

Support Service Providers for People who are Deaf-Blind

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Meeting a Critical Need for Support Service Providers

Many citizens of the United States are deaf-blind. The most noteworthy research, completed in 1982, reported a total population over 730,000 individuals with dual sensory losses (Wolf, Delk, & Schein, 1982). Contemporary data suggest that individuals who are deaf-blind accounts for about 70,000 people (Deafblindinfo.org, 2006). For citizens who are deaf-blind living in the United States, assistance from family, friends, and professionals is often the difference between living productive lives or sitting alone at home or an institution. Fifty years ago, families lived in close proximity. People who are deaf-blind relied on support from their extended family. They tended to reside with family and not work or socialize outside the home. Opportunities for involvement in the community were limited.

Today, people who are deaf-blind are no longer sheltered by their families. They live in the communities of their choice and are employed in every possible sector of the economy. Many

individuals who are deaf-blind are teachers, program administrators, and businessmen and women. Present-day people who are deaf-blind are valued members of society. They marry, raise families, are involved in their communities, and live productive lives just like other Americans. However, the combination of hearing and vision loss presents a variety of challenges to everyday tasks.

Definitions and History

What is meant by “a person who is deaf-blind”?

A basic and concise definition of deaf-blindness is a concomitant loss of sight and hearing that is severe enough to limit a person’s ability to conduct many functions of daily life. People who are deaf-blind may be completely deaf and blind, or they may have some usable hearing and vision, yet it is the effects of a dual sensory loss that combine together to create a unique circumstance.

(See Appendix A).

What is a Support Service Provider?

The term “support service provider,” or SSP, was coined in the 1980s during a convention of the American Association of the Deaf-Blind (AADB). The success of these conventions had always depended on the work of interpreters and guides to make it possible for the delegates who were deaf-blind to work and socialize in an unfamiliar environment. Most of these SSPs were volunteers. By developing the concept of support service providers, AADB began the work of defining the duties and responsibilities of SSPs, and ways to give them greater professional status. This in turn helped make it possible to set up programs and SSP services for people who are deaf-blind in their home communities.

A support service provider can be any person, volunteer or professional, trained to act as a link between persons who are deaf-blind and their environment. They typically work with a single individual, and act as a guide and communication facilitator. They

may be hearing, deaf, blind, or deaf-blind. This paper will discuss the needs, requirements, and skill set for support service providers, as well as various approaches and programs to provide SSP services to people who are deaf-blind in local and state areas.

The SSP serves as the eyes and ears of the person who is deaf-blind. There are two key components of an SSP's function:

- 1) The SSP provides access to the community by making transportation available (by car, bus, or other conveyance), and serves as a human guide while walking.
- 2) The SSP relays visual and environmental information that may not be heard or seen by the person who is deaf-blind. This is done in the person's preferred language and communication mode.

An important aspect of the relationship between the person who is deaf-blind and an SSP is that the former makes all decisions. The SSP can provide information to the individual to assist in considering options, but at no point should the SSP make choices and decisions. The professional SSP strives to be helpful

but objective, supportive yet empowering, and sparing in expressing their personal preferences while providing services.

Historical Perspective

In many respects, perhaps the first and most famous SSP was Anne Sullivan, who was Helen Keller's teacher, friend, interpreter, and guide for most of her life. With Anne Sullivan's help, Helen Keller learned how to communicate, and became the first person who was deaf-blind to earn a college degree when she graduated from Radcliffe College in 1904 (Helen Keller, 1905, 1913).

Prior to Helen Keller, only three other persons who were deaf-blind had received an education. They were Victorine Morriseau of Paris, France, and Laura Bridgman and Julia Brace, who were students at the Perkins School for the Blind in the U.S.A. (Collins, 1995).

In the 1900s, education and services for individuals who were deaf-blind slowly improved. By 1937, people who were deaf-blind themselves began to organize when the American

League for the Deaf-Blind was founded by Frances Bates. The League gradually evolved from a service organization into a membership organization for the deaf-blind. It held the first national convention for the deaf-blind in Ohio in 1975 and became the American Association of the Deaf-Blind (AADB) at its convention in San Antonio, Texas in 1979. In 1967, the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) was authorized by an act of U.S. Congress. One of the founders of this organization who made a presentation to Congress explaining the need was Dr. Robert J. Smithdas. He was only the second person who was deaf-blind to receive a college degree.

