....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 outt 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 ofnight 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 sppecialist spends one day doing IL information and resources referrals. I give the person the informatin 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 cntact, the IL specialist that is monitoring might not be the one that delivers all the services, you might get Colleen for attendant management, Bill Shelden 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 changes anyway, because we are on a permenent 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 underthat 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 arrangments, 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 h 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 relationaship.

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 youhave got to do it, so I believe what yousaid, that people must have professional behaviour...
usa3a.1

Jim Tuscher

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 yousaid, OPD or OTJ, 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 thing ....shuffle, 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 youget 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 upp 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 2 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

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

END

What that means is basically we work with persons in terms of direct services, pretty muchon 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 an 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 coonsultation, 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 interupt. 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, whocould fill the slot.

JE: Specialist, to what extent

IL specialist, doing the same kind of the basicallyas 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 backgound 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 oftenhappens, we know of other centres where they have done this and it does not work. You have to have someone, too, that has the backgound 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 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 attedant. 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 moore referrals, we are real surprised and happy and gratified because it is happening. It has a lot to do with the community educaton 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. Aother 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

END

St Louis is a difficult city to work in because it is conservative and conventional. It takes a long time to get things done here, the state of Missouri is a bit like that. What brought us together was a number of issues, mainly the transportation issue. In 1974 we put together a very loose coalition task-force, comprising of a number of different disability organisations, like the Easter Seal Society, Muscular Dystrophy Group and the Arthritis Foundation along with some advocacy groups run by disabled people - that issue drew us together. It was a controversial issue, and we had a lot of opposition from the press - opposition from private businesses and obviously, opposition from the transit companies, but finally we swung the press over to our side, and when they came out with some editorials in support of our position, then things started going really well. Other groups started joining us, and we went from strength to strength, won our case with the buses and grew.

We are still a loose group and St Louis is not a good example of what can be done. There are a lot more other cities that have been much more successful, like Chicago, Berkeley is because firstly it is a smaller community that reaches out over the Bay Area, and they have been around a long time. They have also been successful in attracting people from all over the country. It is a kind of utopia.

JE: That is why I feel it is important to see other places and centres, because Berkeley is the cream, and is not representative of the rest of the country

It is mind boggling in that it is so large. They claim to have a staff of about 180. I mean that is large when you compare it with other ILPs that operate with a staff of 15-20 people.

This country has a great many problems, and the disabled community is very fragmented. A good example of this is the American Disabled Freedom Rally going across the country right now. By the time it reaches Washington it will have almost broken down, which is sad. In May we had another rally, one in Washington and one in Chicago. I went to the one in Chicago and we had a turnout of about 2000 which was good, considering it was concentrating on Chicago and its surrounding area. In Washington they only had 2000 and that was supposed to cover the rest of the country - when you talk about rallies in Washington, you are talking about 50-200,000 people. The farmers had a rally and had 100,000 people there and held up traffic for about a week, the Gay Movement had about 50.000 at a rally there. Groups trying to get something accomplished inn Washington really have to turn out a lot of people, and the disabled have not been able to get that kind of support, but it is very difficult getting people together on certain issues and to go out into the streets and demonstrate. I think this principle applies to the local level on a number of different issues. The IL movement has helped us more than anything else. Right now we are trying to put together a national coalition of ILPs, which would consist of 160 or 170 programmes in this country, and it would be the voice in Washington. We are looking at this coalition being privately funded, so it is not controlled at all by any federal money, and it would be a voice for all the ILPs as well as a communication device, so that we could communicate with each other. Since about Nov 79, do you know the whole history of how we have been funded

JE: I know the federal government came in in 79 and helped out 10 CILs

We are one of the original 10

JE: Who are the others

New York, Chicago, Maine, some were broken down into cities, in the rural areas, like in Maine, they gave the money to the state, and the state gave it out to two or three rural programmes, State of Washington, Massachusetts, Kansas, N. Carolina, S. Carolina, Rhode Island.

JE: So all the others had to find their funding through other sources

Well, it is called Title 7, Title 7 funds come through the rehab act, and the new one is about 5 years, at $200,000 a year, which is not a whole lot of money, but it gets you going. There are two funding cycles in each year, so in 79 they funded those, they approved them in mid Sept. and we got our money at end of Sept., it went very fast, we were ready to do it, we had the staff, and if we did not have the staff, we knew where to go to get staff. A lot had trouble getting going so they did not get established till the following March. But then again in April of 80 and August of 80 they funded more and at that point they had 125, they funded something like 85, then in 81 they funded some more, they just had a review process in August, 70 applications to fund 15. What they are trying to do is fund one in each state, they have to do that, but it is not real good. What is happening is that the second round of funding there is a breakdown in the whole IL movement in my opinion, they funded a lot of programmes politically, because states wanted some money, they funded a lot of programmes which are not philosophically ILPs, they are being run by non disabled people, who are strong bureaucrats, who really don't have a good understanding of the IL concept. I think that could be very harmful to us if we are not very careful especially in the formation of the national coalition. In fact we are starting to see a fight develop over the membership guidelines. Judy Heumann and I are working on them, I am the Chairperson of this group and Judy is the Vice Chairperson. The membership thing is going to be a real battle because we have seen some people like Good Will are funded with Ohio money

JE: Who are they

Good Will Industries is a traditional sheltered workshops. They see this IL money so what they do is they go out and hire a disabled person here and there and put together an ILP, that is scarey for me, those things worry us, we are not sure what is going to happen. If they get enough control, then those of us who are staffed by disabled people, we are going to lose our control, so that fight is going to occur in our first national meeting, probably next spring. Everybody is going to have to come up with their own money, it is going to be difficult, it has taken us over a year and a half to put this thing together, just to the point where we have got some bye laws, we have just mailed out all the bye laws to everybody to review. But we feel the coalition is extremely valuable

JE: So what do you plan to do between now and the spring

I think we are in a strong position. I guess what really scared me is, there is Good Will Industries in St. Louis, just a couple of blocks from here, we were looking for another IL specialist to hire and there was a woman who applied from Good Will and she was going to take the job and she turned it down, because they offered her more than we could offer, and I am scared to think that they might try to go for something in the IL movement, all they have to do is to stick it in their own budget, they are large enough, with lots of money, to call her the IL co-ordinator or whatever, so that in order to get federal money, all they have to say is we have had a programme for a year. They actually serve more physically disabled people than anybody else in the state, but you have to look at the service they deliver and the service we deliver. What they do is they put people onto a kind of assembly line situation, workshop, where they are folding clothes and those kinds of things, and then call it job development. The service we run is a very long detailed process so you do not work with as many people.

For example if a counsellor from voc rehab, one counsellor will carry maybe 175, 200 people onn a case level, but one of our IL specialists will carry maybe 25 people. So the numbers is a big difference, but the amount of time you put in with each individual is very expensive. The meeting you were supposed to go to is going to be held in November, and we are hoping to get a lot of these IL representatives there, and we can hold some kind of discussion about bye laws, where to hold the spring meeting ... Right now we want to get people to respond to the bye laws, back to the bye laws committee, the Chairperson is in Chicago

JE: Do you find it difficult communication wise in the states

It is a little difficult, mainly by telephone, but that even gets costly. It is hard to get together. Judy travels a lot, I travel some, but not as much as she does. Since she has to go across country, sometimes we try to arrange our meetings around Judy and those California people, so they can stop off, try to work it out that way. We had a meeting in March here in St Louis, the ten original programmes, along with Judy Heumann and Lex Freeman from Houston, and it has taken us that long to get the bye laws out and it is only because you are trying to carry on running the operation as well as trying to get the byelaws out, as well as trying to deal with conference calls, work out things that way, it just takes a long time

JE: Are Reagan's cuts going to affect the budget you receive

No. Not this time. Reagan's plan was to put everything into block grants, the money then goes to the state, they have got to put together a social service block grant and they are going to lob us into it. That means our money will be lumped into this pile of other money, and 25% of it will be taken away and serve rehab adoption agencies, child abuse centres. Disability programmes will be out there competing against other programmes.
It is ridiculous. A fight really took place in Congress, I think the senator who led the fight was Senator Noel Lanker, from Mass. He has a disabled son, Downs Syndrome, and he was mainly fighting for the Developmental Disabilities Act, to keep that funded, but he was also fighting for other categorical programmes, those programmes that are actually administered and funded from specific agencies at federal level and IL was under rehab. So, through Leiker, through Senator Tom Hagan, Missouri, and some others we saved the programme. IL is a small budget, it is $18M for 82, it only goes to $19.5M in 83 and 84, so it has been saved at the moment. Now the money has been allocated for those years to 84. Now Ronald Reagan has just said that he is going to come back and push again for block grants and he will probably do that right after the State of the Union address, which he gives in January every year, this glorious speech, tells you what he is going to do. So we have to prepare right now. I suppose 83 and 84 it will get rougher than 82, because what he has done is he has promised all kind of stuff to defence, but he has also promised all his citizens that he is going to give us all these tax cuts, he has got this huge gap that he has got to fill, and he is going to go at social service programmes, education, universities are really ... so we don't know what is going to happen

JE: Are you able to function on the money you receive at the moment, or do you need other sources

It covers maybe 45% of our work. Our budget is almost $0.5M

JE: So where do you find the rest

I spend maybe 70% of my time fundraising. We find it through private sources, we have got another federal grant, through the community services admin, to serve the urban disabled poor and those in institutions. We are now trying to get another federal grant in this county, there is a difference between the city and the county, so you serve a lot of rural areas, so we want to serve that area. Then the rest of the money comes from private contributions. For example in October we start a major fund raising campaign, we are going to be doing everything from major letter writing campaign to businesses ...

JE: Do many businesses support you at the moment

They are starting to. We have to build some credibility in the community, so people know who we are and we have been established. We have done this over several years .... you must see the video film, made by the vice president of our board .... We made it originally to take it to congress, we use it also for educational purposes. We take it to organisations, we took it the other night to a businessmen's organisation, we give a talk along with the film. We have been inviting benefactors to see the film, like we had three on Thursday, and all of them walked out saying they were going to increase their contributions towards us, so instead of giving us $5000 a year, it is $10,000. That has been very successful. The Mayor of St Louis is coming in next week to see it, we are constantly showing this video tape, trying to get it out to the community, because it seems to deliver the message in the most effective way, you never show it without a discussion. It actually interviews four people who we served here and they talk about how it has helped them. One person has lived in hospital for ten years, she is a quad, and she moved out today into her own apartment, she could not do a thing for herself, she could not even feed herself. The film shows those kinds of things. So that is a good tool, we had it all donated to us. The company who made the film donated their time, it would have cost us around $10,000

JE: When did it originally start

We started this organisation in 1970, till 1979 we were in operation with three people, Colleen my wife, she now works two days a week, but we have a daughter, and a secretary. But when we got the grant, we expanded and now we have 13 or 14. Jim joined us .... Nancy, ... They were all taking a chance, Jim left a job and came here. We pay a comparable salary.

JE: What are the biggest problems

We have a lot of new housing. We met with the St Louis Housing Authority, they are responsible for public housing in the county, until we talked with them they were building accessible housing and filling it with non disabled people, so we talked with them and they are going to build more accessible housing as well as making sure that accessible housing is set aside for disabled people. We have a new building commission in the city of St Louis, who is just super turned on to accessibility, he has been pushing for it for years but he has been in Cincinatti until recently. We have a Mayor who is starting to enforce the building codes requiring that private development includes a certain percentage of accessible housing, we have laws that say that but were violated until just recently, we are starting to see more enforcement. For example, there is an old building going to be renovated down town, it is going to cost about $18M, and he is requiring the developer to make the entire building accessible, every bathroom, every closet, office, absolutely everything. The Mayor lets out leaks to us, I think he wants those tobecome public, sothe developers know there is a movement to stop violating the building codes. So you need laws. Our approach, ... the boulevard, there is 83 apartments for disabled people, our idea originally was to build that because there was a need for housing, but that did not solve the problem

JE: How do you feel about that now

No way I like it, there are lots and lots of problems. That does not mean it has not done any good, it has. there are a lot of people living there, who gained a lot of success and are doing very well, but I think they would have been able to achieve those same successes by living in standard apartments if they had been available, so hopefully we won't have tobuild any more of those. Psychologically it is much better for disabled people or anybody to live in ordinary housing, the minute you segregate you run into all kinds of sociological problems. Housing is a tremendous need here and attendants is a big problem. that is probably the biggest problem. Missouri still does not have a law where funds are set aside for an attendant. For instance, if you moved to Missouri and you did not have ajob, there are no monies available for you to hire an attendant. If you get a job and are making $15,000 a year, you need to pay $5,000 for an attendant, that is not very good. We hopefully have a law that is just passed, although it is not funded yet, hopefully there will be funds set aside for attendant services

JE: So how do people manage now

Voc rehab in Missouri has an 18 month extended evaluation, so what you try to do is to get disabled people into this, so for 18 months Voc rehab has to pay for their attendants, hopefully by that time there will be a law passed ....

(Interview continued over........

JE: You could not really getthrough to anybody, the organisation is so large. It is really interesting hearing you talking about the problems in St. Louis, because they are similar to those in England, like housing. In California they don't seem to be problems, they have got great libraries of accommodation available, which would be unheard of in England, even in 20 years time I think

I don't know what kind of funding you are going to go for

JE: In England the funding is, you talk about fragmentation, what the government provides comes from about four or five different agencies, DHSS, Social Services, Health Authorities etc., after that it is charitable income, raising it from businesses ...

What is good about this country is that you can dupe the Federal Government, if you really get good at it, there are books out like the Federal Catalogue, which... you can go through these books and find all kinds of funding sources, for example, community services administration, which serves poverty programmes, they funded a lot of our community action agencies in the '60s, which were working mainly with poor blacks, so we heard about them and we went to our congressman, Richard Geffard, we talked to him about some funding sources and he said well, why don't we check out the community services administration. At first we have to ...... obviously the disabled fit in the poor category very easily, we also pointed out that the disabled are equally distributed throughout every section of the community, so you have as many living in the ghetto areas, in the poor black areas as you do in the affluent areas, so we went up for a grant and we got a grant and we are on the second year now of that .... now Reagan is planning to cut out that agency, but he is going to stick them into the department of education so their funding may still be available, but if you look around, you can do this in England now, there might be some funding sources that youare not aware of, that might be interested in funding a programme

JE: Yes, we have looked into that, there are a few possibilities of something like that, but it is not easy

The other thing is that there are private foundations in this country who like to give out matches, in other words, if you can get $100,000 from the federal government, then the foundation will give youanother $100,000, if it is like a research project or a pilot project

JE: I think that is a difference between the States and England, there is more money available, it is very difficult getting money like that to that extent anyway in Great Britain

Are there any humanitarian charities

JE: There is this book you can get, it is a library of all the trusts available and some support medical ... you can rig out something and try and get money out of them, but until you have got a building then nobody wants to support it and that is the problem, just getting a place sorted out, we are just trying to find a house for people to live in and that is what is difficult, houses in the Southampton area. The project I am involved in is Project 81, but there are lots of people who want to do something similar. The idea is to try and create situations ... in England, if you are not married, if you do noot have a family to look after you, if you do not have the money to pay for a care attendant and you do not have your own home, then there is no choice, you are in a hospital or in an institution of some kind, so what we are trying to create is a place where we can just ... individual people, not married people, can just go out and live by themselves without any of those prerequisites. We are also trying to set up a model where people can live in a house together, not a group living ... at the moment we are just going for one disabled person living in a house with two people and two people living in a house with four people and things like that, trying to create a model where it can happen anywhere else in ... The funding on the housing side is going to come from an agency called the Housing Corporation, that funds special projects, housing projects for one parent families whatever ... that is the sort of money you can get, because it is on the open market, our difficulty is actually buying a property in as fast a time as somebody else who actually has the money available, it is impossible, it is a real problem and we can't rent accommodation because the majority of accommodation is not adaptable or it is up steps. It is only the very modern bungalows where the houses are on the ground level.

There is nobody to turn to

JE: No, we are on totally new territory, there is a thing called the Grove Road Scheme, Ken Davies, Gini met them on her travels, Ken and Maggie Davies, they are two quads, who set up two flats, with other quads in, and upstairs they had what was known as helping families. They rented out the accommodation upstairs to those people who would help them out with the care ... those quads are very independent, they can get in and out of bed themselves and drive cars and they were near as independent as you can get, it could not be something you could base a model on, so that is ... the only other situation is an organisation called SHAD and this guy is CP and he and four people from an organisation called Community Service Volunteers and they do various commuunity orientated projects, he had four of these people living withhim, and some got him up, some put him to bed and others went and did other community projects during the daytime. So we have got no one toturn to, we have to convince the professionals, the social services, the AHA that it is going to work. That isour big problem, everyone is in support of it, because everybody realises the economic sense of it, it is going to cost a third of what some one is paying in hospital or residential home, is not more in a hospital in fact

We have been breaking down some figures, we broke down the cost of a person living in hospital and a person living in the community. The cost of living in a hospital is $44,000 a year, for living in the community is about $13,000 ... would anything like that from us help you, if they look at the US

JE: I think it would be helpful, just the comparison, even then we still have to prove the case it is going to work, we have to get a place

Any place, it does not really matter where you live, if you prove it is economically wiser to get people out intothecommunity. The argument economically is so strong that the humane issue is rather put aside. If we would help we would like to, we will pack up all this information for you

JE: I think that could be helpful

We are starting to serve more people in the community, people who are very poor, and we are trying to put those figures together on each one of them, like over a year's period, course that will take a year, even longer, but Ithink that information will be extremely valuable, even in another country. It only happens if disabled people get together, because everybody assumes that we are sick, that we need a certain ... and until the ... see us .... that is the whole thing about independent living, we see the people come in here, you can sit and talk to tthem all day long, but you bring people in here and they will hang around for a while

END

INTERVIEW STARTS HERE!

Assertive able bodied women are not regarded highly in this part of the country, so disabled assertive women .. forget it, and I am getting increasingly frustrated for my friends

It has to come, like for us, we need to do something for the St. Louis area, like some of the things they do in California, there is just no way, we need an audience, what I intend doing is talking to a few people I know, that is the way to do it ...... goes on about a series of films about sex ..... goes on about desensitisation, hit them with every word they were never allowed to use ... Rosalie Osney believes that people are too sophisticated for that and I think that maybe some are too sophisticated, but there are some others ... There is two films been made, which I hope I can see, people with CP talking about their feelings as children and the kind of taboos that they were exposed to by their parents, then the second film is the same people talking about their experiences as adults

...... continued...

see over..

We have a guy who is, who went up to a girl, the guy is disabled, with head injury, he is in a motorised wheelchair, he goes up to this girl, who is very cute, very petite, she had a brain tumour when she was 18, so she is, she is just really a very cute looking girl, looked at her, and says, I want you to be my woman. There is another person who went up to her and said things a little more strongly. The point is, I know the guy personally, what he is trying to do is just assert himself, the other problem is those girls have absolutely no idea how to relate to him, feel about it, they said they get terribly frightened and they feel this guy is some kind of a crazy sexual pervert, and before you know it the whole thing starts to just snowball and other people start talking .. it happens a lot with people who have been disabled since birth, but it happens with people who have not been disabled since birth

Gini: Because they miss that stage of development, you know sitting round the corner reading dirty books, and all that stuff young people do

Or they did get caught doing it and got told it was really bad

I think the problem is even more difficult for women

Gini: I think of St Michaels school for cripples, when they menstruate they have to go stay home, what does that put in their minds. They will take care of them when their bowels stop, but they won't take care of this.

P.T.O.

Colleen Starcroft/Care Attendants

JE: Max said we should talk to you about care attendants. Getting the money to pay for them. We can't base anything in England on California or the university experiences, we need something more grass roots

There is a number of things. First of all we don't have any decent attendant legislation in this state to pay for physical assistance. We tried and there has been a piece of legislation through this last legislature that does make some money available for physical assistance, but it is not enough and it goes through the state Medicaid system, it may be there will be enough for a lot of lower level injuries, you may be able to get three hours a day, but you can't get the extra. So there is a number of ways of working this. One is we put together an advocacy test for young people that have something to benefit by getting some things passed by the state, like attendant legislation, one of the things they want to work on is working with our legislators to either get that bill amended or to get something better, because it is really a sad situation. The other side of it is, we have to make do with what we have right now, we have people who want to live independently anyway, so we are doing different kinds of things. There is a state funded agency in St. Louis that is called the Regional Centre for the Developmentally Disabled. Everybody makes up their own mind what they want to do, we say..."Do you want to live at home?...Do you want to move out and get your own place?...Do you want to have an attendant live with you?... Do you want to have an attendant who comes and goes?...What is it that you want to do? That is the first thing, because a lot of people don't really know... and very soon they are going,"So tell me what I am supposed to do?" so we say, "No! This is for you to make this decision".. and I always talk about this when I talk about attendants, because it is very easy for somebody to become dependent on some one else to get their physical assistance for them. So we throw it back to the individual, we say, "YOU decide what you want to do, when you come to a decision that you are comfortable with, then we can start working in the direction".

What we do is we talk about what is in their neighbourhood community that might be a possible source of people;- who are unemployed, or people who are maybe Do Gooders, or students, whatever. Are there some local agencies that place people? That find jobs for people. What do you have to work with that is already there so you don't have to go out and create something else? And that is everything like church groups, highschools... Some people talk about advertising in the newspaper but you can do that if you are really skilled at screening calls and interviewing, but if I am dealing with some one who has no experience, I suggest that they don't try the newspaper. If you use the newspaper you get a lot of response, but the people we are dealing with are so desperate to get help .... you can progress to that later on, and we present it as an option, but we really say, "Don't". "Stay away from that until you have a little bit more experience, because you don't know who is coming in your house". Then we talk to people about the kinds of things that you ask an individual, the kinds of things that you are looking for, and I have every body write up a Job Description. It puts an individual in the position of having to organise what your needs are and really giving this some serious thought, because people living with parents or in an institution. They take things that could easily be missed for granted. They list those things and do a job description.

The other reason I encourage people to do this is that, during the interview, the interview is divided in two parts. The first part is a time for discussion when you get the person to talk to you. You get them to tell you about themselves, the kind of questions you ask get them to start talking to you, and then, at the end of that, (that can go 5 min. to 15 min. depending on how talkative you are and how talkative they are), you then start talking about what this job is and details. My feeling is there is no reason to sit there and tell somebody what your bowel routine is and what your bladder routine is and how you go about it if you have got no desire at all to hire this person. So what I tell people is, if after the first part of the interview, you don't feel good about this person, you then say, "I will let you know what I am going to do",.. and get rid of them. But if you think the person might be a good possibility, then you go into the second part, which is where you really explain. You pull out your job description and go through it and say, "If there are any questions you can ask them?" The thing about that is if they see this job description and they agree to take the job, it is in black and white what they have agreed to do, and if problems come up at a later point in the relationship, they can relate back and say, "Well you know you agreed to provide this service, I am paying you this amount of money...(which is also on the job description)... you agreed to work these hours and you are not doing that and I am going to have to let you go, or we need to work something out here". , But it is another handle for them. It is also useful for people who have difficulty in communicating, it makes certain things clear

JE: Do you have guidelines to help them?

Unfortunately, because I am only there two days a week, the guidelines are in my head, but there are three or four on the market. We use an evaluation form too. This sets out the maximum time it can take for certain functions, we encourage people to use the evaluation form and job description. Like a contract, but use the evaluation form as a delineation of all the things the attendant will do, but we also encourage more than one attendant, so one attendant may not be doing bladder care, but another attendant will be...

Gini: I know people who use 3 or 4

Ma..... has 10 aweek. She likes lots of people coming in and out the house. It is her preference

Gini: A different high school kid every day after school, another one after dinner, and people throughout the weekends, and older women in the morning

The nice thing about having as many as you can handle is that you don't burn out one, that's a real problem with attendants

Gini: Some people can deal only with one person

I do tell people, especially initially, that it does not make any sense to only think of having one attendant because initially they may have problems, if somebody has never dealt with attendants before, their first few experiences are not gong to be that great. You can sit and talk it over, read books and everything, but until you have actually been through a couple of relationships you don't have any real stability there, so I tell people that you have got to think in terms of getting at least two, one can be a main attendant, one can be a backup, if that is the way you want it to go, or you can split up the load so that you can rotate, they get every other weekend off, so I think also from my experience as a physical assistant, I wear a white hat, in the office I wear an attendant hat, it is because you can burn a person out

Gini: One thing that is extremely valuable are former attendants, who leave to get married, go to school, if you keep in touch with them, make a friend of them, keep their addresses, in an emergency I have seen people come from one end of a big city to another to take care of somebody and stay for a weekend, if they have established a good relationship. You must get this relationship to make people want to do what you are asking them to do

When I am working with somebody I spend a lot of time with them and so I pick up things from their personality. If I pick up that this is a person who has a tendency to be demanding, I call it to their attention and I let them know....there is a way that you have to relate to these people. They (PCA) can turn right around and walk right out the door, so you have to be sensitive, you have to tell them when they are doing a good job, compliment them, be thoughtful, take them out for a hamburger, do something nice ...

After they have got it all sorted out, job descriptions etc. The next thing we do is we talk about the problems that come up.

JE: Have you found the role playing exercise to be helpful?

Well at first they laugh and joke, but I play it real straight, they sober up quick, and I used to think maybe they take it as trite or silly, so I always ask them, do you think it is helpful, and they say oh yes, I never thought you would ask me this, or that. And I assume different personalities, based on my experience with attendants. At some point in the discussion we have to talk about how much money they have got, you have to sit down and figure out a budget, how much of their money goes to each different thing, how much is going to be left over for physical assistance, and then you have to start scrapping around with whatever you have got. If congress is not going to pass a law for physical assistance natinwide, you have got to scrap it all together any way you can.

JE: Does Medicaid help out in any way?

This state has some money through what is called Home .... Chore Service, you have to be certified, to have a certain income level which is low, and you have to get on the waiting list, so there is different things, so the source of public money is not great, so one thing that some people are doing, there are several, one that is working is to have someone live in your apartment, room and board and some spending money. Another one is to have people who live in the neighbourhood and just come in in the morning and maybe come back at night and you share your dinner with them and also some extra money, or you can pay them by the hour at minimum, I don't think it is the greatest way to go, but there are some people who will work for minimum wage. Our minimum wage is $3.35 an hour,so that is peanuts and it is not easy to get somebody. Another thing is that people are sharing attendants. They will get one, and they need to get up at a certain hour ...

Gini: It is rare and I have never seen it work, cross that off

Usually five or six people all like the same attendant

Let me clarify, the deal of sharing an attendant is where the people are living in a building and there are several people in that building who want attendants, so the attendant can go from apartment to apartment, but again that is something they work out

I've never seen it work

Gini: This is one of those picture book disabled, all disabled people just sitting like little dolls in a ...

The reason it does not work is that even in a traditional programme like CP, where it has been traditionally staffed, hired by an outside person, and then staff are responsible for providing physical assistance to seven people in the same building, in the same apartment, where apartments are right up the middle of the building, or next to the elevators ... those people left those programmes and went into their own and wanted nothing to do with the attendant that somebody else down the road had

Gini: That is Fokus system, and if they start not liking ..... you have to make your own person to person relationship

There are people who I won't do PCA for because I can't stand them, but there are people who I love and would do anything for, but they can't stand me either

JE: Could you send me some of those evaluation books. What about the problem of flexibility of attendants. Like getting to bed when you really want ...

We have the same kinds of problems, it depends on your attendant, it depends on whether the person lives with you or not, I talk with people about being flexible, your attendant might want to go out late, you might have to agree, since they are going to be out till 2 am, you might go to bedearly one night, to give your attendant some help. If your attendant lives in, or maybe if your attendant is a single person - would not mind spending a night,so that when you come in late and ..the other thing is, if it is going to become a regular habit, maybe you can work it out with whoever you are going to be out with. The thing about having a number of attendants is a good idea, because the attendants do burn out, by and large, if you have an attendant who is a busy person, or a student, they are not going to stay around that long, because being an attendant is not mind challenging work and it certainly is not a way to get around in the world, maybe for you but it is not for the attendant, so if you have those kind of people you have to expect that your turnover is going to be pretty high. The other thing that I was opposed to initially but we are trying it out to see how it works, is to utilise people who have a disability themselves as attendants, but could be attendants, and just see what happens

Gini: Don McGuin had a CP for years who was totally unemployed by anybody else and she could get her out of a rocking bed and wheelchair, and it was absoolutely incredible how .... and I have also seen blind and wheelchairs a number of times, and another thing I have seen is people who are mentally ill, you go to the chaplain of the mental hospital, and ask for somebody stable who is going out with nowhere to go, one girl I knew just got herself supplied for a lifetime with attendants like that, but you have to watch that, but you have to know the source, you know the chaplain, this is what is important, get to know the sources, know somebody at the school, high up

The other thing about living in, you have subsidised housing in England don't you, well, one thing that is a workable deal is there is a woman who moved into an apartment and the apartment is subsidised so she only pays 25% of her income, minus any disability related expenses, so her rent is about $90 a month, in an apartment that goes for about $325, so the government pays the rest, but now she has something to offer, she has an apartment with an extra bedroom that is a nice apartment, so she has a woman who had a stroke on one side who is living with her in exchange for room and board, and the woman who has paralysis on one side is also looking for another job, the woman she is living with is a quad and the woman who has the paralysis ... they are right now working out getting up and going to bed at night, then she is going to look for another job in the daytime, as is the woman who is in a wheelchair, so they are both going to try and bring in some money, but even if neither one of them can they have SSI and they can make it. The two of them sharing expenses and the one has the extra bedroom that the other one needs, it is a workable deal, if they get along well. In the Independence Centre, which Gini sits on the board of, is a place that works with people who have mental health problems and their executive director and their board is very interested in getting involved with finding placement as attendants for some people

JE: There's a couple of pilot schemes like that going on in England at the moment, using people with mental difficulties to help out

Another thing that I have picked up that some disabled people don't like, a person who needs an attendant, you say why don't you consider hiring a retarded person, no way. Then I have to talk to them and say, listen there is a prejudice there, we are talking about a person who has something to offer you and their disability is not something that is going to inconvenience you, in fact it could be helpful, and why don't you just consider it, I'm not saying you have to do it, but if a person has no money, you have to think of the options, and I say this is not the only thing that you will be able to do, but you have got to think about it, some of them say yes, some say no, I'll live with my parents and put up with their nonsense, or I'll move out with a retarded person, so it just depends what each person wants to do

There seems to be some controversy in this country about whether or not an Independent Living Programme or any kind of an Agency that serves the disabled ought to find attendants and screen them and train them and have them available for disabled people to come and get. We are not clear on what way to go here. When we first started out we had an attendant training programme, I argued with the experts and said, you've gotta train attendants otherwise they are not going to last, and they said you are crazy, if you train them ...

