



# **PARTNERING FOR THE SUCCESS OF CHILDREN WITH HEARING LOSS TASK FORCE REPORT**

Department of  
Public Health  
Interagency  
Coordinating  
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Information and perspectives from the following documents helped to inform the work of this Task Force:

The National Agenda for Moving Forward on Achieving Educational Equality for Deaf and Hard of Hearing Students, April 2005

Meeting the Needs of Students Who Are Deaf or Hard of Hearing: Educational Services Guidelines, National Association of State Directors of Special Education, Inc., July 2006

Early Beginnings for Families with Deaf and Hard of Hearing Children: Myths and Facts of Early Intervention and Guidelines for Effective Services, Laurent Clerc National Deaf Education Center, Feb. 2002

A Brighter Future for Children with Hearing Loss -Closing the Gaps in Educational and Health Care Services, US Dept. of Health and Human Services, Office of Disability, May 2005

Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs, Joint Committee on Infant Hearing, Oct. 2007

Requests for copies of this document may be sent to [Patti.Fougere@state.ma.us](mailto:Patti.Fougere@state.ma.us)

It is available on-line at: [www.mass.gov/dph/earlyintervention](http://www.mass.gov/dph/earlyintervention)

**DEPARTMENT OF PUBLIC HEALTH  
EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL**

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**JANUARY 2009**

**Introduction**

The Department of Public Health Early Intervention Interagency Coordinating Council created a Task Force to advance the Early Intervention system of care and services for young children with hearing loss. The primary goal for the Task Force is to ensure that families have information about, and complete access to, services that enable infants and toddlers who are deaf and hard of hearing to develop age-appropriate language, social, and cognitive skills in the families chosen communication mode.

Three public forums were held across the Commonwealth to solicit input from the field. Individuals attending the forums included audiologists, early childhood educators, consumers, program and agency administrators, speech/language pathologists, teachers of the deaf, and other interested parties.

Five focus groups for parents of young children with hearing loss were conducted in specialty service programs across the state. Parents shared their perspectives about what had and had not been helpful about their early intervention and specialty service provider experience through these forums and via written surveys.

The Task Force met from February 2007 through October 2008. Task force members have also consulted with other groups and individuals, both within Massachusetts and in other states.

**Task Force Vision Statement**

The Task Force is committed to developing a comprehensive, high quality, accessible system of programs and services for young children from birth to three with hearing loss and their families in collaboration with other involved agencies and groups.

## **Recommendations**

Based upon discussions among the Task Force members, major recommendations have been developed across seven broad areas outlined in this report. Some of the recommendations can be implemented through changes in procedures and practices at the agency and local level. Others may need approval, statutory language, and/or funding support by the Governor and the Legislature or be supported through grant programs. In implementing the recommendations, the Task Force will continue to involve key constituent groups, individuals, and agency staff. Many of the implementation details will benefit from further discussion, input, and work from parents and professionals in the field.

### **1. Infants and young children identified with hearing loss and their families need immediate access to the expertise of professionals knowledgeable about hearing loss**

It is essential that families receive support and information from professionals trained in providing services to children with hearing loss and their families to help parents adjust to their child's hearing loss, understand the importance of early access to communication, and begin learning what needs to be done to ensure that their child's development is on track. Public comments supported the need for this access to be offered as soon as possible after the hearing loss is confirmed and in a systematic manner. Families should have access to professionals with expertise in all modes of communications, including American Sign Language (Bilingual-Bicultural), Auditory Verbal Therapy, Cued speech, Oral (Auditory Oral), and Total Communication.

Any child with a hearing loss should have access to a "medical home", a philosophy of care that emphasizes the role of the primary care physician in providing not only the typical primary medical care of the child but also as a focal point for the support of parents and family, the coordination of specialty medical care, the provision of referrals for various services, the assurance of timely follow-up and the medical interface for educational interventions.

