Iowa Symposium on Hearing Loss: Impact on Children and Their Families

September 28 & 29, 2012

Dr. Shannon Sullivan, Iowa EHDI Chapter Champion
Tammy O’Holleearn, Iowa EHDI Coordinator
Iowa EHDI Chapter Champion

- Collaborate with Child Health Specialty Clinics and Iowa Department of Public Health on EHDI activities and initiatives
- Provide leadership, guidance and education to pediatricians and other pediatric health care providers on EHDI issues
- Attend the National EHDI Conference
- Provide education to AAP members and others on EHDI activities (newsletters, resident and student education, grand rounds)
Iowa EHDI Chapter Champion

- Attend quarterly state EHDI Hearing Screening Advisory Committee Meetings
- Participate in AAP EHDI Regional Conference Calls
Chapter Champion Work in Iowa

- Presentations to medical providers at UIHC, Blank Children’s, Mercy Medical Center and FQHC in Waterloo
  - Made possible through AAP EHDI Education and Training Award
- Surveyed learning (pre/post survey) at Iowa Health
- EHDI tool kit
- UI electronic medical record
- Promoted “just in time” information, Guide By Your side / Care Coordination
- EPSDT newsletter
- ABP EHDI MOC education program
Other AAP EHDI Chapter Champion Activities

• Tele-audiology (CA, TN, WI, IA)
• Tracking and documentation NICU population (CO)
• Adding hearing screening results to State Immunization Registry (AZ, HI)
• Re-screening in PCP office (MT)
• Survey LTF families (KS)
• Military facilities (uniformed services)
• Better tracking home births (UT)
• Care coordination tool kits
• MOC Education Program
• Tracking / surveillance esp. Medicaid population (TN, DC)
• Access to Audiology (West VA)
Iowa's Early Hearing Detection and Intervention (EHDI) program works to ensure that all newborns and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, medical intervention and family support.
Who makes up the EHDI System of Care?

- Iowa Department of Public Health provides administrative oversight to the EHDI program within Iowa
  - [www.idph.state.ia.us/iaehdi](http://www.idph.state.ia.us/iaehdi) (EHDI website)
  - [www.idph.state.ia.us/](http://www.idph.state.ia.us/) (IDPH website)

- Child Health Specialty Clinics
  - [www.chsciowa.org](http://www.chsciowa.org)

- AEAs, Private Practice Audiologists, ENTs, PCPs, EA, EHS
EHDI Program Goals

• Develop and sustain a comprehensive coordinated system of care for Early Hearing Detection and Intervention in Iowa.
• Meet the National EHDI Goal of 1-3-6.
  – "1" - All infants are screened for hearing loss no later than 1 month of age, preferably before hospital discharge.
  – "3" - All infants who do not pass the screening will have a diagnostic audiologic evaluation no later than 3 months of age.
  – "6" - All infants identified with a hearing loss receive appropriate early intervention services no later than 6 months of age.
• Provide technical assistance to birthing hospitals, Area Education Agencies, and private practice audiologists relative to the hearing screening program and their responsibility under the law.
EHDI Program Goals

- Statewide implementation of a Web-based surveillance system to assure all newborns are screened for hearing loss and receive follow up services, as needed.
- Facilitate data integration linkages with related screening, tracking, and surveillance programs to minimize infants “lost to follow-up”.
- Review data to identify children with potential for hearing loss to ensure those children receive appropriate, timely early intervention services.
- Collaborate with Individuals with Disabilities Education Act, Part C (Early ACCESS) to strengthen early intervention services for children who are deaf or hard-of-hearing.
- Ensure families with children zero to three who are deaf, hard-of-hearing, or at risk of late-onset hearing loss will be linked to a medical home and receive family-to-family support.
Snapshot of Iowa’s Data
### Race/Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011 (Preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>86%</td>
<td>86%</td>
<td>86%</td>
<td>86%</td>
</tr>
<tr>
<td>African American</td>
<td>5%</td>
<td>5%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>2%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
<td>6%</td>
<td>6%</td>
<td>7%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9%</td>
<td>9%</td>
<td>9%</td>
<td>9%</td>
</tr>
</tbody>
</table>
## Snapshot of EHDI Data – Birth Screens