Otto: Was it your professional background that made you think this

What did make me think that, maybe it was, I think one of the things I thought was there is so many different techniques like changing catheters and bowel routines and all this stuff, my thought was, if you bring a person in cold turkey and say OK you've gotta do my bowel routine, they are going to go ... I can't do this, but if somebody takes them aside and sits them down and says, let me tell you what this is so you don't get scared out of your mind. I thought this would work, well what happened was we had a couple of training sessions and we trained these people and I did the training, none of them wanted to be attendants after that, none of them

Otto: I spent a year writing a thesis about training attendants. I believe it is the professional background, you cannot believe that people without any qualifications are able to do this, while you have studied for years

Gini: But they can, they can do it better than you can

That's what happened. So what we ended up doing was, one day I said to Max, listen, "What are we doing?".... we stopped it. When I go round the country, and I hear people saying we have gotta train attendants, and I am sitting there saying, we did that, it does not work, and they are going... "Well maybe what you need to do is ..." Do you know what they are doing in Houston, I don't know if they are still doing it, they have gotten a local junior college to give credits to people who go through a 14 hour course in how to be an attendant, the centre there goes and teaches the course and the people who sit on the course get certified! I said well first of all it does not work, we tried it, TRAIN THE DISABLED PEOPLE, let them worry about it, it is their responsibility. If you train the attendants, they become dependent on you. I said the big thing is if you put somebody through a course, you give them a certificate and they come out, "I'm certified to be an attendant", they are going to want to work full time and they are going to want to be paid a decent salary...because they have got this training. And I said even if you teach them in this course that you might get three hours here and four hours there, when you get out, if the disabled people aren't trained what difference does it make, because they have to know how.....

If the attendant has been trained they are going to come in and say, now I know how to change a catheter and we are going to do it this way. The other thing that happens, we did this training programme and at the same time as we were training disabled people, I was spending hours training disabled people, after all this was done and the disabled people were trained and it was time for them to go out and find their attendants, I had said to them we have trained some people as attendants and you could call there and get some names, you could interview them yourself, so what did they do, they called, were given a name etc. and then they would come and say I can't find an attendant, have you got any attendants, and they are sitting floundering around because they don't have any attendants, and I said, I told these people it is their responsibility, they have had the training, they know how to find their attendants, they have to go out and swim. So Max said, what are you going to do, and I said, I am going to tell them to go and find their own attendants, I don't have any attendants, so next phone call came in I said I'm sorry, I haven't got anybody, you will have to find your own attendants, you know there were two people with severe CP, both of them called me inside of a week and said, have you got any attendants for me, I said, no, sorry, we are not even doing that any more, inside of two weeks, both of them had attendants. I thought, well, that is the end of that argument, you just train them (the disabled) and let them go off and do it

Gini: You should not be training them, the disabled it should be done at the rehab. centre. That is what they are doing at Woodrow Wilson

They don't do that here in St. Louis. They don't know the first thing. Some people just have good common sense. It doesn't seem to be just whether you have a disability since birth or a disability that occurs later in life. Lucy has found it helpful, she has some questions we are going to talk over, but the smart thing about Lucy is, and people like her, if they know they have a problem they will go to someone who they know can help figure it out, and there is a lot of people who won't do that, but they keep coming back to you saying OK I've got this problem, are you going to solve it. My approach is, no, that's your job, you solve it, and they do. If they want to make it they will do it. I had a real hassle with a woman on our staff who is a dynamite woman, she is sharp, she is everything, but she felt that this woman who is a quad maybe in her interview with her attendant did not make a few points clear, she had the attendant come back and she sat down with the attendant and with this disabled woman and the three of them talked and it turns out that this woman had made her points clear, so when the people left I said to her listen we have got to talk about something, if you think that she did not make her point clear to her attendant, you should talk to her about it and explain what your concerns are, so that she can then go back and do it herself, she said yes but I don't think she really knew how to do it, so I said where did you end up, she said well she made her point clear, and I said see when she is finished with us we are going, we are supportive, but she has to deal with things herself, it is her responsibility, and if you have that attendant come in and sit down with you, you are then seen as an authoritive figure by that attendant,and you totally steal her thunder, you sitting there as a representative of this big organisation, and that poor little crippled lady, and that attendant is going to relate to you. And I said, the problem is you had to pick the office next to mine to do it, and I heard you ... The whole point of IL is that people come to an IL programme because they are expecting something different and some of them come because they want to go out and do their own thing, some of them come because they want us to take care of them, but to everybody you say the same thing, OK you want to live independently, this is your life, you better start making your own decisions, we will feed you all kinds of information, we will throw options, alternatives at you, we will let you use our phones, we will listen to see how you say things, tell you how you can say things better the next time, but it is your life, you have got to live it. When the day comes that you have got everything out of us you need, when you go out, that is it, you can call us back for this and that, but you are on your own, you have got to be ready for that, and there are people who frankly can't deal with it, there's people who just never come back, they may later on, but they are just not at that point yet.

We lay out all the things we can do, and we say what would you like to work on first, you make a list of the things you want to do first, second, third, if they stop coming, we say fine, if they call three months later and say I'd like to come in we say fine. We try not to be in a position to judge people, we don't try to tell them, "You have to work, you have to go to school, you have to this or that"... we just ask what it is they want, and often they will say I want this and this, and after working with us for a while they will say, "Oh, I think I might like to do this too".

JE: What about people who have spent a long time in institutions

This lady I have been telling you about who is quad and has got this attendant, she just moved into her apartment yesterday, she has been living in the county hospital for ten years, her name is Mary, she has common sense, but for years she did not care, everything was done for her, her family until last week said she was crazy, told her she should not leave the hospital, she had no right to leave the hospital, so with her we had to start from basics

Gini: I would always use one example, a spina bifida baby who was abandoned by the mother and she was there for 20 years in hospital, until one therapist, said wouldn't you like to move out, and she taught her everything, took her shopping ...

END

The Whole Person is a voluntary organisation which started about three years ago. A man with MS and his wife basically got it going and then gradually other people joined in. They have been doing voluntary projects for some time. They had a panel, speakers bureau, of disabled people, one group who was physically disabled and the other group has experienced mental disabilities and they were going out to schools and churches and then they started working on some other things such as incorporating disabled people in things such as rehab. team training, and other examples. This all started three years ago. It is all voluntary, there is no one being paid, but Paul Levy, who is president, was basically working full time for nothing from his home. He also started to put together a newsletter, and I think he probably gathered together every name he could find in Kansas City and put it on the mailing list originally, got the board together, incorporated, basically got the word around via the newsletter and it still comes out every other month. It is really well written. That was beginnings, then they got into some Section 504, they filed a suit against the city, and they filed a suit against the University of Missouri, Kansas City, and they filed a suit against one other group, who I can't recall. They have won every suit, they have all been found non compliant and they have made corrections, though not ideal corrections, at least the University is still awfully inaccessible, they are trying. They have one attorney working with them and I have never met the man, I don't know if he is still acting, I know he is still a member of the organisation. They started collecting dues, so there was a membership structure, membership elects the board. That is pretty much what was going on before they applied for a Title 7 grant to set up a CIL. At that time they also started to do peer counselling and they started a trauma line, which is a 24 hour crisis intervention programme and they have disabled people that will respond if a disabled person calls in on the line. It is the same number as Human Rescue, which is a 24 hour crisis intervention service, so it is a kind of offshoot of it for the disabled person. That is working very well.

Then they have also done some projects regarding accessibility. The Whole Person advised the Higham Regency on their designs. It is still our most accessible hotel. I don't think there has been a great deal of technical assistance given except on very very large projects like the Higham, that was obvious, there was going to be this luxury hotel and there was absolutely no reason for not seeking some disabled individuals advice on accessibility, so that went very well. They got the grant for the Centre last September from Rehab. Services Admin., a whole $200,000

JE: Is that enough

That is plenty. Right now it is plenty. They did not have to go through the State Rehab. Agency because the State of Missouri chose not to apply ..... and I think our centre is pretty rare because of that, there are only a total of five that have direct grants from Washington, they don't have to go through a State agency

JE: Do you know the other ones

.... Lawrence, Kansas, Vibernum, Missouri ... I think the League of Human Dignity, Nebraska. The others are in other regions and I just don't know what they are. It has been very nice for me, I came from a CIL in Massachusetts, where we did have contracts with our state agency and it just made things much more complicated than they needed to be. I see it as a waste of time and energy. The Mass. Rehab. Agency as far as State agencies go is probably a very good one, because they do serve the most severely disabled population. But what I do find in Kansas and Missouri is that that is true, people who would normally be accepted as clients in Mass. are 'too severely disabled' in Missouri and Kansasand that is really crazy. They also have better support services there. Our centre has been operational since mid January, our staff is together, our programme is together, we are getting a lot of referrals, but now I see my job as the Project Director as really working on the support services.

JE: How many people do you have on the staff

Total. 7 full time paid, 6 full time summer employees doing a housing survey and we have one full time volunteer volunteer corps leader and one part time volunteer volunteer assistant corps leader. So there are really only 7 of us, though we might have a new contract with another private non profit who may be getting a 504 training and technical assistance grant. If they get that grant that will expand our staff, we will be part of the training and technical assistance programme. Right now I like it small

JE: You don't want to get too big too fast

I've seen that happen in other centres and if you don't get your organisation and act together before you start to grow, you can't plan your growth, you tend to start tripping over yourself and what I have seen happen is that services to individuals fall off. I get real worried about that. I see my job too as training a disabled person to take my place, because I really want to get into a problem that was new and do that initial planning. When everything is rolling well that is when I want to leave and do the same thing somewhere else. ....

I talked to the new director of the Cincinnatti programme, same old problems, why do they think they have to re-invent the wheel, there is information available, even though it is informal.

Gini: In Arizona, I have two extremely good friends there, one of them a para, she called me up and said, we have got our CIL, we have hired a nurse and a social worker, I said, what are you doing with a nurse, do you want a nurse telling you what to do. So they hired a nurse, not disabled, a social worker, not disabled and a director, not disabled and they think they have a CIL. Right now, they two leading disabled in the city are fighting so, she has got off the board. She is splitting the disabled community in half

Mass. has been doing this for 7 years. That conference I went to on .... The deputy director of VR in California, Caroline Brash, was talking about ... for Service. Now this is really important information, most directors of CILs don't have a lot of management experience yet, the conference was so good because it was going to direct that issue along. She sat up there and said she did not know of any state where they are funding peer counselling or getting any fee for service money for medicated .... They are doing both in Mass. .... That is my problem with Elmer Bartels, I keep saying he is not a consumer, he keeps saying he is, but I keep saying he is a commissioner. Medicate has been paying for personal care in Mass. for over five years and that is a fee for service and she did not have that on her list and I thought, that does not make any sense to me at all.

(tape turned over....)

~~Assertive able bodied women are not regarded highly in this part of the country, so disabled assertive women .. forget it, and I am getting increasingly frustrated for my friends~~

~~I has to come, like for us, we need to do something for the St. Louis area, like some of the things they do in California, there is just no way, we need an audience, what I intend doing is talking to a few people I know, that is the way to do it ...... goes on about a series of films about sex ..... goes on about desensitisation, hit them with every word they were never allowed to use ... Rosalie Osney believes that people are too sophisticated for that and I think that maybe some are too sophisticated, but there are some others ... There is two films been made, which I hope I can see, people with CP talking about their feelings as children and the kind of taboos that they were exposed to by their parents, then the second film is the same people talking about their experiences as adults....END..~~

When a programme has been around that long, whatever its problems are, you would think at least they should know something about it.

My personal opinion is that often you have a collective group of people, maybe able bodied, probably disabled, who have been called 'leaders' of some kind, so they get some group together that goes after an independent living branch or private money or whatever, to really get something going. By virtue of the fact that that person may have been a leader in the community, does not mean that that person 1. has organisational skills, has management skills, or is even willing to let go enough so that other people who do have those skills or otherwise can help pull it together. OK so they start their own programme and think they are doing something brand new and then when they find out somebody else did it ten years ago, it hurts the ego. They don't like advice. My main thing was, here are the problems I have seen, lets talk about them so you don't have them yourself, if you've seen the problems, then you can avoid them, and you can talk to people in a lot of places in this country who know what the problems have been. I think that is partly rehab. services fault, they have never set up a repository, there are several across the country that have bits and pieces but there is no one place where you can get it all

JE: It is necessary to document it all

I don't think there will be a place for me when I get done in Kansas City, by that time there should be enough disabled people around

JE: How many around at the moment involved in the staff

At my centre, we have three direct service people, one blind, one deaf and one in a chair, and our volunteer co-ordinator and our bookkeeper, she has a minor disability, one able bodied direct service person, who worked for nine years in mental health. We are not really serving people that are chronically mentally ill, because we have a transitional living consortium which is supposed to do that. In our staff background we wanted somebody with that expertise, then our secretary, our librarian, receptionist, she is able bodied

Gini: You should go up to Washington, find out what is wrong

I would love to do that, I mean I only see what is wrong with the system and if you see what is wrong you can see how to fix it

Gini: I think you would be beautiful

I would love to do that, then I would become a bureaucrat too. My personal feeling is that I would not sell out, and I have seen that happen to other able bodied people, maybe I think I am stronger than I really am, but I firmly believe that I could do that. I would love to do it just because there are so many things that relate to IL that beg for a national policy, and with the current administration, national policy is the last thing on earth we are going to get

JE: We have got the same problems in England, I think everywhere has them .....

My impression of Berkeley was that everything that they were sending to us, written materials, struck me as being somewhat condescending. They did refer to people who come to Berkeley for services as clients, and that is one thing that I was morally opposed to, we are talking about a peer relationship in many cases, we are not talking about 'clients', we are talking about peers, and there is a subjugation that occurrs. Everything they were writing had clients in. Then I saw their film and I guess my attitude is just not quite as cold, brash and rude as what I thought I saw in that film. It is a video tape. Then the other thing is that I get the feeling that they go after a lot of money and use it for what they want to use it for, not necessarily what they promised to do, and I think that is unethical, I think that is the kind of straw house that could collapse, it could hurt all of us if we were found to be misappropriating funds, so those are my three concerns, but I have never been there.

Gini: You will run into this in Berkeley, great hostility towards non-Californians, non-disabled and non almost anything except themselves

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.... When I came to work in ...... centre, there were all these folders with nothing in them. I asked everybody, I said why can't we put things together so we have got policies, got procedures, we can always change them, he says that as soon as you do positive procedures you become a bureaucrat. ....has this huge place, a farmhouse in Mass. and you go in and you say, is this a CIL, relaxed, sort of a mellow group, western Mass. is sort of a mellow place

JE: What other centres have youworked at in Mass.

Just ..... We had one week when we were threatened by Medicaid on our first attendant programme, we got together as centres, the five that were existing at that time. They were holding back payments, and there were a number of systematic counter programmes going on and it was the first time that the centres were able to get over their own turfy issues and sit down with each other and talk, and when we realised that you all had some common issues, it was great and we met like once every six weeks, so I got to know the other programmes really well. I never got to know NE and SE Mass. very well, I got to know Worcester and Boston centre very well, and then when I came out here I tried to do the same thing, on the Kansas side, and that group has gone, like four directors, we meet every six to eight weeks and we talk about advocacy and planning and a lot of things that we know are going to affect our programmes and we can't do a lot in CILs if our communities can't change, and our communities can't change because the laws are screwed up, then we have got to go and change the laws. In Missouri we just met for the first time last week, the three programmes in Missouri, so I am on both sides of the fence. So I hope we can get as much done as I feel we are getting done in Kansas. A good example is we are supposed to be getting referrals from the Voc. Rehab. agencies, we don't really have a contract with them, so there is really no obligation that they should do it, except for the fact that the regional and the federal structure sits on the state agency and says now why aren't you. We have had one referral from Missouri Voc. Rehab., we have had 25 from Kansas, Kansas is one third of our service

JE: So what else do you do to get referrals

We have just done brochure mailings and presentations to hospitals. We have done pretty well, we get about one a day, about half of the people that are referred to us, we ask for self referrals, sometimes we get them, sometimes we don't, about half the people that we meet tend to stick with us for a while to work on some issues, half of them I think expect us to do everything, we won't, we say we are just here to help you organise the structure of what you are trying to do, but you are going to have to take responsibility for it yourself, they usually drop out. The Whole Person has a housing project being built, 20 units, it is going to be a mixture of able, disabled, on 202.

JE: Is that difficult

Yes, it is difficult, almost impossible. Well it is not against the law, I think they had to take a different perspective .....

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The worst thing is to become dependent on government funding, here today, gone tomorrow. In this country government grants last for a year, maybe three years, and if you are lucky you might get extensions for four to five. They only go to demonstration programmes. What is ironic is you demonstrate the need, you demonstrate how to fix the lives of the people you are serving, the way that brings them out of institutions or provides them with independent living and they go on to vocational training or goals that they set for themselves. The government says OK, you proved it, and that is it. You look around, like, where are we going from here, and suddenly you are left holding the bag so to speak. The private sector in this country are made up of foundations. Foundations have the same philosophy, they call themselves seed money grants. They provide the initial money for you to start up, then they expect you to carry on after that. I guess they figure you can develop some sort of funding base that is ongoing and that the money they give to you is just to start up in the interim until you do that. Well they don't tell you how to do it, how to find this money, so you are left up to yourselves. I have been learning from the very beginning, it is all trial and error, quite a bit of error, a lot of obstacles that we had to overcome, some that we should never have had to overcome. We have had to scrape, we have had to hustle, we have had to come up with ideas ourselves, we are developing our private funding, to reduce our dependency on government funding, it takes a long time, we are in existence now since 72. We are still dependent on government funds, it may take another 10 years before I could say we could even reduce it by 50%. We are developing our corporate contacts, corporations of this country are probably the worst of the lot as far as giving to the private sector. Of all the money in this country given for charitable purposes they give the smallest percentage. That needs to be changed around. We are working on that and we are beginning to get more and more money from the corporate sector. Our wheelchair repair shop is getting more and more profitable, we are trying to get into sales of other items than wheelchairs, but again we are fighting local businessmen, we are fighting the rules and regulations of the corporate that supply us with the goods, so there is a few things that we have to overcome. If we do that I think we could go a long way towards supporting other programmes in CIL. We are developing other kinds of fundraising methods, from benefits and stuff, other ideas that we want to get into that could generate income, reduce our dependency on foundations and government. We have been successful in getting a pot of money passed by the state of California to support independent programmes. It comes out of the governor's budget, it is being administered by a statedepartment called the department of rehabilitation. They administer the money. This could make it a source of ongoing money for the first time in the history of disability, it could be a permanent source of money, at least for California programmes. We will be starting a study to demonstrate the effectiveness of our programme, how it affects disabled people's lives and preparing for employment. The legislature will probably take kindly and say well, this is a good programme, we need to continue it, and therefore it becomes a permanent part of the budget every year, which will be a great relief to all the programme people. It would be a nice percentage of the total budget that we picked up probably, which is a good feeling because the programme directors, for the most part, that run ILPs, probably 70% of their time is worrying over where the money is coming from.

JE: Max Starcroft in St. Louis said the same thing about spending all his time raising money

Max is a relatively new project, it is even more difficult when you are a new one like his. If you establish yourself you get that much credibility with those who have got the bucks. We are not an agency like Easterseal, where they can go out and raise millions of dollars, we are just starting brand new, competing against that sort of thing. We are at a disadvantage. CILs been around for 10 years, and we have been more successful, like, since Jan of this year up till the end of this month, we have raised from all kind of ways, in the private sector, $130,000 which is not too bad. It takes planning, it takes development.

One way to do it, we have developed an alternative board called our advisory board,friends of CIL, made up of local businessmen and community leaders. Unfortunately they are middle businessmen and leaders, not the ones who have got the real clout, but these guys can help us raise money, and they will become more part of us and more active as time goes on. The real ones are the head of corporations like Klorox, Levi Strauss, Bank of America, Crocker Bank, you get their presidents to serve on a board of trustees and that is the most difficult. First of all you have got to have an entree, they have got many obstacles in their way. The key is to get hold of just one of these guys, once you get hold of one of them, they bring in their peers, then you really got it made, that's something that I think all of us are shooting for. We are coming closer and closer. I have known one of the sons of the Levi Strauss and have developed a good relationship, friendship, in fact he is the vice president now of our local baseball team, we want to get the team to do some kind of fund raising benefit for us in the coming year, and that is entree tohis father, and up to Levi Strauss.

I think when we came together, it is not to deny able bodied, but I think the way of thinking of the programme has to come from the disabled themselves, that is important. Able bodied people feel hurt and left out because they are working there and they think, you mean I won't ever be able to become a manager or a director here. But they got twice as many other opportunities for that, to maintain that kind of control that is the way it has got to be at the CIL. You don't get men running women's programmes or whites running blacks programmes, I think that is important. I think able bodied people have a place in a supporting role and lending their expertise, but then again I think it is up to the disabled people to decide whether they want to use it or not. Like our board of directors, we started out as a consumer board, we had no knowledge of how to be a board member, any more than we had background of running a programme. One of the weaknesses of a consumer board is they tend to get involved with the day to day running of the agency, because they think they should be involved in all the decision making on a daily basis, which is pure bull. There are certain rules that boards have and they should be maintained, many consumer groups go through that sort of problem, most of the others have too. I think, though, it is important for the majority of the people on the board to be consumers because you don't lose that control. I think though there is a place for able bodied people with expertise and background in that area, like people with legal backgrounds, accounting backgrounds, business people who are .... Lets face it, you are running the programme like a business, so you need people with that kind of background. Again the majority of the voting power should be in the hands of thedisabled person.

... they get things a little easier than other members of the population..... like everything had to have a vocational tag to it somehow, if you did not have that you weren't worth anything, you've got to have a job connection, or training, there is a strong work ethic, like saying you've got to have a job or you're worth nothing. We have been fighting that saying, if a person can maintain his independent living life style and that in itself takes all his wits and resources, that is sufficient, that is worthy. I lived from 1960 till I moved to Berkeley, about 1970, all that time I lived on my own, independently. I don't think people comprehend the stress of that. I would go to bed at night thinking, if my attendant don't show up next morning, if my attendant gets in an automobile wreck, what am I going to do, I don't have anybody else I could call, nothing. I had attendants who would come dragging in, because they were sick or had hangovers, the pay was nothing, it was amazing. In bed I had no link with the outside world. When I am up I can phone, but in bed I am helpless. ..... demonstrates phone, based on executive phone ..... for a long time I had to pay $12 extra a month for this, now it has been cut to $6.50, so my total monthly charge for the phone comes to $17/18 a month.

Another key factor that has helped disabled people is our wheelchair repair shop. Before we came along if your chair broke down, the whole thing went back to the factory, you were stuck in bed, it was thought to be a luxury to have two chairs. Nobody thought of going into business with wheelchairs,so they did not even do it, so it has been a profitable business for us. They talk about disabled people becoming employable, living independently, maintaining a life style on an equal level with non disabled, then allow you to wait four weeks for your chair to come back to you because that is the way the system is. For years it used to amaze me, Voc. Rehab. would train people, educate them, getting them ready for employment, when one main ingredient was how to keep people mobile. Now we can repair something on the spot.

The city of California has a medical programme, called Medicall, it is the most comprehensive medical programme that this country has, it pays for everything, buying a wheelchair, maintaining it. Wheelchairs are so costly. We did a study a few years ago, it took about $400 a year just to maintain a wheelchair, that was about five years ago, I am sure it is more than that now. Using Medicall you get Medistickers and POA stickers. Medistickers are for doctors. For wheelchair repair you go in, they write up what they call a TAR, they send it in to Medicall field office for approval, they send it backsaying it is OK, then our shop gets a POE sticker, they stick it on the form and the state pays for the repairs. That whole process takes up to 90 days, so you can see why the business has got to have up front capital, for salaries, overheads, while you are waiting for that first invoice to come back with the money you spent 90 days previously, so that is a drawback.

We started piecemeal. We started out with $2600, that was to buy tools, parts, plus a three quarter time repair person

JE: What is a good publication to read

Accent on Living, Paraplegia News, Achievement, those three are probably the best publications around, but they are not going to help you find out how to set up an IL programme. A lot of it is regional stuff, like news about Illinois is boring if you live in Nevada. A lot of states don't have CILs, like here in California we have the best programme in existence today. Up to now you get $768 a month to pay for an attendant

JE: They didn't in St. Louis, it was a real problem trying to find ways to pay for an attendant

People write and say, well how did you get started here. You really can't say, because what happened back in the 50s what was called an Attendant Programme got put on the books for those who were temporarily disabled, they had this programme to help people who were recuperating at home. It was worded in such a way that it could be interpreted to go for any person who was disabled, so we began utilising it in that way. At that time youcould get $150 a month, and then they had another category if you could prove something medical. Over the years we have improved on the programme, or helped withlegislation, in fact we saved the programme at one time. This guy who runs the country now, Reagan, used to be our governor, he tried to ruin more programmes, and we took him to court, that guy is heartless as far as I am concerned. We got a court ruling and not only did we save the programme, but we got it improved upon, we got a cost of living increase. We usually end up writing to the legislature about a bill, so we can set it up. Many states are trying to do that, New York I think, but they are still not like ours. To put it all in a nutshell, if that programme did not exist I would not be here today talking to you. In the early days there were not many disabled people living in the community. As the attendant programme made that possible ..... if you need someone to get you up every day, the best way is to hire that person yourself, that is important. If someone else is sending the attendants out that is just another form of institution, you can't schedule the hours .... That is hard for people to understand, legislators, people who run these agencies, why it is so important for you to have that power to hire and fire, why you have to set your hours and stuff like that, they just can't comprehend that

JE: In England most schemes are managed by able bodied organisers. They are not that flexible. I know you have to consider your attendant's needs as well ...

It is a give and take, it is not strictly one sided. I am a great believer that you have got to be careful with your attendant, that has been one of the hardest things that we have had to convey to disabled people. There is something special that develops between an attendant and a disabled person, as an attendant you are an extension of that disabled person, you are their arms... that means a lot of things that are personal, you just can't expect them to do more than what you are paying them for. I have seen disabled people say well I'll hire you for two hours, and then work them for twoand a half, three hours. You see disabled people say, I'll be there at 8.00 and then not turn up until 10.00, and the attendant has been sitting around waiting. If you behave like that, what you do is you burn it for the rest of the disabled, because there is a catchment out there of people who are potential attendants, and once you start burning them that number gets smaller and smaller. There's always a few that do that, or they don't pay on time, you can't do that. Then, we've seen the other half of the work, attendants can come in and they are so strong, they dominate, we have to remind disabled people of that too, don't let that happen, you've got to control your life. It can happen both ways and we see ourselves as advocate for both.

Like you said, late hours and stuff like that, you can't take advantage of that. If you ask them to do that, then they must be able to ask you sometime, could you go to bed an hour earlier so that I can go out. So it is give and take. Having more than one attendant is important too, because if your one attendant can't come in, like I always try to arrange it that I have a different morning attendant from the night attendant, I'd ask also, can you ever come in on an emergency, if the other person is sick. If they can then that is a little safeguard for me

JE: The attendance allowance in England is not enough to employ attendants

What would you pay an attendant for that kind of work

JE: Between 1.60 - 2.00 an hour

Some people need attendants 24 hours a day, living in attendants. To afford that, they will take money out for that person's food and lodging, because rents are so high. Say you are disabled and you find an apartment, it is about $400 a month, so you let an attendant have the other bedroom, you take it out of their attendant care money

JE: I gather people have trouble with attendants. I met a guy this morning who said, the good ones never hang around too long because they have got better things to do, the bad ones, they go anyway because you have got to get rid of them

I have been pretty lucky, I have only had a couple of really bad ones. Most of them have had mental problems or something like that. Three of my attendants went on to become RNs, they worked for me for a couple of years and they were so turned on by the work, they went and became nurses. In some areas it is a lot easier to find attendants, Berkeley is a lot easier because there are students and also you got a transit population, who come here for a couple of years, who want to earn enough money to live off, enough to pay for food and rent wherever they are staying, because most of their clothes are out of free boxes, they don't need much money. They can get by being attendants. If you go outside this area to ... lets say Eldorado, where your population has a higher income, you won't find that kind of a population, so it will be more difficult. One of the things I used to do before I came to Berkeley, when I was living on my own, you contact hospitals or nursing homes, those people who work in those places for the most part are orderlies, don't make a heck of a lot of money, you can get them for a couple of hours in the morning time to get you up, or in the night. Otherwise it is difficult, as the guy was telling you, they are here today, gone tomorrow, they can't afford to work for $3.50 an hour, they need an 8 hour a day job

JE: Accessibility is a problem in England, when did the kerb cuts happen in Berkeley

What happened in Berkeley was that as the students moved more out into the community, in particular South Campus, the area where CIL is right now, Telegraph Avenue had been renovated about 1972/73, that was really a first for us here .... then with the state laws about accessibility, so it was tending towards that sort of thing anyway, new construction kerbs became mandatory. As more people moved out into the community there are pockets where people live that they wanted ramps built to the university .... So they go and say, we would like kerb cuts made at such and such a street corner .... this happened for a couple of times, then we thought all our energies are going asking for kerb cuts, we decided well hell, we are going to go before the council and we will ask them to put kerb cuts all over. But we used proper channels, you go through channels you know, so we said OK we will. We went to the public purse department, which in our city governement is responsible for street maintenance and stuff like that which cuts would be part of, so we went there and had a meeting, we said look, we want to propose something, we want the city to put Kerb cuts all throughout the city of Berkeley, not just in downtown areas, where traditionally kerb cuts always went because they seemed tothink that disabled people only go down town. They said OH that's too costly, it will never be done, this has never been done before, you'll never get it done, you don't do things this way. So we says, baloney, we'll get it, so we told them that, they said they would do everything they could to stop it from happening, so we wrote our own resolution, we presented it to the council and this guy who was on our staff at the time, we thought we would do something really good for them and make it really look slick and proper, so we then requested a date and time to go before the city council, which they accommodated, we also requested that they move to an accessible place, because in those days the city council chambers were at the top of city hall and there is a flight of 5000 stairs, so what we said was that whenever we go before them could they hold it in an accessible place. We also then asked every single person that we knew that lived in the Bay area, we didn't care where they lived, so long as they came, we also asked all groups that supported this concept to come this night and support us. So that night, you couldn't believe it, a mass at the city council, all these people, all of them supporting us, it must have blew their minds because I don't think they had ever seen so many disabled people in their lives and we got the resolution passed, we presented it to them and there was only one dissenting vote and the dissenting vote had to do with the certain wording, that was corrected and that person changed their vote, and what we got was $30,000 every year to provide wheelchair kerb cuts throughout Berkeley and that the city public works department was to work with CIL and identify the areas in which we wanted them, we could prioritise the areas, and that's how we got it. That was 72/73. The public works were pissed off at it and for a long time they resisted working with us, but after a while they became our strongest advocates. Because what had happened, we exploited this, we told everybody how we had won a victory, we passed out copies of our resolutions so that other communities could use them, Berkeley suddenly became a centre of attention, also from the city governor's perspective, apparently the public works departments have an association and they get together periodically and talk about common problems, well I found out that every time they go to these, people want to know how Berkeley did their ramp programme and these guys are suddenly now stars, they like that. If you hear PR going through the city of Berkeley, they talk about how they helped develop CIL .... We were lucky, all the kerbs are flush with the street, or only maybe half an inch. You can go all over without having to worry about a kerb, some of them are too steep and stuff, but they are all right

JE: England is inadequately provided

Probably because they are all old and institutionalised

JE: Also it seems more normal for disabled people to have jobs here

That's what happens in this country, that I think is bad, these people are held up as super crips, gee they made it, you can too, without any benefits ... they even talk themselves, say, I can do it, you guys can too. I think one of the greatest disservices we had in thiscountry was Ironside on TV, I've done it so you can do it. The thing I think is funny, he lived in the worst city, architecturally, it is hilly, San Francisco, all stairs everywhere. The one thing that came out of this programme though was the vans, that started the whole thing

JE: Vans is a problem as well

People hear about us, they want to help, one woman left $9000 to us in her will. We get stuff donated to us, like right now we have got a 47 Cadillac out there, we are going to sell that. People give us like refrigerators, corporate donations. Sometimes people will hear about it and they will send in a donation, so when you name gets in the public eye, and they see what you are doing and they like what you are doing

JE: What is the general public attitude in this area

All over Berkeley the disabled are received very well, we are not picked upon as freaks or anything like that

JE: I meant the radical side of things

The disabled sort of came out at the right time and started asserting ourselves, the conservatives and the radicals took us under their wing, it is interesting that we were everybody's darling, then as time went on we became more of a political football. The general public, they see us all the time, we are part of the scenery here.

