



# Lessons Learned in Sharing EHDI and Part C Data: Background, Current TA and a State Story

IDIO Conference  
August 15th



# Using the Post-it Please tell us about EI & EHDI data collaboration:



# Presenter/Partner Introductions

- DaSy/ECTA TA Providers: Haidee Bernstein, Sharon Walsh, Gary Harmon
- Centers for Disease Control and Prevention (CDC), Early Hearing Detection and Intervention Program (EHDI): Dr. Tonya Williams, Deidra Green
- National Center for Hearing Assessment and Management (NCHAM): Karl White
- Arizona Part C Data Manager/CQI: Annie Converse
- Office of Special Education Programs (OSEP): Christy Kavulic
- Health Resources Services Administration (HRSA)

# Agenda

**Welcome/Introductions**

**EHDI Overview (EHDI Program/Centers for Disease Control)**

**EHDI Data Sharing Challenges/Solutions (NCHAM)**

**Report Out of Challenges/Solutions from States**

**IDEA/FERPA Regulations and Impact on EHDI/Part C  
Data Sharing**

**TA Example: Arizona Part C/EHDI Linking Story**

**EHDI Outcomes Data Committee**

**Actionable Next Steps for Each State**

# Show of Hands- Which Program do you Represent?

- Part C
- 619
- Both
- Birth to 21 or 3-21
- EHDI
- TA Providers
- Other

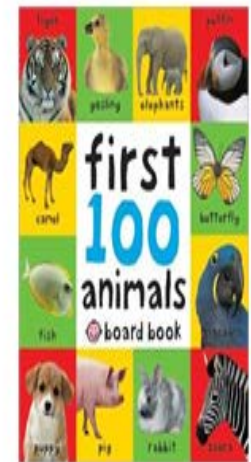
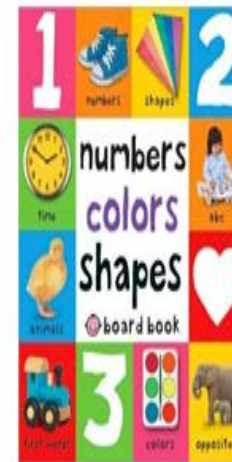
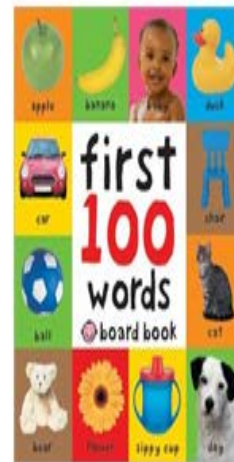
# How knowledgeable are you about the EHDl program?

- A lot
- A little
- None

# Do you currently work collaboratively with the EHDI program in your state?

- Yes
- Some/Starting
- No, not yet

# Reminder: Successes and Challenges







# CDC's Early Hearing Detection and Intervention (EHDI) Program

**Tonya Williams, PhD**  
**Centers for Disease Control and Prevention**  
**Division of Human Development and Disability**  
**Child Development and Disability Branch**  
**EHDI Team**

**DaSy Meeting**  
**August 15, 2018**

# Outline

- Background
- EHDI 1-3-6
- Hearing Screening and Follow-up Survey
- Functional Standards
- Next steps

**Background**

# Public Health Problem

- Congenital hearing loss affects one to three of every 1,000 live born infants in the United States.
- Hearing loss can have a negative impact on a child's development.
- Early Hearing Detection and Intervention (EHDI) program aims to ensure that all newborns are screened for hearing loss and receive needed services.

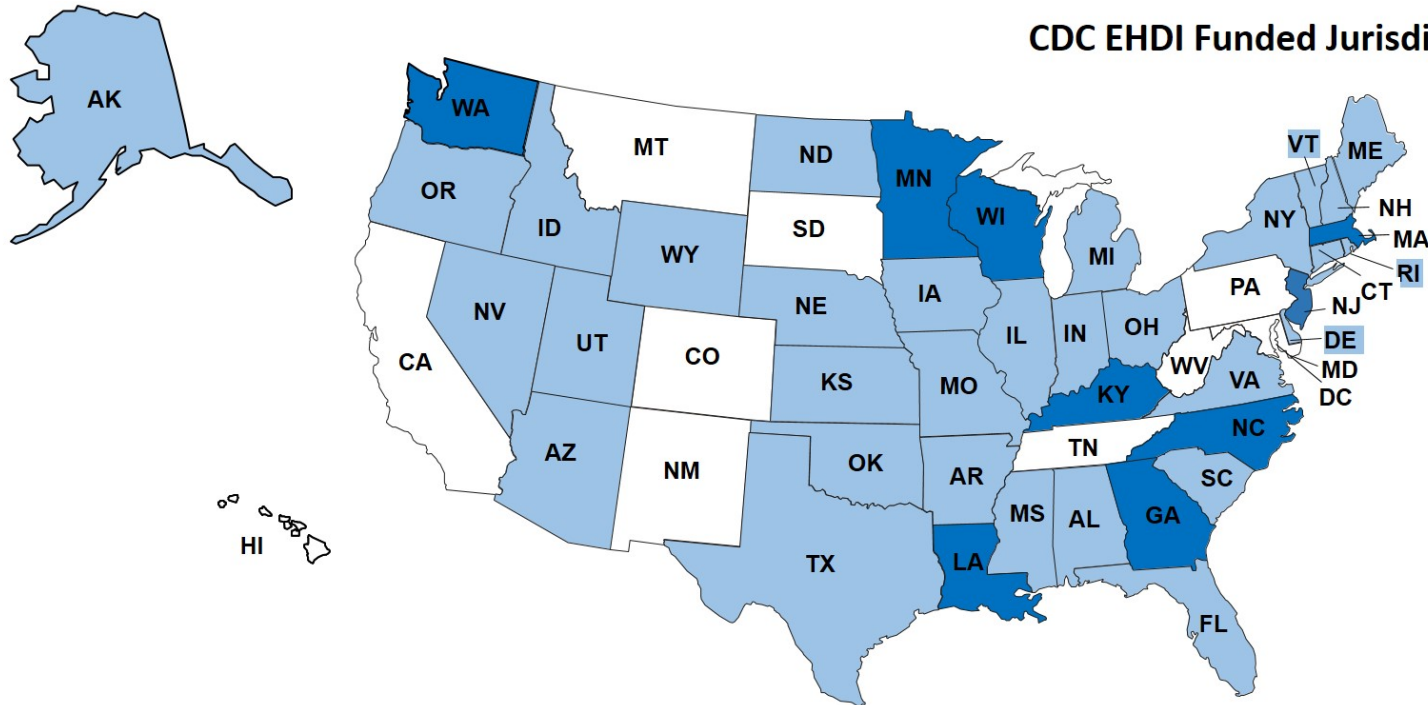
# Background

- Newborn hearing screening endorsed by 3 national organizations
- Congressionally-authorized support (S. 652, EHDI Act)
  - Reauthorized CDC, HRSA, and NIH until 2022
- No federal law
  - 41 states, Guam, and D.C. have statutes or guidance
  - Requirements vary
- All states have an EHDI program

