

Florida Department
of Education
Division of Vocational
Rehabilitation

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GUIDE ON SERVICES TO
INDIVIDUALS WHO ARE
DEAF-BLIND*

* This supplements “Guide on Serving
Individuals who are Deaf, Hard of
Hearing, Late-Deafened, and Deaf-Blind”

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Note: For reference purposes, vocational rehabilitation (VR) counselors are identified as counselors throughout this guide.

INTRODUCTION TO DEAF-BLINDNESS

This guide is designed to assist counselors in rehabilitation service delivery to individuals who are Deaf-Blind. General practices for service provision may be found in the (Division of Vocational Rehabilitation) DVR publication titled, "Guide on Serving Individuals Who are Deaf, Late-Deafened, Hard of Hearing, or Deaf-Blind."

WHAT IS DEAF-BLINDNESS?

Deaf-Blindness is a combined loss of vision and hearing. This dual sensory loss has a significant impact on daily life functioning as it blocks access to communication, environment and people (Deaf-Blindness Resources).

Deaf-Blindness is a unique disability population (Lauger, 2013). Individuals with Deaf-Blindness may encounter different ranges in both hearing and vision and may or may not experience a total loss of auditory and visual perception. Certain individuals will experience hearing loss first and vision loss second while others experience the opposite. (Wolff-Heller, Kennedy, 2001).

Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is a national rehabilitation program serving youth and adults who are Deaf-Blind. The following is an excerpt of the definition of Deaf-Blindness as written in The Helen Keller Act (to read in its entirety, visit <http://www.hknc.org/WhoWeServeDEFINITION.htm>).

The term "individual who is deaf-blind" means any individual –

- (A) (i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both of these conditions;
- (ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(B) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment or obtaining vocational objectives.

HOW MANY PEOPLE ARE DEAF-BLIND?

According to the 2007 study by the National Center on Deaf-Blindness, it is estimated that 45,000 to 50,000 persons are Deaf-Blind living in the United States.

[Reference Gallaudet University Library -

<http://libguides.gallaudet.edu/content.php?pid=119476&sid=1029203>]

ETIOLOGY OF DEAF-BLINDNESS

There are many disorders and diseases that can result in an individual becoming Deaf-Blind. The most common are: Rubella, CHARGE (Coloboma, Hear anomalies, choanal Atresia, Retardation of growth and development, and Genital & Ear anomalies), Usher Syndrome, genetic disorders, and illness. These can also lead to a wide range of hearing and vision losses which can be progressive.

It is important to find out the:

- individual's diagnosis and causes so service professionals will know what to expect in the future when serving individuals who are Deaf-Blind; and
- Age of onset which may determine how the individual who is Deaf-Blind communicates.

COMMON EYE CONDITIONS INVOLVING DEAF-BLINDNESS

Common eye conditions affecting individuals who are Deaf-Blind include Retinitis Pigmentosa, Macular Degeneration, Diabetic Retinopathy, Optic Nerve Atrophy, Cataracts, or Glaucoma.

Approximately fifty percent (50%) of individuals have Usher Syndrome (Usher I, Usher II and Usher III). Usher syndrome is a genetic disorder with hearing loss and a gradually developing vision loss.

- Individuals with Usher I are born deaf and begin to lose vision usually in their teen years.
- Individuals with Usher II are born hard of hearing and start to lose vision at a slower pace than individuals with Usher I.
- Individuals with Usher III are usually born with normal vision and hearing, or with a mild hearing loss, and start to lose both senses later in life.

The vision loss associated with Usher Syndrome is called Retinitis Pigmentosa.

Retinitis Pigmentosa is an eye condition that causes decreased vision at night and in low light, loss of peripheral vision, and in advanced stages loss of central vision. Usher Syndrome can also generally cause balance difficulties (Frequently Asked Questions about Deaf-Blindness, 2009).

Macular Degeneration is an eye condition that affects many individuals who are Deaf-Blind. Macular Degeneration causes blurred, distorted, dim vision or a blind spot in the center of visual field. Peripheral vision is generally not affected.

Diabetic Retinopathy is another eye condition that results from the damaging effect of diabetes on the circulatory system of the retina. An individual with this condition may experience floating shadows in vision, blurred or hazy vision, dark or empty vision, problems with color perception or vision loss.