JE: The frequency and normality of seeing wheelchairs around here is astonishing, true integration

We have had to fight for it, and after we became successful, other factions of the community started picking at us, in the sense that we are competing for the same dollars as other programmes and some of the other ethnic minority groups are saying CIL has got all this money and why are you guys funding them and why can't they use that money, and they don't understand that much of it is restricted money, you can only use it for what they give it for, and we at CIL have taken on many special projects never think of doing so we are doing studies and research and stuff like that, they general public don't understand, they see the budget and think we are fat and sassy and in reality we are not. Sure we have a large budget but the people are all underpaid and overworked like most communities, so we have got to fight that kind of battle with our community. Overall I would say from the community at large we are accepted as people. From time to time you will find screwballs, traditional attitudes, but you are not going to eradicate that for a long time. So I would say generally living in Berkeley is better than say in Oakland, which is right next door. The activism and involvement of us in our own community has made life bearable here, but in Oakland it is a whole different story and you have got a whole different political machinery, a whole different attitude of people, you don't see disabled people interacting or in andaround like you do in Berkeley, so it is a different scene, though what we have done in Berkeley has certainly overflowed into the other communities, so they are better than they were 10 years ago, but they are not quite the same as Berkeley. It is beginning to happen as disabled people emerge and are more out in society and are out on the street and stuff like that. We in Berkeley are overflowing into other communities, because Berkeley can't hold all the crips, so we are starting to move into other communities, so that is helping out. As we become employed, as we become more active as far as shopping, restaurants... can't help but happen, it is happening in pockets all over the country. I'd still say that we have only scraped the tip of the iceberg, we still have about 90% to go. Transportation is finally becoming accessible

JE: We had trouble catching a bus, the driver could not get the lift to work

We as a group are monitoring it, because if we are not careful, what will happen is that it will slide and before you know it they will try to think out a way to shut it off. The governement now, because of a lawsuit by a group of people, trying to change the whole accessiblity thing in transportation, it is going to set it back, they want to put transport back in the hands of the community, well the cmmunity has not got the bucks to maintain transportation for disabled people, so it could end up like it was ten years ago. Lucky for us ..... or Daisy Transit here has already got accessible buses. Barts is fairly accessible, but you have got to be aggressive to use it , you have got to be able to ask the right questions and push yourself forward, the sort of things many disabled shy away from, like where they elevators are located and so on. Well, it is there, so I can't really complain a lot about that. It was the first mass transport system to be accessible, at least you can get on and ride it, it rolls around like a billiard ball. I think the stories about it have got way out of proportion, breakdowns are sort of a running joke with everybody

JE: One quad we met who works in Oakland talked very highly of it

You can go right round on it, I think it is just 60c

JE: How do you bring people together

It was not easy. A lot of it happened by chance. The timing was right, the political atmosphere was right, that is an important ingredient you have got to work at. The University of California had at that time a programme of housing students, they had a hostel. What had happened, was a number of problems and frictions had developed between the students and the dept. of rehab. over the way they were living, what was happening up there and stuff like that. Many of the students were into dope and stuff like that and the counsellors would come up and try to rattle the chains and stuff like that. What they wanted was sweet nice young disabled people, who went along with the status quo and did not say anything bad. Well disabled people want to do what everybody else wants to do, try everything, experiment. So, that plus, many of them were saying, we are going to school, getting a degree, what is going to happen when we get out, there is not going to be anything out there for us. Some thought, even while we are going to school, why can't we be living out in the community like everyone else. So, there was a number of students on campus, so they got themselves a programme funded, one of them went back to Washington and lobbied and got disabled people included in a special fund for minority students, at the office of education. That funded a student programme at the Univ of Calif that would provide support services to students while they were going to school and they could also live in the community. So for the first time, there was a programme to support disabled people to live in the community, provide them with attendants, accessible housing, if not, help to make it, like building a ramp, helping them with getting all the money that they are entitled to under the at that time, State Programme, just general counselling, wheelchair repair and some minimal transportation, the key services for disability to maintain an independent living lifestyle. At the same time we also felt, well, why don't we also include the blind. The blind situation in this country had been run by the National Federation of the Blind, for many many years, and another group called American Blind Council or something like that. They were all traditionalists and had got complacent and were not doing anything. There was a young group of blind people who were dissatisfied with traditional groups and were breaking away from that. So these young blind students also became part of the student programme. So those were the two groups originally involved. The disabled students ranged from post polio to spinal cord injured. This was a student programme, their services were strictly geared towards students, they were supposed to only serve students. However, the supposed to never happened. They did serve community people, so long as it did not interfere with the students going to school, because that was the priority. I had just discharged from hospital here in Berkeley, after surgery on my back for sores, and met a disabled guy. I had all these visions of going back to school, having all these support services to help me out, won't have to worry about them. I used to live independently before this, I lived with another disabled guy, we had to find our own attendants, housing and we just did not have anay resources to turn to, you had to hustle everything yourself, it was a tremendous burden, 24 hour survival. I never did go back to school. I started running the student programme, filling in my tolerance and recuperating, started talking to the students there and the people who were running that programme. We started talking about, you know, we really need another programme to serve the community, because the demands were getting overwhelming on the student programme by the community at large, so we started planning our programme. It would be like the student programme, but more comprehensive. It would be a real voice for the disabled for the first time, run by the disabled, one that would be controlled by the disabled, all the decision making would be done by the disabled, and we would become an advocacy group for the disabled, and we could serve the Berkeley area and surrounding communities, just little bits and pieces of Oakland and Albany and places like that. At that time we did not have any comprehension that we would be where we are today, or the impact that we would have. We did see ourselves as a model, we always thought, well we will set up satellite programmes, we will help other comunities to do it too, so we had that vision. So we began as a group and that group became the first board of directors. At that time there were only about 6 to 8 active people in that group, then there was an additional 6 to 8 people on the peripheral, that were not active, but would give us advice, expertise and help. This first active group became the first incorporators of CIL. It was a working committee and we began writing proposals and planning, to get the programme together. We had no money, nothing, just a lot of time committed to the idea. We had mobility only in the sense that we lived in the community in our apartments and we had electric wheelchairs so we could get together, we did not have to worry about automobiles or buses, I think that was important too. All the original 8 were disabled. That was myself, Ed Roberts, John Hessler, ... who was blind, Hale .... CP, ... spinal cord, Judy Taylor spinal cord. The bulk of us were spinal cord.

In fact I don't think it mattered whether we were different disabilities or all spinal cord. The services we were talking about were important to anyone who was confined to a wheelchair. That was the important thing that drew us together, there were also a lot of common areas that we share with the blind, they have mobility problems, they have financial problems, housing, rights issues, so we became a coalition, which was unique and different, particularly as traditional so called disability groups would shy away from all the other disability groups. It was important politically, because numbers have power. Legisalators are very bent on knowing what the masses out there want, that means they are going to get elected, they are going to listen to the largest groups, and disability is a large group, I don't think they realised that, but we began showing ourselves from time to time, so they realised that we were something to be reckoned with and a political force. We did some things that amazed them and proved our political power. This first group went out for money, it didn't work too successful, we got a planning grant from the feds. First of all, another key ingredient is developing contacts, people in key places that can help you and who believe what you are doing. In our case we were lucky, there was a guy at Univ of Calif, called Urban and Regional Urban Studies I think dept., he knew the commissioner at that time of rehab services admin, Washington DC, they were personal friends. He himself had done a lot of studies in rehab, so saw that what we were talking about obviously had a direct link to rehab, so we began getting contacts with the feds and got them interested in what we were doing. Interestingly a couple of them saw that what we were talking about was the kind of thing that had been talked about, but never attempted to put together, so they funded us through what they call a project development grant, actually the feasibility study, and to define the facility from which to provide these services. This study was sort of interesting because here we were, disabled people, doing a feasibility study, like we already knew it beforehand, we also purchase these services ourselves, being disabled. So we complied with the grant and it went for one year, got ourselves a little two bedroom apartment, had a staff of about 11 people, all we could find was a two bedroom apartment on the third floor of an apartment complex, set it up like an office, nobody was full time, that way we maximised peoples time, we split the money around, so everybody got some reward for what they were doing. Also it had to do with our benefits, because if we earned over a certain amount we would lose our benefits, if you earned under a certain amount you could keep it, so we all worked full time even though we were getting about a quarter time money, so we got a lot out of everybody. After that first year we learned a lot of lessons, not to put a lot of faith in what the government says they are going to do, because they have a way of changing eveything. During that year we worked with the government closely in developing a lot of legislation, a lot of programme ideas that they wanted adopted. What happened at that time was there was a really strong piece of legislation got vetoed by Nixon, we wrote a proposal for half a million dollars, we thought we would get funded, but we never did get funded. They told us they would extend our grant, we needed more time to finish our work, the very day we were supposed to get a phone call from Washington to verify it, we also got another phone call to say that we were not going to get it. We did not know what to do, we had put all our energy into this one thing and nothing has happened. I think one of the things that helped us to maintain what we were doing was our ingenuity and our resourcefulness. We went to the Univ of Calif and got a grant to carry us for four months. We developed a contact there, the vice chancellor, now a friend of the CIL, through their funding to community agencies, which they do from time to time, they gave us $17,000, that saved the day. Also it changed our whole philosophy on fund raising, we realised we can't go out for one source to fund everything. A group like us had no track record behind us, that is why it was important to go for these contacts, and while all this was going on, with little or no money, we were still providing services as best we possibly could. Then lo and behold, what happened was that we ...... the foundation game, and also revenue sharing came on the scene, which was a source of money that came from the federal government to the local levels of government to be used for social service programmes and/or anything that they want. In this country I would say 90% of the money that came down through revenue sharing went into bricks and mortar, buildings and monuments, jails and stuff like that, but the population here was very social service conscious, in Berkeley and Oakland. So once we became aware of it, we sent in proposals to the city of Berkeley, because we were the first disability group, plus we had made our political connections beforehand and both government bodies were aware of us, so that helped as well, at the same time we got a small grant from San Francisco foundation, $30,000, so there we were, we had the county money coming in in March, that was $68,000 and Berkeley's money was $10/15000, so now we were set in motion, and that is the thing that got us going, we suddenly grew out of the apartment and moved to another place on the university avenue, and old landmark building, and we were ejected from there, because we were a fire hazard and the elevator caught on fire a couple of times, we had to be evacuated by the rescue teams, that made a lot of good news, but the fire marshalls saw fit to prohibit us from staying there, so we ended up where we are at now, we have been there since 75. Things began growing right at that point, when we got the revenue sharing. Ed Roberts became director of CIL, we started getting a couple of federal grants, things like that. I think disability was then a new thing emerging, and I think we wrote good proposals, and the programmes we were talking about were sound

JE: The contact and communications between you in the early days must have been important

That was very important, that is where we were able to weed out a lot of things, and clarify things, the philosophy, the goals of the programme, write proposals, I am amazed at some of the people that have worked for CIL and been proposal writers, the writing was like prose, so beautiful some of the stuff, and the information that came from meeting and talking with each other. At the beginning it was like a family, there was a lot of closeness. Now it has got so big, and it is like everybody is strangers. In those days we resisted a bureaucracy, we resisted paperwork, we did everything we possibly could to not comply, but we found out that it had an adverse effect on us too because what happened is that realities came in like, auditors would come and audit your books, and they would go tracking information, you got to do that if you want to get funding from them next year, you got to have a good accounting system, good records and stuff, we thought we could get by just by the fact that we were good guys and providing a good service, but you had to comply after a while. So we learned the hard way, it took several years to finally get things back in order from our accounting system, now everything is in order, but I think it was our belief that we would rather spend our dollars on providing services than shuffling papers, but we learned and we had to become more bureaucratic, it has been a hard pill to swallow for many of us. I realise it has got its benefits and it has paid off, because we have got larger bucks out of the city because of it, it is like growing pains or something, we grew very fast, probably too fast, and that left room for sloppy work on the paper areas of it. But that is mostly internal stuff. As far as what we said we were going to do and what we were carrying out, there was nothing they could fault us on there. But for anyone going into this game, start out right away by keeping good records, you cover yourself.

JE: There seems to be very little written apart from Hale Zukas' History of the CILs

He has taken a little bit of a liberty there too, I would like to see that thing expanded to about five times

JE: The problems when you started out must have been endless

When we got our first few bucks together to pay a secretary ...... we played poker .... and that is the way we payed our secretary. Another thing that has to be realised by people getting involved, 1. is hard work, 2. is long hours, a lot of frustrations, there may not be many rewards at the beginning, that is the hard part because unless you build each other up, you get tired, feel like there is not going to be anything gonna happen, you just gotta keep fighting and battling. Little victories can come out of that, to pick you up. Every time that has happened, there have been a lot of peaceful valleys, then suddenly bam and it just picks you right up, it is like a rollercoaster ride. It can be any number of things, it can be an article in a newspaper that talks about how ..... your programme is, that lifts you up, you are getting in the public eye

JE: Lots of people have said they would like more documentation of Berkeley. Like Bruce Curtis wrote 27 ways of .... that was so clear

That document is good. Bruce used to run this programme in Passadena. He got a little political and they ousted him. We asked him to come up and work for us and he worked for us for a while, he volunteered, we did not pay him any salary, we paid him consultant fees from time to time, he would do some of the outside things, then he got a job in Houston Texas. He wrote the paper when he was with us. He and I went to Denver for a conference, on the way back I was reviewing the thing we were talking about, the plane suddenly went into this dive and I thought that was it, and he says, do you really think this is it, and I says, yea this is it, and I am sitting there thinking, I wonder if it is going to hurt, and all of a sudden the plane just levelled out, and I told him, you can wait, I'm not reading this, I'll read it later. I asked the stewardess why the pilot did that, and she says, I don't know, maybe he got an order from the tower or something, the guy never did come on and say why. But when you start off with programmes you don't have time for documentation, you want everybody involved in the immediate problems, planning what is going to happen tomorrow.

So as time went on we never did get round to hiring somebody to go back and write up what had happened, that has neverbeen done except for what Bruce has done. Also, I have worked with other programmes, like Judy and myself went to New York, Albany, we worked with seven programmes from the state of New York, we made two trips back there, but all this came from the knowledge that is in our heads, talked about it, we had some documentation, forms, stuff like that, but you have to also feed the in between stuff, how youdeveloped, how you nurtured it, how you made contacts, it is not written down, tthough we have developed some manuals and right now they are gathering dust, because that unit is no longer funded because some funding came from the state dept of rehab, technical assistance, we got a grant funded for 51 months, it only ran a little over a year because ....

JE: Ok, if you can tell me a little bit about what you are doing here

My name is Gary Grey, I do attendant referral work. We interview attendants and we go to the client, and we work out with the client what kind of grant they are eligible for, like In-home support service, that is done by the County Welfare Department, each county has their own, what they do is, one counsellor will go to a person's house and evaluate that person, and then they give you a set number of hours and then the money goes that way. The attendant is different, they come in here and we interview them, we try to see if they have any disability awareness, we ask questions about like where they worked, references, ID

JE: How do you advertise for them

Newspapers, radio, TV. They are all Bay area

JE: In terms of the number who come to you, how many of those do you take on

Usually nine out of ten

JE: What is the success rate

About 70%

JE: Out of the 30%, what are the main <u>problem areas</u>

Communication, on both sides. They don't know what hours they want, what the money is, they argue about their duties, what they gotta do when they work 2

JE: Do you have a job description

We try to give a brief overview, we don't know what the specific needs of that person is. I need an hour, but some people can do it in 45 mins. It depends how fast that person can work. It depends on how you two get co-ordinated, that is the way it works

JE: What other problem areas do you see

I think the money, if we had more money we could get more qualified attendants. They get $3.35 an hour paid by the county. If you earn over the limit you don't get that

JE: Is there ever a shortage of attendants

It goes through cycles, people coming to school, people leaving school, summertime, the middle of Christmas, August, December, March. A lot of the attendants are students

JE: Could you define what an attendant is

TYPE

The majority are 17 to about 30, we have had a few 14 or 15 year olds, some could be young mothers. They can work in their own time, they all want to work from 9 to 3, this way you can arrange your own schedule. You can go intothe emergency attendant plan, when you need an attendant within an hour 2 this is more advanced here than anywhere else. Iwas in Illinois, I was in New Jersey lately, and there were no emergency attendants. We have a list of names, male and female, and you go through the list and pick out ....

JE: Do you have situations where attendants sleep in

We have got living in attendants, they get flat rate

JE: Does that give them enough money to live

It depends, not really

JE: So they probably do other things as well. Is there any training system

No, on the job training. We tried to set that up

JE: What has been the problem

Money. If we ever get the money to do it, I think it would be an advantage to the attendant and to the client, because they would know what they were doing. Many of the attendants that drop out did not know what they were getting into

Voice in the distance: I can give you a classic example of that if you want, when I first started playing the attendant game, and I use that term loosely because I have done it for so many years, I hired a lady to work for me on the weekends and I told her there would be some personal care involved, everything was cool you know, the first day, she came in, Oh, I gotta do that, I gotta think about it, so then we had a talk, I said well look, I told you this, she said, well I did not know it was going to be like that ....

JE: So how many of you work here

Nobody full time, one full time attendant co-ordinator, we are all half time and quarter time ..... That is because of money and if we earn over so much .... That is bad. Gary works Monday and Tuesday, John Jo comes the next day, it is difficult, he does not know what Gary has done, if we had all full time people, that would not happen

The Voice: To deal with that we make people fill out an application which we put in the file, if they are not in the file, we make them fill out an applicaton

It is good now, it is a good system that needs to be improved. It could be improved by all full time workers

The Voice: More solid grants too, none of this revenue sharing business

JE: So how many on your referral system, how many attendants do you have

2 Right now, 150

JE: How many clients

2 About 260, some of them get their own attendants

JE: It seems the grant system is complex. Is Reagan's block grant system going to affect the money people have to pay for attendants

It will because if the county gets the money, that will be it, it might go to the police department or whatever

1 I think people need to be <u>assertive</u> and know what they want to get done, and know what needs to be done. A lot of people don't do that. America has been brainwashing them into accepting things as they are

JE: What happens if problems arise between clients and attendants

We do mediation. We try to avoid people going to legal means, because once it gets that far it is no good

JE: What about clients abusing their attendants

There used tobe more of that than there is now, people are beginning to realise, when they lose them they can't get them back, then they got real problems, they know that

JE: Larry said it is difficult to find good attendants who will stay

The good attendants are going to move up the ladder, it is like a beginning point

JE: If somebody's attendant walks out, have you a system to call on

We try to do our best

JE: ....

usually it comes down to personality, or inability to communicate. It can lead to rather serious problems later on

(A period of inaudible conversation ....)

JE: So if you had the funds you would organise training of attendants

I would

I would make it so that all the people we interview were made to go through training and see the movie, see what the movie says, ask questions. I think when they can see what is going on, it is a lot better

END

OK, how I got involved in CIL. I first heard about CIL on a programme on KPFA, which is our FM sort of radical underground radio station, Bay area. I heard about this place and I went to one of their meetings, and at that time they had a two bedroom apartment on Hayes Street, near the university. They were an outgrowth of the physically disabled students programme on the University of California Campus. They were just getting started because some of the university students, disabled students, were finding themselves ready to graduate and they did not know what was going to become of them out in the community, so they thought they would start a comparable organisation to the one for physically disabled students, out in the community

JE: What year was that

About 1972, and they were in this two bedroomed apartment, about 10 people, the nucleus of the organisation, and the first money they got was a $5,000 grant, and I kept calling them up and saying, I'm available towork, and they would say well we don't have anything yet to pay anybody with, but I finally did get a job with them, as a medical door, going in for medical service, for wheelchair repairing. I first came to work here in 1974, so they had been going already two years, and I was a medical doer, and a transportation despatcher, we had one van at that time, which I would schedule, one van and one driver. Pretty soon I discovered I could not schedule the van and take phone calls and complaints and all the stuff I had to take, and also do the billing, so the billing was given over to somebody else, and I have never worked here full time, but I spent the time that I was here doing the van schedule, and I did that for a couple of years, and I became a counsellor. We had a federal grant for three years to study the efficacy of the peer counselling model, disabled people counselling other disabled people. We have always known it was a good idea, because other disabled people can't run the usual poor me games, and we as counsellors can have more credibility. We thought it was a pretty effective model, but the feds wanted us to find out for sure, so it was a three year project that went on for a fourth year, and then when that was finished, I came to work here in the intake department, and I have been here ever since. I think I started here in 1979. So I have worked for the same organisation all this time

2 counselling

JE: In the early days when you first got involved with the PDSP, that was with Ed Roberts, Phil Draper, John Hessler

I was never part of PDSP because I ...., but those were the folks, yes

JE: You were one of the link people really with the change over from the student set up, to the more community orientated set up

I guess you could say that, except that it was a couple of years before they were able to hire me. I was just kind of hanging around on the fringes for a while

JE: Could you tell me a bit about intake

We cover a lot of different areas, it is not only taking case histories on people, that is specifically what we do, but

2 INTAKE

JE: When people first phone up with a problem, this is one of the first places they contact

Yes, this is the first place that we get information about them, but in addition to getting information about would-be clients, we do an awful lot of information giving, like the person I have just been talking to is an old client of mine who I have not heard from in 2 or 3 years, she was supposed to call me back last week and she never did, so she catches me now, she wanted me to give her an answer on a silver platter, whether her doctor was any good or not, well she has got to figure that out herself, so anyway, I give advice to people who are stuck in some place, I give information, people like you who are studying, trying to figure out what it is about, and

2

then a lot of people just walk in off the street and say do something for me. What else, I have even done tours, people wanting to see the place

JE: Once people have got in touch with you, you start a file, where does it go from here

We keep an original copy of their intake and we make as many copies as are needed to go to the various departments

JE: So there is not one source for everything

No, we are the hub of the wheel, the spokes go out in all directions. 2 INTAKE We are supposed to do follow up too, which is harder because you can see it is hard to follow up when you are already being besieged

JE: How many of you are working here

There's Sandy and myself, she is three quarters time and I am half time, and then we have Aleho, who is here ten hours a week, so all of our hours together only add up to one and a half people, it is not really satisfactory

JE: Have you been affected by the cut backs

We are just beginning to be. Before the Reganomics we are still feeling the effects of . Three or four years ago, a local politician named Jarvis, he is a real estate man, estate agent, also in the state legislator. He was hearing from his constituents, the wealthier ones, that they are unhappy with the tax burden in this state,so he put through this measure, it passed on the ballot. It did not pass in San Francisco, it passed in the rest of the state. Drastic property tax cuts, and of course the property taxes are what support all the services, so for the first little while it was not so bad because the state had surplus money, but now the state is feeling the pinch, as if it weren't bad enough already, then old ...... came along and whatever money the state had has been spent. Have you heard of Mag fly, it is a .... and fruit fly, they are stopping fruit coming and going and they have been spraying like crazy

JE: When did that start happening

A month or so ago. So the state is in no position to bail anybody out, and then when the Reganomics really hits, then I don't know what is going to happen. It would be really tough for this place to be shut down

JE: It seems like in the IYPD, every country is cutting back on their social services

We saw advertisements for the Cheshire Homes, we are not crazy about the idea. They look just terribly paternalistic

JE: What were you doing before you got involved with CIL

For a long time I was married and raising children, then I had a chance to become a taxi despatcher from home, at that point it was an advantage not to have to leave home, I still had young children. Then, they couldn't hear me very well from where I was, so I went to their office. Then that job fell through, they lost their insurance because they acted as an informal ambulance service for people who were hurt in the People's Part Riots, so I became unemployed, and I found out I made as much out of unemployment as I did working for them. In those days I wasn't even on benefits because I was married, I had my husbands income to keep me. You might say Taxi Unlimited raised my consciousness, because I was not very politically aware up to that point. They were very poorly paid and in the drug culture and everything else, so for a middle class,middle aged housewife it was quite a turn around. Then I had another job in between that job and CIL, I guess I have been here longer than anybody except Phil Draper. People come and go here at a rapid rate, there is not an awful lot of job security, grnts come 2 and go, money comes and goes and people come and go with the money. I am a stay put sort of person. It is the first job I ever had in my life that I got because of who I was and not in spite of who I was, and that feels really good

JE: Are you happy with the way you have seen CIL develop

We grew too fast, now we are paying the price for it. There's good reasons why we grew too fast. Every time you want money to do a certain study or whatever it has got to be new, innovative, something that has never been done before, like when you write your PhD thesis, it has got to be brand new. So every time we heard of money anything to do with disabled people, we would go for it, and it meant expanding in all sorts of funny kinds of ways, it is like a tree that is growing with no particular control, it is 3 all wild and woolly and crazy, and the money would come in and we would hire a bunch of people, then the money would quit, so the growth was not planned

OUTCOME

JE: Difficult to maintain organisational integrity - small is beautiful

We should have stayed small

JE: This is what I have heard outside, people feel this place had got too big and impersonal

It is fragmented. There are 150 to 200 people working here. We used to know each other. We are down to about 100 now, but when I first knew them they had 10. You can't do much of a job with 10 people, but at least when you need to know something you can communicate easily, now one of our great failings is lack of communication

ORGANISATION CUTS

JE: Who makes decisons about new directions, new programmes

It comes from the administration basically, like they wrote a grant and we got money to work with mentally retarded and we did not know until the programme was upon us, and we did not have any experience, and we felt very // betrayed. One aspect of CIL runs out and gets the money, but it is the service provider that has to work with it

JE: So who is the administration

Board of directors consists of the director and then various deputies, it is getting top heavy with deputy directors

JE: What is the ratio of disabled to non disabled

About 50,50 and there are some people that are very unhappy with that. I personally would rather have this and be more like the world we live in

JE: I suppose there is a danger in the future that you never know who is going to be in the key decison making positions, this is a worry with nondisabled

We might get back to the old model which we are trying to get away from, non disabled telling us what we should be doing

JE: Do you see how to counteract that

I think it is happening in spite of us now, we are being chopped down. It hurts a lot of people, we get more fragmented than ever, but life has a way of seeking a balance, it may be something we have to go through. I just hope we can survive it, because if you prune this poor tree too much it can't survive

JE: How do you motivate disabled people

END

Tuesday, 15th Sept.

Critical of CIL. Main criticism,interesting reflection on how he saw CILs, obviously influenced by his friendship with certain disabled original individuals who were in Berkeley. He talked a lot about the power struggle and seemed to think that CIL developed out of a group of hippies who were more into making Berkeley into what it was at the time, at the end of the sixties, the hippies paradise where they had been enjoying themselves, sharing a community experience, but claimed, which is interesting, first I've heard, that Ed Roberts came in with the main political force and changed things, because of his radicalism and his way of looking ahead at things in tthe future. A lot of people apparently didn't like this way ahead, but obviously it was necessary because the CIL I don't think would have developed without it. It's all part of the anti-authoritarian, anti-leadership approach, which obviously is prevalent in Berkeley, it is there today. I think people like to go and do their own thing in co-operatives and in group set ups and not under leadership, but there again, you've got the, even today, he pointed out how the same kind of things happen, with Judy Huwman being there as a leader, there are people there working, there's a conflict between that kind of leadership and the community orientated set up, which some of them would more or less prefer.

....

