

**Deaf Self-Advocacy Training:**

**Curriculum Toolkit**

Second Edition

**Suggested**

**Training Approaches for Deafblind Audiences**

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**Introduction**

The adaptations provided in this section were developed by Jean Healy and Janet K. Marcous, two Deafblind professionals and, vetted by a panel of experts. The curriculum was then and field tested by ten Deafblind DSAT Trainers in August 2013. These ten Deafbind individuals came together for four days, working long into the night each day. Under the training leadership of Lillian Garcia Peterkin and Laura Thomas, they experienced the curriculum first hand as Deafblind consumers, taught parts of the curriculum as Trainers and then provided feedback as Experts. DSAT extends its sincere appreciation to this group of ten for their contributions:

Ashley Benton (NC) • Lee Clark (MN) • Elaine Ducharme (MA) • Andy Granda (CA) • Victoria Ann Magliocchino (FL) • Karen Parks (CO) • Kim Powers-Smith (TX) • Angela Theriault (WA) • Christopher Woodfill (NY) • Bryen M Yunashko (IL)

The Second Edition *DSAT Curriculum* (2013) includes seven modules. Each module include content information, suggestions for group discussion, role-play and other activities. For purposes of this Supplement, each module was reviewed independently to match content and activities with Deafblind training approaches, communication and visual needs, and Deafbind experiences.

This document provides suggested training approaches for Deafblind audiences, including tips for Deafblind trainers, information on support service providers and interpreters, additional resources specific to this audience, and a glossary of related terms.

As part of the Supplement, but located in a separate document, is *DSAT Video Vignette Summaries*. Both of these documents comprise *Enhancing the DSAT Experience for Deafblind Trainers and Consumers Supplement* (2013).

The trainer is expected to teach the content provided in the Second Edition *DSAT Curriculum* (2012), while being aware of and ready to discuss specific Deafblind experiences. As noted, the Second Edition *DSAT Curriculum* (2012) is available in electronic Braille and in Word 12 point without color or graphics on this disk. It is also available in Disk #1 in .pdf with color and graphic enhancements.

Each module adaptation follows the format below.

* Appropriateness of Overview, Goals and Objectives, with suggested additions or changes
* Estimated length of time needed to fully teach the Module
* Suggested discussion items, case studies and/or role-play activities
* Specific Deafblind informational points

Do make sure to refer often to the Second Edition *DSAT Curriculum* (2012) and the *DBSAT Video Vignette Summaries*. Do this when learning the information and when creating your presentation and content to meet the particular access and knowledge needs of your audiences.

The DSAT curriculum utilizes a great number of video vignettes. Depending upon your audience, the video vignettes may or may not be appropriate. To aid you in understanding the goal and content of the video vignettes, refer to *DBSAT Video Vignette Summaries*, which provides a general summary of each vignette*.*

In those instances when video is not the best training tool, replace the video with a discussion, case study and/or role-play that covers the video content. In this way you, as the trainer, can control the pace and pause when needed to match the participants’ communication. Suggested role-play and discussion items are provided throughout the document.

The NCIEC DBSAT Workgroup hopes you find this information helpful. We look forward to receiving any feedback you may have.

**Module One:**

**Advocating for Yourself and Others**

1. Overview, Goals and Objectives are appropriate for Deafblind participants

1. Estimated Length of Module: Six Hours
2. Trainer-Led Discussion, Case Studies, Group Discussions, and Suggestions

**Key issues**

This module focuses on the special and specific challenges that face Deafblind individuals as they advocate for communication access.

* Introduction to Deaf Self-Advocacy Training and Discussion of Successful Advocacy Strategies:

The trainer asks Deafblind participants to list what works for successful advocacy.

* **Communication Challenges**

The trainer gives examples of challenges individuals may experience with communication access.

**Case Study**

Interpreting for Medical Appointments

Role-Play: A person is at a medical appointment where there is no interpreter provided, even though a request was made in advance.

Follow-Up Group Discussion Topic: There is an interpreter at the medical appointment but he or she is not qualified or skilled as an interpreter.

In-Class Discussion: Discuss the participants’ reactions to the role-plays. Ask the same questions as listed in the Second Edition *DSAT Curriculum,* In-Class Discussion box (page 16).

* **Deafblind-Specific Advocacy Example**

To advocate means to give support for something and to create change to get what you need or want. You can advocate for yourself or for other people. For example: you find your state agency plans to cut Deafblind services from the budget. The reduced level of service will affect you and many Deafblind people in your state. This makes it difficult for you and other Deafblind people to get the support and services you need to maintain your quality of life. You contact the state agency and ask them to keep the full range of Deafblind services. This does not help. The state agency plans to cut Deafblind services regardless.

You decide to discuss this issue with other Deafblind people in your state. They agree that if the services are cut, life will become very difficult. You and the other Deafblind people decide to meet with the head of the state agency to discuss the issue. When that does not lead to a solution, your group decides to write letters to local legislators (see Appendix A, Module 1. Letter can be modified to match this Deafblind issue) to ask that the funding be restored for Deafblind services so Deafblind individuals can continue their quality of life, like everyone else. This is one example of how to advocate.