# Role of CDC

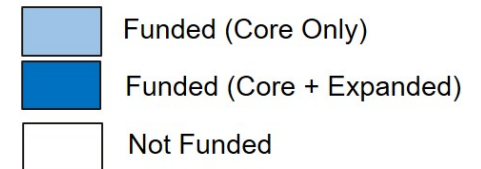
- State-based EHDI **Information** Systems (EHDI-IS)
- Collect, analyze, and disseminate national **data**
- Improve tracking and **surveillance** system related to language-acquisition evaluations and intervention services
- Coordinate development of standardized **data** management procedures
- Promote integration, linkage, and interoperability of systems to exchange EHDI **data** between clinical care and public health
- Study and **report** on the costs and effectiveness

## CDC EHDI Funded Jurisdictions Year 2 (44)



### Funded Territories

- American Samoa
- Guam
- Marshall Islands
- Northern Mariana Islands
- Puerto Rico

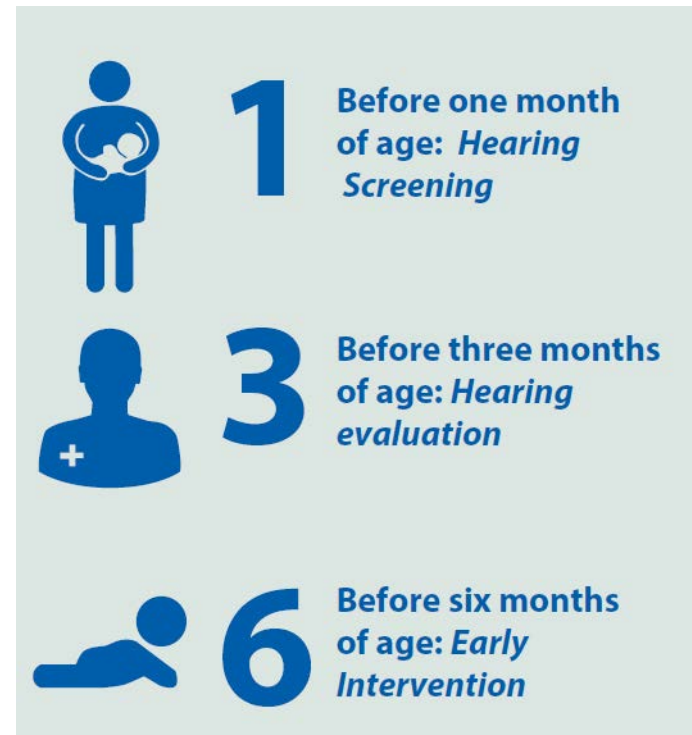


# **EHDI 1-3-6 Plan**



# Joint Committee on Infant Hearing Benchmarks and EHDI

- *Early Hearing Detection and Vocabulary of Children With Hearing Loss*
- Significant impact on vocabulary outcomes by meeting 1-3-6
- Early identification → Increased vocabulary



## Highlights from the JCIH Position Statement (2007)

- Screening information and audiology diagnostic should be promptly transmitted to the medical home and the state EHDI coordinator.
- Data-management and tracking systems should be implemented.
- An effective link between health and education professionals should be established to ensure successful transition.

# **CDC EHDI Hearing Screening and Follow-Up Survey (HSFS)**

## What is the HSFS?

- Data collection tool provided to each state and U.S. territory to capture aggregate EHDI data
- Data include information on infants born in the jurisdiction and tracked by the EHDI program
- Objectives:
  - To provide detailed and accurate data that reflects progress by state EHDI programs towards the 1-3-6 benchmarks
  - To provide data for national estimates on hearing screening, hearing loss, and early intervention enrollment status

# Hearing Screening and Follow-up Survey



- Approved by Federal Office of Management and Budget
- Available data 2005-2016
- Annual and voluntary survey
- Aggregate data
- Two-year reporting interval

# What do the HSFS data help us do?

- Improve & strengthen EHDI program and data management systems
- Ensure infants who are deaf or hard of hearing are identified in “sensitive” period for language development
- Ensure early intervention to support language, cognitive, and academic development
- Provide data for Healthy People Objectives



# Available Data

- Screening, diagnosis, and intervention (*all infants*)
  - Reasons for not receiving services (died, refused, etc.)
  - Lost to follow-up / Lost to documentation (LFU/LTD)
- Type and severity
  - Sensorineural, conductive, mixed, auditory neuropathy
- Demographics
  - Maternal age, education, ethnicity, and race
- Data not collected
  - Risk factors , insurance data, outcomes

# Lost to Follow-up/Lost to Documentation in EHDI

- Definitions
  - Lost to Follow-up (**LFU**): Did not receive services
  - Lost to Documentation (**LTD**): Received but results not reported
- LFU / LTD occurs between:
  - Hearing Screening – Rescreening
  - Screening – Diagnosis
  - Diagnosis – Intervention



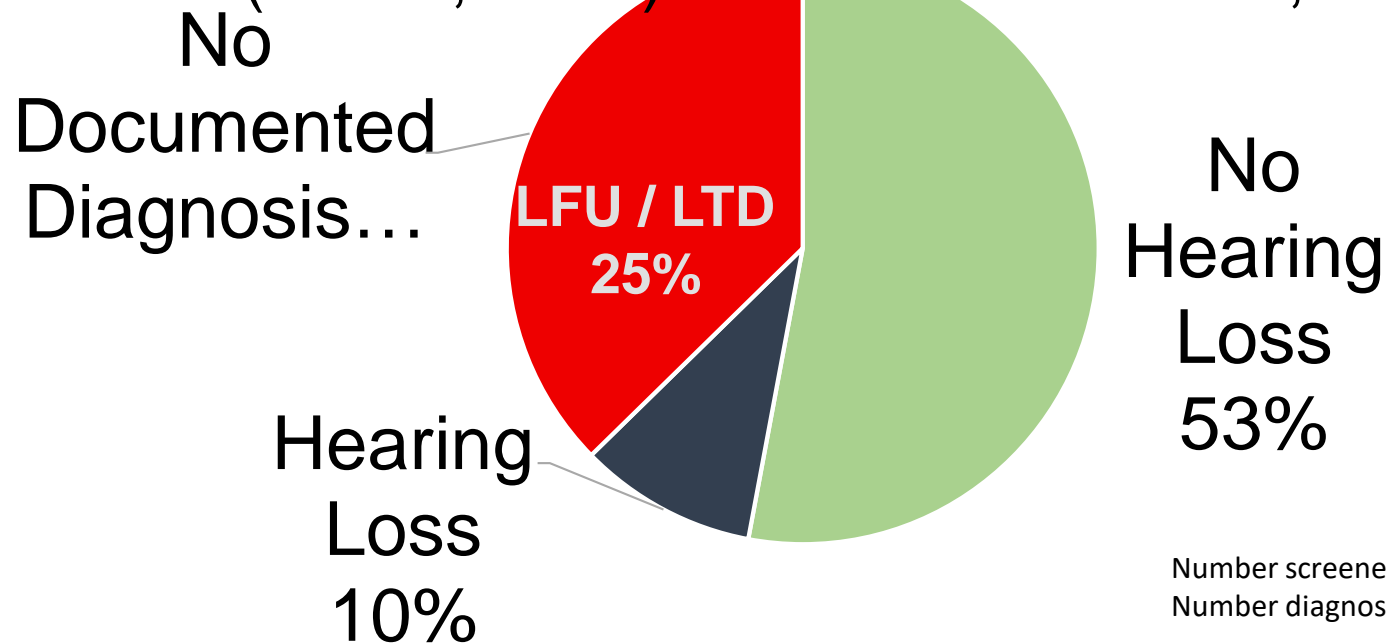
# Early Intervention-related Data Fields

