

What that means is basically we work with persons in terms of direct services, pretty much on a one to one basis. just a myriad of services, I'll go get you one of our files later on and you can see pretty much, we have like 25 or 26 with a lot of flexibility of services. In terms of independent living skills aware of feeding and dressing and taking care of themselves, advocacy, knowing the legal rights of a disabled person, job seeking skills, we are sort of ... we are also, even though we are in direct services, we are local liaison, sort of middlemen between where a person is coming from and where a person is going, or sees himself as going in life. So, for instance, if they would come to us for job seeking skills, we would make sure they know that we were not actually going out and seeking employment for them, we would act as a support system and be a resource to them to learn how to conduct themselves in an interview, write a resume, do whatever is necessary to programme themselves for employment, but not really actually go out and help them seek employment. So independence is the name of the game and that is really where we are. Services as middle men, even though we are on a direct line one to one, I can't actually explain it because it is easier for the people we are serving to actually get that concept to ... they are not always clear about what their role is and what our role is. As to living skills, attendant management, hiring and maintaining an attendant or a PCA, educational consultation, vocational consultation, we have a director of deaf services, again Maria ... was here with the video when I first came in, she is a secretary as well as full time interpreter, she is with the registered interpreters of the deaf which means she can be on call as well as many other individuals in the city to go out and actually interpret for an individual who is trying to make a court appearance or trying to take a child to the doctor, or trying to communicate in whatever way they needed, so they would call her for interpreting services. She also does help in the office setting. She also does legal correspondence that a person would not understand, sometimes they have jargon, language that is not always understood by themselves, so she interprets anything they want to bring in and keeps that purely confidential. Use of the TTY. Telephone used by deaf persons. Bill Shoven, who is our director of deaf services is on vacation, he is himself deaf, he would do a far better explaining job than I am. ...

JE: Small is beautiful

Yes, but I am sure Max has told you that our staff has grown incredibly in the last few years, from 3 to 16. So even though we are in the infantile stage, there are lots of things that in the developmental stages. So, back to services, so we have that myriad of deaf services as well as the other services we provide. Any individual who would want to contact us and take advantage of those services. I am not naming all of them, I am leaving a lot of them out, so if you have any questions please interrupt. Today, we each take a day, we feel it is imperative for our staff to have contact with the people who phone in or walk in, sometimes the case, to speak with them, rather than just turning them over to a secretary, so we each have a I and R day, information and referral, today is my day so it is a little hectic. What happens is we try and talk to the individuals on the other end and number one find out what they know about paraquad, many times they have no idea where they are calling, sometimes they just say pick up the phone and try this place, maybe they can help you, so we try and give them as much information as we can and also find out what their needs are, and if they are really wanting to come in to us or if one of us needs to go out to their home, you know that's it. Which is fine, but many times it means that they really want to come in to us and they are really shy, so that is one of our philosophies, we also do a lot of community type education, speaking engagement, we have lots of requests for teachers for the community, especially those who are involved in special education and want to get their adolescent students involved in independent living, so when they are 21 they are automatically out of school and nowhere to go and no resources to look after yourself, you have got to link them into some services, and possibly into some schools too, to let them know we are here and we are a resource

JE: I think that is a very important aspect of your work. Something they started up in some centres. I read a report, I know they were doing that in Berkeley but they have had to cut that out, because of the lack of funding. I think going to schools is really vital because that is where you start

We are working also with the family group, doing some family consultation, a group of parents of handicapped children who wanted to build a residential centre for their kids, the parents are worried about what is going to happen to them. So, we went in an effort to try and explain the concept of independent living and the fact that segregation is not the way to go, by the end of three hours yesterday we had a totally reverted concept about the way these parents wanted to go, so we are going to keep that as an ongoing group now, and I think it is going to snowball as I think these parents were very interested and had other parents in mind, in terms of who could take advantage of this kind of thing. Our problem is not so much a question of financing, but our problem is the release of staff time to be able to carry all these things and do this balancing act, that is what it really amounts to and that is the real thing that we are up against. We have a real problem, we have been recruiting now for about six weeks, an independent living specialist, we have a real problem trying to find a qualified disabled person, who could fill the slot.

