



OVERVIEW

Welcome to SSPNJ! This Overview presents the role of an SSP working in New Jersey. Before you commit to our 10-hour, 3-module training program, we would like to provide you with more information about the role of an SSP so that you can decide if this job is really for you.

What is SSPNJ?

- SSPNJ is a collaborative effort between the New Jersey Commission for the Blind & Visually Impaired (CBVI) and The Center for Sensory & Complex Disabilities at The College of New Jersey (TCNJ); the project is funded by CBVI.
- The goal of SSPNJ is to encourage community integration for adults who are deafblind. We do that by promoting and supporting employment through the services of our statewide network of SSPs.
- Because SSPNJ is a consumer-driven program, deafblind individuals select and schedule their own SSPs, up to 16 hours of SSP services each month.
- SSPNJ provides SSP training, maintains an Approved SSPs List, approves all SSP assignments and ensures adherence to all program policies.
- SSPs do not work for TCNJ; rather, they're independent contractors who are hired by our program participants. Our SSPs are inspired to provide a high level of professional service and are committed to supporting the rights of deafblind persons in accessing their environment and community.
- This program is offered at no charge to New Jersey's eligible deafblind residents.

What is an SSP?

A support service provider, or SSP, is a trained professional who provides visual and environmental information, provides human guide services and facilitates communication so that a deafblind person can make his own informed decisions. You could say that the SSP acts as the eyes and/or ears and mobility guide for a person who is deafblind. The relationship between the deafblind person and the SSP is a partnership based on trust and open, honest and comfortable communication.

SSP History

The SSP model originated out of the need to support individuals who are deafblind when they would attend the national conventions of the American Association of the Deafblind, a national organization that promotes the interests of the deafblind community. Since the 1980s, SSPs have provided supports that allow deafblind delegates to fully engage in all aspects of these conventions.

Growth of the SSP Concept

Gradually the concept of the SSP as a means to gain greater independence and access to the community is making its way beyond specific domains such as AADB and its traditional volunteer role. The role of the SSP is moving toward establishment as a professional service to the deafblind community. In states across the country, SSPs facilitate a deafblind person's ability to:

- Maintain a healthy, independent lifestyle
- Further their education
- Find and continue employment
- Enjoy full access to family, friends and community

SSPs in New Jersey

The State of New Jersey recognizes that SSPs provide a means to gain greater community access for people who are deafblind. Because our program is funded with federal vocational rehabilitation dollars, **our focus is on employability**; most other SSP programs across the country focus on social activities and essential services, such as medical appointments or food shopping.

New Jersey's SSPs support our deafblind residents in activities related to employment, which means preparing for, finding and keeping a job. A wide variety of activities support this goal, including those related to looking for a job, staying healthy, maintaining a home, and participating in community-based activities and peer support groups.

In other parts of the country, SSPs provide transportation for deafblind people; however, that is not the case in New Jersey. NJ's deafblind residents take public transportation, utilize the paratransit system or a hired service (like a taxi), or have a relative or friend drive, but under no circumstances are NJ's SSPs driving deafblind residents.

When is a person considered "deafblind"?

Many people think that a person who is "deafblind" can't see or hear anything; however, that is not necessarily true. The New Jersey Commission for the Blind & Visually Impaired describes "an individual who is deafblind" as one who:

1. Has a visual acuity of 20/70 or worse in the better eye with corrective lenses, or a visual field of no greater than 40 degrees (fully sighted people have a field range of 180 degrees), or a progressive visual loss with the prognosis being one or both of these conditions; and
2. Has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss that has a prognosis leading to this condition; and
3. For whom the combination of these impairments causes extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment or obtaining a vocation

Deafblindness is not as simple as deafness + blindness

When thinking about deafblindness, it's important to remember that deafblindness doesn't mean deafness plus blindness. It's a separate, unique disability that requires specific skills to make sense of the world when your ability to both see and hear is compromised. Some deafblind people use sign language to communicate, but others use their voice. Some read braille, some read large print, and some read regular print. Some see better off to the sides, while others see better in their central fields of vision. There is no "one size fits all" approach to deafblindness, and so, when working with deafblind people, the SSP needs to be flexible and ready to adapt her skills to what the deafblind person wants. The way the SSP utilizes her skills is paramount to promoting independence for the individual who is deafblind.

