DEAF-BLINDNESS IN COLORADO

HOW MANY COLORADANS ARE DEAF-BLIND?

Accurate data on Deaf-Blindness is not currently gathered at the state or national level, so it is not known exactly how many people in The United States are Deaf-Blind. However, we can make both low and high estimates based on available recent data from a number of sources. Using Colorado Community Inclusion Data[1], Helen Keller National Center, and 2010 and 2014 US Census estimates, we estimate the number of Deaf-Blind people in Colorado at **approximately 5,000, rising to more probable 21,000 people** when including adults who have lost their vision and hearing due to aging.[2] The wide gulf between these low and high estimates highlights the need for accurate data on Deaf-Blindness in Colorado.

ARE MOST DEAF-BLIND PEOPLE BORN THAT WAY?

Approximately 10% of the general population has a hearing loss from birth or during their early or mid-adulthood. Approximately 1% of that group is also blind or has serious vision loss, from birth or during their early or mid-adulthood. In Colorado, this is approximately 5,000 people. Adults who lose vision and/or hearing due to aging therefore represent the majority of the estimated 21,000 deaf-blind people in Colorado. A small portion of the low-end estimate of 5,000 deaf-blind people are children under 18, but the majority are adults not served through the Colorado School for the Deaf and Blind in Colorado Springs.

HOW DO DEAF-BLIND PEOPLE COMMUNICATE?

Deaf-blind individuals use a wide range of communication styles that include American Sign Language (ASL), Tactile ASL (TASL), finger spelling, print on palm, braille, text to speech, and voice. In addition, communication is augmented by personal listening devices, hearing aids and cochlear implants. Assistive technology such as video phones, tablets with large print text, braille displays combined with smart phones, computers with software to magnify text or convert text to speech or braille can expand the individual's ability to communicate. Other tools such as FM and other amplification systems, CART services (Onscreen real-time large print typing of communication that is taking place) or sign language interpreters using specialized techniques improve communication in various settings.

IS THERE A DEAF-BLIND CULTURE THE WAY THERE IS A DEAF CULTURE?

No. Because many deaf-blind people lose their vision and/or hearing due to aging, because deaf-blindness affects people in a broad variety of ways and at different times in their lives, and because deaf-blind people use a variety of communication methods, there is less of a distinct culture of deaf-blindness than there is a culture of deafness.

---

[1] In 2014, the Colorado Department of Public Health and Environment, the University of Colorado, and the Colorado Statewide Independent Living Council collaborated on a mapping project called Community Inclusion in Colorado. The project used 2000 US Census data and the 2009-2013 American Community Survey to estimate a wide range of demographics and disabilities in Colorado for emergency preparedness purposes.

[2] It is a generally accepted estimate that approximately 10% of the general population has a hearing loss. Within that group, approximately 1% are also blind or have serious vision loss. http://www.deafblindinfo.org/faq.html. Other sources include:

- Sansing, W. (2006). Prevalence of persons aging with dual sensory loss. Presentation at Creating Roads to Independence for Persons Aging with Hearing and Vision Loss, Atlanta, GA (February 2006)
- http://www.coephtmaps.dphe.state.co.us/cdphe_maps/briefingbook/?bookId=d55f496aa4c548a98ff607006004ceee
- Helen Keller National Center http://www.hknc.org/AboutUsWHOWESERVE.htm
- 2010 US Census Data
- 2014 US Census data

WHAT KIND OF LIVES DO DEAF-BLIND PEOPLE LEAD IN COLORADO?

What IS common to many deaf-blind experiences is isolation from meaningful contact with others, a life-long struggle to accomplish many of the tasks of daily life that others take for granted, chronic underemployment, and poverty. This experience is especially common in Colorado, where there are very few services available for deaf-blind individuals, where few deaf-people are eligible for existing services that might help them, and where many deaf-blind people are unaware of the services that do exist and for which they might be eligible.

