

JENNÉ CHALFANT INTERVIEW, PART ONE

Hello I'm Jenné [name-sign] Chalfant. I'm a deaf-blind person, a mother of four children, 3 boys – they are all hearing – and my youngest is a girl.

I've lived here [in Seattle] for more than 13 years. I moved here from San Diego, California and coming here – that was the very first time I entered the Deaf-Blind World. It was awesome. Before that I knew nothing about the Community and felt alone and isolated. But coming here I found out many – I learned so many things over the last 13 years; I am blessed to live here, to have many people here in this community. The DB Community is wonderful and exciting.

Interviewer: Can you tell us what that means “DB Community”?

Jenné Chalfant: A DB Community means being together! It is a critical mass¹ of people who are alike, who share the same experiences of life so you don't feel alone. It's an empowering experience even though the exact type of vision varies and there are people with all kinds of different personalities and backgrounds, but there are many of us with Usher Syndrome and you feel that you can relate to one another and share, make a connection, so we don't feel alone.

But that's not all. It also means opportunities for a social life, for work, including having our own organization, so there's an opportunity for leadership, to educate and learn from one another. You learn there are many things you can do and you have enthusiastic encouragement from other DB people who tell you and each other “Yes, yes, you can!” In other states, by comparison, DB people are isolated, all alone, isolated, lonely and sad. They look for support but there is none; there are no services. Deaf people have a community, they have services, but DB people are totally on their own, left out! So what it means to have a community is to have connections, a place to belong as a family and not be all alone.

Interviewer: When did you decide to use an SSP? Who influenced you?

Jenné Chalfant: I remember when I first had the experience; it was before I moved here. I went to a retreat at Seabeck in Washington, sponsored by the Seattle Lighthouse for the Blind, Inc. They sent the applications out nationally and I decided to apply. When I read the form, it asked if I needed an SSP. I was totally clueless what that meant. I did not understand the term, didn't know what “SSP” meant; I had no idea. So, I just thought “Whatever...” and sent in the form. Then when I got to the retreat, they

¹ “Critical mass” is a translation, not a term of art used by Jenne, but given many previous conversations with Jenne herself and with other DB people this is clearly the concept to which she is referring.

immediately started talking about 'match-ups' and 'teams' and I was thrown. It was all so new to me. I had to ask "What's a match-up? What's an SSP?" So they explained it all to me – that I would have someone to act as a guide and give me visual information. I was amazed that it was a possibility. I had always just followed along with my boyfriend or my son – went with them – that's the way I'd always done it. The idea of an SSP totally disrupted the way I had thought before.²

It was so different and at first I was somewhat 'off balance' because it was all new, but surprisingly, I saw that it gave me so much more power. It was my decision as to what we did. The SSP explained what was available, all the choices of things to do and totally left it up to me as to what I wanted to do. It was exciting; there were lots of things I wanted to do. The SSP just said "sure" and repeated that they were there just to provide their eyes, to guide me where I wanted to go. It blew my mind. And that's how I learned about SSPs.

Interviewer: What do you use an SSP for now? Is it mostly grocery shopping or shopping for clothes, that kind of thing?

Jenné Chalfant: For sure the most hours are used for grocery shopping. The second thing I use an SSP for is to go to my kids' activities. It's important that I can connect with the school and so on.

Interviewer: When do you think a DB person should start using an SSP's services? Do you think it is primarily for people who are totally blind or can an SSP really be useful to someone with tunnel vision, please give us your opinion.

Jenné Chalfant: In my opinion it's wide-ranging; it's up to the individual DB person to choose. It's an individual choice, but in my opinion the DB person should use an SSP because it gives you so much personal power. Using an SSP gives you power. If you depend on a family member or friend, you're dependent in a way that's not healthy. You want to be independent, to make your own decisions, with the information you get. You can do things on your own because the SSP works for you, I mean you work together. The SSP will drive. The DB person can't drive so they're often trapped, and they miss so many things, even when they "can see"; everything takes so much more time and it's a waste.

