

INTERVIEW WITH DON MEYER

My name is Don Meyer. I was born in Mississippi and grew up in Oregon as a hearing-sighted person. I entered the Army after high school graduation at the age of 17, and after coming out of the service, I worked in heavy industry. I did a lot of hunting and fishing, different things that were very hard on my ears, which turned out to be noise sensitive.

So my hearing degraded and gradually got worse and worse. And then in the mid '70s, I realized something was wrong with my eyes. But doctors never found it. In fact, one doctor, the head of the eye clinic at Sacred Heart General Hospital in Eugene, Oregon, even had the nerve to tell me when I complained that anything wrong with my eyes was all in my head. Well, of course, after that it was another two years with problems getting worse and worse before I could go to another eye doctor. This time I asked around to find -- to try to find a good doctor.

This one, when he asked me what was wrong, I told him. And by then I was feeling really bad about the situation. And I told him I don't know. Maybe it is all in my head. That doctor though said, "No, it's not in your head. There is something wrong with your eyes. I can tell that simply by the way you [use your eyes to] look. Now what we have to do is find out what is wrong." And he went into extensive testing and found out that I had dominant retinitis pigmentosa.

Now, I was adopted. So there was no family history to know that I would most likely come down with it. As my eyesight got worse, I got in contact with the Oregon State Commission for the Blind, and after another year they finally got me to go to the school for the blind. There I found out for the first time that I, myself was a Deaf-Blind person and they were having their very first Deaf-Blind program at that time -- but didn't tell me until I got there.

It was quite a shock. But even then I still had to struggle to get the counsel I needed to deal with the impending blindness. While at the school for the blind, they took the Deaf-Blind group up to Washington State, to the Lighthouse, ... Red Barn Ranch Camp [which] at the time [had] both weekend camps and the summer camps. It was there that I first began to associate with [other] Deaf-Blind people.

At home in Eugene there were no services, so in December of 1980, I moved to Seattle to join the Deaf-Blind Community where Theresa Smith and others involved with the fledgling Deaf-Blind Community here in Seattle helped me. And have advanced since to the point now where 32 years later that I am quite comfortable with my Deaf-Blindness. But still I need help to survive. I live in my own home by myself... I need help to take care -- to get the items that I need to take care of my house, my yard, my wood shop. SSPs are invaluable to me. Without them, I don't know how I could survive. I certainly would not be able to survive in my own home.

Interviewer: Would you possibly like the idea of having somebody with less skill, maybe

an ASL3 student, who would go to shopping for you? And then you'd have your 12 hours of SSP time. And you could use it for whatever you wanted and if you wanted to go to the grocery store, you could do that too. Does that sound like a good idea or not?

Don Meyer: Hmm. That is a complicated question about having other people take a list and go shop for you without you because there's always decisions that have to be made. For example maybe I want some ice cream but I'm not sure exactly what kind of ice cream I want, and what's on sale. They might not have my flavor. But, if I am there, I can make the choice. The other person maybe make the choice according to their taste and not mine.

Interviewer: So that brings me to the question do you have access to something like a cell phone? Can you read a cell phone? Can you use a Blackberry with Braille? Or the DBC, say, the Deaf-Blind communicator¹? Can you use that? So I'm thinking the shopper goes to the store and they have your list, but they're out of the ice cream you wanted. If they were both hearing, they would just call on a cell phone and say they're out of chocolate. What do you want? Or strawberry is on sale. What do you want? Or whatever. Do you have that kind of communication?

Don Meyer: That is a possibility to help alleviate the pressure on the amount of time that a Deaf-Blind person and an SSP have together. But my personal preference is to do it myself with an SSP. In some situations, once in a while, yes. Giving another person a list and maybe their being able to communicate with me through the DBC would help. It's something that would need to be experimented with, and to find out what areas it would work in. Maybe it would not work good in food or maybe it would there but not at the hardware store and vice versa. But also that would kind of tend to tie me up while that person is in the store shopping for me. That's almost the same as my needing to be there if they're calling me.

Because for myself with Braille, it takes time. But it is a possible alternative, especially if, for example, the Deaf-Blind person is ill, or recovering from surgery or whatever.

I live alone in my own house with a yard and a house and a wood shed to take care of, all three of what I could not do without an SSP. My main recreation is woodwork. I work with wood; make jewelry boxes, cribbage boards, you name it, kitty condos, things like that. It is something I can do and enjoy. The same way with my yard. I have built three raised garden beds where I grow vegetables. This year I've changed two of them into asparagus beds, or I'm trying to. None of this could I do without an SSP's help. None of it! Simply there's nobody else that could help me. People can't communicate with me. Neighbors can't communicate with me. So they're not going to help. Other people have busy lives. For myself, SSPs mean survival. I want to live independently and be my own and be my own self. For me to have to go to a nursing home or whatever or an institution, would kill me. Same thing -- I feel the same

¹ Technology that is accessible to a DB person. See Accommodations.

way about having be forced to move to an apartment where I can't get outside and do things myself. To be cooped up in that apartment with those walls with the darkness and silence that I have to live in it would be more than I could take. I know about 20 years ago I read in the "New York Times" -- my Braille edition of the "New York Times" - that the Supreme Court had ruled that it was cruel and unusual punishment to put a convicted murderer in isolation. I'm not a murderer. Why put me in isolation? I want to live. I want to have people. It's life. It's human.