

**Increasing Genetic Referrals for Children Identified through EHDI –
An Action Guide for Providers Serving Children who have Hearing Loss**

Region 4 Genetics Collaborative
EHDI Follow-up Workgroup
Logic Model H.O. #5 08.20.09

Assumptions

Children with permanent hearing loss and their families may benefit from genetic services

Families should have the opportunity for genetic consultation

Families need to be informed of the opportunity for genetic referral/consultation

Opportunities for providing information about genetic services exist throughout the EHDI follow-up process

Parents of children with hearing loss who understand the benefits are more likely to obtain genetic services

Providers need to educate families about the opportunity for genetic referral/consultation

Providers who understand the importance of genetic consultation for families who have a child with hearing loss are more likely to refer or offer genetic referrals to those families

Providers need to understand the value of genetic referral/consultation for families who have a child with permanent hearing loss

Strategies

Identify opportunities for offering referral for genetic consultation throughout the EHDI follow-up process

Develop and disseminate recommended Region 4 Guidelines for Primary Care Provider Follow-up of children who have diagnosed hearing loss that includes genetic referral

Develop and disseminate information for providers (audiologists, primary care provider, interventionists) on how, when, why to refer

- Web-based presentation/training module to increase provider awareness and knowledge
- List of genetic contacts for each Region 4 state
- Powerpoint presentation for incorporation into other provider training

Develop and disseminate information for families on the importance of genetic referral when an infant is diagnosed with hearing loss

- Brochures for providers to give to families
- FAQs on the importance of genetic referral and consultation when an infant is diagnosed with permanent hearing loss

Outcomes

Improved follow-up practices for children with heritable disorders who are identified through EHDI

Increased number of children who have hearing loss who are appropriately referred for genetic consultation

Increase number of children with hearing loss who might benefit from genetic services who receive a genetic consultation

Improved outcomes for children who have a permanent hearing loss and their families