Key Responsibilities of an SSP

- Relay visual and environmental information in the person's preferred language and communication mode
- Serve as a human guide while walking and on public transportation, paratransit, or taxi or other hired service
- Provide access to communication, facilitate communication and provide casual interpreting so that the deafblind person can participate in community activities (this is done in the deafblind person's preferred language and communication modes)

Overall, an SSP provides support that enhances independence and promotes greater community integration. The relationship between the deafblind person and the SSP is a partnership based on trust and open, honest communication. The exchange of unbiased environmental information is essential to the relationship so that the deafblind person can make informed choices and decisions.

Relaying Visual and Environmental Information

"An important aspect of the relationship between the person who is deafblind and the SSP is that the person who is deafblind 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."

-From the SSP White Paper (AADB)

An integral emphasis of an SSP's work is the provision of visual and environmental information. *The key is to describe without judgment* so that the deafblind person can make his or her own interpretation of the information. Here are some examples of the kinds of information that an SSP would describe to a deafblind person:

- Who is in a room
- What people are doing
- What people are talking about

- People's moods
- How many people are waiting on line
- Reading a menu in a restaurant
- Locating items in a store

In a grocery store, for example, the SSP might say: "This is the aisle with the pasta sauce." "The bananas are green." "A young man is stocking the shelves." "Four or more people waiting on every register."

Serving as a Human Guide

SSPs must be skilled and flexible in providing safe, comfortable guiding services. Deafblind people use a variety of mobility tools. Some use a dog guide, some use a cane, while others prefer a human guide. Some use a mixture of these. Some may navigate independently using a cane, but rely on someone for assistance with crossing a street or in a busy parking lot. For all these reasons, SSPs should always consult with the deafblind person for his preferences for safe travel.

Facilitating Communication

SSPs are not interpreters, but they are required to:

- Effectively communicate with deafblind people
- Facilitate communication for deafblind people in community settings

Deafblind people use a variety of communication modes and technology to communicate. Some use sign language, and there are different types of sign. Some use their voice. Some use technology like FM systems and the Deaf-Blind Communicator.

As an SSP, you're not required to know and use all of these languages or technologies. In fact, before accepting any assignment, we ask that you always consider your own skills, the activity and the person who is deafblind. SSPs accept an assignment only if they are completely comfortable and confident in their ability to communicate, guide and complete the activity.

Examples of Facilitated Communication

As an SSP, you would provide communication access for a deafblind person in activities like these:

- Grocery shopping
- Using a sales associate in a department store
- Making routine banking transactions (deposits/withdrawals, opening/closing accounts in person and at an ATM)
- Using a videophone or TTY, where the SSP relays the operator's communication to the deafblind person, and then the deafblind person signs or types his reply
- Buying a bus or train ticket
- Determining what to order in a restaurant and placing the order

“Of Such Small Difference”

- by Joann Greenberg

[Henry Holt & Company, 1988 (pp 122-124)]

In this passage, John is a deafblind guy who is attending a party. Pay attention to the skills John uses to identify people and navigate his way through the party venue.

Leda was still interpreting, and he smiled more and told them it was practice and felt their laughter and their interest. Tricks, really. Lee, at a touch, “Oh, you’re black, I think,” and she drew away. “How –” He had only touched her cheek, brushing. “Very smooth skin, even older women who are black, this smoothness, and you wrinkle later and not in the same places.” Scent with her, of heavy, melony fruit. Marlene, a woman of tiny, nervous little pulses and twitches. Tiny hands, tiny fingers, a small woman, cool. Soap and the smell of her nervousness. She was bleeding her period: a metallic tang on her breath and in her hand-smell. Sam had told him that the smell was probably metabolic – ketones, he called it. John was still pulling his own face for pleasantness. Ted: a firm, confident hand, a regular face, crisp, thick hair. The smell was warm oil – baby oil. Now John did want to smile, but his face was sore from smiling. Louise: a big hand like a man’s. No perfume. A body-smell of liquor and soap and something from a body cave, exciting, not pleasant but provocative, and all the hair of him rose in reaction. He touched her face; ordinary, a wide forehead, rough hair, dyed maybe. He wanted to wrestle with her and then make love. It was the smell of her, a smell of sex-ready, because there were lines in her face that made him know she was older. Hugh, a soft hand, delicate. Hands were often cold-sweat, but this one was warm and pleasant. Oh, a beard. The beard was thick but the head hair was thin. Glasses. Smell of what he ate: spicy food. An undersmell of bad teeth, subtle, though, so not dentures. Leda again. Her familiarity was a relief. Groups were tiring for John. “Have a canapé.” He didn’t want to hold a plate, so he used the napkin. A pleasant, salty taste – fried, warm, wettish. Oh, cheese, fried. Strange. He had something else, too. Hot dog, very small, like eating fried fingers. He got up and went through the group, saying politely as he passed, smell by touch, by shadow, “Excuse me, Benet; excuse me, Lee; excuse me, Ted.” He was moving toward the kitchen, trying for a line almost true to the house’s long axis because that was without furniture and would lead to the kitchen. He was there in twelve doublesteps, touching Hugh, who was at the opening. He had met this pattern often with the Sighted. They like to group at doorways. He wondered why, since it stopped the go-in and come-out and was inconvenient for everyone. “Excuse me, Hugh,” he said and went past, and there, as he expected was Leda. “May I have some more of that cheese thing?”