.... was one of the participants on the freedom rally and had some intriguing stories to tell about the interpersonal conflicts that went on on that journeyand the hassles on the day to day living survival trip and those who wanted to stick to regular routines and procedures and deadlines and those who wanted to go on and enjoy themselves and let the dynamic, organic situation grow out of it. They had a psychological group encounter, before going they had a group leader involved in asking them what they thought would be the most difficult part of their trip, they thought it would be the privacy, which it wasfor him, but for others it was just simply a difficulty in getting on with each other. The attendants were on strike in Chicago, but he left them go by because of the sheer overwhelming burden of responsibility that they had in getting up every day at 5.00 and getting to bed at night almost at 2.00, loading and unloading the vans, getting people up, as well as the sheer driving, quite an incredible responsibility, not many individuals would take on in this extent, but still the adventurism, the love, the romanticism that inspired Eric to do it and in the end they did it and it seemed the after effects, even talking to people today in Berkeley at CILthat that movement has come back and is strong, and it has a new place, a place that is obviously going to develop an awarenes and a consciusness that is going to influence the way ahead for disabled people, and now that CIL is getting so cut back I think they are going to have to come to the rescue, and if they don't come to the rescue then the people that arereceiving the services, all the disabled crips, frm all over the States and in some ways almost using the services that CIL is struggling to keep alive. They are going to have to come to the helm and help out because otherwise CIL just simply won't go on because everything is being cut, the kids project is being cut, the technical assistance unit is being cut, even the job employment section now and that is quite something because it is such a crucial area that they have had such a high success rate in and also has proved to be such an invaluable service to disabled people in the community, particularly when other job programmes, like the Berkeley Youth Employment services, which is the main employment services for many years, is threatened with closures because of the block granting system, funding through the Comprehensive and Training Act CETA through Dept. of Labour and operated by the city offices and human services has been cut back and it is in the same funding source asthe job employment section of the CIL and they have two or three weeks to live and they have to get together in looking for alternative funding sources. They live worlds apart by having funding in different sources, now they are feeling the crunch they have got problems. END.

Greg Sanders/Administrator - Berkeley CIL.

The thing I can talk about the most, I have been around CIL a lot, but now I am an administrator, like a public policy advocate. Like the centre is here to help people get public benefits and services, but unless the government provides those services, then the centre would be worthless. I work on things like self security benefits and attendant care type of programmes at state and federal levels. You don't have much attendant care do you

JE: It is not the same as here, it depends where you live

BENEFITS

Here, first, each of the fifty states it is different. In California, the basic system is we have got the SSI programme, which is your basic income maintenance. Assuming that you are low income and don't have any other money from medical care and social services, then you get health insurance, federally it would be called Medicall. Then the feds give the state a block of money and say use it on social services however you want. This block grant has been there for a number of years, when they talk about decentralising federal government, there is kind of two issues. One there is no problem of giving states a lot of money and having discretion, but the difference in the past is that, they were with the one hand giving the states money, with the other hand they were giving the states what is called categorical programmes, and those programmes assured that the basic benefits would be there. If you have got a strong federal role in the categorical programmes, then if you want to go beyond that and give the states discretionary money, then that is fine. So, our problem with the current federal proposals to decentralise government is that they are decentralising those basic categorical programmes, which we really have to have. Looking at the money the state does get, which is referred to as Title 20, because it comes out of that title. For a long time California has had an attendant care programme, it was in the late 70s that like 58 counties, or local sections of California, we pushed a lot of legislation to one single state programme, which was consistent in all those counties. It was critical in terms of being able to go to school from county to county. There was a lot of things in the programme that would not be there without a strong consumer perspective on how they were developed. Things like, if you need a lot of personal care, and there is a need for you to have control over the attendant, and also to have the financial ability to pay them for a flexible schedule. The law provides two things, one, you have the right to hire and fire the attendant, and to train them and supervise them if you have got the ability to do that, and also you have got the right to get your attendant care cheque at the first of each month, that way if an emergency came up during September, I could fluctuate things however I wanted to. At the end of the month they would fill out time sheets, showing the name, social security number, and the amount of care each worker, and they would sign it, and I would sign it, and it would go in and be processed, all the taxes and give the attendant some coverage, like disability insurance, things like that. The way the programme was basically worked would be say a person in the community, they maybe just came out of a rest home or something, would contact a local county welfare department, tell them, I need attendant care, they would send a social worker to my home, for on site evaluation, and basically during that interview, weighted mostly on what I said I needed, with some back up from doctors, we would I guess assess just how much care I needed in terms of hours per month. Then let's say the paperwork is all done and I can authorise the 100 or 200 dollars a month. Then I need to go out and find an attendant, and actually there's two ways it can happen, and the county has a lot of discretion in this. The counties can 1. sign a contract with a home help agency or something similar to that and the county will then notify that agency of the hours I needed, and that agency would contact me and arrange a schedule and send their employee. I don't like that system. If I need a substantial amount of personal care, then I can elect the other system, the county can't stop me, but the problem with someone else's employee coming in is 1. they are responsive to their agencies, and they are coming in with a predesignated list of services to provide and they can't be flexible about what is going to go on in a given day, plus there is a definite awareness that they are going to .... So, if they need a lot of personal care, or if my county

P.C.A

wants to give me the option to do it, the other method is, I would be authorised $200 a month, I would go and find my own attendant, make sure the service was delivered and each month I would report who worked for me, and it is great if you are severely impaired and you want somebody to get you up in the morning and you want to be independent during the day, and to go to bed at night, a lot of people would do something like have one morning attendant five days a week, a second morning attendant for weekends, and the same with the night time, weekends and weekdays, so four different attendants. That way you don't burn out anybody, and if someone gets sick you have got three other attendants to look to. There is kind of a demand in the labour market for that type of part time work, like especially if you are near a campus and there are students, or a housewife is looking for extra work or something. It kind of fits, but it also does not work as well in a rural area, where there is a lot of distance between houses, maybe not a large labour pool and people have a full time job of survival. There are some advantages in going through an agency that maintains a pool

JE: What if you don't like the attendant the agency sends

Maybe, if the agency you are dealing with is a friendly one, you can call them up and say send someone else. But especially with the fiscal crunch on the programme, if it happens you are lucky, and there's no guarantees in the programme that it will happen, and that is a real big problem

JE: How does this system work for you

For me and most all my friends it works great.

JE: Is there a problem with good attendants moving on ATTENDANTS

Most people here work three months or six months. I have got an attendant now that has worked for a year and a half .... That is kind of why we have a CIL. It kind of plans for that kind of manoeuvre, it makes it so it is no problem at all. You are basically on a week's notice from your attendant, you come to the CIL and get another person, and it demands that you have got an organisation in the community that is responsive to consumers and knows, well, say, when you come in for an attendant referral, it is real important that the unit understands what the consumer wants and it sets you back as a consumer if you come in and you say, I need a new attendant and they just give you a list of names. It is a lot nicer if they went through an interview and gave the prospective attendant a little bit of orientation, you are getting some feedback about the person, especially with the tight community, many of the peer counsellors been there a long time, they kind of get to know what you like and don't like, it kind of personalises the referral system. If you don't have consumers, if you got unimpaired people doing that, then with the best of intent, they just lose that sensitivity, and it can be a real problem, so I think that attendant care was the thing that made IL happen in California.

JE: That sums up the whole problem in England

Have you talked to people in our access project. Eric Dibbler has kind of gone through a lot of local things, like getting wheelchair ramps in this community and so on. We have got another project, that is called access. It is like, one of the problems if you move into a house and you have got a friendly landlord, one of the problems is, first how do you get a person that knows how to build a ramp, second, where do you pay for the materials, so that is the scope of their project. I think the project also is in a whole network throughout the state to cross architectural barriers, and that has been a major policy victory, I think, in the States, is that we have strong federal laws requiring the removal of architectural barriers

JE: The laws are not strong enough in England

It is just bananas what the administration in Washington is doing right now, but what can I say about that. Some of the examples are like, say this block grant concept. One of the things that has just happened here, like I have just described this great attendant care programme we have, the feds have basically cut the amount of money they are going to contribute by 25%, sent that down to the state and then told the states that they could blend this money in with previous categorical programmes if they wanted. One bill, which probably got its final vote about three or four hours ago, would have taken all the social service money, put it in a pot, and passed it to each of the 58 sector counties. Now in California where we live, we have access to one of fifty eight programmes. The biggest technical thing, without being political about it, it is almost impossible for each county government to have the expertise and so on to really develop a programme and with one central state government, we could go there , write our comment and come out with good programmes, and it is dumb to think there would be that kind of consumers that could press vigorously each county. That bill almost came out doing that, I think it is going to be changed dramatically today, but we came that close to losing this programme just out the window. I am just kind of waiting to see, I think that it is going to take a lot longer, round about a year or something, but I think that this whole philosophy is going to get rejected, that Reagan proposes and so on, his general policies, and especially his cuts in the area of social services. I think his philosophy is to eliminate all federal financial participation in social service programmes and throw the burden on the state, but they can't raise the revenues to do it, and so they may think, well we will go back to the private sector will do it.

They know that won't work. The price is that if that did work it would require society to take a step backwards, and get rid of some of the ideas of social mobility and so forth and go back to the days when the whole family worked on the farm

JE: I saw a disturbing programme about blacks in Mississippi

Mississippi is a great example, they were one of the poor states, and also the state government provided almost absolutely nothing, so when the feds make their cuts, it is different from California, with a real good history of being involved in social programmes, 25% in federal dollars hurts in California, but at least there is some state programmes to buffer the cuts, but I just don't know what is going to happen like in Mississippi, people who have young children or are disabled, they can't work, they have got to eat, I tend not to think we are going to have riots and stuff, it is plausible. I think there are limits to how far you can compare Thatcher's policies and Reagan's, the policies might be similar, but her economic environment is much different. I think with disability, the real issue that is going to surface is like we have brought people out into IL situations and if we cut those people back now and they try to get back into institutions, they are not going to get accepted

JE: The economics is crazy

I think we will be vocal enough that they will see that we have come a long way, obviously they are not going to cast us in the gutter, it is really cheaper to keep us in the community. They did not want to accept that. I have heard a state senator say I don't care where you put those people if it saves money. They just don't understand that you can't warehouse people, they maybe got away with it a long time ago.

JE: California is lucky with its funding for attendant care, St. Louis for example does not have this

Did Gini talk much about attendants, she was trying to look at other state models and make it work in Missouri. Was she making any progress

JE: She was not making any progress statewide, because they have real funding worries, they are federally funded

I am real interested in them, because we surfaced out of the state that already had supportive services.

(End of tape - interview continued on new tape)

P. T. O.

JE: Housing in England is .... transportation .... what worries me is you've got too many things you need to get going at once

For myself, transportation is the one to .... the cost of putting lifts in buses .... besides what is the use of having transport if you haven't got the houses to get into

JE: That's right, you need someone to get you up and get you going around ...

....

JE: So, other than that, what is central to policy. You need a hard core of people ..... things that have happened always have taken three or four people who have done all the hard graft and others have hung on .... Gini Laurie's library is the best in the world on disability. It's got all the publications throughout the world, she has given me a lot of publications that will help us to get going when we get back. This book, 'How to Set up an Independent Living Centre', 27 questions on how to do it. It's very simplistic and clear

Bruce's first centre, in Pasadena, went bankrupt, this was real interesting because I think what happened they got a lot of people involved, a lot of folks want to get involved because they are social activists, they are kind of lost people without a cause ..... you have to have a strong focus in order to serve the disabled community, and it is a temptation to bring in things like labour movement, suddenly people want to have social control of your organisation, collective decisions, that's what I like but collective organisation doesn't really work. When you have got such a socially emotional issue it is really hard to stay focused without some kind of guidance ..... and Bruce's organisation lost that. 3

JE: He was making collective decisions

Plus there wasn't the discipline that comes of realising we can only do this much at a time. Bruce always tried to look at the state of the whole world, without first getting his bit together. We are going through that problem now in that you got people who have become among the top national advocates of ..... social security .... and one of the best, if not the best ..... of the disabled. There is other people that know about the programme in terms of being a consumer and we've got at least three people that are national counsellors in that area. On one hand we have that but on the other hand we've got a bunch of ..... and we've kind of got to learn ...... and got involved in state and federal government and you never really develop the funding sources ..... say like I moved up to state government, there's nobody to come in behind me ....

JE: To take over from what you have done .....

You can't be both an advocacy group and a community orientated unless you clean your act up in the community first and that's how I look at policy in the administration. I want to rebuild with the emphasis on making our services quality in the community and it's like we are really bad now

JE: That's the criticism I have heard of CILs, people have to kind of focus their energies to get the act sorted out. I have heard the criticism, look you have got too big, now whether it likes it or not, it seems to be having to cut, that's really sad at a time when you see all these different programmes disappearing

There's something real healthy in that, we had to get overextended because we were basically the first and somebody had to go out there and make the independent movement and get some ideas presented and so on. We started in '72 and we were the only ones and now here we are in '80 and there's 17/20 like us in California and others all over the country. Now we can afford to come back, if wedrop out of the national picture there's others there that will pick it up and I think, like, in the '70s, well forget the date, early in the movement, one together strong voice of an organisation can mould national policy, but aftersay 5 or 10 years, national government is going to look back and say well where are your constituents, are you an issue in one state, or are you an issue everywhere and I think it is real healthy for us to step back and if we rebuild ourselves and move back into national policy, all the other states will have caught up with us, we may still be a leader, but there will be others just as good as us and there will be more of a team approach towards tackling the job. My feeling is that if we can take the kind of cuts they are having now, and it is really tough on us, and accept the discipline that is put on us by the state or the community, and if we can do that well, then in a year or two we will be ready to rebuild again. I can accept the cuts if I keep that frame of mind, it's really tough. There's a couple of people that don't want to go in that direction, they think that we have established some national precedents and we have got to stay here and fight for them, even if that is going to be a lost fight... and they want to stand and fight. I guess thats the problem with a Civil Rights Movement thats its so emotional, the first easy step is to go out on the streets and yell, or togo in the public hearings and yell, but then the movement gets more sophisticated and you get policy changes or to keep what you've got, you've got tohave technical expertise to be able to deliver your message in traditional lobbyist type manner. In ours your strength as a consumer, visibly, there was a great movement in the Congress and yet a problem with social security, where to be disabled, the definition would be 'unable to work'. If you went to work and earned just a little bit of money, you weren't disabled and lose all your benefits, so that meant you didn't go to work. They kind of thought, well, you are disabled, you can't work. Then when a group of us showed up in Washington, where they could look at us, we didn't even need to make our speeches, they obviously knew right away, hey, these folks can work and if they didn't want to look at social factors, here's a group that's getting money, if we help them to go to work, they won't need so much of our money, so fiscally and socially it made a lot of sense, but they didn't really believe either the fiscal argument or the social one until they saw us and it was real important to get consumers involved in that. We've kind of done that and they've seen us, and the shock value of seeing us, and now they're used to that, and now for us tobe politically effective, we've got to be exactly the way you are in general politics in delivering a good argument with political finesse and also arousing folks back in the districts so that people who are voting know that that's an issue

JE: This is another problem area. How do you motivate those people that don't get involved, that don't actively participate, because you are providing an amazing amount of services, for an incredible number of disabled individuals, how many of those are coming back and supporting you at a time when you really need that kind of support?

This might happen while you are still here. The federal fiscal begins 1st Oct., that's like two, three weeks from today, and so soon we are going to begin to see the announcements of things that are going to start taking effect in October, November, and they are going to begin to realise just how deep this threat is and I think folks that we have created access for in the community, that have become involved in the community, they like that mainstream position, don't really want to come back and deal with us, accepting ...... and I'm glad they are there and I'm glad that they can be independent, but I think that it is too early in the movement to assume that their integration is safe. They have to come back and protect that. Also there is this whole second generation of people that are still just moving out the institutions and just being reached. They are a little bit more severely impaired and a little bit more sheltered than the first generation were, so they are going to be a whole new change in the movement, like just before our meeting I was meeting with some of the rally folks and they kind of represent that, it's interesting, the rally didn't come out of the independent living network, the rally generated a whole new network of basically grass roots consumers that weren't affilliated with anybody.

Greg Sanders.

(7)

JE: Michael said this is like a community of friends, we just got together because we disagree with what the government is doing, and this is what we are doing.

I think their success is not to be measured in what message they delivered today or yesterday, but just in the fact that they have stimulated a whole new attention from a lot of new people. It's going to begreat when they surface, I can't predict when they are going to surface or how, but I think they have largely succeeded in that without knowing whether they are aware of what they have done

Maybe these people will fade away or whatever, but the attention that they started Ithink will have an effect. Like they have reached out to people and got them involved, and if just half a dozen of the people reached in that trip get involved, half a dozen people can change the world. I am talking about disabled, good clear consumer advocates. It doesn't take that many, if you think of one articulate, technically knowledgable disabled person, backed up by a whole community or whole state of disabled people that know what they want, then they can create the pressure and that one person can deliver the message and can make it all work. That's a lot of 'ifs' to happen.

JE: Like in St. Louis there must have been a dozen disabled people, plus 8 or so others and so everywhere they went they had that .....

St. Louis is going to get awful powerful little group

JE: I was impressed for something in tthe mid West, you usually get the impression that there is nothing going on there, but they have got a little group of very together people

That is the whole future of the movement in the States, those little groups out in the middle of nowhere can be the ones that get the social attention in the next few years and carry the momentum of the whole mission.

END

Judy Newman/Exec Dir Berekeley Cil.

NEUMANN

INDEPENDENT L. ETHOS

JE: What do you think CIL has done for the disabled community

I think that the movement as a whole has shown disabled people that we are able to make achievements that we never thought we could, and has also given us a sense of self power that I think we did not have as many of us did not have that sense of power as do have it now. I also think that people who were really the disenfranchised are possibly benefiting even at this point from the movement and the fact that we have been able to show that our commitment is to disabled people, irrespective of the severity of the disability of the people that are involved. I think the movement has also been very effective in working with legislators because we have begun to show that we have a political power base, and that is really what politicians begin to look at, do you have people who vote and how many of them are there. That certainly has not been as successful yet as we would like it to be, but considering the fact that we have a history of disenfranchisement, then over a very short period of time really the IL movement has, even CIL, we started in 72, we did not start providing services until 74, you are really only looking at the movement starting in the last 8 or 9 years, so, given the number of years that the movement has been developing, we have really made incredible gains. Many of us are concerned about lots of things that are going on, one of them, obviously, is the Reagan administration, the terrible effects his proposals are going to be having on disabled people, and I think we were over the last eight years really working upwards, we were winning the battle, and what his programmes have been attempting to do is to push us all the way back to the beginning. That is very discouraging, I really believe that many of the people in this country, including myself, have become very discouraged over the last 8 or 9 months, it is amazing to see what this one person has been able to do. The propaganda that has been put out, and the lying information, the absolute lack of concern for the needs of poor people, irrespective of what he says. I think it is going to take all of us a while to catch our breath again. The other day there was this huge demonstration in Washington against Haig where 50,000 people showed up, I think we in this country really need to be inspired by what people in Europe are doing in relationship to our administration, like the German demonstration. I think people should be crazy over the ludicrousy of what is going on in this country, the financial power that this country has, not only for our own people, but over the world, it is a devastating thought. Really what the administration has been attempting to do here is to basically dismantle all the civil rights provisions and to detonate all the progressive pieces of legislation, rehab legislation, special education legislation, which has been created over many years of struggle. The IL movement is going through changes. We are on an upswing downswing, flailing back and forth, but I was impressed with the fact that I met an Englishman a few months ago, who had lived through the first few years of Margaret Thatcher, and it made me in fact believe that it is possible that we can succeed through this marsh, on a day to day basis it is discouraging, but I keep thinking about the British people that I meet. But I know that the struggle that we are going through now is going to get more difficult......

CUT BACKS

(Telephone interrupts interview. Interview terminated and picked up at later date.)

Judy ~~H~~Ne~~y~~uman/Exec Dir Berekeley Cil. ②

I think the reality of what is happening here is that programmes that have provided services that have enabled disabled people to become independent I.L. are closing. There has never been a really strong commitment on the part of government agencies to provide effective services for disabled people. I mean, the independent living movement has started because both government agencies and traditional non-profits have basically not served disabled people effectively. Not only have they not looked at us as a whole and provided services from birth to death and a range of support services, but they also have not had a commitment to believing that we can in fact make achievements and I think that that has been a significant point of the independent living programmes, that with very scarce resources programmes have been able to do a lot more than many programmes with a lot of money, so it is very discouraging to see programmes that have made such changes in the lives of .... you know, in the case of the parent advocacy programme you are looking at not only impacting on the lives of disabled children by getting them appropriate education, but in many cases by having parents come to a place like CIL you are also making them believe, in effect, their children are going to grow up, which is a big problem with parents of children, they continue to think of their children always and not as children that are going to become adults, and then when they think of them as children that are not going to become adults, they also think of them as children that are not going to be able to make achievements, so for parents to come to a place like CIL, they get to see, they get both the services and they get the role modelling and that is true also for adults. When I think of the job development programme, it brings to mind, not only have we placed many disabled people, not only have we allowed and supported disabled people in making their own choice of work they want to get involved in, but we have also influenced many employers and got the employers who previously did not accept disabled people as employees in those jobs. Now I think one of the errors that we have made along the road is that we have not been CRITIQUE capitalistic enough, I think that is the problem of many non-profits, that the politics of many of the non-profit programmes, and us included, has been really to be disenchanted with a lot of the traditional political structures because we have been excluded under the traditional capitalist and really all other political structures to a greater or lesser degree. So we have been trying to create a more, an environment where there was more interest in all people, and in doing that we have worked for less money, we have worked long hours, and we have not done such basic things as charge fees for service to the employers. So, although we have placed between the job development programme and computer training programme over 600 people in jobs, we have never charged any of those employers for our services and many of us have felt that if we were to charge... see, if the law was strong and being enforced and there was a real commitment on the government to make employers hire disabled people, then if we were to come in and say, we are going to charge you a fee for placement, they would be more likely to pay it because if they did not hire disabled people, the government would come down on them, but if the government is basically saying we are not going to care, with all the non-disabled people out there looking for work, and you come in saying you want to charge a fee for your service, there is really no reason for them to have to pay that fee. In the case of parents, we have thought about charging fees to parents for advocacy work and education and then we have been reminded that then we probably would not get poor parents and really the middle class and upper class parents can afford to pay for lawyers, so we really have been serving a population that do not have the money to go other places for services so we really looked away from charging those fees.

JE: So you see the way ahead as charging fees ...

FUTURE

I think that is one of the ways, also one of the ways is for us to set up some businesses, but then again you look at ...., I think we have to set up businesses, but we have been talking about it for years and no programmes have done that successfully yet. We need business advice, we need capital. To set up a business you need capital and you need people who understand how to run a business and many of us are social service workers and we have never ... I would say we have more experience in running a business because CIL and the other programmes are businesses, but they are not a business in the same way as a restaurant or boutique store or movie theatre, any of those. It is a different business and you are not able to get government money in those kinds of businesses, so much anyway. So I think the other thing that really scares me a bit about what is going on is that disabled people have accepted in the past very little and accepted it gratefully, and one of the reasons that has happened is because people have been afraid of losing the little bit that they have had and in many states that is still the philosophy, that people are afraid of losing the little that they have so they are not after rocking the boat and over the next 6 month to 1 year as the cuts become clearer and people finally believe that they are in fact happening, people will, I believe, begin to take to the streets a lot more effectively, because it is both going to be a set in of depression and anger and I think, what I was afraid of with the demonstrations in England was the fact that in this country guns are not outlawed and police use guns and people have guns and the only thing that saved the lives of a lot of people in England was the fact that you have such strong gun control. In this country, when those kind of riots start happening, and they inevitably are going to start happening, the cities are going to burn and a lot of people are going to be killed and the result of that is going to be, I fear, that we will have the upper class and the administration blaming the poor people. There will not be the acknowledgement, unless there is effective media communication, that many of this has happened because of the programmes.

JE: But will they demonstrate all over the country?

Well, those kind of demonstrations will take place in the cities, they have happened in Florida, they will happen probably all over the place, Chicago, Detroit, New York, Massachusetts, Florida, California, where people are highly unemployed and there is nothing for people to do. Then their kids are going to be affected too, when food stamps are being cut back, it is one thing to have unemployment, which we have always had, it is another thing to have unemployment and your kids not being fed, because they are not getting enough food at school lunch and on and on. One of the people in our office wrote a letter to Mrs. Reagan stating that she thought that it was pretty terrible that the week that lunch programmes for kids are being cut, she went out and spent over $200,000 on a china set and I think that really typifies the mentality of that administration. It is grotesque in the truest sense of the word. When they talk to us about tightening out belts, then spend over $200,000 on a plate ....

JE: When I was in St. Louis I spoke to Max Starcroft and he was also concerned about the cut backs in health, because seeing as they are federally supported, they weren't sure what was going to happen, and he was spending 85% of his time contacting business men and making a lot of very strong business links in that community and he seemed quite confident they could almost be self supporting in a while because of that. He mentionned the National Coalition of Independent Living Centres and that some more of us working together with different groups, trying to get through the problems that they are going to have economically might be of value

I think working with the business community, which we have been doing for years, is absolutely critical.

The National Coalition of Independent Living Programmes, being totally candid, I think it is very important that the groups get together, I also feel that if the government does not cut back the funding for the independent living programmes, it might have a chance to get off the ground, if, over the next few months, the budget to those programmes are cut, there is not going to be any money for the people to get together to have a meeting. Which has always been a big problem in the disabled community. Cut off our money and we can't get together

JE: You mean nationally

I mean locally as well. If you don't have transportation, people can't get out of their houses, you can't have a local meeting. You multiply that problem to trying to bring together people from at least 150 to 180 programmes in this country to sit down and talk. We have never been together before, we can give each other assistance, there is no doubt about it, but the reality of the situation is, most of the Independent living programmes have not embarked on fundraising, they have depended on governmental money. Now St. Louis is a wealthy community and he also, I think through his father, has business contacts which does not hurt, and that is not the case for most programmes, most programmes do not have ... Now the Hawaii programme has been picking up foundation money, they have started, a number of the other programmes are getting foundation and corporate money. Besides the needs of our community, however, are not met by those donations, foundations are on a certain level like the government, they only give money for 1,2,3, years in this country, so that although foundation money is certainly important, we do everything we can to take it, it runs out and then frequently no other foundation or government agency wants to pick up a programme that somebody else already started. So unless you have your own capital to maintain that programme, the programmes die, that is one of the biggest causes of the closures of services and programmes in this country, is not having been able to get the capital, private capital to maintain those programmes.

Now the ILP coalition, the national coalition, I think, could, in fact, give people information on how to do fund raising and provide people with that kind of assistance. It could set up guidelines. It is a coalition, and coalitions are important, coalitions wind up having to represent the middle of the road of the philosophy of the group as a whole. Now this coalition has things like Max and Arris, which are really more to the left and then you have programmes which go to the right, we are going to have to fall down some place in the middle, so we definitely will be able to do things, this is if we ever get together to have a meeting. We still have not met, you know we had one meeting in the spring

JE: He said there was hopefully going to be a meeting in November in that place in Kansas, but that hotel fell to the ground, I don't know whether that is going to happen at an alternative venue later on. The criticism I have heard in a lot of places, even in England, is that the CIL here got too big, too fast and it's like its become impersonal and its sort of all over the place, how do you see that, how do you think that has affected the whole management and structure of the place?

I have a lot of feelings on that. One thing that unfortunately happened here was that our programme, being the first programme, had no one else to learn from, so that is a big problem. So we made lots of mistakes that we were then able to talk to other people about so that they would not make the same mistakes, which is an advantage to the other programmes, to have learnt from our mistakes. We also did not start with any secure funding, unlike programmes like Max and the others, where they startedwith at least three years solid funding, unless some catastrophe happened, they knew they were going to get at least that amount of funding, and there also was the benefit of having seen... well, we did not have appropriate staffing in the beginning, we did not have money in the accounting department, in other words we did not have the kind of staff that we should have had and we did not have a. the expertise or b. the funds, so people were trying to ... maybe we tried to do too much too soon, I think, maybe, you know, what we recommend to groups now, when they are applying for money, is that they apply for a solid core administrative structure and build the services on. The most important thing to run the operations is to have a core administrative staff. We never have been in that situation because we did not have those funds and when those funds came out, we were ineligible toapply for them, as they were only for new programmes. We lost out every which way that you could possibly figure out. Now, the other thing that I think we have done, that the other programmes have not done, is that we have been able toshow that, we are probably the only programme that is actively serving physically disabled, blind, deaf, mentally retarded clients. To the best of my knowledge, there are no other programmes that are doing that. We are also serving children and parents. Now, to that extent some people might say we have done too much too soon. My feeling also has been that if we did not do it, most of the places would not do it, that we kind of kept pushing to say that this model could serve more people and that you do not need to set up all these separate programmes, that you can do it under one umbrella, that the integration of disabled people being served under one programme is very important, that the sooner we learn how to work together as a group, the strength of the movement will be significantly enhanced, and I really perceive independent living programmes as being programmes that are the political background of the disabled movement, because without our services, people can not get out to organise, a person who can not get out of bed in the morning, can not really begin to start thinking about how to organise. I think you have to see that one of the reasons why California has been so active is because of the Independent living programme and that other states, as they organise independent living programmes, they become more active communities also. I think one thing that has been very bad is that we have not been able to get money for things that we needed, like appropriate administration, so that, had money and bookkeepers to administer it etc. we would not be having some of the problems that we are having right now. But I think there has always been a group of people on the outside who would want a programme like this to fail and I think one of the things also in the disabled community is that we don't know how to deal with power. CIL has been a very powerful organisation, one of the reasons it has been so powerful has been because of its size. Because we have reached out to so many people, that we have been able to impact very positively on the lives of many many people. The problems that have been going on here are really financial problems, and the commitment I think of the staff and the needs of people have grown, more and more people keep moving into the community, so although this place is not what everyone wants it to be, a lot of people are coming, so there must not be a lot else out there

JE: They are moving into town like anything, every day you are finding out about somebody else. How do you feel about that. It must be an incredible strain, having more people coming, more services to provide, now without the money, do you know how you are going to go ahead?