Optic Nerve Atrophy is the degeneration of an optic nerve, which carries vision information from the eye to the brain. Individuals who have Optic Nerve Atrophy may have dimmed or blurred vision as well as a reduced field of vision.

Cataract is a condition in which the lens of an eye, that is normally clear, becomes cloudy or opaque.

Glaucoma is defined as a disease in which the pressure of the fluid inside the eye is too great, resulting in a loss of peripheral vision (Glossary of Eye Conditions - see page 13).

COMMUNICATING WITH INDIVIDUALS WHO ARE DEAF-BLIND

Individuals who are Deaf-Blind have a wide range in degrees of vision and hearing loss and utilize various approaches in communication. Different communication options include:

- Tracking sign language in contact with the signer's forearm.
- Tactile identification of sign language into the hands of the individual.
- Close vision requiring the signer to be in very close proximity to the individual.
- Distant vision requiring the signer to sit at quite a distance to allow the individual to see the entirety of the interpreter and the message.
- Spoken English with a variety of technologies to enhance residual hearing.
- Print on palm for an individual who has never learned sign, but does not have residual hearing any longer.

Whichever modality the individual who is Deaf-Blind uses to gain information from the world via residual vision or hearing and/or touch is the individual's preferred communication method. Individuals with available residual hearing may use amplification (hearing aid, pocket talker, cochlear implant). Those who are Deaf-Blind and use sign language may utilize touch (tactile communication) to converse.

Individuals who are Deaf-Blind do not all share similar lifestyles or needs. They differ significantly in etiology, age of onset, degree of vision and hearing loss, communication preference, educational background and life experiences. Not everyone who is Deaf-Blind experiences total vision and hearing loss. Communication preferences will depend on which sense the individual loses first, whether it is hearing or sight. Individuals who first lose their vision are more likely to utilize assistive listening devices or technology using braille. Those who first lose their hearing tend to utilize sign language through either tactile or close vision and will require the use of an interpreter.

Effective communication is paramount for successful rehabilitation. When providing VR services to an individual who is Deaf-Blind, one must know the individual's preferred communication mode for receiving direct information. An individual who is Deaf-Blind and applies for VR services may indicate a request for sign-language or tactile

communication on the referral/application form. It is important that the request for a preferred method of communication be honored to ensure that effective dialogue occurs between the individual and the counselor.

IMPORTANT FACTORS TO CONSIDER

Cultural Aspects

Individuals who are Deaf-Blind have an ongoing need for daily communication to stay in touch with the world. Whenever we meet such individuals, it is important to be aware of their method of getting our attention and make appropriate introductions and exits during conversations. The following steps may be helpful:

Step #1: Tap the individual on the shoulder and wait for him/her to turn towards the tap. If the individual moves back and visually scans the surroundings, he/she will attempt to communicate visually. If the individual reaches out with a hand, he/she will attempt to communicate by hand (tactile). Once connection is established, the first priority is to make an introduction. It helps to take time to introduce names and roles.

Step #2: To make an introduction, say “Hi, this is {state your name}. I am your VR counselor.” Once the individual recognizes who is communicating with him/her, interaction may begin. It is also good practice to let the individual know when someone is leaving the conversation and where he/she is exiting. (Southeast Regional Transition Institute Team, 2013).

Logistics and Environment

All staff need to be fully aware and prepared to make environmental adjustments to ensure effective communication. This includes attire of the interpreters, room lighting and seating arrangements. The staff should also confirm the individual’s preferred mode of communication, type and degree of hearing/vision loss, and seating preferences before each meeting/appointment so they can effectively advise the interpreters if necessary. (Goujon, 2000).

Time

To ensure a good flow of communication, extra time may be necessary in appointments. The counselor may need to plan in advance to accommodate the individual’s communication needs (Southeast Regional Transition Institute Team, 2013).

Breaks

Communication involving individuals who are Deaf-Blind can be physically exhausting. It is a good practice to plan for and offer a few short breaks during appointments. It allows for both physical resting and an opportunity for the individual to “absorb” the information that was presented. (Southeast Regional Transition Institute Team, 2013).