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| **Did You Know?**  A study commissioned by the Department of Education in 1980 estimated that between 42,000 and 700,000 individuals have some level of both vision and hearing loss in the United States. See Turkington, Carol, and Allen E. Sussman, eds. (2000). The Encyclopedia of Deafness and Hearing Disorders, second edition. New York: Facts on File, Inc., p.62., cited at <http://library.gallaudet.edu/Library/Deaf_Research_Help/Frequently_Asked_Questions_(FAQs)/Statistics_on_Deafness/Deaf-Blind_in_the_US.html>. |

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| **Did You Know?**  The American Association of the Deaf-Blind (AADB) was founded in 1937 as the American League for the Deaf-Blind, and was incorporated in 1940 in New Jersey. It was initially a service organization to help set up homes for Deafblind people, and later, provided Braille to print and print to Braille transcription services, shopping services, and a Braille lending library. During the 1950s it became a membership organization, and after various name changes, was re-named the American Association of the Deaf-Blind in 1979. AADB held its first national convention in 1975 near Cleveland, Ohio. In 1984, it became a 501 (c) (3) organization. AADB provides advocacy, trainings, workshops, and involvement with legislators, manufacturers, and other entities on behalf of Deafblind people. |

* **Importance of Advocacy**

Advocacy is important for many reasons. Advocacy helps people get what they need, such as jobs, captioning, services and interpreters. Establishment of the Deafblind Community Access Network (DBCAN) in Massachusetts is an excellent example of successful advocacy in the community. Individuals, their families, interpreters, Deaf and hearing supporters came together to advocate for statewide support service providers (known in Massachusetts as DBCAN providers) for Deafblind adults. What if the people of Massachusetts had never come together to advocate for provider support?

* **Communication Access with an Interpreter**

The trainer explains possible self-advocacy outcomes of requesting an interpreter for medical appointments.

* **Communication Access list**
  + TTYs with large visual and Braille displays
  + Communication Facilitators (CF) with videophones
* **Applying Your Learning**

How does having a skilled interpreter make a difference for individuals? Deafblind participants may list ways and discuss.

* **Suggested Activity**

Create your own PROFILE (hand out pre-drawn body shape on paper). Who are you? What are your communication needs? What are accommodations for your needs? Work in pairs, then the other describes his/her partner’s needs. Purpose – retain information, express communication access preferences, confidence building and importance to know “thyself” before doing self-advocacy.

**Module Two:**

**Self-Esteem and Self-Determination**

1. **Overview, Goals and Objectives** are appropriate for Deafblind participants
2. **Estimated Time**: Six hours
3. **Trainer-Led Discussion, Role-play, Group Discussions, and Suggestions**

**Key issues**

This module focuses on how loss of sight may impact a person’s self-esteem, which can lead to a lack of self-determination. A Deaf person who loses their sight to Usher Syndrome or for other reasons, has to develop additional self-esteem so they can feel proud of themselves, including their blindness or vision loss.

It is highly recommended that a great deal of time is spent discussing these key issues when teaching this Module.

* **Self Esteem Challenges**

Self-esteem for a Deaf person is often rooted in their ability to see; they feel good about the information they pick up and what they can do as they rely on visual cues and information. Once these visual pieces, such as facial expressions, begin to wane with loss of sight, it impacts how a person feels about their ability to function. This leads to diminished self-esteem and new challenges with self-determination.

In general, many Deaf people are fearful of blindness, and the issues surrounding self-esteem can be both external and internal. If a Deaf person loses the support they once had from friends due to their ongoing blindness, it may impact their sense of self-esteem. They may begin to use negative self talk, constantly belittling or putting themselves down. Because they cannot see as they once did, they may find their communication needs ever changing. If they are met with rejection for asking people to sign slower, or for using tracking or tactile signing their self-esteem and self-determination can be impacted.

**Case Study**

Losing Vision

Group Discussion: A Deaf person has just found out he or she is losing sight. List the issues that come up. Discuss each one, talking about specific issues that make them feel bad.

Group Discussion: A Deafblind individual is being told by an eye doctor that they can no longer drive and would need to learn to use a cane. How will this affect their self-esteem, as well as their self-determination?

Group Discussion: An individual now legally blind has learned that they will no longer receive services from a Deaf agency. Now, instead, they will receive services from an agency that deals with blind people. How does this impact their self-esteem?

Group Activity: Make a list of all the feelings that come up while thinking about the above role-play.

Role-Play: Once it has been discussed fully, create a role-play that shows strategies to approach these challenges and positively impact self-esteem.

Closing Discussion: Talking about these issues and putting them out in the forefront can help reduce negative self-talk. It is the isolation of one’s feelings that causes negative self-talk. A more positive self-image may result by openly discussing these feelings.

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| **FYI**  Most agencies serving blind people have no experience dealing with Deaf people and often do not have communication access available. |

**Case Study**

Stigma Associated with Vision Loss

Role-Play: A Deafblind individual who is learning to use a cane has many bad feelings about this because they no longer are anonymous. As a Deaf person they could walk down the street unnoticed, but now the cane is drawing attention and the person is feeling self-conscious.

Group Activity: Discuss the role-play above and list all the issues that come up.

