Kentucky’s Journey to Mandating Audiology Reporting and Reducing Loss to Follow-Up

Clinical and Augmentative Services Division
Commission for Children with Special Health Care Needs

Kentucky
UNBRIDLED SPIRIT
EHDI History in Kentucky

• **1986** HB 404—established the Hearing High Risk Registry—administered by CCSHCN

• **2000** HB 706—established Universal Newborn Hearing Screening Mandate—Part of KIDS NOW Early Childhood Initiative
  – Funded in part by Tobacco Settlement $$
  – Funded also by HRSA-MCHB and CDC grants
  – All hospitals with 40+ births per year
  – Established data collection and tracking guidelines

• **2009** HB 5—established mandatory reporting of audiology diagnostics for age 0-3
<table>
<thead>
<tr>
<th></th>
<th>Jul - Sep</th>
<th>Oct - Dec</th>
<th>Jan - Mar</th>
<th>Apr - Jun</th>
<th>YTD</th>
</tr>
</thead>
<tbody>
<tr>
<td># referred on all risk factors (including not tested)</td>
<td>2191</td>
<td>1965</td>
<td>1721</td>
<td>1788</td>
<td>7665</td>
</tr>
<tr>
<td># not tested</td>
<td>58</td>
<td>54</td>
<td>61</td>
<td>51</td>
<td>224</td>
</tr>
<tr>
<td># of infants screened</td>
<td>2133</td>
<td>1911</td>
<td>1660</td>
<td>1737</td>
<td>7441</td>
</tr>
<tr>
<td># referred on one or both ears</td>
<td>726</td>
<td>604</td>
<td>500</td>
<td>524</td>
<td>2354</td>
</tr>
<tr>
<td># receiving follow-up testing*</td>
<td>1256</td>
<td>1288</td>
<td>1330</td>
<td>1221</td>
<td>5095</td>
</tr>
<tr>
<td># of follow-up tests reported**</td>
<td>621</td>
<td>647</td>
<td>623</td>
<td>602</td>
<td>2493</td>
</tr>
<tr>
<td># identified with permanent childhood hearing loss</td>
<td>4</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>16</td>
</tr>
<tr>
<td>(Born, Screened and Identified with PCHL in Qtr)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Total entered into the EHDI database during this period, not all tested during this period

**Total reported to EHDI during this period
House Bill 5

Voluntary Mandatory Audiology Reporting
Anne Swinford, Director of Clinical and Augmentative Services, CCSHCN
Two things you never want to see being made:

1. Sausage
2. Legislation!!!!!

HB 5 was a perfect example of that
<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>7/08</td>
<td>EHDI Advisory Board recommends mandated follow up reporting</td>
</tr>
<tr>
<td>8 &amp; 9/08</td>
<td>Kisler &amp; Swinford draft a legislative proposal</td>
</tr>
<tr>
<td>10/08</td>
<td>Swinford presents to CHFS Cabinet Secretary Miller – becomes a Cabinet signature proposal; sent to Governor</td>
</tr>
<tr>
<td>12/08</td>
<td>Proposed EHDI legislation is selected as a part of the Governor’s legislative package</td>
</tr>
<tr>
<td>12/08</td>
<td>Decision to have companion bills House &amp; Senate - sponsors arranged</td>
</tr>
<tr>
<td>1/6/09</td>
<td>Session begins: HB 5 introduced</td>
</tr>
<tr>
<td>1/8</td>
<td>HB 5 to (H) Health &amp; Welfare Committee</td>
</tr>
<tr>
<td>2/5</td>
<td>Kisler &amp; Swinford testify at (H) Health &amp; Welfare; bill passes &amp; sent to full House</td>
</tr>
<tr>
<td>2/12</td>
<td>HB 5 passes 98 – 0 in House</td>
</tr>
<tr>
<td>2/13</td>
<td>HB 5 sent to Senate; SB 160 introduced in Senate and sent to (S) H &amp; W</td>
</tr>
<tr>
<td>2/23</td>
<td>HB 5 sent to (S) Health &amp; Welfare</td>
</tr>
<tr>
<td>3/3</td>
<td>SB 160 – Kisler &amp; Swinford testify in (S) H &amp; W – problems with wording</td>
</tr>
<tr>
<td>3/6</td>
<td>SB 160 passes Health &amp; Welfare and goes to full Senate</td>
</tr>
</tbody>
</table>