<table>
<thead>
<tr>
<th>Category</th>
<th>2010</th>
<th>2011 (Preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Births</td>
<td>38575</td>
<td>38054</td>
</tr>
<tr>
<td>Screened</td>
<td>37806 (98%)</td>
<td>37349 (98%)</td>
</tr>
<tr>
<td>Pass</td>
<td>35445 (92%)</td>
<td>35067 (92%)</td>
</tr>
<tr>
<td>Did Not Pass</td>
<td>2367 (6%)</td>
<td>2282 (6%)</td>
</tr>
<tr>
<td>Missed</td>
<td>279 (.7%)</td>
<td>169 (.4%)</td>
</tr>
<tr>
<td>Refused</td>
<td>278 (.7%)</td>
<td>284 (.7%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>104 (.3%)</td>
<td>129 (.3%)</td>
</tr>
<tr>
<td>Moved out of State</td>
<td>0 (0%)</td>
<td>1 (0.0%)</td>
</tr>
<tr>
<td>No Screen Outcome/ Medically Fragile</td>
<td>4 (.01%)</td>
<td>4 (.01%)</td>
</tr>
<tr>
<td>Passive refusal/Lost</td>
<td>103 (.3%)</td>
<td>118 (.3%)</td>
</tr>
</tbody>
</table>
## Snapshot of EHDI Data – Outpatient Screens

<table>
<thead>
<tr>
<th>Category</th>
<th>2010</th>
<th>2011 (Preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Needing Screened</td>
<td>2646</td>
<td>2451</td>
</tr>
<tr>
<td>Screened</td>
<td>2258 (88%)</td>
<td>2101 (86%)</td>
</tr>
<tr>
<td>Pass</td>
<td>1963 (77%)</td>
<td>1850 (75%)</td>
</tr>
<tr>
<td>Did Not Pass</td>
<td>299 (12%)</td>
<td>251 (10%)</td>
</tr>
<tr>
<td>Refused</td>
<td>7 (.2%)</td>
<td>14 (.6%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>2 (.07%)</td>
<td>4 (0.2%)</td>
</tr>
<tr>
<td>Moved out of State</td>
<td>57 (2%)</td>
<td>62 (3%)</td>
</tr>
<tr>
<td>No Screen Outcome/ Medically Fragile</td>
<td>3 (0.1%)</td>
<td>1 (0.04%)</td>
</tr>
<tr>
<td>Birth Screen to Audiological Assessment (no outpatient screen)</td>
<td>79 (3%)</td>
<td>88 (4%)</td>
</tr>
<tr>
<td>Passive refusal/Lost</td>
<td>242 (9%)</td>
<td>177 (7%)</td>
</tr>
</tbody>
</table>
### Snapshot of EHDI Data – Diagnostic Assessments

<table>
<thead>
<tr>
<th>Category</th>
<th>2010</th>
<th>2011 (Preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Needing a Diagnostic Assessment</td>
<td>379</td>
<td>340</td>
</tr>
<tr>
<td>Screened</td>
<td>283 (75%)</td>
<td>265 (78%)</td>
</tr>
<tr>
<td>Normal Hearing</td>
<td>118 (31%)</td>
<td>124 (36%)</td>
</tr>
<tr>
<td>Unilateral/ Bilateral loss</td>
<td>73 (19%)</td>
<td>40 (12%)</td>
</tr>
<tr>
<td>Refused</td>
<td>3 (0.8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>2 (0.5%)</td>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>Moved out of State</td>
<td>9 (2%)</td>
<td>9 (3%)</td>
</tr>
<tr>
<td>In Process (Unilateral/Bilateral—Transient or Not Yet Determined)</td>
<td>52 (14%)</td>
<td>91 (27%)</td>
</tr>
<tr>
<td>In Process (No Assessment)</td>
<td>3 (0.8%)</td>
<td>66 (19%)</td>
</tr>
<tr>
<td>Total In Process</td>
<td>55 (15%)</td>
<td>*157 (46%)</td>
</tr>
<tr>
<td>Passive refusal/Lost</td>
<td>117 (31%)</td>
<td>*10 (3%)</td>
</tr>
</tbody>
</table>
Refer Rate by Hospital Level

