Opening Doors: Collaborating to Develop Family Friendly Resources

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Commission for Children with Special Health Care Needs

LINCOLN TRAIL DISTRICT
HEALTH DEPARTMENT

EVERY CHILD
PROFICIENT & PREPARED FOR SUCCESS
Kentucky Department of Education
Problem Identified

Lack of consistent family-friendly resources for families with children newly diagnosed with hearing loss
The Light Bulb Moment

• 2007 EHDI Conference
  – EHDI 2007 Session attended by both Fran Hardin and Eric Cahill
  – Understanding Hearing Loss…A Resource Kit for Parents and Professionals
    • Oakland Schools, Waterford, MI
Six Questions to Consider

- Is the layout user-friendly?
- Do the illustrations convey the message?
- Is the message clear?
- Is the information manageable?
- Does the [media] make the reader feel “this information is meant for me?”
- Is the reading grade level less than 9th grade? Is the pamphlet easy to read?

-from the NCHAM Newborn Screening Toolkit CD
Getting Started

- **Focus Group**
  - Early Intervention Providers (First Steps)
  - Kentucky School for the Deaf
  - Health Department
  - EHDI Program
  - Parents
  - Teachers
  - Interpreters

- **Examples from other states**
  - Parent Information Kit, MA
  - KEY Handbook, KY
  - Kosair Children’s Hospital, KY
  - Oakland Schools, MI
    - Including video and CD
  - Infant Hearing Guide, AR
  - CCSHCN Resource Binder
What will work for Kentucky?
Stakeholder’s Suggestions

- Family Friendly
- Following the Michigan example
- Keep it simple
- Keep it short
- Include additional resources in another format if possible (i.e. CD or Video)
We went to work

• Our overall message
  – Beginning the journey
  – Providing a starting point
  – Not overwhelming

• Plans for distribution
  – At point of diagnosis, via Diagnostic Audiologists
  – via KSD Outreach
  – via EHDI Program
Funding

• Initially: MCHB HRSA “Building Community Capacity Grant”
  – Reasons identified in LTDHD BCC Committee to use grant monies for project
    • Lack of consistent educational materials in KY
    • Grant required statewide outreach efforts in 3rd year

• Future funding ideas
Lessons Learned

- Don’t reinvent the wheel
- Obtain permission for photographs
- State/Agency guidelines for publications
- Time
- Cost
Take Home Points

- Consistent message
- Collaboration is vital
- Don’t have to reinvent the wheel
- Have Patience!
- Creative Funding Ideas
Special Thanks…

- **Oakland Schools**
  - Waterford, MI

- **The University of Arkansas for Medical Sciences**
  - Little Rock, AR