At the 2003 AADB Conference in San Diego, CA, delegates spoke of the need for national SSP services to help insure the independence of people who are deaf-blind throughout the United States, and expressed frustration regarding limited services in specific pockets of the country. The following year, the AADB and the Deaf Blind Service Center of Seattle, with support from the

HKNC, began the work of setting up the National SSP Pilot Project to make these services a reality for all people who are deaf-blind who need them. As of 2006, there are five statewide programs, 14 other states with some SSP programming, leaving 31 states without any support services for individuals who are deaf-blind

The Roles and Responsibilities of an SSP

The roles and responsibilities of spoken and signed language interpreters have long been established by professional organizations, codes of ethics and conduct, and university-based training programs. The corresponding duties and obligations for SSPs are not yet clearly articulated. Discussions have occurred in the interested communities, and some clarity is emerging (Jordan & Pope, 2004; Morgan, 2001).

Interpreter and SSP roles both differ and have numerous similarities. Some of the precepts they have in common include: remaining impartial, maintaining confidentiality, and working in a

variety of settings. The differences fall into several areas.

Interpreters work with people who are deaf, hard of hearing, *and* deaf-blind. SSPs work solely with people who are deaf-blind or have a combination of hearing and vision loss. Interpreter education is available from colleges and universities and can culminate in state and national certification. SSP training is presently less formal, often taught in hands-on workshop format or through life experiences working individually with a person who is deaf-blind. There are currently no state or national certifications or licensures for SSPs. While interpreters are paid based upon their certification and/or the rate established by the referring agency/community, SSPs often volunteer or barter their services. Several established SSP programs do compensate their service providers. In many respects, the role of the SSP is facing the same challenges that interpreters faced 20 or 30 years ago. The service provided by the SSP is of no less value to the person who is deaf-blind than that of an interpreter. Nonetheless, it has taken

additional time for our society to recognize the SSP as a notable profession.

What SSPs can do:

- SSPs can serve as a guide when escorting a person to/from a meeting room, a restroom in an office, or through a lunch line during a workshop.
- SSPs should provide visual and environmental information which can take several forms: describing who is in a room, the activity and mood; reading the menu if the print is not legible and voicing/interpreting that to the person who is deaf-blind; or locating food items in a grocery store.
- SSPs can provide support to individuals who are deaf-blind in their homes, at their place of employment, in their own community or elsewhere.

As part of focus groups during the 2006 AADB Conference, delegates who are deaf-blind were asked to describe how they use SSP services. A wide variety of responses were elicited: shopping,

reading mail, attending social, family, sports, theatrical events, camping, workshops, museum tours, and others.

What SSPs cannot do:

- SSPs cannot provide personal care, e.g., bathing and grooming.
- SSPs do not run errands alone for the person who is deaf-blind.
- SSPs do not make decisions for the person who is deaf-blind.
- SSPs do not teach or instruct.
- SSPs should refrain from formal interpreting in medical, legal, business, or other settings. An SSP who is also a professional interpreter should be careful to differentiate which role they are assuming in any particular situation.

Support service providers do not replace the roles of other professionals, including personal care attendants, teachers, and interpreters.

The Process of Developing SSP Resources

Personnel

Recruiting and training of support service providers are two very important aspects of providing services that support people who are deaf-blind in the United States.

Recruiting

Various natural resources exist to identify potential SSP candidates. People interested in providing services should be sought out and provided appropriate training. These might include the following.

- Family Members can take on the role of being an SSP for an individual who is deaf-blind, supporting the person during family-based events.
- Friends are often a resource for SSP services. Some individuals who are deaf-blind experience isolation, and friends and peers fulfill an important function. They often come with additional personal qualities of trust and respect.

- Members of the community that share common cultural components can be a good support. For example, if the deaf-blind people are culturally Deaf, recruit members of the Deaf community as they often share the same values and communication. If the consumers are senior citizens, identify other older adults. Likewise, college students might prefer to have SSPs their own age. Discussions held during the 2006 AADB Conference confirmed this strategy.
- Interpreter Education Programs (IEPs) throughout the United States are an important recruiting resource for potential SSPs. This can be especially true when the IEP includes training in tactile and low vision communication techniques, and aspects of deaf-blind community and culture.
- Business associates in the vocational setting may be recruited to provide SSP services to the working individual who is deaf-blind.

