Evaluation of the Iowa Early Hearing Detection and Intervention Data System

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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

- Birth Admission Screening
  - 1 Month
- Follow-up Screen & Diagnostic
  - 3 Months
- Early Intervention
  - 6 Months

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
Evaluation Design

- Guidelines for evaluating public health systems
- Staff interviews
- Electronic survey of users of system

User Survey

- Methods
  - 33 multiple choice and open-ended questions
  - Distributed by email messages, posting on system login screen, announcement at EHDI symposium

- Results
  - Response rate 128/146 = 88%*
### Survey Results

#### Demographics

<table>
<thead>
<tr>
<th>Position</th>
<th>No. (N=128)</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse (RN, LPN)</td>
<td>66</td>
<td>(51.6)</td>
</tr>
<tr>
<td>Audiologist/Audiology tech</td>
<td>34</td>
<td>(26.6)</td>
</tr>
<tr>
<td>Receptionist/secretary/data clerk</td>
<td>16</td>
<td>(12.5)</td>
</tr>
<tr>
<td>Nursing Assistant</td>
<td>3</td>
<td>(3.0)</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>(7.0)</td>
</tr>
</tbody>
</table>

#### Facility Type

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>No. (N=128)</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birthing Hospital</td>
<td>90</td>
<td>(70.3)</td>
</tr>
<tr>
<td>Area Education Agency</td>
<td>34</td>
<td>(26.6)</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>(3.1)</td>
</tr>
</tbody>
</table>

### Method of Data Entry: Screening Results

- Manual Entry: 93%
- Import from Another Data Source: 1%
- Import from Equipment: 9%
- Unknown: 3%
- Other: 0%
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

- 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
- 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

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

<table>
<thead>
<tr>
<th>Event Present</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>A</td>
<td>B</td>
<td>A+B</td>
</tr>
<tr>
<td>False Positive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>C</td>
<td>D</td>
<td>C+D</td>
</tr>
<tr>
<td>False Negative</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>A+C</td>
<td>B+D</td>
<td></td>
</tr>
</tbody>
</table>

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

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<td></td>
</tr>
</tbody>
</table>
10. Positive Predictive Value (PPV)

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

Conclusion: Usefulness of the Iowa EHDI 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

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Thank You