HOW CAN WE CREATE EQUAL OPPORTUNITIES FOR DEAF-BLIND COLORADANS TO LEAD INDEPENDENT LIVES?

In truth, deaf-blind people *can* be self-sufficient, hold jobs, pay taxes, own homes, raise families, engage with the larger community, and contribute to society in unique and enriching ways, provided they have access to some very basic supports. Many other states have already asked this question and come to the same conclusion: There are four important types of services that can enable deaf-blind people to be independent in their daily lives:

1. ***Assistive technology*** for communication with others and safe interaction with the environment.
2. ***Interpreters and Support Service Providers*** (SSPs) to enable communication with other people and to navigate physical and social environments.
3. ***Orientation and Mobility training*** to teach deaf-blind people how to navigate safely on public and other transportation; and
4. ***Employment and Housing supports*** such as skills training, reasonable accommodations in the workplace, assistance finding and keeping appropriate housing, and in-home assistive technologies.

All of these services can largely be accomplished through the addition of 1.5 staff to the Colorado Commission for the Deaf and Hard of Hearing and the creation of a very small service program for SSPs and O&M training.

As Americans, we are defined by our diversity, and it is our chief strength. By funding these basic services, by enabling deaf-blind people to access the same opportunities other people have, deaf-blind individuals can wield the strength of their diversity to Colorado's benefit.

INTERESTED IN LEARNING MORE?

This fact sheet was created by the Colorado Deaf-Blind Task Force, which is an all-volunteer group of deaf-blind Coloradans who encompass the most common types and experiences of deaf-blindness. For more information, please contact Cynde Vaughn at cyndevaughn@msn.com, Heidi Zimmer at heidi.zimmer07@gmail.com, or Carolyn Haas at carolynhaas@me.com.

DEAF-BLIND TASK FORCE PROPOSAL NARRATIVE

This proposal is based upon the concept that individuals who are deaf-blind share the same rights as their fellow American citizens to pursue a self-sufficient and productive life that include meaningful relationships with other people and their communities. Deaf-blindness is a combined loss of hearing and vision. The best way to understand the impact of this dual sensory loss is to look at deaf-blindness as a continuum which can range from a complete lack of vision and hearing to varied combinations which may include some degree of usable vision or hearing. This combination is especially significant since these are the two primary ways we take in information about our environment and interact with people. It is not uncommon for deaf-blind people to be isolated from meaningful contact with others and struggle with a compromised ability to accomplish many of the tasks of daily life that most people take for granted. The combined impairment of vision and hearing is occurring more frequently among our fellow Coloradoans, especially the aging population and veterans returning from military service.

Donald is one such individual who served in Iraq until he was injured as a result of a nearby exploding I.E.D. While among the few in his unit who survived, Donald lost most of his hearing and was left with very limited speech discrimination, even with the assistance of powerful hearing aids. Donald returned to civilian life and received support from the Veteran's Administration and the Department of Vocational Rehabilitation to reintegrate into the workforce as a computer programmer. A few years later, he began to experience loss of vision resulting from macular degeneration. Now as a deaf-blind person, Donald was unable to benefit from learning traditional "talking" software used by others in his profession who adapt to their blindness or low-vision. He found that he not only needed to learn new complex, tactile ways of interacting with his computer and work station, but that he was unable to acquire the necessary skills in a traditional learning environment. Adding to his frustration, Donald found himself isolated from his friends, co-workers and former military buddies. He did not possess adequate adaptive communication skills necessary to socialize face-to-face, make or receive phone calls, text or communicate by email. Like the majority of individuals who experience this dual sensory loss, Donald did not consider himself to be "deaf-blind," since he still had some minimal degree of auditory and visual perception. He was unaware of existing services and technology that could assist him in reclaiming his career and regaining his independence. While Donald is a determined and motivated individual, he will still need access to trained and informed professionals along with a functional network of support to succeed in living a self-sufficient and productive life.

