

Proposed Activity for EHDI Workgroup:

Increase access to genetics services for children identified through universal newborn screening or other EHDI services.

Why:

- 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.

Assumptions:

- Audiologists working in EHDI programs need to be knowledgeable about genetics services in their state.
- Genetics programs in states need to be knowledgeable about the EHDI 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.

Strategy:

Collect data on the diagnosed children in each state

Are they referred for genetics services

Of those that are referred and receive counseling – what is the breakdown of syndromic vs. non-syndromic

Outcome: formulate how to better educate families, professionals and others in early intervention about genetics and hearing loss, etc.