



Importance and Progress in the Standardization of the Reporting and Analysis of EHDI Data

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Presentation Overview

- Background
 - Progress
 - Challenges
- Why is data standardization important?
- Reasons
- Examples
- Current activities



Reference

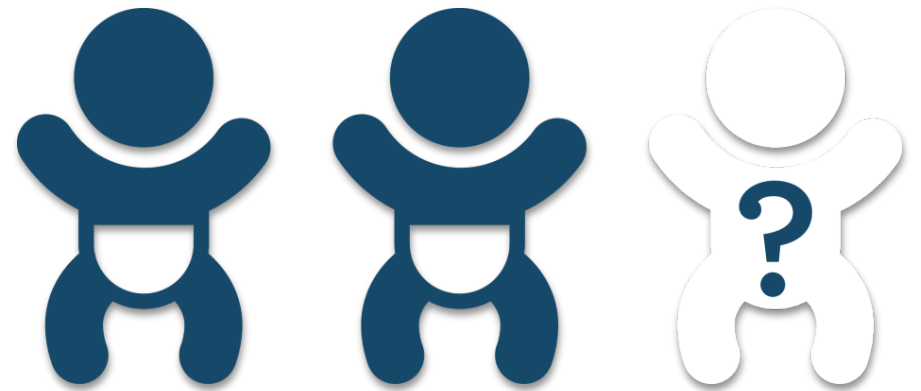
- “Progress in Standardization of Reporting and Analysis of Data from Early Hearing Detection and Intervention (EHDI) Programs”
- Recommended Citation
 - Alam, S. Satterfield, A. Deng, X. & Mason, C. A. (2016). Progress in Standardization of Reporting and Analysis of Data from Early Hearing Detection and Intervention (EHDI) Programs. *Journal of Early Hearing Detection and Intervention*, 1(2), 2-7. DOI: 10.15142/T3JG6D
 - Retrieved from <http://digitalcommons.usu.edu/jehdi/vol1/iss2/2>

Background

- More deaf and hard of hearing (DHH) infants are being identified early
 - Early identification helps avoid developmental delays
 - Over 6,100 infants identified early (2014)
- Some infants do not receive recommended follow-up
 - Diagnostic testing and/or early intervention
- Loss to follow-up (LFU): Did not receive recommended follow-up
- Loss to documentation (LTD): Follow-up provided but results not reported

Key Points

- EHDI Goal: Early Identification
- Complete and accurate data is essential
 - Help ensure DHH infants receive diagnostic tests and intervention
 - Assess progress and areas for improvement
 - Key at all levels



Why is Standardization Important?

- When data is not standardized it impacts usability and value
- Issues
 - Incomplete and inconsistent data is inaccurate
 - Inaccurate data impedes follow-up
 - Summaries and comparisons
- The JCIH stated that standardized reporting is crucial and that all federal and state agencies should standardize data definitions for higher quality and more reliable data (2007 Position Statement)

Lack of Standardization: Reasons

1. Completeness of data
 - Functionality of EHDI-IS
 - Multiple reporting sources
2. Documenting services
 - Variation in reporting requirements
3. Calculation of data
 - LFU/LTD

Calculating of LFU/LTD

- CDC EHDI Annual Survey
 - Unable to contact the family
 - Family contacted but unresponsive
 - Reason unknown
- Variation
 - Different formulas
 - Inconsistent classification / reporting
- Lack of standardization = Confusion

