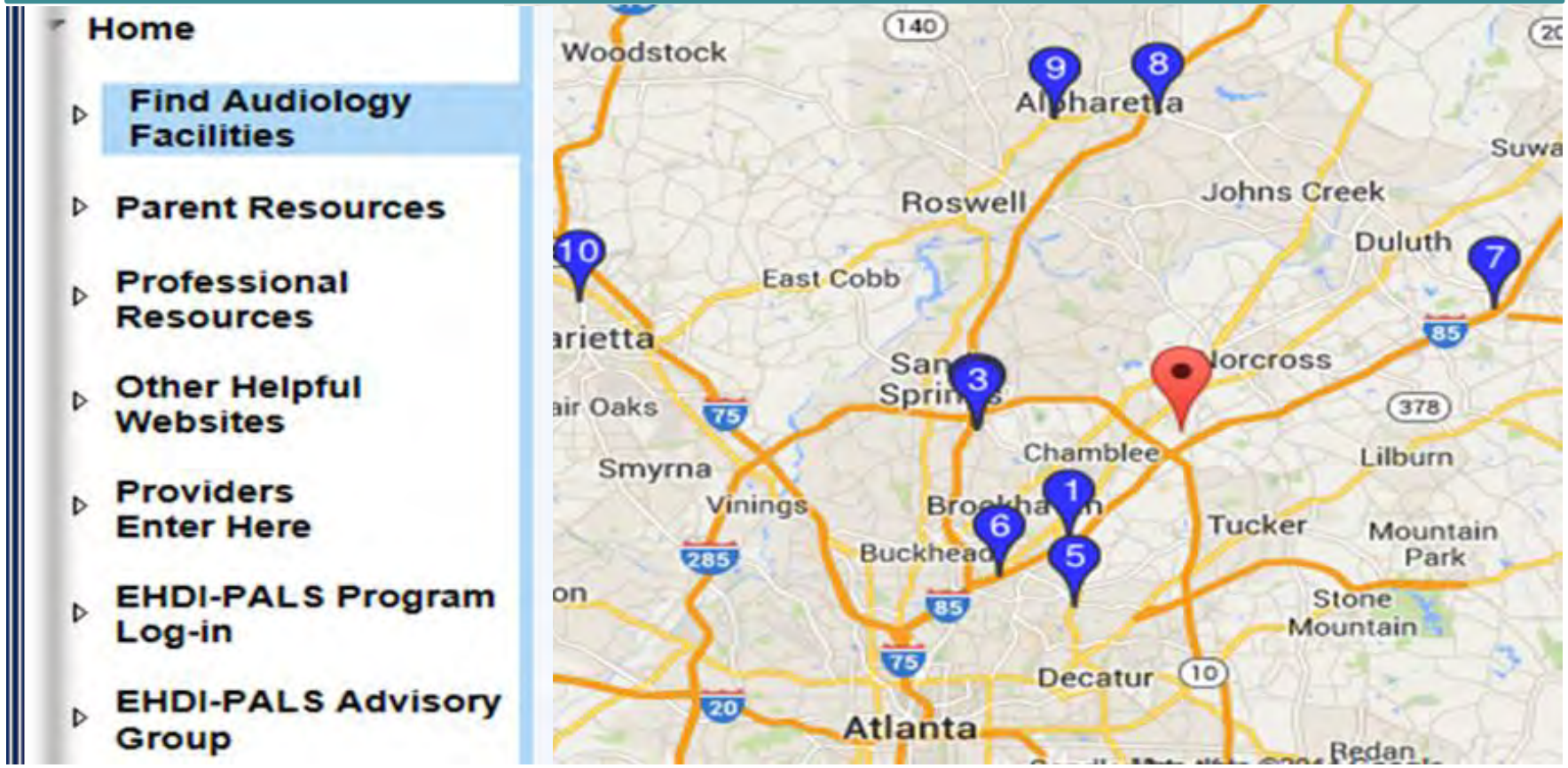
Making Data Usable Nationally: EHDI-DASH