A large number of deaf-blind people in Colorado live isolated and dependent lives. Finding jobs, getting around the community safely or independently, finding housing, and communicating with other people are all activities where deaf-blind people encounter significant barriers. They are frequently faced with inadequate and limited options such as having to be dependent and live with relatives or in an institutionalized setting. Deaf-blind interactions with law enforcement and the courts are often frustrating and frightening. For example, an individual who can't hear, see, or verbalize their needs is misperceived as being dangerous or mentally incapacitated simply because of the lack of a mutually intelligible mode of communication.

Jason, a 69 year old retired farmer who had gradually lost his hearing and vision in the course of his work on the farm, learned this unfortunate reality when he was erroneously arrested as a result of a misunderstanding while visiting his local shopping mall. On this occasion, Jason had made arrangements to meet a friend and became disoriented while navigating to their meeting place in the mall food court. He had taken a wrong turn ending up behind the checkout counter of a store specializing in expensive women's clothing and jewelry. As he was touching the register and other items on the sales counter in an attempt to determine where he was, he attracted the attention of store personnel who had stepped away to help a customer. Jason was unable to effectively explain his actions or respond to questions from the manager or mall security, and law enforcement was contacted. It is quite

likely that if Jason had been connected to deaf-blind supports and services, he would have been aware of strategies for coping with this type of situation: perhaps something as simple as carrying a laminated set of cards explaining his needs and requests for support, or having the assistance of a G.P.S. connected with an Apple Watch to provide him with tactile prompts for navigating.

Like Jason, many deaf-blind individuals have trouble communicating with others and engaging in normal daily activities both business and social. For instance, they may struggle just to navigate in a building while going to a medical appointment or job interview. Issues as simple as finding a particular building entrance/exit, locating elevators, specific offices or just finding someone to ask for help can easily present significant challenges. In social situations such as going out to eat with friends, a deaf-blind individual is often unable to participate in a meaningful way, see who is present, read facial expressions, or hear and understand what is being said by companions and food servers.

Accurate data on deaf-blindness are not currently gathered at the state or national level. Thus it is not known exactly how many people in the United States or in Colorado are deaf-blind. In fact, part of this proposed plan addresses the need to gather hard data on deaf-blindness in our state. We can make both low and high conservative estimates based on available data. Using 2000-2014 Community Inclusion Data at the low end, and the Helen Keller National Center and 2010 US Census estimate at the high end, we conservatively estimate the number of deaf-blind people in Colorado at a minimum of 5,000, rising to a more probable 21,000 when including those unrecognized individuals who are losing their vision and hearing as a result of aging.

In order for programs and services to be successfully implemented in Colorado, consistent outreach, networking, resources and funding must be identified, developed and coordinated. The Colorado Deaf-Blind Task Force has put together a plan to lay the groundwork for service development and provision for Colorado's deaf-blind population. Please take a few minutes to read this proposal for bringing deaf-blind services to Colorado.

As Americans, we are defined by our diversity, and that is our chief strength. In truth, deaf-blind people *can* be self-sufficient, hold jobs, pay taxes, own homes, raise families, engage with the larger community, and contribute to society in unique and enriching ways, provided they have access to some very basic supports. So what is the solution? How *do* we bridge the gap between those with Deaf-blindness and the world in which they live? Many other states have already asked these questions and targeted consistent program areas for service solutions. There are four important types of services that can enable deaf-blind people to be independent in their daily lives:

1. Assistive technology for communication with others and safe interaction with the environment.
2. Interpreters and Support Service Providers (SSPs) to enable communication with other people and to navigate physical and social environments.
3. Orientation and Mobility training.
4. Employment and Housing: skills training, reasonable accommodation in the workplace, assistance finding and keeping appropriate housing, and in home assistive technologies.