Example: Reasons for not receiving Follow-up

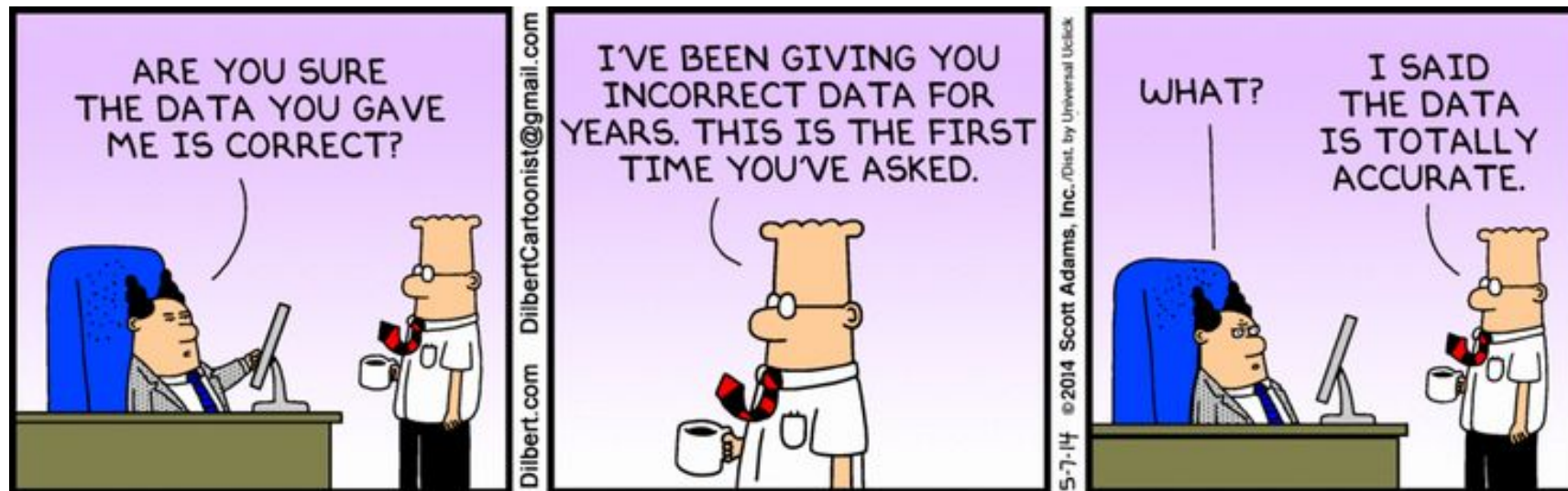
Total Not Pass: 800

Reason for No Follow-up

Non-resident	29
Moved out of jurisdiction	15
Medical reason	0
Physician did not refer	1
Infant died	8
Parents / family declined	22
Parents contacted but unresponsive	295
Unable to contact	4
Unknown	14

Example: How many infants are LFU / LTD?