TECHNOLOGY FOR INDIVIDUALS WHO ARE DEAF-BLIND

Technology makes it easier for individuals who are Deaf-Blind to communicate with others and to live more independently.

- Computers can be accessed using technology including braille readers, Closed Circuit Television (CCTV), and zoom screen magnifiers.
- Voice over software can enhance residual hearing to access email and make phone calls.
- Refreshable braille devices, smart phones/iPads/tablets can be used to communicate one-on-one with others. Various signalers can be used to alert an individual who is Deaf-Blind.

To see examples, visit National Deaf Blind Equipment Distribution Program website (<http://www.icanconnect.org/>) for latest technology.

SUPPORT SERVICE PROVIDER (SSP)

SSPs are service providers who assist or explain the immediate environment/ surroundings to an individual who is Deaf-Blind. They are not interpreters, but are conveyors of information regarding space around the individual who is Deaf-Blind. Once the individual receives information, he/she is empowered to make decisions as to what to do next. For example, if the individual uses an SSP to go to an appointment with the counselor, the role of the SSP may be to transport the individual to this appointment, guide him/her to the waiting room and explain the environment of the waiting area and meeting room. The staff or vendor interpreter may meet with the individual prior to the start of the appointment to learn how the individual wishes to communicate. Again, the role of SSP only serves to provide information and supports to the individual.

Like interpreters, SSPs remain impartial, maintain confidentiality and work in various settings.

The SSPs will not answer any questions on behalf of the individual so the individual should be asked directly. Additionally, SSPs do not:

1. Provide personal care
2. Run errands without the individual
3. Teach or interpret medical or legal business
4. Make decisions for the individual

Those who serve as interpreters need to be reminded that SSPs play a different role. (Bourquin, et al, 2006).

It is common knowledge that not everyone who is Deaf-Blind knows how to utilize an SSP and/or an interpreter. The loss of both visual and hearing senses creates dependency on others for information or access to the world. Isolation is a common issue among individuals who are Deaf-Blind. It is helpful for the counselor to ask the individual to share his/her limitations or concerns.

THE REHABILITATION PROCESS FOR INDIVIDUALS WHO ARE DEAF-BLIND

The key to successful rehabilitation is full participation in the process and services by the individual who is Deaf-Blind. Equal and full participation involves the provision of effective communication throughout the VR process.

Any VR service, inclusive to an individual who is Deaf-Blind, must consider effective communication as the primary factor for success. Other factors that are also significant to overcoming barriers to employment, include, but are not limited to, personal adjustment to vision and hearing loss, orientation and mobility, transportation, communication access, self-advocacy skills, adaptive technology, adaptive skills for community living, development of social opportunities and social skills, and provision of SSPs (Watson, et al. 2008).

It is essential the individual's communication needs are determined in advance so proper supports and modifications are in place before and during every meeting/appointment. The staff must also keep in mind that any interactions with the individual may require extra time for communication. It is challenging for the individual to process large amounts of new information using non-verbal modes of communication (tactile communication) during the appointment. Therefore, it is important to help

ensure clear communication between the individual and the counselor during appointments.

It is good practice to case note all methods of communication, services and accommodations provided during each appointment either in the VR office or at an external location. This practice ensures that necessary documentation is available when the case is reviewed. In addition, such documentation shows that VR is in full compliance with both Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act.

DUAL CASES WITH THE DIVISION OF BLIND SERVICES

The Division of Vocational Rehabilitation (DVR) has a [Memorandum of Agreement \(MOA\)](#) with the Division of Blind Services (DBS). The agreement details how individuals with visual loss who require services from both divisions can be effectively served. If an individual who is Deaf-Blind applies for DVR or DBS services, the initial local office division's supervisor contacts the other division's local office supervisor to jointly assign the case to a VR counselor and a DBS specialist. Together, the VR counselor and the DBS specialist will determine how the individual should be served. It is good practice for DVR and DBS staff to meet and discuss whether the case should be a dual case involving both divisions at the same time. Or, if one division should take the lead and full responsibility to serve the individual while the other division provides consultation as needed.