- Number of babies with a permanent hearing loss who were referred to IDEA\* Part C programs
  - Number referred by 6 months of age
- Number of babies enrolled in and receiving Part C services
  - Number receiving services by 6 months
- Number receiving non-Part C services only
- Number being monitored only (not receiving any services)
- Reasons for not receiving services

\*Individuals with Disabilities Education Act

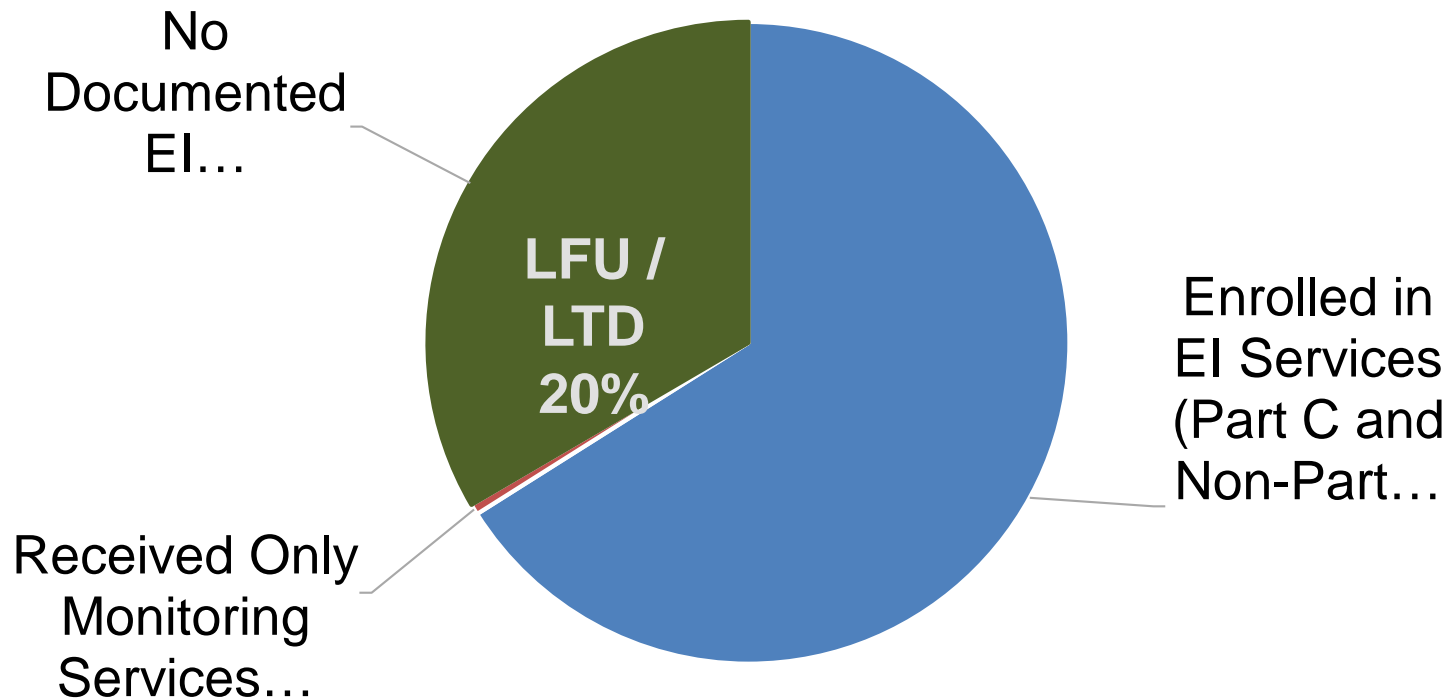
# Hearing Status of Infants Not Passing Hearing Screening

