Integrated Data Systems: Successes & Challenges in the Indiana EHDI Program

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Presentation Overview
Presentation Overview

• EARS
  o Day-to-day use
  o Data items reported
  o Reports
• Successes/Benefits
• Challenges
• Next Steps
• Discussion
What is EARS?

EHDI Alert Response System
What is EARS?

**EHDI Alert Response System**

**IOT**

**API**

**ISDH Repository**
- Core
- Birth Defects
- Newborn Hearing
- Newborn Screening
- VR Birth Records
- VR Death Records
- SAERS
- VR Fetal Death
- Morbid Obesity

**DMZ - FIREWALL**

- Internal / External Web Applications
- ISDH Gateway Apps
- INSTEP
- EARS/EHDI
- Sickle Cell
- Cystic Fibrosis
- Birth Defects Registry
- Acute Care
- Maternal Mortality
- MODE
- SAERS
- Person Search

**API**

- Vital Records
- IU/Regenstrief
- Physicians
- Hospitals
- ISDH - MCSHC
- FSSA

**EARS/EHDI**

**INSTEP**

**MODE**

**SAERS**

**Person Search**

**Internal / External Web Applications**

**ISDH Repository**

**Newborn Hearing**

**Birth Defects**

**Newborn Screening**

**VR Birth Records**

**VR Death Records**

**SAERS**

**VR Fetal Death**

**Morbid Obesity**

**Early Hearing Detection & Intervention Program**
Why was it created?

To improve…..

Follow-up on babies
  Not screened
  Not passing UNHS
  At Risk for delayed onset of hearing loss
  Diagnosed with hearing loss

Communication among
  Hospital staff
  EHDI staff
  Audiologists
  Guide By Your Side & Families
  First Steps – System Points of Entry

Data reporting capabilities
Hospitals Report “Exceptions”

Exception Codes

<table>
<thead>
<tr>
<th>Not Screened Due To:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Deceased/Terminal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Transferred Out</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Hospital Error</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. NICU</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Unauthorized Refusal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Religious Refusal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Equipment Failure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Initial Screen Next Month</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Rescreen Next Month</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>New Patient Intake:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Transferred IN</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Passed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Passed At Risk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Did Not Pass UNHS: (complete Refer To section)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Did Not Pass At Risk</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Use the following values to define to whom the child was referred, check all that apply.

<table>
<thead>
<tr>
<th>A. First Steps</th>
<th>B. Primary Care Physician</th>
<th>C. Audiologist</th>
<th>D. Ear, Nose &amp; Throat Physician</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Children who did not receive hearing screening....

Deceased

<table>
<thead>
<tr>
<th>PID</th>
<th>Child’s Name</th>
<th>DOB</th>
<th>Mothers Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NICU

<table>
<thead>
<tr>
<th>PID</th>
<th>Child’s Name</th>
<th>DOB</th>
<th>Mothers Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Hospital Error

<table>
<thead>
<tr>
<th>PID</th>
<th>Child’s Name</th>
<th>DOB</th>
<th>Mothers Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Hospital Report “Exceptions”

Children who did not pass UNHS or have risk factors....

<table>
<thead>
<tr>
<th>Code</th>
<th>MRN</th>
<th>Go</th>
<th>Infant Name</th>
<th>DOB</th>
<th>Mother Name</th>
<th>Mother Phone</th>
<th>Physician Name</th>
<th>Physician Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>MRN</td>
<td></td>
<td>Child’s Name</td>
<td>7/18/2010</td>
<td>Mother’s Name</td>
<td>Phone #</td>
<td>HAVEN, ROBERT</td>
<td>765-386-7301</td>
</tr>
</tbody>
</table>

Some exceptions are considered “Hold-overs”

<table>
<thead>
<tr>
<th>PID</th>
<th>5</th>
<th>3</th>
<th>Rabbits, Chase</th>
<th>Male</th>
<th>5/21/2010</th>
<th>1</th>
<th>9</th>
<th>Trans. Date</th>
<th>Select Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>PID</td>
<td>5</td>
<td>3</td>
<td>Walling, Dry</td>
<td>Male</td>
<td>7/3/2010</td>
<td>1</td>
<td>4</td>
<td>Trans. Date</td>
<td>Select Facility</td>
</tr>
</tbody>
</table>

Indiana Hospital has reported: Code = 4(NICU) Screened = N/A Refer to = N/A
EHDI Staff Receive Alerts

Children who did **not** receive hearing screening....

<table>
<thead>
<tr>
<th>Priority</th>
<th>Source</th>
<th>Message</th>
<th>Child’s Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Hospital Error</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Hospital Error</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Religious Refusal</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Religious Refusal</td>
<td>Child’s Name</td>
</tr>
</tbody>
</table>

Children who did not pass UNHS or have risk factors....