OVERVIEW OF NEED AREAS:

1. Assistive technology for communication with others and safe interaction with the environment:

Deaf-blind individuals use a wide range of communication styles that include American Sign Language (ASL), Tactile ASL (TASL), finger spelling, print on palm, braille, text to speech and voice. In addition, communication is augmented by personal listening devices, hearing aids and cochlear implants. Assistive technology such as video phones, tablets with large print text, braille displays combined with smart phones, computers with software to magnify text or convert text to speech or braille can expand the individual's ability to communicate. Other tools

such as FM and other amplification systems, CART services (Onscreen real-time large print typing of communication that is taking place) or sign language interpreters using specialized techniques improve communication in various settings, allowing many deaf-blind individuals to successfully participate in activities like trainings, education, meetings, community gatherings, even enjoy attending entertainment venues such as the theatre, museum or a guided tour.

Communication is one of the most essential functions to bridge the barriers between the deaf-blind world and the hearing and seeing world. If we connect these two worlds we can begin to diminish the isolation and many of the challenges a deaf-blind person experiences.

Consider Connor, a 17 year old young man who is hard of hearing and has limited vision as a result of a rare genetic disorder. He has been in special education within his local school district throughout his academic journey. Though he received services sufficient to support his school performance, he was not provided with good socialization skills training. He lacked the understanding and communication to interact with his peers in a spontaneous and comfortable manner. Therefore, he became isolated from his peers and social experiences as a direct result of his dual sensory limitations. This situation did not change until he was able to utilize iCanConnect, the Federal Communication Commission's National Deaf-Blind Equipment Distribution Program (NDBEDP), administered in Colorado by the Commission for the Deaf and Hard of Hearing. This program, which provides telecommunication equipment and training for eligible deaf-blind individuals, is an excellent step in attacking the communication barrier. This program enabled Connor to have accessible equipment including a computer system at home that was designed to meet his specific needs. Since receiving his internet and telephone access equipment, Connor has established a YouTube channel to share his research in unique specialized areas of interest with others, as well as a Facebook account to post videos and pictures of him engaging in normal family events and recreational activities. His peers were better able to see him as a person, with similar and differing interests and abilities. Their perception of him began to change, and they began to accept him as being a peer and at least on some level an equal. His improved communication enhanced his socialization in person as well as via text and instant message. By connecting Connor's home, school and social world; he became engaged in his peer group as an individual rather than just a young man who was known only by his special needs.

2. **Interpreters and Support Service Providers (SSPs) to enable communication with other people and to navigate physical and social environments:**

With trained interpreters and appropriate communication systems, deaf-blind individuals can talk easily with others, live in communities of their choice, own their own homes, and train to be successfully employed in jobs that pay competitive salaries, potentially moving them off of government subsidized incomes.

Amber is deaf-blind, deaf with low-vision resulting from Usher Syndrome. She has established a successful personal and work life with sufficient training, support and access to communication resources. Amber is a homeowner and a parent of 2 children. She has worked for the federal government for more than 20 years and has an active personal and work lifestyle. At one point in her career, Access-A-Ride through RTD STOPPED servicing her residential area resulting in her inability to independently go to work. In order To keep her job, she needed access to this public transportation system. She felt forced to sell the home she loved and raised her family in to move to an area that was within the new boundaries served by Access-A-Ride. Amber is able to accomplish many activities of daily living requiring the need to communicate such as grocery shopping, attending school conferences, doctor appointments, recreational and social events in her community and traveling abroad. She relies on assistive technology, text and video relay service to do business transactions, communicate with friends, family, co-workers, teachers and new acquaintances. Other vitally important services that enable Amber to function so well include Tactile ASL interpreters and Support Service Providers.