Re-create the Role-Play: Show the Deafblind individual accepting their cane, turning their embarrassment to feeling proud about learning their new skill and for meeting the challenge of learning to use a cane. This takes courage, a key to a Deafblind individual’s feeling of self-esteem.

Group Activity: Discuss the above role-play, talking about how important it is to recognize the bravery of the Deafblind individual. Once one realizes that it is courageous to be able to go out in the world and navigate with a cane, independence is created. With independence comes greater self-determination and more self-confidence.

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| Did You Know?  Vulnerability is NOT WEAKNESS, but COURAGE. It takes courage to go out in the world as a Deafblind person! It takes courage to feel good as a Deafblind person. |

**Case Study**

Finding it Hard to Read Signs

Group Discussion: Communication changes for Deaf people losing sight. Too often they want to pretend they can still use their vision to follow signs when, in fact, they are having a great deal of difficulty. They start to feel embarrassed and begin negative self-talk about their ability to follow signs the way they used to. Discuss the issues involved in this situation.

Role-Play: A Deafblind individual is sitting in a group while watching someone sign, and turns to a person next to him or her and asks “what did that person say?” That person replies and says, “What’s wrong with you, you blind?”

Group Activity: Discuss the above role-play listing all the possible feelings that come up. Identify the negative self-talk that could occur and discuss why this happens.

Re-create the Role-Play: Demonstrate a positive outcome. One example might be: When the person says to you “What’s wrong, you blind?,” you could say “I am struggling with not being able to see. I do have a visual problem, but that doesn’t mean I am unable to participate. I just may need to use communication in a way that is different from yours.”

This is a key issue: To be successful, it is extremely important for self-talk to be positive. Visual signing is a core identity in Deaf culture; it’s a lifeline. When it changes due to vision loss, the Deafblind person’s identity is disrupted. This factor needs to be carefully addressed in order for self-esteem to lead into self-determination. Without doing so, the Deafblind person may become more and more isolated.

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| **Did You Know?**  Isolation is caused by the lack of communication with other people. It is crucial that the Deaf community be taught to embrace and support their Deafblind members. |

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| **FYI**  Deafblind individuals who are not involved in the Deaf community face all of the above issues related to their own communities. The issues are just as vital and important to challenge and resolve. |

* **Appendix I Module Two Activity**

The Negative Self-Talk Scenario is appropriate for Deafblind individuals, keeping in mind that the negative self-talk discussion includes blindness as mentioned above. This activity is good as long as the key issues around being Deaf AND Blind are integrated. The key word is INTEGRATED, meaning not just Deaf or blind, but both Deaf and blind.

* **Appendix II Activities for Deafblind Individuals**

All activities are appropriate for Deafblind individuals. However, to save time, it is recommended that the first activity be deleted; the other activities will use plenty of it!

* **Additional Suggested Activity**

**Hug Exercise:** hug the person sitting next to each other.

**Module Three:**

**Working with Interpreters**

1. **Overview, Goals, and Objectives** are appropriate for Deafblind participants. In addition, include the following objective: Compare and contrast between a qualified interpreter, a qualified Deafblind interpreter, and a provider/Support Services Provider (SSP) who knows sign language.
2. **Estimated Time:** Four hours
3. **Trainer Led Discussions, Case Studies, and Group Discussions, and Suggestions**

**Key Issues**

The skills needed to interpret for Deafblind individuals are different than those needed to interpret for Deaf individuals.

**Case Study**

A Hospital Visit

In this case study, a child has stomach pains and visits the hospital with his Deafblind mother and the mother’s SSP/provider. A nurse expects the SSP/provider to interpret and when told no, brings in another nurse who has beginner ASL skills.

Role-Play: Role-play this scenario.

Group Discussion: Discuss why the SSP/provider and nurse who tried to sign should not be considered interpreters. Also discuss why the Deafblind mother was so frustrated with the communication.

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| **FYI**  Deafblind individuals can teach interpreters to be skilled Deafblind interpreters. |

* **Illustration 3A in Curriculum**

**This illustration shows a man visualizing a tree while making the** sign for “tree.” The interpreter sees the sign, visualizes the tree, then turns to the hearing consumer and speaks the word “tree.” The hearing consumer then pictures a tree.

Describe the illustration for Deafblind participants and the steps that an interpreter has to go through to interpret even a simple concept.

* **Characteristics of a Skilled Deafblind Interpreter**

Group Discussion: The trainer asks participants what are the characteristics needed to be a skilled Deafblind interpreter. List and discuss them.

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| **Did You Know**  Certified interpreters have passed an exam demonstrating specific skills. Certification does not mean an interpreter will be qualified for all situations. Often if you request a certified interpreter with Deafblind interpreting skills, you are likely to get someone who is able to interpret successfully for Deaf people but not Deafblind people. Many people do not understand or know what to do with the word “blind” in conjunction with “Deaf” and ignore the blind part. It is recommended that Deafblind people have a preferred interpreter list and that they ask that interpreters from the list be contacted. |

Discussion: Discuss creating a preferred interpreter list. Why is this important and how do you do it**?**

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| **FYI**  There are other certificates offered through RID such as the Oral Transliteration Certificate (OTC) and the Specialist Certificate: Legal (SC:L). While RID does have a member section titled Interpreters for the Deaf-Blind, there is no certification offered specifically for Deafblind interpreters. |

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| **FYI**  The National Task Force on Deaf-Blind Interpreting (NTFDBI) is a collaboration between AADB, RID, and NCIEC. The goal of this collaboration is to increase the quantity and quality of interpreting services for Deafblind individuals. |

**Discussion: Building upon the discussion in Module One, talk about** what “accommodation” means in relation to interpreting and how each person may have a different understanding of the meaning of “reasonable” accommodation. For instance, requesting an interpreter for a doctor’s appointment next month is reasonable. Is it reasonable to request a specific interpreter for an appointment the same day? Is it reasonable for Deafblind people to request specific interpreters? Discuss other examples of reasonable and unreasonable requests.