I don't know. It is very depressing for me, because people come here because they know people who have made it here and some of the people who come here are people who are not activists

JE: They come because of the services. That's what I mean, you got the level of activists and then you've got a lot of consumers who are not contributing towards keeping CILs moving

They are like the average non-disabled person. The average non-disabled person goes to the store and they buy their food and they don't ever get involved in any of the issues around, whether the store is charging too much money, whether the store is selling food that people don't want sold, whether the candy is in the front of the store or the back of the store. You have a handful of people that want to get involved in dealing with the politics of the store. Most people just want to buy their food their, and they just want to buy it as cheaply and efficiently as possible. I am really hoping that ... CIL will survive, I have no doubt about that. It is going to change in size, but I have real problems when I think about what is going to happen to many other programmes.

END

......which is health, educational welfare work, running the kids project, are you familiar with that, mainstreaming, more educational type programmes etc. Well, this has happened before, but most recently, of course, with Reagan, he has done a pretty good job of cutting most of the money. We have had to severely cut back services, if you had come a year ago, this place would have been twice as busy, and twice the staff, but we had a real pare down of services. For our department we have had to go out to the private sector for funding, I mean corporations and individuals in the community, and we have done .... what we do is we send out a residential solicitation, which is a huge mailing of about 25,000 letters signed by a prominent person in the community who is involved with CIL, could be a bank vice-president or a wealthy person, whose name is known. Then, from this letter, we get monies back, so that is part of the way we raise money. To the corporations we submit proposals, they have not been terribly responsive, part of the reason has been attitudes in terms of how they perceive disability, whether the attitude is still around institutionalising people or sheltered workshop, it is changing, but traditionally they are more for the telephon type approach, where the disability of the disabled person is mental, there is still a lot of awareness that has to be done, but on the other hand, because of social conscious pressure, they do have what they call, corporate responsibility, that they have to support x number of local agencies. So, I think within the last year we have increased support from all the corporations, using the tag oof IYDP, going into the big corporations, offering them technical assistance around employing the disabled, what that might mean in terms of attitudes of other employers, making the workplace accessible to people that we have here, and just generally permitting that to happen and once that is generated, hopefully they will give money. Also, explaining to them how much it really costs to maintain somebody in a hospital. Here it is estimated $400,000 to maintain someone in a state hospital

JE: So you are the co-ordinator of all the procedures involved

Right. So, we submit proposals to all the big corporations, we follow it up with a personal visit, from either Judy or Phil. Then we have major fund raisers. We try radio stations, celebrities like the Oakland Ace Baseball Team, sponsor things like this. The problem we have run into is everybody and their brother right now is doing this. We are having a wine reception that a company is sponsoring, we are having a Country and Western dance in the spring, the Oakland As had a big baseball strike here, but now that they are back they are going to do something, we don't know what. We have had people on our community board from the community do little things for us, like the .... have had speakers from CIL would address their group and we have raised a little bit of money that way, and that is two fold, it is community education plus it is fundraising. We try to sort of balance that. We get a lot of requests for speakers to churches and groups. We are having a big dinner, which we have never had before, with Iztac Perlman, he was here a year ago, so that is going to hopefully raise, the estimate is $40,000, which for us would be a lot. That would involve companies buying tables, and individuals buying tickets at a very high price

JE: How long have you been here

A year. There is Reuben and I. Before we came there was essentially nothing, so it has sort of been a slow beginning and we are still just emerging out of the chaos

JE: What was your experience beforehand

I was a publicity director of the United Way, Pittsburg, Penn. and then I was a freelance writer. My real experience is public relations, I've done some fund raising for United CP, but not to the extent that .... but it is sort of interchangable I think public relations and development, because it is all community involvement

END

Job development set up about 5 years ago. It started with a very small thing in the department of rehab. Part of the rationale on rehab funding, this is something that they are supposed to be doing. What tends to happen is that rehab kind of works with clients on a vocational sense of a to z and we sort of work from the xyz of that whole concept, so by the time the people are coming to us for services they are already job ready. They already have the training, skills, education, work experience, so that they are competitive in a job market. They usually have a pretty good idea, although we do a bit of refinement on that, of where they want to be in terms of what type of job. The other aspects of their life are together, so that they are able to go out and do touting for jobs, which takes a lot of time. So if a person is looking for a house or apartment as well as looking for a job, we tend to refer them to housing. Or if they have psychological problems or a difficult emotional period, or if financially they are not together enough to really be able to sustain a job, there are other units within CIL that we can refer them back to. So we are the last stop on the IL merrygoround. At this point people have achieved IL and have achieved some training or skills, such that they are ready to go out and work, that is where we come in

JE: Was this one of the last departments to start up

Right. It is now really concerned with poor service in that many disabled people are looking for work, and the kinds of frustrations that people face anyway looking for a job are so much compounded if you have any disability. They kind of discriminate, the explanation a person has to deal with going for a job, talking much more about their job limitations, or the accommodations that they are going to need. There's many more hurdles a disabled person has to face and we offer a support network as well as intensive counselling. So our programme has two bents, one is dealing with clients, and in clients we work with them on identifying their job, we talk with them about developing good job seeking skills, resumee writing, filling in applications, dealing with interviews, which is really the crux, because the interview is where you are really going to sell yourself into a job. We focus a lot on having a person talk about their disability, the job related limitations of the disability, quickly, succinctly, sort of get it over with, so that you can spend the rest of the time talking about what everybody talks about, your skills. We do encourage clients to deal with their disability on job interview, if it is related to their employment. If you have a disability that is nothing to do with the job that you are going to be performing, say that, if it is an obvious physical disability, and if it is a hidden disability, you make a judgement, if it is a disability that will not affect you on your job, like arthritis, for example, if you don't need any accommodations on the job, there is no reason tobring it up. However, if you have epilepsy, or something that might well at some point have some effect on your job, we do encourage people to deal withthat in a job interview. It can do a lot of good if youdeal with that assertively and quickly. We feel that most interviews take such a brief amount of time, it is importnt to get that over with. We assist people in developing job search strategy, and in that utilise contacts that we have developed over the years in this programme, personnel people that we might know in specific companies .... we work with the client in a team approach and basically are trying to enable the client to develop the skill they need to look for a job independently. We don't look for the jobs for the client. For example, I might know of a company that has jobs along the lines that the client is looking for and what may in the discussion work out is that the client is... I may make an initial contact or the client may make the initial contact and I supply the names, then the two of us sit down and try to map out, if it is a field that we have not developed a strategy, to locating quarters that the client might have skills in or be qualified for. We meet regularly, we have a sort of a counselling mode and a .... we have a strong counselling background. Many people will come to a place which is called Job Development, though actually other problems have been going on for quite a time, maybe problems that require intensive counselling. If the client is having a hard time talking about things in an importnt situation, in an interview situation, then it is possibly because there may still be some difficulties in accepting their disability, self confidence. It is important that those be dealt with, and that a sensitive client is supported

JE: Do you find that job seeking brings to the surface things which have been pushed aside

Yes. We really push for having very strong counselling skills, within job development, a vocational counselling background. Good counselling skills, good intake skills, good interviewing skills. In the first couple of interviews you are really getting a lot of information from the client, on which we base the judgement of whether the client is job ready, have there been appointment problems in the past, if the client has been fired, why, things he did that need to be dealt with before the person goes on a job search. So that is more or less the clients side of it. Then the other side of the programme is working with employers, concentrating on developing contacts for our clients. To set ourselves up as a resource for employers, even if it is not a referral from our clients, perhaps a disabled person comes off the street who goes for a job, there might be som questions that the employer has about accommodations, or they may have some questions about making their facilities accessible, they may have some questions about how much an interpreter costs, whether the TPY costs .... Very recently we have embarked on a much more technical assistance kind of approach. In the past we were giving out all this kind of free information to employers and recognise now, in the light of Reagan's budget cut, our programme is going to be scheduled for reduced funding at the end of this month. We are CETA funded, Comprehensive Employment and Training Act, established about four or five years ago to assist groups that had been traditionally unemployed or underemployed, so our programme got CETA funds, but Reagan is doing away with CETA, this is the last year that CETA will be in operation. So we have decided that what we really need to do is set ourselves up as a consultant to employers and provide services on a fee for service basis to employers, such as training on disability, awareness training, to personnel ..... the biggest problems are always additudinal barriers to getting jobs, it is not the ramp to be fitted, it is the supervisor making a lot of prejudgements based on their ability to accommodate the job. So we have embarked on doing training sessions with employers. We are also providing on a fee for service basis technical assistance aboutt physical access. Talking with employers about how to set up recruitment systems to recruit disabled workers, how to do outreach. All that comes from selling it to employers on a fee for service basis, with that we might be able to actually become self supporting. We have several proposals out right now to receive money for that project. We have done a small sort of test, we got two employers to test out the model of workshops that we have been giving, training and also physical access survey, it got a tremendously positive feed back. Both of those companies have written a good recommendation for our proposal, so we feel quite confident that we have good models. We feel many employers that we talk to continue to express a commitment to hiring disabled employees, whether or not federal regulations are deregulated, which again looks like it will happen withthis administration. They have bought the idea that there is a whole pool of potential workers outthere, but there are still some problems to be worked out in terms of really assimmilating disabled persons into the workforce, we can be there to help that along. Companies pay consultants for a wide range of products, why not this. So I think we are finally, after five years, being forced to get creative, get smart about marketing programmes. Employers that we have established a good reputation with by referring qualified disabled applicants ....

JE: You will be able to stay on the road then

Yes, we are hoping. Most of the boards who review this proposal need thought, so we probably will lose our funds before we get other moneys, however I feel fairly confident that one of the proposals at least will come through and that the programme will be able to continue in some form

JE: Do you see any trends, types of people you are helping

We have primarily focussed on serving severely disabled persons. That has not so much been the problem, I think the greatest resistence comes, for some reason, in hiring a blind person. I think it is based on a stereotype, it really requires a blind person to be able to go in and explain how they have done work in the past or how they have training. We have worked with a real broad range of disabled persons and a broad range of skills as well. We don't have a field enquiry base, but whether a person is job ready. Job ready can be a high school diploma and some work experience or they could have just graduated from law school, we work with that kind of range of people. In terms of trends I would say that one real bright new field that is really opening up to people is the computer field. I think that has happened because there is such a .... it is one of the few occupations that still at this point has great number of openings, and because of that disabled persons who have been trained in this field are getting employment because they desperately want workers, and it is lucrative. Many of the companies then retrain people

JE: I thought there was a separate computer set up

We work together, but pretty much they work with their own clients

JE: Can you give me any figures

We have worked with approximately 550 clients, of whom we have maintained a placement rate of between 60-65%, this is tremendously high, the national average placement rate for the disabled population is about 20-25%. I think the model of the programme that we have developed is very successful, intensive high impact, working very closely with clients, many of the clients who have not been placed have dropped out of the job search for one reason or another, personal problems, exacerbation of disability. It has been recognised as a model programme by the president's committee

JE: Do you co-operate with any other CILs

We have done a lot of training of other ILPs, unfortunately many of the new ILPs, job development is about the last ...

JE: How do you rate job development in the IL programme

I think it is very important, there are not any kind of services out there. Rehab pays a lot of attention to people up until they are trained, then they don't have the time to work with people individually in really getting their job seeking skills sorted out, that's when you fall, if you don't have good job seeking skills all the training in the world is not going to get you a job. Personally I feel it is a really needed service, however, if you have a limited budget and the choice is attendant referrals, peer counselling, housing, job development, and you can only run two of those programmes, I really do hope that at some point the government or someone recognises these services as vital and that they will be funded at a level ..... literally a third of our time is spent in survival, seeking out funding, reporting back to the government

JE: Who does that

We all do, it is not centralised. I am the director of a programme, so I do more of that and less of the client contact, however, it is very frustrating, I prefer to spend my time drumming up more business contacts, establishing a business advisory board, getting a group of employers who are very committed and building on our technical assistance programme, that is where I prefer to spend my time, rather than researching foundations and looking for money, which is what I find myself doing. In terms of CIL as a whole, something that would be helpful would be to have a centralised group to do that for the whole agency in a more planned kind of way, however it is very difficult to get money from those kinds of positions, and it is really a kind of Catch 22, specially right now, it is very depressing, every month there is a new programme that is leaving, the Reagan administration is just killing us, it is very sad to me. I spoke with a blind man from England, who had a show on TV called 'Does he take sugar', he did talk about Thatcher and it was like a blueprint for what is going on here. What gets funded here by charity are places like Goodwell, workshops for disabled people that do nothing to encourage people to IL, it makes me so angry, things like Gerry Lewis telephon, things that are almost totally run by able bodied persons, which is not in itself bad, but people whose philosophy and mind set is very old fashioned and those programmes get huge amounts of private funding. CIL, we are in a strange position because politically we are activists and for that the Reagan administration would love to see us wither away, and in some way that is happening, on the other hand, we provide services that are extrememly vital. I am looking forward to about 5 or 6 years from now, when they are swinging the other way

JE: How many staff do you have

We have lost staff along the way because of funding, at our largest we were 12 and now we are 4, and we will be losing three of those people at the end of the month unless we get other funding, so even at CIL it may be possible that there won't be a job development programme, but we are trying to be optimistic and we are sending out a lot of positive information about the programme.

END

I work in intake, I work in the homebound project, which is probably one you have not heard of, and I also work on accounting. So you are really interested in the homebound project. The homebound project is the federal government grant for rehab services admin. It went one year and it got renewed for the second year, although the budget got cut a bit. Basically the homebound is sort of like a CIL in miniscule, and the difference is we have a budget for transportation, literally to go out and visit the clients, or bring the clients in, and they don't have to scramble around to get people to help with transportation, we just charge it to our transportation budget. In transportation they have the money, or they don't actually have it, they have it in the county, and transportation sends them a bill to homebound project, which is paid out of the homebound project ... I mean it works that way basically. So we can go out and interview the clients. Our basic role is to work with clients who are institutionalised, in their homes, can't get out too much, those are the people we really want to go after, but we can work with just about anybody that has got multiple problems, maybe somebody has just moved out here and they have got a miriad of details they have got to work together

JE: How do you initially contact those people

What we have done is outreach, to let people know that we are here

JE: It seems the areas outreach and homebound probably cross

What would happen anyway, if they contacted CIL as such and they looked like they were going to be a long term project, a client who was going to need a lot of services and a lot of case management, then they would refer them to homebound anyway. Then we send out literature to nursing homes, to institutions. There is a big hospital in San Fran, it has got 1,100 people, it is supposed to be like a rehab centre

....

JE: How do you contact those sort of people

It is very difficult .... some people just don't want help. Either they are happy in that situation, or they are just totally trapped .... we have to be real careful in our working with clients not to lay our expectations on them, which is what we see as their potential, maybe not what they see, what they consider independent living is maybe in the nursing home to say I want to get up at this time and go to bed at this time. What we try to do is find out what they are calling us about, what is it that they are looking for, specifically. Sometimes they don't know how to say it, and sometimes their beginning goal may be much smaller than their long range goal. Not everybody wants what we call IL

JE: It should not be forced upon them

It is not something you want to put on somebody if they are nott ready to do it. Anybody who expresses concern and care about IL, I don't think they are being crazy or anything. Sometimes they don't want to admit it because they think other people have made it and I say, don't worry about it, let's work on your concerns, let's imagine the worst thing you think could happen, what kind of things are available ...... let's work on and on so that the most horrible situation in that head has an answer to it, then if they are stuck on that, it is not like they can't think at all, so they can say well that could work if I changed this around, just so they don't feel paralysed, your mind does not work because you are in this appalling situation, don't know what to do, as long as you can feel, I can work it through, I might have to call a lot of people, do a lot of things, but I can do it. Then one thing leads to another, you get this idea, you get that idea. I have found that just talking with people, this is the situation, how are you going to handle it, they get confidence, or I could do this, or I could do that, suddenly they are doing it

JE: But as you said, there are people who want to do nothing

Yes, it is hard sometimes to accept it. Although sometimes they are not ready for it, it is too threatening right now, so you say, that's fine, but if you think about it and it starts to sound better we are still here, so give us a call

JE: A social worker once said to me that for some people it is too late after a couple of years

I think she is looking at it from a realistic standpoint, after two years it really does get harder, but I don't think it is ever too late. Human beings are very different and what might take one person six months, might take another person six years. Until they get to that point where they get to realise, I don't want to be like this the rest of my life, everybody does all kinds of things, we have to leave space for individuals to have that kind of individuality. In a way I think after two years you think, oh it is going to take a little bit more, but what you really need there to really make it work is the person wanting to do it, that makes all the difference in the world. If everybody else is working their heads off to do it, and that individual really does not want to do it, has not got the motivation, that real concerted effort, it might work , but it is never going to be really together. Some people don't see it as a realistic alternative, when you start telling them what IL means. People who have not experienced it might think that there is not all that much to it, but just the idea that you have got to make sure somebody is going to be there in the morning, if you are doing this ideally, you make the decisions, you pay, you do all these kinds of things every day, youhave choices, and you have to do all these things, it gets tiring sometimes, it is like a full times job just .. and so many things can go wrong, you have gotta be able to think fast, to think of alternatives, all these kinds of things, it is a rough job, and people can see that and they think, I'm not up to doing it. You have got to give them some kind of a credit for at least seeing that, I don't think everybody who chooses not to do it in the beginning is just lazy, I think that just their own capacity to deal with something is not strong enough. I really try withmy clients to give them a sense of what they are really getting into, and also hope they are not the kind of person who once they have hired an attendant the attendant is responsible for them, they are just walking from one to another, they really have to be ready to do all those kind of things, it is not an easykind of a thing, but if they can talk about this and really know what they are getting into and are ready for it, then it makes all the difference in the world, if they want to do it and if they are ready to do it, that is part of my job, to get them ready

JE: How many of you do that

The homebound project has a blind peer counsellor, he is supposed to work with blind or people who have got low vision, but he also works with others besides that, we havea deaf peer counsellor, who works with deaf people, and this includes IL skills, like our deaf counsellor does work at the ILS house and has cooking classes over there, you should see Carol Courier, head of the ILS programme. Then we have an ILS counsellor, if I have a client who needs to learn certain skills, I can go to this person and say can you concentrate on this. Then we have two peer counsellors who deal with all disabilities, Bill and myself. Then we have a rehab assistant, she does a lot of work with the co-ordinator of our programme.

JE: How lond have you been doing this

On and off since January 76, not steadily all the time, I did a lot of volunteer work here, working for my masters degree, one of my internships. I went to Inyat College, San Fran, it is a branch of Univ of Calif. I did a lot of my internship here and I did some in San Fran

JE: How many days do you work here

Four, and I also work in accounting, which is my way of relaxing here, unfortunately my time overlaps, so sometimes I get called for a client, but I realy enjoy learning a new skill. Unfortunately this kind of position is not going to be salaried for very much longer, we are not going to be able to get paid for it, our social service things are just going down the drain. I am really concerned that what is going to happen is that as the economy gets tougher and tougher, when the clients call up and you feel like you can't help them, you begin to feel like, I can't handle another case like this, I can only do so much, it is too much

JE: You must have attracted large number of disabled people to this area, looking for support etc, so it will be really tough all round

It makes people less willing to take those little steps that before they might have been willing to take, because you feel like how much am I willing to jeapordise what I have got now, maybe gain something, but also maybe to lose it, and yet by just staying where they are, they lose it anyway, but it is real hard for me to say too much to them, because it might be their choice, you don't like to push them, because if they fail you begin to feel it is your own failure too. I like to be really balanced aboutit, say, so this, for instance take a job, but you have got to realise by taking this job you may be risking losing all your benefits

P.T.O.

JE: So there is a disincentive to work

They tried to make it more of an incentive, but it is only up to a certain point

JE: Can you explain that

It is very difficult because each case is ... First of all there is two different kind of benefits, there is SSI and SSDI. SSDI is from the federal government, it is a disability insurance, for instance if someone has worked for a certain amount of quarters and then they get hurt, or go down with some kind of disease, and they are able to be certified as being disabled, then they can collect from the federal government a certain amount of money, because they paid into this benefit fund, or if they are disabled and their parents supported them, and one parent dies or retires, then they can collect off of it. It gets very difficult. Now, SSI, Supplementary Security Income, is paid out from the state, but a big chunk of it is from the federal government, the state pays part of it too. It is very difficult for me to say how much, because it can vary from like $100 to I think the ceiling is maybe $6 or 700. SSI in this state is $439 a month, this is for disabled physically, mentally, emotionally, elderly. Disabled children can qualify but not for so much, I think they get $300. Now there is all kinds of little things that I don't want to go into because it does not help. Now, what happens is that you go and take a job, and you start collecting money, you start getting paid. If you are on SSDI, if you earn money over 9 months, you can get it collected for 9 months and it is what is called a trial work period, you can get this amount of money for 9 months and not jeapordise your benefits, after that you do jeapordise them, but if you quit any time up to that 9 months ... Now, to make matters more confusing, if you are severely disabled, in California this is more prevalent than in other parts of the country, you can do it all over the country but most people don't know about it, you can do something called a self support plan, which basically says to dept of rehab and federal government, I can be self supporting, but in order to be self supporting I need certain type of equipment, a lot of people go for vans, they say they need a van, some people go for certain more education, people say they need certain clothes, certain tools. Usually wheelchairs are paid for by Medicall, so they don't need to do that, but if they are not on some kind of benefit where they can get motorised wheelchairs, then yes they would put something like that

JE: What about the ongoing maintenance

Well, you could do it for a while. Now, what also happens here is that you are allowed to deduct expenses from your income, what you need to be self supporting, for instance transportation, but they only allow a certain amount. If you need to repair your wheelchair and you have to pay for it yourself, and you need your wheelchair to be independent, you can deduct that, maybe you have to pay an attendant extra amount of money other than what you already get, for them to come earlier in the morning, or to stay longer, you can deduct that, you can deduct your lunches, you can deduct work related expenses, expenses you might have that you did not normally, that you would not be paying out if you did not work, and that is deducted from your total income, to get it down to a certain level, and also there is employer subsidies, which I don't know exactly how that works, but if your employer changes your job description, your employer gives you some assistance, and you can take the monetary value for that down too. In other words the game is to make your amount that you earn, deduct enough from it so that it goes below what is called the SGA, Substantial Gainful Activity, SGA is about $300. Basically the way this crazy system works, they believe that if you earn over $300 you are not disabled any more, it is nothing to do with how disabled you are. It is crazy. That is it in a nutshell, and there is a lot of ifs and buts about it, there is a whole lot of crazy things, but according to the system if you earn over $300 ..... You can lose everything, then you have to go out and earn it. There is a real farce, there is a lot more to it, and so for a lot of people, who can live on $300. There are people who are clever and are able bodied and don't have all these extra expenses, they really know how to spend their money, they have a place to live that is not very expensive, maybe they can get along

JE: How much a year can you get out of Medicall

Medicall, I'm not sure, their schedule is kind of strange. If you are on SSI, at all, even one dollar worth of SSI, you can get Medicall. Otherwise, you have to qualify financially. Sometimes what will happen is that some people that have to pay are deductable, which means that you pay so much of your medical expenses and then they pay whatever after, some people have $600 deductable, horrendous, but if you are in hospital $600 won't take you very long, you pay that and then after that they pay. Some people have like $300 deductable, what you do is get all your medical expenses in one move, say you are going to get your chair fixed, you have a doctor's appointment, you go to the dentist, you schedule them all in one month so you have more than $300 worth, you try and do it that way. I have never seen how that works exactly, but I have been told that that is how you do it, you schedule all this stuff in at once.

END

JE: I understand you are involved in the San Francisco CIL, I was interested in what you were doing here

That is what I was going to start off with. I remember getting involved with the San Fran IL crowd. After I had been severely disabled about a year, and I was getting back into school, and I did not know what field to get into, so I said, well why don't I get into something that I might know something about, which is rehab or disability, that is me now, so I had better start learning now about me and disability, so I got into the rehab counselling programme at San Fran state university and first year internship I did at the IL project in San Fran. It was not easy getting that as a placement because it was felt at that time that IL projects were run too loosely and did not really deal with clinical rehab matters, psychopathic behaviour etc. So I really had to fight to get in there.

JE: When was this

I think it was 74. What had happened before that, I was feeling really at a loss as to what I could do in this new role as a person with a disability and so I heard about the IL project, so I went there and I volunteered, working there summer and ...... and it was real chaotic, because I had never worked a kind of ordered or structured system and I did not do too well at that, but it did give me the idea I could do something, I could write and I could talk well with people, so I began to have confidence in myself. When I got into the Rehab counselling programme I was determined to get placed in an IL project, really get into it, really work and working with other disabled people. That did not occur my first year, because I had to have a more structured, clinical base, I went to UC Hospital, but my second year I got placed at IL project and I was doing peer counselling, working with people with different disabilities

JE: Was this at the CIL

Yes, it is called the Independent Living Project of San Francisco, and my supervisor was disabled, and a real sizzly woman, visually impaired. It was real important for me to have a supervisor that was sizzling, who I could relate to, who kind of treated me like a colleague and not as a dumb student. It was very important that I could maintain my self esteem. Also, while working there at that place, at a rehab centre called Ralph K Davies

JE: I remember the name there, Dr Chigiliano

He used to be there, when I had my rehab about two years prior to that, he was my doctor, he had very loyal staff. He left within 3 or 4 years, he is now at St. Josephs. One thing was really interesting for me, I went out there with another guy who was placed from the state programme, he had .... and I am an amputee, and part of our assignment was to work on the spinal cord injury clinic there, people would come to us on a drop in basis, while they were waiting to see the doctors, we would talk to them about why they were there and also inform them of IL project services in San Fran, a lot of those people go to rehab and that is their whole life really, getting the bodies back together, but there is no information about the outside resources. How you get back into the system is not an easy matter 2 we were there I guess as role models, we had brochures, we could tell them about services and also their families, so that was part of my experience. Also, working on a rehab unit, this was the third floor, and this was where all the disabled people who were getting about, who were not acutely ill were. We got to meet with them and we co-facilitated a group, where these people, who were patients there, would talk about the problems of being in the hospital, some of their concerns, and it was not all around hospital issues, but also what do we do when we get out, how do I deal with my mother who is overprotective, what is available, how do I walk down the street with this halo on my head. Really kind of heavy issues. It was real gratifying that our time there, at night, a lot of time took precedence oversocial activities, which were important too, but it kind of let us know that people had serious issues on their minds too. Somtimes that is a problem with rehab, is that they just want to focus on the recreational 3 side, which is valuable, but they tend to ignore the process of making the transition from an institution like a rehab centre back into society, that is scarey, so we dealt with that. That is how I got into the IL programme. After I had graduated I was so committed to this place, I stayed there for about another year and a half, just recently left, doing volunteer work. During that time I was involved with peer counselling, training other peer counsellors, doing root work, also starting a live in attendant programme. This other man, who was co-ordinator, and myself, we wrote a programme trying to get a live in attendant programme off the ground. We felt there was a need, actually there is a need on the part of clients, but it is real hard to fill that need, difficult getting attendants. It seemed like a lot of people were willing to be attendants, only on a live in basis if the person did not need any personal care. If they had to deal with bowel or bladder routines, forget it. It was hard, that project is kind of put in the back burners for a while, it is still a dream, when we have the resources to fill it. I had a lot of experience there and it was hard giving up working there, part of me was afraid to take on a paying job, afraid I might lose my benefits, that was the main concern, my benefits, my attendant, what if I got sick, all these fears were forever with me. The director of this programme knew me because I had done an interview with her, I guess she remembered me and knew that I did a lot of outreach, so she told me there was a position open here. I wanted to do it, but then again I did not want to get away from my home base, I decided to do it, I came in and worked in counselling, felt very good, very comfortable, because that staff is very supportive, they have a lot of expertise, in therapy, family counselling, I felt really at home. I thought, hey, the skills I have learnt at school, I can really put to good use here, use my case reportings, I can put together a file, I can do follow up, I was really doing good. Then this position as deputy director came up on a shared position. I was not too confident of myself, it was kind of scarey going for something new, something I had no training in. Something told me, why don't you give it a try, at least you will know, so in May I started this job and it has changed. At first I was supervising seven departments, involving attendant referral, counselling, housing, outreach, financial advocacy, telesensory equipment, that got narrowed down when some of the departments lost their funding, and it got kind of confusing, there was so much to do, so many crises, low morale ..... this is over the last three months, a lot of things have happened, with cuts in budgets and loss of staff, loss of programmes. Cuts My position became real dubious, like what do I do here, so we all went to a Management by objectives training, it put me and my mind anyhow bang on focus. I've got to determine what it is I do, set priorities on what I do, and be real clear, so that I don't go off on a tangent and do something that takes away from one of my chief responsibilities, so I am getting that together, and just as I am getting that together, I was on an appointed basis and the appointment ran out, so I had to reapply for my job, and I got it again, on half time basis like I want. In that job I am still supervising three of the departments I had before, intake, attendant referral and counselling, though my role in counselling has changed in a way I like a lot, in that role I will be supervising intern students from different rehab and social welfare programmes, you need someone as a supervisor who has a degree in their field to give the whole experience credibility. I am looking forward to doing that. Then I am going to be co-ordinating volunteer services and in-service training and conducting tours, and one of my favourite things is outreach. I will be supervising an affirmative action officer, finding out what that means, it is going to involve going to a lot of affirmative action meetings and meeting with different caucases, minority caucases etc. What I really like to do most of all is outreach, I feel I can go and tell different people in the community about what is available, not only in this area, but in San Fran too. When I do outreach for CIL I do it for IOP too, because I feel it is important that we don't compete, we need to band together and work together and make sure that clients know all the resources, all the contact people available to them. Next week I am going to be talking to a class over at State College, who are going to be seeing this film, slide show on disability, called Images. Then I am going to talk to the class about their reactions to the film and their feelings about disability, probably sharing a little bit about my own experiences as a disabled person. It is amazing to me to see progression. I started off not really being too confident in myself as a non disabled person, then becoming disabled, having to build up self esteem, having to look within myself for some kind of self worth, really starting from scratch and just, it seems like it was out of my control, the more I did the better I felt, the more I knew I could do, just by doing, doing, doing. So I want to be able to share that experience. I heard that there are a few disabled counselling trainees there, maybe they will get inspiration to work at ILCs too

JE: Can you tell me about the kids project KIDS

I know when I first became disabled, I did not really ... I was kind of fearful of kids, because of their honesty, they are not going to wonder what is going on, they are going to come up and at that time I was not really into talking about my disability, I just wanted to ignore it, and even today I don't go round thinking I am disabled 24 hours a day, it is a part of me, but sometimes I forget, but usually kids will remind you and will want answers. I think it is a wonderful idea going into the schools, an adult teacher, maybe with a disabled student, and talking with them, and also bringing along the equipment, children are fascinated by wheelchairs and the whole gamut, they are just really turned on to it.nx:Celeste White.2
It is funny because at first kids made me feel very uncomfortable, then I realised they also made me feel comfortable because I had got to deal with the issues that were painful to me, you can't keep denying it. I have done outreach in hospitals too, like talking to .. I guess I am particularly interested in working in hospitals, I feel like when I had my disability, 2 before I became severely disabled, that is where I came across in general 3 the most insensitivity to who I was, I may as well have been a prisoner with a number. So now I have gone back and talked with the staff of hospitals, from housekeeping to interns, just talked to them about my experiences, sometimes I talk about myself or come with a panel of disabled people, who put them in the roles of disabled people, chairs and earplugs and blindfolds and give them tasks to do within their own environment in the hospital, and they come back and you say, how was it for you,it opens up a lot of communication. You just ask people what do they think about disability, what do they say, but by them sharing a little bit of your life it opens up a lot of communication. So, I like doing that, gearing my lecture to whatever ... sometimes I feel a resistence, like what is going to happen now, and it is important to pick up on that and touch on that too in the lecture, so one of my most gratifying things is doing outreach

JE: Is there any other way that outreach works, as well as general communication with the community at large

I know that in job development it is a way that CIL will hopefully start 2 getting money by training, for example job development, I went to Wells Fargo Bank and talked with the supervisor, personnel supervisors, on how to screen and interview disabled people, really providing them with a lot of technical assistance. So that is one way. Also, I think as far as affirmative action, reaching more disabled people, will be a way of telling people that CIL and agencies like this are willing to help people. Sometimes people come here and they don't see anyone who looks like them or speaks their language, they don't want to come in, so it is very important when you are doing outreach, to let other agencies know that there are volunteer positions open here and there are jobs here, to get more multiracial, multicultural group, so that is another purpose, so that the outlying community can feel like it has been centred. That is what happened in deaf services. Gale who is in deaf services, came as a client 2 need in a wheelchair, needing a certain type of service, realising he could not communicate with anyone because we had no sign language, so he started a programme and that is what needs to be emphasised in outreach, that we don't have all the answers, we don't have all the personnel, but you do, we can work together, and that is how I see my job as an administrator. I would be terribly burnt out and terribly egotistical if I thought I could do everything, and I know I don't, so I have to make sure that I have a good working relationship with staff and managers, so I can say, OK you want to get the sort of training, what resources do you know that we could tap. This job is not like a one man show, you have to work with other people. I don't think anyone working here needs to be working here for their own ego trip, it just doesn't work

JE: Who are the other directors, there is Phil Draper, Judy Hewman ...