DASH: Data Analysis and Statistical Hub
ehdidash.cdc.gov/IAS/

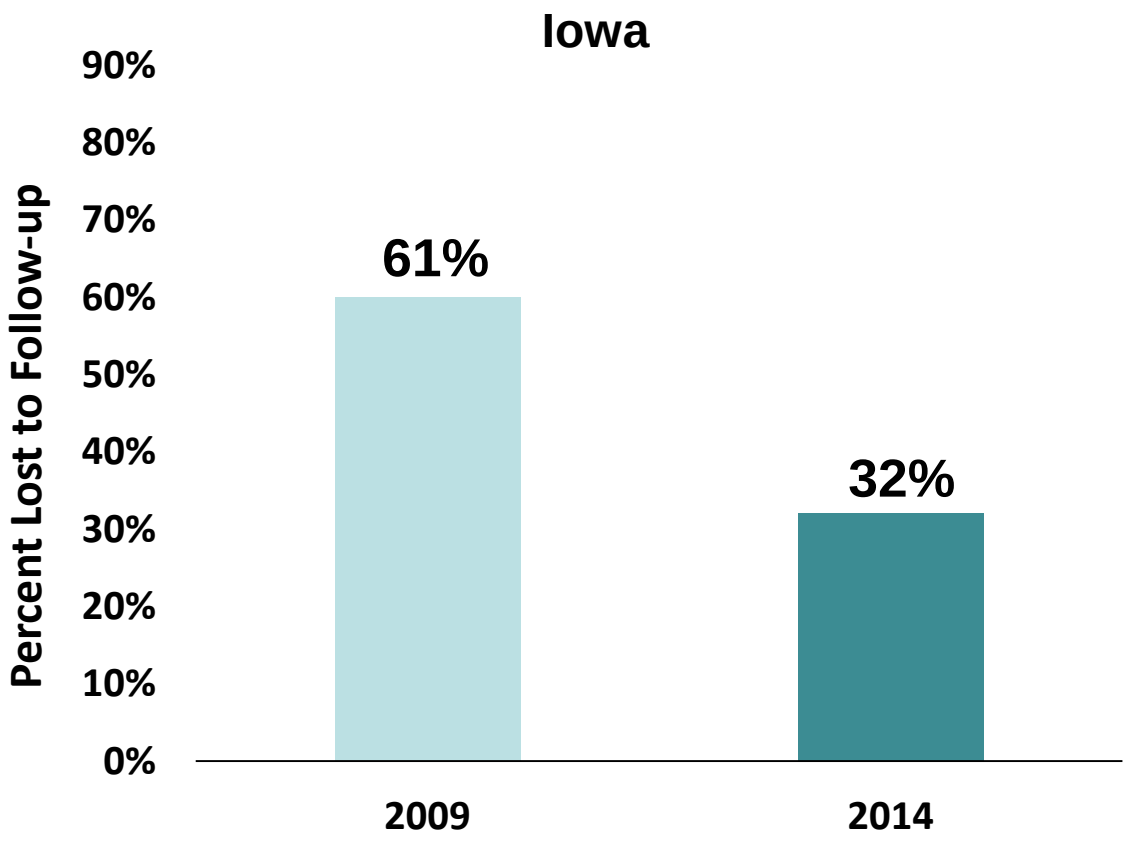
Making Data Usable for Parents: EHDI-PALS