(HSFS, 2016) Total Not Pass = 65,156

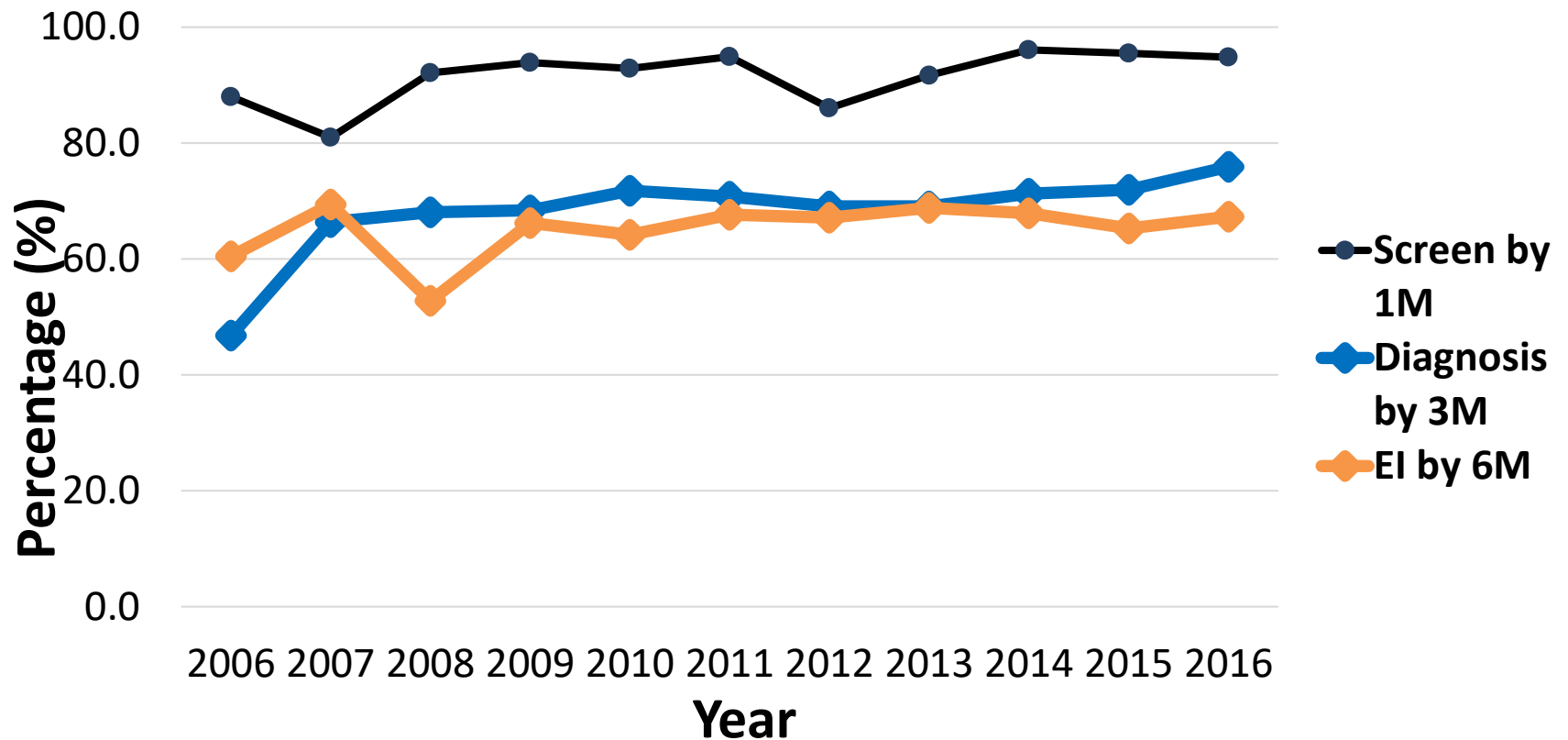


## Documented Intervention Status of Infants with Hearing Loss

(HSFS, 2016) Total w. Hearing Loss = 6,337



## Meeting the 1-3-6 EHDI Benchmarks, (U.S., 2006-2016)



Source: CDC EHDI  
HSFS

## EHDI and EI Arrangements

- EHDI has direct access to the EI data system
- EI providers can enter information directly in EHDI-IS
- EHDI provides the demographic data on the patient and EI provides the EI information back to EHDI
- No arrangement

# Functional Standards

# Effective EHDI Information Systems

- **Completeness and Quality**

- Guidelines and data definitions
- Support from stakeholders such as hospitals, physicians, audiologists, and EI programs

- **Data Use**

- Services & outcomes
- Monitor progress / areas for improvement
- Engage stakeholders

# EHDI Functional Standards

- Developed by CDC and jurisdictions
- Intended to identify the operational, programmatic, and technical criteria that all jurisdictional EHDI programs should implement during the process of developing, using, and evaluating an EHDI-IS
- 8 programmatic goals / standards for each goal
- Goal 4: Document the enrollment status, delivery and outcome of early intervention services for infants and children <3 years old with hearing loss.
- [www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html](http://www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html)



**Next Steps**

## Efforts to make improvements in capturing EI data

- Learn more about EI programs
- Learn more about the reporting barriers that states are facing and try to develop strategies to overcome the barriers
- Support the EHDI Outcomes Data Committee



## Websites

- EHDI: <https://www.cdc.gov/ncbddd/hearingloss/index.html>
- HSFS: <https://www.cdc.gov/ncbddd/hearingloss/2016-data/12-2016-HSFS-508.pdf>
- Data: <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>
- Functional Standards:  
<https://www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html>

# Thank you & Questions

Tonya Williams: [TWilliams10@cdc.gov](mailto:TWilliams10@cdc.gov)

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [www.cdc.gov](http://www.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



# Dr. Karl White

Director, National Center for Hearing Assessment and Management

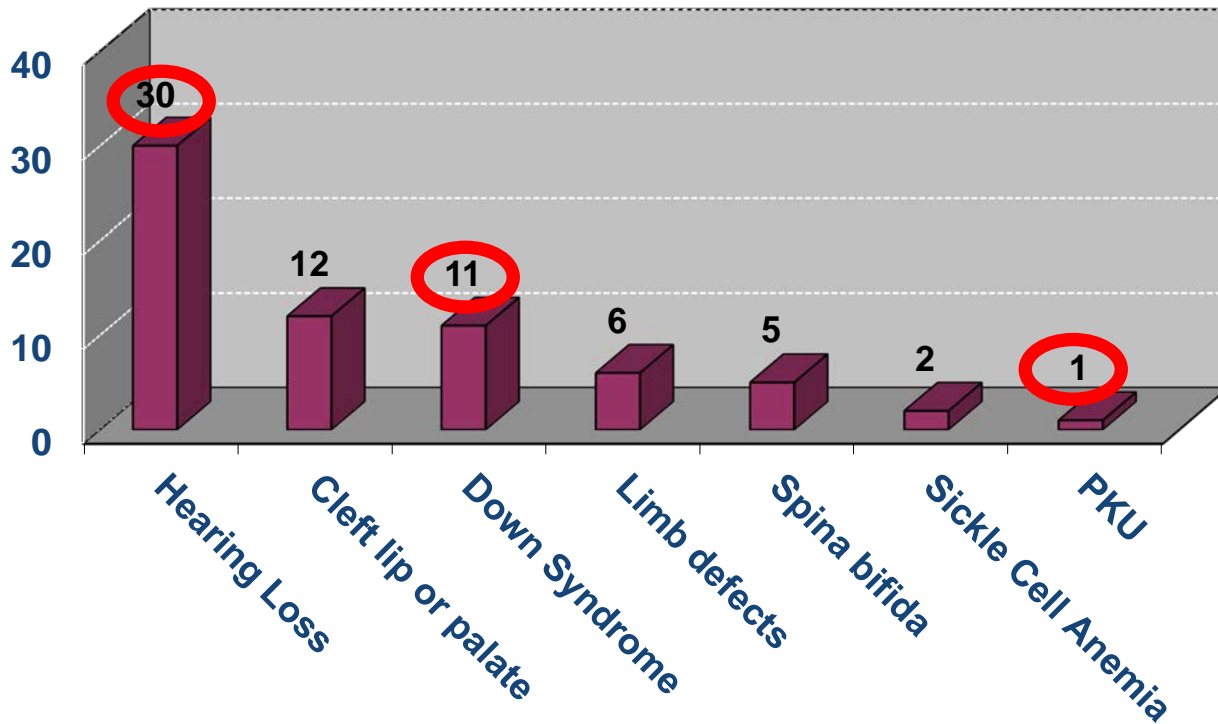
Emma Eccles Jones Endowed Chair in Early Childhood Education