Support Service Providers (SSPs) are specially trained professionals who work specifically with deaf-blind individuals providing visual and environmental information, communication access, transportation and guidance within the physical environment. This could mean an airport, train station, medical facility, restaurant, grocery store, fitness center or any number of possibilities that reflect the wide variety of errands and community activities which we each engage in as a part of our daily lives. This support can also take place at home with activities such as reading mail, identifying and labeling food, or locating and organizing clothing, personal possessions and household cleaners. An SSP typically works with a single individual, and acts as a guide and communication facilitator. A trained SSP is helpful but objective, supportive yet empowering, and limits imposing their personal preferences while providing services. The SSP is therefore, by definition, not a natural role for a friend or family member. The provider requires training and a measure of accountability to be effective. Support Service providers are not the same as interpreters. Their roles differ in several key areas. Specially trained sign language interpreters work with people who are Deaf, hard of hearing, and deaf-blind. SSPs work solely with people who are deaf-blind. While the interpreter translates communication that a person who is deaf, hard-of-hearing, or deaf-blind is unable to hear and see, the SSP serves as the deaf-blind individual's eyes and ears in situations requiring this support. A professional SSP can also assist a deaf-blind individual in employment and other professional settings.

Consider Jacquelyn, a deaf-blind curriculum planner and workshop facilitator. She utilizes adaptive software to conduct internet research, prepare her materials and conduct webinars. When she facilitates an onsite workshop, she is assisted by a professional SSP who sits behind her to provide tactile cues discreetly on her back and arm. Pro-Tactile and Touch Signals are a system of cues which provides Jacquelyn with environmental information such as where people and tables are located, when there are questions, where the questioner is sitting, when someone entering or exiting the room, people's emotional responses and when multiple people are in agreement or have questions. This assistance is all carried out without interrupting Jacquelyn's presentation or causing delays while the SSP is providing these cues.

3. **Orientation and Mobility training:**

A combined deficit in hearing and vision can make travel and navigation difficult, dangerous or even life-threatening. The instruction of blind and/or deaf-blind people to navigate safely in their environment is referred to as Orientation and Mobility Training or simply "O&M". O&M training can refer to navigation as simple as learning to get around in a new home, workplace or other unfamiliar building, or it can be more complex, such as traveling to a new part of town on public transportation or exploring transportation solutions when planning a trip to another city, state or country. O&M instruction is essential to providing guidance in determining an individual's ability to travel safely given their unique combination of vision and hearing impairments. An O&M trainer may teach someone to work with specialized mobility tools such as a guide dog, a vibrating white cane, specialized glasses or a talking G.P.S. unit. Other assistive technology which can be very helpful include traffic light signals that vibrate when a green light or walk signal is present, large print signage and/or verbal cues announcing stops on public transportation and smart phone applications that provide maps, scheduling information in large text or speech. Individuals will have differing degrees of hearing and visual perception. So their capacity to perceive an approaching light rail or public bus will vary, as well as their preferences and abilities to use existing compensatory methods and devices. Orientation and Mobility instruction is far more specialized for deaf-blind due to the wide range of communication styles with which the trainer must be familiar to effectively teach students skills for safe navigation, self-orientation, interaction with the public and strategies for coping with emergencies.

In the absence of Orientation and Mobility training, a deaf-blind individual is often faced with either depending on someone to drive them where they need to go, paying for expensive taxi or ride share services, depend upon poorly managed accessible paratransit services, or travel independently and possibly be at risk of a serious injury.

Suzie is a 38 year old independent contractor who travels throughout the state to train deaf-blind individuals in the use of accessible telecommunications equipment. She received O&M training as a young blind adult and she has gradually lost much of her hearing. She has had to maintain an awareness of her degenerative hearing, and be willing to constantly reassess and acknowledge the limitations these changes present with regard to her safe travel. She can use a guide dog effectively to move safely through buildings, down sidewalks, and across some streets. However, there are unsafe weather conditions and busy street crossings that are simply too difficult for her to navigate. She has some understanding of the light rail system. And she is able to hear an approaching train; however she is not able to distinguish it from the locomotive system that runs parallel with some of the light rail lines. Since every light rail station is designed differently, she cannot predict the location of accessible ramps, track crossing points or bus transfer points. In short, every time she needs to travel to a new location, she must carefully plan her route, assess the weather conditions, and evaluate all potential hazards such as construction sites and road closures due to special events. Even with the most careful planning, there are times when Suzie is still presented with unsafe and frightening situations, such as when she becomes disoriented by an emergency vehicle rapidly approaching with sirens wailing while she is in the midst of crossing a major intersection. There are many situations which require her to hire expensive car services, rely on poorly managed and unreliable paratransit systems or choose to stay home and forego social and employment opportunities.