#### **The Task Force recommends that:**

- A central referral system to Specialty Services for children with hearing loss becomes a continuation of the Parent Outreach component of the Universal Newborn Hearing Screening Program
- A system of tracking intervention status at contact points, parent questions and concerns, and the resource and referral information provided to families is developed
- A system that decreases the barriers to contracting with specialty service providers be established by the Department of Public Health

- Every child should have a primary health care provider who knows that child individually, cares about him or her, is aware of his or her medical needs, and is capable of providing culturally sensitive and appropriate medical services.

Early intervention must include an understanding and provision of services and programs that address the linguistic, communication, social and cognitive needs of children who are deaf or hard of hearing.

**The Task Force recommends that:**

- Early Intervention programs designate particular staff(s) to be the key service coordinators for children with hearing loss in their programs. These service coordinators will collaborate with specialty providers to ensure that appropriate resources are available to families.
- The Individualized Family Service Plan (IFSP) team for all children with hearing loss includes a provider that is trained in providing services to young children with hearing loss and their families
- Ongoing, periodic assessment data should guide the determination of language and communication use, placement and support services. Qualified evaluators should be able to administer an evaluation using the language and communication methodologies used by the child and select and administer evaluation tools that reflect the child's aptitude or achievement level.

**2. Professionals provide families of young children with hearing loss complete and unbiased information about hearing loss, communication development, the importance of early access to language, and available hearing technologies, including hearing aids, FM amplification systems, and cochlear implants**

Families must be recognized as the earliest and most important resource for their child and must be treated as informed, equal, and collaborative partners by professionals who have appropriate training and experience. Parents must be recognized as decision makers who will make choices about language and communication approaches, educational placement, and support services as part of a process, rather than as a one time decision. Decision-making involves keeping an open mind, flexibility, awareness of the child's language progress and the effectiveness of communication strategies they are using.

**The Task Force recommends that:**

- Professionals are trained in the provision of unbiased information to families no matter what their personal biases or preferences might be
- Written information about the various communication approaches used by individuals who are deaf and hard of hearing, communication development, the importance of early access to language, and available hearing technologies is made available in a variety of languages
- Parents have opportunities to meet deaf adults, other parents of children who are deaf or hard of hearing, and children who use a variety of communication modalities to help inform this process
- Professionals recognize the cultural influences on families understanding of hearing loss, use of technology, and use of services
- Professionals identify barriers to participation (e.g., transportation, language, geographic distance, etc.) and collaborate with the family and other providers in an attempt to reduce those barriers
- Professionals encourage parents to make ongoing decisions about communication approaches based on an awareness of the child's language progress and the effectiveness of the communication strategies they are using
- Professionals recognize that decisions related to language, communication and placement are not static and may change over time. Families must be referred to providers skilled in the family's chosen mode(s) of communication.
- All personnel (including Deaf mentors and ASL instructors), have access to ongoing support and training opportunities to develop and expand their competence in providing family centered services to children who are deaf/hard of hearing

**3. Parents are provided with information and services specific to the unique needs of children with hearing loss and strategies that promote and support their child's development**

General information on child development, language development, and hearing loss should be available to all families of children with hearing loss. Parents should be offered access to relevant professional, educational, and consumer organizations that will provide them with the skills and knowledge they need.

**The Task Force recommends that:**

- Family and child centered programs should focus on the development of an enriched communication environment for the child, including assistance in the development of an appropriate communication mode and language for the child as well as services so that the family members can communicate fully and effectively with their child. Family centered programs emphasize the role of the parent as the child's first – and primary – teacher and support parents as they acquire the skills to foster their child's development in all areas.
- Opportunities for ASL instruction is offered to all families and available to those who are interested
- Professionals will support positive parent-child interactions that utilize a range and or combination of visual, manual, and auditory strategies
- EI Specialists are provided with updated information, materials, and resources to help them provide appropriate services to families of children with hearing loss. EI Specialists and professionals for children with hearing loss will collaborate to offer coordinated, comprehensive services for all children.
- A flow chart is developed for families to illustrate the pathway from identification through intervention