OUTREACH AND REFERRAL

The process of outreach and referrals for individuals who are Deaf-Blind may require additional effort and time by the counselor. The counselor may also work with various contacts such as:

- Deaf Service Centers
- Centers for Independent Living
- Florida School for the Deaf and the Blind
- Public School Special Education Programs
- The Helen Keller National Center Representative
- Division of Blind Services
- Rehabilitation Centers and Lighthouses for the Blind
- Florida and Virgin Islands Deaf-Blind Consortium

During the initial contact, it is also essential for the counselor to inquire about the individual's communication preferences at referral/application and prior to the initial interview.

INTAKE

A comprehensive and thorough intake interview allows the counselor to gather information such as needs, strengths, and history of the individual. Communication access needs to be arranged as well. During the intake process, it is important to arrange for extra time when working with an individual who is Deaf-Blind. During the intake interview, the counselor will explain the VR process, plan for services, and the individual's rights and responsibilities. Often, the counselor will need to conduct the session at a slower than usual pace. The counselor needs to ensure that any information discussed is clearly understood by the individual. The slower pace allows the individual to process the information coming in tactilely or through other means and to ask any questions as needed.

ASSESSMENT

Arranging assessments for individuals who are Deaf-Blind can be a challenge. The providers need to determine appropriate test batteries, appropriate norms and control bias in test procedures.

The responsibility for providing accommodations at assessments for the individual falls upon the VR counselor. The VR counselor shall notify and provide the service provider with details as to arrangements for necessary accommodations. However, if DBS arranges for assessments, DBS is responsible for any accommodations that are needed.

If this is a dual case and the individual who is Deaf-Blind will benefit from a comprehensive out-of-state assessment (i.e. Helen Keller National Center), the VR counselor and the DBS Specialist shall refer to the MOA on sharing costs to avoid duplication of services. If the VR counselor and the individual choose to use an in-state program for assessment, it is a good practice to provide information on Deaf-Blindness and communication access to the provider.

INDIVIDUALIZED PLAN FOR EMPLOYMENT (IPE)

The success of an Individualized Plan for Employment (IPE) requires effective joint planning and understanding between the individual who is Deaf-Blind and the counselor. For individuals in dual cases with both DVR and DBS, each division will develop separate IPEs. Both divisions are to coordinate the provision of the services under an IPE to avoid duplication of services. Copies of the IPEs shall be shared between the VR counselor and the DBS specialist.

SERVICES/OTHER RESOURCES

It is helpful for the counselor to inquire with local providers on available community services and resources to make it possible for successful rehabilitation of an individual who is Deaf-Blind. Local resources include accessible transportation, support services providers (SSP), and available community programs for on-going support. Many Centers for Independent Living as well as Deaf Service Centers provide community services that may help individuals who are Deaf-Blind.

Another useful resource to consider is contacting Helen Keller National Center's regional representative for Florida. Florida's HKNC representative can be found on the HKNC website (www.hknc.org).

Other resourceful websites on Deaf-Blindness:

- American Association of Deaf-Blind (www.aadb.org)
- National Center on Deaf-Blindness (www.nationaldb.org)

JOB PLACEMENT/CLOSURE

Providing job placement services to individuals who are Deaf-Blind can be a challenge. There are many steps to consider when working with individuals who are Deaf-Blind, such as assisting with job applications, educating employment service providers and employers, providing effective communication during job interviews, ensuring accessibility on the work site, and providing job coaches when required.

CASE CLOSURE/POST-EMPLOYMENT SERVICES

When an individual who is Deaf-Blind is placed on a job, it is helpful for the counselor to follow-up with the employer to ensure that it is a mutually beneficial placement and to assist with any issues that may arise (post-employment services). The areas of

communication and mobility are common issues in employment and may require post-employment services. The counselor may need to provide the employer with resources and guidance on providing accommodations after DVR closes the case.

STATEWIDE TECHNICAL ASSISTANCE

To receive technical assistance concerning all issues covered in this guide as well as other issues related to interpreters and services to individuals with hearing loss, contact Deaf, Hard of Hearing, and Deaf-Blind Services at DVR headquarters.

The phone numbers are as follows:

- Toll-Free 800-451-4327 (Voice or VRS)
- 850-245-3353 (Voice or VRS)
- 850-270-5325 (VP) or 850-298-8818 (VP)

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