

Findings from the SSP Surveys

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At the present time, there are no national standards, curricula or certification for Support Service Providers (SSPs) in the United States. As a result, the expectations for the role of the SSP and the DeafBlind person who uses these services may differ, depending on where the individual is in the country. To begin to determine core competencies, standards and best practices essential to developing a national SSP training curriculum, and eventually, the process of national certification of SSPs, in 2017 we undertook the development, circulation and analysis of the data obtained from two surveys: *The National Support Service Provider (SSP) Survey on Curriculum & Training* and a *DeafBlind Survey*. Additional goals of the surveys were to build a Nationwide SSP Database, and to support funding initiatives for current and new SSP programs.

According to the *Active Support Service Provider Programs* list compiled by the Helen Keller National Center in May, 2018, 28 states and the District of Columbia offer a total of 34 SSP programs across the United States (Jordan, 2018). Combined, these programs serve about 1,100 DeafBlind people. The annual American Community Survey, sponsored by the United States Census Bureau, suggests that approximately 2.4 million people experience a combined, “serious” to total hearing and vision loss (Molloy College, 2015). Putting these figures in another perspective, if approximately 1,100 DeafBlind people use SSP services, and the likely number of people with a “serious” combined loss of hearing and

sight is 2.4 million, then the percentage of DeafBlind people using SSP services is less than 1 percent.

SSPs are important to DeafBlind people because they provide access to environmental information, safe guiding and travel, and communication. Information and access empower all people to be more active and involved.

The National SSP Survey on Curriculum & Training

In 2015, a national SSP Task Force was formed to focus on developing a curriculum and certification process for SSPs. The National SSP Survey on Curriculum & Training was realized through the work on this Task Force. A community of 18 volunteer Peer Reviewers provided insights on the content, edited and provided general feedback prior to the survey's release.

The main objectives of the research were to discover:

1. The number of skilled, experienced SSPs in the United States
2. The characteristics of SSPs
3. The skills necessary to successfully perform the role of the SSP
4. The training experiences of SSPs
5. The role of the SSP in the "real world"
6. Areas of success
7. Areas for improvement

In the survey, experienced SSPs were asked to respond to more than 100 detailed questions regarding SSP training, experiences, skills and knowledge that

they believe are necessary to support DeafBlind individuals in leading independent and empowered lives. “Experienced” SSPs were defined as those who had:

1. Completed at least 15 paid and/or volunteer assignments; and
2. Worked with at least five different consumers; and
3. In their assignments, used a variety of language, mobility and communications skills.

Surveys were circulated February 1 to May 1, 2017 to all of the SSP programs on Helen Keller National Center’s 2016 list of SSP programs, as well as to DeafBlind camps, DeafBlind organizations and agencies, DeafBlind travel groups, and SSPs and DeafBlind people known to the researchers.

In all, 279 SSPs responded.

The SSPs reported providing services in 38 of the 50 states and the District of Columbia. Washington State had the highest number – 52 – probably because of Seabeck Camp. The other notable pocket was in the Mid-Atlantic states of New York, New Jersey, Pennsylvania, Delaware, Maryland and Virginia, as well as the District of Columbia, and extending west to Ohio. There were smaller pockets in Minnesota, Texas, Florida and California, with about 20 responding from each state.

Determining the characteristics of a “typical” SSP helps to identify those individuals who are likely to provide skilled, consistent and continuous services for the DeafBlind community for years to come. Using these general characteristics to recruit prospective SSPs may prove useful in the determination

of levels of funding allotted toward a program's basic training for beginner SSPs versus a budget for more sophisticated and complex training for seasoned, professional SSPs.

Generally, responses indicate that a typical "experienced" SSP is a hearing/sighted woman, over the age of 45, who has personal connections to the DeafBlind community and who has provided SSP services for more than six years. Specific findings include:

- **Gender** 71 percent women, 28 percent men
- **Age** 59 percent were older than 45, 28 percent were between the ages of 31 – 45, and 13 percent were age 30 or younger. These ages suggest the maturity and life experiences necessary to not only appreciate and commit to the value of the role, but also to develop and hone the skills necessary to do it well.
- **Hearing & Vision Status** More than half (54 percent) were hearing/sighted, while 42 percent were deaf or hard of hearing and sighted. Five people who are DeafBlind completed the survey saying that they serve as SSPs for other DeafBlind people. Two SSPs with low vision completed the survey; no blind individuals completed the survey.
- **Years of Experience** 62 percent have been providing SSP services for six or more years; 42 percent have been providing services for more than 10 years.
- **Relationship** 77 percent reported a personal relationship or friendship w/ someone who's DB.

The top five characteristics SSPs describe as “Absolutely necessary” are:

- Keeps confidentiality: 253 (91 percent)
- Good communication skills: 250 (90 percent)
- Respects consumer choice: 248 (89 percent)
- Patient: 244 (88 percent)
- Flexible: 227 (81 percent)

The types of languages and communication methods the SSPs use most often are: American Sign Language (90 percent), Tactile American Sign Language (80 percent) and spoken English (60 percent). Additional communication methods include ProTactile and Haptics, English-based signing, writing notes, assistive communication technology, Print on Palm (POP) and texting.

About 60 percent of the SSPs report that they are volunteers all or most of the time. Only 40 percent are paid all or most of the time. Of those who are paid, about half earn \$15 – \$20/hour, and about a quarter earn \$21 - \$25/hour. Most feel their pay rate is fair, but they also said that pay should depend on skills such as fluency in sign language, and demonstrated competence in guiding and mobility. No one mentioned that the pay should include knowledge of the skills of blindness.

