

....they may not be able to come here there are in fact people that are living on the third floor and you knock on the door and they have to yell out the window and then throw a key down to you so you can come up. There are some very inappropriate housing arrangements out there. There is a woman who used to throw her wheelchair down a flight of stairs and then bounce out onto the porch and get somebody off the sidewalk to lift her into her chair. So it is kind of an outreach. She also works in here, delivering services to people she finds out in the community and co-ordinating services. We have an adaptive equipment specialist, who is an occupational therapist by training and she tries to keep track of the latest adapted equipment, new ideas, she also goes out in the community, working in somebody's kitchen, to see how they function, generate ideas for working more effectively, she tries to design adaptive equipment, simple ideas, she tries to get people in the community that will make them inexpensively

JE: Could I have a copy of that plan

Introducing pictures of each person on the staff. Have you seen a list of services we offer. Are you interested in how people go through our organisation. When a person is referred here, or refers themselves, they can come in a variety of ways, often they call because they want to know how to get hand controls for a car, you explore that bit with them. (interrupted and returns to talk extensively about services for the deaf)

Then go on to discuss some of the services of CIL, Otto comments on budget management programme. It is explained that crips from institutions or parental homes have failed to develop these skills and therefore need training, especially in the context of handling state and federal benefits. Also, the importance of how to live more economically, by avoiding the high costs of specialised medical aids and equipment and making do with equally satisfactory standard purchases. (bucket instead of night bag). The only people in this country that get these things free are veterans. They get in the region of \$24,000 a year without being taxed, which is a pretty good living.

JE: Tell us about what you do as Programme Director

It is basically trying to co-ordinate the various programmes to make sure we are heading towards our goals. We are trying to get a contract with Southern Illinois to deliver services, through Voc. Rehab. and just those kind of things, all the co-ordination, details

JE: Do you have monthly meetings

There are several strategies. At top level we have monthly meetings with a consultant, who is paid to help us develop our programmes, he used to work for Cornerstone Foundation, Chicago. Max and myself we will meet and just plan strategies like what should we be doing in the next year. Or making out the outline for a grant proposal to take to government or a private foundation. If we feel a particular need. Then on a weekly basis, Max and I meet. In terms of developing financial resources, the Board has a resource committee, kind of planning the financial future. Max and I discuss various commitments, public speaking kind of things, decide whether it is worthwhile and we should do it, we get an awful lot of demand for that. That is planning and development. Back to people coming in hand control for car is cut and dried compared to something like an information referral, each independent living specialist spends one day doing IL information and resources referrals. I give the person the information they ask for, then I start exploring, ask if they mind if I ask a few questions, ask them how they are living, working, going to school, get an idea of what their life is like, health, get an idea of whether they want shoot for a job, get into a school programme, or maybe they are sitting on the third floor doing nothing, then we may try to get them in for services here and Voc. Rehab. When they come here for services, the first thing we do is take them down the workshop and get a whole bunch of information,

their abilities, their living situation, what they are able to do, what they want to get from us, list of services, have them list services they would like from us, which ones are really important to them, which ones they would really like to start with. Somebody acts as their contact, the IL specialist that is monitoring might not be the one that delivers all the services, you might get Colleen for attendant management, Bill Sheldon to teach budget management, so it is basically the way people are routed through their services

JE: Do any of these services cost anything for the person coming in, at an advisory level

No, we are on a grant, so we have the luxury of being able to do it for nothing at the moment, but we will at some time start charging fees, especially to Voc. Rehab.

The IL programmes were set up by a Title 7, Part B. grant. Part A is appropriation for Voc. Rehab. to enable them to purchase services from IL centres. Part B funds set up the IL centres themselves, it is all on the Rehab. Act of 1968, sorry 73 set it up, things were amended in 78. They kind of put the curbs on so that Part A cannot purchase services from Part B. We probably could not make charges anyway, because we are on a permanent contract to Voc. Rehab.. It would be like an employee charging an employer for services other than salary. There are department of Mental Health funds to buy services, we have got some fees paid under that programme. I guess the important thing is if you get anything set up is to have it funded just to exist, or to set it up so that there are funds coming in to be used to buy programmes

JE: What about those centres that don't have that kind of funding, do they have to charge

I think Berkeley has some arrangement with Voc. Rehab. in their state, they don't get the Part B. funding, they were before the federal funds. They have had some fees for services arrangements, we do things quite differently, the way they had it set up is quite different from us. Our costs are around \$40 an hour.

So, I meet once a week with the service monitors, for supervisory meetings.

JE: Incredible names

Yeah, we try to stay away from typical agency terminology, they call them case managers in other agencies. We try not to consider ourselves as an agency and the people we help as clients not cases. I think those terms tend to dehumanise, once you are called a client, the scales tilt against you. In business to be a client is to be 15 up, but in human service area, once you are a client, you are the bottom of the ladder. So we don't talk about the people we help as clients or cases, they are people. I can see where the terms might help, in trying to differentiate between groups of people, however, I think just regarding them as people is a constant reminder and helps to establish the peer relationship.

JE: What were you doing before you came here

Counsellor in a Community College here in St. Louis for ten years. I am learning management and organisation skills OJT. As you look at different programmes you will probably see different philosophies as to the type of people on the staff. Let me tell you about our philosophy here. We try to hire disabled people who have been about and been involved in advocacy, and are aware of the issues and have professional degrees in social work, counselling or Voc. Rehab. We figure that we are getting the best of two worlds, that we are getting disabled advocates, who know the disabled side of issues and so on, we are also getting people with professional skills who know how to deal professionally

Otto: In California it is so different, people rushing in and out, and people on the staff have no qualifications. In Los Angeles I was a little bit shocked when I saw the team of 40 people and 36 without any qualifications, three social workers and one psychologist. I met so many people who have been counselled by handicapped people with no professional qualifications, who could not differentiate between C4 and C7 and all they could say is, I did it, so you have got to do it, so I believe what you said, that people must have professional behaviour...

