

I was a community resources co-ordinator, did a lot of public relations kind of things. The reason I guess they told me, was my background. A whole lot of public relations, I had been doing some sex counselling with families. I guess Karen thought I was a good balance for the programme, not only in community resources, but also have a client load, and also be able to do a lot of in service training, not only awareness of being disabled, but at the same time be able to serve clients, whatever else I am asked to do. When Karen is gone, then Jeanette takes over, when she is gone I take over. As director she is in and out a lot. So the first thing I did when I came on the job, I did a lot of follow up. Some of the people here had already mailed out brochures and a letter, pretty much explaining very briefly our programme. I had to come along and call a lot of these people up and offer to come in, talk to the directors, talk to the staff and give them a more broad explanation of what we were doing, what our philosophy is. We go with a friendly approach, we don't put demands on anyone. We do open ourselves up to Jeanette and I are in the process now She contacted all the medical people, all the hospitals in the county that we serve, agencies like community nurses, home help type people, and her and I have been going out and doing some in service presentation to some of these people.

JE: What is in service

Explain our programme, give a little history, how we started, why we started, and then explain what we do. Make ourselves very much available to the outreach then we offer to go back and do some sexuality work with them, and they were very receptive to that, so we are going to go back and do that. As you know, that is a big gap in the rehabilitation process, it is a big gap anywhere, sexuality. For various reasons, 1. people just avoid that in their hospital study. 2. They don't know where to start, what do I say to someone that is spinal cord injured, I don't know how he functions sexually. Most people think that you don't do it, your body is paralysed, therefore your sex is also paralysed. There's some myths attached to that also. So we make ourselves available to that, that sort of opens it up to them and makes it easier. I don't know how we are going to present it, is myself and Debbie Heath, do you know about Osteo Genesis, a bone disease,

JE: Was she doing sex counselling

Yes. She is in medical school. She and I were doing a lot of that in New Mexico, sort of sexuality workshops in that agency. Now since Jeanette and I are going to be doing it, we will probably take a different approach, but pretty well follow the same type of agenda that we followed before. You see Debbie covered a lot of the medical aspects, what takes place physiologically. We both covered what happens psychologically. Pretty much covered adjustment to an acquired disability, she would cover adjustment to a congenital disability. I would go and relate some of my personal experiences as far as how I adjusted sexually, not only sexually, but socially, emotionally, it all sort of works together. Anyway we are going to be bringing together some kind of a programme here as to how they should be going about whatever kind of sex counselling they do. What I always ask them not to do is not to say anything. OK if someone asks a question about the subject of sex, instead of responding in a negative way, you can say I don't know, or, I'll try to find out, but don't say you can't, because that can be really devastating

JE: It is dreadful at Stoke Mandeville

I don't know if I told you, two or three weeks after I was injured, an orderly came in to change my catheter, he held it over me and he said,

I hope you were never planning on getting married, and that just wiped me out, I believed him, because he is the only person who ever came along and told me. I would ask nurses what is the matter with me, I don't know, will I be able to walk again, I don't know, how come I can't move, I don't know. So he is the one who came in and told me something, he made a statement and I believed it. The guy did not mean anything, he obviously felt I have got to tell this guy. some guy might ask well, would you go out with me if I could walk, what he is really looking for them to say is, I will go out with you now. All the little things are so important, people can be listening to all those comments that nurses make. I always felt more comfortable talking to nurses than anyone else. Very seldom would I ask my doctor really sensitive questions, you ask them about bladder infections and those kind of things, but nurses are the ones you ask about So that more or less sums up what I do. What I would like to do is try to get some of the civic organisations, the rotary club, the lions club, let them know about it. A lot of those organisations are looking to help someone. What I am looking at is to say we have a client in Rosswell, or St Joan, for rehab, about to be discharged, he is going to go back home to his little house, up ten steps, what can you do, we can't do anything, so if we can get someone to donate the labour and the wood, we can supply a ramp

JE: What have they done before

A lot of them just stay home, I would imagine, they just stay inside. When they go somewhere, they will get people to help them down the steps, but there again, a lot of them are probably able to get the neighbours to throw together a bunch of boards for a makeshift ramp, because there is a lot of friendly unity that exists up there. Disabled people are looked upon as people that should be sympathised with, ah this poor guy, let's do what we can for him. And that can be a problem too

JE: Over protective

Yes. People are really religious up there too, you have a really heavy Catholic background, so the handicapped are looked upon as, ah poor thing. So I have to get through that before I can even get to the client. You have got to do some awareness stuff with the families

JE: So that is one of your skills

All of us. We all have to be able to do more than just one thing. I can't just come in here and wear a tie and talk to agencies and directors. I have got to be able to take off the tie and go into the homes of clients. You have got to have that variety. I have to be mobile.

JE: How do you deal with the Indian community

I was at the Indian hospital talking to some field nurses and I was asking them some of those things, and I asked them, what is my approach. Silence. Do I go and approach them just the way I approach anybody else. They never thought of that. I have known that certain things are taboo. I have a friend who is a teacher, she was doing a puppet show, and one of the puppets was an animal that the indians held sacred, and she got in really bad trouble for doing that. What they did say, well there will be a lot of silence. You will go and talk about the programme and all these things that you may be able to do and they just sit there. You might answer a question that you think they needed, for example, do you know how to go about getting a wheelchair, so then you try to find other ways to get them to talk, sort of answer the questions for them. Anything that is government,

not represented by their own, they are suspicious of. It is a barrier, so they are going to go in and maybe leave a brochure laying on a table. I think, once they have learned to trust you, then maybe it will get started. I think it is going to take a lot of time. If it is rural, they are all real close knits. You are the only one from the outside, being looked at as a stranger, as a social worker type. So we are trying to approach the agencies first, let the agencies put a word in for us

JE: How is the relationship with the agencies

For far we have done really well. We were afraid of the agencies being territorial, but that has not happened. We want to work with someone else, we can't serve every need, but they probably can't either. In some cases they will provide attendants or transportation, but they won't provide peer counselling. The people may not know about all the programmes of all the agencies, that may or may not be able to help, so we come across and approach that, hey we are here to help you guys out, we have a staff that are disabled, we can offer peer counselling. Other than that we just go across and really stress the IL idea and expand on that, and I can share some experiences with them myself, at a time when I did not know this or I did not know that, when I went about getting the van, the whole process took a year, and if I had had someone who had maybe gone through those steps and already gotten one, then that could have helped me out. Like when I got mine I made myself available, some key issues here, transportation, education, employment, you can't do these things without learning to drive by yourself, the whole social aspect, the whole IL. I usually sum things up by saying, well I am just like you, only I am sitting down, but I want the same things that you want, I want to go the same places you go. I know that I can't ski down a mountain, but I would like to be able to go up there and watch the people ski down that mountain

JE: What I really want to ask about is attendants

On the attendant issue, you might start with Gene, because he put together the attendant manual, he can share some of his ideas about how to go about it, and about how he and I have gone about it

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