<table>
<thead>
<tr>
<th>Priority</th>
<th>Source</th>
<th>Message</th>
<th>Child’s Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Did Not Pass</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>✘</td>
<td>MSR</td>
<td>Did Not Pass At Risk</td>
<td>Child’s Name</td>
</tr>
</tbody>
</table>

Children who are diagnosed with hearing loss....

<table>
<thead>
<tr>
<th>Priority</th>
<th>Source</th>
<th>Message</th>
<th>Child’s Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>❗️</td>
<td>DAE</td>
<td>Send Tool Kit</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>❗️</td>
<td>DAE</td>
<td>Send Tool Kit</td>
<td>Child’s Name</td>
</tr>
</tbody>
</table>
EHDI Staff Receive Alerts

Additional Follow-up...

<table>
<thead>
<tr>
<th>EMAIL</th>
<th>Email Response by</th>
<th>Child’s Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMAIL</td>
<td>Email Response Due</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>DAE</td>
<td>DAE Follow-up Appt. Lapsed: Call Audiologist</td>
<td>Child’s Name</td>
</tr>
<tr>
<td>Letter Response</td>
<td>Delayed Alert: Letter Response Due Today</td>
<td>Child’s Name</td>
</tr>
</tbody>
</table>

Clerical Staff Assistance …

| BATCH | Batched Letters Are Ready For Printing. |
EHDI Staff Processes Alerts

Review of Child Health Profile (CHIP)
Demographics  File Status
Responses  UNHS Results
DAE Data  GBYS Data
Notes

EHDI - Child Health Information Profile

Name  RABBIT, CHASE BENNETT  PID  
Gender  M  Race  BLACK OR AFRICAN AMERICAN
DOB  05/12/2010  Ethnicity  NON-HISPANIC, FILIPINO, PORTUGUESE
Birth Order  1  Birth Facility  COMMUNITY HOSPITAL MUNSTER
Plurality  1  Birth Defects  No Confirmed Birth Defects

Mother's Name  RABBIT, MAMA  Address  1234 SUNNY WAY, INDIANAPOLIS, IN 46258, County: LAKE
Father's Name  RABBITS, DADA  Phone  317-555-1212
PCP's Name  @GOOD DOCTOR  Phone  317-555-1212

Alerts

<table>
<thead>
<tr>
<th>PRIORITY</th>
<th>SOURCE</th>
<th>MESSAGE</th>
<th>CREATED</th>
<th>DELAY TO</th>
<th>ASSIGNED TO</th>
<th>RESOLVED</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>MSR</td>
<td>Did Not Pass At Risk - Child's Name</td>
<td>7/29/2010</td>
<td>7/29/2010</td>
<td>Laura Gutwein</td>
<td></td>
</tr>
</tbody>
</table>
2010 DAE Data

- 2,501 DAEs submitted
- 2,250 individual children
- 107 audiologists
- 81.5% submitted electronically
Short-term Follow-up Guide By Your Side
Outcomes Form in EARS

- Parent Program Coordinator sits within the EHDI program
- 12 Parent Guides located across the state
- Provides up to 6 visits
  - First visit in person
  - Remaining meetings at location and frequency requested
Guide By Your Side
Outcomes Form in EARS

### Referrals
- **Connection with Family Support Organization:**
  - Yes
  - No
  - Unknown
  - Recommended
- **Genetic Eval and Counseling:**
  - Yes
  - No
  - Unknown
  - Recommended
- **ENT Eval:**
  - Yes
  - No
  - Unknown
  - Recommended
- **Vision Eval:**
  - Yes
  - No
  - Unknown
  - Recommended
- **Other Provider or Service:**
  - Yes
  - No
  - Unknown
  - Recommended

**If yes, please specify:**
- Received Genetic Eval/Counseling:
  - Yes
  - No
  - Unknown
- Received ENT Eval:
  - Yes
  - No
  - Unknown
- Received Vision Eval:
  - Yes
  - No
  - Unknown
- Received Other services:
  - Yes
  - No
  - Unknown

**Please specify Other Service/provider:**

**Children with Special Healthcare Services info. Received:**
- Yes
- No
- Unknown
- NA

**Parent Toolkit Received:**
- Yes
- No
- Unknown

### How was child referred to GBYS:
- **Guide by Your Side**
- **First contact:**
  - UNHS
  - First Steps SPOE
  - EI Provider
  - Self
  - Audiologist
  - Physician
  - Hands and Voices
  - School personnel
  - Other
- **Enrolled:**
- **Completed:**
- **Parent Guide**
- **Child Moved Out of State:**
  - State moved to
- **Name of Informant:**
- **Last Updated:**