Professor of Psychology

Utah State University

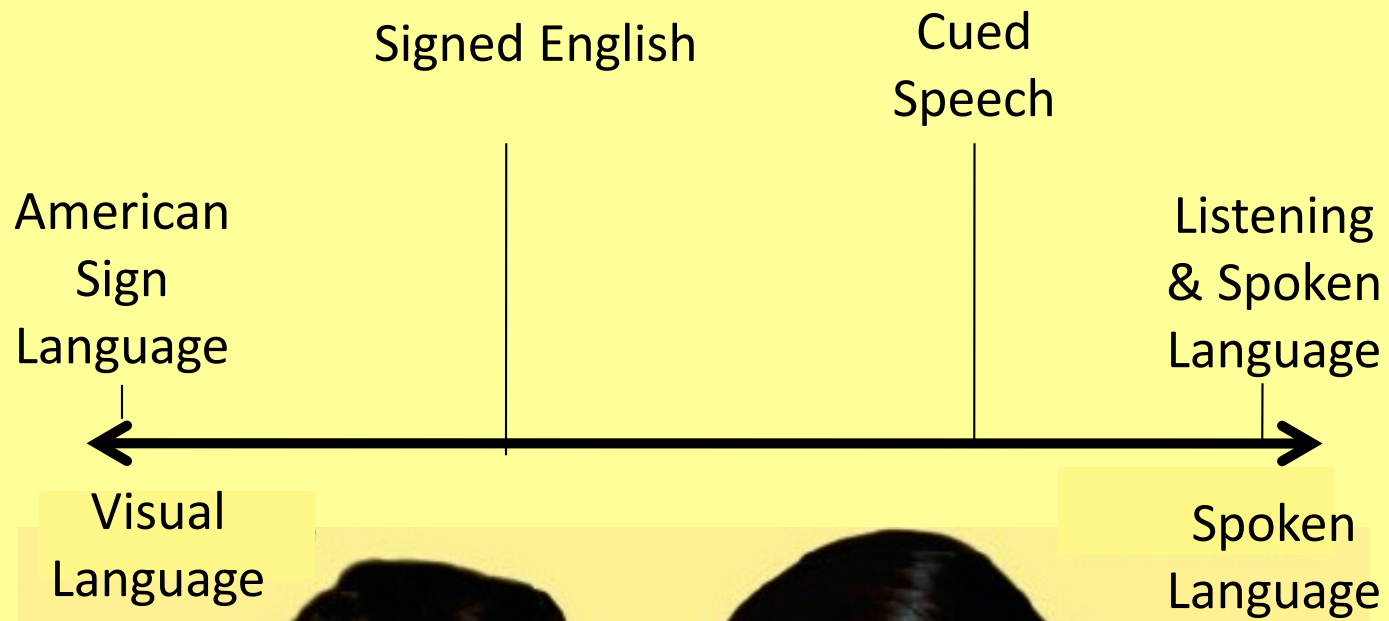


- ✓ Permanent hearing loss occurs more frequently than any other condition for which we can screen at birth



Incidence per 10,000 births
















**Spring is my favorite season.  
The sun shines bright. The  
flowers begin to grow. I  
like spring.**



Audio and picture courtesy of Susan Nittrouer, Ohio State University



# What enabled us to move from ....



There



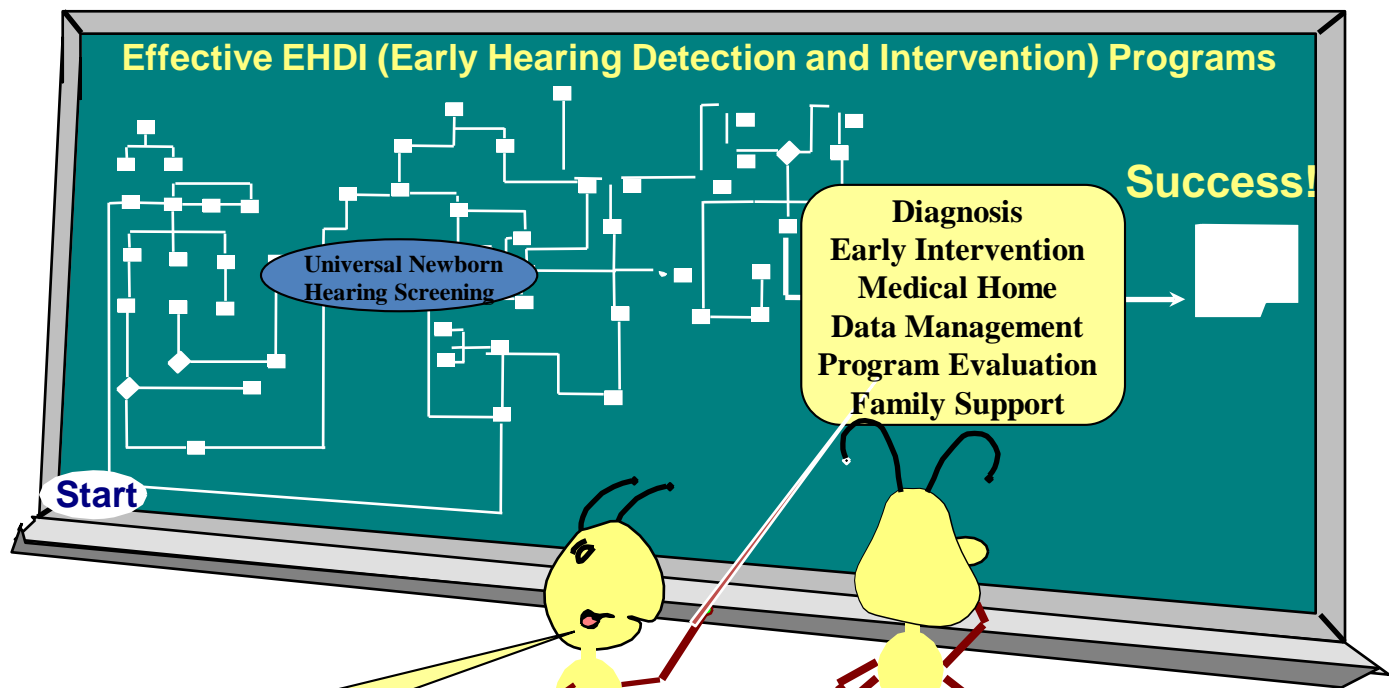
Here?



Earlier Identification of  
Hearing Loss

Availability of Better  
Hearing Technology

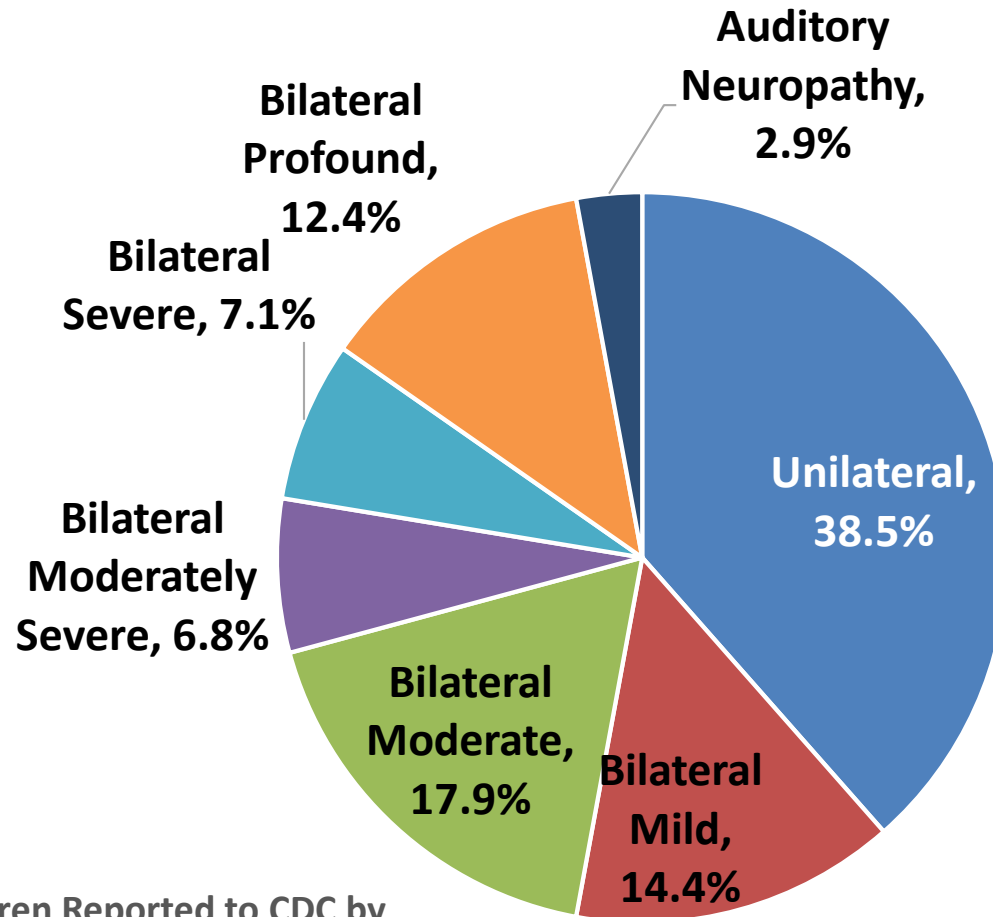
High quality, comprehensive  
Early Intervention programs  
that focus on teaching  
LANGUAGE