“They’re all talking about you,” she said. “You stopped everyone dead.”

“Is my fly open?”

“How do you know who everyone is? How did you find your way straight here? They think it’s a trick; they think you can see.”

It was a trick, in a way. He had learned long ago how the Sighted are amazed when blind people remember. They talked about intensification of the remaining senses to a supernatural level. It wasn’t true, of course. It was only an indication of how serious he had to be about the messages of smell and touch. He had played this game before, mystifying the Sighted with what was obvious and what they did not want to accept: that their bones were different and their smells personal and identifying, that their habits were not entirely being controlled: sweats, cold-spots, twitches, tremors, odors, like the steam

and the water of cooking that escaped the pot lid and that both Corson and Arthur had spoken of as metaphors for various things. They had both told him that such steam, held in too long, can blow metal apart. He had also learned long ago that the Sighted did not like knowing about their odors and tremors, so he said, “Direction is easy, thanks to you. You showed me the place before, and room to room, so I learned it. Now I’m here to eat some of that cheese thing.”

Qualifications to Use SSP Services

- An adult (over the age of 18 and out of the K-12 school system)
- Eligible for services from the New Jersey Commission for the Blind & Visually Impaired
- Preparing for work, looking for work, maintaining work
- A New Jersey resident living in the community
- Capable of directing and managing an SSP

Qualifications to Become an SSP

- An adult (over 18 years of age)
- Demonstrate appropriate communications skills
- Demonstrate a clear criminal background record as evidenced by a fingerprint check
- Have access to the Internet and knowledge of Microsoft Word
- Have a valid driver’s license or other state-issued identification
- Successfully complete SSPNJ’s training program
- Agree to participate in at least three approved professional development educational seminars/programs and/or volunteer opportunities within the field of sensory disabilities every two years, at least one of which will be hosted by the Center for Sensory and Complex Disabilities at The College of New Jersey

SSPNJ Training Program

- **Module 1**, the **Group Training Seminar**, is an interactive, small group learning and sharing experience that includes hands-on activities and philosophical discussions. This seminar provides an in-depth exposure to the role of the SSP. Approximate training time for Module 2: 4-5 hours
- **Module 2** is a 1:1 training experience. You are teamed up with a trainer, and you begin using the skills you’ll need to work effectively as an SSP. You’ll meet at an agreed-upon location in the community, and you’ll focus on getting around safely and effectively in the environment. Approximate training time for Module 3: 2 hours
- **Module 3** offers another opportunity to work 1:1, but this time you’re working with a deafblind trainer in a community setting. There is compensation for this module only. Approximate training time for Module 4: 3 hours

“Quest for Self-Improvement Leads to Deaf-Blind Symphony”

-by Diane Lane Chambers

In this passage, interpreter Diane Chambers discusses her discovery of the deafblind world and her role as an SSP.

In cities like Seattle, where a large deaf-blind community gathers around the Lighthouse for the Blind, or in the state of Louisiana, where an estimated 800 persons with Usher’s Syndrome live in the Cajun community, interpreters have the opportunity to become highly skilled at working with the deaf-blind population.