There are three deputy directors of services, that deal mainly with the services, we have fourteen departments. One woman is full time, Anita Ballman, she covers Access, Transportation, counselling, blind services, she is visually impaired, and youth work, and she does a lot more into the budgeting things. My staff train me on budget, I know nothing about that. She attends a lot of the funding meetings, like Berkeley City meetings and meetings with funding sources, so she covers that. We all have a weekly managers' meeting. The third one is Greg Sanders, he covers more like advocacy, housing, very active in the legislative, policy, he is more legalistic, legislative minded, very organised. It seems like I am more people oriented in that I feel more confident doing like the volunteer thing, in service training. We are just kind of playing with the roles, some overlap, but not too much, we want to make sure that the staff comes to the right person

JE: Do just you three meet, or the whole management

We just got our new positions about two weeks ago, it is new territory, but today is going to be our first meeting where the three deputy directors meet together. We have a supervisor who has been trying to do everything, but her main job is to keep the budget and fiscal thing together, she meets with us and finds out what is going on in the different departments. We are supposed to be working directly with the managers and staff

JE: In England we are still trying to prove the economic sense of attendants

I remember when I first became disabled, I really did not want to even get out of bed. I have a daughter, my attendant took care of my daughter, took care of me and it was through her kind of general coaxing that I finally got myself out of bed and realised that I had more to do than feel sorry for myself. I had a lot to feel sorry for, but I had a lot of other stuff to do too. over the years I have had many many attendants, and each attendant I have had has been the kind of person that I have needed at that particular time, first I needed real nurturing, after that I had a kind of venturous one, finding accessible routes to the grocery store, always encouraging me to go a little further, she got bored at being at home. All these people, whether they have been good, bad or indifferent, they have helped me on my way. So it is very important. A lot of times the problem is not only having money to pay attendants, but working with attendant burn out, say a person needs 8 hour attendant, I don't care how great a person you or your 2 attendant is, you are going to get on each other's nerves sooner or later, what is going to happen if your attendant is sick, who are you going to get, there is no kind of trade off between attendants, like, can you help me with my client because I have got to take two weeks off, there needs to be a attendants - system like that, where you could have emergency attendants

JE: What do people do if their attendant is not there

It is too bad you can't visit San Fran IL because there is a co-ordinator there who is very responsive. A lot of times people would call in and say, I need an attendant, he would drop everything and we had an emergency list, four or five pages long, and he would just read off names and numbers. Like when I was working on this live in attendant thing, I had it all laid out, and then more things started being added, what do you do to check the references, what do you do if the person can't pay to have an attendant referred to him, because this was going to be a paid referral system, so we had to think about sliding scales. As problems come up, you have to find solutions, there is always snags, but you have to continuously be responsive. One thing in San Fran, we were able to write articles about our need for attendants in different papers and sometimes that would bring about attendants and then recently they had a public service announcement where someone from the local TV station PIX contacted the centre there and said, was asking about some other kind of programme, and the attendant co-ordinator happened to be there and said, we have an attendant programme that could use some publicity, and they did about a four minute thing on it, and he said that as soon as it was aired, 70 people called up wanting to be attendants. When you think about the air that the media has, it is very important to tap them and to get them to be responsive to what we need. Here it has been kind of a problem, it seems like the media a lot of times are willing to do things only on kids with the idea of poor kids. It was very hard for us to tell this particular media people that yes, children need help too, but so do adults, let's not just focus on the poor crippled kid image, give this money because of your pity. There are adults too, they are not pitiable, they just need opportunities, and we have a lot of suggestions, like we wrote out scripts. First we had ideas, that was not good enough, so we wrote scripts, like, a day in the life of someone, let's write out dialogue, the whole thing. It brings out a lot of creative forces, you have to be able to create your own programme, sell it to the media

JE: How many staff do they have at San Fran

Less than 20. I liked it. Working in the two, at first I thought, this is real chaotic, then when I got here I thought, this is the chaotic one

If people need attendants they fill out a form, then they go to the job board, pick out three cards and then go to him for an interview. He kind of makes a subjective decision on whether they look any good

JE: Gary said if there was the money it would be nice to give some basic training

I think so too...

.... a part of it comes from the person true enough. I think in order to build up some one's confidence, the attendant should really have an idea of what it is that you need

JE: I think some training is important. I think it is also important to guard against exploitation on both sides.

Right

JE: Is it unusual here for a female client to have a male attendant

2 attendants

Yes, it is more common to have a female working with a male. My first few attendants were women, but I had an electric chair, you could remove the batteries, put it in your trunk and be off, and there was no woman that could do that. A lot of them were very petite women. So then Isaid, well what am I going to do, I am so conscious about my body, so I decided I needed to get the help I needed. Also, I thought a lot of friends would say, oh, you've got a male attendant, what is going on, and if you are married, they will say, what does your husband think about it. I just kind of ignored that and the man I had as an attendant, he was a hit, he really was. He could do the work. I told him, I said, I think I am going to feel a little uncomfortable. He said, well, it doesn't bother me at all. Isaid, I might, but I'm sure I'll get over it. But I let him know that I felt a little uncomfortable, but at the same time I felt he was the most competent person, he was more in line with my personality. A lot of times I would talk to clients and they would say, no I don't want a man. I remember when Ifirst needed attendants Ihad a lot of men calling and I just said, oh no no, that is just not done. I changed, so.....

END

Has anyone told you what KEYS stands for. It is KEYS to introducing disability in the schools and I went to a session for children in one of the schools and a session for teachers in another school. What it is is disability awareness, there is one component of it goes in elementary schools on a schedule and it is in one of the articles but it is generally two or three times a week for an hour or so, that is pretty good intensive experience. Children with disabilities go with disabled adults and it is the children that the main purpose of the experience, interaction experience, is for children in the elementary schools to talk, mostly for the first time with a child like them who has a disability, so they have a chance to, first the child talks about his disability and then the children in the class can ask about it. They are finding that parents have told their kids not to talk about it, not to look at the kid, so they are really starting from square one and the session I went to in Oakland was really inspiring because you could just see the changes and the opening up happening to the children. In the case of the teachers, another part of the project is we have weekly in service training sessions for teachers, they get off early and go for two or three hours, grown ups with disability each talk about their kind of disability and personal experience and then they various ways of trying to get some sense of disability, the teachers will be in wheelchairs or there is an exercise with blindfold, and that type of thing, only it is not exclusively that, it is a lot of different things. The reason there is to try to sensitise teachers to the children who have disabilities who are in their classes, so they can get more of a sense of the commonality instead of the differences. Mainly the project is based on making people aware of the ability and the qualities that people have in common because it is very easy to look at a disabled person and think about the disability, so that is really what it is based on. There are a lot of other parts to it. There is a whole puppet component which I have not seen in action, and I am not sure how that is used, or what they are trying to achieve with it, it is unique I understand 3

JE: Does it include people like me going and talking to schools about my disability, or is it only children who go in and talk

The session that I went to, and adult who was disabled talked first, very similar to what you are saying now, but with him, but this was being filmed and I don't know how typical that was, but it is typical for children to talk about their disability, when it is with the children's groups, I don't think the children do it for the staff in service training.

JE: Do they do the children and staff together

No, they do them separately, so the teachers do something else, or maybe they assist, so they have no part in that, it is designed for children. We have a recent, like about 5 years I guess, requirement that disabled children be integrated into the regular schools and the regular classroom wherever possible and that has put a lot of teachers in contact with disabled children for the first time and the same with children, sothis goes as a compliment to that advance, which we are hoping won't be backed up by Reagan, because he is rewriting a lot of regulations, revising or eliminating a lot of the regulations, so I guess that is why the schools have been receptive to the programme. The two sessions that I witnessed were both extremely impressive and I can't imagine anything that would do what that did. I think it was like 90 minutes twice a week for the childrens groups, it is built into the curriculum and it goes on for a semestre and it is in the elementary schools, and they do like two or three schools in a community at a time and when I went they were in Oakland, and I am assuming that the in service, which was one afternoon a week continues for the semestre. It is not cursory, it is very intensive, it is an ongoing thing and it is intensive, they are really serious about it. They don't go in now and then or infrequently or spotty, like once a month, they go in all the time. Once a week for teachers and two or three times a week on a schedule, built in to the curriculum, and I think the grades are 3 through 6, that would be aged 8 to 10 ....

JE: You must have a big staff to do that

They have four or five and they are cutting back, they have not got money to fund the programme, so I am not sure what pieces they are going to drop
.... tape over....................
It is clear we have been modelled in the year that I have been here. We had BBC, did you see the result of that, kids should have been in there, because they were more moved by that than anything. No I am sorry, I was not here when BBC were here, it was NBC did a thing called 'The Largest Minority' and it was in that

JE: We had 'A World of Difference', the one the BBC did .... (talks at length about the BBC program)..........So Kids might still be coming back?

It definitely is coming back

END

JE: The whole development of the disability movement right now, needs a lot of people to come on, many people are called but few get up and do things, now is the time when just a few more could really help and get things moving

The other thing is that a lot of people come here and they live in Berkeley and they are nice and comfortable and safe and they never go back to their own community with the knowledge that they have gained. Then a lot of people do go back and I think that is one thing that could happen, coming here and being real comfortable and safe and having things real accessible and then not going back to your own communities, helping to establish something there. Every day I am here I think, do I ever want to go back to Boston. Cambridge has a certain level of accessibility, but all in all it is real bad, the East Coast buildings are very old, expensive to modify

JE: That is the same in Europe

One more thing I just wanted to mention about is, a factor I think is going to be really important, which has been real important in my life and will be real important to the success of the disabled movement in the future, is those parents right now, today, that have disabled children and have disabled adults in their home, that they can make a big difference in people's lives. I had a very strong mother, she advocated for me when I was too young to say anything, she fought to get me into schools, get me into places where she thought I should be, and if it was not for her being so strong, I think I would be less so myself now. She was inspirational to me, my father was strong, real good too. Parents make a big difference in people's lives, if they are feeling guilty, if they are depressed about their child,if they are smothering their child, that kid is going to have less opportunity to learn self reliance and to self confidence, so we need to really stop and work with our parents

JE: I'm still trying to normalise mine

My mother is motherly, she still has her twinges of Oh God how can you go 1000 miles away from me, but on the other hand she is very supportive and she knows that Ican do it, and she worked real hard to get me to be physically independent and not dependent on her for things, to go to the bathroom to get dressed, when I was first in a chair I was much more dependent on her. She wanted me to go to college so she pushed me into learning how to take care of myself and that has made a big difference. And for those people that don't have parents who do that, that is when an advocate or counsellor really can be important, that a lot of what I did when I was counselling was working with parents, helping them to adjust, helping them to at least leave their kids alone for five minutes, to be supportive

END

JE: You have to provide your own attendant?

We have to provide our own Attendant from either the Dept of Social Service or a friend or a family....

.....(Another voice... "Hi! I'm Lori"..... and then this voice takes over!)......

Its to provide accessible housing at a real cheap rate. And we do room and board and all utilities at these two houses, there's another one right behind it. So basically, I guess, at the end what I'm saying and what we have been talking to Cheshire about is that we provide a resource in the community and that there are IL situations, there are barrier free apartments not far from here that are independent, but we do co-operative living for people who don't want to live alone or don't have the resources to live alone, or they might be a point in their life, they may have come from their parents house, and not be ready to live alone, because they have not been trained or because they do not want to. So basically what we do have is two houses here and one in Santa Cruz, the one in Santa Cruz we just rent rooms and it is all accessible and people are responsible for shopping, cooking and cleaning. Here we have a room and board and utilities, witha manager, three meals a day

JE: So in Santa Cruz they have to do a lot more for themselves. What about an emergency type situation

In Santa Cruz it is pretty much up to them to decide to call the fire department, which would be just like anyone else living alone. Here we have an emergency call system

JE: I was thinking more of physical care

Attendant care? Well in Santa Cruz it is just like living in any other house, you have to wait for someone to come in or phone. Now here we have a manager on call 24 hours, he lives in, and we also have an emergency call system with a beeper for the middle of the night, so that someone from the back house can communicate with the beeper at the front. There have been times, even here, when people have called the fire department in the middle of the night, because their phones are right next to the bed. Really we encourage people to use whatever resources they need, whatever the problem is.

At the very beginning, people are coming to realise what each person can do for the house, like Bruce has done dishes, I think, for ever. It is his choice, or vacuum, or dust, or make telephone calls, or whatever it is, everybody does something. It is quite disruptive to have someone come in from the Board of Health or Social Services, sneaking in kind of to see how we are doing

JE: In the beginning they did that a lot, did they

Yes, they wanted us to be licenced, we will fold before we will ever licence

JE: Are you still having problems on that

No, it has been two and a half years. They just decided we are not bothering anyone and we are legal and people are happy here.

A resident: What I wanted to ask you, we could do with a maid

To get someone to do dishes would be too expensive, but once a week someone to scrub the apartments, do the windows, walls or bathrooms

Resident: I generally find the bathroom dirty, and I am taking charge of it

But I don't think I can solve that really, I think that is something, like the board said, you either have a house member take it over, or you use paper plates, or I guess we will find something else to do, or get a maid

JE: So there is five people living here

Four in the back house and then there is five in the front house, we call it one, but it is obviously two houses

JE: How many people on the board

13. We alternate the board meetings between the two houses, we meet once a month. An idea which the house is working on now is that we would like house meetings,not formal, but we havenoticed that people don't all get together in one place, they will say something is wrong tosomeone else, but not really express it to everyone, so I think the Board is just generally said ......

JE: Who make up the board.

Originally Dorothy Nicholl started on the board and then people have given us names, and the house has suggested people like the Manager, people from the house, but it is not formal, we don't have someone on the board from the house which we are talking about right now that is a voting member

JE: Are there any disabled people on the board

Yes.

JE: People in thelocal area

Yes. That originally started with us and have disabled children, or disabled themselves. Rob Johnson has moved into the Santa Cruz house a couple of monthhs ago. We are real lucky in California. In Nevada it is very different, most disabled are from Nevada come to California, because they make about $100 a month and do not have any medical coverage. Here we have attendant care, Medicall for emergencies like wheelchairs, basic medical coverage, emergency coverage, attendant hours and social security allotments, which enables people to make a choice. Those that arenot eligible for that programme, there is of course always convalescent hospitals here, and if nothing else you can be assured that you will have some medical attention at a convalescent home, a room at least, I do not know what you can get beside that. People can go there to recover from a pressure sore or something like that, like Bruce here broke his hip, something that we would not handle here. We really don't provide any medical care, that is something we have been talking about and we are really not sure what to do. For instance if someone does have a severe pressure sore, I think what we are not clear about is when it is our turn to say it is getting serious, you better go somewhere.

JE: Ideally it should be up to the person themselves to take care of them so they don't have pressure sores

Right, but when is it our place to say, you seem real set with that cold, you should go get checked, and when is it their place to say, it is my cold and I am fine. I am into my third year here, and the idea is for me to phase my positon out and for the house to run everything, I am really generally phasing everything out and I only down here maybe once a week at the most

JE: So the disabled can take total control

They get a cheque once a month and the accountant turns it over once he has paid the basic rents, they pay all the bills

JE: How do they come to live here

Originally I think Dorothy scouted every place around here, sent out notices, to convalescent hospitals, who did not want to lose people who were easy, to social services. She even went to the convalescent hospitals and walked through and looked at people, kind of spying really. Then we put ads in papers, and word of mouth. We know we are not getting across really to a big cross section. How do you guys do it over there

JE: A variety of ways .... (tells them about democracy at Le Court)

These people hire their own manager here. It is their money, originally the board said no, they have to learn how to do it, but after a while we realised these guys have to live with it. So now the house pretty much does it all. I come down an oversee it and tell the board what happened,just so they know what goes on, we are not here to make decisions or anything. When I first came, the attitude of the board was, well here is a group of people we really want to help, and now it iss more, they can pretty much help themselves, we are just here because legally we have to be, and if they need something feel free to ask. They have shown that no catastrophe is going to happen if the board does not stay close, I think in thelong run that is the way it is going to be.

JE: Where do most of the people come from, anywhere or local

Local are the first choice, because we bill ourselves as local, but we have had people call from like San Jose, but not too far away, we have had a couple of calls or a letter from say, LA or something

TAPE OVER

(Tape side A (Lori Guiliani) ... inaudible until after half way)

JE: Ed Roberts made it to a meeting on the Saturday

He has got good support too, his wife

JE: Oh yes, he has got a very good scene, but he needs it, he is so severely disabled

(Another voice):- He has done a real good job down here, some of the money that has come down here is earmarked specifically for CILs, things that probably would not have happened had he not been disabled

JE: He has taken a lot of criticism for it too

(Continues inaudible,..........)

END

..... vocational training that CIL does, they might refer someone to training elsewhere, CIL might if they don't have any other programme themselves. It was started by IBM, they really brainstormed the whole thing, a number of years ago they had a fellow in marketing who became disabled - quadriplegia - and they gave him the choice of either retiring and collecting disability or they were willing to retrain him. He wanted to be retrained, so they retrained him as a progrmmer, it was the first time it had been done with a disabled person and it worked out so well, they thought it was a good idea. They thought it would suit a lot of disabled peole all over the country, so then they started looking around for likely locations to set up programmes, and they found just about all the things they needed to set up a programme here in Berkeley, those are the ...... They found CIL here already in existence, they found the state Dept of Rehab was real open to the idea, the only other thing they needed was a business advisory committee, so they set it up for us, all the customers round here are all IBM people anyway, so they have really got a handle. So they just had a big wig at IBM call up the big wigs, Crocker Bank, Bank of America, Standard Oil, and tell them what they are trying to do, and ask them to appoint someone from their company to become a member of the advisory committee for this project. That's how it started

JE: Amazing, I did not realise IBM were behind it

They are really the company that started the whole Hire the Disabled movement, there has always been goodwill, march of dimes, but there has never been a company standing up and saying hey this is something we can do, start supporting people, hire them, give them work. So the three legs, it is kind of a tripod, would be State Dept of Rehab, BAC Committee and CIL, without any of those I don't think we would be able to function at all, certainly without the Business Advisory Committee, that is the thing that makes us different from other programmes. Probably half our total budget is donated directly or indirectly by business. One of our greatest expenses is computer time. We use $200.000 a year computer time and right now we are getting computer time donated from Chrysler and Standard Oil and IBM is going to start giving us some computer time soon. We have the BAC committee, and every year we assign people to the sub committees, we have 7 or 8 sub committees. Just to give you some examples, one of them is a curriculum committee, where business people will help us a great deal and make sure we are teaching the right things, make sure we are not teaching something that is outdated and outmoded, make sure we bring in new things that might be up and coming, skills and languages. They also help us place students, we have a placement sub committee, the guy that heads that is a recruiter inthe city, for a recruiting company, so he has a lot of contacts, he knows about the skills that are necessary for obtaining a job, he will come in and talk to the students, towards the end of the course, about resumee writing, interview skills. We have a work experience committee, the last six weeks of the programme, after all the class work is done. The programme is nine months long. Strictly business application computer programming, very intensive. Equivalent to a two year programme at a state college or community college, so it comes real fast and heavy, you really have to want to programme,you really have to have a lot of determination to get through this programme. They can figure on 8 hours a day on average, including weekends

....

We have occasionally around 50% drop out rate, usually it is around 40%, for various reasons. If it is a problem of disability, very often they will drop out of the programme, take care of what has to be done, and come back the next class, we try to do that when we can. The ones that drop out permanently are ones that just can't hack it, can't hack the work, don't have the logical skills that it requires, or they find out they don't want to programme, that is probably our biggest problem, people just find out they don't want to do it, too much work. People that do get through the programme, find it is a lot easier on the job than it is in the programmes, it really is worth sticking at

JE: When did it all start

About 75, this is our sixth year and the IBM fellow was injured a couple of years before that. Talking about the work experience in the last six weeks. Companies are willing to sponsor a student, or take a student in to their data processing shop, provide them with a supervisor, and let them do programming work for six weeks without pay, we don't want them to receive pay, that endangers their SSI benefits

JE: What about paying for the programme

That is where Rehab comes in, just about all the students are clients of Rehab, either that or they are clients of veterans administration, a couple of those, but almost all of the are Rehab. The cost of the programme is over $7000 a head, so it is not the type of thing where people come in and put the money down on the table

JE: With such a high success rate, I expect it encourages a lot of people

Definitely. We found out how valuable we are to the state this last year, they wanted to, not cut our budget, but hold our budget to last year's level, and we had been held at that level for two years, so it would have been the third year that we would have been expected to work at the same, which is impossible. So we went to the state, talked to the Director of Rehab, took our business advisory committee head and another businessman, and we talked to them, we extended ourselves, we made a commitment that if they would increase our budget by another $40,000, as an investment or a loan, if they would give us that money now, we would make sure that we would not come back in any year subsequent to that asking for more money, and they liked that idea a lot, they gave us the extension, they gave us the extra $30,000,now we are in the midst of making sure that we will have thefunds to make up the difference for next year and the year after that, so we are involved in a lot of fund raising activities, all different ways that we can think of to bring in more income

JE: Does fund raising involve a lot of your time

Let me introduce you to the Director, Joni here is the Director, does fund raising take up a lot of your time

Joni: It is a whole new ball game, we have never had to do it before. Companies already give us computer time, now we are going to be asking for more, so it is going to be really tough, and then we have to compete in our organisation with other services, they are out trying to fund raise, so companies will say, well we gave to wheelchair repair and now you want some. We are the most practical programme, because we are actually training people, so they like to give to us, but we just compete and it is strange, it is real hard.

The state would love to do anything they could for us, and they do where they can, but they are being cut drastically, they have got a lot of programmes to support. It is a sticky situation, time will tell, I am real confident right now that we can do it, next year and maybe the year after that, I don't know what the overall effect is going to be

JE: I heard there was a 90% success rate, that must give you a lot of weight. Can you tell me more about work experience

I don't know if I made it very clear, but all the time we are looking for companies to sponsor us for six weeks, to give them experience. Often that turns into a hire, the company gets to know the employee, likes them. If they don't get a job at that company, we tell them that there is no obligation to hire them, but if they don't hire them, the confidence that the students have gained is amazing, they would not be as work ready if they just walked out of the classroom, they know that they can do the work, they have the experience of working in a shop, they are not frightened any longer, they feel confident. It is nice to start in a situation where you know you are not getting paid, it is just a temporary thing, even if all your worst fears came true, you found you can't do the work, it is just work experience, not your first job. The first week is traumatic, and being disabled, some of the folks here being recently disabled, spinal cord injuries, it is a big emotional change they have to go through, and I would say that is the most exciting part about working here, seeing the people gain confidence, they can be shaking and nervous about being among so many disabled people, nervous about their own abilities to do anything, whether they are changing career, or for some of them it is their very first job. It is just incredible to see the difference it makes, and the fact that it is disabled people working together provides a real supportive atmosphere. I have seen people come in here with terrible hang ups over their disability, and leave without those hang ups, they see a lot of people are a lot worse off than you are. Often I have found, when I was growing up in this society, it feels like you are the only disabled person. I was literally one of two disabled people in my high school, it was a huge high school, 7000 students, every one else is able bodied, and it has a large effect on that, this place does. The range of disabilities is incredible.

JE: Do you find there are more spinal cord injured

A lot of spinal cord injury, a lot of blind, a lot of deaf. We have a very good sized deaf population in the Bay area, CP, post polio, MS, just about everything you can think of at one time or another, we even had a sickle celled anaemia fellow that we are real concerned about because that involves, you have crises, you have to spend time in hospital, you never know how often that is going to happen, and sure enough with this fellow, it did turn out, three months in the programme, he would just collapse, have to go to hospital for a week, but he was brilliant, and even though he missed a lot of time, he was by far the best student in the class. He is working for IBM now, IBM is real good about hiring too, they took Nelson knowing that he would probably spend a lot of time in the hospital, time off work, so their response was well, can we set him up with a terminal at home, I thought that was wonderful, and they have done that

JE: Being able to work at home is a real important step

The computer age has done that. It is all together in a little box right in front of you, you just have to be able to work a mouthstick or your nose or whatever, just be able to work those little keys. If they think speed is going to be a problem, if one of the students is real slow at typing, things like programming it is all cerabral anyway, if anything it is good, because those programmers are the ones that have to learn the short cuts, those are the ones that don't get on the tube and spend a lot of computer time debugging and altering the programmes, they do it in their heads or on paper beforehand. The companies love the disabled programmers, they have real good working habits. You have the old familiar story that they tend to be more loyal, stay with the company longer, more of a sense of loyalty once a company does hire them, we have just got real good feed back. It has been real successful, the state has told us that we are their most successful in the state, and I think that would also mean we are one of the most successful programmes of its kind in the country

JE: Do many other CILs do this

When IBM started our project they started a number of others across the country, this map points out the locations. The whole group together is called the ARPDP, Association of Rehabilitation Programmes Data Processing, and that is the newsletter, one of our ex directors is working for Kaiser Lumen now, she is putting this thing out so the articles in there will be about our project, which is nice. The different projects do it differently.

JE: They are all on the East Coast except you

I don't know why, they tried to start one in LA, from what I understand, there is something about this one, ours was the second one they started, and there is something about it, because IBM has been trying to figure out why ours is sosuccessful, the other ones are still in existence and doing well, some have come and gone since it was started, a few of them have collapsed, but there is some combination of qualities here that work real well

JE: The SIA are keen to get into computer programming

One of the things that we have been interested here,now we are too busy, but trying to think of other occupations that would be as suited for severely disabled people, electronics technicians was one idea, but that would only work for a para, you have to have good hand co-ordination. There is bound to be others, I am sure as jobs are becoming more computerised it will happen, there will be a broader range, where you don't to do programming or nothing, I hope anyway, that should happen

JE: Are there lots of instances where people actually go out and find jobs themselves

Very frequently, the less involved that I can be in it, the better. To put it esoterically, if I find someone a job, it is like I am inflicting my choices, but if they go out and do it on their own, the significance of that to them is tremendously important. If I find them a job it is just an extension of something that has been happening all their lives, lets do this, lets get you into this programme, here's a nice job for you. I think that is one of the most important functions that we can serve here, to get them out of that mode. I insist from the beginning, when I first start working with them, that I am not going to get them a job, I will help them find their own job. So what usually happens is, the work experience is a great way to start, they are getting experience, even before they have to look for a job, experience in a shop, experience talking with managers. They find out from the company if there is any chance of them getting hired full time, and if they are not, there is still that experience of having dealt with these people, they have got a resumee by this time. Very often within a few days they will have plans of their own, the ones that have not got hired by the work experience, that is not always going to happen. Most often students might ask for a few tips, or a list of addresses, they will get back to you a week later and they will have ajob. If I am real lucky, two thirds of the class will be able to do that by themselves, those are pretty secure people. There is always a few that, usually don't have language skills, communicaton skills, don't know how to deal with business people, haven't done it before, real uncomfortable at it, come across either as too nervous or.....

END.

JE: America is a model for the world at the moment

I have a feeling the rest of the world is going to catch up very quickly, not all of it, but many countries, those that can afford it. I wonder what is going on in Arabian countries ...

JE: You can't find out

I think there's a lot of cultural problems

JE: There are a lot of Arabs as private patients in Stoke Mandeville ..... (diatribe against Stoke follows)

There is an article here about Arabs getting overcharged for things

JE: They get exploited, they were in Stoke ......

....

JE: We stayed with someone in St Louis who had adopted a four year old Indian girl, they were going to get their second from Honduras, they already know the child, they are trying to get things moving. The problem is with his disability, they might not accept it

I think we are better in different regions of the country, but the country is so big ......

