

Evaluation of the Iowa Early Hearing Detection and Intervention Data System

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Iowa EHDI Advisory Committee Meeting
January 6, 2011

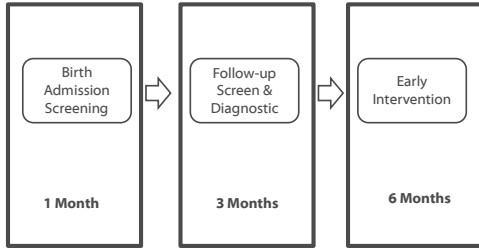
Outline

- Discuss public health importance of childhood hearing loss**
- Describe framework of Early Hearing Detection and Intervention (EHDI) programs**
- Describe Iowa EHDI data system**
- Discuss evaluation design**
- Provide credible evidence**
- Make recommendations**
- Share lessons learned**

Background

- Impact of congenital hearing loss**
 - 2 to 3 infants per 1,000 live births
 - Learning difficulties, language delays, behavior problems
- Universal Screening Recommendations**
 - United States Preventative Services Task Force
 - HRSA/American College of Medical Genetics
 - Congenital vs. progressive hearing loss
- Joint Committee on Infant Hearing (JCIH)**
 - Position statements & practice standards

System Components and National Objectives

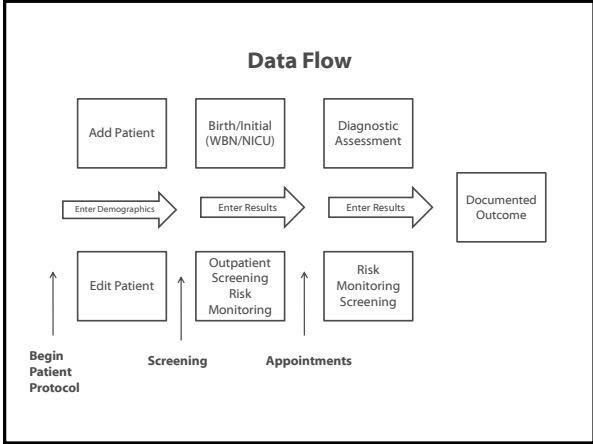


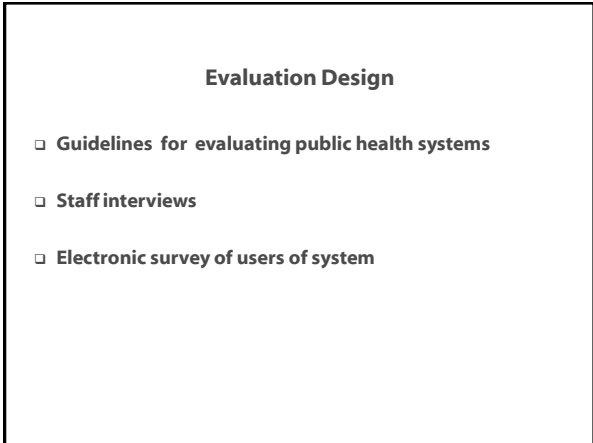
Stakeholders

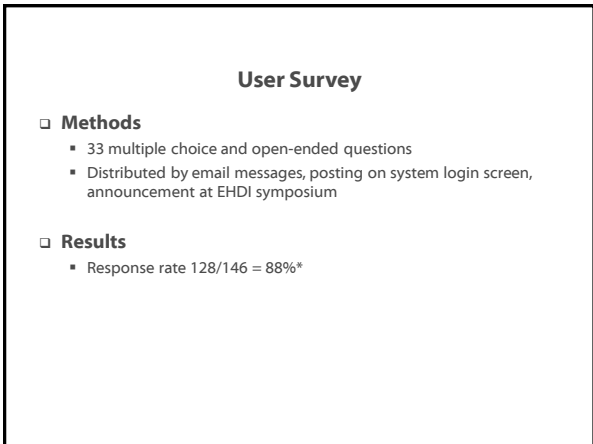
- Public Health officials
- Iowa Department of Education
- Policymakers and legislators
- Birthing facilities
- Healthcare providers
- Newborns and families

Iowa EHDI Data System

- State surveillance system for follow-up and referral under secure authenticated web access**
 - Contract with external vendor
 - Used by birthing facilities, Area Education Agencies, private practice audiologist
- Features**
 - Comprehensive hearing screening and assessment data
 - Identification & tracking
 - QA reports (birth admission screening, follow up, aging)
 - Notifications, letters
 - Appointments
 - Identification of clusters