In Colorado, where I work as a free-lance interpreter, we have consumers with varying degrees of vision loss including those with Usher Syndrome. However, like many states, we do not have a large, deaf-blind community that depends on tactile interpreting. Nevertheless, I enjoy this type of interpreting and for the past twenty-five years, have kept my “hand” in it while pursuing opportunities to sharpen my skill and understanding of this unique population.

Most of the requests I receive for deaf-blind interpreting are for medical, social service, or vocational rehabilitation appointments. Some consumers require tactile signing, some use the tracking method and others need close range interpreting. In each setting, I am ultra-observant of the environment. Because blind and deaf-blind people are not privy to visual information that triggers ideas and thoughts in our minds, I have a responsibility to describe the surroundings in my interpretation. I include relevant objects and people. I describe their behavior and actions, as well as interpret what I hear. And, I accept the added role of support service provider, or SSP as it’s more commonly called.

In this role, I anticipate what assistance a person needs, so I can act accordingly. For a vocational rehabilitation intake, I am not only the interpreter for an Ushers client, I am the interpreter for the blind counselor who is doing the interview. For the counselor, I interpret verbally, the signed communication as well as the client’s actions. “She’s searching in her purse for her identification card,” I say. Near the end of the interview, I say to the counselor while we wait, “She’s still reading the forms.”

In more casual settings, like a restaurant, I offer to interpret the menu. When the food comes, I let my deaf-blind friend know what delights have arrived and where they are located on the table, or on her plate. After lunch, when she sets two bills on the table to leave for a tip, I am obliged to ask her, “Do you mean to leave a six dollar tip?” “No, she says,” gratefully. She thought the bills were both ones.

As interpreters/SSPs we offer assistance, and we look out for hazards. We don’t seat persons in unstable or broken chairs. When we’re outside, we offer warnings about nearby animals, or about puddles on the sidewalk. We alert them when we are about to move onto escalators, or moving walkways. We watch for oncoming cars while crossing streets. We’re alert to sharp or jagged objects like a broken soap dispenser jutting from a restroom wall. We must always be ready to react on behalf of our charge.

Working with the deaf-blind can bring unexpected surprises and wonderful opportunities—even in small towns like Conifer, Colorado, where I live. In 1998, I began work with an elderly gentleman with Usher Syndrome, named Bert Riedel, who had lost his sight and hearing in his later years. Bert was wanting to learn tactile sign language at the age of eighty-six. His family, who lived in my community,

called to ask if I would teach them, some “basic signs.” When I accepted the job, I expected to do that, even though I knew there was no such thing as “basic signs.”

What actually transpired were six impactful years in a teacher-student relationship, in which I was not always the teacher. While Bert learned to read tactile signs from me, I learned from him that it’s never too late to improve ourselves, or our situation in life. “Learning! Learning is the Key,” Bert would often proclaim. From Bert I learned about life, about attitude, and gained a deeper understanding about deafness and blindness. From notes I kept in a journal I wrote a book about our journey.*

Because of my experience with Bert, I considered myself knowledgeable about deaf-blindness. But, there is always more to learn about this diverse group and about our role as interpreter/SSPs. In August of 2004, I traveled to Seattle, Washington, to the Seabeck Conference Center where every year, for one week in August, the Seabeck Deaf-Blind Retreat is held. I went to the Seabeck camp to volunteer as an interpreter/SSP. Immersed into *deaf-blind world*, I tested all of my skills and abilities:

One can learn a lot in a short amount of time at Seabeck. Right away, I see that it’s customary when introducing a deaf-blind person to spell their name first, followed by a name sign. Included is a sign for sighted, or the sign for Usher Syndrome, with a sign depicting the person’s degree of sight. The hands show the “box of sight limitation” around the eyes, or the tunnel of vision closing shut. From this I know how much vision a person has, or who is totally blind. I know how I must adapt my communication and my service as an SSP.

