

## **Deafblind People and Support Service Providers in the 21st Century**

Paul Deeming  
DeafBlind Services Minnesota

Katherine Gabry  
DeafBlind Community Access Network of New Jersey

Mark Gasaway  
Disability Advocate & DeafBlind Community Access Network of New Jersey

Beth Jordan  
Helen Keller National Center

Randall Pope  
DeafBlind Individual

Elizabeth Spiers  
Virginia Department for the Blind and Vision Impaired

### **Authors' Note**

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## **Abstract**

People who are deafblind face unique and complex challenges every day in accessing information, communication, transportation, and their communities. Without readily available access to these foundations of everyday life, the ability to make informed decisions, remain independent, and perform daily living tasks may be compromised. Basic human needs may go unmet and essential human aspects of well-being—self-confidence, self-sufficiency, and self-worth—diminish.

A viable solution exists: the support service provider (SSP). The SSP provides a vital human connection to information that is missed when one has limited or no vision and limited or no hearing. This white paper examines the history of SSP services, the role of the SSP, why the SSP is necessary, and the process of establishing these services.

This SSP White Paper, *Deafblind People and Support Service Providers in the 21<sup>st</sup> Century*, is the second edition. The first, published by the American Association of the DeafBlind, was called *Support Service Providers for People who are Deaf-Blind* (Bourquin et al., 2006). Four of the original authors as well as two additional ones collaborated on this new version.

Since 2006, the number of SSP programs has increased from 19 to 35, and the scope of the SSP's work has evolved. Across the United States, less than 1% of individuals who are deafblind have access to these services; yet for those who do, a significantly improved quality of life is reported. The intention of this paper is to serve as a resource for understanding the role of the SSP and the positive outcomes—increased self-confidence, self-sufficiency, and self-worth—that deafblind people can achieve when they have access to these vital services.

*Keywords:* SSP, Support Service Provider, deafblind, DeafBlind, Deaf-Blind, SSP White Paper, services for DeafBlind

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## A Note about Terminology

People who are deafblind describe themselves using several similar terms that are rooted in the individual's native language and cultural identity. These terms are characterized by whether they include a hyphen and/or capital letters.

This paper uses the term *deafblind* to refer to the general population of people who have a combined loss of vision and hearing. The term preferred by each individual, organization, and agency contributing to this paper is respectfully reflected in these pages.

In 1991, Dr. Salvatore Lagati (Italy) began advocating for removal of the hyphen in the longstanding internationally used term *Deaf-Blind*. His premise was that the condition is not as simple as "deaf plus blind" but rather a distinct and unique set of circumstances where "the dual losses can be multiplicative, rather than additive" (1995, p. 306). As a result of his effort, most countries outside of the United States do not use a hyphen.

The use of capital letters signifies acceptance and pride in a community.

Whichever term an individual prefers is his or her choice and should be respected. The terms below are among those in use today:

- **deafblind** – A diagnosis of a combined loss of vision and hearing.
- **Deaf-Blind** – Established in the U.S. Code of Federal Regulations and the Helen Keller Act (Appendix A). Also: **deaf-blind**
- **DeafBlind** – Acceptance and pride in DeafBlind culture and community.
- **DB** – Denotes any of the terms listed above.
- **Dual sensory impairment** – Describes a later onset of vision and hearing loss, usually where one sense compensates for the other.
- **Blind-deaf** – Those who consider themselves culturally blind and become deaf later in life.

## Overview: Deafblind People and Community Access

Millions of people living in the United States have a loss of both vision and hearing and may be considered deafblind. The actual number is difficult to determine for several reasons. First, the federal definition of *deafblind* describes a concomitant loss of hearing and vision that causes “extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation” (Helen Keller National Center Act, 1984, 1992). The complete federal definition can be found in Appendix A. To diagnose “extreme difficulty,” assessments can be conducted clinically and/or functionally. While clinical assessments can offer an objective measure of an individual’s level of vision and hearing, functional assessments rely on self-reporting and observation and sometimes use different criteria, all of which can result in unreliable data (World Federation of the Deafblind, 2018, p. 15). Second, no one agency or organization in the United States maintains a definitive, full count of the number of individuals who are considered medically or functionally deafblind.

Nevertheless, information is available to estimate this number. In 1982, Wolf, Delk, and Schein estimated that 734,275 people in the United States had a severe to profound hearing loss and legal blindness (p. 8). In the years 1999–2006, Swenor, Ramulu, Willis, Friedman, and Lin (2013) estimated 1.5 million individuals ages 20 and older were deafblind with the overwhelming majority older than age 70 (pp. 312–313). In 2014, a study conducted by Molloy College estimated approximately 2.4 million people in the United States were deafblind (Helen Keller National Center, 2020). Most recently, in its report *Inequality and Persons with Deafblindness*, the World Federation of the Deafblind (2018) indicated that 0.85% of people ages 5 and older in the United States are deafblind (p. 16). Using this percentage and the United States Census Bureau’s population count of approximately 330 million on December 31, 2020, indications presume approximately 2.8 million deafblind individuals in the United States. Of those who are deafblind, the vast majority are senior citizens (Swenor, et al, 2013, pp. 312–313), and approximately 11,300 are ages birth through 21 who are served through federally funded state and multi-state deafblind technical assistance projects and the National Center on Deaf-Blindness (National Center on Deaf-Blindness, 2020).

As noted in the original SSP White Paper (Bourquin et al., 2006, p. 3), historically, deafblind people in the United States often lived with or near their family or relatives and depended on their support; they did not work or socialize outside the home, and opportunities for community involvement and participation were limited. Assistance from family, friends, and professionals was often the difference between living on their own in the community and living in an institution.

The disability movement that began in the early 1900s challenged the barriers and prejudices that people with disabilities faced in their desire to be active, accepted members of their communities. These actions led to civil rights laws and legislation in the latter part of the 20<sup>th</sup> century. The Education for All Handicapped Children Act was signed in 1975 and is now known as the Individuals with Disabilities Education Act (IDEA). This legislation entitles children who are deafblind to a free and appropriate public education that includes individualized supports and strategies as well as vocational planning. In addition, technological advancements, the provision of workplace accommodations, self-advocacy, and equal rights legislation have opened the doors to individual growth, professional development, and careers for people who are deafblind.

While these recent cultural changes have resulted in significantly improved opportunities for deafblind people, the combined loss of vision and hearing may still present a variety of unique and complex challenges in accessing communication, information, transportation, and the community. Hersch (2013) noted that these challenges can limit one's ability to make informed decisions, remain independent, and perform daily living tasks, and further, that these challenges often lead to reduced self-confidence and higher rates of stress, depression, and isolation (pp. 446–449). As a result, basic human needs such as obtaining food, health care, fitness, and safety may go unmet. Essential human emotional needs of belonging, esteem, acceptance, and being understood and valued may go unfulfilled.

Nuccio and Smith (2010) noted that while deafblind people today may be better able to "find gainful employment and live independently," these opportunities may still be dependent on the supports of those who are skilled in working with deafblind people (p. 2). The assistance of skilled professionals such as SSPs can facilitate a transition from dependency to independent access and participation in

society. Catherine Stutzman (2020) of the Center for Disability Rights (CDR) in Rochester, NY documents such an example. Stutzman writes of a young woman who faced barriers in accessing her hometown—barriers typically encountered by deafblind people in accessing the larger community—that made her fearful of living on her own and dependent on her parents for assistance with various tasks and transportation. Before moving to Rochester in 2015, she learned that SSPs from CDR could assist her in living more confidently and self-sufficiently. Because of these services, she “achieved a lifelong dream of getting her own apartment and using SSP services to maintain her independence: grocery shopping, buying furniture, going to the bank, and getting involved and better acquainted in the Rochester community” (Stutzman, 2020). Her newfound freedom to access the community led to more involvement, responsibilities, and greater independence, as well as the anticipation of finding a job and completing a bachelor’s degree.

