

Hear from the Start, Talk for a Lifetime
Early Intervention Assessment

AG Bell currently is gathering information from state chapters to gain a comprehensive understanding of the roles of their states' healthcare and early intervention systems in educating families of newborns that children with hearing loss can learn to listen and talk. While we are launching this questionnaire for the first time in 2006, AG Bell proposes that chapters gather and evaluate data each year to measure each state's progress in serving families of children with hearing loss who choose spoken language.

This information will be useful on several levels:

- Initially, to inform the planning and implementation of *Hear from the Start, Talk for a Lifetime*, a multi-year education and awareness campaign designed to help parents of children with hearing loss and the professionals who serve them get the facts about spoken language.
- Specifically, we plan to use this information to help determine which states will serve as the first phase of the campaign's implementation at the grassroots level.
- Ultimately, an annual "audit" also will be useful at the state and national levels to raise awareness of the link between early childhood hearing health and language and social development.

Our goal is to collect information that will help identify areas where we can help shape positive developments at the state level.

Snapshot of the Type of Information to Collect

Below is a general overview of the type of state-level information we are seeking, but please use the detailed questions beginning on the following page when collecting your data.

- Annual percentage of newborns screened for hearing loss.
- Percentage of birthing centers with comprehensive systems for referring newborns to screening.
- Percentage of children diagnosed with hearing loss before age 3.
- If possible, the percent decrease in the median age children are diagnosed with hearing loss.
- Percentage of hospitals and birthing centers that provide families with written material about audiological follow-up for children who fail the screening.
- Percentage of hospitals, birthing centers and audiology/speech-language pathology clinics that provide families with written material about the complete range of communication options for children who fail the screening.
- Percentage of early intervention agencies (Part C) giving families written material that includes information about hearing technology and spoken language.
- If possible, the percent increase in children from birth to age three with hearing aids or cochlear implants.
- Existence of state deaf education guidelines that cover all communication options, including spoken language.

Questionnaire Instructions

Chapter responses to the following questions will be reviewed for accuracy and comprehensiveness. We ask that you submit the information to us by **August 30, 2006**.

- To supplement the data you provide, please obtain copies of official reports and/or data collection results where available.
- Please provide contact information for champions and key stakeholders where noted.

Potential Data Sources to Consult

- Annie E. Casey Foundation KIDS COUNT Program – www.kidscount.org
- Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities – www.cdc.gov
- National Center for Hearing Assessment and Management – www.infanthearing.org
- National Governors Association – www.nga.org
- United States Department of Education – www.ed.gov
- United States Department of Health and Human Services – www.dhhs.gov

Assessment Deadline

Chapters that complete their assessments by August 30, 2006, and are chosen for the pilot group for the *Hear from the Start, Talk for a Lifetime* campaign will earn a \$1,000 stipend for their chapter treasury, payable by October 30, 2006.

Early Intervention Questionnaire

Government

- List by name the state and local legislators who are recognized as champions of pediatric healthcare.
- List by name the state and local legislators who are recognized as champions of education rights.
- List by name the state and local legislators who are recognized as champions of children with disabilities.
- List by name the state and local legislators who your chapter has been in direct contact with during the last year regarding these issues. (Explain why.)
- Provide as much detail as possible on specific legislation that has been passed in the last year relating to the above issues (including the title of the legislation, its proponents and a sentence explaining the bill’s relevance).

Healthcare

- Is Universal Newborn Hearing Screening in your state mandatory or voluntary? What is your state’s standard/requirements for newborn screening in your state?
- Who are the key stakeholders in Universal Newborn Hearing Screening/Early Hearing Detection and Intervention in your state? (Consider the roles of the EHDI task

- force/advisory committee, physicians, parents, schools for the deaf, etc.)
- How many newborns are screened for hearing loss in your state each year? What percentage is this? (Obtain data from your state EHDI system.)
 - If historical data are available, how does this percentage compare to five years ago? Two years ago?
 - Provide a list of the hospitals and birthing centers that offer maternity services in your state. (Obtain contact information and, where possible, statistical data from your state EHDI system or other state agency.)
 - How many and what percentage of those facilities perform newborn hearing screenings?
 - How are hospitals and birthing centers without newborn hearing screening programs referring families for screening?
 - How many and what percentage of those facilities provide parents with written resource materials about the importance of audiological follow-up for children who fail the screening? (Provide samples of materials.)
 - How many and what percentage of those facilities provide parents with written resource materials about the complete range of communication options for children who fail the screening? (Provide samples of materials.)
 - Provide a list of audiology/speech-language pathology clinics in your state.
 - How many and what percentage of those facilities provide written resource materials about the complete range of communication options to families of children diagnosed with hearing loss? (Provide samples of materials.)
 - How many children are diagnosed as deaf or hard of hearing in your state each year? What percentage is this? (Obtain data from your state EHDI system.)
 - How many children are diagnosed at age three or younger? What percentage of all children in your state diagnosed with hearing loss is this?
 - How many children are diagnosed after age three? What percentage of all children in your state diagnosed with hearing loss is this?
 - What is the median age at diagnosis? If historical data are available, how does the median age at diagnosis today compare to five years ago? Two years ago?
 - Provide a list of hearing aid distributors in your state. How many and what percentage of new pediatric patients ages three and younger do they serve annually?
 - Provide a list of cochlear implant centers in your state. How many and what percentage of pediatric implantations for children ages three and younger do they perform annually?

Early Intervention

- Who is the lead agency for the *Individuals with Disabilities Education Act (IDEA)*, Part C, Infants & Toddlers?
 - Department of Health
 - Department of Education
 - Other _____
- Who are the key stakeholders in *IDEA*, Part C, Infants & Toddlers, in your state?

- How are children referred from newborn hearing screening/identification to Part C early intervention services?
- Provide a list of early intervention agencies (public and private) responsible for early intervention services. Please include a list of public and private agencies that provide service coordination. (Obtain contact information from your Part C lead agency.)
 - How many and what percentage of those facilities provide parents with written resource materials about the importance of audiological follow-up for children who fail the screening? (Provide samples of materials.)
 - How many and what percentage of those facilities provide parents with written resource materials about the complete range of communication options for children who fail the screening or are diagnosed with hearing loss? (Provide samples of materials.)
- How many and what percentage of children ages 3 and younger are categorized as deaf or hard of hearing? (Obtain data from your Part C lead agency.)
- Who are the key stakeholders in deaf education?
- What are your state's deaf-education guidelines regarding communication options, including spoken language? (Provide samples of these guidelines.)
- Who are these guidelines distributed to and who do they govern – pediatricians? Audiologists? Early interventionists? Others?

Parent and Consumer Groups

- Which professional and consumer organizations are known advocates for pediatric healthcare in your state (e.g., state chapters of the American Academy of Audiology, American Speech-Language-Hearing Association and American Academy of Pediatrics)?
- Which parent and consumer groups are known advocates for education rights and children with disabilities (e.g., Parent Information Centers, Protection & Advocacy Groups, deaf advocacy groups)?
- List by name the professional and parent organizations that your chapter has had direct contact with during the last year. (Explain why.)