Attitudes, Knowledge and Practices of Physicians Related to EHDI

Karl White, Ph.D.
Utah State University

Mary Pat Moeller, Ph.D.
Boys Town National Research Hospital

Lenore Shisler, M.S.
Utah State University
Project with Pediatricians

- Pilot Focus Groups (N = 21)
- Formal Focus Group Work (N=27)
- Internet Based Survey (N=263); Paper Survey (N = 1,968)
- Resource Development
  - Field test, revise & disseminate

NIDCD & MCHB supported
Methods

- Designed survey based on focus groups and internet responses
- Field tested survey at medical society meetings; developed Spanish version
- Invited state EHDI coordinators to participate
- Mailed survey & cover letter; reminder postcard 2 weeks later
Survey Question Examples

- **Attitudes:**
  - Do you think NHS causes parents undue anxiety or concern?
  - Do you believe UNHS is worth what it costs?
  - Please list any concerns you have about NHS, diagnosis and intervention.
Survey Questions Examples

- Practices:
  - Approximately how many children with permanent hearing loss (EXCLUDING OTITIS MEDIA) have you had in your practice over the past 3 years?
  - List any specialists to whom you routinely refer the family of a child with permanent hearing loss (list the types of specialists).
Survey Question Examples

Knowledge:

- What is your best estimate of the earliest age at which:
  - A child not passing the screening should be seen for follow up testing
  - A child can be definitively diagnosed with permanent hearing loss
  - A child can begin wearing hearing aids
  - A child with permanent hearing loss should be referred to early intervention

- Enter age estimates _________________
States Involved in Survey of Physicians

N = 21 States + Puerto Rico
Physician Survey: Demographics

Gender:
- 53.2% Male
- 46.8% Female

Location:
- 62.5% Metro
- 24.1% Small town
- 13.3% Rural

Moeller, White & Shisler, 2006
<table>
<thead>
<tr>
<th>Practice Settings</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private/Community Clinic</td>
<td>75.6%</td>
</tr>
<tr>
<td>Hospital</td>
<td>10.4%</td>
</tr>
<tr>
<td>Medical School/University</td>
<td>5.8%</td>
</tr>
<tr>
<td>Other</td>
<td>3.6%</td>
</tr>
<tr>
<td>Unknown</td>
<td>3.7%</td>
</tr>
</tbody>
</table>
Practice with 0-5 Population

- 0-10 years = 40.2%
- 11-20 years = 28.6%
- 21-30 years = 22.5%
- 31+ years = 8.7%
Children with SNHL in past three years of practice

- National: 3.13
- Pediatricians: 3.32
- Family Practice: 1.25

ENT X = 16.95
Importance of testing all newborns

- 3% Pediatricians;
- 6% Family Practice
- $p < .001$

Very Imp
Somewhat
Unsure
Not Imp
Very Unimp

Percent Respondents

4.4%
Does NHS cause undue parental anxiety?
Positive Findings:

- Most of our physicians receive screening results (88.61% >)
- But…12% of pediatricians and 17% of family physicians receive < 50% of results!
- Most know that infants should be referred immediately for additional testing (89.2 < 3 mos >)
- But…24.3% unsure NHS is worth what it costs
Concerns about NHS

- Too many false positives
- Costs outweigh benefits
- Loss to follow up
- Need for training
- Unclear about procedures; complex
- Inconclusive results
- Need for parent education
- Need for funding & better equipment
Confidence in Counseling
Parents following Screening

Level of Confidence

Percent Respondents

Very

Somewhat

Unsure

Not

11%
Risk for late onset SNHL

Percent Respondents

Risk Factor

- Menigitis*
- NICU*
- Cleft Palate*
- CMV*
- Syphilis*
- Family*
- Mom >40
- Heart
- Colds
- Hypotonia