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Jim Tusher

That is one of the differences you will find, going to Berkeley

JE: I think it will be interesting going from this side

Otto: Seeing this one, I would say that is like the Germans would build it up, professionals

JE: There again I think there is a certain element of what you said, OPD or DTJ, learning on the job, but you have got to have that professionalism. I think particularly in a place like St. Louis, trying to get it together, trying to get credibility, that is so important, that is what we find trying to get things off the ground in England, whether you like it or not, you have got to be credible and you have got to communicate to the professionals, otherwise they will always think they are the experts

Yes, a lot of the work we do entails talking to doctors, social workers, rehab. counsellors, etc. and often those people, in particular rehab. counsellors, are dumfounded to find out that our IL specialists have disabilities, like Maria probably has better qualifications than all the rehab. counsellors in the area. It gets back to the status thingshuffle, crunch, shuffle if we get a quad, who wants to discuss something, we will get someone to act as a peer consultant, that is where we get people without qualifications, to talk about practicalities, something real nitty gritty, just orient them to the process and turn them loose with the disabled person, if the IL counsellor can't spend the time. So we try to work a non-professional peer sharing thing at that level

Otto: I always feared in California that they could not help with some things, they had no training ...

Street knowledge, it is very important, but when you get on the phone and try to get something on with a rehab. counsellor, social worker or doctor ...

JE: But there again, in California they have got the guy who is director of rehabilitation services, Ed Roberts

We have got some people, like Greg Sanders, works in CIL and he describes himself basically as a ski bum, somebody who skis and nothing else, and he broke his neck and he is probably one of the top experts in the country, and he has no professional background, but he has On Job Training. He got interested in social security benefits and so, he goes to Washington and puts pressure on the ... and talks about the disincentives. A disincentive is where a person has gone through training, like computer programmer, and the job they are training for starts at \$15,000, \$12,000 a year, when they go on the job, almost immediately, they lose many benefits, so that is a disincentive to work. So a lot of qualified disabled people will sit at home, because they don't dare go out and get that job. If something happens and you lose your job, it takes three years to re-establish your benefits, and what are you going to do in the meantime. Most disabled people in this country fear that nursing home or institutionalised living might scoop them up

JE: It is like that in England. Are they trying to do something about it in the States

We have a woman who is volunteering here and we really want to pay her because she is putting in an eight hour day five days a week, but she has SSI, Social Security Income Supplement, she could earn up to \$75 a month, as soon as she crossed that magic mark, then she starts losing her benefits. She was going to college in the term time, so she did not want to mess up her benefits. If she had been allowed to earn money, then she would not have had to lean on Voc. Rehab. so hard and she could have helped pay for her school. Did Max tell you we are in a fiscal crunch right now.

JE: What, about this thing in April, when the budgets change

We are on a big campaign ourselves, in terms of cost effectiveness

JE: We are having the same kind of problem, trying to show the cost effectiveness in England

We are going out of our way to be conservative. This person here will be saving at least \$30,000 a year, and she is only four years old, so in another 20 years that will be around \$600,000. That's in today's money, it does not take in the effect of inflation. It is intended to duplicate that all over the country. That is if she never goes to work. If she goes to work, then we can get better, although with disincentives she is not too likely to work. I think in Oklahoma they have worked out that you can support four in the community for the price of one in an institution

Otto: How many clients do you serve

Last quarter, three month period, we served 82 people

Otto: Are you based on a small area, or do you try to serve the whole St. Louis area

We try to serve the whole St. Louis area and parts of southern Illinois. That 82 is a little bit misleading, that only counts the people with whom we have had significant, set up a file. There are a lot of people that we served without doing an intake, or evaluation, all that stuff, and it does not count the number of information referral calls, which is a service in itself. If you counted the people who have received any kind of service from us in a quarter, it would probably be in the region of 700 to 1000 people.

JE: Do any of the universities in St. Louis have special services to provide for disabled students.

Yes

JE: I ask that because Berkely and Boston have grown out of the university. This one has not.

No. The three community colleges all have small programmes to assist the disabled. Washington University has one which is up on the third floor, with no elevator, which is interesting

JE: So the disabled students are pretty well catered for

No, not at all. They get pretty good services in the two year community colleges, simply because they are the newest campuses in the area. For the most part the others are all, you see section 504 leans pretty heavily on various parts of the community, education is always the weak sister in the lot, education you have got to lean on pretty heavily, education is becoming more accessible if the government is doing the leaning.

JE: Do you have any dealings with students because of gaps in services

that the universities are not providing, do you ever get called in there or do you try and keep more community orientated

Sometimes we go and talk to the students at the various schools, sometimes the student services co-ordinators will call us up and ask about a particular problem. But pretty much in terms of note takers, readers, interpreters etc. they have their own process for handling that kind of thing on the campus

JE: And care attendants

Yes.

JE: It seems you are quite unique in being of the community, with no involvement with the university

.We are not unique among the original ten though

JE: I have heard about Vermont, Gini said they went out to find people who needed services, and that was a different approach again, the need was there

U We would not be here if it was not for Berkeley and Boston and Ed Roberts. You have probably heard the story about how Voc. Rehab. would not fund Ed Roberts because he was too severely disabled, now he heads the agency, I'm sure there is a nervous counsellor somewhere

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