

DEAFBLIND SUPPORT SERVICE PROVIDER TASK FORCE REPORT



January 2016

This report is prepared by the Illinois Deaf and Hard of Hearing Commission. It summarizes the work of the Task Force and its final recommendations.

DeafBlind Support Service Provider Task Force Report

EXECUTIVE SUMMARY

On November 10, 2011, in response to concerns regarding the lack of services for the DeafBlind community, the Illinois Deaf and Hard of Hearing Commission (IDHHC) authorized the formation of the DeafBlind Support Service Provider (SSP) Task Force. The goal of the Task Force was to explore opportunities to increase awareness of the need and opportunities for SSP services. Its purpose was not to repeat the work of previous Task Force or Working Groups though the Chicago Lighthouse.

In July 2012, IDHHC sought letters of interest for members of the SSP Task Force from a variety of sources including:

- DeafBlind Individuals;
- DeafBlind Service Providers;
- DeafBlind Organizations; and
- Representatives from Illinois Rehabilitation and Home Services Programs.

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IDHHC Director appointed seven (7) members throughout the State. The Task Force convened for a total of eight (8) meetings between October 31, 2012, and May 14, 2015.

IDHHC appreciates the contributions and expertise of the Task Force members. Through the work of the Task Force, IDHHC gained a better appreciation of challenges the DeafBlind community faces and proudly presents the Support Service Providers (SSP) Task Force Report.

INTRODUCTION

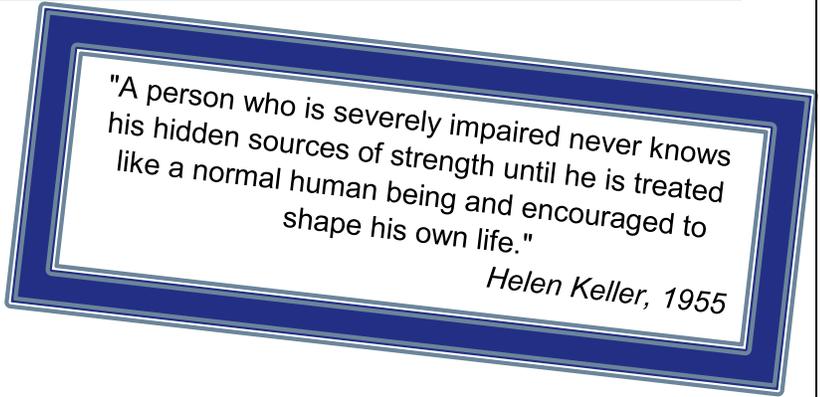
The Task Force elected to use the spelling "DeafBlind" over "Deaf-Blind," "Deaf and Blind" or "Deafblind." This is meant to emphasize the unique set of challenges faced by individuals with both a hearing and vision loss; not

identifying by the disabilities separately. It is undisputed that with appropriate services DeafBlind individuals are capable of more productive and independent lives. The Task Force's ultimate goal is to establish a state program which provides DeafBlind individuals the service of Support Service Providers.

Support Service Providers (SSPs) are specially trained professionals who enable people who have combined vision and hearing losses to access their environments and make informed decisions. SSPs provide them with visual and environmental information, sighted guide services, and communication accessibility. (American Association of the Deaf-Blind) The Task Force looked at other definitions of SSPs but was concerned that descriptions of "activities of daily living" would be misunderstood to encompass activities involving personal care such as bathing or eating.

The DeafBlind community is very diverse and utilizes various modes of communication depending on the extent of an individual's vision and hearing loss. When determining who should be classified as DeafBlind, the Task Force felt strongly that the focus should be on the ability to communicate and not so much on a medical diagnosis. The Task Force felt the definition of DeafBlind by the Illinois Department of Human Services best suited to accomplish this goal.

Any loss of hearing, occurring at any age prior to or post acquisition of normal spoken language, that precludes processing of linguistic information through audition, with or without a hearing aid, and visual impairment of 20/70 in the better eye corrected or a visual field of 20 degrees or less. 59 Ill. Adm. Code 111.20



MISSION STATEMENT

The DeafBlind Support Service Providers Task Force shall analyze national programs and current State policies to determine what changes, modifications, and innovations are necessary to enhance the quality of independent living and resources available for the citizens of Illinois who are DeafBlind.