Nuccio and Smith (2010) describe SSPs as a “foundational service” for deafblind people and suggest that without them, those who are deafblind will continue to be “isolated in the extreme, an isolation that compounds over the years, making it harder and harder to participate in the wider society in a meaningful way, even when other services such as skilled interpreters are provided” (p. 2).

## **The SSP Solution**

### ***Definition: Support Service Provider***

A support service provider (SSP) serves as a connection between someone who has a combined loss of vision and hearing and the surrounding environment.

Specifically, the SSP:

1. provides access to visual, situational, and environmental information;
2. serves as a human guide; and
3. facilitates brief casual exchanges of spoken and/or signed conversations.

The SSP works with one deafblind person at a time providing information and access tailored specifically to that individual so that he or she is better able to make informed choices and decisions and more fully access and participate in the larger community. The deafblind person must be able to manage their SSP services and provide direction, leadership, and guidance to the SSP. Services are typically

provided in home, recreational, vocational, and community settings. In all instances, the SSP does **with** the deafblind person, not **for**. Mutual trust and preserving confidentiality are fundamental to establishing a successful working relationship. As such, SSPs and consumers do not discuss each other's choices, activities, purchases, or any other personal, business, social, or confidential information with anyone. The only exception to this rule is reporting serious issues of health, safety, or illegal activity that threatens the individual's well-being. (Note: Some SSP programs may have additional reporting requirements, but in general, confidentiality is to be maintained.)

SSPs provide assistance with daily activities such as grocery shopping and errands; navigating throughout the community, communicating, and accomplishing tasks in environments such as stores, laundromats, and doctors' offices; labeling foods, medications, and clothing; making telephone calls; and participating in family, community, recreational, and social events and activities.

Overall, deafblind people report that by using SSPs, they are better able to enjoy life with greater self-confidence, independence, and self-sufficiency. In a 2017 survey, deafblind people described the positive outcomes of using SSPs as: "very important ... in the independence of the deafblind," "[filling in] communication gaps so we can access our communities," "less worries and reducing fears," and feeling "more secure and more relaxed" (Gabry & Gasaway, 2018). In addition, 95% of the survey respondents said that SSPs provide an "important service" to deafblind people. These findings affirm the results of a 2006 focus group at a conference of the American Association of the DeafBlind (AADB, 2010).

### ***Cultural Identity among Deafblind People***

Language and communication form the foundation of personal cultural identity. The ways in which a deafblind person experiences the world, acquires language, accesses information, and processes experiences are largely based on when their vision and hearing loss occurred, as well as their current amount of usable vision and hearing. With more than 80 causes of deafblindness (Anne Sullivan Centre, 2020), the deafblind community is rich in diversity and expression. Each deafblind person has a unique background, educational experience, and language and communication preferences.

Understanding this cultural diversity and respecting each individual's preferences improves the probability of successful interaction. There is no one "right" way to communicate with deafblind people, and while technology may be beneficial, no tools exist to remove all communication barriers. Another consideration is that while partial vision and/or hearing may be useful at times, they may also be unreliable.

**Spoken language** is most often used by those who relied on their hearing to acquire language. These individuals typically identify with the norms and culture of the larger hearing community in which they live. They use speech and their residual hearing for communication and are often aided by technology such as hearing aids, cochlear implants, and assistive listening devices and systems. Successful communication can be facilitated by speaking clearly, naturally, and at a slightly slower pace; pronouncing words properly; using facial expressions and body language to add to what is being said; and conversing in quiet, well-lit places.

**Signed language** is most often used by those who were born deaf and experience vision loss later. Those using visual sign language may prefer slower, more precise signing in a smaller space. As their vision decreases, they may rely on tactile forms of language, including tracking or Tactile American Sign Language (TASL), and touch. They may culturally identify with the Deaf community's reliance on visual language and an emphasis on vision as the primary sense.

**Individuals born with a combined vision and hearing loss or who lose these senses prior to acquiring language** may rely on their sense of touch and/or their residual vision and/or hearing to acquire life experiences, including the development of language and communication skills. Those born deaf who benefit from cochlear implants, hearing aids, and assistive listening systems may develop spoken language and identify with the larger hearing community and/or a signed language and identity with Deaf culture.

## **History of SSP Services**

In 1975, the National Association of the Deaf-Blind of America (now the American Association of the DeafBlind [AADB]) began holding national conventions. A multitude of volunteers, some of whom provided pro bono professional services such as sign language and voice interpreting, braille transcribing, guiding, and visual

description, made it possible for deafblind people to participate fully in these conventions. Former AADB President Roderick Macdonald coined the term *support service provider*, or SSP, in the early 1980s to recognize the volunteers' unique skills and the essential services they provided. In his history of AADB for the years 1981–1983, President Macdonald (2020) described the process used to create the term:

Professional interpreters volunteering their skills ... students just learning to sign ... family members who were really just guides ... At first everyone was just called a "volunteer," but some professional interpreters, while offering their skills without pay, were not comfortable being lumped into the pot with volunteers who were really just companions. Many felt it was not respectful of their profession, and so we searched for a new name for our support providers. I asked some of the interpreters what they did at the conventions, and the answer was "provide support services." I said OK, from now on you are *Support Service Providers*, and the term SSP was born. An SSP could refer to anyone from certified interpreters for the deaf to sighted guides, provided they were providing skills to support the independent participation of deaf-blind consumers. Our friends in Canada were part of this early discussion, but they liked the term *Intervenor*, and they use that.

By the late 20th century, the concept of the SSP was spreading across the country. In 1999, SSP services were available throughout the states of Minnesota and Washington and regionally in Little Rock, AR, and Milwaukee, WI (Jordan, 2020). Deafblind people were enthusiastic about using services that provided objective, unbiased access to information, the surrounding environment, and communication.

However, the skills required and the demands of the job made it increasingly difficult to find consistent, reliable volunteers. In 2003, deafblind people at the AADB conference in San Diego, CA, "spoke of the need for national SSP services to help insure the independence of people who are deafblind throughout the United States, and [they] expressed frustration regarding limited services in specific pockets of the country" (Bourquin et al., 2006, p. 8).

As a result, in 2004, a National Support Service Provider Pilot Project began with the goal of expanding and improving SSP services throughout the country. This effort evolved through the leadership of the DeafBlind Service Center in Seattle,

WA, with partner agencies Helen Keller National Center in Sands Point, NY, and the American Association of the DeafBlind, which was then located in Silver Spring, MD (Jacobs, 2010, p. 18). Agency representatives and deafblind community members met with legislators in early 2005 to explain the project and to advocate for funding (Cué, 2005). At the 2006 AADB conference in Towson, MD, approximately 35 deafblind individuals attended an SSP Forum where they discussed their use of SSPs, the importance of SSPs, problems in getting services, and the support they wanted from AADB to secure SSP services (AADB, 2010).