While it’s often impossible for deaf-blind people to participate in team or group activities with hearing people, at camp I experience how it is possible for them to enjoy group activities like a game of Pictionary, modified by the substitution of modeling clay for pen and paper, or a team competition scavenger hunt, using clues printed in braille. On the scavenger hunt, a deaf-blind deaf woman depends on me to guide her as her team speeds across the campus. We scurry up a hill, on our way to the hot tub where we are to search for a hidden clue. She trusts that I will lead her around hazardous objects. I hustle her around some low hanging tree branches. Panting, we arrive at the hot tub, where she dips her hands into the warm water. She feels across the bottom where she discovers a weighted plastic bag. In the bag, she finds a piece to a puzzle and, printed in braille, directions to where the next clue is hidden. She reads the clue and shares it with her deaf-blind teammates. With quickened steps, we set off again, this time “to the school house”; she directs. There, the deaf-blind team searches for balloons. They scour the classroom, until they find them. They think to pop the balloons. Behold! Inside one are more pieces to a puzzle and another clue. We speed off to the front porch of the lodge where the deaf-blind team races to beat the competition in their search for the one wooden rocking chair where the next clue is concealed. There are many rocking chairs. It requires careful, tactile attention to each slat of wood, each arm, each rocking leg, each seat, each chair back, until the hidden clue is found. In the end, the puzzle pieces must fit together, to read the message. Perceptive fingers of the deaf-blind team work together, to find the straight edges. They place them in a square. The puzzle is solved! The SSPs read the message to learn what the team has won. It’s candy; the favorite reward. On a different excursion, a deaf man with impaired sight does not need me to guide him around obstacles, but I do need to warn him about a bump in a sidewalk and an expected step leading into a casino. I do not need to guide him to the slot machines; he can find them on his own. He doesn’t need me to interpret when the bells and whistles go off. The flashing lights and spilling coins tell him he has hit the jack-pot. Another deaf-blind man plays blackjack. With his competent interpreter/SSP at his side, he grins widely in his challenge against the dealer.

As SSP's we are flexible and adaptable. We use judgment as to when to assist and when to be respectful and give a deaf-blind person independence and privacy. It's appropriate to allow one, who is familiar with her surroundings, to walk independently to her room as she wishes. But, I follow with my eyes, watching her step carefully up the stairs; her hand on the rail. I always ask when I'm not sure, whether someone needs assistance. Deaf-blind people are only disabled from hearing and seeing. They're not disabled from thinking and doing for themselves.

On an afternoon boat ride with another camper, I paint with my hands the panorama of the Olympic National Forest which meets the shore of Puget Sound. I interpret the words of our boatman. There's no need to interpret the sensation we feel; the excitement of the cool, wet wind intensified by the speed of the boat. I marvel at the diversity among us as I sit at the dinner table, facilitating a conversation between a deaf-blind woman and her friend. I copy-sign her friend, who sits across from us. Sharing our table, is an older woman, with more hearing than sight. She relies on her SSP to speak loudly in her ear. A young athletic-looking man, who is hard of hearing and has poor vision, speaks to his SSP. She is my new friend, whom I met on the bus on our way to Seabeck. She introduces me to the young man. From across the table, I am not sure if he can see me better or hear me better. I use my voice and sign at the same time, "Do you use ASL?" I ask. He strains to see my signs and turns to my friend for help. "Do you use ASL?" she repeats aloud. He looks back to me. "Yes, I'm bicultural," he says. I use ASL and I speak English."

At Seabeck, I find it profoundly striking how a group of seventy deaf-blind people from throughout North America functions as a whole. In the dining room when a speaker addresses (signs to) the entire group, I see deaf and hearing SSPs interpreting at every table; hundreds of hands working silently together, like moving parts of a well-oiled machine. Communication flows rapid, and fluid throughout, in a spirit of camaraderie.

At Seabeck, I witnessed the highest caliber of interpreters and SSPs in action. I learned what a difference it makes when an interpreter/SSP is well-matched with her deaf-blind camper. When we are in sync, four hands and two minds become as one instrument. In tandem, there are no barriers in *deaf-blind world* to boating, jet skiing, biking, and shopping. There're no impediments to conversation, dancing and games. All of us together, we are instruments of an orchestra. I went to Seabeck on a quest to improve my interpreting and my guiding. What I found was a Deaf-Blind Symphony.

In Conclusion

If working as an SSP in New Jersey seems like something you would like to pursue, please complete the Refresher and e-mail it to us at ssp.nj.tcnj@gmail.com, and be sure to confirm your scheduled meeting with SSP-NJ staff.

Thank you for your interest in improving the quality of life for New Jersey's deafblind residents.