* denotes significant correlation with late onset SNHL.
Referral to Specialists

The graph shows the percent of respondents consulting different specialists. The highest referral is for ENT specialists, with 80% of respondents consulting them. The lowest referral is for specialists in Genetics and Eye, with 9.7% of respondents consulting Genetics specialists. Other specialists consulted include Audiology, EI, Neuro, OT, and Genetics, with varying percentages.
## Ages at which....(1-3-6?)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>&lt;1</th>
<th>1-3</th>
<th>3-6</th>
<th>6-9</th>
<th>9+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing Aids</td>
<td>51.9</td>
<td>10.8</td>
<td>12.4</td>
<td>15.4</td>
<td>9.6</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>38.1</td>
<td>9.1</td>
<td>11.2</td>
<td>22.3</td>
<td>19.3</td>
</tr>
<tr>
<td></td>
<td>61.6</td>
<td>8.0</td>
<td>9.8</td>
<td>13.2</td>
<td>7.4</td>
</tr>
</tbody>
</table>
Candidates for Cochlear Implants

![Bar Chart]

- Bi Profound: 74.3%
- Bi Mild-Mod: 15.5%
- Uni Mild-Mod: 5.9%
- Unsure: 27.1%

Hearing Loss Category

Percent Respondents 100  80  60  40  20  0

Bi Profound* Bi Mild-Mod Uni Mild-Mod Unsure

48.5
Confidence in Talking with Parents about…

![Graph showing confidence levels for different topic areas]
Did your training prepare you?

![Bar chart showing the percent of respondents for 'Yes,' 'No,' and 'Unsure' categories for the total group, pediatricians, and family practice categories.]

- Yes: Total Group, Pediatricians, Family Practice
- No: Total Group, Pediatricians, Family Practice
- Unsure: Total Group, Pediatricians, Family Practice
Primary Sources of Info on NHS

Frequent Internet Use = 51.7%
<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAP</td>
<td>56.8%</td>
</tr>
<tr>
<td>AAO</td>
<td>1.9%</td>
</tr>
<tr>
<td>AAFP</td>
<td>6.6%</td>
</tr>
<tr>
<td>State</td>
<td>1.1%</td>
</tr>
<tr>
<td>AMA</td>
<td>0.3%</td>
</tr>
<tr>
<td>CDC</td>
<td>0.5%</td>
</tr>
<tr>
<td>USPSTF</td>
<td>0.7%</td>
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Continuing Medical Education: Most Successful Methods

- Learning linked to clinical practice (including tests of knowledge & evaluation of clinical practice needs)
- Educational meetings with interactive components
- Outreach events
- Use of multiple interventions (e.g., Outreach + reminders; Grand rounds with case study discussion + reminders)

Davis, et al, 1995; Davis & Maxmanian, 2002
Topics Judged as Needs (In prioritized order):

1. Protocol for f/u
2. Early intervention
3. Contacts for more information
4. Screening for late onset SNHL
5. Patient Education Resources
6. Impact of HL on language
7. Screening at well-child visits
8. Hearing Aids and cochlear implants
9. Genetics and hearing loss
10. Counseling families about screening results
11. Screening methods
<table>
<thead>
<tr>
<th>Question</th>
<th>National n=1,981 (16.1%)</th>
<th>MN n=153 (24%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn Hearing Screening is very important</td>
<td>81.7%</td>
<td>78.4%</td>
</tr>
<tr>
<td>Newborn hearing screening causes excessive parent anxiety</td>
<td>8.4%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Universal newborn hearing screening is worth what it costs.</td>
<td>75.7%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Very confident in explaining results of newborn hearing screening to parents with questions</td>
<td>48.0%</td>
<td>53.6%</td>
</tr>
<tr>
<td>The earliest age you can fit a child with hearing aids is 3 months or older</td>
<td>52.7%</td>
<td>48.3</td>
</tr>
<tr>
<td>Percent who would refer a child with a permanent hearing loss to a geneticist</td>
<td>8.8%</td>
<td>13.1%</td>
</tr>
<tr>
<td>Percent who frequently use internet to access information about medical topics</td>
<td>51.7%</td>
<td>51.0%</td>
</tr>
<tr>
<td>Feel that training was adequate to deal with needs of infants with permanent hearing loss</td>
<td>18.0%</td>
<td>20.9%</td>
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<tr>
<td>Percentage of respondents who are pediatricians</td>
<td>60.3%</td>
<td>83.7%</td>
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Positive changes seen, but more education is needed