In 2008, the DeafBlind Service Center (DBSC), working on its own now, received a \$335,043 federal appropriation to develop Phase I of the project (Jacobs, 2010, p. 18). Phase I included developing a curriculum to train deafblind people to direct and work with SSPs, for SSPs to learn how to work with deafblind individuals, and for DBSC to pilot the use of the proposed curriculum in three areas of Washington State (DBSC: Phase I, n.d.). In June 2010, DBSC completed Phase I with the publication of *Providing and Receiving Support Services: Comprehensive Training for Deaf-Blind Persons and their Support Service Providers* (Jacobs, 2010, p. 18–19). In July 2010, DBSC received an additional federal appropriation of \$200,000 for Phase II of the project to enhance the curriculum with slides, videos, and other instructional support materials (Jacobs, 2010, p. 19). Due to a lack of funding, the curriculum has not been updated (A. Theriault, personal correspondence [K. Gabry], May 26, 2020) but is still available (DeafBlind Service Center, n.d.).

In 2015, a volunteer, grassroots effort of deafblind people and SSPs from around the country formed the National SSP Task Force. The group focused on two paramount concerns: a national SSP training and certification program and changing the term “support service provider” to another term that more accurately reflects the role. Terms developed by deafblind people and considered by the Task Force were Access Provider (AP) and DeafBlind Environmental Facilitator (DBEF). The group formally dissolved in 2016 without selecting a new term, but several members continued to contribute to training and certification efforts by conducting national surveys to identify the core content areas and philosophical concepts necessary for the provision of these services.

Due to their experiences using SSPs at the AADB national conventions and, subsequently, at deafblind camps and retreats, some deafblind individuals

successfully advocated for the establishment of SSP services in their home communities. Since 2006, the Helen Keller National Center has conducted a biennial survey of SSP programs across the United States. Below, the results of the 2020 survey are compared to those of the 2006 survey, which were included in the original SSP White Paper.

Figure 1: SSP Programs in the United States Survey Comparison: 2020 to 2006 (Jordan, 2020, 2006)

	<b>2020</b>	<b>2006</b>
# of States with SSP Services	29, plus DC	14
Total # of Programs	35	19
• # of statewide programs	23	6
• # of regional programs	12	13
# of Deafblind Served	1,276	Information unknown

*Note:* Some states offer both statewide and regional programs. Because some deafblind people use more than one program, the actual number served is probably lower than indicated.

Some programs restrict eligibility based on funding source requirements related to age or a vocational goal. Most of the programs (28 of 35) use the term SSP to describe the provider; other terms used include Provider, Access Provider (AP), and Co-Navigator (CN) (Jordan, 2020).

## **Key Components of the Role**

Over the last 40 years, the scope of the SSP's responsibilities has evolved to include four key components:

1. To relay visual, situational, and environmental information that may not be seen or heard by the person who is deafblind, such as:
  - describing who is in a room, where they are located, the activity, and the mood;
  - locating items and areas in stores, businesses, and other settings;
  - reading a restaurant menu, mail and bills, recipes, books and magazines, labels, and instructions for the use and maintenance of technology and appliances;

- providing information about clothing (such as color, fabric, style, price, and manufacturer's recommended care);
- conveying that others have arrived (such as a nurse or doctor, friends, wait staff, or salespersons); or
- alerting the deafblind person when it is their turn for service or that their ride has arrived.

Information is provided objectively in the deafblind person's preferred mode of communication, and relayed respectfully, clearly, and as completely as possible. In all instances, the SSP does **with**, not **for**.

2. To provide safe, efficient, and effective access to the community by serving as a human guide while navigating with the deafblind person, such as:
  - walking; or
  - traveling by paratransit, hired ride services, buses, subways, planes, trains, boats, and automobiles. Some SSP programs permit SSPs to use their own vehicles to transport deafblind people while others do not.

In all cases, the SSP respects the mobility tools—such as a long white cane, dog guide, and various types of technology—used by the deafblind individual.

3. To assist in providing access to brief casual communication exchanges of spoken and/or signed conversations in home and community settings, such as:
  - asking a question in a store;
  - ordering in a restaurant;
  - assisting with the transaction of purchasing a bus or train ticket; or
  - keeping a deafblind person connected to a casual social conversation.

While SSPs may assist with casual communication, they do not provide interpreting services for more formal contexts such as doctors' appointments, legal or law enforcement, education, meetings, or financial or legal contracts.

4. To comply with preferred practices, ethics, and professional practices of this developing field, including:
  - respecting the privacy, integrity, and confidentiality of the person who is deafblind;
  - recognizing personal and physical limitations; and
  - maintaining professional boundaries.

While the scope of the SSP's responsibilities has evolved throughout the years, a review of the original SSP White Paper affirms that what the SSP does not do has remained generally the same (Bourquin et al., 2006, p. 12). The SSP **does not:**

- provide personal care or hygiene assistance (such as bathing, grooming, hair or nail care);
- provide yard or household maintenance, move furniture, or store items;
- run errands alone for the person who is deafblind;
- make decisions for the person who is deafblind;
- teach or instruct;
- interpret (SSP programs must adhere to their individual state laws and regulations regarding interpreting and SSP roles); or
- advocate for the person who is deafblind.

### ***SSP Philosophy: Professional Distance, Objectivity, Respect***

In the original SSP White Paper, Bourquin et al. (2006) suggest that the first and most famous SSP may have been Anne Sullivan, Helen Keller's teacher, friend, interpreter, and guide for most of her life (p. 7). Upon closer examination, however, observers today would say that their relationship was too close for Anne to be considered an SSP. Due to the intimacy of their friendship, personal and professional boundaries were crossed every day, with Anne very much controlling the information available to Helen.

In the early years of the SSP term, the role was perceived as that of a "friend" and "helper." Today's SSPs realize that keeping a professional distance is necessary to maintain a level of objectivity—to be able to provide just the facts—and the ability to respectfully step back and allow the deafblind individual to exert control and leadership in the relationship. In accordance with this goal, the preferred practice is that the SSP not provide services for anyone with whom they have a close, personal relationship, including family members. This practice ensures that information is presented accurately and impartially, and kept in confidence.

A fundamental tenet of the SSP philosophy is respect for the deafblind individual's leadership and choices. The SSP remains impartial and does not make recommendations, choices, or decisions for the deafblind person. Nor does the SSP

take action on behalf of the deafblind person. Mutual respect, understanding, and honesty are vital in developing and maintaining a safe and trusting partnership.

When the deafblind person asks for the SSP's suggestion, the SSP respectfully and tactfully declines to offer an opinion. Instead, the SSP may read printed information or offer tactile exploration, if these options are available. If still undecided, the deafblind person can ask the SSP for assistance in finding a third party who can provide additional information. Examples might include finding a sales representative to provide a demonstration or asking a restaurant server if an entrée includes a certain ingredient. Additional examples can be found in Appendix B.

### ***Comparison of Roles: Intervener, Interpreter, SSP***

Access to information is critically important for all people. Those who are deafblind may depend on interveners, interpreters, and SSPs, among others, for access to information.

**Interveners** may be considered a related service for children in the educational system under the Individuals with Disabilities Education Act (U.S. Department of Education, 2018). The intervener in the United States works one-on-one with a child providing access to the environment, as well as reinforcing educational goals that include the development and use of both receptive and expressive language (L. Alsop, personal communication [K. Gabry], July 18, 2019). A hallmark of the role is building a trusting relationship to support the growth of social and emotional development. In educational settings, the intervener works under the direction of the teacher and Individualized Education Program (IEP) team, not the deafblind child. Intervener competencies have been recognized by the Council for Exceptional Children, and national credentials and certifications are available. More information can be found at <https://www.nationaldb.org/national-initiatives/iqp/>.