Many individuals may think a SSP is there to “do things” for the DeafBlind. This is not the goal. The goal is to provide the DeafBlind with information that allows them to lead a self-determined life. “Self-determination has been described as “The ability to define and achieve goals based on a foundation of knowing and valuing oneself” (Field and Hoffman, 1994). Some of the major components of self-determination are:

- knowledge of self and others;
- personal management;
- effective communication;
- self-advocacy and advocacy within systems;
- decision-making;
- goal setting; and
- problem solving.”

By Debra Sewell, Curriculum Coordinator, TSBVI <http://www.tsbvi.edu/resources/2680-becoming-empowered-through-self-determination-skills>

The Task Force agreed that the qualifications of an SSP should include:

- Minimum age of 18 years old with proof of identification;
- Ability to effectively communicate directly with the DeafBlind through various modes used by individuals who are DeafBlind, including but not limited to tactile, tracking, close vision, restricted visual field space and spoken language;
- Ability to effectively and safely guide individuals who are DeafBlind within the community as needed including the event of an emergency;
- Ability to travel throughout the community with the individual who is DeafBlind as required. If providing transportation within the scope of services is required of a SSP, proof of valid driver’s license, insurance and safe driving record is also required;
- Exhibit an understanding of DeafBlind culture; and
- Not to act as an interpreter or decision maker for the DeafBlind individual.

TASK FORCE MEMBERS

Bryen Yunashko, DeafBlind Consumer

Karyn Campbell, DeafBlind Consumer

Laura Ebersohl, Licensed Interpreter

Ingrid Halvorsen, Department of Human Services, Division of Rehabilitation Services

Renee Ingalsbe, DeafBlind Consumer

Julie Somers, Department of Human Services, Division of Rehabilitation Services

UNDERSTANDING THE DEAFBLIND COMMUNITY: THE CHALLENGES WE FACE

Tamara Ward's Story: My name is Tamara Ward and I want to share my experience of using someone to take me places and assist me in my daily needs when necessary.

I had no idea that there was such a thing called "Support Service Providers (SSP)" existed until my first trip to the American Association of the DeafBlind (AADB) conference back in 1998. It was somewhat scary and exciting at the same time. I didn't know whether I should trust this person who was assigned to me and how to best use them. It was a "learn as you go" experience for me. The use of an SSP was a valuable tool to use in order to maintain my independence and remain in my community. This is especially important in the rural area of deep southern Illinois where I live. There is a need for SSPs here. For example, when I take a bus or a type of public transit to a store, it takes me there and drops me off. I then need to navigate the store on my own. Because of my deaf-blindness, this task is very difficult because I am unable to find a particular item; in result, I have to ask someone where this particular item is. Once there, I still have to figure out the cost of the items printed on the shelves. This can be daunting! This is one of the areas of why using a SSP would be extremely important.

There are other places that the use of a SSP would be beneficial such as when I go to a doctor's office. As I live in a rural area, it is difficult to do things on your own. Transportation is too hard because there are different buses that come to one stop and I am not sure if this specific bus is the one picking me up. Because of that, I have to ask the driver. However, most of the time I am not able to understand the driver due to my disability and this proves to be a barrier. This leaves me frustrated in figuring out how to deal with them while trying to be independent. In result, I have to depend on my friends who are willing to drive me places: whether that be at the store and help me shop, check in at the doctor's office, attending the triage area of the local hospital. When a friend is able to take me, I try to make things easier by having my list where my friend is able to read and get to the items quicker rather than wasting the time of my friend's. While this is effective and efficient in using a friend for assistance, it makes me feel I am a burden on them.

You may wonder how I choose a person to assist me so let me explain, and I is actually fairly simple. I provided some training on "How to Assist DeafBlind Individuals" as a consultant when I worked for the local community college as a part of their Interpreter Training Program. It didn't take long for me to find a couple of students who had the qualities I was looking for in a SSP. To me, it's all about honesty and respect. In fact, one of those students, whom I value greatly, went beyond the generalized training received in school and received additional, advanced training in becoming an SSP. I now use her as a SSP. I also received further training

as a DeafBlind person to learn how to better work with an SSP and how to further benefit of using one. In result of these trainings, I was able to share the experiences with the community college. Having good communication skills and being able to trust are essential keys in working with a SSP.

