

## **CHARGE Syndrome Information: Vision**

Donna Bent

Certified Orientation and Mobility Specialist

Certified Teacher of the Visually Impaired

Children with CHARGE often have vision impairments due to colobomas. Most children with colobomas have a visual field loss, typically in the superior (upper) field. There may be blind spots and acuity problems in addition to the visual field loss. Iris colobomas can result in extra sensitivity to bright lights, even indoors. In many cases, one eye is more severely affected than the other, causing monocular vision and lack of depth perception.

Understanding (as much as possible) the extent of the child's "visual bubble" (how far out and how well can the child see) is critical for educational planning. A child who can pick up a paper clip on the table may not be able recognize the teacher at the front of the room or even facial expressions at relatively close range. A child with CHARGE probably also has significant hearing impairment and vestibular (balance) abnormalities, both of which also impair the amount and quality of information received from the environment. Ideally, a DeafBlind specialist can be consulted to help understand the complications associated with dual sensory impairment [see Technical Assistance].

A Certified Teacher of the Visually Impaired (CTVI) can help provide ongoing functional vision assessments and make recommendations for improving visual skills. Accommodations should be made for safety as well as for the visual enhancement of the environment. Even if the child does not appear to be severely visually impaired, learning can be challenging due to a combination of factors specific to CHARGE as well as the additional sensory losses of hearing impairment and balance issues.

With a field loss or monocular vision, it is difficult to follow a line smoothly or a series of lines systematically. Reading or any type of precise near reading work is both challenging and fatiguing. Large print, bold lines, underlining, or a line marker can be helpful.

A visual field loss also requires a child to scan systematically in order to receive the full visual picture. This can make following a signed conversation and receiving all the information quite exhausting. In a traditional educational setting, visual information may come from signing (distance), handouts (close up) and computer projections or a chalkboard (distance). Children have difficulty processing all of this information together in a coherent manner. It is also exhausting for the child to do this for extended periods of time. Teachers of the Visually Impaired can help with compensatory strategies for accommodation and strengthen visual skills. The CTVI can also assist the classroom teacher in adapting materials and the environment to make learning more successful.

Children with CHARGE typically have difficulty moving through space and learning through the visual sense. A Certified Orientation and Mobility Specialist (COMS) can help people with vision impairments to learn to move through space more safely and

efficiently. Almost all individuals with CHARGE have difficulty maintaining balance. There are specific Orientation and Mobility techniques that help compensate for the poor balance. Visual field deficits affect safety while moving as obstacles or drop offs may be missed. Many children with CHARGE have difficulty transitioning in different environments. Orientation and Mobility training provides structure and specific training that make the transitions more efficient and safe.