Interpreter roles and responsibilities, as described in the 2006 White Paper, have "long been established by professional organizations, codes of ethics and professional conduct, and university-based training programs" (Bourquin et al., p. 9). More information can be found at <https://rid.org/about-rid/about-interpreting/>.

While interveners support the development of language, interpreters and SSPs assume a standardized language system is in place. Comparing the scope of work of interpreters and SSPs reveals the following similarities and differences.

**Similarities** (Bourquin et al., 2006, p. 9-10):

- remaining impartial
- maintaining confidentiality
- working in a variety of settings

**Differences:**

- Interpreters work with people who are deaf, hard of hearing, and deafblind. SSPs work only with people who have a combined loss of vision and hearing.
- Interpreters work with one individual, several people, a small group, or a large audience. SSPs work with one deafblind individual at a time.
- Interpreter education is available from colleges and universities. SSP training is often presented through hands-on activities and workshops sponsored by service agencies and organizations or through individual life experiences working with a person or persons who are deafblind.
- Interpreters can earn state and national certifications, specialized certificates, and state licensures (state laws and regulations vary). There is currently no such opportunity for SSPs.
- Interpreters are paid based on their certification and/or rates established by agencies, communities, or the individual interpreter. While SSPs may be paid, the *National SSP Surveys Results* reports that 59% of SSPs are volunteers (Gabry & Gasaway, 2018).

The work of support service providers may be performed alongside that of other professionals such as interpreters, social workers, counselors, teachers, advocates, and personal care attendants. Persons in the role of the SSP should not accept payment for multiple roles during the same assignment.

## **Establishing & Maintaining an SSP Program**

A successful SSP program requires collaborative initiatives among individuals, organizations, and agencies with regard to planning, systems development, personnel coordination, proactive and flexible management, and ongoing program

evaluation. Central to these themes are funding, building and retaining an SSP team, training, and successful strategizing.

### ***Funding***

When a program has stable funding, it can consistently pay its SSPs a fair wage, and it is generally recognized that SSP programs are most effective when the providers are paid. As a historical comparison, the Vocational Rehabilitation Act of 1965 marked the beginning of paid interpreting opportunities for American Sign Language interpreters in the United States. In some respects, the SSP is facing similar compensation challenges that interpreters faced prior to 1965.

The Americans with Disabilities Act of 1990 places the responsibility for effective communication, including the use of interpreters, on places of public accommodation, such as state and local governments, businesses, and nonprofits that serve the public. In the 2014 revision of the ADA, the U.S. Department of Justice included the following statement:

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 access the community at large.

It has been 30 years since the ADA was originally enacted and seven since it was updated. While there is no federal funding allocated for SSP services, Jordan (2020) found that state funding exists for 25 of the country’s 35 SSP programs in the form of legislated appropriations, Medicaid or Medicare funds, vocational rehabilitation funds, or a combination of these sources. Fourteen programs rely on less consistent, less sustainable resources such as volunteers, donations, grants, and local fundraising (some states use multiple sources of funding) (Jordan 2020). In all, sources of funding include:

- State, county, or regional grants, private foundations such as United Way, donations, and fundraising events.

- As noted in the original SSP White Paper, states may develop contract partnerships between their agencies, departments, divisions, and service providers in human services, vocational rehabilitation, independent living centers, deaf and hard of hearing programs, blind and visually impaired programs, mental health services, and developmental disabilities; these may be one-time funding sources or annual contract funding (Bourquin et al., 2006, p. 18). Some funding sources specify service provision to certain groups of individuals such as senior citizens over the age of 55 or individuals with employment goals.
- Legislative creation of new laws with funding allocation. This has often resulted in a significant source of funding that can be used for SSP services and also training for SSPs and deafblind constituents. Jordan (2020) found that 10 states have authorized legislative appropriations to recognize and fund SSP services at the state level.

Securing consistent funding is essential for any SSP program. Successful advocacy in this effort is often supported by deafblind people who actively educate state and federal legislators and lobby for specific funding. The expansion of SSP services is dependent on the leadership and participation of deafblind individuals who can affirm and advocate for the value of these services.

### ***Meeting the Needs: Building & Retaining an SSP Team***

At the heart of any successful SSP program is a multi-faceted team of well-trained, dedicated SSPs who are compensated to provide consistent, highly skilled services that meet the needs of the program's consumers. Building and retaining the team involves ongoing planning, communication, needs assessment, and program evaluation. These initiatives are usually undertaken by administrators, consumers, and SSPs who proactively collaborate to identify needs and develop innovative solutions.

To know, understand, and be able to meet the needs of their consumers' individual situations, some programs ask their consumers to complete a needs assessment. Questions may include the types of communication used, mobility tools used, dates and times that services are typically requested, and the variety of settings where services may be required. Programs must then recruit SSPs to meet the needs of

consumers in the service area. For example, a program may need to fill SSP situations similar to these:

- a community where 75% of the deafblind people are not working and prefer to make appointments, shop, and run errands in the daytime on weekdays;
- shopping for intimate apparel and personal products;
- a fully deafblind artist selling handcrafted products at a craft fair;
- going to the gym with a strong, fit, and active young person and going to physical therapy with someone older who recently had a hip replacement;
- a community where 90% of the deafblind people use spoken communication;
- a consumer who has asthma and severe allergies to animals, cigarette and cigar smoke, and various products and scents;
- deafblind people who use service dogs; and
- participating in community activism events.

Considering that training each SSP represents a financial investment of about \$500 (Gabry, 2015, p. 1), a goal for a new SSP program with 10 deafblind consumers might be to develop a team of 20 SSPs over the first year and to retain at least 75% of these SSPs for at least five years. *Immediate and inherent in this process is thoughtful, goal-oriented recruiting.* The goal's long-term benefits include building consumer trust and confidence in the program's ability to provide consistent, highly skilled SSPs as well as demonstrating a sensible and forward-thinking use of funds. As the number of seasoned, experienced SSPs grows, a larger percentage of the training budget may be spent on higher-level skills training rather than the instruction of basic SSP skills.

As programs seek qualified SSP candidates, references and background checks are often used in the application process to gauge a candidate's potential to be trustworthy, of good character, reliable, and respectful of safe and conscientious professional practices. In addition, some programs require regular ongoing background checks.

The following community resources often yield potential SSP candidates:

- **Deafblind People.** Deafblind people often recruit SSPs from trusted and respected friends, religious institution members, co-workers, and community and family networks. These are often people with whom they share common

cultural characteristics such as communication methods and values. For example, a culturally Deaf DeafBlind person may recruit members of the Deaf community, and seniors and college students may refer potential SSPs who are their respective ages.

It is important to note that while family members can provide a rich pool of resources and valuable assistance, especially during family events, there are several reasons why the SSP role should not be filled by a family member. First, the ability to provide objective information is compromised when individuals have a close, personal relationship. Second, deafblind people may want to preserve confidences and not share some personal details of their lives with family or close friends. Third, the family member may not wish to serve as an SSP and would welcome an SSP's assistance. Consider these examples: It is difficult for a spouse to purchase an anniversary gift when the other spouse is their SSP; a teenage boy may not be comfortable going on a date with his father as his SSP; and at a wedding shower, sisters may prefer to visit, eat, and enjoy the opening of the gifts separately rather than one sister being responsible to ensure the other's access to the festivities.

