

Interviews with Four Experienced SSPs

The objective of this reading assignment is to give Deaf-Blind consumers a better understanding of SSPs' perspectives on working with deaf-blind consumers, in order to have, in the long run, healthy relationships with SSPs.

Theresa Smith interviewed four SSPs as a panel.

Rayford Dominguez, who is deaf, working as the Coordinator for SSP Services at the Deaf-Blind Service Center (DBSC) and occasionally as a freelance interpreter for DB people.

Kelly Laubenheimer, who is hearing, employed as the receptionist and Administrative Assistant at DBSC.

Johnnie Peterson, who is deaf, employed as an interpreter and interpreter coordinator at the Seattle Lighthouse for the Blind.

Kristy Hoshi, who is hearing, and a certified interpreter currently working at the Seattle Lighthouse for the Blind.

The questions are below along with panelists' comments were videotaped, translated by Anne Del Vecchio and edited. (Interviewed December 2011)

Question 1:

How did you learn about the Deaf-Blind community?

Ray Dominguez: I moved to Seattle 6 years ago. One night I was invited to a birthday dinner, where I met a woman named aj granda. She was Deaf-Blind and read sign language tactually, which I found interesting. At that time I didn't realize Seattle had a large number of Deaf-Blind people. aj introduced me to her friends, Johnnie Peterson and Salwa Rosen, and other members of the Deaf-Blind community. There was mention of something called an "SSP" within the Deaf-Blind community, but I had no idea what that meant. I had been working for Home Depot, but after a while I left that job. I was looking for other work and aj asked me if I'd be interested in becoming an SSP. I thought, "Why not?" It meant driving people around by car, taking them places and working with a variety of Deaf-Blind people, and that type of work suited me well. So I bought a car and one thing led to another. I pretty much was immersed in Seattle's Deaf-Blind community thanks to that first introduction by aj.

At the time I began working as an SSP through the Deaf-Blind Service Center. I didn't know the Deaf-Blind community that well and I hadn't had any formal training. I learned

from friends like aj and Jelica Nuccio, and just sort of picked up the skills as I went along. That's how I became an SSP and have been doing it for the past 6 years.

Kelly Laubenheimer: I started taking ASL classes [at the local college] in 2003. I began learning the language through my classes but I wanted something more advanced. That's when I heard about a Silent Weekend on Orcas Island. During that weekend, I attended a workshop that was presented by Jelica Nuccio and her husband, Vince. I was entranced! I learned about Deaf-Blind culture – it was fascinating. After that I couldn't get enough...I immersed myself in the Deaf-Blind culture and community.

Later my friend and roommate told me about a Deaf-Blind woman who needed help getting to her gym to workout. It was basically like volunteer SSP work¹. I wasn't sure whether I could do it at first but I accepted; I met her and from that point on I fell in love with that woman and I loved the work! We had fun going out...we went to the YMCA once a week to workout...we had fun and really enjoyed each other's company. Ever since that first one-to-one experience, I've truly enjoyed being part of the Deaf-Blind community.

Kristy Hoshi: I [didn't start out as an SSP, but] initially focused on the Deaf-Blind Community and spent time just interacting with Deaf-Blind friends. Later I became curious about what an SSP does, so I had the opportunity to meet with Jelica Nuccio and was lucky to receive one-on-one training from her. Initially, she would guide me while I was either blindfolded or wearing vision-loss simulation goggles. After that, I was ready for more formal training so I went to DBSC. There were many cool Deaf-Blind people in the community who took me under their wing.

Johnnie Peterson: I moved to Seattle, not because of the Deaf-Blind Community but because my sister lived here. She taught in the Interpreter Training Program. I hadn't begun to meet people in the community because I was holding several odd jobs at the time. That was around the time of 9/11, when the airliners flew into the World Trade Center, and suddenly there was a downturn in the economy and jobs were hard to come by. My sister suggested that I spend time meeting Deaf-Blind people and getting involved in the community by becoming an SSP. So I decided to check it out by

¹ Different communities divide or categorize support service in different ways. Seattle uses the term 'SSP' generically to mean a person who guides and provides visual information with some 'light' interpreting. It is used primarily in opposition to the term or category 'interpreter'. A 'DB-interpreter' is one who has both skills (typically certified as an interpreter by the RID) and performs the role of both. In other communities e.g. Boston, a person who is paid for SSP work is called 'provider' while 'SSP' denotes a volunteer. Some DB people (as in Bapin's interview) refer to the person who incorporates both roles as an 'SSP'. It is therefore important to be clear how the particular speaker is using the term.