* **How to Receive High-Quality Interpreting Services**

There are many actions you can take to make sure you receive the best interpreting services possible. For Deafblind individuals it is important to make the request as far in advance as possible and ask for a certified interpreter who is skilled with Deafblind interpreting. Give names of specific interpreters you know are skilled. Suggest a place for the interpreter to stand or sit. If you can’t see an interpreter because of the room set-up, your location, your vision, or there is not enough light, you can ask the interpreter to move. The interpreter may have another idea and discuss it with you. If there are other Deaf/Deafblind people, include them in the discussion to ensure that everyone can see the interpreter. Remember to speak up when something is not working for you and share your ideas.

* + You can work with a Deaf interpreter if you choose. The trainer can refer to the Synopsis of Video 3.3: Working with Deaf Interpreters.
  + The Synopsis of Video 3.4: Three different scenarios for discussion are included with choices of actions to take. The trainer can lead a discussion on what the best responses might be.
  + Requesting a Qualified Interpreter: To make the scenario in Video 3.5 relevant to Deafblind participants, it is suggested the trainer use the following role-play in place of the video: A Deafblind person goes to the emergency room with an SSP and a nurse wants the SSP to interpret.
* **Suggested Activities from Appendix B**

Under the Suggested Activities in Module 3, #1, Convoluted Communication is described. This activity would work well for Deafblind participants.

* **Additional Suggested Activity**

“Interpreter Got Talent” …three participants become judges, while the trainer plays out three different interpreter scenarios (two inappropriate, including one wearing a yellow shirt with dark sunglasses and one proper/ethical). Judges use voting cards with Braille numbers on the upper right corner.

**Module Four:**

**Ethics and Working with Interpreters**

**1. Overview, Goals, and Objectives** are all appropriate for Deafblind participants.

**2. Estimated Length of Time:** Six hours

**3. Facilitator Led Discussions, Case Studies, Role-Plays, and Group Discussions, and Suggestions**

**Key issues**

This module explores the professional ethics of interpreters.

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| **FYI**  Deafblind individuals have a right to a qualified Deafblind interpreter. |

* **Ethics and Working with Interpreters**

Interpreters who work with Deafblind individuals must have training. This does not mean they took a single workshop or had an interpreting job with a Deafblind person once or twice. Interpreters need formal training in Deafblind interpreting.

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| **Did You Know?**  Most interpreters have not had training in Deafblind interpreting. Deafblind interpreter training includes Sighted Guide Techniques (see Glossary) and includes incorporating visual information. |

**Case Study**

An Untrained Deafblind Interpreter

An interpreter shows up for an assignment unaware that he would be interpreting for a Deafblind consumer. Somehow this vital information was left out of the request. Key factor: this interpreter has not been professionally trained in Deafblind communication strategies.

Discussion: Talk about various approaches to the situation in the case study above. It is important for the trainer to notice if any of the Deafblind participants feel obligated to accept this interpreter because they are fearful to assert themselves.

**Case Study**

Interpreters Do Not Always Make Good SSPs

This video may not be appropriate for Deafblind audiences because Deafblind interpreter ethics have not been listed yet and need to be seen as viable. Instead, the trainer should consider the following activities.

**Case Study**

Guiding Deafblind Individuals

Role-Play: An interpreter “thinks” they know how to serve as a sighted guide for a Deafblind consumer; this can be made humorous by showing an interpreter trying to guide a Deafblind person through a doorway while trying to get through at the same time.

Recreate the Role-Play: Participants can come up with appropriate responses to the role-play above and re-create another, more successful role-play.

* **Interpreters as “Helpers”**

This is a tricky topic when it involves Deafblind individuals. First it’s important to define “Helper.”

Group Discussion: Have participants create a list on how they view a “Helper.” From this, choose those terms that are positive because Deafblind individuals do need assistance in ways Deaf people do not. Through this activity, the word “Helper” can be changed to a positive one meaning a person giving needed assistance. Visual considerations are a key factor. An interpreter who is trained to work with Deafblind people is mindful of boundaries and will ask if the Deafblind person needs assistance and not just assume.

The first item on the bulleted list needs to be changed. It currently states, “Deaf people are not dumb.” Be sure to emphasize the positive by using the term “intelligent” rather than “dumb.”

**Case Study**

Children Interpreting for Adults

Children should never be put into adult roles. This is essential for Deaf and Deafblind parents to understand. It is a difficult situation no doubt; however, it needs to be emphasized.