Living in a rural community where economics take a hard hit, the DeafBlind find it hard to reach out to be part of the community. Transportation systems in rural areas can only do so much and do not reach all corners of the community. Communication is usually lost which leaves DeafBlind individuals feeling frustrated. There have been many times where I got frustrated in situations, for example with the transportation systems, and I end up calling my friends to come and take me home. However, sometimes there isn't anyone available because they are busy with their lives such as working at their jobs or simply because they aren't being paid to help me which is really frustrating. Consequently, it makes me want to just forget it and I then walk away feeling awful.

Having a SSP can be a powerful tool for DeafBlind individuals in order to remain independent and not being dependent on family and friends. Naturally, a DeafBlind individual may want some privacy when going to places and a SSP can provide this. I feel empowered when I have the benefit of using a SSP rather than a family member or friend.

I sincerely hope this helps you understand why having a Support Service Provider (SSP) in a rural area in Illinois is very important. I hope that the state will take this to the next level by creating a SSP program statewide so DeafBlind individuals can use this valuable tool to lead an independent life.

Renee Ingalsbe's Story: Growing up as an independent individual before my vision deteriorated, I was able to do things a normal person would be able to do such as travel, go shopping, drive my own car and so much more. Over the years, I slowly lost my independence due to my vision restrictions.

As I grew up traveling with my family and continuing the love of traveling with my husband and children over the years, the trips have decreased and the trips aren't as much fun anymore. Because it feels like my husband and children have to do everything while I stand back waiting for guidance. For example; if I were to get up in the middle of the night to go to the bathroom, I would need to wake up my husband to guide me. I am not able to start the fire or put it out or be able to enjoy the outdoors such as staying at the campfire when my husband was ready to go to bed. Because of my vision challenges, I need to remain at my husband's or children's side which created a burden on them. For these reasons and more, my family no longer wants to go camping and this saddens me greatly.

The deterioration of my vision has caused tremendous difficulties on my daily duties such as going shopping. As demands and lists have grown longer, it is very difficult for me to shop. When I seek assistance from store workers on finding a specific item that I'm not able to find, communication is a difficulty. Because of my hearing loss and vision loss, there is no way for us to communicate. I have turned to my husband to do the shopping.

As burdens keep building up on my husband and children, I need to find a way to gain my independence. I know if I had a SSP, a lot of my struggles would no longer be such an issue. I could continue my tasks with the use of a SSP. My husband and children would not hold mountains of burdens that aren't their responsibility. There was a time when we needed new furniture in result of a flood in our home. Our landscaping needed some work. Our house had no curtains, in result I had to turn to my sister for help in finding curtains online. I know if I had a SSP in these situations, our lives would have been so much easier. I would feel as a whole. My family would be happier.

AREAS OF CONCERNS

1. Identifying DeafBlind Population

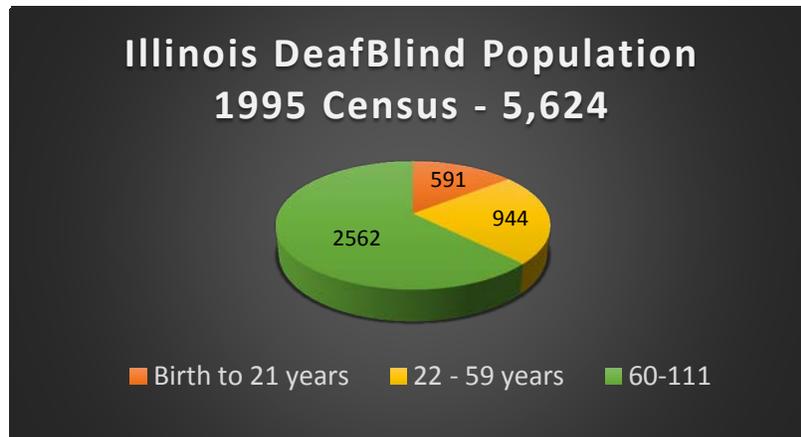
The precise number is difficult to establish because of various definitions of what qualifies as DeafBlind and no formal tracking measures. At times, programs do not accurately track this population as it is inconsistently identified due to the classification of primary and secondary disabilities. Additionally, many DeafBlind individuals are not identified if they don't receive services due to living with parents or family or within a residential institution.