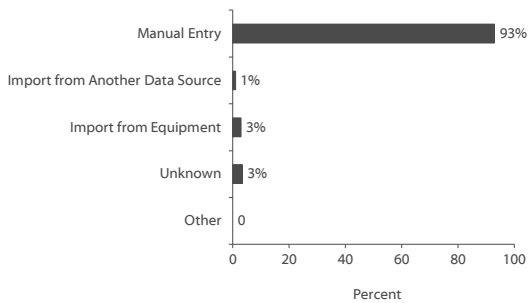
Survey Results

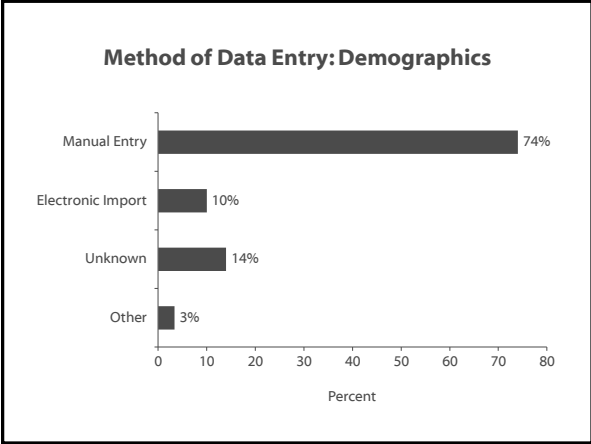
Demographics	No. (N=128)	(%)
Nurse (RN, LPN)	66	(51.6)
Audiologist/Audiology tech	34	(26.6)
Receptionist/secretary/data clerk	16	(12.5)
Nursing Assistant	3	(3.0)
Other	9	(7.0)

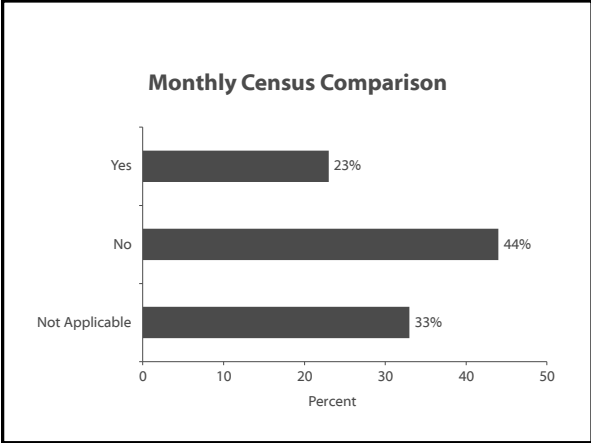
Survey Results

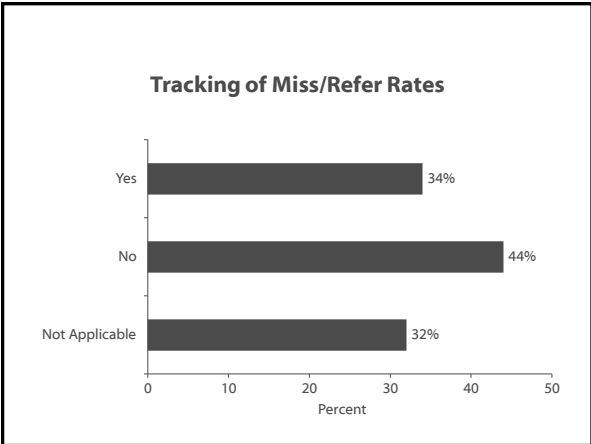
Facility Type	No. (N=128)	(%)
Birthing Hospital	90	(70.3)
Area Education Agency	34	(26.6)
Other	4	(3.1)

Method of Data Entry: Screening Results









1. Usefulness

- ❑ **Affected by the system attributes**
- ❑ **Does the system:**
 - Detect health-related events of public health importance in a timely manner
 - Provide estimates of the magnitude of morbidity or mortality related to the health-related event
 - Identify risk factors
 - Detect trends
 - Lead to improved practices and prevention

2. Representativeness

- ❑ **Accurate description of the occurrence of health-related event :**
 - over time
 - distribution in the population by person and place

2. Representativeness

- ❑ **Aim to capture screening data on every birth**
- ❑ **38959/39777 births (98%) were screened in 2009**

3. Acceptability

- ❑ **Willingness of persons and organizations to participate in the surveillance system**
- ❑ **Assessed by considering the interaction between the system and its participants**
 - Persons reporting cases
 - Persons with health-related event