* Educating Hearing People

Deafblind individuals often arrive at appointments, e.g. a medical appointment, with a “provider” (See Glossary). The medical staff might assume that the provider can interpret, so the Deafblind person has to explain carefully and clearly that the provider’s role is not that of an interpreter.

**Case Study**

When VRI is Not Possible

Role-Play: A Deafblind person requests an interpreter for a medical appointment at a hospital. The hospital staff instructs the Deafblind person to use VRI, but this Deafblind person needs to use tactile or close range signing, thus needing an interpreter to be present during the various tests. The Deafblind person must educate the health care workers.

Group Discussion: Discuss the above role-play and determine if the approach used was effective or needs to be changed.

Role-Play: Adding to the above role-play, a Deafblind person arrives with a provider and is confronted with the question “Why can’t she interpret for you?”

Group Discussion: Discuss the above role-play and determine the most effective solution.

Role-Play: Re-create a role-play that covers both A & B to show a positive outcome while explaining and educating. More discussion may follow.

Closing Discussion: Be sure that strategies identified in the role-play scenarios include role clarification between provider and interpreter. Deafblind individuals may need support to clearly explain the difference between a provider and an interpreter. It is important to discuss strategies that are realistic to the Deafblind person.

* **Key Terms**
* Ethics
* Behavior

While defining these terms, it is important to note slight differences in interpreting tasks when interpreting for Deafblind individuals. For example, it would seem rude to a Deafblind individual if the interpreter did not assist them with visual information. Is this an ethics issue that needs to be carefully looked at? Do we need to include in the Code of Professional Conduct (CPC) that there are specific tasks a Deafblind interpreter would need to do?

* **Appendix Activity**

Group Activity: Design a Deafblind Code of Ethics and Code of Professional Conduct

Much of the content would correlate with existing definitions; however, there are some very specific areas Deafblind people need to identify. Deafblind participants would take a look at each item within the CPC and determine if it is completely appropriate for Deafblind interpreters or if there needs to be an adjustment. This activity would enhance self-esteem and self-determination, which would lead to a stronger self-advocacy presentation when both working with interpreters and educating the public.

* Additional Suggested Activity

Role-play the different RID tenets and have the others guess which tenet it is.

**Module 5:**

**Interpreting Services Using Video Technology**

**Recommendations**

1. **Overview, Goals and Objectives** are appropriate for Deafblind participants. Most of this module is applicable to Deafblind participants, including the Case Studies. Did You Know? Points, FYI points and explanatory information about Technology/Software, Telecommunications, Text Relay, VRS, VRI can be taught as conveyed.

Videos 5.2, 5.3, 5.4, 5.5 are not adaptable for role-play. It is suggested these videos be shown or described to Deafblind participants but that they be stopped frequently to allow interpreters to catch up and for trainers to clarify segments of the videos.

1. **Estimated Time for Module:** Four Hours
2. **Trainer Role-play-Led Discussion, Role-play and Group Discussions, and Suggestions**

**Key issues**

This module focuses on how Video Relay Interpreters (VRI) may be ineffective in the hospital and other settings, and the importance of informing personnel in these settings when VRI is not a viable option and that it is necessary for an interpreter to be physically present.

**Case Study**

Using Video to Talk With Others

A Deafblind individual with low vision uses a videophone with VRS and cannot see the interpreter’s signs because the interpreter is wearing a light colored shirt. The Deafblind person does not say anything and communication is confusing. Both the Deafblind person and the interpreter are frustrated and the hearing person disconnects from the call.

Group Discussion: Why did the hearing person disconnect from the call? What are the benefits of working with an interpreter on video to talk with hearing people over the phone? Why is it important for Deafblind individuals to state that they need an interpreter with a high contrast color shirt and for the interpreter to use a slower signing pace?

Role-play: Trainer models or participants take turns practicing how to convey this information to VRS.

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| **Did You Know?**  The Deaf-Blind Service Center (DBSC) in Seattle is contracted with the State of Washington's Office of Deaf and Hard of Hearing to provide Communication Facilitator (CF) services and video communication awareness for Deafblind community members. DBSC is the first and at this time only agency in the US to provide a CF program.  Deafblind individuals use Communication Facilitators to access videophones (VP) and Video Relay Services (VRS). A CF is a skilled signer who copies sign language from a caller, as shown on a videophone screen, and provides visual information to a Deafblind person, through close vision or tactile sign language, during VRS and/or face-to-face calls with another signer.  Source: [www.seattledbsc.org](http://www.seattledbsc.org) |

**Module 6:**

**Preparing for Self-Advocacy**

1. **Overview, Goals, Objectives** are appropriate for Deafblind participants.
2. **Estimated amount of time:** Four hours
3. **Trainer-Led Discussion, Role-play and Group Discussions, and Suggestions**

**Key Issues**

This module reminds the trainer that when preparing for Deaf Self-Advocacy, the very diverse Deafblind community has a wide range of communication needs, communication access opportunities, attitudes, behaviors and beliefs related to self-advocacy. Additional time should be spent on this topic so that everyone’s unique situation is addressed.

Module 6 emphasizes the importance of attitude and how attitudes are both internal (inside thinking) and external (what outsiders think) about Deafblind people. It is important to note the distinction between the two and to recognize that we can only control our own personal (inside thinking) attitudes. How we think about ourselves is very important.