Cabinet for Health and Family Services
Time Line continues…

3/10    HB 5 passes (S) Health & Welfare
3/10    SB 160 passes Senate 38 – 0; sent to House
3/11    SB 160 sent to (H) Health & Welfare
3/12    SB 160 passes (H) Health & Welfare – sent to Rules – where it sits….
3/13    HB 5 posted in Senate “Consent Orders for the Day”; but then removed to “Regular Orders”
3/14-25  NO action on either bill – Politics all over the place!
3/26    LAST DAY OF THE SESSION
        with help from our Partners in the KY Commission for Deaf & Hard of Hearing; &
        a "white knight-Senator"    HB – 5 sent back to (S) Health & Welfare
        (we agree to make wording changes that were in SB 160 in next legislative session)
        HB 5 passes (S) H & W; goes to (S) Rules; then to (S) Regular Orders of the Day
5 pm 3/26 – HB 5 passes the Senate  36 – 0; then sent to House; both House & Senate
leaders sign off and deliver it to the Governor

3/27  HB 5 Signed by the Governor !!!!

Next Step:  REGULATIONS
Regulations for Implementation of HB 5

N. Carolyn Kisler, Audiology-EHDI Branch Manager, CCSHCN
The Development and Pathway

- Regulations with forms internal review
- Regulations External Reviews
- Regulations to Frankfort
- Meeting with A.RRS Committee Chair and full committee accepted and sent to Joint Health and Welfare Committee for December Meeting.
- Final Approval with implementation date of 1/4/2010

Cabinet for Health and Family Services
Regulations for HB 5

• Regulate (transitive verb)
  – To control or direct according to rule, principle, or law.
  – To adjust to a particular specification or requirement.
  – To adjust for accurate and proper functioning.
  – To put or maintain in order.

• Regulations do not repeat the Statute.

• Regulations define and direct the how to meet the requirements of the Statute.
911 KAR 1:085. Early Hearing Detection and Intervention Program

- Established 2 Levels of Approved Infant Audiology Assessment Centers
- Established Application Process
- Established Guidelines for Publication of Approved List
- Established Process for Removal from the list
- Established Guidelines for Center Updates
- Established Reporting Requirements
- Established Appeal Rights

Cabinet for Health and Family Services
Core Elements for Both Level 1 and Level 2 Centers

- Employ at least one (1) audiologist who:
  - Is currently licensed in Kentucky
  - Has experience testing children in the age range newborn to three (3) years; and
  - Performs all evaluations; or
  - Directly supervises audiology externs performing evaluations;

- Annually calibrate all measuring and testing equipment; and

- Submit a complete application and assurance packet in accordance with Section 3 of this administrative regulation

Cabinet for Health and Family Services
Level 1 Centers

- Possess the capacity to complete the following tests:
  - Otoscopy
  - Tympanometry;
  - Ipsilateral acoustic reflex measurement;
  - Contralateral acoustic reflex measurement;
  - Ear-specific behavioral observation audiometry;
  - Speech awareness threshold;
  - Speech recognition or reception threshold;
  - Play audiometry; and
  - Either: Otoacoustic emissions with diagnostic or screening capabilities; or ABR screening with threshold information;
Level 2 Centers

Meet all the requirements of Level 1 Center and Possess the capacity to complete:

- Otoacoustic emissions with diagnostic or screening capabilities;
- Frequency-specific ABR
- Bone conduction ABR; and
- Real ear measures.
Approved Infant Audiology Assessment Centers in Kentucky as of 2-18-10