- It depends...
 - Maybe 48%
 - Probably 39% or
 - Could be 2.3%



■ **Option A (everything): 48%**

— $(5+29+15+0+1++22+295+4+14) / 800$

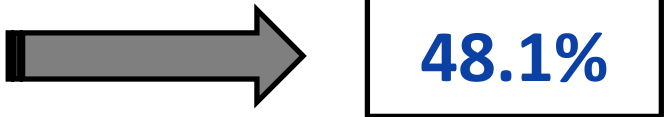
■ **Option B (CDC): 39%**

— $(\text{Unresponsive} + \text{Unable to Contact} + \text{Unknown}) / 800$

■ **Option C (limited): 2.3%**

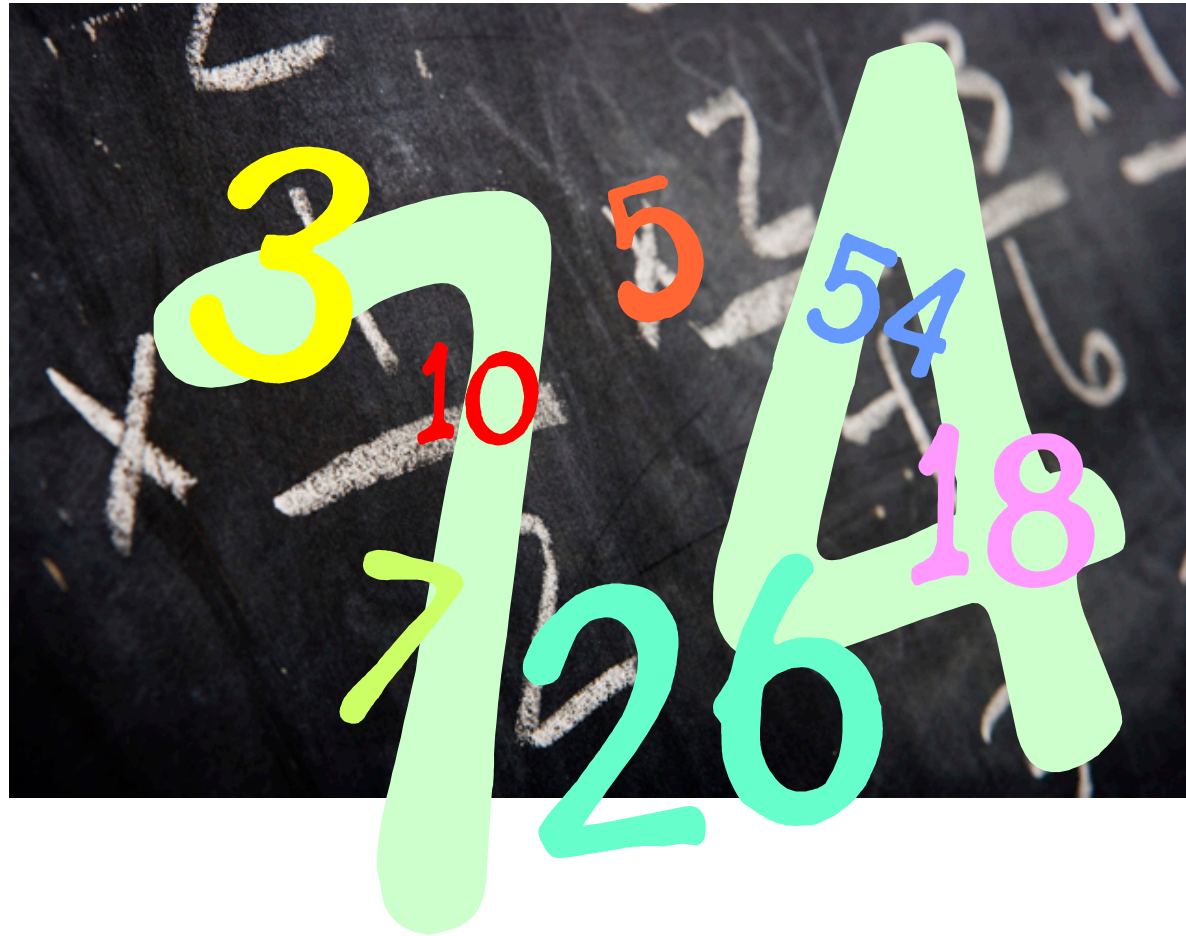
— $(\text{Unable to Contact} + \text{Unknown}) / 800$

Reason for No Follow-up	
In process	5
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48.1%

Know the Formula



What is being done?


- Updated CDC EHDI Hearing Screening and Follow-up Survey
 - Revised and expanded data definitions
 - Trainings
- Functional Standards
 - Technical and functional requirements for a complete EHDI-IS
 - Specific data items (Should, Shall, and May)
 - <https://www.cdc.gov/ncbddd/hearingloss/ehdi-is-functional-standards.html>
- National Data Tools and Standards
 - Interoperability between clinical health record and public health systems

Tools and Standards

- Code Sets
- Messaging and Document Standards for
 - Newborn hearing screening results
 - Hearing Plan of Care
 - Quality Measure Execution
 - Newborn Admission Notification
- Quality Measures
 - National Quality Forum (NQF) endorsed (*work to drive improvements in healthcare*)
 - Hearing screening prior to hospital discharge (NQF#1354)
 - Audiological evaluation no later than 3 months of age (NQF#1360)
 - Signed Part C Individual Family Service Plan (IFSP) before 6 months of age (NQF#1361)

www.cdc.gov/ncbddd/hearingloss/ehdi-hrt.html

Summary

- Lack of standardized EHDI data occurs for 3 key reasons
- Multiple effects
 - Receipt of follow-up
 - Quality and accuracy of data
 - Program effectiveness, success, and opportunities
- Standardized data  helps ensure DHH infants are identified early



Next Steps

- Improving and maintaining data standardization requires effort
 - Commitment and collaboration
 - Programs, providers, the CDC, and other stakeholders.
- Accomplish by:
 - Increased awareness
 - Improved reporting (procedures and EHDI-IS)
 - Technical assistance
 - National data standards

Thank you

www.cdc.gov/ncbddd/hearingloss

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 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.