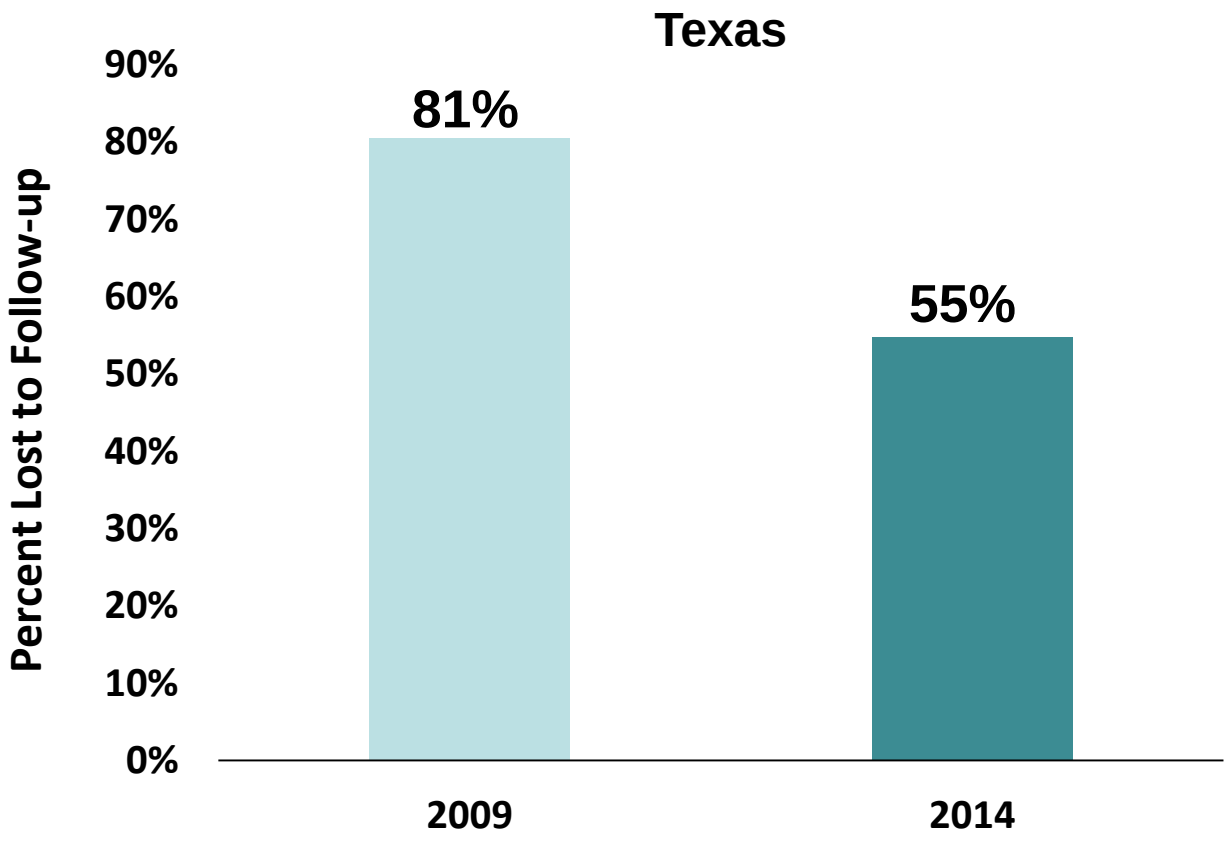
EHDI-PALS Facility Locator



PALS: Pediatric Audiology Links to Services
ehdipals.org/

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





cdc.gov/ncbddd/hearingloss/ehdi-data.html

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

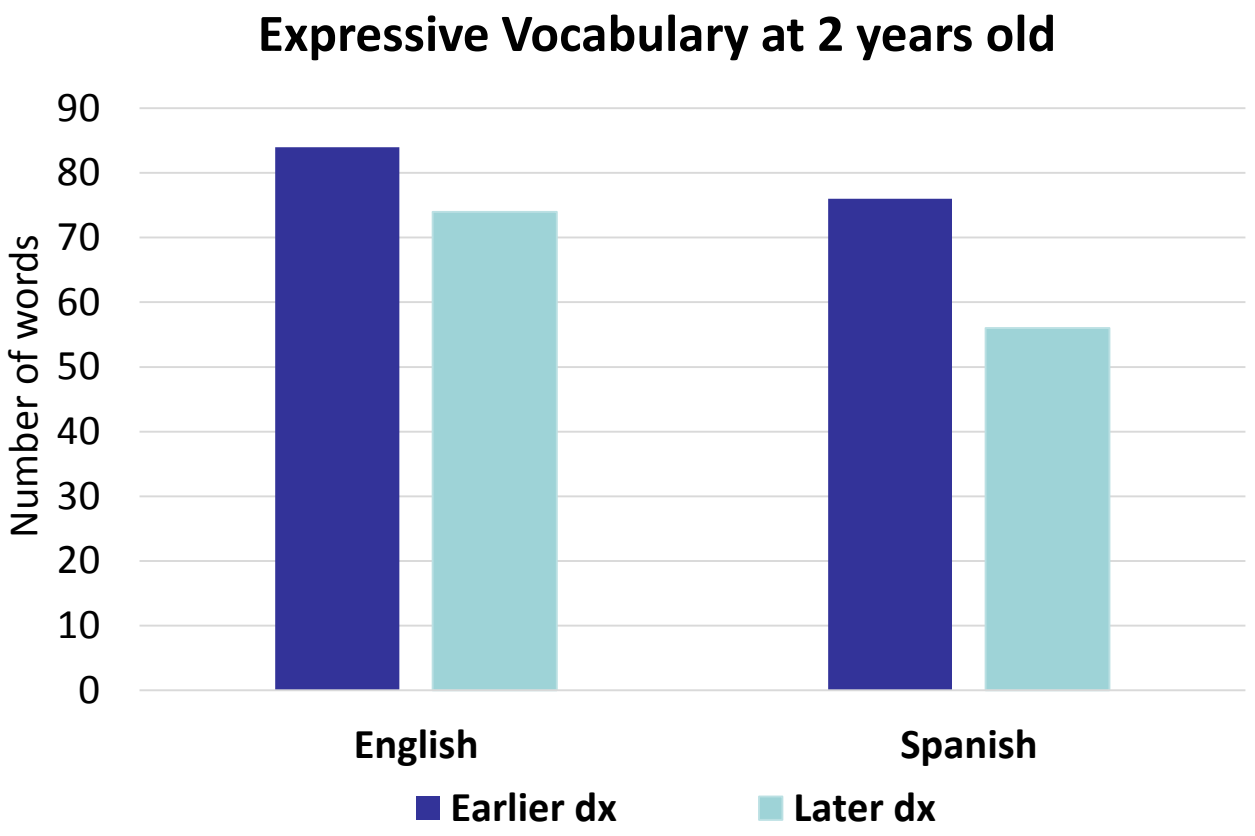
- **CDC-EHDI large state loss to follow-up project**
  - Formal partnership
  - States with ≥150,000 births per year
    - California
    - Florida
    - Illinois
    - New York
    - Texas

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

Sedey A, Yoshinaga-Itano C, and Wiggin M. *13th Annual Early Hearing Detection and Intervention Meeting*, 2014.

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
EHDI	**82%**	**82%**
Other	**63%**	**76%**

Tu S, Mason CA, Wall T. *15th Annual Early Hearing Detection and Intervention Meeting*, 2016.

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