“One size” will not fit all; multiple strategies are needed

“Just in time” resources; protocol steps

Action-oriented resources focused on medical management, family counseling

Many topics “needed” but at a manageable level

Additional resources (e.g., peer education and internet) needed
Other Important Health Care Providers

- Pediatric Nurse Practitioners
- Nurses
- Midwives
- Physician Assistants
- OB/GYNs
Focus Group Themes:

- Limited experience with confirmed hearing loss in infants
- Considerable experience with babies who pass second screening (some “complacency” about “refers” in talking with families)
- Reporting barriers: “Most often we are under the assumption – which is a bad assumption – that if they were not told anything, then it was a pass.”
- Improved monitoring (WIC form, Immunization visits, checklist)
- Increase public awareness
Focus Group Themes

- Audiences that need to learn with us:
  - The Public!
  - Specialists: OB, ENT, Prenatal Class Teachers
  - Parents
  - Day Care Workers
  - School Nurses
  - Newborn Nursery Workers
  - Office Staff
Information Wanted vs. Received by Parents When Hearing Loss is Diagnosed

- Degree of loss
- Auditory system
- Amplification
- Educational options
- Speech/Lang dev
- Etiology
- Home activities
- *Written Information
- *Financial Support
- *Emotional Support
- *Parent Contacts
- *Referral Sources

Martin, George, O'Neal, & Daly (1987); *Sweetow & Barrager (1980)
### Parent’s Attitudes About Newborn Hearing Screening

**After all hearing tests were completed, how did you feel?**

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<tr>
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<td>Confident about what I needed to do next</td>
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Hearing needs are going unheard for kids in Utah

By Amy Joi Bryson  
Deseret Morning News

PLEASANT GROVE — Two years ago, Norm and Taunya Paxton discovered silence had crept into their home — a silence that would forever change their life: They learned their middle child, Chance, was profoundly deaf.

"It's like being thrown into the deep end of the pool and not knowing how to swim," Norm Paxton said.

The discovery left the couple flailing in their efforts to confront the mixed messages they received from doctors, the lack of coordinated support from hearing advocacy groups and, what they say is the surprising indifference of the insurance industry.

"There's absolutely no guidance," said Taunya Paxton. "It was worse than shooting in the dark."

Beyond coping with the new-found disability, the Paxtons were shocked to find hearing aids are not covered by most private health care plans and are largely priced as if they were best left to parents of the more wealthy. That can be problematic when the devices regularly run into the thousands of dollars.

"Part of the industry's denial process is to keep kids in the dark," says Rich Harward, the state's coordinator for the Speech and Hearing Association of Utah. "Most plans pay for eyeglasses. Very few pay for hearing aids.

"Most plans pay for eyeglasses; very few pay for hearing aids," he said. There are some out there who have helped, she said.

The Paxtons, covered under Internationals Health Care (IHC), appealed, having been told by IHC officials early this year it would be "irresponsible" for them to modify their plan to include coverage.

"There's absolutely no guidance. It was worse than shooting in the dark."
"There is not an awareness out there. Another parent is going to find out their child is deaf and say, 'Thank goodness I have insurance' and they will find it isn't so. They will go through the same battle we have."

"The market is so incredibly price sensitive, we are being told to take away benefits rather than add them," said Kevin Bischoff, vice president of public and corporate affairs of Regence BlueCross BlueShield.

8 states require hearing aid assistance for kids
Utah group hopes to get insurance firms to help

By Amy Joi Bryson
Deseret Morning News
Where Families Find Support

**Family**

**Professionals**
- Family Friends
- Neighborhood Places of Worship

**Existing Communities**

**Parent-to-Parent**

**Information**
- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

**Formal Parent Support Groups**
- Deaf Specific
- General Disability
- Informal Parent Support

**Deaf/Hard of Hearing Adults**

**Deaf Specific**

**General Disability**

**Existing Communities**

**Parents**

- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/Physician
- Speech/Language Pathologists
- Hospital Staff
- Communication Instructor/Specialist

**Mentors**

**Role Models**

**Family Friends**

**Neighborhood Places of Worship**