- **Level 1 Centers**
  - 10 Private Centers
  - 3 CCSHCN
  - (Title V) Centers

- **Level 2 Centers**
  - 11 Private Centers
  - 9 CCSHCN (Title V) Centers

Cabinet for Health and Family Services
Potential Infant Audiological Assessment & Diagnostic Center Questionnaire

Applicant Agency Information

<table>
<thead>
<tr>
<th>Date: ___</th>
<th>Applicant Agency Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency Name:</td>
<td></td>
</tr>
<tr>
<td>Authorized Contact:</td>
<td></td>
</tr>
<tr>
<td>Title:</td>
<td></td>
</tr>
<tr>
<td>Email Address:</td>
<td></td>
</tr>
<tr>
<td>Agency Physical Address:</td>
<td></td>
</tr>
<tr>
<td>City:</td>
<td>State:</td>
</tr>
<tr>
<td>Making Address of different?</td>
<td>Yes</td>
</tr>
<tr>
<td>Agency Phone:</td>
<td>Toll-Free</td>
</tr>
<tr>
<td>Medicaid Approved Provider?</td>
<td>Yes</td>
</tr>
<tr>
<td>First Step Provider?</td>
<td>Yes</td>
</tr>
<tr>
<td>Approval Level Requested</td>
<td>Level 1</td>
</tr>
</tbody>
</table>

Population Served

- Please check all age ranges for whom your agency provides diagnostic audiology services.
- Birth to 3 months
- 3 to 6 months
- 6 to 9 months
- 9 to 12 months
- 12 to 24 months
- 24 to 36 months
- Over 36 months
- None of the above

Audiological Services Provided

- Please check all services that your facility provides for infants & toddlers.
- Inotmance Measures (Tympanometry & Acoustic Reflex Thresholds)
  - 250 Hz
  - 1000 Hz
  - Multi-Frequency

- Otoacoustic Emissions
  - Discriminant
  - Transient Evoked

- Behavioral Testing
  - Visual Reinforcement Auditory
  - Combined Play Auditory

- Auditory Brainstem Response
  - Screening only (AABR)
  - Bone Conduction Click Threshold
  - Frequency-specific

- Intervention Services
  - Amplification selection & fitting
  - Speech-language pathology
  - Auditory habilitation
  - Amplification verification: probe microphone

- Medical: primary care physician
- Social services or counseling

- Sedation
  - Is sedation available at your facility? Yes No

- At what age does your current policy & procedure recommend sedation for AABR?
  - Birth to 3 months
  - 3 to 6 months
  - 6 to 9 months
  - 9 to 12 months
  - 12 to 24 months
  - 24 to 36 months
  - Over 36 months
  - None

*Continued on reverse*

Cabinet for Health and Family Services
Convergence: Funding, Legislation, Technology, and Programming

FUNDING

HB 5

Reduction of Loss to Follow-up

KYCHILD

REGULATIONS AND IMPLEMENTATION

Cabinet for Health and Family Services
KYCHILD

Electronic Data Submission

N. Carolyn Kisler, Audiology-EHDI Branch Manager,
CCSHCN
Audiology Reporting KYCHILD

- Web based submission of audiologic diagnostics
- Password protected—Passwords issued to individual audiologists not to centers.
- Data transferred from KYCHILD to Platform
- Downloaded from Platform to CUP—KY EHDI database
- On site Training provided to all approved centers by EHDI staff
Accomplishments and Targets

HB 706 2000

KYCHILD 2007

2009 99% Screened before 1 month

HB 5 2009

KYCHILD 2010

Regs 2010

75% before 6 months 2012
85% before 3 months 2010

KYCHILD EI 2011

Cabinet for Health and Family Services
1. Don’t reinvent the wheel
2. Cover all of your bases
3. Never give up
4. Be thankful for helpful friends & help others
5. Reap rewards & Celebrate success