- **Interpreting Education Programs.** College interpreting programs prepare sign language interpreters and may offer classes specific to deafblind communication, culture, ethics, community, human guide techniques, and use of touch. Students in these programs may be interested in serving as SSPs.
- **SSPs.** Skilled and knowledgeable SSPs can be an excellent community resource for finding new SSPs.
- **Agencies and Organizations.** Deaf and hard of hearing commissions or departments, state agencies for the blind, the Helen Keller National Center, and deafblind clubs and organizations can be helpful in identifying possible SSP candidates.

### ***Training for SSPs***

When SSPs are able to efficiently convey information, deafblind people are better able to consider options and make knowledgeable decisions, independently manage and maintain their home, and confidently access and participate in their community. At present, there is neither a current standardized national SSP

training curriculum nor a national SSP certification. To ensure consistency in skills, knowledge, and expectations, some advocates support the development and implementation of a national standardized training curriculum and certification process, as well as a code of professional conduct. Until that happens, a number of SSP programs have developed their own training. Those that have given permission to be included as a resource in this paper are listed in Appendix C. (Please note that this inclusion does not indicate endorsement of any program by the authors.)

SSP training should be offered in as many areas as possible to meet the needs of the deafblind consumers. The *National SSP Surveys Results* identified the following core training content areas and philosophical concepts for SSP candidates (Gabry & Gasaway, 2018):

- 1. Communication and Communication Practice.** SSPs must be skilled in the communication methods used by their consumers, which may combine verbal or non-verbal, spoken or signed, visual or tactile, gestures or “home signs,” print or braille, or assistive technology. Some deafblind people use Haptics, a “standardized system for providing and receiving visual and environmental information as well as personal reactions/social feedback via touch signals on the body” (Helen Keller National Center, 2018). In addition, the social philosophy of protactile (PT) uses “*tactile reciprocity* [turn-taking] as opposed to one-way tactile reception, *contact* [touch] space as opposed to the air space of visual signers, and *proprioceptive* [the sense of self-movement and body position] constructions as opposed to visual classifiers”; at the time of this writing, research and data were being reviewed and analyzed regarding PT as an emerging language natural to the DeafBlind community (J. Clark, personal correspondence [P. Deeming], September 10, 2019). SSPs must be skilled in the communication used by their consumers and should always confirm the deafblind individual’s preferences for language, touch, and positioning. Communication must always be clear and respectful.
- 2. Roles of the SSP and the Consumer.** The roles of the SSP and the consumer must be clearly documented, communicated, and understood by all so that everyone has the same expectations for a successful experience. Elements essential to a productive working relationship include philosophical concepts such as respecting the consumer’s lead, developing a good working

relationship, practice in community settings, and understanding the situations and settings where SSP services can occur.

3. **Guiding.** SSPs need to be skilled in human guide techniques. The deafblind person should always take the lead in demonstrating and confirming his or her preferences. Human guide techniques are most often, but not always, taught (to the deafblind traveler) by instructors who are certified in orientation and mobility. It is important to note that from time to time, standard techniques may be modified to meet the unique needs of each deafblind person and the environments where they travel.
4. **Environmental description.** SSPs should be skilled in identifying visual, environmental, and situational information and describing information without bias. The deafblind person and SSP should confirm the deafblind person's preferences for what and how much needs to be described.
5. **Professionalism.** SSPs are expected to follow preferred practices and ethical standards that include respecting confidentiality, building trust, maintaining boundaries, recognizing one's own personal and physical limits, and managing challenging situations.

A chart highlighting the general findings of the *National SSP Surveys Results* can be found in Appendix D.

SSP training is often offered by SSP programs, state agencies, deafblind individuals, and deafblind organizations and camps/retreats (Gabry & Gasaway, 2018, p.5). SSPs usually receive training through a combination of formal instruction and community experiences. Training is often directed by deafblind people who have experience using SSPs, seasoned and experienced SSPs, and program administrators. Specialized training may be offered in topics such as mobility, protactile, Haptics, visual and environmental description, ethics, mandatory reporting, and business management; individuals with expertise and/or certification typically present these advanced concepts.

### ***Training for Deafblind People***

Training for deafblind people must provide a comprehensive understanding of the benefits of using SSPs, the program's security measures, and the knowledge and skills necessary to assume leadership in the SSP-consumer partnership.

Fundamentally, Deafblind people need to be made aware of their eligibility for SSP services and the benefits of using them.

Deafblind individuals may not know about SSPs and may be comfortably dependent on family members or friends. An example is a deafblind person who prefers to use her husband for SSP duties because, in her mind, he knows her and her needs, and she doesn't have to advocate for herself as she would using a professional provider. However, should her husband become injured or ill or pass away, she would have no assistance. Also, by using only her husband, she further isolates herself from the larger community by becoming completely dependent on him for all her access needs. If she is given the opportunity to use an SSP and develops a comfort level and trust with that SSP, she may find a renewed sense of independence, relieve the stress on her husband, and develop a community of her own.

To ensure confidence and safety, the program's security parameters and the value of confidentiality between both the SSP and the deafblind individual must be clearly defined and explained. Finally, specific topics must be addressed. These include the roles of the SSP and the deafblind individual, the appropriate use of SSPs, managing and directing them, clearly conveying communication and mobility preferences, planning ahead, making choices and decisions, managing and resolving problem situations, and working within the policies and guidelines prescribed by the program.

When deafblind people and their SSPs share the same expectations, the probability of successful experiences and satisfying outcomes will be greater.

### ***Successful SSP Program Strategies***

Seventeen programs in 16 U.S. states have provided SSP services for 10 or more years (Jordan, 2020). Common preferred practices include:

- consumers' leadership in advocating at the legislative level;
- fairly paid SSPs—a fair wage respects the value of the service and advances the role within the profession, and without this component, retention becomes a paramount concern;
- a philosophical approach that respects deafblind individuals, their leadership, and their choices;

- visible and respected program administrators and coordinators active in the local deafblind community;
- documented and clearly articulated roles, responsibilities, and policies for consumers, SSPs, and administrative staff that include standards for a professional code of conduct, regularly updated background checks, and consequences when policies are violated, as well as clear administrative directives to manage these and other challenging situations;
- training for consumers and SSPs to ensure shared expectations and program cohesiveness;
- use of deafblind mentors/trainers within the training process to model quality SSP service provision across the continuum of this diverse community;
- the expectation that consumers contact and secure their own SSP from the program's approved list (the coordinator assists in securing the SSP only when necessary); the coordinator confirms that the activity is within the parameters of the program and approves payment;
- the use of a variety of SSPs depending on the circumstances of the assignment such as the setting, activity, and type of access needed as well as to promote professional boundaries;
- formal feedback and evaluation from consumers and SSPs that is sought regularly and given serious consideration by program coordinators;
- regular consumer advisory meetings; and
- willingness to adapt as the program and the profession evolve.

## Conclusions

People who are deafblind want and deserve the same opportunities to live a full and active life as afforded their family, friends, neighbors, and co-workers. Yet the daily challenges deafblind people face in obtaining accessible communication, information, and transportation can severely limit their ability to achieve this goal.