### Participating:
- Yes
- No, but PC follow-up
- Declined Follow-up

### First Visit:

### Visits:

### Signed Release Onfile:
- Yes
- No
- Refused

### Date state notified by ISDH:

### Role of Informant:

### Last Updated By:

**Early Hearing Detection & Intervention Program**
### Other EARS Features

#### Secured Email

<table>
<thead>
<tr>
<th>PID</th>
<th>Message Preview</th>
<th>Reply To</th>
</tr>
</thead>
<tbody>
<tr>
<td>5042647</td>
<td>Please follow-up on the child below. If you have questions</td>
<td><a href="mailto:juschulte@isdh.in.gov">juschulte@isdh.in.gov</a></td>
</tr>
</tbody>
</table>

---

**Message Content**

```
---------ISDH USE Please Do Not Remove ---------
Mother Name: MAMA DENISE RABBITS
Address: 1234 SUNNY WAY, INDIANAPOLIS, IN 46268
Child Name: CHASE BENNETT RABBITS
Child DOB: 05/12/2010
Child Sex: Male
Phone: (317) 555-1212
County:
PID: 5042647
Alert Id=42285
```
Other EARS Features

Alert Processing

<table>
<thead>
<tr>
<th>Source</th>
<th>Priority</th>
<th>Created</th>
<th>Alert Message</th>
<th>Resolved</th>
<th>Resolved</th>
</tr>
</thead>
<tbody>
<tr>
<td>dae</td>
<td>high priority</td>
<td>11/9/10</td>
<td>dae follow-up appt. lapsed: call audiologist -</td>
<td>12/1/10</td>
<td>** passed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>dae **</td>
</tr>
<tr>
<td>uda</td>
<td>high priority</td>
<td>12/2/10</td>
<td>batch letters</td>
<td>12/2/10</td>
<td>f/up letter:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>85 oos did</td>
</tr>
<tr>
<td>nodelay</td>
<td>high priority</td>
<td>12/2/10</td>
<td>finalize case -</td>
<td>12/2/10</td>
<td>f/up letter:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>85 oos did</td>
</tr>
<tr>
<td>letter</td>
<td>high priority</td>
<td>12/2/10</td>
<td>delayed alert: letter response due today -</td>
<td>12/2/10</td>
<td>ehdi file</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>finalized</td>
</tr>
</tbody>
</table>

MSR Submissions

<table>
<thead>
<tr>
<th>Reporting Period</th>
<th>Opened</th>
<th>Closed</th>
<th>Late</th>
<th>Contact on file</th>
<th>Created By</th>
<th>Closed By</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 2010</td>
<td>11/10/2010</td>
<td>01/05/2011</td>
<td>No</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
</tr>
<tr>
<td>11 2010</td>
<td>10/08/2010</td>
<td>12/03/2010</td>
<td>No</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
</tr>
<tr>
<td>10 2010</td>
<td>09/02/2010</td>
<td>11/10/2010</td>
<td>No</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
</tr>
<tr>
<td>9 2010</td>
<td>08/04/2010</td>
<td>10/08/2010</td>
<td>No</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
</tr>
<tr>
<td>8 2010</td>
<td>07/01/2010</td>
<td>09/02/2010</td>
<td>No</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
<td>MSR Contact</td>
</tr>
</tbody>
</table>

Additional reports completed by NBS IT support staff in a timely manner
Benefits
EARS & Integration

• **For hospitals**
  – Only enter “exceptions” on the MSR
  – If child is already known, fields will be pre-populated
  – Easy tracking of sick babies (transferred and NICU) through Hold-over list

• **Audiologists**
  – If child is already known, fields will be pre-populated
  – Enables EHDI to assist in timely manner with families who do not return
Benefits

EARS & Integration

• **EHDI Staff**
  – Reduced data entry
  – Increased contact with families and professionals
  – Access to IBDPR reported conditions
  – Automatic notification of deceased children
  – Automatic update of adopted children
  – Access to other contact information if names or addresses have changed
  – Improved timeliness of follow-up procedures
  – Improved data reporting accuracy and capability
Challenges
EARS & Integration

- Security
- Managing of account creation
- Matching data from different sources
  - Current match rate about 85% after adding additional fields in March 2010
- Identifying & merging of duplicate files
- Multiple births
- “Ownership” of specific data fields
- “Place in line” when changes are needed
Next Steps

- Additional “canned” and ad hoc reports
- Improved matching by including blood spot “K-number” to optional MSR fields
- Additional data item collection as part of the iEHDI contract
- GBYS Parent Guide access to EARS
- PCP access to newborn screening data
Discussion...
Contact Us

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317-234-3358  
ghutsell@isdh.in.gov

Julie Schulte  
317-233-1264  
juschulte@isdh.in.gov

Website  
www.hearing.in.gov

Toll Free  
888-815-0006

Indiana State  
Department of Health

Early Hearing Detection & Intervention Program