The SSPs participating in the survey were trained by more than 55 different organizations, including state agencies, DeafBlind organizations and camps. Sixty-six percent of the SSPs went to a formal training. Of these, 62 percent felt prepared for their role after training. Fifty-five percent report that they have attended two or more SSP training programs/workshops.

Other than through formal training programs, SSPs develop their skills through interactions with DeafBlind people. In fact, on a scale of 1 – 10, SSPs gave their training programs a grade of 8.2, and they gave their DeafBlind mentors a score of 8.6

Ninety percent of SSPs reported that they would welcome a national certification. This certification can be realized only after national standards, consistent formal training and a process toward certification are developed, which will be a rigorous and dynamic process. This has happened for American Sign Language interpreters and interveners.

In consideration of the core concepts and content areas that the SSPs believe are necessary, nine areas emerged. The content areas mentioned as most important are communication and communication practice. Specifically, this includes language skills, and areas like respectful communication, positioning, touch communications, determining what should be communicated, getting someone's attention and including everyone in conversation. Another content area that emerged regards general information about the roles of the SSP and the consumer, including respecting the consumer's lead, developing a good working relationship and practice in community settings. A third area is professionalism, and this includes confidentiality, building trust, maintaining boundaries and managing challenging situations. Mobility, SSP environments, describing the environment, DeafBlind culture and basic information regarding the definition of the term "DeafBlind" round out the content areas.

One of the goals of the survey was to establish a National SSP Database. The goal of the database is to aid DeafBlind people who are traveling to another state

for personal or business reasons in finding an SSP at their destination. About 120 SSPs are currently included in the database, and some have already assisted DeafBlind people who are traveling to conferences, family functions and vacations.

The DeafBlind Survey

The DeafBlind Survey was circulated in the fall of 2017. It was a short survey – only 10 questions. Initially, the results seemed disappointing with only 217 people responding. Of the DeafBlind people who replied, nearly 80 percent knew that “SSP” means Support Service Provider. However, and perhaps more importantly, 95 percent - 206 people – said the SSP provides an important service. Of the specific components of the SSP’s services, DeafBlind people said that the role of the SSP involves: guiding (82 percent), providing visual information (82 percent), providing environmental information (77 percent) and promoting independence (72 percent). Almost everyone provided positive comments on how the use of SSPs changes lives for the better.

As mentioned, at first, it was disappointing to see such a low number of DeafBlind people responding to the survey. However, after some consideration, a number of probable reasons may be offered as to why this was the case:

- Many are continually adjusting to the slow progression of loss of their sight and hearing, and do not think themselves as “DeafBlind,” or “like Helen Keller.”

- Since only approximately 1,100 people use SSPs, most don't know what the SSP is or how the SSP can assist.
- Of the 1,100 people who use SSPs, perhaps many take these services for granted, and don't realize that their responses are important.
- Some DeafBlind people couldn't access the survey without ASL support, or because they didn't have the technology; attempts were made to accommodate these individuals, but it's suspected that some were not able to respond.

Like the SSP Survey, the DeafBlind Survey was developed in conjunction with a team of eight volunteer Peer Reviewers. The survey was sent to all the SSP programs, as well as DeafBlind clubs, organizations, camps and everyone known to the researchers. Considering a typical marketing response rate of 15 percent, of the 1,100 DeafBlind people who use services, a typical number of respondents would be 180; our response was 217. Therefore, while 217 seemed disappointingly low compared to the possibility of 2.4 million DeafBlind people across the country, compared to those who are aware of the role of the SSP and have the opportunity to use one regularly, it is a respectable response rate of 20 percent.

Conclusions

As DeafBlind people have become aware of the value of SSP services, the demand and necessity for professionalism, standardized and consistent training and training content, and a national certification have become evident. It was remarkable that 90 percent of those who took the SSP survey would strongly

welcome a national SSP certification. In addition, whether paid or unpaid, SSPs see their role as dedicated professionals.

The results of these surveys can ultimately support the provision of SSP services – either volunteer or paid – in states without a program, and the survey results may also support current programs in expanding. However, the bottom line for this research to become meaningful in the start-up or growth of any SSP program is the crucial need for initiative on the part of members of the DeafBlind community. DeafBlind people must step forward and take responsibility for creating a strategic plan to establish and/or ensure the perpetuity of these services that DeafBlind people say are critical to their independence and well-being.

Certainly, the information realized through the surveys can also support the development of a national SSP training curriculum and certification process; however, to realize these goals, again, it must be DeafBlind individuals who are taking an active role in advocating for these services.

It is time for a call to action: All of you who have both a hearing and vision loss should begin to start working with your state's DeafBlind community to become visible to the general population. Only then will the public and government sectors become aware of the capabilities of the DeafBlind and the DeafBlind community. Show who you are and how SSPs are integral to your independence.

As the DeafBlind movement grows, we can hope to impact positive changes on the national level to the Americans with Disabilities Act (ADA). This is vitally important because at the present time, SSPs are not considered an appropriate

accommodation under ADA. Rather, the role that Congress has determined is a match with the SSP is an aide. This is insulting to all of us who use the skills of our SSPs as our eyes, ears, mobility guides and communication facilitators. It is equally insulting to those of us who are SSPs and who have honed our skills in American Sign Language, touch communications, environmental description techniques, technology, and orientation and mobility. Contact your legislators. They need to hear from you to understand why SSP services are important to you, and not only you as an individual, but also you as a vital member of your community. Empower others to do likewise!

Educating your community, your state legislators and members of Congress is the key to making change that will impact the independence and respect for all who are DeafBlind. It is time to create change!

References

Helen Keller National Center Project: The Feasibility Review. (2015) The Community Research Institute at Molloy College Department of Sociology.

Jordan, Beth. *Active Support Service Provider (SSP) Programs*. (2018) Helen Keller National Center.