Good work, but I think we might need a little more detail right here



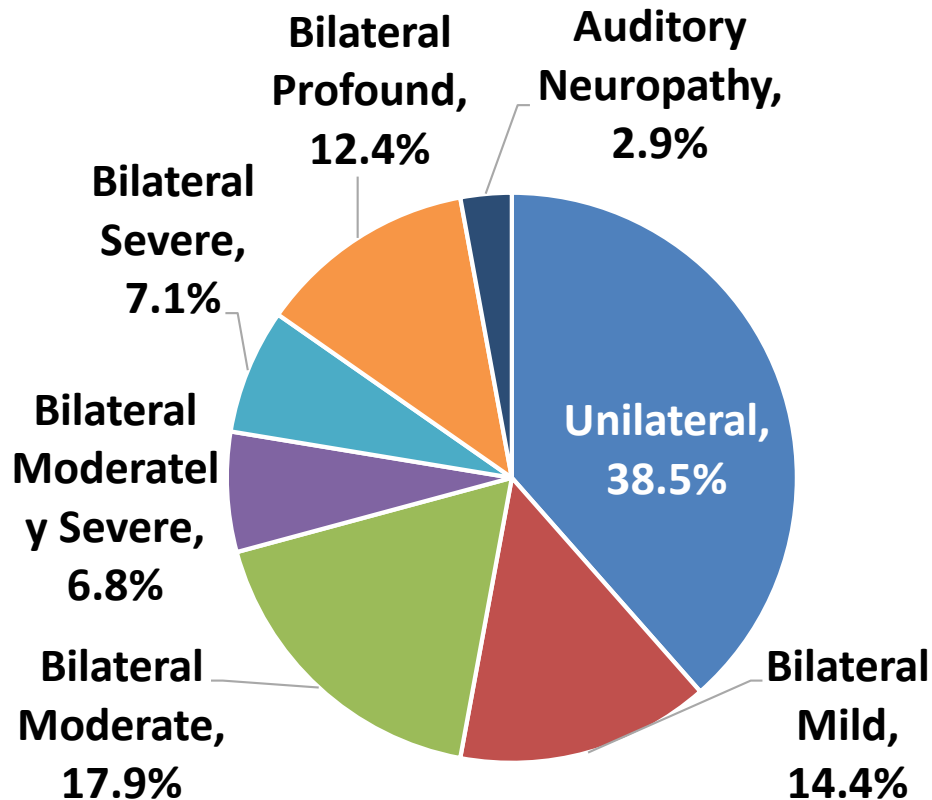
# Who is EHDI Serving?



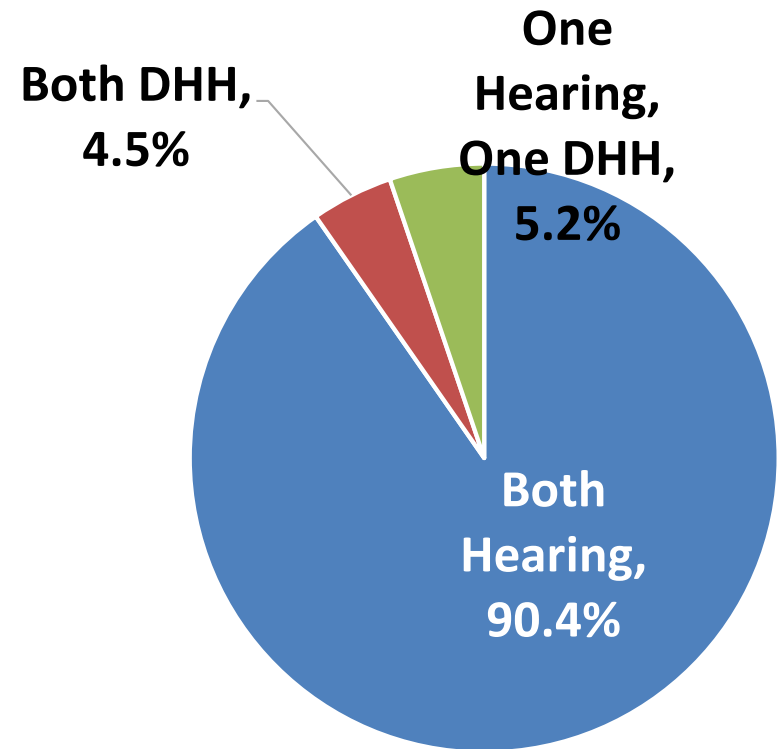
Hearing Status of Children Reported to CDC by  
EHDI Programs (2012-2014)



# Who is EHDI Serving?



Hearing Status of Children Reported to CDC by  
EHDI Programs (2012-2014)



Hearing Status of Parents In Gallaudet 2011-2012  
Annual Survey of DHH Children and Youth