Suzie is more fortunate than many deaf-blind Coloradoans who have not had an opportunity to receive any O&M training or information about available transportation options. Part of the reason for this is that there are limited program opportunities for a deaf-blind person to receive this type of training. For example, there is O&M available through the public school system for children K-12, as well as through the Department of Vocational Rehabilitation if the deaf-blind person has an active case open for employment services. The only other available option is to seeking hire an O&M trainer on an hourly fee for service basis. Many available O&M trainers have not received specialized training to enable them to communicate with or understand the special challenges facing a deaf-blind traveler, have awareness of effective assistive technology solutions, or be well versed in sign language.

4. **Employment and Housing: Deaf-blind individuals may require services such as skills training, reasonable accommodation in the workplace, assistance finding and keeping appropriate housing, and in home assistive technologies.**

As stated above, assistive Technology is one of the most critical supports required to enable deaf-blind people to be self-sufficient and live or work independently. Telecommunication equipment such as specialized phones, tablets, stand-alone magnifiers, computers with magnification or text to speech screen reading software, and Braille displays help deaf-blind people to access email, engage in conversation via video phone or web camera, surf the web, and otherwise explore limitless social and intellectual boundaries. Other equipment that can aid deaf-blind people living independently includes devices such as a signaler that beeps loudly, flashes and/or vibrates to alert the person of the ringing of a doorbell, phone or safety alarm. Once alerted, an individual can answer the door or respond to a smoke detector. Some of these life changing technologies are currently being made available through existing programs like iCanConnect which provides telecommunications equipment and training for deaf-blind individuals through the National Deaf-Blind Equipment Distribution Program (hereafter referred to as NDBEDP). Other existing assistive technologies can aid in face-to-face communications, allow for participation in meetings, shrinks the noise level in a room by using microphones that filter out all but the prominent speaker in a crowd. Technology is ever changing and evolving. Cochlear implants and specialized hearing aids bring hearing and speech recognition to people who have otherwise completely lost any functional hearing.

The crucial role of using assistive technology in enabling a deaf-blind person to live and work independently can be understood better when considering an example of someone like Ray Anne. Ray Anne is a deaf-blind homeowner, parent and grandparent as well as a systems analyst, earning a 6 figure income working for a fortune 500 company responsible for the backend programming and monitoring of global worldwide G.P.S. aircraft tracking. Prior to

receiving training and supportive assistive technology, Ray Anne was unable to financially support herself and her children. She could only hold a job earning minimum wage. Today, she is the primary wage earner in her family, supports several young grandchildren and is providing a home for her aging father and stepmother. This is just one example of a deaf-blind individual for whom assistive technology is the determining factor as to whether they will be able to live independently, pursue an education, work, and access their community.

Colorado currently has a limited array of services available for deaf-blind people, including NDBEDP and the limited employment and housing services which are available to the general population. Many deaf-blind people in Colorado are unaware of these services, some of these services are not tailored to the unique needs of deaf-blind people, and some programs are insufficiently funded for deaf-blind people to access them to the degree that would enable independence.

The first crucial steps are clear. We need to find and identify Colorado's deaf-blind people and connect them to those services that already exist. We need to get a more accurate sense of how many people in Colorado are deaf-blind and where they are located. And we need to establish some basic SSP and O&M services for the many who aren't eligible for the very small SSP and O&M services that currently exist. This can be accomplished through the addition of 1.5 Commission for the Deaf and Hard of Hearing staff and the creation of a very small service program for SSPs and O&M training. The Colorado Deaf-Blind Task Force, in collaboration with these new Commission staff will work on the next steps, which involve developing, expanding, and creating an array of fundamental services necessary to level the playing field for deaf-blind Coloradoans.