* **Preparing for Self-Advocacy**

**Case Study**

When a Hospital Refuses to Pay for an Interpreter

Role-Play: A Deafblind person is being told to bring his or her own interpreter for a medical appointment.

Group Discussion: Discuss how the Deafblind person handled being told to bring their own interpreter on a medical appointment. The trainer may model other responses, such as showing the Deafblind person being passive, backing off, and not saying anything, which is a negative approach to the situation. Explore why the Deafblind individual is being passive, as this could lead to important attitudes that may be beneath the surface for many Deafblind individuals.

Re-create the Role-Play: Create a new role-play that demonstrates a realistic yet positive approach to the situation in the previous role-play.

* Job Interviews

Before this discussion, the trainer should assess the make-up of the Deafblind participants. It may be that most are not in the market for employment, but are looking to improve upon their approach toward requesting interpreters for many other situations. If this is the case, replace this topic area with discussions such as those below.

**Case Study**

A Teacher Needing an Attitude Adjustment

A Deafblind mother has two hearing children and will meet with their teachers to learn about what needs her children may have and how she can assist them. She needs to request an interpreter.

Role-Play: The Deafblind mother requests an interpreter to meet with her children’s teachers. An interpreter is located and the meeting is set up. The teacher(s) were unaware that their pupils have a Deafblind mother. Their attitude is one of disbelief that the Deafblind mother could be of any assistance to her hearing-sighted children’s studies.

Group Discussion: The above role-play is littered with layers of attitudinal discrimination. Explore all possible layers and the basis of the discrimination. Discuss how to handle these attitudes in the most realistic positive fashion. It may mean that the Deafblind individual would need someone to team with them as a co-advocate, and it is important that this possibility be respected.

Additional Note: Deafblind individuals may be in very complex situations such as the one above and although they have maintained their self-esteem and have a positive approach to self-advocacy, the situation may require a team approach. If this is necessary, it does not mean that the Deafblind person is incapable, but rather that the external situation is greater than what one person can manage on their own. These are realistic situations that many Deafblind individuals encounter daily.

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| **FYI: Dealing With Discrimination**  Deafblind individuals are often discriminated against because people are “fearful of or threatened by” people who have disabilities such as deafblindness. Deafblind people need the encouragement to advocate for themselves and foster their positive self-esteem. Being aware of these dynamics and discussing them are ways to support and encourage self-esteem. |

* **Applying Your Learning**

This section addresses the realities of what a Deafblind employee might be grappling with. For example, a Deafblind employee might need a CCTV (see Glossary), special lighting, and a Deafblind interpreter to do their work. An agency for the blind is often involved to provide some of the necessary equipment.

Most often, Deafblind culture trainings are not provided to employers working with Deafblind employees. So, after all of the visual needs have been met, it would be important to find out if the employer would be further willing to accept accommodations such as interpreters and cultural mediation. This is an important issue related to reasonable accommodations. Although the Deafblind person has every right to an interpreter to attend monthly meetings, it is crucial to evaluate their position in the environment. These issues need to be addressed with honesty, yet carefully and sensitively.

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| **FYI**  Often an individual who is Deafblind may not be able to find employment. This is not necessarily due to the Deafblind person’s “negative attitude;” rather, the marketplace has yet to make itself “Deafblind friendly” and thereby willing to make their environments accessible to meet both visual and communication needs. This reality needs to be addressed. It is important that the Deafblind person does not “personalize” this reality. This is a time where the Deafblind person’s self-esteem needs to be cultivated and nurtured. When employment is not an option, Deafblind individuals may volunteer in a number of different venues. This contribution is important because it leads to the Deafblind person’s sense of well-being within the community. |

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| **FYI**  Deafblnd people who have early Usher Syndrome may be able to do various duties while their vision is still intact, so in these situations, the Deaf component of this module would be appropriate as long as the possibility of losing more vision is addressed. |

**Case Study**

Diminishing Sight on the Job

A Deafblind person with Usher Syndrome, who has good vision, is interviewed for a job and is hired. The employer is willing to provide an interpreter for monthly staff meetings since it was discussed at the interview. As for individual meetings, the employer and Deafblind employee have agreed to use instant messaging on the computer.

Role-Play: The Deafblind person is experiencing more loss of sight, and is finding it harder to do some of the assigned tasks. What do they do? How do they address these issues?

Group Discussion: Discuss the above role-play to determine if the visual accommodation that the Deafblind individual needs is reasonable. Is this a point where the Deafblind person needs to request equipment from a blind agency? How does the employer handle this? Set up additional role-plays to address these issues.

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| **FYI**  Internal attitude is about how we approach a situation and project a positive result. External attitude is the attitude of others who may have negative beliefs or assumptions when dealing with Deafblind individuals. Awareness of the difference between internal and external attitudes is crucial. An individual who is projecting a positive, solid, and well-balanced attitude yet who may be met by someone who has a negative attitude toward people with disabilities such as Deafblindness, should not “internalize” the outside negative attitude. They need to recognize it is outside of themselves. Discuss what the Deafblind person can do when they encounter someone with a negative attitude towards them. |

* **Suggested Activities**

Use the above Case Study to engage in a debate. Create two teams, whereby one team debates from the employer’s point of view and the other team debates from the Deafblind advocate’s point of view. Choose a moderator to ensure fairness and a note taker to keep track of the discussion.