Quarter 1  Quarter 2  Quarter 3  Quarter 4  Quarter 1  Quarter 2  Quarter 3  Quarter 4  Quarter 1  Quarter 2  Quarter 3  Quarter 4  Quarter 1  Quarter 2
2009  2010  2011  2012

Level I  Level II  Level III  State Goal
Family Refusals

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Refusals</th>
<th>Home Birth Refusals</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>244</td>
<td>181</td>
<td>74%</td>
</tr>
<tr>
<td>2009</td>
<td>267</td>
<td>199</td>
<td>75%</td>
</tr>
<tr>
<td>2010</td>
<td>288</td>
<td>240</td>
<td>83%</td>
</tr>
<tr>
<td>2011 (Preliminary)</td>
<td>296</td>
<td>239</td>
<td>81%</td>
</tr>
</tbody>
</table>
Outpatient Follow up Received

Follow-Up Needed
Follow-Up Received

2008: 2914 (75%) 2193
2009: 2833 (79%) 2237
2010: 2552 (87%) 2243
2011 (Preliminary): 2361 (88%) 2075
Diagnostic Follow up Received

- **Diagnostic Assessment Needed**
- **Diagnostic Assessment Received**

<table>
<thead>
<tr>
<th>Year</th>
<th>Diagnostic Assessment Needed</th>
<th>Diagnostic Assessment Received</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>226</td>
<td>141</td>
<td>62%</td>
</tr>
<tr>
<td>2009</td>
<td>258</td>
<td>185</td>
<td>72%</td>
</tr>
<tr>
<td>2010</td>
<td>296</td>
<td>204</td>
<td>69%</td>
</tr>
<tr>
<td>2011 (Preliminary)</td>
<td>243</td>
<td>171</td>
<td>70%</td>
</tr>
</tbody>
</table>
# Home Birth Outcomes

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011 (preliminary)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Births</strong></td>
<td>432</td>
<td>451</td>
<td>443</td>
</tr>
<tr>
<td><strong>Total Screened</strong>¹</td>
<td>93 (22%)</td>
<td>85 (19%)</td>
<td>71 (16%)</td>
</tr>
<tr>
<td><strong>Normal Hearing</strong></td>
<td>111 (26%)</td>
<td>90 (20%)</td>
<td>79 (18%)</td>
</tr>
<tr>
<td><strong>In Process</strong></td>
<td>6 (1%)</td>
<td>2 (0.4%)</td>
<td>1 (0.5%)</td>
</tr>
<tr>
<td><strong>Hearing Loss</strong></td>
<td>1 (0.2%)</td>
<td>2 (0.4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Refused</strong></td>
<td>200 (46%)</td>
<td>240 (53%)</td>
<td>239 (54%)</td>
</tr>
<tr>
<td><strong>Deceased</strong></td>
<td>6 (1%)</td>
<td>7 (1.5%)</td>
<td>4 (1%)</td>
</tr>
<tr>
<td><strong>Moved out of State</strong></td>
<td>2 (0.5%)</td>
<td>0 (0%)</td>
<td>1 (0.2%)</td>
</tr>
<tr>
<td><strong>Lost Contact</strong></td>
<td>106 (25%)</td>
<td>110 (24%)</td>
<td>118 (27%)</td>
</tr>
</tbody>
</table>

¹The number of infants screened within 3 months of birth
Home Birth Outcomes 2009

- Normal Hearing: 111, 26%
- Lost Contact: 106, 25%
- Refused: 200, 46%
- Deceased: 6, 1%
- Moved out of State: 2, 1%
- Hearing Loss: 1, 0%
- In Process: 6, 1%

Lost Contact, 106, 25%
Home Birth Outcomes 2010

- Normal Hearing, 90, 20%
- Lost Contact, 110, 24%
- Refused, 240, 53%
- In Process, 2, 1%
- Hearing Loss, 2, 0%
- Moved out of State, 0, 0%
- Deceased, 7, 2%
Home Birth Outcomes 2011