attending a Deaf-Blind class², and that's when I started to get the idea of what it was all about. I had a close friend named Salwa (Rosen), who was a student in the Interpreter Training Program (ITP), and she kept introducing me to various Deaf-Blind people. As I met more and more of them I realized I was drawn to that type of work, and decided I wanted to become an SSP. Eventually I stopped my other job and began working full time as an SSP. That's how I first became involved.

Question 2:

Why did you become SSP? What does the SSP role mean to you?

Kelly: What it means for me...It's interesting...When I began in the interpreter training program, my teachers emphasized the importance of socializing in the community, getting out and meeting Deaf-Blind people and getting volunteer hours working as an SSP. So (as I spoke about earlier) I volunteered as an SSP driving a woman to her gym and helping her with her workout. I learned how to guide her to the treadmill machine, setting the incline, and speed to her liking and then letting her workout alone for about 15 minutes. When the time was up I would meet her and guide her to the next machine.

Another time I was waiting at a bus stop and I happened to meet a Deaf-Blind man; we got to talking and I helped guide him to his home. Well, I didn't know it but he later met with the SSP coordinator at DBSC and suggested to him that I should become an SSP because he thought I had what it took to be an SSP. So the coordinator approached me and asked if I wanted to contract with DBSC to become an SSP. I was quite surprised that this man had told him about me! It was really the SSP coordinator who finally convinced me that I could do a good job and that this would be a good opportunity to practice my signing skills. So I contracted with DBSC and have been working with that same Deaf-Blind man ever since. It's been 3 years working with this same person, but we're a really good match for each other. We do all kinds of things together. From my

² The Seattle Lighthouse for the Blind sponsors a series of community classes during the academic year. These classes are open to all. DB people who want an interpreter sign up in advance and pay a minimal fee per quarter. Interpreters are all volunteer, although there is a core team of professional interpreters and mentors paid by the Lighthouse. Topics are general interest and may be topical (e.g. "Earthquakes" after the devastating 2010 earthquake in Haiti). This is a mutually beneficial arrangement as the student interpreters in the local program have an opportunity to practice and receive support while the Lighthouse continues to develop a pool of future interpreters and DB people are informed.

experience as an SSP, it means taking the person out food shopping or to the bank or doing other things³.

Ray: I remember I started working and thought I would be a good match for one Deaf-Blind man who liked going to the hardware store and working on mechanical things like cars, lawnmowers, working around his house, etc.. This was right up my alley. So I accepted. What's more I had a big car with room in the back for loading equipment, and this man wanted an SSP with that type of vehicle. The first time I was scheduled to meet with him, I didn't show up. I just completely forgot – this was all so new for me. Later he emailed me and asked why I didn't come - I realized I hadn't called him or explained why I couldn't make it or anything. He explained to me why communication is so important to Deaf-Blind people, especially when their allotted time with an SSP is so limited. He said if I had a conflict or something I should at least show up and tell him that I would have only limited time with him that day or reschedule, but at the very least I should keep the lines of communication open.

I had no understanding of how crucial SSP time was for a Deaf-Blind person, when their other options were so limited. We sighted people have the luxury to just go out and shop any time we want to. We can do things on the spur of the moment. But Deaf-Blind people don't have the choice. That's when it hit me; then I understood what he meant. So from then on I stuck with my commitments. [Working together] was a little awkward at first. It took a while to get our guiding and communication signals clear. He said he wanted to go to Home Depot to get some kind of tool. When we got in my car, I realized we had another challenge to overcome because he expected to be able to talk tactually with me while I was driving. Apparently his past SSP's all were able to do it. But in my case I drove a stick shift so it was very difficult to shift gears and maintain hand-to-hand contact with him at the same time. As I crossed through many intersections I had to keep asking him to pause the conversation while I shifted gears. But the interesting thing was that as we crossed each street he would name the streets we were passing; apparently he had a very good sense of the area and could tell from the movement of the car where we were. I had assumed as a Deaf-Blind person he wouldn't have that type of intrinsic knowledge, but he certainly did.