* **Additional Suggested Activity**

Write the following situations on individual cards:

* Attend an all day workshop at a Deaf agency.
* Coordinator for a DB group going to an amusement park.
* New job as a software developer for Apple.
* Schedule for a colonoscopy.
* Parent/teacher meeting for son’s behavioral problems.

In pairs, create a plan of action for advocacy and specify what laws applied to each situation.

**Module 7:**

**Utilizing Resources for Action**

**1. Overview, Goals, and Objectives** are appropriate for Deafblind participants

**2. Estimated Length of Time:** Three hours

**3. Trainer-Led Discussion, Role-play and Group Discussions, and Suggestions**

**Key issues:**

There are no key issues for this Module. Insert the following resources that Deafblind people can utilize.

**Federal Level:**

* Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is a national rehabilitation program (www.hknc.org)
* National DeafBlind Equipment Distribution Program (NDBEDP) funded through FCC, go to <http://www.fcc.gov> (www.fcc.gov or www.icanconnect.org)
* Foundation Fighting Blindness has a Deafblind component ([www.blindness.org](http://www.blindness.org))
* American Foundation for the Blind expands possibilities for people with vision loss including those who are Deafblind (www.afb.org)

**National Level:**

* Usher Syndrome Family Network: this is an excellent supportive networking resource

(www.usher-syndrome.org)

**State Level:**

* Commission or Department of Services for the Blind – many stateshave Deafblind Vocational Rehabilitation (VR) services with provisions for the hearing blind or the Deafblind person. The Deafblind person may choose to receive VR services through the Deaf VR agency or the blind VR agency
* Disability Policy Consortium (DPC) (some states have a Consortium or a similar disability rights agency). The DPC's mission is to advance the rights of persons with disabilities. (In Massachusetts go to www.dpcma.org.)
* DeafBlind Organizations - some states have established organizations, such as the Washington State Deaf-Blind Citizens (www.wsdbc.org), Massachusetts’ Deaf-Blind Contact Center ([dbccoffice@gmail.com](mailto:dbccoffice@gmail.com)), etc.
* DeafBlind Services of Minnesota (www.dbsmllc.org)
* DeafBlind Service Center Seattle, Washington (www.seattledbsc.org)
* Massachusetts DeafBlind Community Access Network (DBCAN), a program of DEAF, Inc. (www.deafinconline.org)
* DeafBlind Project – each state receives federal funds to provide educational support to Deafblind individuals.

**Listservs:**

* Professionals Serving Deaf-Blind Consumers (PSDBC) information and resource sharing (psdbc@tr.wou.edu)
* There are a number of listservs specifically for Deafblind individuals that share information and advocacy tips. Search “Deafblind Support Groups” in any computer search engine.

For information on individual state resources, contact the HKNC regional representative. Deafblind individuals are also good resources for information and services that they may have accessed and used.

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**TIPS for Teaching**

**Participants Who Are**

**Deafblind**

Always remember to:

1. Point to the Deafblind person wishing to make a comment and continue pointing until all participants have a chance to see the participant or be tactually ready.
2. Always identify yourself before signing/talking.
3. When possible, use a background that is dark for ease on the Deafblind participants’ eyes (black drapes work well). Bring clips so the drapes will hang nicely. Have available a roll of black, plastic table cloth if a door, table or window needs to be covered.
4. Recommend that interpreters bring a “CDI tool box” that includes an iPad or Notebook with the Trainer’s PowerPoint. In this way, color, background and size of the PowerPoint can be adjusted so the participant would be able to see it. Moreover, the interpreter can refer to the PowerPoint on the iPad/Notebook while interpreting instead of looking behind her what is on the screen.
5. Always know how many Braille or large print copies you will need. When making handouts, use goldenrod or cream color paper. The electronic Braille copy of the Student Manual will be on Disk 5. As a reminder, refreshable Braille is not compatible with Windows 7.
6. During question time, be aware of each participant’s ability to get the information that other participants are asking/receiving. Promote patience and support for those whose communication access may take longer.
7. Allow time for the Deafblind participants, trainer and interpreters to determine the logistics --best seating, positioning and communication.
8. The main trainer may need to stand in one particular spot; moving a few inches could mean a big difference to a participant relying on vision.
9. Set up cues to inform the Deafblind participant(s) of changes: “now show DVD,” “DVD done,” “go back to your seats,” “situation practice time,” and always share what’s happening in the room.
10. Have working surge strips and cable cords available. It is suggested that tablecloths be black and all cords be out of sight as much as possible. Bring grey duct tape to tape down cords on floors to avoid tripping.
11. If showing DVD clips, allow time for the Deaf-blind participants to adjust their eyes from darkness to light and vice versa.
12. If an interpreter is working with a Deafblind person, allow 20-30 minutes before the assignment for them to become acclimated with each other.
13. If possible, use a large-flat screen monitor for close up viewing of DVD clips.
14. Encourage Deafblind participants to help with room set up. This provides an opportunity for the participants to get a feel of the area and the equipment being used for the training.
15. Make sure that Deafblind participants indicate their particular communication needs BEFORE the training.
16. Always use the term Deafblind rather than Deaf.