Until the late 20th century, access was provided by friends and family members who would assist with daily activities such as shopping, getting groceries, going to doctors' appointments, and household tasks like reading mail and paying bills. While family and friends may be well-intentioned, they often have their own obligations and responsibilities and may not be readily available. At the same time, the person who is deafblind may feel guilty about infringing on others' time and

uncomfortable sharing personal business and information with family and friends. As a result, the deafblind person may stay home rather than seek necessary medical attention, bother a friend for a ride, or ask a family member to assist with shopping. Mail may go unread. Bills unpaid. Needed repairs unobserved. Basic needs such as food, clothing, medical care, and human interaction may be left unmet. Loneliness, isolation, depression, low self-worth, and frustration can set in.

### ***SSPs: The Best Solution***

In 2006, the authors of the original SSP White Paper concluded that there is a better solution than the options presented above, one that “has evolved through the experiences and knowledge of the deafblind community and their supporters” (Bourquin et al., p. 19). That solution is the SSP, an individual who provides access to visual, situational, and environmental information, human guide services, and brief casual communication. The SSP performs his or her role with the deafblind person’s guidance and leadership, and often while integrating technology, new communication methods such as Haptics and protactile, virtual communications, and enhanced transportation options. The SSP always does **with**, not **for**. Through access provided by the SSP, deafblind individuals may be better able to:

- overcome the unique and complex communication and transportation challenges they face every day;
- be more aware of what is happening around them;
- maintain a healthy, confident, and self-sufficient lifestyle;
- make more informed choices and decisions;
- efficiently conduct personal business;
- maintain a safe home;
- enjoy greater access to family, friends, and the community; and
- reduce isolation.

Deafblind people have recommended that the SSP be a federally recognized, paid, full-time, certified professional (AADB, 2010). The SSP is the best solution.

SSP services are available in 29 states and the District of Columbia, with most of the programs on the coasts and in the southeast and southwest. While these programs are a start, they serve a small fraction of the people who are deafblind in

the United States, and funding streams may further restrict eligibility. Moreover, 21 states do not offer any SSP services.

### ***Challenges to Implementation***

The development and implementation of SSP services are often dependent on the resolution of critical challenges that include:

- **Securing reliable, long-term funding.**
- **Lack of visibility.** Because deafblindness is a low incidence disability (less than 1% of the population affected) and few SSP services exist, the concept of self-sufficient, empowered deafblind individuals is non-existent in the larger community. A visible presence of deafblind people confidently using SSPs in community settings would open more minds to the service and its benefits.
- **Identifying deafblind people within each state who can advocate for funding and program development.** Lawmakers need to meet self-sufficient, confident deafblind people who use SSPs, and they need to understand how many deafblind people use—and how many more could use—this service.
- **Finding agencies and organizations to provide program development, training, and coordination.** They may be willing but don't have the qualified personnel, experience, or systems to satisfy the requirements of state or federal funding sources.
- **Finding consistent, reliable SSPs.** The demands of the role necessitate comprehensive knowledge of myriad skills and settings, as well as the ability to flexibly adapt to situations and environments.
- **Lack of standardized training and compensation.** Deafblind people depend on the SSP for accurate information, and they entrust the SSP with safe travel; they deserve a professionally trained provider, and SSPs deserve a professional level of training.
- **Lack of compensation.** Typical compensation today means an hourly wage with no benefits or a volunteer capacity. With the broad-ranging skills necessary to perform the job and the responsibilities with which they are entrusted, SSPs deserve a professional level of compensation.

Despite the challenges, successful SSP programs have developed across the country. Established programs, some with more than 10 years of experience, are now sharing their expertise with newer programs through workgroups such as Helen Keller National Center's National Community of Practice. Challenges no longer seem quite as insurmountable when programs work together to develop proactive interventions, pursue innovative solutions, and achieve higher levels of satisfaction from both consumers and providers.

### ***Actions Needed***

The need for SSP services continues today—and perhaps is more essential than ever—as the population ages and awareness increases of the positive impacts of these services. Deafblind people describe SSPs as essential to their independence and well-being, and the U.S. Department of Justice considers SSPs “a critically important link enabling [deafblind people] to access the community at large.” Yet, of the approximately 2.8 million deafblind people in the United States, only five of every 10,000—less than 1,300—have the opportunity to access these services.

Since 2003 the deafblind community has indicated their need and preference for the use of SSPs. It is now time for deafblind people, federal and state agencies, deafblind organizations, and all who care about this community to join in advocacy for further recognition, establishment, development, and standardization of SSP services and their expansion to all states.

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## **Verification of Content and References**

Jordan Kralik

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## Appendices

### ***Appendix A: Federal Definitions of Deaf-Blindness***

The federal government uses specific terms to define what it means to be deaf-blind. These definitions are the established criteria that qualify a person to receive services under federal and state education and rehabilitation systems.

**The Individuals with Disabilities Education Act (IDEA)** is a federal education law that applies to all children birth through 21 years of age with disabilities. The law ensures that all children with disabilities receive a free and appropriate public education (FAPE), including early intervention and transition to adulthood services. IDEA regulations include this definition (2017):

Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

Adults, ages 18 and above, who are deaf-blind are protected by the **Helen Keller National Center Act – Title 29-Labor, Chapter 21, § 1905** (1984, 1992) with the following definition:

- (2) the term “individual who is deaf-blind” means any individual -
  - (A)(i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;
  - (ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(B) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or

(C) meets such other requirements as the Secretary may prescribe by regulation; and

(3) the term "Secretary" means the Secretary of Education.

### ***Appendix B: Alternatives for Offering an Opinion***

Because humans generally want to help each other, it can be challenging to avoid crossing boundaries. Yet, keeping a professional distance is necessary to maintain a level of objectivity and the ability to step back and allow the deafblind person to exert control and leadership in the relationship. When asked by a deafblind individual, the SSP must respectfully and tactfully decline to offer opinions, recommendations, choices, or decisions. The suggestions below are offered as a guide and by no means should be considered exhaustive.

#### ***Instead of offering an opinion ...***

<b>When asked ...</b>	<b>The SSP ...</b>
"Do you think this will work for me? Should I get it?"	Reads printed information and offers tactile exploration if these options are available.
"Do you think that meal has onions?"	"You can ask our server. He's at the table to our right. Shall I get his attention?"
"Do you think that's right for me?"	"Shall we find someone who can provide more information or a demonstration?"
"What phone do you use?"	"The phone that's right for me. It fits my budget and what I need it to do."
"I need your opinion: What should I do?"	"What are your options? What more information do you need?"
"What do you think? Should I get this?"	"It's really up to you. What other information do you need to make the decision?"
"Would you call the (program) and get me on the waiting list?"	"I'll help you find the number, and I'll be here with you when you call; you need to lead the conversation."
"What's the best ... (appliance, brand, food, computer, etc.) ... "	"It really depends on you, what you're looking for, and what you want it to do. We could look at reviews together online. Would that help?"