So that was my first experience working as an SSP, but now that I've worked with him for a while we've developed our own form of communication and I've gotten to know

³ Given the limited number of hours SSPs are paid, DB people typically prioritize these three tasks: grocery shopping, doing banking (e.g. reconciling checking account statements) and doing errands such as getting a haircut or shopping for clothes.

how he thinks and can predict what he wants, so we're able to get more done in our time together.

Other experiences I've had are attending the Seabeck Retreat⁴ which I really enjoyed very much. It was an opportunity to do fun things with Deaf-Blind people, to watch others interact and to learn so much from more experienced people by observing them and then incorporating those skills in my own work. I would "borrow" techniques from Deaf SSP's – the experts – about how to give visual information to a Deaf-Blind person. I learned a lot at Seabeck. Deaf-Blind people are so smart. They would teach me and give me feedback saying, "Yes, you're doing it right!" or "No, no don't do it that way - stop!" It was nice to get that feedback.

Johnnie: My first opportunity to really know what it was like to be an SSP took place at Seabeck Camp (retreat), where we stayed an entire week. It was a great learning experience. Then another friend of mine told me I could work as an SSP. That was around the time when my other work was downsizing, so I decided to try it out. I became an SSP and began working with only one Deaf-Blind person, and continued working with that one person for a pretty long time. I think that suited my comfort level and allowed me to learn the ropes. You see, I had no formal training as an SSP back then. So I learned by doing: taking this person shopping, to the bank, reading and generally doing more and more tasks. That's how it all started.

Kristy: My experience as an SSP started by meeting the Deaf-Blind person at their home. They would get into my car and I would drive them to various locations to do errands. They came prepared with a plan, written on paper. First we'd go the grocery store, then we might go out for a walk to exercise. They had planned what they wanted to do during our time together, whether it was for two or four hours, which we would have agreed to ahead of time. Reading mail is another example. If they were fully blind, how else would they read the mail? So they would open the envelopes and I would read it to them, signing tactually. It might be junk mail or some other type, like a bank statement. So it was mostly that type of thing.

Question 3:

What would I do when working with a Deaf-Blind person who has never used an SSP before?

⁴ The Seattle Lighthouse for the Blind sponsors an annual week-long retreat at a conference center on the Washington Peninsula called Seabeck Conference Center. The retreat is so well known among members of the DB Community that it has come to be known simply as "Seabeck" or "SB". Again this is mutually beneficial as the Lighthouse recruits workers and trains new interpreters who volunteer for the week although many professional interpreters volunteer year after year.

Johnnie: Most Deaf-Blind people in this area already know how to use an SSP. But I once worked with someone who had developmental disabilities and used SSP services. I was used to working with fairly independent Deaf-Blind people, but with this person it took a lot more work to draw him out and find a way to help him express what he wanted. Yet I wanted to encourage him to use me to support his needs. I didn't want to force my opinion and thoughts on him. But in the beginning he wasn't used to having independent thoughts. It took a while, but he did get the hang of it.

Speaking of training, I recall that it wasn't until recently that the Seabeck Retreat began providing SSP training prior to the start of Deaf-Blind camp. Now that the trainings have started, I can see a big difference. New SSP's have a steep learning curve and we have the ability to give them feedback immediately. But it's the same thing - Deaf-Blind people may not have the training to know how to work with an SSP. It's interesting, in Seattle, Deaf-Blind people know how to work with an SSP, but at the Seabeck Retreat, Deaf-Blind people [from other areas of the state and country] may need training to learn how to use an SSP because many of them have had no experience with an SSP and think the SSP is there to *help* them. We try to explain, "The SSP is not here to *help* you; you get to make the decisions for yourself." It's interesting to see the impact that the Seabeck experience has on Deaf-Blind people from other places. They realize for the first time that they can make decisions for themselves. It's really interesting. I wish they had training for SSP's and training for Deaf-Blind people, teaching them how to use SSP's too. Both would be nice.