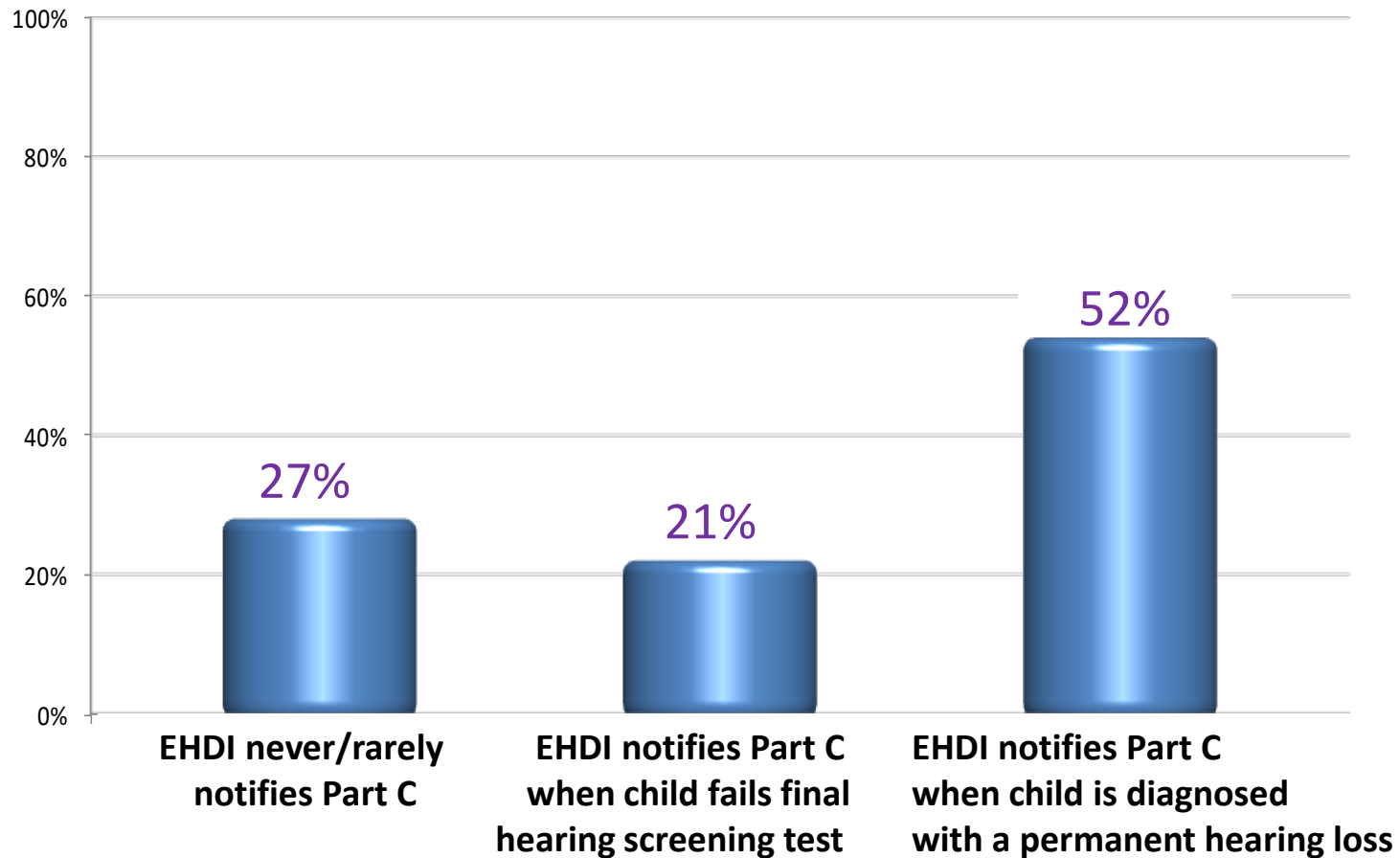
May 2008

# the impact of privacy regulations

How EHDI,  
Part C, & Health Providers  
can ensure that children &  
families get needed services

1. Have HIPPA and FERPA regulations affected EHDI's ability to provide effective services?
2. What strategies are used to facilitate the exchange of information and to connect children to services?
3. Does your state have legislation, memoranda of agreement, and/or policies in place that make compliance with HIPAA or FERPA easier?
4. Are the following entities (PCP, family, Part C, Family Support Organization, EHDI Program) notified when:
  - a child fails the hearing screen
  - a child is diagnosed with a hearing loss?
5. Does Part C notify EHDI when children who are DHH are enrolled in Part C?

## When does the EHDI program notify Part C Early Intervention about individual children?





Search [infanthearing.org](http://infanthearing.org) 🔍

[Home](#)[Components](#)[Resources](#)[States](#)[Legislation](#)[About Us](#)

Last Modified: 05/13/2015

#### EHD/ UNHS Resources

- [Quality Improvement](#)
- [Newborn Hearing Screening Training Curriculum](#)

### Addressing Privacy Regulations

NCHAM conducted an investigation into the impact of privacy regulations on the exchange of information and

# Recap: Successes and Challenges



# Sharing Personally Identifiable Information (PII)

- IDEA and FERPA generally require parental consent to share PII
- Except .... in IDEA with participating agencies or when Part C is notifying LEA for referral purposes
- Except....Several FERPA exceptions exist to sharing PII without parental consent
- One FERPA exception is the Audit and Evaluation exception that requires development of a Data Sharing Agreement
- Logical strategy to use for EHDI/Part C sharing

# EI & EHDI Partnership

## ❖ Key Considerations:

- In which agency/department is the EHDI program located?  
Where is the state's EI program located?
- Where are the EHDI data and EI data housed? Separate or same data systems?
- What data are the EI program currently sharing with the EHDI program?
- What data are the EHDI program currently sharing back with EI?
- What additional data do you both want to share?



# Data Sharing Agreements/ Memorandums of Understanding (MOUs)

- **Data Sharing Agreement or MOU**

- Prepared and completed by both EHDI and EI programs
- Generally includes information on:
  - Purpose of the Agreement/MOU
  - Background
  - Activities/Responsibilities
  - Data Elements to Be Shared
  - Security of Data
  - Data Management
  - Reporting
  - Effective Date/Duration
  - Other important info relevant to your state (specific projects or activities)





# Data Sharing Agreements/ Memorandums of Understanding (MOUs)

- **Dept of Education Resource:** IDEA Confidentiality Requirements (what can and cannot be shared)  
[https://studentprivacy.ed.gov/sites/default/files/resource\\_document/file/idea-confidentiality-requirements-faq\\_0.pdf](https://studentprivacy.ed.gov/sites/default/files/resource_document/file/idea-confidentiality-requirements-faq_0.pdf)
- **PTAC/DaSy Resource:** Data Sharing Agreement Checklist for IDEA Part C and Part B 619 Agencies and Programs  
[https://dasycenter.sri.com/downloads/DaSy\\_papers/DaSy\\_Data\\_Sharing\\_Agreement\\_Checklist\\_Acc.pdf](https://dasycenter.sri.com/downloads/DaSy_papers/DaSy_Data_Sharing_Agreement_Checklist_Acc.pdf)

# Data Sharing Agreements/ Memorandums of Understanding (MOUs)

- Where to start?
  - Review current Agreements or MOUs between EI and EHDI
  - Modify or add-to current agreements vs. new agreement?
  - Consider other state EHDI/EI program data sharing agreements and MOUs
- Access Technical Assistance if needed from PTAC, DaSy and/or ECTA





# DEPARTMENT OF ECONOMIC SECURITY

*Your Partner For A Stronger Arizona*



Arizona



# Arizona Early Intervention Program



DEPARTMENT OF ECONOMIC SECURITY

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ARIZONA DEPARTMENT OF HEALTH SERVICES

