

# What is DeafBlindness

Individuals who are deafblind represent a low incidence disability and within this group there is great variability. The majority of individuals who are deafblind have some residual vision and/or hearing and may also have additional physical, medical and/or cognitive challenges. Individuals are considered to be deafblind when the combination of their hearing and vision loss impact's their ability to communicate with others and to access information. Most individuals who are deafblind require unique adaptations and services to meet their educational, vocational, and independent living needs.

## Prevalence

To date – there are 234 children identified in Massachusetts (birth to age 22) and # of adults

## Common Causes

- Usher Syndrome - the leading cause of deafblindness – is an inherited condition that results in hearing loss and a progressive loss of vision from Retinitis Pigmentosa (also called RP). The hearing loss is thought to be congenital, and ranges from moderate to profound. The RP can occur without hearing loss.
- Prematurity: More than one out of every ten infants born in the United States is born prematurely. Advances in medical technology have made it possible for infants born as young as 23 weeks gestational age (17 weeks premature) to survive. These premature infants, however, are at higher risk for serious complications, which includes vision/hearing loss, respiratory problems, and brain damage.
- CHARGE Syndrome: CHARGE syndrome is a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. Most individuals with CHARGE have hearing loss, vision loss, and balance problems which delay their development and communication. All are likely to require medical and educational intervention for many years

## Impact of Deafblindness

Often the combination of both vision and hearing loss results in significant challenges in the areas of communication, education, and independence. Many children who are deafblind require thoughtful and unique educational approaches to reach their full potential. Whereas, adults who are deafblind often require supports to access services, live independently and connect to the world.

A person who is deafblind has a unique experience of the world. For people who can see and hear, the world extends outward beyond their reach. If the individual is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach and they are effectively alone if no one is touching them. If a person who is deafblind has some usable vision and/or hearing, as many do, her or his world will be enlarged. Many individuals have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term "deafblind" is great.

## Support Needs:

Individuals who are deafblind need highly specialized supports and services in order to communicate with others and conduct daily activities in their home, school, workplace, and community. Without these supports and services, they face extreme isolation and a lack of simple day-to-day interaction with people and our world. Some of these critical services and supports include:

- Access to Communication Partners and Interpreters
- Transportation to Work, Medical Appointments, Legal Services
- Environmental Supports and Modifications, Orientation and Mobility Training
- Families of children or adults who are deafblind often need support to learn how best to communicate with their son or daughter, to provide their child support in the community and to advocate for their child's rights and access to services. For many families, they also face isolation and confusion, trying to navigate local and state systems that are often mired in bureaucracy. With support, families can learn how best to their child in the community and to foster independence and access to information and services.