It is estimated that the national DeafBlind population is between 40,000 – 60,000 individuals.

The 2014 National Child Count of Children and Youth who are Deaf-Blind reported Illinois serving 416 DeafBlind children under the age of 21. The National Child Count is the first and longest running registry and knowledge base of children who are deaf-blind in the world. It is conducted by National Center on Deaf-Blindness funded by a grant by the U.S. Department of Education. The Helen Keller National Center indicated that it has 568 individuals over the age of 21 registered from Illinois in its National Database.

The most comprehensive Illinois Census of DeafBlind was conducted in 1995 by the Interagency Agreement Committee for Individuals who are Multiply Handicapped with both Visual and Auditory Impairments (IAC). The Census was conducted with the cooperation of the following state agencies:

- Department of Aging;
- Department of Children and Family Services;
- Department of Human Services;
 - Division of Mental Health
 - Division of Developmental Disabilities
 - Division of Rehabilitation Services
- Department of Public Aid (now Healthcare and Family Services);
- Division of Specialized Care for Children;
- State Board of Education; and
- Philip J. Rock Center.



The Task Force intent is for SSP services to be available for DeafBlind individuals to live independently. Those in the age group of Birth to 21 years are typically still receiving services through the educational setting and living at home. In looking at the data available, the Task Force concluded an SSP program in Illinois would need to provide services to approximately 500 – 700 DeafBlind individuals.

2. Communication Access

The combination of a dual sensory loss of hearing and vision severely impacts an individual's ability to communicate, access information and generally get around without assistance. As a result, those who are DeafBlind often have to rely on family and friends to complete everyday tasks. As Illinois requires anyone providing sign language interpreting to be licensed under the *Interpreter for the Deaf Licensure Act of 2007, 225 ILCS 443/et seq.*, the Task Force looked at the following categories of communications: interpreting, environmental cues and direct communication/information.

A. Interpreting

Interpreting refers specifically to those communications where a licensed interpreter is required under the Licensure Act. It does not refer to communication between 2 individuals without the use of third person interpreter; this may also be referred to as direct communication.

Task Force members expressed concerns regarding the lack of a specific certification or designation for sign language interpreters providing services to the DeafBlind. In addition to general interpreting services, some DeafBlind utilize special skill sets such as Tactile Interpreting or Close Vision Interpreting. <http://visionlossresources.org/programs/dbsm/pro-tactile-training>

Currently, there is no certification test which allows a sign language interpreter to demonstrate their proficiency in these special skill areas. As such, the Illinois Licensure Act does not identify special categories of sign language interpreters for the DeafBlind. It is necessary for the DeafBlind to be able to specifically identify the skills needed when requesting a sign language interpreter including whether that sign language interpreter is expected to provide any additional services. Many sign language interpreters will not provide guiding or environmental cues unless agreed to in advance.

B. Environmental Cues & Information

In addition to communication requiring an interpreter, the DeafBlind miss out on environmental cues and general information. Without this information, the DeafBlind must depend on others for things such as shopping, using public transportation and completing daily tasks. This often becomes a burden for family and friends to continually provide this assistance.

A new emerging trend in the DeafBlind community is a technique known as ProTactile. "Pro-Tactile involves a system of feedback cues called "backchanneling" that provides the communicators with information about each other, their responses to what is being communicated, environment, etc. It is also an effective way to provide feedback to a DeafBlind presenter about the audience's responses and reactions to their presentation in real time."

http://issuu.com/dbtip/docs/pro-tactile_understanding_the_touch

Currently, there are limited training opportunities or consistency in the provision of ProTactile services. It is important that a DeafBlind consumer work directly with the provider to identify the various cues that will be used. SSPs were given an opportunity to work with members of the Task Force outside of their meetings to learn the basics of ProTactile. During follow-up meetings, the DeafBlind members received interpreting services by licensed sign language interpreters and the SSPs provided the ProTactile services.

The use of SSPs is essential for the DeafBlind to receive information. With the assistance provided by an SSP, the DeafBlind are able to lead independent and self-determined lives. The SSP is there to provide visual and auditory information; NOT make decisions or complete personal care tasks.