*Health and Wellness for All Arizonans*

# Lead Agency Structure



DEPARTMENT OF ECONOMIC SECURITY

*Your Partner For A Stronger Arizona*

- Division of Developmental Disabilities
- Arizona Early Intervention Program

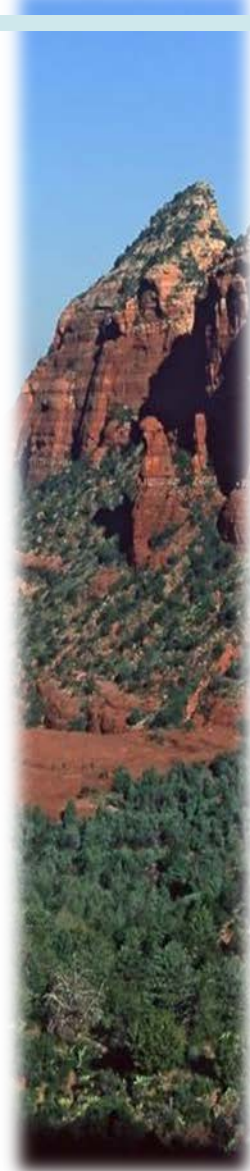
# Ear



ARIZONA DEPARTMENT OF HEALTH SERVICES  
*Health and Wellness for All Arizonans*

- Office of Newborn Screening
  - Early Hearing Detection and Intervention Program
- Office of Special Healthcare Needs

# Reasons for Data Sharing

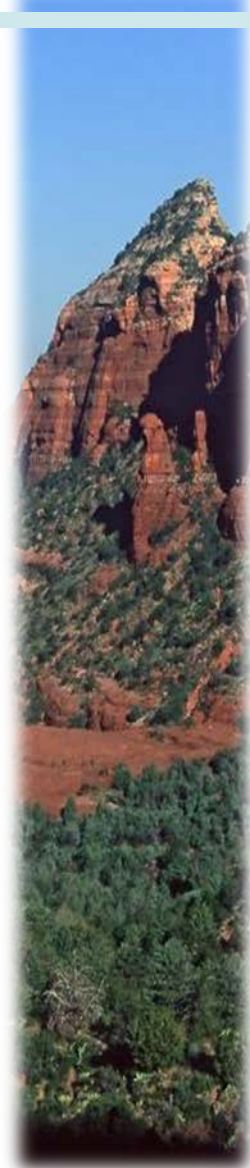
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- Improve federal reporting
  - Improve compliance with state law for reporting hearing screenings
  - Analysis of Child Find Activities
  - Automate the Process
  - Answering critical questions like: Are we making a difference?

# Status of Data Sharing

- 
- Centers for Disease Control (CDC) Cooperative Agreement
  - 5 Program State Agency Interagency Governmental Agreement
  - Interagency Service Agreement
  - Draft Data Sharing Agreement



# Next Steps

- 
- Finish preliminary reviews
  - Privacy Technical Assistance Center (PTAC) Review
  - Finalize Agreement
  - Develop business requirements (user stories)
  - Develop application programming interface (API)
  - Update procedural safeguards booklet
  - Use as a template for data sharing with Part B

# CDC Early Childhood Outcomes Data Committee



# Review of 2016 Committee

- Formed in April 2016
- Partnership between CDC EHDI and UNC Chapel Hill, which includes both DaSy and ECTA
- Goal: To make recommendations to the CDC EHDI program about potential outcomes data that the EHDI programs could collect, including from Early Intervention/Part C programs
- Ended in December 2016

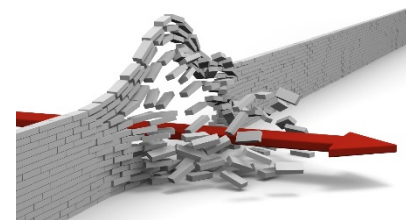
# Review of 2016 Committee

- Discussed challenges with collecting EI/Part C data for EHDI reporting
- Reviewed the functional standards related to EI (Goal 4)
- Utilized two Workgroups to examine potential EI data that could be used by EHDI programs
- Made recommendations about modifications or additions to the functional standards

# 2018 Committee Overview

- Formed in February 2018
- Two Workgroups:
  - WG1: Data Sharing
  - WG2: Outcomes
- Meet as WG for two months, then full Committee every three months
- Membership includes EHDI state coordinator, Part C coordinators, TA staff, researchers, CDC/EHDI staff, family representatives

# Challenges Identified



- Parental consent and data sharing – what data can and cannot be shared? How can states share data without parental consent?
- EI Data Systems vary greatly from state-to-state, including the types of data collected and how data are stored
- Need for increased communication between Department of Education and CDC at top levels
- Lack of understanding of EHDI in EI programs (especially at the provider level)

# Review of Workgroups

- Workgroup 1: Data Sharing
  1. Guidance on data sharing between EHDI and Part C
    - Review articles from NCHAM
    - Develop fact sheet(s)/guidance document
  2. Identifying state MOUs/Agreements
    - List of MOUs/Agreement for EHDI TA website
    - Best practices from states (including inviting states to present)
  3. Develop standardized forms
    - MOU/Agreement template
    - Parental Consent
  4. Dissemination

# Review of Workgroups

- Workgroup 2: Outcomes
  1. Make recommendations on measures from 2016 Committee
    - Use side-by-side comparison of recommended measures
  2. Develop new recommended outcomes/functional standards
    - Standardized data collected by EI (including family outcomes)
  3. Discuss feasibility/likelihood that recommended measures can be collected (prioritize importance of outcomes)



# Potential Committee Results/Recommendations

- Workgroup 1: Data Sharing
  - Survey EHDI coordinators about challenges with data sharing
  - Update guidance documents from NCHAM (2008)
  - Dissemination
- Workgroup 2: Outcomes
  - Finish reviewing 2016 Committee recommended outcomes
  - Review new recommended outcomes
  - Develop critical questions for recommended outcomes
  - Develop measures for recommended outcomes

# What this all means

- Continue working with all partners (DaSy, ECTA, NCHAM, OSEP and HRSA)
- Continue collaboration at the local, state and federal level to reduce barriers and minimize challenges



# Future Work and TA Support

- Do you want assistance with data sharing between Part C and EHDI in your state?

- Contact:

Gary Harmon [Gary.harmon@unc.edu](mailto:Gary.harmon@unc.edu)



# Actionable Next Steps

- What are your next steps when you return to your state?
- Who will you work with to move this forward?
- How can DaSy help?



# Resources

- **Centers for Disease Control (CDC), Hearing Loss in Children** (<https://www.cdc.gov/ncbddd/hearingloss/facts.html>)
- **CDC EHDI Program Page** (<https://www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards-.html>)
- **National Center for Hearing Assessment and Management (NCHAM)** (<https://www.infanthearing.org/>)
- **Health Resources Services Administration (HRSA) Universal Newborn Screening and Intervention Program** (<https://mchb.hrsa.gov/maternal-child-health-initiatives/early-hearing-detection-and-intervention.html>)

# Resources

- **DaSy Data Governance and Management Toolkit: Data Partnerships Section** (<https://dasycenter.org/data-governance-management-toolkit/governance-of-data-partnerships/>)
- **Early Childhood Technical Assistance (ECTA) Special Collection: Deaf and Hard of Hearing**  
<http://ectacenter.org/topics/earlyid/idspecpops.asp>
- **Privacy Technical Assistance Center (PTAC): Privacy and Data Sharing**  
<https://studentprivacy.ed.gov/privacy-and-data-sharing>

# Contact DaSy

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