Indiana’s EHDI Alert Response System (EARS): A Year Later: Successes and Challenges

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Overview

- Background: Integrated Data System (IDS) and the EHDI Alert Response System (EARS)
- Working in the EARS environment
- Successes and Challenges
Landmarks in Data Integration in Indiana

- 1974- Regenstrief Institute began working on data integration.

- Mid-1980s-ISDH started moving forward with data integration.

- 1993-Indiana Legislature mandated the creation of the State Health Data Center.

- 2001-Operational Data Store developed.
IDS Data Sources

- IU Lab Data – Newborn Screening/Hearing
- Hospital (Reportable Birth Defects – UB92)
- Vital Records Birth
- Vital Records Death
- Vital Records Fetal Death
- Electronic Lab Reports (Regenstrief)
- Cystic Fibrosis
IDS Users

- Newborn Screening
- Vital Records
- Data & Statistics
- IBDPR
- Epi Resource Center
EHDI Program in Indiana
EHDI in Indiana

- In 1999, the State Legislature passed PL91-1999 which mandates screening of babies in Indiana for hearing loss.

- 16-41-17-10 states that ISDH is responsible for:
  
  "A centralized program that provides tracking, follow-up, diagnosis, management, and family counseling and support."
EHDI in Indiana

- Approximately 88,000 live births per year
- 103 Hospitals & 3 Birthing Facilities
- Approximately 800 Home Births Annually
Indiana EHDI Data 2007

- 98% received UNHS
- 1.95% did not pass \( n=1743 \)

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal hearing</td>
<td>65%</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>7.6%</td>
</tr>
<tr>
<td>In process</td>
<td>2%</td>
</tr>
<tr>
<td>Died/moved/refused</td>
<td>4.6%</td>
</tr>
<tr>
<td>LTF/LTD (screen to eval)</td>
<td>20.8%</td>
</tr>
<tr>
<td>LTF/LTD (HL dx to EI)</td>
<td>20.9%</td>
</tr>
</tbody>
</table>

Prevalence of Hearing Loss 1.5 per 1000 screened

Data calculated Jan 2009
EHDI Alert Response System (EARS)
What is EARS?

EARS is a web-based application that:

- allows hospitals and audiologists to quickly and accurately enter information directly into a data store;
- allows Indiana EHDI staff to view these entries almost instantaneously; and
- generates alerts and informs the appropriate staff member that the next follow-up action should be taken.
History of EARS

- **2005** — received grant from the CDC to fund the development of EARS
- **2006** — began development of EARS
- **2007** — began pilot testing EARS with the help of 4 central Indiana hospitals
- **2008** — EARS moved to production and trained 80% of hospitals — began pilot testing of audiology reporting section — conversion from ODS to IDS began
- **2009** — ODS/IDS conversion almost complete - additional hospital training scheduled — begin development of web-based audiology training
Working EARS

- Health Data Center Gateway
- Log on to system
- Step by step-Hospital Data Entry
- Checking an EARS Alert
- Processing an EARS Alert
- Communicating by secure E-mail
- Step by step-DAE entry
- Backdoor Information
EARS Welcome
EARS

- Enables Improved Communication between EHDI Staff and ….
  - Hospital Staff
  - First Steps - System Points of Entry
  - Audiologists
  - Physicians

- And here’s how…. 
Hospital Staff Report
“Exceptions”

- Not Screened
  - Deceased
  - Transferred
  - Hospital Error
  - NICU
  - Unauthorized Refusal
  - Religious Objection
  - Equipment Problems
  - Screening Next Month

- Did Not Pass UNHS

- Passed but At Risk
EARS Exceptions

- Did Not Pass
- Passed At Risk
- Rescreen Next Month
- NICU
EARS “Hold Overs”

- Babies who have not been screened

- “Hold overs” must have an updated code to complete final submission of report

- If screened, results will be displayed
Exceptions Create Alerts

- High Priority
- Medium Priority
EARS
Child Health Information Profile
CHIP

➢ To be added
Alerts Create Responses
ARC

➢ To be added
Diagnostic Audiology Evaluation

- To be added
Responses Enable Case Determination

➢ To be added
(H)EARS Challenges

- Buy-in, training, and use of the system
- Increased technical support to end users
- Increased internal workload
- Data Integration
  - Conversion
  - New HIPAA-covered entity
- Communication with the data system
- Evolution of the EARS application
(H)EARS Successes

- Improved accuracy and reporting by hospitals (direct data entry)
- Increased timeliness of data sharing
- Improved relationships in EHDI system
- More accurate identification of children through larger database (IDS)
- Reduced loss to follow-up
- and documentation of children
- Easy to access, paperless, “active” system that “works” for the user
- Foundation for other Newborn Screening applications
(H)EARS the Real Conclusion