

## WHITE PAPER

### **Pennsylvania Citizens who are DeafBlind are not Receiving Much-Needed Services**

#### **Introduction**

According to the Federal Communications Commission (FCC) <sup>1</sup>, there are an estimated 509,000 persons living in Pennsylvania who are deafblind. Many of these citizens live hidden and isolated alone at home, with a family member or within an institution.

Data collected through surveys and public hearings in 2013 reveals that people who are deafblind desire greater independence and self-reliance, including completing their education, attaining employment, raising a family, engaging in local activities, and contributing to society. What poses the greatest challenge to accomplishing these goals is the communication barriers due to hearing and vision loss.

Those challenges can be mitigated and greater independence achieved by using a Support Service Provider (SSP), who bridges the gap between the individual who is deafblind and their environment.

#### **Definition of Deafblindness**

Deafblindness is a condition represented by a coinciding loss of both sight and hearing. The impact of these losses is so severe that an individual's ability to communicate easily and effectively with others and function within the environment is limited, resulting from limited access to visual and/or auditory information. A person who is deafblind might still be able to hear or see a small amount in an optimal settings, but in a loud or busy environment, the same person would be rendered completely deaf and completely blind. Deafblindness can also range from a mild loss to complete loss along both the hearing and vision spectrums.

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<sup>1</sup> Implementation of the Twenty-First Century Communication and Video Accessibility Act of 2010, Section 105, Relay Services for Deaf-Blind Individuals. Released April 6, 2011. Page 68 of report.

## **Communication**

As mentioned above, deafblindness encompasses a wide spectrum of vision and hearing loss. It, therefore, holds true that individuals who are deafblind may have unique needs and preferences. For example, a person who is deaf could be a native user of American Sign Language (ASL) with late onset vision loss which would necessitate the use of close-vision signing (ASL received within a smaller signing space) or tactile ASL (signing which uses touch rather than vision for reception).

While persons who are congenitally blind or have early onset vision loss and later lose their hearing might use hearing aids or other assistive listening devices. Some persons who are deafblind may use technology primarily for communication. Such technology may include a computer connected to a braille display which enables the user who is deafblind to read braille and type responses which appear on the computer screen for a sighted person. This type of technology configuration can be used for face-to-face communication or when communicating with someone across the room or via the internet.

Other communication methods used are speechreading, print-on-palm (using the index finger to write individual block letters on the palm of the person who is deafblind), communication cards (printed messages the person who is deafblind can identify using braille labels affixed to the cards), and more.

Despite the myriad of communication methods available, having reliable access can remain a challenge. Hearing aids and other assistive technology can be expensive and require initial training or ongoing adjustments. Fluency in ASL takes time to master and requires the person with whom the individual who is deafblind wants to communicate to also know ASL.

Print-On-Palm is very slow, and many people with multiple disabilities may also have neuropathy which precludes their ability to perceive tactile sensations. Most individuals who become deafblind later in life are typically unprepared for the many communication challenges. Thus, many individuals with vision and hearing loss that occurs later in life may not possess skills necessary to compensate. For these individuals, learning ASL or how to use assistive technology can be extremely difficult - making their communication challenges even more daunting.

## **Definition of a Support Service Provider (SSP)**

Anyone can be a SSP, but in Pennsylvania to be a SSP with the DBLWS program, they must successfully complete required training because the SSP serves as the ears and eyes of a person who is deafblind to facilitate their interaction with people and the environment. The goal is for the person who is deafblind to make an informed choice based on all auditory, environmental, and visual information they may miss without the assistance of the SSP.

One of the primary duties of a SSP is to assist with communication by translating what was spoken aloud into the preferred communication modality of the person who is deafblind. For example, a SSP could use tactile sign language or speak into a microphone connected to the individual's hearing aids to inform them what a sales clerk is saying, and vice versa.

An example of a SSP being a conduit of communication would be when the person who is deafblind is requesting information from a server; however, SSPs do not function as an interpreter. For example, a SSP does not interpret for a doctor's appointment or a meeting between an employee who is deafblind and their supervisor.

While working, a SSP should be capable of guiding the person who is deafblind using DBLWS approved human-guide techniques. This is an important component while accompanying a person who is deafblind to a store, medical appointments, meetings, and other venues outside of the home.

Another important task of a SSP is to describe visual aspects of the environment to allow the person who is deafblind to understand the layout of a room, consider clothing options in a store or select meals from a menu. The SSP should always defer to the person who is deafblind to make decisions about whether more or less information about the environment is wanted.

