

In September 2002, the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) initiated a legislative outreach program to establish educational policies that incorporate auditory learning and spoken language options for children with hearing loss and their families through an early intervention Best Practice Model. The following spring, AG Bell developed five “best practice” criteria based on data collected from 10 states on the types of information parents receive about communication options and how the information is delivered.

Goal

To increase awareness of auditory learning and spoken language options and education by ensuring that parents receive unbiased information about all available communication options when a child is diagnosed with a hearing loss.

Method

Individuals in 10 states - California, Maryland, Massachusetts, Nevada, New York, North Carolina, Ohio, Pennsylvania, Rhode Island and Utah - participated in an interview to determine present practices for disseminating information to parents about communication options. Participating states were selected based on the presence of a local AG Bell chapter and their receptiveness to the issue.

Data collection focused on survey questions presented to private practitioners and state and agency representatives, including early intervention program managers, service coordinators, program coordinators of Early Hearing and Detection Intervention Programs, parent outreach specialists and educators, audiologists and special education personnel. Interviewees answered questions regarding bias in materials and information presented to families, the process of referral from diagnosis of a child’s hearing loss to early intervention services, and recommended state models to improve service delivery to families and children.

The information gathered from the survey identifies criteria for a Best Practice State Model.

Supporting Information

The *Individuals with Disabilities Education Act*, 20 USC §1431-§1445, Infants and Toddlers with Disabilities, Part C, provides support for the criteria identified in a Best Practice Model. The legislation encourages states to develop and provide comprehensive, coordinated and multidisciplinary systems of early intervention services with an emphasis on interagency collaboration.

The legislation also intends to enhance each state’s capacity to expand and improve existing early intervention services provided to infants and toddlers with disabilities. The family-centered service delivery model inherent in early intervention practice recognizes and values the family’s vital role as caregiver and decision-maker when identifying family strengths, resources and priorities and when determining services for their child.

Further, the legislation provides that each family have access to a service coordinator who promotes the family’s confidence and competence to make informed decisions and assist the family in accessing resources and services. State models of service coordination emphasize training to ensure that service coordinators attain competencies in working with families. Recommended competencies include the ability to share complete and unbiased information with families and to gain knowledge of service providers and their specialties to increase options for children and families in the early intervention system.



Discussion of Best Practice Model Criteria

The best practice model includes five criteria, which were based on the data gathered on the status of early intervention services in the 10 states that were surveyed.

1. Parent(s) who have children identified with hearing loss must receive a printed, standardized resource manual that includes clear, objective, explanatory information on each communication option:
 - a. Auditory-Verbal (Unisensory),
 - b. Oral or Auditory/Oral,
 - c. Bilingual/Bicultural (ASL/ESL),
 - d. Cued Speech, and
 - e. Total Communication

Rationale: Parents must receive information about communication options in a standardized format in order to make informed choices and decisions regarding their child’s intervention and education.

Status: There is a wide disparity in information and materials provided to parent(s) when children are identified with a hearing loss.

- Materials given to parents can be specific to a particular communication option endorsed by a program or linked to a particular curriculum utilized by a program.
- Materials can be gathered from one or many different agencies like the Alexander Graham Bell Association for the Deaf and Hard of Hearing, Oticon, Inc., or the National Association of the Deaf.
- A regional provider of services publishes a resource guide; however, it is not distributed statewide to all regions.
- Options can be verbally explained to parent(s) without any follow-up written materials or resources.

- Providers of audiological or hearing services use their own discretion when providing materials to parents.
2. Parent(s) must receive a standardized, printed resource manual from a state-designated representative trained to present the information on communication options in an unbiased and impartial manner.

Rationale: In order to make informed knowledgeable choices about a child’s education and intervention, a parent(s) must receive information about communication options in an impartial and unbiased manner.

Status: Numerous individuals from public health departments, educational agencies, non-profit agencies, private industry and multi-agency state systems present information to parents on communication options. In most states, no specific entity or one professional is designated to provide information to the family. The family is in contact with multiple persons across agency systems.

- A person may be from a specific auditory/oral or ASL program or from an agency that promotes a specific curriculum.
- A parent’s initial contact after the child’s confirmation of a diagnosis can range from pediatricians, to parent educators, audiologists, service coordinators, special educators, parent educators or outreach consultants.

3. Designated representatives who provide information to parent(s) must participate in annual trainings and workshops to develop knowledge of all communication options and topics relating to hearing loss.

Rationale: Educated and knowledgeable representative personnel can provide information in an unbiased and impartial manner.

Status: Service providers and persons initially in contact with families do not have extensive backgrounds or knowledge on all hearing loss topics or number of communication options available. Practitioners in the field who have experience and background in a single communication mode deliver information; information on educational options can be influenced by the availability of that option in a particular location of the state.

- Several individuals who were interviewed stressed that trainings on topics related to hearing loss and communication options provides the tool to educate personnel to present information in an impartial and unbiased manner.
- Trainings dedicated to information about all communication options and hearing loss topics are being initiated or ongoing.
- Several trainings are tied to specific curriculums utilized by state programs.

4. Interagency agreements, state guidelines and task force committees will provide the mechanism by which parent(s) and children receive cooperative visits and information sharing between early intervention providers, early hearing and detection programs and non-profit agencies providing services to children with hearing loss.

Rationale: A state system that provides collaboration and planning between Early

Hearing and Detection Intervention Programs (EHDI), Part C, Infants and Toddlers administration, universal newborn hearing screening, tracking and follow-up procedures and providers of hearing services allows for improved coordination of information and service provisions to families.

Status: Interviewees stressed that collaborative efforts, interagency team approaches and joint visits between parent educators, service coordinators and direct providers of hearing services with families allow for information and services to be provided more efficiently.

- Many states have located both universal newborn hearing screening programs and early intervention programs in one state agency division.
- One state has plans to move both administrative systems into the same state division in the future.
- One state provides interagency agreements between the direct service provider, school for the deaf, state early intervention agencies and the department of health.
- One state has initiated a state task force to address issues of newborn hearing screening, follow-up tracking, diagnosis and referral to early intervention programs.
- One state's public law mandates referral to early intervention officials when certain circumstances occur under follow-up screening and tracking initiatives.

5. Criteria are mandated to be provided in each state as a Best Practice Model.

Rationale: Mandating a model which includes each of the four criteria would provide assurances that unbiased information and all communication options would be available to families and children.

Status: There are no states that currently mandate all criteria recommended in a Best Practice Model.



Early Intervention Best Practice Model



3417 Volta Place, NW
Washington, DC 20007
Phone: (202) 337-5220
TTY: (202) 337-5221
Fax: (202) 337-8314
www.agbell.org