



# COMMUNICATION CONSIDERATIONS A-Z™

## *Genetics*

### **1. What do we know about genetics and deafness? What are related linguistic considerations?**

When children are identified as deaf, often the cause is described as unknown. Most commonly, the child with inherited deafness is the only such person in the family, therefore making it difficult to identify the cause. We now know that genetic inheritance is a very likely cause for approximately 50 to 60% of this group. One third of all genetic deafness is syndromic, meaning that it is characterized by hearing loss in combination with other medical or physical characteristics. Two thirds are labeled as nonsyndromic, meaning that only hearing loss is present. This categorization is true for most deaf people with inherited deafness. This inherited deafness can be congenital or occur at any time after birth. Some types of deafness can be caused by the interaction of specific genes and environmental influences, including some drugs used to treat major illnesses.

Of the estimated 400 genes for deafness, only a few dozen have been characterized. The size and complexity of many of these genes make testing difficult. Testing is now widely available for the most common forms of genetic deafness, most famously for the connexin 26 gene. Diagnostic testing after a deaf child's birth can be beneficial in preventing or preparing to deal with potential complex medical issues related to certain types of syndromic deafness, or in minimizing progressive hearing loss. A review of available information suggests that the results of individuals with linguistic homogamy (using sign language to communicate) who marry each other reveal a significant increase in the frequency of connexin deafness. However, most genes for deafness are typically transmitted through an autosomal

recessive pattern. What this means is that there is often no guarantee of generational deafness.

The possibility for selecting specific genes or genetic mutations, including those that can result in deaf or hearing characteristics for babies, is becoming more likely with advances in genetic research. There are significant psychosocial implications regarding genetic inheritance and the possibility of choosing “human characteristics.” However, whether individuals decide to make such selections or not as they proceed to have children is greatly influenced by cultural beliefs, experiences, and perceptions conveyed by their social communities. Those who select or prefer deaf characteristics are likely members of the culturally Deaf community who take pride in their Deaf heritage and American Sign Language. They perceive themselves as individuals who are leading normal lives and resent being pathologized as having a condition that the scientific community is working to eradicate through the development of advanced genetic technology.

## **2. What issue is at the forefront of genetics related to deaf characteristics?**

The search to map the different genes for deafness is ongoing. One critical issue has to do with the moral and ethical dimension. There are two basic perceptions related to the value of eradicating genes for deafness. One perception is framed within the context of medical necessity to facilitate access to audition and spoken language as well as the reinforcing of “deaf” as a negative way of life. The other perception is framed as the denigration of the value of deaf lives and the reinforcing of medical eugenics and cultural genocide in terms of allowing the culturally Deaf community to contract.

Underlying both perceptions is the comfort level of both deaf and hearing societies about affirming the possibilities of children who are deaf as having “lives worth living,” able to maximize their potential, and demonstrating they are not a burden to the larger society. The fact is that when reproductive choices for deaf characteristics are made, many people tend to see this as counteracting prevailing views of “normalcy” and the necessity of hearing. They may see such choices as wrong. Even though accepting diversity has become more “status quo,” society at large continues to view the identification of deaf children and the reliance on visual language/communication approaches as less than ideal despite the heightened interest in American Sign Language. However, many parents have affirmed how special their deaf children are, and what new worlds it has opened for them.

## **3. What genetic aspects should parents and professionals be aware of?**

Professionals increasingly need to be educated about conditions and traits that are associated with specific genes, either syndromic or nonsyndromic, since these have psychosocial, educational, and medical implications that can affect the lives of deaf children. Knowledge about these conditions and traits can lead to more appropriate programming recommendations that have the potential to facilitate the optimal development of the deaf child.

Genetic counseling can be valuable for parents of deaf children in, for example, getting accurate information about etiology, potential medical or psychological aspects, and whether future children may manifest syndromic or nonsyndromic deafness. Such information can be reassuring for parents as they

proceed with the process of raising a deaf child. Parents should be aware that genetic counselors and professionals with knowledge of genetics are available to help them understand their deaf children and how best to help facilitate their development.

## 5. Where can I go for more information and resources on genetics?

Those who would like to know the references for the information presented here can contact the author (contact information follows this section). Additional sources that parents might be interested in include the following:

Arnos, K. (2002). Genetics and deafness: Impacts on the Deaf community. *Sign Language Studies*, 2, 150-168.

Harvard Medical School: Center for Hereditary Deafness (2003). *Understanding the genetics of deafness; A guide for patients and families*. Cambridge, MA: Harvard Medical School: Center for Hereditary Deafness.

Van Cleve, J.V. (2004). *Genetics, disability, and deafness*. Washington, D.C.: Gallaudet University Press.

**Author: Irene W. Leigh, Ph.D.**, has presented and published widely in areas covering psychosocial aspects related to deaf and hard-of-hearing individuals and their parents. The author wishes to thank Dr. Kathleen Arnos for her assistance with the genetics information included in this article.

Irene W. Leigh, Ph.D.,  
Professor, Doctoral Program in Clinical Psychology  
Chair, Department of Psychology, Gallaudet University  
Email: irene.leigh@gallaudet.edu

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*Communication Considerations A to Z™ is a series from Hands & Voices that's designed to help families and the professionals working with them access information and further resources to assist them in raising and educating children who are deaf or hard of hearing. We've recruited some of the best in the business to share their insights on the many diverse considerations that play into communication modes & methods, and so many other variables that are part of informed decision making. We hope you find the time to read them all!*