....

JE: It has got to have some effect in England, people are political there but you have to have lawyers, disabled lawyers

You have got to have people who really understand the med ....who won't sell you out like a bunch of do gooders, and the disabled people really have to be involved in setting the priorities, tell the lawyers what to do. That is what we are trying to do in our office. I am running another project, getting private lawyers involved in servicing disabled people, and we are training them in the law, and we are going to be doing intake on the cases, interviewing clients, determining what is the best approach, and then referring them on to different lawyers, that is just starting, I don't know if it will be successful or not, but it could be a good source of income for us, because a lot of the laws that we have allow for attorneys fees to be awarded, if you are successful, the other side has to pay your lawyer, and sometimes punitive damages also, especially in California for discrimination, you can get more than just the amount that you were injured, but damages for breaking the law. If we get that then we should be able to get part of the fees that the lawyers collect to help us in our operation. One of the more inventive projects that we have for getting money in spite of the federal government. We are also getting to private foundations

JE: Are you having much success with the private foundations

Slowly, you just can't move it too fast, they have an awful lot to learn about disability rights. They really don't understand what we are talking about. In this country we have had the horrible telephons to deal with, they were fostering a lot of negative attitudes about disabled people. Those attitudes are just widespread and on top of that, if you try to collect money, they say didn't you get money from the telephon, and you say no, in fact we actively campaign against the telephon, we don't like it ...

....

.... has a periodical look at our books and we require a receipt for everything, it is just very tight run. There is a certain size I think that if youget above, you start having real problems, and CIL have got big problems. Too big, too fast. The staff feel very alienated from the people who are running the place, there is a real division in many of the minds of the people who work there, between workers and Management. I don't think that exists with our organisation. That is important. We really have a chance to learn a lot

JE: You were part of CIL when youfirst started up

When we started up I was on CIL board, I was in law school. We started Disability Law Resources and it was part of CIL for a while and then Bob ...., my boss, the guy who runs this, decided that the place really had to be separate, for accounting reasons, the CIL could not keep track of money, and partly because he felt that an organisation involved in legal advocacy needed to be separate from aservice organisation. You really have basic conflicts between staff and programme objectives if you are trying to develop from one organisation. You lose certain advAnctages. It is harder for us to really have out feet firmly in the community and in the community's needs, but if we provide direct services of one sort or another, we have some indication of what people really need, what direction people need to go in. As long as we stay run by disabled people, it is a sort of assurance that we are really still relating to what the disabled community needs

JE: they still have that conflict because they still have advocacy

Yes, but it is more individual advocacy, more direct services, and in a way it is a direct service itself. A lot of the broader advocacy is done by us, and we don't have that much of a conflict, but whenever you get into direct services, on a legal basis you are going to have that conflict too. Youshould give the staff, some of whom really want to work on individual cases, and some of whom want to do class actions and broad based impact work, and sometimes it is difficult to do both. So our project is basically involved in the broad based work, that is where we can be most effective. It is very hard, individuals discussing problems, maybe it is just not the right case to take up to the Supreme Court, and youhave to say, no, I'm sorry it is not going to work. But you have to get rather hard nosed about it, be interested in how the law's developing, and the precedental value of what is going on. That is a bit complicated. In the legal service in general you have that basic conflict. I have been reading 'Simple Justice', a book by .... .. Kruger, about the black civil rights movement, and how historically they developed their strategies, how they very consciously chose the cases they wanted to raise, in what state, for what reason. It sure is helpful on how to do effective strategies and how to work out law reform. It is very well written, full of lots of details, and I just have learned a whole lot from reading the quarter or so, it is very interesting about history, it illustrates the constant back and forth between the property ownership minded people and the individual rights minded people .....

JE: Your boss is disabled too

Bob ...., he is a ....

JE: What kind of decision making process, do you have a board ..

We have one but it does not have any power. Decisions are made by a corps group of people within the organisation, depending on the decision that has to be made, the group is smaller or bigger. We are also now engaged in setting long term objectives, we are going to be holding a meeting in November, civil rights groups from women's groups, blacks groups, Chicano groups and the ACLU, American CIL Union, and a lot of other major public interest and civil rights

JE: They are the people that put up solidarity

No, they were the Labour Union. In November we are having meetings of all these people and together we will devise some long term strategies. Looking at two basic issues, one is voting rights, how to organise people around voting .... you have got to demonstrate like old people are, that you are going to vote in block and why you voted, you can do it with money, but we have not money, we just have votes. We will be working with black people .... and we will also be looking at the problem of law enforcement, and devise strategies that are workable, so as to ....

JE: Do you think there is a likelihood of that happening with a Reagan govenment

I think that Reagan's programmes are starting to fall apart, and the advantage of having a totally unprincipled Congress, like we have at the moment, is that all they care about is getting elected, once Reagan starts losing support I think he is going to have a very swift fall from grace. The people of this country are going torealise that he is out to gouge most anybody, and his programmes can't answer the kind of problems that we have and that he really does not intend to answer them, he just wants to turn the clock back 80 or 90 years. I think experiences in England are helping to accelerate that process, we are just having the same problems, only bigger. His whole approach has been so devastating, the impact of what he is doing has not really been felt yet.
What is going to happen to America, it is just going to be so horrible. Congress is just going to be so busy, trying to sort out crises. I think once the tide has turned, disabled people are perceived as having strength, as we have been perceived as having in the last year or so, they won't cut it all, we will just have to work along. So I am optimistic, in the short run it is going to be awful, but in the long run, if we can get all this right wing stuff out of our system, people will see that it does not work.

We have soup first ....

END

ED ROBERTS.

We are here to talk about Disabled Peoples International. A new and I think very exciting organisation of people with disabilities. It seems to me that this could be our chance to bring the latest phylosophy, technology and especially the whole self-help approach, to the world. The idea is to help people take control of their own lives; to make people less dependant on Government or anyone else...but to play the game at several levels. The first would be through the UN and we have sought or are in the process of being granted from many of the organisations including, UNESCO, WHO and ILO (International Labour), and many other worldwide organisations within the UN,... are in the process of endorsing the new organisation, and funding it. They are especially helping to fund the Singapore Conference which will be a World-Wide first, bringing together leaders in organisations from around the world - from every corner of the world - with votes to vote on a new Constitution and to discuss ... and to elect a World Council, a council of people from each continent... two representatives from each continent.

It sprung out of the Winnipeg Conference... and there were more than 300 people with disabilities there, and even more friends, who came together to try and bring a strong clear International voice to the affairs in the world that dealt directly with those of us who have disabilities and especially those who have more severe disabilities... but we are also in the process of being set up so we can do consulting with nations and developing nations. We dont want the emerging world to adopt the old principles of segregation and charity that just are no longer acceptable and if we are to have a say in our own lives, (many of us have gained a measure of that say), where the world can join us, to help our brothers and sisters, wherever they may be, to do the same. To help them with technology. For example, Ralph Hodgkiss in Berkeley has a wheelchair that can easily be adapted and used in places like Nicaragua and anywhere in the world, out of indiginous kinds of raw materials. Our interests and the interests of disabled people everywhere are very similar, I may be talking about civil rights here today, and in many places around the world people are talking about survival, so we have a tremendous range of possibilities and things to work on but we must do it collectively, so that each of our interests need not be subjugated but that by coming together, all disabilities, including the mentally ill and those mentally retarded.

I think the founders - as we envisioned DPI just could play a very significant role, changing the course of a lot of brutality and a lot of prejudice and other stereotypical responses to disability. Right now on the council we have two people from each continent. In the main the leaders are from Canada, Ireland, Sweden, USA, Singapore, Costa Rica, Argentina, Zimbabwe and French Mauritania, all representatives are disabled. The Council by bringing together people from round the world will begin a process that should bring all people in the world with disabilities closer together. Building on the strengths of the already worldwide orgainisations. Deal in the main with specific disabilities, on deafness, blindness, mental retardation etc., but the key to DPI is that it must be a coalition of all disabilities, by disabled and for the future of all disabled people. It is clear that our role as disabled people in each country is to begin to reach out, for example, in Zimbabwe our delegate needs used clothing, so any group that would like to take up a collection of clothing, they sell that and use the income to support their organisation. There are so many things that we can do together if we learn more about each other. The main job in the next few months is to spread the word about DPI and to join with us. Read our draft constitution and provide input. Two of the very specific tasks we have taken on are a lawsuit in Germany that allowed people to get money back on a package tour of another country because they were depressed by the presence of disabled people among them. The other issues have to do with airlines, just being able to move about and all the different regulations and problems with electric wheelchairs and white canes and all the patronising treatment that disabled people get in general from international carriers, so we have a lot of work to do together. This will be an organisation where we set the priorities, our dream really is to do something in many areas, one is prevention. The number one cause of disability in the world today, and there are estimated 1/2 billion disabled people in the world today, the number one cause is malnutrition. It means that as we get involved in organisation we will be also providing a lot of technical assistance to help prevent disability. It means that the vision is not to gain more for people over and above those who live in a society but to gain an equal opportunity within a society, so if everyone is poor you are not going to make a disabled person rich, but equal.

JE: What about those disabled people in DPI who have difficulty in leaving their country to go to Singapore? Is there any way that they can be helped to get there?

Well, we have been very seriously thinking, we realise that it is the first and many people will want to attend who will not be able to, from all around the world and we hope to have money for scholarships for people from developing nations, at least for some from each country, depending on population, we hope to get that from the UN , but we are expecting in the developing nations people to go to their governments and talk about becoming a part of this because the government is not going to send somebody, that is not how we work, we work within organisations but the government could participate and be supportive in the UN and also provide transportation, so I would think you all would want to get this organisation legitamised, contact your Irish colleague and he will, I am sure, help out.
The Irish representative's name is Liam McGuire and I will give you a list of people, because we are just the first year people, the organisers, and there will be elections for regional representatives, we hope to follow this and immediately set up regional offices and have the real strength in the regions as well as in the central, we have talked about differing places as a kind of central headquarters, but we have not come to any real conclusions on that. We have thought a lot about it and the more we think about it the more excited we get, the more people we can get involved with us, the more perspectives, the richer the diversity, the stronger we will be and I think politically we will address an issue that applies to the right and the left. Disability is such a chancy thing and so many of us have a chance to have it in our overall lifespan that the future, what we see needs to happen, a way be prepared for all of us. Our American coalition of citizens with disabilities is in the process of becoming directly involved with DPI and I am also on the board of our ACCD so I have become a good link to the international movement. There is a wealth of diversity out there and a lot of things are happening. In a few weeks I am going to Japan and the responses to disability, or lack of response in any society is very culturally based and one of the things that we know very little about is how in differing cultures, what are the cultural effects on disability. In India you may be a chosen one, but you also may be chosen to beg for your livelihood. There's a lot of things, it's a fascinating area. In Japan a Quad who is a member of the Japanese parliament is going to be a representative on our committee, so there are somevery interesting people around the world involved already.

JE: What about some of the older, more active nations that so far are not on the committee, like Holland, Denmark ..... how do you see them coming into it?

Well, that's why I think Singapore becomes very important, as representatives from each of those countries need to be there to represent their own country and their interests within DPI and help to organise the regions as well, the people that are in now will not necessarily be on the World Council after December, there will be a vote on who is going to be represented, what countries, you know two representatives from each continent, or how one rotates representatives, or how one gets continuity and still keeps communication going and trust going in the middle of international tension and differing idealogies, religions and cultures . I think that is probably going to be our largest challenge.

JE: Surely with the world climate as it is at the moment, with inflation rising, unemployment rising, things are obviously getting harder for disabled people to try and go ahead because of the lack of funds coming from the government, agencies etc., surely this is happening internationally, that kind of exchange would be of benefit to all countries.

Also, so many of us have equipment that we throw in our closets, I mean all our clothes and equipment that we didn't want in the first place, but we took, a lot of that could be used in other places in the world, so there's so many possibilities for exchange, plus a lot of our more educated people, and our engineers and people who have experienced disability as well as have professional kinds of credentials can be extremely helpful to developing nations, but more than that DPI can put the spotlight on a nation, where there are atrocities, overly segregated systems, no movement for change. I think the international light of publicity can be very important to governments, so I think there are so many ways that we can be helpful to each other that we have just begun to explore. Never feel that the process has gone too far, it is just beginning.

Independent Living Movement.

JE: One thing that really intrigues people in England, I think it is mainly because of the structures of our country, is how the independent movement has got so strong and so widespread in California particularly, and the whole issue of power politics and how you have been able to influence the system in more wa[illegible]than one, particularly with the attendant care grants that have become available for handicapped people to be able to pay for their own attendants, it is almost unheard of not only in England, but even in other states.

There are a few states beginning to do it. It came from a struggle for freedom on my part and a few others. Number one job was political, we had to deal with the people that made the laws, second with the folks that enforced them, or didn't enforce them or selectively interpreted them. The other was training, the whole idea that we needed to get ourselves to the point where we could organise our own community, bring enough leaders along with a belief that we have a future but we have it together. The recognition that we had to do short term things for success, I don't know if you know about the Saul O'linsky organising. He was a very famous Jewish organiser and organised around Chicago a lot of black neighbourhoods. He took an issue like no toilet paper in a black high school and made it into an issue that they won on and then began to gain. We began to win our individual welfare cases first, got the expertise of how to fight the system, to find what some people would call loopholes, but we would call opportunities for experimentation. We believed we could live independently and we knew we needed some kind of system run by us t[illegible] would control that, and that is how independent living came about. It never was just housing because that is an expensive approach and only one part of an overall philosophy, and we had to work on everything at once. If we weren't working on transportation and housing as well as the real gaps in service, as well as the laws themselves, we couldn't give the whole system. We began with the assumption that we were whole people and that no one small system gives us the lot, health system, social system, you name it .. we do too.

JE: Did you never feel at that early time that you had taken on too much?

We had a dream, we had a vision, all of us were dreamers I guess and recognised that you can't, that you have to go for the whole thing, you can do it, one thing at a time, but you can also figure that without getting together a few strong people at the start, I mean we recognise the tremendous power we had with a very few people. Probably in the beginning 10 of us. The vision, I was kind of leader of it, because I knew what we needed to do and take charge of our own lives and that leads to a lot of things. Not have to be dependent on anyone but ourselves, at the same time recognising that we are all interdependent and I could help you in one way and you could help me in another. The thing was though in being independent we had to provide for people's survival first of all, we were very poor. I came out of a working class family and most of us came out of if not working class families, families who were struggling. Especially, individuals who struggle after disability, struggle against old attitudes. We began to realise that it could be a strength as well as a weakness. We would go into a legislative's office and perceive that they had got all the stereotypes about what we were, they felt terrifically sorry for us, we knew we could get what we wanted, because we could exploit those stereotypes and often we don't exploit what we have, we have a lot of strengths in the way people view us, so you have to really exploit those kinds of stereotypes. At the same time you have got to bring people along and laws along and we are a very rights orientated and law orientated society.

JE: How aware were you at that time of the laws?

We had very few. I am a little bit vague, but directly it is related to the 1973 Rehabilitation Act which read that in reference to the more severely disabled, the Right to Education for Handicapped Children law, for many years children did not get any education, now people have aright to that, a right to participate in that and a coalition of disabilities got that, not one disability. All disabled people working together for common objectives, supporting each other on independent objectives, I think that is ...... I don't want to overestimate how well organised we are, because while we have been at this in California for 15 years, we've still not made a difference in election, we are not seen as electoral power, which I want us to be seen as. That is why these solidarity day demonstrations that we are going to around the country become key because we have to begin to show our dissatisfaction at the Regan policies. Cutting social programmes and especially cutting the more progressive social programmes. One measure of whether a programme works or not is whether it leads people towards taking charge of their own lives, if you have grown dependent on a programme and that programme leaves you or it +abandons?| you, .. there in the wrong place... we're not holding those systems accountable for us to move.... thats where the hole +IDPC?| thing becomes so strongly you've got to play it for yourself... So we fight for ourselves.. nobody else will (pick the same +references? weapons?|).. and if thats what we're trying, we have many allies. The fact is that most of us will be disabled so they might as well get people prepared for all of our future. I think we go to employers now and we talk, we don't talk about social and moral obligations, even though I personally think it is their ... we talk about their bottom line ... a good employee helps their problems. It's just that simple. And if there is real richness in our diversity, we think the folks out there in our society just don't know .... an awful lot about disability..... that's why integration becomes so critical and transportation on every area and we are the first group that is going to take a lot of heat about changing buildings and about making our society mobility accessible as well as socially and economically accessible. And when it comes to our civil rights people talk about costs and we are people who are too expensive. What, are people's futures too expensive? We are going to make a choice. We are increasingly, in all of our societies, making a choice, where fewer and fewer of us are supporting more and more people on confed. aid. People work for years to join our club now and become disabled and have some kind of disability because they dislike their jobs or whatever. We can put people like that in better jobs and other areas, those who really want to work, and a figment of our society doen't have to be left out, that disability is not the worst thing in the world, that people's attitudes towards us are pretty bad.

JE: It takes a long time to change, inborn inbred. People don't know anything, don't know any better.

But the only way that's going to happen is for us to get out there with them and that is why I personally dedicated my own self hoping to ensure that the next generation, the young people, grow up with disability and have non-disabled people knowing each other, and the young people with disability have a future and believe in themselves, that they do have one. Their parents act as if they do. Rather than the self-fulfilling prophecy of ....

JE: That why Berkeley ...... is one of the few places in the world where you see a total integration of

They are going to take our money all the same ....

JE: That's just California

No, I think it's happening everywhere in different degrees, and in Europe as well.

JE: There's a lot of people moving to California in order to benefit from what has been set up. Do you think they ought to stay in their own areas to work for changes there and so establish the ILM in a much stronger way nationwide

Well, we have a lot of people come to California and that has created a nucleus that is like a catalyst for tremendous things happening all over the state and in addition we have changed a lot of the national laws so it is happening that way..... so that independent living centres like CIL have been set up all over the country, more than 100 now, popping up very quickly, so that is positive, those will be a nucleus as well for political as well as social organisation of the movement, but there are things that have been going on in other places, other college campusses, Illinois, New York, Mass. Texas, Michigan, you name the states, Florida, there are movements now, groups of people that we need to bring together. So that is our mission, our mission is grassroots organising. Making people aware that they got to get involved and help others take charge of their own lives as they take charge of theirs. Because there is nothing more powerful than the peer approach. Not everone should do it because some peers are bad at it, but there is no reason why people can't go into almost any field that is available by getting in there and fighting it out. I mean, you need to support each other ...... we need to insist that we are involved in projects that are 'for our good'

JE: The problem we find in England is penetrating the rehabilitation field because that is where the peers need to be involved in counselling. In the system in England rehabilitation doesn't exist, the credibility is not there. The professionals have always believed that they know best and no doctor ever leaves a spinal injury unit and goes out and visits a person in their home. They repair your bodies ...

We talk to them .... they need telling, you spent a lot of money saving our lives and now we need to ......ourselves, the lot of us, in the community, because that is where we need to be, we've got to be, we can't be in institutions or hospitals or homes, we have to have a choice, choice is a really important thing, and even if they want to start out in a group home or larger institution, people should be moved on, people should feel that they can move on ....

JE: But there is no choice ....

That's right, a lot of people now don't need to go through institutional living, they can go right on into the community, but you have to have an attendant system. Get that community support. The only one that knows what those needs are, are the disabled people and there is one thing I want to be careful of, the most powerful approach is one where a professional, who is not disabled, but a professional who has come for an experiential point of view. Like, we can bring a lot of painting of people, so many ways that you can find out little things, one showing another how they do things is better than a year of description by an OT. But if you have the OT and the Counsellor together you are going to be able to help that person much faster. That's the reason for all those schools, along with poets and mathematicians and every area.

JE: I notice that you train your own physiotherapists

Absolutely. Take them out of the institutions and bring them out into the community with us. A difficult system, but we are finding, even with the most severely retarded person, it wasn't that they could not learn, it's that we did not teach. Now we are learning how to teach and we can teach people with profound disabilities a job and how to work and you can teach a person vocational as well as living skills. People have a right to their fullest potential, whatever that is, and to be seen as having potential. We did some experimentation here with severely retarded people on assembly lines, and what you do is you do a task analysis of an issue, you break it down into smaller learning units and you teach it, once a person learns it, which can be relatively quickly, they don't make mistakes and they don't get bored at it so they just turn out great work, so they may do a lot fewer, but their productivity in terms of the numbers that go through are passed on, and then the old attitude thing comes in because people don't want to be compared with the work of a retarded person, because they are not worth much. That's why I work on all the issues, because I believe a retarded person is equally or more oppressed than I am. We have a new organisation called 'People First' here in California, it is an organisation of the mentally retarded speaking for themselves, so frank, so honest, such an honesty, a willingness to speak up, this is a very positive thing. In DPI that's it 'speak for yourself'.

Those are some of the more important things. I think these next ten years are going to be real exciting here.

END.

So I think you will find that we are quite different, being more urban centres that you visited, in fact that contrast became more evident the first week, when Max Starkloff visited us, the first day I was on the job. We immediately sensed some real differences between some of the things that he talked about and what we knew we were going to deal with here. Because I have lived in New Mexico for 13 years, and there is just tremendous differences between that and St Louis, I grew up 60 miles outside St Louis, so I know.

JE: Did you find he was basing his ideas on St Louis

Some of it. It was pointed out to him by several staff members that we are dealing with something just entirely different. We are a small city, we have a big mixture of cultures here, we have indians, Spanish Americans, Anglos, hippies, artists, we have everything, and to some point I think we take some pride in being able to allow that all to exist,not to say that there are not problems, because there surely are. But most of us in this kind of business really work hard at keeping that as positive as possible......... If we are going to influence people to consider the needs of the disabled, we are going to have to go about it in a very persuasive and alliance kind of way. Because all of us who first came together in March, we needed the programme, we needed each other, we did not know how that was going to evolve. Well, we are still very young, we are only six months down the road, we have already worked out a lot of those kinds of issues. I think our quota on the staff has been pretty much half disabled and half able bodied. On the initial team, there are five people on the team. The team is Tom, who is knocking at the door .... , he is a quad, Jean is a quad, ... who is blind, Andy who is able bodied, and myself, I am able bodied, ... is able bodied, so we have a mixture .... for the most part we feel it is important that there be a working interaction relationship between able bodied and disabled. One of the feelings that we got from Max was that it would certainly be preferable if we were all disabled. My own personal philosophy does not align with that, and I could not work here ......

JE: He does not run his centre that way

He doesn't? That is interesting

JE: A lot of people in key positions are disabled, but there is quite an ablebodied staff there, admin staff most of them, but still they could not function without that kind of backup ...... same in Berkeley, again the key people are disabled

Carol and I wondered at first how we ever would have got off the ground if she and I had not been here, because there were tremendous problems at that time. Yolande could not see, Gene did not have a lift in his van, he had to be lifted in and out of his van. We were scratching our heads a lot and trying to sort out a lot of these issues, and dealing with our own feelings in the staff. I feel very good about that, it has certainly really come together, it is not perfect

JE: How did the centre start here

Actually, it came from a person in the admin at DVR, he met Bill, he is from DVR .... a woman that was above him actually generated the whole thing, oversawthe writing of the whole thing ....
....

JE: I expect that is what Max was suspicious of

The grant was not awarded to DVR, it was awarded to New Vistas, she wrote the grant .... New Vistas is an organisation that has been here about 10 years, that serves the developmentally disabled, so they got it. We are pretty much independent of them geographically, we are serving a different population, however we do have a crossing of clients at times. Everyone who came to this programme had never been involved in New Vistas before, except Andy. He had been doing some evaluation work with New Vistas.

JE: So who laid the framework, who advertised for you

New Vistas. there is an executive director and an associate director. The assiciate director was incharge of getting us off the ground. They first hired Karen, and Karen and the associate director did. Karen has really effectively guided us through a lot of the rocky times.

JE: So were clients referred to you or did they find you themselves

A combination of both things. There was a list from DVR, like their 1979 clients, we went through that list and we wrote all those people letters and brochures. Then we did a lot of community relations, just to make people aware of us

JE: What kind of response have you had from the community

It has been slow, but it is beginning to happen more and more

JE: How about fund raising

We are very fortunate, we are funded for this year, but we are going to have to start doing that soon. I know the funding is not going to last for ever. It is the next thing we are going to have to tackle, I know it is real hard. I am not interested in that kind of thing ......

JE: Tell me about what you do

I see clients on an individual basis. I run two groups, one of disabled people, and one, that is coming soon, of family members of disabled people. I have a particular interest in that. I also do some work at a hospice in Alberquerque, I run that kind of group of family members of dying people. When this request came from one of the family members I just really liked the idea. The group has just been a real positive experience, to most, for the most part most of the disabled people are homebound, require a lot of physical care, for example, two of them are, most of them are road accident, brain injury, whose potential for employment or rehabilitation in the community is pretty rare. The responsibility for their care has fallen to these people, what I have found is that their involvement is unique ... the guilt that they feel for the times that they do go out and enjoy themselves. I think with my nursing background I just have a natural interest in that kind of thing, I have a lot of experience of .... The clients that I see individually are those in a transition to IL, and that is a real joy, to take them and start out from where they are now, and see down the road, how we can work together, that is a real special thing

JE: How easy is that here, there seem to be a lot of architectural barriers

Santa Fe is terrible. There is a lot of impetus in the last couple of months. The ......s wife has been chairman of a committee to do a survey of the city, and that has just been concluded, and that is going to put a lot of pressure on people to do things, and that is because of IYDP. I hope, if you come back to Santa Fe in two years time, you will see a lot of improvements. For the most part, I think, as a group when we meet together, we have to choose a place that is accessible, it is a real good education, it is a real positive experience. I really feel that in Santa Fe it is a matter of education. Also, we got to talk to the businesses, it is a real tourist town, and if we want to keep that up we have got to pay attention to the needs of the disabled

JE: Hotels are a problem in Santa Fe ... (extensive discussions on hotels). What is the attendant care situation here

Ask Tom ....

Max told me he did not believe in therapeutic counselling and I do, they only believe in peer counselling, and it made me really pause for thought, having just taken a job here. I believe in a wholistic approach to a person, and I believe that first of all you and I are human, and I believe that both you and I have suffered, maybe in different ways, but we can speak across that. I think it is real important that I am here, and I am real glad to be here

JE: I understand Max's point of view because of the past .... but I also agree with you regarding a wholistic approach

There are some situations where I am totally inappropriate because I cannot do peer counselling

JE: I feel you should have a peer counsellor with you, that way you would have a whollistic

There is a lot of exchange of clients, so that is the way we approach it

END

I was a community resources co-ordinator, did a lot of public relations kind of things. The reason Iguess they told me, was my background. A whole lot of public relations, I had been doing some sex counselling with families. Iguess 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

Fo 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

END

JE: What exactly do you do

Little or nothing. Two of us are training couriers, me and Andy, and the other part of my job would be doing intake work and outreach work. So I would go round to different agencies, looking for new clients, getting information on programmes and people who could use our services, writing letters and stuff to clients, phonecalls. .... we will go and check his .... for free

JE: Do you have a lot of response from that

Not as much as we would like

JE: What are the nine counties you cover

....

JE: Did you choose to cover those areas

This programme is different in that it is a rural programme, it is experimental. Kansas has a rural programme too, but we are serving several different cultures, and no one else has really got a population like this

JE: Would you have chosen to set up a CIL that way

No. I would have started one in Alberquerque, you have got so many resources there, a transportation system, the city is architecturally better off, there is a large university there, a large attendant programme there, just a lot more things to take advantage of

JE: Why does Alberquerque not have a CIL

There are people that do want to get something going down there, but I think there are some political reasons. We are supposed to expand to Alberquerque in about a year or so, and a year after that expand to Los Crusos, I think it is, so we have a five year period of expansion ....

.... as far as what their disabilities are, what problems they have, what services we provide .... so we can see any patterns, whether there are more mentally retarded or physically handicapped, whether to provide more services, things of that nature

JE: How do you go about getting your attendants

It is a real tricky situation because this area is so rural, it is real hard then. We could get an attendant registry, name, age, type of experience they have had, that sort of stuff, which somebody looking for an attendant would want to know, but if a person stays on the role two weeks, they drop off

JE: That soon. I thought you might be able to tap the counter culture

The population here is about 50,000, but in any one day there could be 100,000 people here, because it is a big tourist place, and people looking for work, they may be applying as an attendant just as a form of work, not because they want that particular job. We did try putting an ad in the papers for handicapped persons wanting an attendant or for someone who wanted to work as an attendant, we got a limited response, I don't know why

JE: Where was the most response, from the attendants, or from the disabled people

Mostly from the attendants. Ithink because it is a transient city, people are really eager to find work here, to be able to stay here

JE: Why do you think so few disabled responded

It is real hard to reach a lot of people, they don't read the newspapers, they don't watch TV or radio. The majority of them don't have phones

JE: Is it difficult to identify the disabled people

We send letters out. We go to agencies that work with handicapped and let them know that we are here

JE: I thought they would have got onto you and asked for an attendant

It is new. You have got to also figure the large Cicanno population that we have here, they are very independent, they are not going to come to an agency, they are very anti government, anti establishment, they won't come, and the indians the same way. They see the presence of a handicapped person as God's way of saying, you have done something wrong, you have got to take care of this person

JE: So despite all the problems, pressures, they see it as God's will. So how do they manage

They just rely on their families, there are real strong family ties here

JE: So what have you done, how have you managed

Very cheaply, we can't afford to pay them, we can't afford to hire someone that is really good. Usually if people provide a bit of experience, ability, they expect a good salary, but I can't pay that much

JE: Isn't there a basic rate

There are some agencies that will say it costs $6 an hour to supply an attendant...... .... I have a two bedroom apartment, so I give one room as part of salary to an attendant

JE: Do you earn enough money here to be able to keep you going and pay for an attendant

Yes

JE: What would you do if you did not have this money

Maybe go off somewhere else. I finished school back in Ohio, I came to Alberquerque about five months ago, so if I didn't find this job I probably would have moved on somewhere else. Somebody drove me out here and left me

JE: You can leave me somewhere .... So there is no way the system provides any kind of benefit or grant or whatever to pay for an attendant

We have something called Title 20 services, critical in home care. Part of our welfare social services. If a person like myself needs an attendant, but they can't afford it, the state will pay for it. However, the state says they only got so much money to work with, so they can only accept so many people. So there are some people that are getting an attendant paid for by the state, but very few, and there are so many people that need it

JE: You must have met lots of people that are having an attendant problem

They end up in nursing homes

JE: Where are the nursing homes, there is one in Rosswall

There is a couple in Alberquerque, I think we have one in Santa Fe

JE: You think. You better find out and close it down

Our biggest priority for a while is government subsidised housing, which is $54 a month for a 2 bedroom

JE: How did you get into this

When I first went back to college after I broke my neck, the handicapped students service office at the university had had a library service for about four years, and I just tried to find all the information I could, so I started getting real interested, last June I started talking to a few different people

JE: The people were Ralph Markwood and Tom Dennison

I will give you their card. They have got a real good outreach ministry.

