

In the School: Deaf-Blindness

By Molly Black, Family Liaison, Pennsylvania Training and Technical Assistance Network (PaTTAN) Deaf-Blind Initiative

When a child experiences both hearing and vision loss, it's referred to as deaf-blindness. When we think of someone with this diagnosis, our (mis)understanding often jumps to thoughts of Helen Keller, who was totally deaf and totally blind. This is not the case for most people with the diagnosis. In fact, the majority of individuals with this label most often have some hearing and vision.

Deaf-blindness is defined as hearing and visual impairment that causes such severe communication, developmental and educational needs that the student cannot be accommodated in special education programs solely for children with deafness or blindness. Cornelia de Lange Syndrome (CdLS) is listed among the leading causes of deaf-blindness.

Common eye conditions in people with CdLS that can impair vision include blepharitis, ptosis, high myopia (nearsightedness), glaucoma, amblyopia (lazy eye), congenital deformities of the shape of the eye, Cortical Visual Impairment (CVI), and retinal detachment (sometimes caused by self-injurious behavior).

Hearing loss can be sensorineural, due to a disorder of the cochlea or the acoustic nerve, or it can be conductive in nature, related to the sound-conducting mechanisms of the ear. Conductive hearing loss may be corrected with surgery.

Individuals with deaf-blindness have difficulty accessing visual and auditory information in the environment. Therefore, educators and parents need to know that it requires special modifications in the home, as well as school. Curriculum and supports for students need to go beyond what is typically needed with a hearing or a vision loss alone.

Typically, when an individual has a hearing loss, his or her vision becomes the best method for obtaining information. When someone experiences a vision loss, we expect his or her hearing to help compensate for what is not seen. However, when a person experiences a combined vision and hearing loss, neither sense effectively compensates for the other.

Understanding your child's vision and hearing loss is an important first step in working with your child's teachers and implementing the modifications that are necessary to support your child in the classroom.

The impact of deaf-blindness on learning cannot be underestimated. According to Project SPARKLE—a self-study program that enhances the ability of parents to fulfill their role in the development of their children—the following are required to help deaf-blind individuals succeed:



- Specific modification and supports to learn and interact with the world
- Glasses and/or hearing aids to make the most of any vision and/or hearing
- Use of touch, taste and smell to access information
- Ability to communicate in ways besides spoken word or print, such as gestures
- More time to gather and process information
- Routine and systematic instruction

Dr. Antonie Kline, the Foundation’s medical director, recommends that all children with CdLS be tested for hearing and vision loss as follows:

- Pediatric ophthalmologic evaluation with cycloplegic refraction
- Pediatric ophthalmologic evaluation annually if indicated by findings on first examination
- Audiology testing every two to three years
- Hearing evaluation through otoacoustic emissions or brainstem auditory evoked response if audiology is abnormal

In conclusion, have your child’s hearing and vision tested regularly. If there is a dual sensory loss, contact your state Deaf-Blind Project. Learn as much as possible about your child’s condition so that you and your child’s school team has a true understanding of this “inability to access information.” Then appropriate modifications and supports can be put into place and your child can make progress in school each year.

Resources

Most every state has a Deaf-Blind Project, which educates school teams and families in supporting children with deaf-blindness from birth through age 22.

Most Deaf-Blind Projects employ family specialists or family consultants (often parents of children with deaf-blindness themselves) who help deliver assistance through trainings, resources and supports to help school teams modify curriculum and learning environments. Find your state’s Deaf-Blind Project office at www.nationaldb.org.

You can find articles about eye conditions and hearing issues related to CdLS on the Foundation Web site: www.CdLSusa.org. Go to *What We Do*, *Family Support Services*. Articles and information can be found in both the *Ask the Expert* and *Publications* sections.

In addition to being a family liaison at the PaTTAN Deaf-Blind Initiative





CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

Molly is a longtime CdLS Foundation Regional Coordinator and mom to Alex, age 20, who has CdLS.

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