### **Appendix C: SSP Program Resources**

The programs below are willing to share their experiences with regard to developing SSP recruiting resources and/or training curricula. *Note: The programs and services listed do not imply endorsement by the authors.*

<b>State</b>	<b>Program</b>	<b>Recruiting</b>	<b>Training</b>
<b>Arizona</b>	Arizona Commission for the Deaf and the Hard of Hearing <a href="https://www.acdh.org/deafblind/statewide-ssp-program/">https://www.acdh.org/deafblind/statewide-ssp-program/</a>	✓	✓
<b>California</b>	College of the Canyons American Sign Language Department: SSP Certificate of Specialization ( <i>within the Interpreter Training Program</i> ) <a href="https://www.canyons.edu/academics/signlanguage/index.php">https://www.canyons.edu/academics/signlanguage/index.php</a>		✓
<b>California</b>	DeafBlind Access <a href="http://www.deafblindaccess.org">www.deafblindaccess.org</a>	✓	✓
<b>Minnesota</b>	DeafBlind Services Minnesota (DBSM) <a href="http://www.dbsmlc.org">www.dbsmlc.org</a>	✓	✓
<b>Missouri</b>	Beyond Interpreting <a href="http://www.beyond-interpreting.com">www.beyond-interpreting.com</a>	✓	✓
<b>New Jersey</b>	Support Service Providers of New Jersey (SSPNJ) <a href="https://njcsd.tcnj.edu/support-service-providers-of-new-jersey/">https://njcsd.tcnj.edu/support-service-providers-of-new-jersey/</a>	✓	✓
<b>New Mexico</b>	Community Outreach Program for the Deaf – New Mexico <a href="https://www.copdnm.org">https://www.copdnm.org</a> <a href="mailto:information@copdnm.org">information@copdnm.org</a>	✓	✓
<b>Washington</b>	DeafBlind Service Center <a href="http://www.seattledbsc.org">www.seattledbsc.org</a>	✓	✓
<b>Wisconsin</b>	Center for Deaf-Blind Persons, Inc. <a href="http://www.deaf-blind.org">www.deaf-blind.org</a>	✓	✓

## Appendix D: National SSP Surveys Results

For a larger version, click on: [https://182cf333-f26b-4415-8be9-e3d4b67d536f.filesusr.com/ugd/fe02dd\\_dc22b253079c4ff78a31e8f268e43385.pdf](https://182cf333-f26b-4415-8be9-e3d4b67d536f.filesusr.com/ugd/fe02dd_dc22b253079c4ff78a31e8f268e43385.pdf)

(Text-only description follows chart)

### National SSP Surveys Results

#### Survey of Experienced SSPs

- More than 100 questions
- Circulated Feb 1 - May 1, 2017
- 279 respondents

**Gender:** 71% (198) WOMEN

**Age:** OLDER THAN 45 (59%/164), 31-45 (28%/77), YOUNGER THAN 30 = 13% (38)

**Have a personal relationship or friendship with someone who is DeafBlind:** 77% (216)

**Hearing/Sighted:** 54% (151)  
**Deaf/HOH & sighted:** 42% (116)

**Years Experience:** More than 10 years = 117 (42%); 6 - 10 years = 55 (20%); 1 - 5 years = 87 (31%)

#### Essential Characteristics

- Keeps confidentiality: 91% (253)
- Good communication skills: 90% (250)
- Respects consumer choice: 89% (248)
- Patient: 88% (244)
- Flexible: 81% (227)
- Functional: 81% (225)
- Knowledge of DeafBlind culture: 79% (221)

#### Languages/Methods Used by SSPs

Visual ASL 90% (250)  
 TASL 80% (224)  
 English - Spoken 60% (168)  
 Pict-Tactile 53% (147)  
 Haptics 18% (50)  
 English-based Signing 11% (30)

#### Acknowledgements

Thanks to the nearly 500 SSPs and DeafBlind people who took the surveys and shared their personal insights. We were also fortunate to have an entire community of volunteers who shared their thoughts with us, collected, tested the surveys, tested the accessibility and provided general feedback - over email, by phone and in person - prior to the surveys being released. Our heart-felt thanks to:

Ryan Hestoff	Ashley Inaba	Cynthia Ingraham	Roy Marvica
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#### Goals of the Surveys

- Determine core competencies, standards & best practices essential for a national SSP training curriculum, leading to the process of national certification of SSPs
- Begin building a National SSP Database
- Outline DeafBlind roles/responsibilities in SSP use
- Provide research support to current and new SSP programs in their quest for funding initiatives

#### Who is an "experienced" SSP?

- Completed at least 15 paid and/or volunteer assignments; and
- worked with at least five different clients; and
- in the assignments, used a variety of language, mobility and communications skills.

**Volunteer:** All/mostly 59% (165)  
**Paid:** All/mostly 40% (111)

**Rate of Pay:** More than \$26/hr = \$10 - \$14/hr, \$21 - \$25/hr, \$15 - \$20/hr

#### SSP Training

SSPs trained at more than 55 different agencies/organizations

Attended formal training: 66% (185)  
 Attended 2 or more trainings/workshops: 55% (152)  
 Felt prepared for the role after training: YES 62% (115), NO 38% (70)

#### Training Satisfaction Rating

Formal Training: 8.2  
 DeafBlind Mentors: 8.6  
 90% of SSPs would welcome national certification

#### Where SSPs Responded Across America

Respondents report working in 38 of the 50 states. The number of responses is indicated below by the size of the dot (note that some SSPs work in multiple states and/or volunteer at camps, such as those in WA and MD):

1 - 7 responses  
 8 - 15 responses

**KATHERINE GABRY & MARK GASAWAY**  
 National SSP Development Alliance  
 (formerly National SSP Task Force)

#### Survey of DeafBlind People

- 10 question survey
- Circulated Aug 12 - Nov 5, 2017
- 217 respondents

#### Is the acronym "SSP" known?

YES: identified as Support Service Provider by 171 (79%)

#### Do SSPs provide an important service?

YES: 206 (95%)

#### Perspective on Role of the SSP

- Guiding: 179 (82%)
- Providing visual information: 177 (82%)
- Providing environmental information: 166 (77%)
- Promoting independence: 156 (72%)
- Providing transportation: 130 (60%)
- Assisting with transportation such as 11hr, public transportation and paratransit services: 101 (47%)

#### Comments on SSP Role

"SSPs play a very important role in the independence of the deafblind."  
 "SSPs help assist in doing things like using IP, helping me to doctor's office to connect to interpreter, assist in shopping at department and grocery stores."  
 "SSPs fill my communication gaps - so we can access our community."  
 "Most services are inaccessible to the deafblind and most customer service personnel can't handle deafblind clients. I received my passport through an SSP. Try that with the government offices."  
 "Some of the great benefits of SSPs are less worries and reducing fears."  
 "When I ask with an SSP, I am a bit more secure, and more relaxed than I do when I ask alone."  
 "I find what is most helpful is SSP visualizing what is around me in words."  
 "Sadly, limits of activities is often defined by the funding source."  
 "The individuals who have been most helpful have provided mainly environmental information and a modest amount of commentary."

### CORE CONCEPTS

#### General Info

**Content Examples:**

- Establishing trust & comfortable working relationship
- Roles of consumer, SSP
- Respect for consumer
- Importance of asking first & respecting consumer choice
- Role of the SSP vs interpreter
- Practice in community settings

#### Visual & Environmental Info

**Content Examples:**

- Detailing visual/environmental info
- Describing without judgment
- Practice
- Confirming consumer choice

#### Communication Practice

**Content Examples:**

- Including DeafBlind in conversations
- Getting the attention of the person who is DeafBlind
- Actions & information to be communicated
- Determining your own level of comfort
- Communication through touch

#### SSP Environments

**Content Examples:**

- Respecting consumer choice
- Ensuring safety
- Appropriate info-descriptions

#### DeafBlind Culture

**Content Examples:**

- Hand-under-hand technique
- Meeting/socializing w/DeafBlind
- Touch as DB culture/philosophy

#### Mobility & Safe Travel

**Content Examples:**

- Human guide practice
- Basic O&M skills & tools
- Guiding techniques/balance issues

#### Communication

**Content Examples:**

- Clear, respectful communication
- ASL, TASL, PIASL, SEL
- Spoken language, ALDs
- Technology, POP, prior

**for more information: nsspcert@gmail.com**

Text description:

The poster is 48" wide by 36" and has headlines going across the top and four columns.