**4. Access to the range of communication approaches is available regardless of where the family lives**

There is an ongoing need to increase the number of appropriately trained specialists in deaf education and early intervention. Pre-service and in-service training and mentoring opportunities should give practitioners knowledge and expertise in general education, education of individuals with a hearing loss, early childhood education, families, and the impact of hearing loss on development, language and communication modalities, and the special education needs of students with hearing loss and additional disabilities



**The Task Force recommends that:**

- Ongoing collaboration by all partners to expand pre-service and in-service training opportunities in the Commonwealth
- Creation of a system to inform all relevant parties of training opportunities in the state and nationally
- Professionals will assist families in identifying specialty service providers skilled in the communication approach(es) they choose
- The data base of Specialty Service providers for children with hearing loss will be expanded to include information about the communication approaches in which they have expertise
- Childcare providers have access to appropriate training to enable them to provide needed supports to children with hearing loss in childcare settings

**5. Families are provided with a variety of options to meet their needs for support and information**

Although hearing loss may occur in as many as 3/1000 infants and toddlers, it is considered a low incidence condition. Opportunities for parents of infants with hearing loss to meet other families in similar situations occur infrequently in many parts of the state. It must be recognized that as the population of the Commonwealth becomes more diverse, the strategies used to provide families with information and support need to expand.

**The Task Force recommends that:**

- Families are provided with ongoing opportunities to connect with other parents of children with hearing loss
- Families are provided with ongoing opportunities to meet children and adults with hearing loss
- The system be designed to ensure that information, support, and services are available to all families
- Regional parent support groups or activities, with considerations for language or cultural subgroups, are provided
- Ongoing technical assistance in general and when facing difficult decisions is offered to all families
- Families are provided with information about adaptive equipment and assistive technology

- Families are provided with information about websites, conferences, books and other media that are relevant to hearing loss
- Specialized resource information is developed and disseminated to service providers for distribution to families who would benefit from access to resources such as: clinicians who are multilingual, Deaf adults from diverse cultural groups, local/regional child groups for infants and toddlers with hearing loss, local/regional parent groups

**6. The transition from IDEA Part C to Part B services is seamless and provides children who are deaf and hard of hearing access to educational programs that provide communication assessment, access, and development as well as addressing academic and social needs**

The transition from a family-centered service to a child-centered system can be challenging. Providers need to assist families in viewing the transition as an opportunity to ensure that their children can participate effectively in age appropriate activities.

**The Task Force recommends that:**

- Families are provided with information about the transition process and the fundamentals of special education law in Massachusetts so that they have the skills and knowledge to advocate effectively for their child
- Families are provided with information about the various educational settings available for children with hearing loss
- Families and providers have strategies to highlight the unique needs of the child with hearing loss as part of the IEP process
- Special Education Directors have resources to inform them about the unique issues related to eligibility, disability, auditory status, need for specialized instruction, hallmarks of sufficient progress in the educational setting for children with hearing loss

**7. Service providers should be knowledgeable about the unique educational needs of young children with hearing loss and the need for content specific information for their parents and caregivers**

Early intervention services should be appropriate to the particular needs of infants and toddlers with hearing loss. Early intervention Specialists may or may not be familiar with the unique needs of infants and toddlers with hearing loss and their families.

**The Task Force recommends that:**

- The Individualized Family Service Plan (IFSP) team for all children with hearing loss includes a provider that is trained in providing services to young children with hearing loss and their families. Such professionals include educators of the deaf, speech-language pathologists, and audiologists.
- Ongoing training is available to Early Intervention Specialists that highlights the unique communication needs of infants and toddlers with hearing loss and the critical importance of early access to language
- Consultation is available from the Children's Specialists of the Massachusetts Commission for the Deaf and Hard of Hearing to Early Intervention Programs , other providers, and families
- All providers (including educators of the deaf, speech-language pathologists, Deaf mentors and ASL instructors, early intervention specialists), have access to ongoing support and training opportunities to develop and expand their competence in providing family centered services to children who are deaf/hard of hearing
- All providers are familiar with the process for contracting with specialty service providers used by the Early Intervention system