Training

Educating SSPs to work effectively is a critical component for program development. It is desirable that provider participants in an SSP program be trained in as many areas as possible that apply to working with individuals who are deaf-blind. Many individuals who are deaf-blind need assistance with communication, transportation and guiding, and to some degree, aspects of independent living. Some advocates support implementation of a standardized training program along with a code of conduct.

Communication: Since the community of individuals with deaf-blindness is so diverse, there are many different methods of communication, including tactile and visual signing methods, assistive listening devices, text reading on a computer screen, braille communication, and others. SSPs should seek to become skilled in as many areas as possible. SSP programs should offer

training in each area of specialized communication used by their consumer population(s).

Guiding: SSPs should be skilled with human guide techniques, and consult with the individual who is deaf-blind for their preferences. There are human guide techniques that are taught by certified orientation and mobility specialists, which may be modified to work better with travelers who are deaf-blind.

Assistance with independence: SSP training includes efficient and effective ways of assisting people who are deaf-blind with shopping, reading mail, and other daily activities.

For an example of a successful SSP training, a program in a southwestern state offers an 8-hour course. The final two-and-a-half hours of the training involves working as an SSP for various individuals who are deaf-blind at the local mall. Each SSP has an opportunity to do 45 minutes of SSP work for three different individuals who are deaf-blind, each having different needs, communication methods, and strategies of working with SSPs.

Funding

Financing support service provider training and direct services requires money. At this time, no coherent and consistent system exists for local, state, or national funding streams. Only 28% of the states have any level of SSP services. These various programs are as diverse as the states where they are provided (Jordan, 2005). Funding sources include donations, grants, private foundations such as the United Way, tax levies, and special fundraising events. Several programs receive funding from contracts between different state agencies. Some examples of these partner agencies include departments of human services, vocational rehabilitation, independent living centers, deaf and hard of hearing services, agencies for the blind, mental health services, and developmental disabilities agencies. Some programs have one-time funding sources while others receive annual contract funding. Some programs have specific funding to provide service to senior citizens over the age of 55.

An example of how an SSP program can be implemented might be a voucher system. In one state program, the consumer who is deaf-blind has twelve 1-hour vouchers, which they can use per month. SSPs are paid \$11 to \$15 per hour, and turn their vouchers into the coordinating agency. Consumers who are deaf-blind can use SSPs however they find necessary, so long as it is assistance to access to information, communication, or environments in the community. Some associations for the deaf-blind provide their training as a fundraising mechanism.

If the future expansion of SSP services is to succeed, greater and more consistent funding resources must be identified and secured.

Conclusions

Why SSPs are the Best Solution

Until now, people who are deaf-blind have relied on friends and family members to provide SSP support. Rarely do those family and friends have formal training. The support is not

reliable. At other times, the person who is deaf-blind may have feelings about infringing on others' time. Often, this will lead the person who is deaf-blind to change their plans or not get out into the community, rather than bothering a friend for a ride or asking a family member to assist with shopping. Unfortunately, this can lead to isolation, depression, low self-worth, and frustration on behalf of the individual who is deaf-blind.

There is a better solution, which has evolved from the experiences and knowledge of the deaf-blind community and their supporters. The time to create a mature, funded, and sustainable network of support service providers has arrived.

Come along, come along

Sing a song with me...

Be my eyes, be my ears,

Oh, be a friend to me!

Aslaug Haviland (See Appendix B)

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Appendix A

Definition of deaf-blindness:

Reference

[http://www.cdhs.state.co.us/DeafCommission/infocenter/deafblind.](http://www.cdhs.state.co.us/DeafCommission/infocenter/deafblind.htm)

[htm](http://www.cdhs.state.co.us/DeafCommission/infocenter/deafblind.htm) . The federal definition of deaf-blindness as used by the Helen

Keller National Center for Deaf-Blind Youths and Adults can be

found at: <http://www.hknc.org/WhoWeServe>

[DEFINITION.htm](http://www.hknc.org/WhoWeServe) . This definition states in part that the term

"individual who is deaf-blind" means any individual

(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.

Appendix B

The poem:

Auslag Haviland, a long-time member of the AADB, immigrated to the United States from Norway and became a naturalized citizen.

Some other useful resources:

American Association of the Deaf-Blind: <http://www.aadb.org>

DB-LINK, the National Information Clearing House on Children who are Deaf-Blind: <http://www.tr.wou.edu/dblink/> or www.dblink.org

Helen Keller National Center for Deaf-Blind Youths and Adults: <http://www.hknc.org/>

Seattle Deaf-Blind Service Center: <http://www.seattledbcs.org>