Reading across the top of the poster, the headline contents consist of National SSP Surveys Results, the four Goals of the Surveys (to determine core competencies, standards & best practices essential for a national SSP training curriculum, leading to the process of national certification of SSPs; to begin building a National SSP Database; to outline DeafBlind roles/responsibilities in SSP use; and to provide research support to current and new SSP programs in their quest for funding initiatives), and the authors of the survey: Katherine Gabry & Mark Gasaway, National SSP Development Alliance, (formerly National SSP Task Force)

Column 1 (on far left) Survey of Experienced SSPs

More than 100 questions were circulated Feb 1 - May 1, 2017, 279 responded

Gender: 71% (198) women

Age: Older than 45 = 59% (164), 31 - 45 = 28% (77), Younger than 30 = 13% (38)

77% (216 SSPs) report having a personal relationship or friendship with someone who is DeafBlind

Hearing/Sighted = 54% (151), Deaf or Hard of Hearing and sighted = 42% (116)

Years of SSP Experience: More than 10 years = 117 (42%); 6 - 10 years = 55 (20%); 1 - 5 years = 87 (31%)

Essential Characteristics: Keeps confidentiality: 91% (253), Good communication skills: 90% (250), Respects consumer choice: 89% (248), Patient: 88% (244), Flexible: 81% (227), Punctual: 81% (225), Knowledge of DeafBlind culture: 79% (221)

Picture of SSP using Haptics on the back of a DeafBlind college student who is talking with friends in a college cafeteria.

Languages/Methods Used by SSPs: Visual ASL: 90% (250), TASL: 80% (224), English: – Spoken 60% (168), Pro-Tactile: 53% (147), Haptics: 18% (50), English-based Signing: 11% (30)

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Graphic of hands waving in the air

#### Column 2

Who is an “experienced” SSP? Three criteria: 1) Completed at least 15 paid and/or volunteer assignments; and 2) worked with at least five different clients; and 3) in the assignments, used a variety of language, mobility, and communication skills.

Volunteer: All or mostly = 59% (165), Paid: All or mostly = 40% (111)

Rate of Pay is shown by a pie chart: \$10 to \$14/hour: about 13%, \$15 to \$20/hour: about 50%, \$21 to \$25/hour: about 25%, More than \$26/hour: about 12%

SSP Training: SSPs trained at more than 55 different agencies/organizations. Attended formal training: 66% (185), Attended 2 or more trainings/workshops: 55% (153), Felt prepared for the role after training: Yes 62% (115), No 38% (70)

Where SSPs Responded Across America: Respondents reported working in 38 of the 50 states. The number of responses is indicated below by the size of the dot (note that some SSPs work in multiple states and/or volunteer at camps, such as those in WA and MD): 52 responses – WA State, 32 – NJ, 27 – MD & OH, 26 – NY, 23 – MN, 22 – Washington, DC, 21 – CA, 20 – TX, 19 – FL, 16 – PA; 8 – 15 responses: AZ, AR, CO, GA, IL, OR, VA; 1 – 7 responses: AL, CT, IN, IA, KS, KY, LA, ME, MA, MI, MO, NE, NM, NV, NC, ND, OK, SC, TN, WI

Training Satisfaction Rating: Formal Training = 8.2, DeafBlind Mentors = 8.6

90% of SSPs would welcome national certification

Core Concepts for SSP Training: This donut-shaped graphic indicates by color the amount of time devoted to each of the nine core concepts. The larger the space on the circumference of the donut, the more time devoted to the concept.

Core Concept #1: Intro to DeafBlind- 5% of training total. Content Examples: Definition of DeafBlind, Vision Simulators, Eye Conditions

Core Concept #2: General Info – 23%, Content Examples: Establishing trust & comfortable working relationship, Roles of consumer and SSP, Respect for consumer, Importance of asking first & respecting consumer choice, Role of the SSP vs interpreter, Practice in community settings

Core Concept #3: Visual & Environmental Information – 5%: Content Examples: Defining visual/environmental info, Describing without judgment, Practice, Confirming consumer choice

Core Concept #4: Communication Practice – 21%, Content Examples: Including DeafBlind in conversations, Getting the attention of the person who is DeafBlind, Actions & information to be communicated, Determining your own level of comfort, Communication through touch

Core Concept #5: Communication – 12%, Content Examples: Clear, respectful communication; Appropriate positioning/modifications; Communication through touch; ASL, TASL, PTASL, SEE; Spoken language; ALDs, Technology; POP, print

Core Concept #6: Mobility & Safe Travel – 8%, Content Examples: Human guide practice, Basic O&M skills & tools, Guiding techniques/balance issues

Core Concept #7: DeafBlind Culture – 7%, Content Examples: Hand-under-hand technique, Meeting/socializing w/DeafBlind, Touch as DB culture/philosophy

Core Concept #8: SSP Environments – 7%, Content Examples: Respecting consumer choice, Ensuring safety, Appropriate info/descriptions

Core Concept #9: The Professional SSP – 12%, Content Examples: Confidentiality, Code of Ethics, trust; Recognizing your own personal/physical limitations; Managing challenging situations; Setting boundaries; Taking care of yourself

Column 4

Survey of DeafBlind People: 10 question survey circulated August 12 – November 5, 2017, 217 respondents

Is the acronym "SSP" known? Responses are shown in a bar graph. Only the YES response has both number and percent: Yes, identified as Support Service Provider by 171 (79%). Other responses: Special Support Person, about 10 responses; Special Services Provider, about 15 responses; Services & Support Provider, about 18 responses; Other, about 3 responses

Do SSPs provide an important service? Responses are shown in a bar graph. Only YES has both number and percent. Yes, 206 (95%); Maybe, about 4 responses; No, 1 response; I don't know, about 6 responses

Perspective on the Role of the SSP: Guiding: 179 (82%), Providing visual information: 177 (82%), Providing environmental information: 166 (77%), Promoting independence: 156 (72%), Providing transportation: 130 (60%), Assisting with transportation such as Uber, public transportation and paratransit services: 101 (47%)

Comments on SSP Role

"SSPs play a very important role in the independence of the deafblind."

"SSPs help assist in doing things like using VP, helping me to doctor's office to connect to interpreter, assist in shopping at department and grocery stores."

"SSPs (fill in) communication gaps so we can access our communities."

"Most avenues are inaccessible to the deafblind and most customer service personnel can't handle deafblind clients. I renewed a passport through an SSP. Try that with the government staffers."

"Some of the great benefits of SSPs are less worries and reducing fears."

"When I am with an SSP, I sure do feel more secure, and more relaxed than I do when I don't have one."

"I find what is most helpful is SSP visualizing what is around me in words."

"Sadly, limits of activities is often defined by the funding source."

"The individuals who have been most helpful have provided mainly environmental information and a modest amount of commentary."

Picture of a young DeafBlind man and a female SSP walking on a sidewalk, with green grass on the sides, and blue sky and trees in the background. He is using a white cane and holding her elbow as they approach a corner.

For more information: [nsspcert@gmail.com](mailto:nsspcert@gmail.com)