- Normal Hearing, 79, 18%
- Hearing Loss, 0, 0%
- Refused, 239, 54%
- Lost Contact, 118, 27%
- Moved out of State, 1, 0%
- Deceased, 4, 1%
- In Process, 1, 0%
<table>
<thead>
<tr>
<th>Lost to follow up/lost to documentation</th>
<th>2009</th>
<th>2010</th>
<th>2011 - Preliminary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost contact/documentation among all babies in eSP™ including children missed at birth</td>
<td>1.5% (598/39671)</td>
<td>1.2% (460/38575)</td>
<td>0.8% (302/38054)</td>
</tr>
<tr>
<td>Lost before initial birth screen</td>
<td>0.3% (100/39677)</td>
<td>0.3% (103/38575)</td>
<td>0.3% (118/38054)</td>
</tr>
<tr>
<td>Lost between birth screen and outpatient screen</td>
<td>15% (442/2982)</td>
<td>9% (242/2646)</td>
<td>7% (177/2451)</td>
</tr>
<tr>
<td>Lost between outpatient screen and diagnostic evaluation</td>
<td>22% (56/259)</td>
<td>31% (117/379)</td>
<td></td>
</tr>
</tbody>
</table>
Celebrate Our Successes

• Improved follow up processes (PCP, parents, audiologists, ENTs, EA Iowa)
• Hospital site visits, efforts to increase best practices
• Quarterly hospital progress reports
• Program evaluation
• Increased quality assurance activities
• Increased provider reporting & reporting via eSP™
• Collaboration with Early Head Start – ECHO Project
• National participation in data project – iEHDI & Sentinel data
Celebrate Our Successes Cont’d

- Decreased refer rates among hospitals (AABR equip)
- Increased no. of providers conducting OP screens
- Developed issue briefs summarizing need and use of hearing aid & audiological services funding
- Increased education re: best practices related to screening, fup to audiologists, ENTs and primary care providers
- Improved fup for Spanish speaking families
- Developed Loss & Found DVD for families
- Increased referrals to GBYS
- Completed National Initiative for Children’s Healthcare Quality (newborn hearing screening/fup)
• Development of EHDI logo
• Providing diagnostic tele-audiology in NE corner of Iowa
• Greater collaboration among bordering states
• EHDI symposium!!!
• Increased participation by EHDI advisory committee members
• Awarded/Completed - 2011 EHDI AAP Chapter Education and Training Grant
• Financial support for families to attend:
  – H&V Leadership Conference
  – National EHDI conference
  – Iowa symposium
Future Efforts

• Education and outreach to midwives, home birth families
• Complete evaluation of provider knowledge regarding screening, diagnosis and recommended follow up
• Increase education and outreach to primary care providers, ENTs (e.g. Medical home toolkit)
• Continue national participation in data analysis projects (LTF, refer rates, themes among lost children, etc.)
• Increase education re: best practices related to screening, fup to audiologists, ENTs and primary care providers
• Train additional providers to enter hearing screen and/or diagnostic assessment results directly into eSP™, eliminate paper reporting completely
Future Efforts

• Continue technical assistance efforts to decrease hospital refer/miss rates and improve timely OP screens
• Increase timely GBYS or family support referrals
• Exploring feasibility and cost effectiveness of expanding tele-audiology across the state
• Improve cultural competence when doing follow up or offering family support
• American Board of Pediatrics (ABP) Maintenance of Certification (MOC) Quality Improvement Project
• EHDI-PALS
• Statewide implementation of case management module
Future Efforts

- Redesign of EHDI website
- Re-write/redesign family resource guide
- Update *Iowa EHDI Best Practices manual*
- Update eSP™ user manual
Committee Membership

- EHDI-PALS (Vicki, Tammy)
- Iowa Department of Education and Iowa Board of Regents, Coordinating Council for Deaf and Hard of Hearing (Tammy/Susan/Kathy Miller)
- Feasibility and Planning Study Committee for the Deaf and Hard of Hearing (Tammy/Susan/Kathy Miller)
- 2013 National EHDI Meeting Planning Committee (Vicki)
- National Improvement Partnership Network (Vicki)
- DSHPSHWA (Tammy)
- Iowa Hands & Voices Board of Directors (Susan, Vicki, Nick)
The EHDI Team

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