

For more information on deafblindness, contact one of the following individuals listed below:

Missouri Deafblind Technical Assistance Project:

Susan Bonner, Project Coordinator

(314) 776-4320 x 3255

Susan.Bonner@msb.dese.mo.gov

St Louis Deafblind Task Force:

Susan Bonner, Task Force Facilitator

(314) 776-4320 x 3255

Susan.Bonner@msb.dese.mo.gov

Kansas City Deafblind Task Force:

Dale Felder, Task Force Chairperson

(660) 584-9482

Dale.Felder@dmh.mo.gov

Southwest Missouri Deafblind Task Force

Ellie Widmer, Task Force SW MO Contact

(417) 839-4414

ellie@abilitiesfirst.net



How to Know If You Are Serving a Person Who Is Deafblind



What is it?

An individual is considered deafblind when that person has both a visual and auditory (hearing) impairment. If the person you serve does not have sufficient vision to compensate fully for an auditory impairment or does not have sufficient audition to compensate fully for a visual impairment, then consider the possibility of the person whom you serve as having deafblindness.

Does deafblind mean the person cannot see or hear?

Actually, no. When most people hear the term deafblindness, they tend to think of Helen Keller, who was totally blind and totally deaf. In reality, most individuals with deafblindness have some remaining audition and/or vision. So, although deafblindness does not always mean a total loss of vision and audition, the combined losses greatly impact an individual's ability to understand the world. Many individuals with deafblindness wear eyeglasses, hearing aids, or use other special devices to improve their vision, audition, and to learn more about what is happening in the world around them.

Why is the combination of visual and auditory impairments important?

Vision and audition are our two distance senses. The world of most individuals with deafblindness is only as big as the area immediately around them and, for some, only as big as the area their fingers can reach. Unless someone is close to or is touching them, they are always alone. Proximity and intensity are essential to using the other senses such as touch and taste. With our ears, we can listen to the radio broadcast of a baseball game in another state. We can

hear conversations across the room or even in the next room. With our eyes, we can look at microscopic bacteria or up at the moon. Through recordings and photos we can listen and view information frozen in time. Try doing that with touch, taste, or smell.

What do you look for to see if the person you serve is deafblind?

Although there is a lot of diversity between individuals with deafblindness, there are some characteristics that many share:

- Many use gestures, non-linguistic vocalizations, facial expressions, and/or physical behaviors as their primary mode of communication;
- Many do not use sign language, even after learning an essential vocabulary;
- More than half do not read at all, however, of those who do, many read at a 4th grade level or below; and,
- About half of the individuals with deafblindness communicate without language and may require assistance when traveling; the other half communicates using spoken or signed language.

The combined auditory and visual impairments often result in a host of challenging behaviors:

- Not being able to communicate effectively, individuals with deafblindness might use inappropriate (self-injurious, aggressive, and/or destructive) behaviors to ensure their needs are met.
- Sensory loss increases the need for sensory stimulation; therefore, many individuals with deafblindness develop unusual or repetitive habits, such as rocking or headshaking, which are occasionally mistakenly labeled as autistic. Some forms of visual and auditory impairments (particularly those that are cortical) result in behaviors often mistaken for indicators of autism.
- Since we develop our social skills through vision and audition, individuals with deafblindness may not pick up on non-verbal

feedback and might develop what may be seen as socially inappropriate behaviors.

The following are some of the health conditions and events, including complications of childbirth, which may result in both a visual and auditory impairment:

- Congenital Rubella
- Congenital Syphilis
- Congenital Toxoplasmosis
- Cytomegalovirus (CMV)
- Fetal Alcohol Syndrome
- Hydrocephaly
- Maternal Drug Use
- Microcephaly
- Neonatal Herpes Simplex
- Asphyxia
- Direct eye and/or ear trauma
- Encephalitis
- Infections
- Meningitis
- Severe head injury
- Stroke
- Tumors
- Medicines
- Chemicals

Many syndromes have associated visual and auditory impairments. A *partial* list of these syndromes includes:

- Bardet-Biedl Syndrome (Laurence Moon-Biedl)
- Batten Disease
- CHARGE Syndrome
- Cockayne Syndrome
- Cornelia de Lange
- Dandy Walker Syndrome
- Down Syndrome (Trisomy 21 Syndrome)
- Goldenhar Syndrome
- Herpes-Zoster (or Hunt)
- Leber Congenital Amaurosis
- Marfan Syndrome
- Monosomy 10p
- NF1 – Neurofibromatosis (von Recklinghausen Disease)
- Norrie Disease
- Prader-Willi
- Pierre-Robin Syndrome
- Treacher Collins Syndrome
- Trisomy 13 (Trisomy 13-15, Patau Syndrome)
- Trisomy 18 (Edwards Syndrome)
- NF2 – Bilateral Acoustic Neurofibromatosis Turner Syndrome
- Usher I Syndrome
- Waardenburg Syndrome
- Wildervanck Syndrome
- Wolf-Hirschorn Syndrome (Trisomy 4p)

