Iowa EHDI – A Work in Progress

Coordinating Council for Hearing Services
November 24, 2008
Prior to legislative mandate January 1, 2004:

- Newborn hearing screening was voluntary
- Inconsistent reporting
- No comprehensive surveillance system
- No way to track individual kids in a central location to ensure follow up
Screening and Reporting Progress

• Legislative mandate – universal newborn hearing screening & reporting
• Birthing hospitals trained to report hearing screens via eSP
• Area Education Agencies & private audiologists trained to report hearing screens & diagnostic assessments via eSP
• Backlog of hearing screens and diagnostic assessments entered into eSP
• Audiology technical assistance and loaner screening equipment available to decrease refer & miss rates
Referrals

- Where do potential referrals come from?
  - Hospitals
  - Parent
  - PCP/Medical Home
  - EHDI program
  - Provider

- What are the referrals for:
  - Re screens
  - Initial screening, if missed at hospital
  - Risk Factors
Percent of Iowa Children Receiving a Newborn Hearing Screen Prior to Discharge

Year

2005
2006
2007
Children who Missed a Hearing Screen at Birth

- 2005: 5%
- 2006: 3%
- 2007: 1%
Initial Newborn Hearing Screening Outcomes ~ 2007

- Passed
- Referred
- Missed
- Deceased
- Refused
Outpatient Screening Outcomes

- Screened
- Lost to follow up
- In Process
### Challenge – Children Lost to Follow Up

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3669</td>
<td>Children who <strong>need follow up</strong> following newborn hearing screen. (children that have referred, unilaterally or bilaterally on the newborn hearing screen or were missed on the newborn screen).</td>
</tr>
<tr>
<td>2889</td>
<td>Children <strong>available for follow-up</strong>. (excludes patients that have moved out of state, refused any further follow-up, have died, or that have been marked as lost contact).</td>
</tr>
<tr>
<td>2499</td>
<td>Children who <strong>returned for follow up</strong> hearing screen.</td>
</tr>
<tr>
<td>2275</td>
<td>Children who <strong>passed their follow up</strong> hearing screen in both ears (91%).</td>
</tr>
<tr>
<td>825</td>
<td>Total number of kids <strong>in process or lost contact</strong> (28%).</td>
</tr>
<tr>
<td>430</td>
<td>Children <strong>lost to follow up</strong> (efforts made to reach them individually or through Medical Home to get them back in, but unsuccessful).</td>
</tr>
<tr>
<td>395</td>
<td><strong>In Process</strong> (follow-up is not yet complete, in need of an appt., kids who were transferred and we are waiting on results from another state, or home births).</td>
</tr>
</tbody>
</table>
Audiological Assessment Outcomes

- Sensorineural
- Not Yet Determined
- Conductive
- Auditory Neuropathy
- Mixed
Celebrate Iowa Success
Screening and Reporting

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Referral/Follow-up

- Administrative Rule Change – Border baby
- Began referral/follow up – babies missed or who referred
- Family support program developed (GBYS)
- Border baby referrals – exchange of information
- Dissemination of high risk factor letters
Quality Assurance

• Surveyed families regarding their knowledge of newborn hearing screening before, during their stay, assistance with follow up

• Quality assurance measures put into place (i.e. data entry, merging duplicates, searching for deceased babies to avoid fup, accounting for all births)

• QA subcommittee formed (Best Practices Manual)

• Protocols revisited, updated, new ones written
Education

• Development of quarterly newsletter (Iowa EHDI News)
• Letter mailed to licensed audiologists reminding them of reporting requirement
• EHDI display created
• Development of new hearing screening brochure (English and Spanish) and communication guide for hospital personnel
• Web site overhaul
Funding

• Draft sustainability plan
• Developed funding program for children in need of hearing aids & audiological services
• Successful applicants for CDC and HRSA funding ~ 2008-2011
Where does EHDI go from here?
Screening and Reporting
Changing Law and Rules

• Bring Iowa rules into line with JCIH 2007 recommendations
• Improve our ability to do follow-up
• Standardize practices across state
Data System

- Improved audiology assessment section is being programmed now
- More systemic data system – better for tracking and follow-up past initial screening into early intervention
Data Integration

• Will happen over the long term
• We have a commitment from Information Management to look at integration that will avoid duplicate entry into multiple data bases with vital records being a main feed.
Referral and Follow-up
Reducing Loss to Follow-up Rate

• EHDI working with other providers to decrease number of kids lost before getting all the services they need
  – Early ACCESS
  – AEAs
  – Private practice providers
  – Hospital screening programs

• Working with other IDPH programs to find families
More AABR screening

• Joint Committee on Infant Hearing recommends AABR screening only for NICU babies
• Any baby who fails an AABR should be rescreened with AABR
• Identifies auditory neuropathy/dyssynchrony
Referrals for diagnosis and intervention

• Follow kids through diagnosis, early intervention and family support
  – Working on rescreens and risk factors now
  – New assessment section in eSP should help
  – Will require working closely with audiologists
Expanding Family Support

• Increase usage of Guide By Your Side
  – What can we do to make it more appealing to families and professionals?
  – Collecting data to support training
• Coordinate other family support groups
Quality Assurance
EHDI Best Practice Manual

• Based on JCIH 2007 Statement and Iowa EHDI protocols

• Written by subcommittee of EHDI Advisory representing
  - EHDI staff
  - AEAs
  - Iowa Department of Education
  - Private Practice Audiologists
Hospital Site Visits

• Will visit each hospital
• Look at strengths and areas for improvement
• Will discuss:
  – Compliance with EHDI law
  – Program quality
  – Best practices that could help other hospitals
  – Follow-up/reducing number of children lost to follow-up
  – Parent perspective
Program Evaluation

• Comprehensive evaluation of entire EHDI system
• Done by someone outside the system
• Use data to drive program decisions whenever possible
Education
AEA Visits

- Discussions with Early ACCESS Regional Liaisons, audiologists, itinerant teachers, anyone else who should be involved

- Discuss:
  - EHDI referrals for EA Pre-service Coordination
  - Follow-up process
  - Guide By Your Side
  - Other family support for families of children with hearing loss
Update Training

• Updates for:
  – New users
  – Current users

• eSP and EHDI program
• In some parts of the state, Amish families often refuse the newborn hearing screening
• Amish parents in focus groups stated that they didn’t have an objection to screening
• Will work with community leaders to determine best way to increase screening rates
Questions

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Thanks for all you have done and will do for Iowa children!