

Center for Independent Living of Central PA

Your LIVING WELL
With A Disability Provider &
Advocacy Organization

Hi, my name is Marsha Drenth and I am the Program Manager of the DeafBlind Living Well Services program (DBLWS) through The Center for Independent Living of Central PA (CILCP). I am also a person who is DeafBlind, this means that I am totally blind and profoundly hard of hearing. Just to share a bit about myself, I am wife to Joseph and a mother to 3 adult children. In 2012, I was matched up with an amazing service dog who provides me with assistance to navigate my environment, alerts to sounds in which I am unable to hear and provides help with balance. When I am not working full time, I have many hobbies that include crochet, working in the nursery in my church, shopping at Thrift stores, reading mysteries, and eating all kinds of chocolate. Growing up I was visually impaired, but still being able to read large print. In 2004, after undergoing several surgeries I lost all of my vision. I now have no usable vision to rely on for daily tasks. In 2007, I began to experience a major hearing loss and am now only able to hear using a Bluetooth microphone system or with the use sign language interpreters for communication. Once I began to lose my hearing, life became very isolating and lonely; not being able to communicate and live independently. I found it so frustrating not to be able to communicate in social settings with persons who did not know how to help or what I needed. Life became very overwhelming, which caused anxiety and depression. I knew that there was a different way, but no one had answers to my questions about hearing loss and how to live independently. Only until I attended the Helen Keller National Center with help from Bureau of Blindness and Visual Services, did I become familiar with Support Service Providers and how they would change my life as a person who is deafblind. In 2015, I graduated with a degree in social work and was soon employed in this position.

In 2012-2013, OVR and other agencies identified a need; Pennsylvanians who were deafblind did not have services of a Support Service Provider (SSP) and the community desperately needed this service. A SSP has 3 main functions— (1) acts as guide, (2) provides environmental information, and (3) bridges the gap of communication, but does not interpret. In short, a SSP empowers a person who is deafblind and gives them the independence they need rather than depending on friends and family. Persons who are deafblind have an increased incident of depression and mental health conditions, from the isolation, and not being able to participate in their own affairs independently. So, OVR, through a grant funded a pilot program to establish a state-wide program which links a person who is deafblind to a Support Service Provider (SSP). The CILCP was awarded the bid and has been in operation since 2014. The plan was always to seek alternate funding through the Office of Long Term Living and the new Community Health Choices. However, those plans are still being worked on, but progress is being made slowly.

DBLWS was notified that OVR would provide funding for a final year, October 1, 2017 to September 30, 2018. After this date OVR, has not committed to being able to provide funding. The uncertainty of funding for DBLWS, will take away the independence that persons who are deafblind have come to depend on for daily tasks of looking for a job, grocery shopping, going to the doctors. The daily tasks that you may take for granted. The Center understands that the funding from OVR was never intended to be sustainable; it is our view that the state of PA and other funding sources have a responsibility to provide financial support.

As a professional who is DeafBlind and also uses an SSP in both my work and personal life; it has been a vital and important way for me to function. When I travel in the state of Pennsylvania to make presentations, I employ a SSP to help with gaining all the information that is needed while attending conferences, conventions, seminars and workshops. For example, checking into the hotel or conference venue, registering for the different breakout sessions, getting to and from the restroom in a crowded room, obtaining resources in the exhibit hall, networking with other professionals, and getting meals. In my personal life, I have been able to experience activities that would have normally **been impossible for me to participate in. For example attending my church's women retreat in the Poconos.** During this weekend get-a-away, an SSP provides information about the setting of our hike, what stores are around when shopping, what meals are in the buffet, and visual instructions when its craft time.

For the past few years, I have had the pleasure to provide services to 80 Pennsylvanians who are deafblind, to help them obtain access to their lives, their community, and services. As the Program Manager I witness the impact of 7,171 direct one-on-one hours that this program is providing to persons all over the state. To be able to help persons who are deafblind overcome that isolation and loneliness, to empower them to become independent, and to know that they are able to live full lives; is a positive feeling. Working with consumers who are deafblind who know that I understand exactly what they are going through and that they too can overcome their challenges. Currently, DBLWS provides Deafblind Pennsylvanians with a maximum of 15 hours per month to work one-on-one with their SSP.

It is important to know that DBLWS is the first state wide SSP program in the US that has been providing services for 4 years. There are smaller regional programs in Pennsylvania and around the country. There are two additional states in which have legislation including Missouri and Colorado. Other states have set up SSP programs through the Office of the Deaf and Hard of Hearing or through the VR program.

Currently DBLWS has trained 84 SSPs through an intensive 16-hour (2 day) training. All SSP are vetted self-employed contracting persons who are paid \$20 per hour for one-on-one services rendered.

It is DBLWS view that the legislation that Representative D. Miller and Representative T. Murt has introduced requires a few important changes so it is the most beneficial to consumers who are DeafBlind. The CILCP suggests language changes to improve clarity of the bill.

Change Section 3 “Support Service Provider” to

An individual who (1) links a person who is deafblind to their environment and (2) who has completed training from a recognized and established organization that provides SSP services

Change Section 3, Support Service Provider, (2), “facilitating communication” to

(2) Assisting with informal communication, such as exchanges with a cashier, server or friend at a social event

(i) SSPs do not perform the role and function of a sign language interpreter

(1) Sign language interpreters are governed by PA laws and regulations

Add to Section 3, definition of an ‘Individual who is deafblind’

The concomitant (a condition associated with another condition) of hearing loss and vision loss or vision impairment causes a communication barrier

Change Section 8 (f) (i) to

Centers for independent living that provide services to individuals who are deafblind. Grants shall be used to provide SSP services to an individual who is deafblind who is working toward establishing and maintaining independence

Change Section 8 (f) (ii) to

Centers for independent living that formally train and coordinate Support Service Providers (SSPs). Grants shall be used to further expand support services for people who are deafblind in this Commonwealth

In conclusion, from my personal experience of using an SSP and the impact I see as the Program Manager; I support this legislation and desire that the HS committee passes it on to the floor. This very needed legislation would not only provide funding for a population that desires to be independent but also starts a process to certify the program and the issues faced by deafblind persons. I hope that you will consider how imperative this legislation is for persons who are deafblind.

Thank you for your time and consideration,

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