



Guidance Document Providing Timely Information about Service Options For Children with Hearing Loss

Several of the Specialty Service Programs for children with hearing loss and some parents are concerned about the limited information sometimes provided to families about service options for children with hearing loss. Consistent themes include the following:

1. Importance of Early Referrals

Current Research about brain development makes it clear that important neural tracks for language acquisition are laid down in the first year of life. It is never too soon to refer a family to a Specialty Program for children with hearing loss. The array of program options may vary with the age of the child, but the information about how to create an enriched language environment should be provided to families very early on. This is not the same as generic language stimulation – the approaches for children with hearing loss are quite different.

2. Share information about Regional Specialty Programs for children with hearing loss with Service Coordinators

Parents may be willing to travel to a Parent/Infant Program for children with hearing loss that is some distance from their home if it offers an approach that appeals to them. It is really the family's decision.

There is also a list of private providers who work as independent contractors available through the DPH Specialty Services Coordinator for children with hearing loss.

3. Inform Families of all program options

The role of the EI Service Coordinators is to provide families with the options and resources to support the family in making informed decisions about communication options.

The potential loss to families of the support and information they can receive from professionals and from other parents in a group for families of children with hearing loss cannot be overestimated. Hearing loss is a low incidence condition. The chances of a parent meeting another parent who has a child with a similar loss, language approach, and co-morbid conditions in an EI group are low. Provide the family with an opportunity to make connections that can provide ongoing support early on.

A child group may or may not offer the language/visual support environment so essential for learning in a child with significant hearing loss. Some Parent Infant Programs may be able to offer training in fairly simple ways to make the group space and teaching strategies more appropriate for children with hearing loss.

4. Inform Families about the Family Sign Language Instruction Program

Some families have not heard about this program until their child is almost three. Significant language learning takes place well before the age of one – and these children have missed out. The decision to participate in the Family Sign Language Instruction Program needs to be made by a family – not by a service coordinator. The service coordinator's role is to offer information to the family about the program in an unbiased way. And it may be necessary to offer information more than one time to some families.

Staff should remember that their own biases should not slip into the information they present to families about service options. For example, telling a family that the “FSLIP is very intense because all of the instructors are deaf” is reflective of the staff’s preconceptions. Families have the right to come to their own conclusions.

5. Set up Communication Channels with Specialty Service Providers

The “Collaboration among Families, Early Intervention Programs, and Specialty Providers” document encourages regular contact through ongoing joint assessment, IFSP participation, co treatment sessions, and transition planning. The Service Coordinator and the Specialty Provider should keep each other informed about progress and concerns, needs for changes in services, scheduling for assessments, transition planning meetings, etc. This can take place through shared session notes, regular telephone calls or emails, and periodic co treats.

The following is a summary of information presented at an Early Hearing Detection and Information Conference that urged all personnel working with infants and toddlers with hearing loss to consider the condition a developmental emergency:

Please address any specific questions you may have to Darla Gundler, Specialty Services Coordinator for hearing loss: darla.gundler@state.ma.us

HEARING LOSS IS A DEVELOPMENTAL EMERGENCY

**It's about the brain – not the ear
The brain needs language stimulation – whether the loss is diagnosed
at birth or later**

WHAT'S YOUR EMERGENCY RESPONSE PLAN TO THAT DEVELOPMENTAL EMERGENCY?

Ask yourself the following questions to ensure you are meeting the developmental needs of the child with hearing loss.

- How are you preparing to help parents in the needs for information and support?
- Do you have sufficient content knowledge about hearing loss and its ramifications to meet those needs?
- None of us can do it alone – we need to help families become part of communities – connected to others in similar situations, introduced to deaf role models. Do we have the resources to make those connections?
- Do you have sufficient knowledge about how to ensure language access to an infant? To a toddler? To a preschooler? In the communication modality their parent chooses?
- Who is addressing needed modifications in the physical environments the child spends time in (noise reduction, lighting, room design, fire alarms)
- When do you bring Specialty Providers with content knowledge about hearing loss onto the team?
- EI Contact is expected to be point person to ensure that all children in EIP with HL are appropriately served, not to be service provider to all.
- Are your expectations for the child high enough?
 - Research tells us kids with HL only can have age commensurate language levels by age six.
- Are you closely monitoring progress?
 - Is the child making one month's progress in one month's time? If not, why not?
 - Are there other learning challenges?
 - Does she have sufficient access to language?
- If the child's language level is falling off, or not growing – how can you get it on track?