Kristy: I believe I had one experience working with a Deaf-Blind person who had never worked with an SSP before. That was difficult and awkward, not knowing exactly how to establish boundaries. Luckily, we attended many community events together where there were a lot of other Deaf-Blind people in attendance, so I would share visual information with this person about who else was in attendance. I'd tell him their names, their roles, and their experiences with the Deaf-Blind community. For example, "He's the coordinator for SSP services", etc. I just tried to help him make connections with the right people. I didn't want to counsel or advise him. My role isn't to educate – that feels uncomfortable to me. The power imbalance is too great. So instead I attempted to help him connect with the right Deaf-Blind people. My point was that I don't feel comfortable being in that "educator" role. Instead I would share visual information. For example, if I saw Theresa Smith in the group I could say, "There's Theresa Smith and her role is..." I would add that background information because the person had just moved here; they had no idea who the leaders in the community were.

Question 4:

Do any of you still interact socially with Deaf-Blind people? Or do you keep your personal life separate? Or are your personal and your professional life closely intertwined?

Kristy: For me, it's important to keep and feed those human connections with Deaf-Blind people, to keep your hand on the pulse of the community by being involved. But, to be honest, my level of interaction has decreased over time. Life has just gotten busy. I've been focused on my home, moving, duties such as working full time...

You're right, where's the balance between those parts of me? I have to assess my own limits as to how much I can be involved, and choose what works for me and what feels like a burden. Saying "no" is okay. I need to take care of myself and take care of the community at the same time.

Kelly: My advice for new SSP's and my advice for Deaf-Blind people; I have many pieces of advice really:

- First is the mutual respect.
- Second is to establish and know your boundaries and use them. It's fine to set up boundaries, but be sure to apply them as well.
- The third thing is... communication; I want to emphasize comfort with communication.
- Next is to understand that no one is perfect. You have to understand and be open...if you make a mistake, communicate about how you will resolve the mistake next time. So those are my 4 pieces of advice.

For me personally, sometimes I notice I do start to avoid the Deaf-Blind community. Part of the reason is because I work full-time here at DBSC, which means I spend close to 40-hours per week here being involved with the Deaf-Blind Community. I get calls and emails and people come into the office. It can be overwhelming, then I go home. I've noticed over the past four or five years, I've tried to be involved in the community; I had passion for the work. But then my Hearing world went by the wayside.

Recently I got married and I'm trying to become part of my Hearing world again. My husband is hearing – he doesn't sign and his world revolves around music. It's a completely separate world! So it's an interesting balance for me. I've noticed I've stopped...well almost stopped volunteering in general. And I've thought about going to camp – the Seabeck Retreat – again this year. I'm still on the fence about it. I'm not

sure. I'm still trying to figure out that balance of where I fit in. It feels a little schizophrenic at times, you know? It's awkward for me...finding that.

Ray: I agree with Kelly. Sometimes I find myself trying to avoid Deaf-Blind people, specifically clients. Keep in mind that I'm the SSP Coordinator and sometimes if there's a Deaf-Blind event and I'll go to be involved as a volunteer SSP or whatever. Inevitably, a Deaf-Blind person will see me there and will want to talk with me about their SSP issues. I try to explain to them that this is not the time, and they'll have to speak with me later. But some Deaf-Blind people want to talk with me right then and there. It's very awkward trying to manage it, seeing as I'm on duty as an SSP and yet they need to talk; it's a conflict of roles. I will tell them I don't want them to talk about it now and we can communicate another time via email. But they tell me, "you're so busy, you're always in meetings, and you're hard to get a hold of". So I have to be more adamant about establishing that boundary and insist that they email me.

... But again there are times when I have to recognize that their time is limited too. How else are they going to communicate with me? Do they have to come all the way over to my office to meet me, or what? So I've encouraged them to email me and I'm happy to set up a time and place that's convenient for them. We can meet at a coffee shop and talk there. So I'm trying to establish boundaries about time and when I'm available, and educate them, at the same time help them to understand it's a two-way street. I tell them, "Imagine if I came over your home all the time and interfered in your personal life that way." And they react with annoyance. I tell them "that's how it feels for me too." (So there's some give and take.)

Of course in my personal life, on my own time, I spend a lot of time around Deaf-Blind people and I have many Deaf-Blind friends. After all, I live on Capitol Hill, so I have several neighbors who are Deaf-Blind. We'll bump into each other on the street and chat, or sometimes I'll join one of them to go grocery shopping. Sometimes I'll share visual information about something I see that they may have overlooked, but it's a very natural thing. It's just part of the flow of conversation. I don't feel like I'm "on duty". There's really a range of how much I'm just there as a friend and how much I provide visual information. It all depends on the event, and who's there and how I feel about my time and I have to think: Am I in the mood to deal with them? Or do I just want to establish firm boundaries?