Shared by Laura Thomas,

Helen Keller National Center

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**Glossary of Deafblind**

**Related Terms**

* Close-vision (or range) Signing - being in the same proximity of a Deafblind individual’s signing space.
* Communication Access - Tools for ensuring access to communication, such as CART, VRI/VRS, interpreters, use of pro-tactile strategies, SSPs, TTYs, Internet and texting.
* Communication Facilitator (CF) (not VRS interpreter) - a Deaf or hearing person who is fluent with ASL who sits with the Deafblind individual and signs, not interprets, to the DB individual what is seen on the VP screen either from another Deafblind or Deaf person or the VRS interpreter.
* Deafblind (DB) – refers to individuals who have combined hearing and vision loss. Four areas of deafblindness are recognized. An individual can be fully Deafblind, can be Deaf with low vision, can be hard of hearing with low vision, or can be hard of hearing and blind. There are different reasons that cause individuals to become Deafblind, such as accidents, brain trauma, childhood diseases, eye conditions (for example, macular degeneration), maternal rubella, aging, Usher Syndrome (more US information below). The communication and visual needs of Deafblind individuals are different as well, depending on the onset of deafblindness, the kind of eye condition, background, education, use of ASL/PSE (tactual or visual), fingerspelling, or spoken English.
* Deafblind Interpreter Qualities:

1. is Deafblind culturally sensitive;
2. wears proper clothing (black, brown, dark purple, forest green);
3. is physically appropriate – hair color (no platinum blondes), left vs right hand;
4. is flexible;
5. is comfortable with touch;
6. uses and shares visual/environmental information;
7. demonstrates patience/mutual respect;
8. is a communication match;
9. has the proper attitude and skills to work with a Deafblind individual;
10. uses a dark background in the setting;
11. encourages evenly paced turn taking;
12. waits until the Deafblind individual refocuses;
13. explains procedures clearly (i.e., eye exam/room will be dark);
14. talks directly with the consumer (“tell him/her … - is a no no); and
15. plans ahead of time with the consumer to establish communication protocols.

* Deafblind Time - it is important not to assume that Deafblind participants comprehend the training information. It is important to stop the process and constantly check in. A Deafblind person’s pace is generally slower and more time may be needed due to visual impact and not being able to follow communication in the same way as a person with regular vision can.
* Guide Dogs – some Deafblind individuals prefer to work with a guide dog. This requires special training at a certified guide dog school. The person who uses a guide dog may be referred to as a “handler.”
* Macular Degeneration (MD) - an eye condition that limits central vision. Those with MD often require that signing be done on the side.
* Orientation & Mobility (O&M) – term used for training individuals who wish to develop their independent skills and learn how to navigate and manage in the environment in the same way as a Deafblind individual. This training is usually done with a white cane. The person who uses a cane may be referred to as a “cane traveler.”
* Sighted Guide Techniques - there is a specific way for sighted people to guide a Deafblind person to allow for ease of movement between both individuals. Training is required.
* Support Service Provider (SSP/Provider – called provider in MA) –Deaf, hard of hearing or hearing person who is trained to work with Deafblind individuals to provide sighted guiding, communication and visual information and transportation to appointments, shopping, classes, events etc. Providers/SSPs are not to be used as interpreters in situations where certified interpreters should be hired, such as, employment, medical, legal, or education settings. Fluency with ASL is not a requirement to be an SSP/provider.
* Tactile Signing - hand on hand signing.
* Technology – Common technologies used by Deafblind individuals are:

1. Computers with large print or Braille displays. Deafblind individuals who are hard of hearing or have CIs might use a screen reader which is a spoken voice that reads what is on the screen to the person.
2. iPhone or iPad can be used with a Braille display.
3. Assistive Listening Devices (ALDs) are used by Deafblind individuals who have some residual hearing and use English as their first language. ALDs, like FM Systems, are designed to improve audibility in specific listening situations.
4. DeafBlind Communicator is a device for those who use Braille.
5. Closed Circuit TV (CCTV) is equipment that enables a Deafblind person to read print. It comes in a variety of sizes, shapes and applications.
6. TTY with LVD (Large Visual Display) - this device is scarce, and is no longer manufactured. However, some Deafblind people rely on it for telephone communication.
7. Telebraille - TTY with Braille output that allows for telephone communication.

* Tracking – a communication method where a Deafblind individual places his/her hand on the signer’s forearm as they sign to “track” movement of the signs.
* Tunnel Vision - a narrow field of vision. Usually, the Deafblind individual needs distance to see signing.
* Usher Syndrome (US) – more than half of the Deafblind individuals in the U.S. have Usher Syndrome. It is a condition that involves both deafness (and hard of hearing) with Retinitis Pigmentosa (RP) which is progressive blindness. Usher has three broad categories:

Usher I - typically someone who is born Deaf who later learns that s/he has RP. Usually the first signs are difficulty seeing in dim lighting and balancing problems;

Usher II - someone who is born hard of hearing and loses sight to RP. This individual may or may not have a progressive hearing loss as well as progressive sight loss; and

Usher III - someone who is born hearing-sighted and during their teen years is diagnosed with progressive deafness and sight loss due to RP.