*What a SSP can do to assist a Person who is DeafBlind:*

- Relay spoken information to/from the person who is deafblind according to the person's preferred communication modality.
- Guide a person who is deafblind to a seat in a meeting, to the restroom, through a buffet line at a reception/party, or through a transportation center.
- Tell a person who is deafblind who is speaking during a conference, who is seated in a room and the overall mood of people attending a meeting.
- Read a menu in a restaurant, read mail at home, read exhibits in a museum or read a kiosk screen at a store.
- Locate food at a grocery store or shopping in a mall.

*What a SSP does not do while assisting a Person who is DeafBlind:*

- Make decisions for the person who is deafblind, whether actively by choosing on behalf of the person who is deafblind or passively by not providing the person all available options.
- Groom, bathe, clean, or provide other personal care services for a person who is deafblind.
- Run errands on behalf of a person who is deafblind without taking that person along.
- Teach or instruct without proper certification and authority.
- Provide formal interpreting services during medical, educational, financial, legal, business, or other special settings protected by legal or ethical constraints.

A SSP who is also an interpreter, personal care attendant, teacher, or other professional must be very careful to remain in the role of SSP throughout the entirety of the assignment with the person who is deafblind.

*Training Requirements through the DBLWS SSP Program:*

Each person that trains to become a SSP in Pennsylvania receives 16 hours of training. Many of the persons who become SSPs have already been working as volunteers with individuals who are deafblind or have been SSPs in other states.

In Pennsylvania, the training is separated into topics such as:

- deafblind etiquette
- communication methods and Touch Signals
- Orientation and Mobility (O & M) techniques
- providing environmental information
- causes of hearing and vision loss
- ethical boundaries,
- hands-on experience working with people who are deafblind

As the three key components of a SSP are facilitating communication, guiding, and providing environmental information, these are the skills focused on primarily during the training.

DBLWS has currently trained 84 individuals to become SSPs in Pennsylvania.

### **Funding of SSP Services**

In 2014, the Center for Independent Living of Central Pennsylvania (CILCP) was awarded a two-year pilot grant from the Office of Vocational Rehabilitation (OVR) and the Bureau of Blindness and Visual Services (BBVS) to establish and manage a state-wide SSP program. The Pennsylvania Statewide Independent Living Council (SILC) and the Office for the Deaf and Hard of Hearing (ODHH) also provided support for the SSP program. Currently DBLWS is working in its third year of funding. All DBLWS SSPs are self-employed independent contractors. They submit invoices for work completed at the rate of \$20 per hour for direct, one-on-one work with a person who is deafblind.

### **DBLWS Support Service Provider Services in Pennsylvania**

Each person who is deafblind receives 14 hours of SSP services per month, which can be used in whatever manner they wish in accordance with the DBLWS guidelines. All participants are required to be 18 years of age or older, residents of Pennsylvania, post high school, and able to direct a SSP. Participants are also required to keep track of their own SSP hours, how many hours have been used and how many hours remain. All participants also have the option to privately pay the SSP for additional hours or to seek voluntary SSP services, which must be arranged directly between the person who is deafblind and the SSP.

Currently, DBLWS coordinates SSP services for 62 persons who are deafblind. Since the DBLWS program began, a total of 4,529 hours of SSP services have been provided to citizens who are deafblind in PA. These numbers are expected to increase significantly as more citizens who are deafblind become aware of the availability of SSP services. Therefore, there will be an increase in the demand for SSP services and the number of hours.

## **Solution – Recommendations**

People who are deafblind have relied on friends and family members to provide support. Rarely do those family and friends have formal training, and the support is often not reliable. At other times, the person who is deafblind may worry about infringing on others' time, which can lead them to forgo community outings, rather than bothering a friend or family member for a ride or to assist with shopping. This leads to isolation, depression, a feeling of low self-worth, and frustration for the individual who is deafblind. It is the goal of the DBLWS' SSP program to help persons who are deafblind become independent, make informed decisions, take charge of their lives, obtain employment, and maintain their independence.