I used to do errands on my own and I spent so much time and energy, my eyes hurt. I had to ride the bus everywhere. By the time I finally got home I was totally wiped. That's a big reason to use an SSP: time and energy. But more than that, the SSP continuously gives you information and that information feeds you. You can share in

² Translator: It was a paradigm shift that caused her to re-think everything.

the funny things that are happening around you, you learn about little things like ambulances rushing by and you feel connected to the world around you. It's safer too, you avoid getting hit. So, it's my opinion that a DB person should go with an SSP but it's an individual choice.

Interviewer: What skills do you think a DB person should learn before they use an SSP?

Jenné Chalfant: Well, I myself never had any training before I started using an SSP. I just didn't know; I had no idea about the rules or policies and learned through experience but I suggest a DB person should have training in being assertive, learning to think about yourself, what you want, and how to make decisions. The key to using an SSP is to know what you want and how to express it. Don't expect the SSP to read your mind or assume that the SSP knows best. No. The open communication between the DB person and SSP is central. Ask for what you want and be specific. Learn the logistics too like being very exact about where to meet and the time. And you as the DB person make the decisions. There are lots of these decisions to make and the DB person should be making them.

So the rules... hmm, let me think. The key concepts are power, making decisions and it's very important to be honest about your feelings. It's not good swallowing your feelings when you feel hurt or unhappy with an SSP. You can talk to the SSP, explain what is working for you or not, ...ok, here's an example, this is a perfect example. Let's say you are going shopping and you and the SSP go into the store and some stranger sees you and is intrigued by the whole process of tactile signing and so on and asks the SSP "What's that? Is she blind?" and the SSP just goes ahead and answers the question without bothering to inform the DB person, just talks with this stranger. The DB person is just left in the dark while the SSP answers the question on her/his own. No. The SSP should inform the DB person and the DB person should tell the SSP that. DB people need training in how to be assertive about those things, and tell the SSP "I want to be informed. I don't want you talking to people without involving me in everything."

I remember one SSP who worked with me whose character or personality was very controlling! She was 'in charge!' She would tell me what to do and I had to be very strong and tell her to "Back off." I told her very, very clearly that I knew what I wanted to do and in what order and was not asking her to plan where we went when. She tried to argue with me that her way would save time and on and on; she would not let it go. I was very firm that I knew what I was doing but she was not happy. So, how we resolved it, after the assignment was over and I went home and calmed down, the first thing was I sent her an email explaining how her behavior made me feel. That didn't work, so then I met with the SSP coordinator and explained the situation. I told him

what happened and how I felt. I included what I liked about the SSP but that altogether it was not working. The coordinator arranged a meeting with the three of us: the SSP, the coordinator, and myself. I expressed my feelings about what had happened and said "If we want to continue working together, then it will have to be with mutual respect, an openness to listen and to admit when we have made a mistake. If we're not able to do that and we continue to have these conflicts, then I would ask for a different SSP.

...So, it's been a total of over 13 years and in that time I've had, let me see, several different people. I would say, all together a total of 7 or 8 different SSPs. I personally like having consistency in SSPs because that way we learn more about each other (personality and style) and can work together better. We can come together to work as a team. Then there is more mutual support, more of a team spirit to the work and it's something we both enjoy. The energy is better; there is a pleasure in working together; we support each other as a team. So I like that consistency. I have had a number of SSPs for just a short time and it's because the service was not satisfactory or other reasons but I much prefer consistency. I currently have a very good situation and I'm satisfied. I have SSP service once a month and it's great. I like my current SSP.

Going back to the issue of an SSP leaving me out – I don't like that but it's not that I don't want the SSP to ever talk to anyone else. If they inform me that we've run into a friend of theirs and they want to chat a few minutes, that's ok with me. I don't think they have to be cold and so professional that they can't say hello to their friend, but I want to be informed. It's polite. I want to know I have your eyes. Deaf people take in all sorts of information just looking around. I can't tell you how much I miss having those deaf eyes, and I know because I grew up as a deaf person. That's why I value so much having a little of that back through an SSP who tells me all the little things they see. I know Hearing people 'see' but... and they let me know what they hear too – things that are amusing and so on, and I learn from that. That's nice too.