<http://deafblindinterpreting.org/the-power-of-pro-tactile/>

3. Americans with Disabilities Act

Most would think that adequate services would be provided for the DeafBlind under the Americans with Disabilities Act. An explanation of auxiliary aids and services and examples is in the Americans with Disabilities Act, Title III Technical Assistance Manual:

Who is entitled to auxiliary aids? This obligation extends only to individuals with disabilities who have physical or mental impairments, such as vision, hearing, or speech impairments, that substantially limit the ability to communicate. Measures taken to accommodate individuals with other types of disabilities are covered by other title III requirements such as "reasonable modifications" and "alternatives to barrier removal."

ILLUSTRATION: W, an individual who is blind, needs assistance in locating and removing an item from a grocery store shelf. A store employee who locates the desired item for W would be providing an "auxiliary aid or service."

However, the U.S. Department of Justice Technical Assistance Publication, Effective Communication (2014) states:

Many deaf-blind individuals use support service providers (SSPs) to assist them in accessing the world around them. SSPs are not "aids and services" under the ADA. However, they provide mobility, orientation, and informal communication services for deaf-blind individuals and are a critically important link enabling them to independently access the community at large.

As the ADA provides for auxiliary aids and services including but not limited to as qualified readers, notetakers, sign language interpreters, large print, and braille documents, it is imperative that DeafBlind individual's make their request in terms of communication access not just the request of an SSP. There are many functions that a SSP provides that may qualify under the requirements of the ADA.

It is important for the DeafBlind community to have access to education and training on self-advocacy skills which will assist them in making request for auxiliary aids and services under both Title II and Title III of the ADA.

4. Employment Services

During the course of its research, the Task Force learned of the Work Impairment Related Work Expense (IRWE) Program with the U.S. Social Security Department that provides work incentives which may be used when the DeafBlind hire an SSP. Another useful program in Illinois is the Work Incentive Planning and Assistance Program (WIPA) through the Illinois Department of Human Services. It is a state funded program created to help individuals receiving Social Security disability benefits (SSI/SSDI) make informed choices about going to work and how it affects benefits.

Additionally, the Department of Human Services – Division of Rehabilitation Services is in the initial stages of a new program Vocational Access Service Providers (VASP). The goal is to provide services to DeafBlind individuals who are already in the VR program working with a DHS Counselor and have an Individualized Plan for Employment (IPE). The Program will be supported by Federal Medicaid Waiver funding and services will be strictly limited to activities involved with getting a job in compliance with Federal Vocational Rehabilitation money. Examples of things that a provider would do for their assigned DeafBlind individual: type a resume for the DeafBlind individual; take the DeafBlind individual shopping for clothes to wear at an interview; and more. Once employment is obtained, VASP services are no longer available.

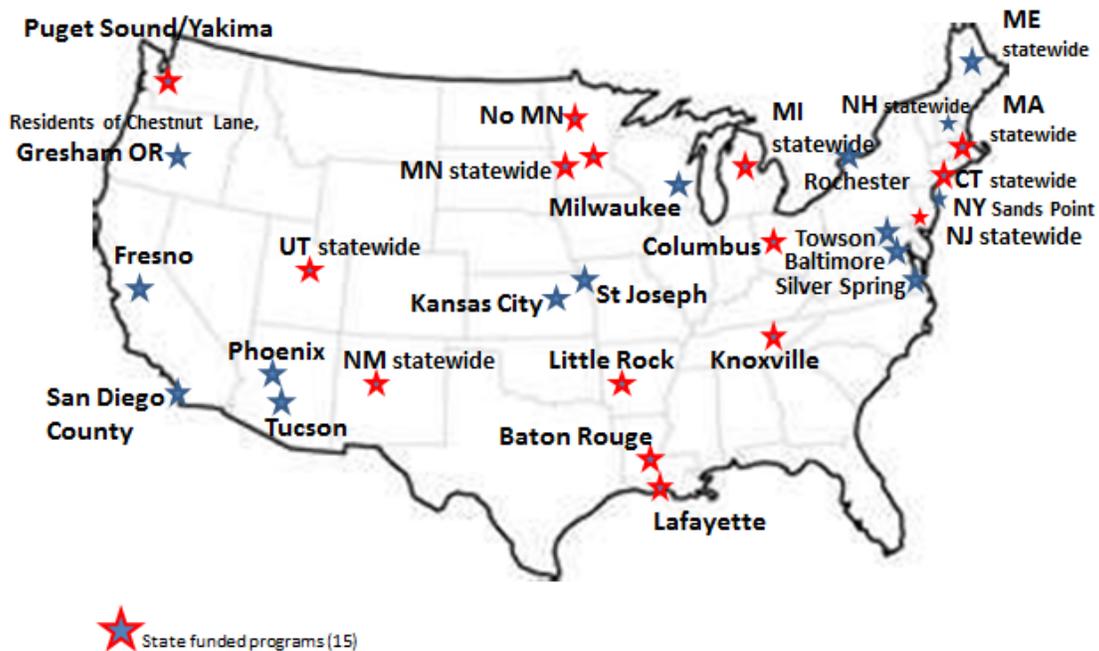
The VASP program is developing the following training modules: DeafBlind Individuals (on how to use Providers), Providers (on how to be one), and Rehabilitation Counselors (in how to work with both the DeafBlind and the Provider).