In order to continue to provide a sustainable SSP program to deafblind individuals in Pennsylvania, DBLWS and many other key stakeholders strongly recommend the following:

1. Create SSP legislation and appropriation. Two states, Colorado and Missouri have legislation. Other states, such as Utah, Massachusetts, and Hawaii allocate funding in their state budget for services to meet the needs of constituents who are deafblind.
2. Ensure SSP services are included in Managed Care implementation through the PA Department of Human Services: DBLWS and key stakeholders also recommend that further efforts be made to determine why SSP services were left out of the service definition under the newly established Community Health Choices managed care waiver under the Office of Long Term Living.

Both of these recommendations, once implemented would provide greater independence, self-reliance, help minimize isolation and give people who are deafblind the ability to make decisions that we take for granted, such as when and where to go shopping, which blue shirt to buy, choosing the time for an appointment, etc.

## **Case Studies**

*Experience of a person who is deafblind without using DBLWS:*

DBLWS was recently made aware of a situation at a major local hospital system in the Harrisburg area, where a person who was deafblind was admitted for a routine procedure, which should have only required a one-night stay. Unfortunately, the stay was nearly four months. After the relatively simple procedure, the hospital staff thought it would be good to transfer the patient to a rehabilitation facility. However, three months passed as the transfer was repeatedly turned down by each facility they contacted -- none wanted to deal with the unique challenges this particular patient presented--deafblindness.

The hospital staff initially arranged for interpreters to help with communication for the first several days. However, interpreters were not secured for the entire stay. This resulted in the patient not being able to communicate with the staff for major medical decisions and other needs except for a few hours each week.

One of the problems this caused was that the patient had no way to choose meals according to their dietary preferences. The patient was unable to read the menu or make selections. The hospital would send food to the room which the patient did not like or was unable to eat. This caused the patient to rapidly lose weight.

This extended stay also had severe emotional and physical effects on the patient, since they were isolated and unaware of their treatment plan. Eventually, the hospital staff reached out for services that provided information on how to communicate with the patient. Ideally, this should have been the first step upon the patient's arrival. The assistance of a SSP could have made this patient's stay much more bearable, by helping the patient make meal selections or aiding with personal communication.

Awareness, training and services like the DBLWS program are vital to help ensure this type of poor treatment does not occur again in Pennsylvania.

*Experiences of people who are deafblind using DBLWS:*

“The quality I value most in my SSP is her flexibility, her openness to any task. Whether I ask for reading boring newsletters or surveys or stain sticking my winter clothes before shifting to a summer wardrobe, she is willing. My SSP has helped me sort through drawers and closets and even supported me in navigating an unfriendly website.

But the best example of her flexibility is to follow me on a new or old route with my dog. If my dog has been overly-sociable on a previous walk, I have occasionally asked my SSP to accompany me. Because of my Deaf-blindness, I cannot tell if pedestrians are coming toward me, at least not until they are quite close. My dog sees them, of course, when they're 100 feet away and may veer gradually to sniff them. My SSP tells me people are coming, and I warn, "Leave it." One of these disciplinary trips a month or so keeps his extroverted nature in check. My SSP has done this several times in inclement weather and has generally been a good sport. I'm so grateful for her help.”

A person who is deafblind in the Philadelphia area writes about how using a SSP has changed her life here. “After teaching Junior high school art for several years, I learned that I was progressively losing my hearing and eyesight. I wondered what I would do with a BFA in painting and a BS in education. During the last thirty years, I slowly switched to sculpture and now present and teach workshops for the blind and the sighted at universities and museums.

As my wireless FM microphone became the only way I could communicate with my students, it became more difficult for me to encourage others to use it properly or to help me with sighted guidance.

Not only has the SSP been the answer to my dilemma, but I am not exaggerating when I say that it has changed my life – both personally and professionally. The tactile signals have guided me and the assistance with my microphone has given me back the ability to handle a recent panel presentation for The Institute on Disabilities at Temple University and to manage the many eye doctor appointments involved with my recent cataract surgery.

Most important, my SSP has made me independent and willing to agree to several more workshops and presentations with a new degree of confidence. I could not afford nor could I find capable professionals on my own to provide this without the important and valuable SSP service.”

A person who is Deafblind in Sunbury PA has been receiving assistance from a SSP for approximately five months. This is what she has written, "Due to my Deafblindness, I needed to learn a way to communicate that did not require sight or hearing. The SSP has been immersing me in Tactile American Sign Language twice a week. I now know approximately 300 words in ASL and am doing very well using Tactile ASL. The SSP has been patient and caring towards my needs while I am now using a different way to communicate. With the help of the SSP, I now have hope for the future."

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