JE: Specialist, to what extent

IL specialist, doing the same kind of the basically as I am doing, working in direct services with an individual, like obviously we would prefer a disabled person and to get a person who has personal skills and a background knowledge of resources. Most of us on the staff have had an extensive background in either disability issues or Jim Tuscher, who is programme director of IL, has a background in guidance counselling. Mine, I come from a special ed. background, teaching background, so we all have a lot of resources to pull on, but we are finding great difficulty in finding those persons who can fill that bill, so we are being very careful not to just go out and take a body and bring them in, it often happens, we know of other centres where they have done this and it does not work. You have to have someone, too, that has the background knowledge and also the personal skills, I guess a little counselling, a little here and I guess whatever else goes into you. It is a real appendage to my career because I basically as a teacher involved in some non direct services and advocacy type groups. This is a real different learning situation. Any questions

JE: The thing I am really interested in is the care attendant, finding them, paying them and all the rest of it

What we basically do is that Colleen Starcroft is an IL specialist and was a physical therapist and she has had years and years of involvement with persons trying to maintain a PCA so what she has done, she is in the process of with another disabled person, one of the volunteers here, is to compile a short vehicle of tricks of the trade, how to do the kinds of things, she is doing that right at this moment, I am not sure of length, time, and availability. But what she does for people who come here for services is to try to give them as much input as possible in relation to, they have no idea about asking for references from an individual, about dissemination of information required for the recruitment of a attendant, so we give them ideas of where to put their little fliers, tell people about the fact that they are looking, she does a lot of role playing with them, interviewing, maintaining and so on. Colleen is pretty much at the moment the expert in that area, it is not really my area, we are hoping, we have a state representative, Harriet Woods, who is one of our county areas of St. Louis, and she has introduced a bill in the state legislature that will hopefully be passed as of July 1982 persons would qualify for monies for a personal care attendant. She has been able to convince whoever in terms of her bill that cost effectiveness wise that would be the road to go, so we are really banking a lot on her. If that does not come to fruition there are other sources I am sure. There are some other sources of funding from people

that we work with, we have developmental disabilities regional centre, which works with people with neurological disabilities and if they happen to fit into the category of cerebral palsy, epilepsy, autism or ... then they can qualify for and also if they are going through a vocational rehabilitation programme, involved in school and or work, there are funds available for attendant care, but there is not a whole lot. Many times it is just by hook or crook. The best chance is if they are involved in Voc. Rehab., either in training, or sheltered workshop, or evaluation period, they are still entitled to some attendant management type care, not 24 hours, of course we discourage that too, the policy is to keep it minimal, only as much as you have to have

JE: Do you have any contact with rehab. centres. In England that is an aspect that is definitely lacking

We do, it is usually the other way round, they contact us. We are getting more and more referrals, we are real surprised and happy and gratified because it is happening. It has a lot to do with the community education we are doing and the services we are giving. To directly answer your question, we try to contact all new patients, there is direct line, especially with the Jewish hospital, which has the biggest rehab. unit. Colleen has a lot more to do with this because of her background

JE: Training attendants.... Colleen

Yes. It is an area certainly that again we work with the individual on. Most people have no idea how to go about training. Also looking at two sides of it, not only training the attendant but thinking of the attendant's side of the picture and working with the person too, making them think of the other side of things, they often think only of their needs

JE: What is this room used for normally

Mainly for staff meetings, and or peace and quiet. I use it a lot for initial evaluation of a person.

The back of the building is a small library with a part time librarian, we are getting funds to hire a full time librarian.

Usually we spend between an hour and an hour and a half when an individual first comes in just getting acquainted, explaining services what we have available, a question and answer sort of thing, but it is not just taking information, but getting them more involved. Then we try and project a short range and a long range plan for that person, talking about who they might be working with. Another person on the staff is a part time Occupational Therapist, she is a specialist in adapting equipment, and is on vacation also. Then we have another referral person, she is very much into driving schools that work with disabled persons and adaptations to cars, she often gives workshops in cooking, and any independent living type skills. She is one of the few people on the staff who is non-disabled

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