5. Other States

The Task Force members looked at other states SSP services. The existing programs varied greatly from State to State. They ranged from single counties of service to statewide; volunteer services, private funding through grants and donations or state run. Many programs were struggling financially and closing or services were restricted.

While it is clear that the services are essential to improving the quality of life for the DeafBlind community, determining a funding source and establishing a statewide program remains problematic during these economic challenging times.

30 SSP Programs in U.S.



RECOMMENDATIONS

Recommendation 1:

Establish a Statewide SSP program for DeafBlind individuals in Illinois.

The Task Force feels strongly that a Statewide SSP Program is essential for the DeafBlind community. It acknowledges this will require new legislation, cooperation among state agencies and an identification of a funding source.

As the purpose of the SSPs is to allow DeafBlind individuals to be able to complete day to day activities independently, one suggestion was to explore allocating a portion of a "service tax" which has been proposed in Illinois.

The program should include:

- SSP services to DeafBlind individuals that are 18 years and older;
- Minimum of 30 hours per month;
- Hands on training requirements for both the DeafBlind Consumer and the SSP; and
- DeafBlind consumer determines areas that services are utilized as long as not for illegal activities.

Recommendation 2:

Develop a voluntary Support Service Provider registry.

With the demand for SSP services increasing, DeafBlind individuals will need to be able to access qualified providers. The Illinois Deaf and Hard of Hearing Commission should work closely with the Illinois Department of Human Services – Division of Rehabilitation Services as it develops the Vocational Access Service Providers Program. In order to be listed on the SSP Registry, providers must be able to show proof of completion any of the below training requirements.

- Completion of the DeafBlind Retreat collaborated by the Department of Human Services, Division of Rehabilitation Services (DHS:DRS), Chicago Lighthouse and Helen Keller National Center (HKNC);
- Open Hands/Open Access Intervener Training;
- DeafBlind Service Center in Seattle, Washington; or
- Any other similar National or State training approved by IDHHC.

Recommendation 3:

Increase its collaboration with the existing stakeholders to improve the availability of resources for outreach and training.

The Department of Human Services – Division of Rehabilitation Services, Helen Keller National Center and the Chicago Lighthouse for People who are Blind or Visually Impaired have a Memo of Understanding to enhance service delivery, improve and enhance employment and independent living opportunities for DeafBlind individuals. In these difficult economic times, it is essential that stakeholders work together to maximize resources. IDHHC should further engage the Centers for Independent Livings as a collaborative partner in outreach and training to ensure availability of resources statewide.

ACKNOWLEDGMENT

IDHHC would like to thank the Illinois Department of Human Services – Division of Rehabilitation Services for their attendance and monetary support in providing the required sign language interpreters to ensure effective communication for the DeafBlind Task Force members.

During the Task Force meetings, DeafBlind members were provided Platform Sign Language Interpreters, Close Vision Interpreting, Tactile Interpreting, ProTactile Services and Support Service Providers.



This publication can be downloaded at
<http://www.idhhc.illinois.gov>.