

January 23, 2020

Hi my name is Sandra Stoffel. I am 61 years young. I have Retinitis Pigmentosa in both eyes and nerve deafness in both ears. I currently have about 2% vision left which I cannot see colors much anymore. Just mostly in black and white. I can't see pictures and television screens are blurred. So much has been taken from me with my vision loss over the years thus putting me in more isolation. My hearing loss is at 70% and I wear two hearing aids. Thank goodness for these or I would be in total isolation. It would be wonderful to have an SSP (Support Service Provider) program in Kansas as it would improve my quality of life.

I have used SSP services in Maine and they helped in all aspects of my life from going to doctors, going shopping, out for a meal or to social functions. With my hearing aids I still miss out on things so it's nice to have someone clarify what I may have missed. As for the loss of my vision, it helps me to have someone give me a visual of my surroundings, people's faces and read me items when shopping.

It's hard being me at this stage of life. I used to see everything and was very independent. I have been hard of hearing since birth and my parents could only afford one hearing aid. I needed two. Back then the aids looked like the old fashioned cigarette lighters with a cord and plug for your ear. What a hideous item for a kid! But at least I could see to lip read. Even teachers would tell kids in class, "Don't move your lips or Sandra can read your answers."

I was in my 20s when I found out I had Retinitis Pigmentosa. It was the worst day of my life. Doctor told me I would be blind on a year. I was devastated. The doctor was wrong but it was hard losing my vision a bit at a time and losing more and more of my world. That's why having SSPs is so important to me as to open my world up again and take me out of isolation and help me live and enjoy life. Thank you.

Sandra Stoffel, Olathe, Kansas