From time to time I've had a few uncomfortable situations ...and I've learned to become more firm about my work hours. I've had to draw the line and require that people make appointments and schedule a time to meet with me. But there are times when there's simply no choice – a Deaf-Blind person urgently needs to talk with me about something right then and there – in which case I may go along with it.

I wouldn't say I "avoid" spending time in the Deaf-Blind community, but I've learned to be more judicious about my time, when I'm working at DBSC every day as opposed to my personal time. Of course, out in public I'm still seen as "Ray-the-SSP-Coordinator-at-DBSC" no matter what I do. But sometimes I just want to be able to put that aside and be just "Ray"... I guess I'd say I pretty much represent DBSC 100% of the time. But I do try to make room for my personal life. Or even when I'm doing some (professional) interpreting, people will still approach me and want to talk about SSP matters. I have to direct them to another time, explaining that I'm busy interpreting – the SSP issue will have to wait for another time...So...sometimes I can be flexible and other times I just have to be firm with my boundaries.

Johnnie: It's interesting, because I come from a Deaf family. Because of my family, I tend to know lots of people in the community and we have a large network of friends. But when I moved to Seattle, I dove headfirst into the Deaf-Blind world. Now when I go to visit a friend in another city, they will ask me if I know so-and-so Deaf person in Seattle, and I find myself not recognizing those names! I realize I know *only* Deaf-Blind people because that's where I spend the bulk of my time. I know I have Deaf friends outside of Seattle, but I don't have much interest in getting to know more Deaf people here. I guess I've found my comfort zone. The Deaf-Blind world here fits my needs. If I wanted to, I could get out and meet more Deaf people, of course. But I'm pretty content in this community of Deaf-Blind people.

It's difficult to navigate between being a friend and being a professional SSP. My take on it is if I'm being paid as a professional SSP, then I remain strictly in that role. The boundaries are more firm and the expectations are clear. But sometimes certain Deaf-Blind people will approach me and ask me, as their friend, to act as their SSP to help them shop for home furnishings or clothes. They tell me their regular SSP doesn't have the skills, and their frustrated with trying to make it work, so they ask me if I wouldn't mind stepping in. In that case, I accept, knowing we both understand my role. You see if I were hired as an SSP, I wouldn't be sharing my opinions. But when someone asks me, as their friend, to take on [add] the role of an SSP [guiding and giving visual information], it gives me permission to share my opinions. I almost prefer *that* type of SSP work! I do enjoy that flexibility to switch between roles, acting as an SSP to help them shop for their home or for clothes, but also sharing my opinions. It allows me to give feedback, as a friend. In the professional SSP role it's a totally different experience. They may ask my opinion, but I attempt to turn the question around and ask, 'Well, what do you think? What's *your* opinion?' They have to make the decision, and I can't help. It's tough! But I have to learn to be able to turn that personal side on and off, depending on the circumstances.

Kristy: I think it's important to keep "friend" time and SSP time separate. SSP's must keep all work-related information confidential, so if the Deaf-Blind person shares something with you as their SSP, you can't go out into the community and share that information. If, during your time as a friend, they share something personal with you, it's fine, because you are part of the community then. You have that connection with each other so you can. I think it's important to keep those boundaries clear and communicate with one another; as Johnnie mentioned; that communication piece is key.

If your connection becomes too close with a Deaf-Blind person, then maybe it's not appropriate to take on the role of their SSP. You have to ask what their level of comfort is. Sometimes you simply don't want a friend in your business! You'd prefer to work with a stranger, or someone you know very little about. So you have to be careful.

Question 5:

What kind of working experience do you want to share?

Johnnie: A positive experience I've had as an SSP: There happened to be a Deaf-Blind person who loved shopping for clothes. That's something I also enjoy very much. So we were a perfect match! Even though we usually were only supposed to meet for an hour at a time, I didn't care! We could shop all day, I enjoyed it so much! So that was my positive experience working as an SSP.

