

Fact Sheet

Points to Consider About Etiologies

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Etiology simply means the cause of a child's medical or disability condition. Etiologies of deaf-blindness can be hereditary/chromosomal syndromes and disorders such as Down syndrome, pre-natal/congenital complication such as fetal alcohol syndrome, post-natal complications such as asphyxia or meningitis, and complications as a result of prematurity. For some children, the cause of their combined vision and hearing problems is unknown, and other children have more than one etiology. To have an accurate diagnosis of a child's deaf-blindness may answer many troubling questions, or it may raise more questions than it answers. The following are a few considerations about etiologies that may be helpful.

- ❖ Professionals need to gather as much information about the cause of a child's deaf-blindness as possible prior to establishing an intervention or educational program. This information will be very useful in understanding many areas of the child's development, such as fine and gross motor skills, social/emotional development, language acquisition, and development of the vestibular system, to name a few. With that said, however, it is also true that...
- ❖ To know a child's etiology is not to say that you know the child. Every child is unique, and many etiologies present skills and levels of disability across a broad spectrum.
- ❖ For some families in which there is no known cause of their children's deaf-blindness (and other disabilities), this absence of a diagnosis can be a nagging mystery that may affect these parents' well being. The lack of a diagnosis might cause parents to question whether or not to have more children, or might cause them to worry about future generations, i.e., the children of their other sons and daughters.
- ❖ Professionals should keep in mind the importance families may place on even casual comments about etiology. A casual mention of a possible etiology might send some families running to the library or Internet to conduct research, and they could very well be unnecessarily frightened by information gleaned.
- ❖ Find out if there are delayed manifestations of a child's etiology, such as health problems that develop later in life. For example, excessive thirst by someone with congenital rubella syndrome might be an indicator of a late onset medical condition.
- ❖ Pay attention to the publication date of print and Internet resources. The speed at which current research is adding to what we know about many conditions is fast, and information may be out-of-date within months, not just years.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals who are deaf-blind. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

- ❖ Be aware that some information available on etiologies may not be factual. This is especially true of information found on the Internet. Before accepting information as fact, consider the reputation of the organization that produced the material, the source of the information, the process used for gathering and interpreting the information, etc. A resource might include stories of one person's experience, and while these might be interesting and helpful, the information presented may not apply to others with the same diagnosis.
- ❖ The value of connecting with another person who shares the same diagnosis cannot be overstated. This is true whether the connection is parent-to-parent, child-to-child, sibling-to-sibling, or grandparent-to-grandparent. Families hear the phrases "I know how you feel" and "I know what you're going through" fairly often, but to speak to someone who truly knows how they feel or what they're going through can be one of the most powerful sources of support, information, and encouragement.