

Region 4 Genetics Collaborative
Proposed Priority Issue for EHDl Workgroup
10/20/08

Increase Access to Genetics Services for Children with Hearing Loss

- 50% of children diagnosed with sensorineural hearing loss are due to genetics causes.
 - Of those, about 1/3 are affected with a complex medical syndrome.
 - Since the majority of genetic hearing loss is caused by recessive genes, family history is usually negative.
- Identification of associated features in hearing loss syndromes may have health saving or life saving implications.
- Audiologists working in EHDl programs need to be knowledgeable about genetics services in their state.
- Genetics programs in states need to be knowledgeable about the EHDl program in their state.
- Families of children diagnosed with hearing loss should receive information about genetics services as a complement to their child's health care.

Can this group look at the diagnosed children in each state and determine if, if at all, these children are referred for genetics risk assessment, counseling, etc? Of those that are referred and receive genetics counseling, what is the breakdown of syndromic vs. non-syndromic losses, age of identification, etc? From this, we can formulate how to better educated families, professionals and others in EI about genetics and hearing loss, etc.