3. Acceptability

- ❑ **Mandated by law**
- ❑ **60% of users reported ease of use**
- ❑ **83% reported system functions are appropriate and sufficient**

4. Timeliness

- ❑ **Speed between steps in a surveillance system**
- ❑ **Consider the identification of the health-related event to the final stages where information is disseminated for public health action**

4. Timeliness

- ❑ **Results must be reported within 6 days of any screen**
- ❑ **64% reported weekly reporting**

5. Simplicity

- ❑ **Structure**
 - Number of reporting sources involved
 - Level of integration with other systems
- ❑ **Ease of operation**
 - Data entry

5. Simplicity

- ❑ **Not a simple system**
 - Complex data flow
 - Over 90 facilities are reporting data
 - Collaborative effort between two state entities

6. Flexibility

- ❑ **Ability to adapt to changing information needs with little time, personnel or allocated funds**
- ❑ **Examples of information needs include changes in case definition or in reporting sources**

6. Flexibility

- ❑ **Flexible**
 - System capable of modifications
- ❑ **Limited Flexibility**
 - Multi-step process of modifications
 - Costly

7. Stability

- ❑ **Reliability**
 - Ability to collect, manage and report data without failure
- ❑ **Availability**
 - Ability to be operational when it is needed

7. Stability

- ❑ **Stable**
 - Required by law since 2004
 - Internal hosting of data system
- ❑ **Less stable**
 - Impacted by resources
 - Reliance on external contractor for software updates

8. Data Quality

- ❑ **Completeness and validity of data**
- ❑ **Can depend on sensitivity and positive predictive value**

8. Data Quality

- ❑ **Underutilization of system functions**
 - ❑ Demographic data import
 - ❑ Birth admission report
 - ❑ Follow up screening report
- ❑ **Manual data entry**
- ❑ **Opportunities for error**

9. Sensitivity

- Proportion of cases of the health-related event detected by the surveillance system

		Event Present		Total
		Yes	No	
Detected by Surveillance system	Yes	True Positive A	False Positive B	A+B
	No	False Negative C	True negative D	C+D
	Total	A+C	B+D	

9. Sensitivity

- Unable to calculate sensitivity
- "False negatives" not routinely documented

10. Positive Predictive Value (PPV)

- Proportion of reported cases that actually have the health-related event under surveillance

		Event Present		Total
		Yes	No	
Detected by Surveillance system	Yes	True Positive A	False Positive B	A+B
	No	False Negative C	True negative D	C+D
	Total	A+C	B+D	

10. Positive Predictive Value (PPV)

- ❑ Unable to calculate PPV
- ❑ 100% of infants do not have a documented final outcome

Conclusion: Usefulness of the Iowa EHDl System

- ❑ Useful system
- ❑ Population-based, universal screening program
- ❑ Appropriate and relevant goals and objectives
- ❑ Addresses a significant public health issue

Recommendation 1

- ❑ Continue user training to utilize system's existing capabilities
- ❑ Will improve data quality

Recommendation 2

- ❑ **Continue efforts to minimize infants lost to follow up**
 - Will allow for a calculable PPV

- ❑ **Create plan to look at false negatives**
 - Will allow sensitivity to be calculated
 - Existing capability of the system

Recommendation 3

- ❑ **Conduct detailed cost analysis**
- ❑ **Obtain long term funding and other funding sources**
- ❑ **Will improve stability**
- ❑ **Common sources of funding from other states include:
general state funds, fee revenues**

Recommendation 4

- ❑ **Integrated child health management system**
- ❑ **Recommended by HRSA/MCHB, CDC and the American Academy of Pediatrics**
- ❑ **NBS, WIC, CSHCN, immunization**
- ❑ **Improvement in data quality, timeliness, acceptability**

Lessons Learned

- ❑ **Information Management is integral and challenging**
- ❑ **Data quality is influenced by multiple factors**
- ❑ **Sustainability is vital**
- ❑ **Coordination and collaboration, financial resources, policy support, ongoing evaluation are necessary**

Acknowledgements

- **CDC**
 - Krista Crider
 - Xidong Deng
 - Marcus Gaffney
 - Cindy Hinton
 - Richard Olney
- **Iowa Department of Public Health**
 - Tammy O'Hollearn
 - Jen Thorud
- **EIS Officers**
 - Ijeoma Azonobi
 - Alejandro Azofeifa
 - Simerpal Gill
 - Ekwutosi Okoroh



Thank You

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