My negative experience was that there was a Deaf-Blind person who liked going to the hardware store. Well, I thought this would fit with my experience since I grew up going to the hardware store with my dad, so I assumed I had the right background for it. But when we got there the Deaf-Blind person was very frustrated with me and we struggled with our communication. We decided to try it one more time, but again he was still not satisfied and very frustrated. I realized I didn't have enough knowledge in this area and we obviously were not a good fit. So I told the coordinator it wasn't working out. However we still are friends to this day, but he would rather work with someone who meets his needs when it comes to shopping. So those were my two experiences, both good and bad.

Kristy: I think if a Deaf-Blind person already has in mind what they want, and they've set a goal or written a to-do list, that really helps me. For example, if we're to go food shopping without a list we can waste a lot of time wandering up and down the aisles trying to figure it out. I feel their time is valuable and they're not accomplishing the things they need to do without a checklist. If they have clear plan laid out, we can do the shopping quickly – check off the items on their list – and move on to do other things. I think this gives the Deaf-Blind person a more satisfying experience, and makes my job easier too. They can feel gratification in knowing they've accomplished what they

planned to do. I think the list helps, and of course communication too – discussing what they want, their expectations, as well as my skills, my limitations – things like that.

It helps if the Deaf-Blind person is assertive. You know, if you're not satisfied my SSP work or we're not hitting it off, let me know! Communicate with me how I can improve, otherwise I'm left clueless and the Deaf-Blind person has to suffer. Meanwhile I have no way to improve my skills.

Question 6:

How is it different working with a DB person who uses tactile signing compared with a DB person who communicates visually?

Kelly: With a tactile person who is fully blind, it can be physically awkward sometimes in the store. Some Deaf-Blind people want the SSP to guide the cart but others want to hold the handle and walk alongside the SSP at the same time. Trying to communicate hand-on-hand while standing in such close proximity is very awkward. I'd offer to stand along the side of the cart, but the Deaf-Blind person wanted me to stand right next them as we pushed the cart. Well it made for some difficulty getting around the store, but I understand that some Deaf-Blind people prefer the physical closeness of their SSP; having that tactual sense of where the other person is at all times. Others are comfortable with more space. Each Deaf-Blind person has individual wants and needs.

[In one way] close-visual Deaf-Blind people are easier to work with than those who are fully blind, but I think it comes down to the quality of the SSP. Some SSP's will assume people with remaining central vision only need someone to push the cart, thinking they can see well enough on their own; and others will be more attentive about giving environmental information, telling them what they see and sharing "FYI's" or tips like "I think you were looking for butter? Well I noticed it was on the shelf about two aisles back..." that type of thing. It really comes down to the SSP. And if the SSP shares too much visual information with the Deaf-Blind person and they're told, "Oh yeah, I already know that," then the SSP incorporates that feedback and changes their approach as they go along. So I see the amount of work between the two groups as being equal.

Part of the SSP role is learning how to read your client, knowing what their needs are and evaluating their signing needs. Some Deaf-Blind people with residual vision still choose to communicate tactually. Which means observing how the communication works; how to make it most efficient. And it takes time. It might take one or two months of working together, going out once a week, to learn their...preferences, if you will. So that's a big part of the SSP role.

Johnnie: I think I almost exclusively work with people who are fully blind. I don't think I've done SSP work with people who have remaining tunnel vision. Most of my time...no

ALL of my time...has been with fully blind, tactile individuals. I can't recall working with anyone who has tunnel vision.

Kristy: I feel as if those Deaf-Blind people with tunnel vision already have more access to information by virtue of being able to see their environment. They're able to take advantage of visual communication from their SSP. When they need to communicate with a store clerk, they can use their SSP to ask the clerk where to find something. So the SSP provides communication access in that case; they don't need the SSP as much for guiding or mobility. For the fully-blind, tactile person they gain access to everything through their SSP. The SSP helps to guide, enables mobility, gives visual information – as in telling them about new products that are on sale, or which shelves products have been moved to. So I think everything goes through the SSP, tactually.

However one danger with a person who has remaining tunnel vision is assuming they can see everything, when they may not. So it requires negotiation to understand the limits of their vision and what type of information they want to be told. As an SSP, you don't want to be overly zealous in telling them everything and constantly interrupting them. Maybe they just want to be left alone, to independently walk around the store. That's why it requires negotiation and communication.

Thank you all – Ray, Kristy, Kelly, and Johnnie!