I just wrote an attendant training manual. Teach people how to be attendants. It is still being edited, it is about 65 pages, I'll mail you a copy, I'll get your address

It is how to teach able bodied people to be attendants for mentally retarded, and how to teach disabled people to teach attendants.

JE: There seem to be a lot of people getting way out attendants

It will probably be like that for a long time, people are looking for any kind of work. One good source is university students, you get away from university centres it becomes harder

JE: You must have found it hard to leave there, you found out about the job while you were there

When I came to new Mexico, I met with some disabled people who reckoned this kind of thing was going to start soon and I ought totry and get the contract for it, centred in Alberquerque, run by the Veterans. They had all kinds of information .... the contract is not awarded yet, but keep your eyes open, so I found out when it was awarded and who it was awarded to, when the grant was awarded, and I found out the guy who bought it

JE: That was the Voc Rehab work

That was through the regional Voc Rehab, it came down through them, I thought I would start out with these people .... they said keep informed, keep in touch, when the job opens up I would apply

JE: Do you know how many people applied for this job

26 interviewed and three times that many applied

JE: What was the ratio between handicapped and non disabled

I don't know. I think there are very few qualified handicapped people. Presented .... get state assistance to go to school, you have got to have quite a lot of ability to get through

JE: So how did the veterans respond, when the money went to Voc Rehab

They were a bit disappointed. It was just a matter of politics

JE: Were Ralph and Tom involved in that

I don't know about Tom, but Ralph was.

JE: How old are they

40s. Tom is from Viet Nam, and Ralph I think was in the Korean war too

JE: The stories we here from outside about the veterans are pretty bad, about how they get left, they don't seem to be involved in disabled politics ....

The Alberquerque group are good.

JE: Quite unique

The ones in alberquerque are a volunteer group, which is a little different from the admin which is all paid staff. It seems the PVA is doing a lot to keep a track of the station. Just last week we had a, we spent $300 to rent a room in the Holiday Inn, to talk on issues .... doing a lot of that kind of thing. It is funded by federal ....

JE: You are restricted then. How do you feel about the way things are working out here

Pretty good. We have staff meetings every Friday, we have a chance to talk about things .... sometimes we can't change them, but at least we understand what is going on

JE: What about housing

It took me a month and a half to find accessible housing. It is a historical architectural problem

JE: What about the Anglos

The bonds are not quite as strong, there are a lot of people from the East

JE: Do you know many personally

A couple

JE: Roughly how many clients do you deal with a month

About 75. Attendant care, peer counselling, advocacy, adaptive aids, wheelchairs

JE: What about wheelchair repair

There is nobody here in Santa Fe that does it, there is just Los Calos, they won't accept Medicaid or Medicall, because they have to wait so long for the money, they want the cash. It is different in Alberquerque

END

Ralph Markwood - Exec Director/PVA - Alberquerque

The Zeta chapter has for many years .... very active in the housing, but we are more on wheelchair accessible housing, we don't actually own any buildings, per se. We work very closely with the public housing authority in Alberquerque, when they have subsidised housing available, now they are calling us. We have worked very closely with the social worker at the St Josephs Hospital and when they have somebody that is being discharged, Hank, they refer them to us. However, it is very difficult to work with most of their clients because most of their clients that they refer to us, they have only been injured perhaps less than six months and it is their first time that they are going to leave the hospital, and most of them, because of financial reasons, are going to have to live by themselves, and they have no experience in that and it does not work out very well. As a result of that we have not pushed that, we are more involved in housing with older spinal cord injured or mobility handicapped people, they have been out of hospital, they have lived on their own, they are able to handle that and we are more successful in that. Most of our clientele are non (dependent?) as it applies to housing, my associate he deals with some other people, he has recently come on about a year ago and has taken over much of the housing referral business and he kind of got into that in a back door way, because he developed an attendant referral system. Well, before the person can hire the attendant he has got to have a place to live, so consequently he became quite interested in housing and I taught him what I knew. I still dabble in it a little bit, but my associate, David Cohen, handles more of the housing now than I do. And that is about where we are at with this chapter on housing

JE: What do you usually handle

I am the executive director of the chapter, my responsibility is to handle the business affairs of the chapter mostly, and to assist the programme directors in areas that they might need assistance in. Of course, I am also the national vice president

JE: Does that involve a lot of fund raising

On the National level, we are exploring some various options here for fund raising. As you expand you always need more money. I believe this is rather unique PVA chapter, it is a small chapter but it has been well known for initiating a lot of innovative programmes and ideas and so forth. You go in cycles depending on the officers and if they are willing to work with you, we seem to be coming back on a high now. For almost a year we were without a membership officer, simply because the man that was our membership officer, his wife was sick with cancer, and died, so he was out of the chapter. Now we have a new membership officer and we are getting momentum going again in that area. The attendant programme has really become quite a good programme

JE: that really interests me

Bill has got quite an applicant list. I think most of the applicants were looking for part time work, they did not want to live in. If I can get back to this new housing complex in Omaha, Nebraska, that was sponsored and developed by the great plains chapter, there is 24 appartments on each site, and the sites are separated by 10 miles or more, and it is their intention to have maybe 2 or 3 quads share one attendant, of course they are just starting up today to rent those apartments, and there were a couple of them that were around Friday when I was over there, for the dedication ceremony. This one fellow had been in a county institution, which is pretty horrible. This severe quad was put in this home by his parents, I am sure there are probably two sides to the story, anyway, this young man has been in an instititution for 16 years, and he is only about 33 now, just a horrible situation, and he has just signed a lease to go over there.

He has very low income, I suppose he receives some money from the county, but .... (tape over)........ At least at this point in time we do not have any great desire to become a landlord and own buildings ourselves. We see our mission more as providing services. Are you familiar with any of the CILs in Houston, Texas. Well that is where our thinking is now, whether that thinking will come out in a few years from now, I don't know, but that is the way we envisage it at this point in time. we are more interested in providing referral services and we do some peer counselling, we have acted .... A few of us do here, and that is about where we are at on that. One feature of our referral system is that you do not limit it. This referral system involves two parts, we advertise, or my associate advertises, for the attendants and then we have the client consumer who needs the attendant. Our mission is to try to get the two together. We do not at this point in time want to become the employer and that is how we get involved in the housing aspect, as we always were interested in housing. The accessible housing in this city is extremely limited, that is for rental, now if the person has a high enough income and can purchase a house, that is a bit different. Most of the handicapped, especially the young handicapped, quite often their injury is before they have gone on to college, their source of income is usually around $250 a month. Without subsidised housing there is no way they can get into housing

JE: What about renting houses, do they get allowances

Those that are, those handicapped individuals, if their income is low enough, they qualify for what is called a Hudd section 8 rent subsidy. An apartment, there is two parts of that programme. One part, the section 8 programme was initiated during the Nixon administration as a device to get apartment owners an incentive to build more apartments. That part of the programme the actual rent subsidy, piece of paper, is held by the developer and that part of the programme is easiest. There are not maximum, there are but they are very high. Now the second part of the programme is for existing housing and those certificates are controlled by the local public housing authority, it could either be the city or the county, but that part of the programme, the maximum allowable rent is about $159 for a one bedroomed apartment. You are not going to have, most of the, and that includes the utilities, and it is extremely difficult to find a one bedroom apartment in that rent range, but that is what is available. The first programme I told you about, where the certificate is held by the developer, that is much more flexible, max allowable rent is much higher

JE: Is it common for PVAs to be involved in attendant referral and housing

No. I know of two chapters, our chapter and we just got into it, and the Great Plains chapter, that is two that I know of, now I would be surprised, we have 35 in the United States, I would be surprised if there were 6 chapters in the entire United States that did anything in this area. Most chapters have steered away from it, as this chapter steered away from it in the beginning, because we did not want to get involved with all the hassle of being an employer and the liability. In this country, if we were the employer and we sent an attendant out to your residence to take care of you and he burnt you somehow, or he dropped you or did any number of things, we as the employer are liable, and that insurance is extremely high, but what we are doing by just being a referral agency, we do not have any liability, and I suppose for that reason we will simply try to stay strictly as a referral agency

JE: That seems to be what most CILs do

Yes. Of course, the largest CIL is in Berkeley. I was out there 3 or 4 years ago and again all they do is just have a list of apartments available, or at low rent to handicapped people if they have got a vacancy. The biggest trouble we run into with our housing is when the housing authority all of a sudden tells us they have a vacancy, we can't always find a handicapped person that is willing to take that apartment at that particular time, and the housing authority, it is rare that you find one that is willing to hold an apartment for a week. They can't afford it. Just about the time that the apartment gets rented, then we will have two people come in hollering that they want an apartment

JE: Are there any other ways of finding accommodation

No, in most cases we are working through the housing authority

JE: Do you advertise for attendants.

Yes. We don't make it a practice, we will accept donations. If the attendant feels we have found him a good employer, he may want to make a donation, we do not charge for our services. We just ran an ad in the paper for 2 PAs and we got an awful lot of calls. it came as a complete surprise to us. My associate is more disabled than I am, and he had stronger feelings on this programme than I did and knew that there was a need for it and his contention was, why have six quads putting an ad weekly in the paper, let's get the client consumer registered and then lets advertise for the attendant and then see if we can match the two together, and I think that makes more economical sense. Just where this programme is going to go, I dont know, but it has generated a lot of activity, I wish you had an opportunity to talk to him

JE: Have you documented any of this

He has. We have got a folder, we try to fill these forms out so that at the end of the year we will be able to go back and pick out some statistics or information.

The DVR, to which I have difficulty giving very high marks, they felt that a programme would not sell to the US Congress unless they had some innovative programme. They thought that by labouring their new programmes for the rural people, that it would be accepted better. I am not saying that they don't need that service up there in Santa Fe, but here we are sitting in the centre of a population of 400,000 and .... What they are going to run into up there is more elderly handicapped, where we are aiming our services more for the young handicapped.

END

Virginia: .... Department of Education and Rehab there was a lot of discussion about the 1976 amendment to the Voc Rehab act. One of the parts of the act that they felt would be funded was the part having to do with CILs, this had to do with taking people who were seriously handicapped and disabled, who were not eligible for DVR services per se because they did not have a clear vocational goal and objective and may never be able to have a gainful occupation, but they could work and do other kinds of things, they could become more independent in their life style, they could help others reach independence. So this was one of the parts of the act that we had a discussion. Dr Swanson asked me if I would try to do something about it, so first thing I did of course, was set up a committee and an office. Then I set up a statewide committee, half of whom had to be either consumers or providers, and we had three or four meetings. There was a very short time element to draft a whole proposal and get it into Washington for funding. We started working on it sometime around 1st Dec 1979, we had to have it submitted by March. We had to have a committee that would review it, give their ideas and so on. We did set up a committee, we talked to them about the problems of the state and because they were consumers and providers they were most knowledgeable people. Their ideas were that we really ought to do something for the people in the rural part of the state, northern New Mexico, where there were very few services, not much transportation, lots of people who need to be identified, to whom they thought we could give services. So we started with this concept. I took their ideas and wrote a proposal and we brought the committee back and let them review the proposal, give their ideas, then we sent it in to Washington. Then I followed it up. I was going on vacation with a personal visit to Washington, talked with a lot of people there. I visited a couple of centres and looked at what was happening. I had also studied a long long time ago at the University of London and looked at the special education programmes and what they were doing in this whole area .... So I just tried to take these ideas and put it together because nothing works unless you have people to carry it out. So when we were funded we awarded the contract to the Vistas, realising that under the state personnell act we would never get it off the ground, and I think that is a fair statement, it is not set up to act quickly or to do things. Then New Vistas set up following the contract that was written, the interviews for people, we had spelled out all the qualifications, what we were trying to do, how we would like to set up a network of services for severely disabled, getting them involved in helping each other, performing the kinds of services not only in rural areas, but ultimately moving into the cities, Alberquerque and Los Crusos. That in a nutshell is what we tried to do, and I have been very pleased with the people we hired, dedicated wonderful people and I think this place is under way. That's it.

Caroline: One of the things that she said, you might really register it on going back, I don't know what kind of system you have over there, if it is anything like that, Virginia had a good point in avoiding that kind of system and doing it by a kind of sub contract, where you can go to private individuals to carry it out, there are many fewer strings attached to handling it that way. You see, to set this project up under the state system, you would have had to write brand new job descriptions, right, the positions would have had to have been established, you would have had to have had eligibility tests, then you would have had anybody that wanted the job take the test and get on the list, and it is really a long rigmarole to go through in order to establish anything. Now once it is there, it is written and stung,it is hard to get rid of it

Going from that point, we really had our work cut out for us. I have a report here which illustrates back to the very beginning.

JE: Do you intend to involve Alberquerque

Virginia: Yes. The idea was that we would start in the northern part of the state, spend at least a year to a year and a half attempting to serve the population and their needs. The next part of it would be a small service centre office, that would take people that have the same kind of problems and develop a network there, probably it would be a one or two person office, but at least co-ordination of services and beginning to take a good hard look at the whole needs of the state, ultimately, if it would go 3 or 4 years, to Los Crusos. You would begin to take a look at what is needed, what has been able to be accomplished, and also the need to go for more dollars, because we do need a total network of services

Caroline: Incidentally, PVA has already asked me if I would like them to build space for us. They would take care of it, and contract with them to do certain kinds of things, like they are already doing searches for attendants and things like that. It would just be a matter of us supplying some money to certain individuals there to operate an office. I think this is something we ought to really look heavily into and move as soon as we can on it, even though it was not written into the grant. That is something for us to keep in mind anyway. OK, well whenever we get started, there are several areas specifically listed in the grant that we were supposed to take care of. One was counselling, to begin with intake counselling, but then, on beyond that, counselling for individuals, the family. In our work we are concerned with the family of the disabled person as well as the disabled person individually. Then we were supposed to look out for attendant care, this was helping disabled individuals to recruit, to train, to utilise, to fire attendants as needed, and vice versa, to train good attendants, so that they were successful. There apparently is a tendency here among some attendants, if they come and stay, they have a tendency to run a person's life, and that is not exactly the kind of service a lot of people are looking for

JE: It is also a matter of training the disabled person to be aware of personality types

It is personality types I guess that are prevalent in this business

JE: In Berkeley they brought out the point that it works both ways, the disabled sometimes exploit their attendants

Yet another person: It is different from getting a job in an office or something, because you have to get into your lifestyle, even what kind of music you like, just more of a broad thing to look at

Caroline: Advocacy is an important area. The peer counselling. There is some of this that has gone on, I still don't feel that this is an area we have got into nearly to the extent that we will be involved later on, and then IL itself, as far as the skills are concerned, and counselling, training, evaluation, the whole bit, housing and transportation. Transportation particularly is a vital concern because we are a rural area, the only mass transit system available is in Alberquerque and that is it. Then we are supposed to put together services, directories, to identify housing, transportation, support services. We are supposed to be involved with health maintenance programmes to facilitate community group living, so that we avoid any institutionalisation. We are involved to a great degree with education and training of individuals for living in the community, participating in community activity. We are involved in many recreational activities, family support I mentionned earlier, we are concerned about families needs, and even friends' needs. In other words, people that surround that individual in the community, it could be the owner of a theatre, we are concerned about people who deal with the disabled population, so that they feel comfortable, so that they can set up more improvements in the environment, make accessibility possible, so that leaves us in an architectural capacity, which we are very much concerned with. Then there is a variety of other programmes and services. The thing is, you have to be all things to all people just about, because of the limitation of staff and because so many people are separated, you just can't get them all together to run down on a Saturday evening for an activity.

JE: Are these objectives

They are included in the programme, we are actually providing services in all those areas

.... Virginia leaves, recommending contact with Jane O'Hearne, overseas director, Boston ....

To begin with, New Vistas got the contract and they found an accessible building, one of few accessible buildings in the town. .... John proceeds to carry on about access to hotels and restaurants, from personal experience .... Anyway, after we got our accessible building, they advertised for my position and I was the first person hired in. Then, after a while we advertised and decided we would be hiring all the other staff one at a time. There is something that is really important, because it did not work, we learnt what did not work as well as what did work. We had to have a variety of characteristics employed together, a team, so if you have intentions of hiring a group of people to do anything, you might really keep in mind what it is specifically that you need in terms of characteristics of those individuals. Here I needed disabled people, we needed Hispanic, Spanish speaking people, we needed people with some real strong professional skills, that could satisfy the needs of the grant.

We had the goals written down, so we had to hire people from disciplines that would satisfy that need, and we needed one or two natives sprinkled in there, people that were really from this area of the country

JE: How did you get into this

They were looking for a director. After DVR wrote the grant, Dr. Keen wrote the grant, then they sent out invitations to bid to various agencies, New Vistas incorporated was one of the places that bid. New Vistas received the contract, the administrative staff in New Vistas looked around to try to find an accessible building and at the same time they pulled together an advisory committee, which is made up of disabled persons, and together they located this facility

JE: Where did you find the disabled persons

Fortunately there are good people on this committee. My understanding of the way these people were invited to participate was that these were individuals who were leaders in the disabled community. They were people who were speaking out, who were looking for services and really advocating for the needs and the rights of disabled people. Some of them are the best known people of the state. When we added another committee member not too long back, we added the person because we needed something that he had, and from here on out, anybody added will be fullfilling a specific need that we have, not a slot for a disabled person, a need that we have that will support the project. That group went on and put up the advertisement in the newspapers for my position, I answered the ad and, interestingly enough, there were no severely disabled people who answered. So when I was interviewed ......

Gene: I myself did not feel qualified to direct the programme, I felt qualified for the job that I ended up with

The ad went out in some DVR periodicals and things like that. It appeared in several states actually, it was advertised in several states. We put out the grapevine contacts, we contacted all the DVR agencies, because we feel that somewhere along the way, there would have been a crossing of paths, more than likely, with DVR, so we were hoping that that would help us quite a bit. That was a difficult situation. One of the things I think we have to face is the fact that there are very few professional severely disabled people in the state of New Mexico, which, in turn, tells us what our challenge is, we have got to get these people out and active and educated, so that they can be more involved with projects such as this. The comment that drifted back to me after my interview was, if only she limped, it would have been alright

JE: Some people feel it is vital that a disabled person should run a programme such as this. Gini Laurie says that initially a good organiser is needed, but in a few years time a disabled person should be ready to take over. To get something off the ground is not all that easy, especially here

Right, and you really get into a whole area of philosophy there, which we have bounced off the walls and upside down and sideways. Part of this is a personal feeling that I have more strongly than some of the rest of the staff. I feel if you have to select a person because they are disabled and not because they have something the project needs, personally and professionally, then you are discriminating, you are creating a difference between two people. From here on out, when we hire in it will be for qualified individuals to satisfy a need with the project. Very definitely we will want to keep a balance of disabled individuals, if we lose some of our disabled staff, we have another professional position open up, and we feel like we have still got to get that representation in there, we will keep looking until we find a person who is not only disabled, but who is qualified to take care of that job. I think that this is going to help us. It really does eliminate the discrimination aspect. I was really disturbed, as I was telling these guys, quite recently I went to Houston and met with directors of CILs from all over the United States. I saw so many individuals there who were directors of CILs, apologising for the fact that they did not have a disability. I can't quite see that, I don't have any apologies to make. I think it does come to the question of what is important. I realise that our philosophy is not everybody's cup of tea. But it is important to recognise what you are saying. If you say that a person has to be disabled to be a director, I would really strongly disagree.

JE: There are a lot of very qualified people in Berkeley

I would personally question the kind of perspective that you have if you have a total disabled staff. I worked in institutions for years, and to me that is a form of institutionalisation, because I think you need a broad perspective. You learn the communication, you learn the tolerance, the patience, the understanding, you learn to communicate if you have got the mixture. You don't have those opportunities to learn if you are segregated

JE: At least half the people at Berkeley are able bodied

I am glad to hear that

JE: They want a normal working environment set up and they see that environment as a combination of able bodied and disabled working harmoniously together. The key positions they feel should be disabled, couselling, a disabled person can teach a lot more than an OT

Gene: Yes, because OTs are trained to have people dress themselves, do as much of the independent stuff as possible, but what they don't think about is, if I am going to get up, completely dressed by myself, I have to start at 3 in the morning

JE: Yes, after such a severe injury, you are left your head, and you have got to use it, and if you are going to waste such a lot of time just to get out to work, you are wasting valuable time

Gene: Some of the myths about us not being able to find employment, you get up at 6.00 am and get yourself dressed, no matter how long it takes

There was a book called Karen, written about a CP girl that grew up, and when she became a teenager finally had to face the question, do I want to spend my time learning to be a professional person, or do I want to spend it learning to be a good wheelchair driver. I think there is a lot of reality in that. There is such a tremendous need from both sides of the fence. We have tried really hard to maintain that kind of balance. There is a very neat pragmatic dimension that comes in I think when individuals .... end of tape ....

We spent the first five weeks of the project in in service training, and this is another thing that I think we would recommend

Gene: .... we all wanted to know everything there is to know about working with our anticipated clients, so we sought the professionals, providers of adaptive aids, nurses, rehab staff, all the different places we could think of that are working with the handicapped, we set up appointments to come round and talk with us about working with the handicapped, the set ups they had, the services that they provided, the mistakes they had made and the things that they had learnt, what they could recommend to us. It took a long time, but boy we learnt a lot

We kept very quiet during that period about the fact that we were in existence, because we knew that we would be inundated with people calling for services, and we did not feel really adequate at that point to start, so we very quietly went about our business and did not let out the publicity on the project until we had already been working for about six weeks or so, then there was a great big aritcle in the newspaper. That worked very nicely, we were glad that we did not broadcast ourselves, because it would have created some tension I think in the community, people calling and saying, well when are you going to give your service, why do I have to wait for six weeks while you get through with your training, if you don't know what you are doing then why are you in business. Again, an important area in here to approach, we had a lot of territory tocover, and we felt that rather than going in a multi disciplinary approach, or inter disciplinary, we had better go for trans disciplinary. I don't know whether I described this the othe day or not. Trans disciplinary means that instead of sending a team, as you would with an inter disciplinary, you might send a psychologist and a rehab specialist together to do something, we send one individual who has a base of skills. This means that each individuals on the team, through the in service, is trained to have the base of skills in our area, such as rehab, counselling, training and a variety of other areas. As long as the problem is relatively uncomplicated, they can take care of the needs of that individual, one person can. If the needs are complicated, they can come back and say, hey Jeanette, I need somebody with a nursing background, this is more involved than my expertise will allow. This has really gotten more staff mileage for us. It works very well to send one individual to see any client that comes along and size the situation up, but we have always got the reserve in speciality areas. So for development in rural communities this is something real serious to think about.

It asks a lot of staff, and I think that it is only fair that staff coming on board understand what it is that they are going to do. For example, if you have a nurse coming on board and then she does not want to do anything but nursing, then she does not belong on a trans disciplinary team, and the same for any other profession

JE: How do you manage for transport, Gene

Gene: I deal most with the local area, so it is not so bad, mostly when I go out in the field it is to other agencies to get referrals, so it is not very often I am going to see the client

Someone Else: We tend to work in a particular county rather than all over the place

And that county comes to identify with that person, rather than having five different names of people that come in and out. If you look on page 16, the top is just kind of housekeeping details of what we did, things that have to be done, and I won't go into that. I would strongly recommend from the very beginning of a project, be sure that you really get onto your record keeping, your inventory lists and things like that, just start it from the beginning, because if you have to go back, and you will later on, and try to retrack all of that, you will go crazy trying to remember something that happened, so it will save you a lot of time if you get your record keeping systems lined up before you actually provide services. In a minute I will come back to tell you about data collection, because that is one of the areas you need to set up, ideally before you ever open your doors. As you can see, I did visit another IL centre, so I had a better idea of what was happening some other places, and pick up some ideas. The people at Hale Irwin, Colorado were really very nice and very very helpful. I am so thankful that I had an opportunity to go there. We had to integrate our project into a total project, whenever New Vistas took us over, so there was a number of things that had to be done to accomplish that. We had to make it very clear as to how we would functin within the total New Vistas programme, because we were a part of something that was much larger. Then we planned and initiated the staff orientation and initial training, this is pretty much what we have just covered, so I won't go into that in detail. Then we put the whole staff together, the development of this project from the beginning has been a team effort, so we all sat around and we divided the project into pieces, we said OK we have got to provide all these services, how are we going to go about it. We started from the beginning and broke the entire programme into segments. These are the segments that we came up with. Each of these segments represents something that we had to do in order to put the puzzle together to form a project. We had to talk about philosophy first, we had to come to some agreements as to what we were talking about, we had many discussions, there were a lot of misconceptions. When one staff person says he is going to do an evaluation, Gene was saying, well that is not what the disabled population needs, then this other individual was having to defend what it meant, we went round and round this on semantics.

Gene: It was really good. We had a lot of things we had to work through, what our philosophy was, what we wanted to provide, who we wanted to reach, and to continue that process throughout our growth, it was very important

Someone Else: I was not here yet, so when I came I had to fit in

The requirements that we made of each staff person coming on board was a willingness to talk openly and frankly with each other, no matter how sensitive the issue, we had to be able to discuss it, and if a person was not able to discuss it, we would tell them that this was not the team to be on, you have to be open in this business, and thank goodness, the team really has functionned that way

JE: So how did you fit in when you came a bit later

Someone Else: I had to fit in to the philosophy, I think that was the first time I was interviewed, but I fit into it real good because I agree with it ......

Nothing is written on stone here either, as society develops, as we develop and see necessary changes, we can adapt. It is not as if everything is so static that we can't deviate. Maybe some of the things we think right now, we won't think ten years from now, but this is the stage of development that we are in, at least we are united in what we think. That is again important for a team, if you have got one person going out for example and saying, hey everybody that is hired in here ought to be disabled and there is a few ABs floating around among the staff, then you got somebody else going out and saying, oh we believe in a balance,you have got a dichotomy in the community, with this group that does not know what they are all about. So it is important that you get a group together and agree on what you are doing and then support it, till the total group makes a decision that you are going to change something, then when it changes the whole group changes at that point in time. Then we talked about our management policies, procedures. This does not sound very significant, but it is probably one of the most significant things we did, as to how do we approach things. For example, if something does not go quite right or there is a question, what is the line of authority, what do you do to communicate your need if you want to get a change made or to get listened to. Well you go up the line, rather than starting at this point and jumping to the executive director, that does not make any sense. We talked a lot about communication, protocol and things like that, so that we would all feel comfortable dealing with each other. Then we really got into the services, the types of things that we would offer, you can see the list, and we talked about how we would offer them, and we talked about who on the team was best qualified to handle each of these service areas. One of the first responsibilities that the staff had was to write their own job descriptions. We had a loose job description when people came on board, then we sat down and everybody became very specific as to their own personal job.

JE: How is the management constituted

Essentially what we are saying here is how we manage our project and our affairs, how the team has agreed that we will manage our project and how it functions,understanding that we have an executive director, that we must answer to, and that the executive director has a board of directors, who she has to answer to, so it filters down, therefore there are limitations on some of the things we do, we can't just go out and do anything we want to, we have to clear anything unusual with the executive director, who then in turn might have to clear it with the board before we can have a final decision on what will occur

Gene: We mentionned the advisory committee earlier, we confer with our advisory committee, which is made up of disabled persons, experts in various fields, to make sure that we are doing right

To clarify the difference between the advisory committee and the board, there is two very different functions that are satisfied there, which you may need to have two committees on yourself

Gene: The board of directors would be a New Vistas operation, these would also be responsible for .... that grow from New Vistas, whereas the advisory committee would OK the policies that we follow, they make recommendations which we can accept or, if we have done more research in that field, find maybe that we cannot meet that need at the moment, we acknowledge that that need exists, they are more in the role of consultants for what the needs are and how to go about filling those needs, whereas the board of directors is really administrative

Someone Else: The board has to cover all of New Vistas, which is four programmes, we are one of the four, and as being one of those four, we have an advisory board and they advise us, but the board advises everybody

JE: What are the other three

Gene: Disabled adult workshop, day care programme and a pre school programme

That is why it is important to have an advisory committee with each of the individual branches, so that we get some real attention from an advisory committee. The board just knows generally what we are doing, they don't know the details. But our advisory committee are really on top of what is going on and can say, hey I think you need such and such, have you considered such and such, they can be more specific.

Programme development, how are we going to do our programme development. By the way, in hiring your initial team again, remember the first people that you hire better be leaders and better be innovative people, so that they can really pick up the ball and carry it very very well. Giving the staff a lot of freedom in that area is very important, so as long as you are sure you have hired the right people, we were very fortunate because we have excellent people in each of those slots. Then we talked about the services a little bit and the final thing was staff training, now staff training did not quit at the end of five weeks, we have on going in service training.

Every other week we have somebody that comes in and does 45 mins to an hour of in service training. We have done it in a variety of areas now and you will see listed the kinds of things that we receive training in. You would be surprised at what your needs are, you are working along and all of a sudden you realise that you have got a real deficiency in an area and you need somebody to come and give you some expertise in that area.

Identification and outreach. This is referring to finding our clients. These people are not that easy to find, and they are not sitting there waiting with open arms, some of them bar the door when you get there, and especially here in northern New Mexico we are dealing with multi culturism, which is not necessarily an easy thing.

Data collection. This is really a very important area, we are so thankful that from the beginning we did go ahead and design data collection forms, which we can give you samples of, that will take care of the questions that we need to ask

JE: I have a conflict about this identification thing, some people just don't want your help

Gene: You can make yourself available, if you are patient, try to get them through, it is a stage of development, still, if they get through it, they are going to know where you are

One of the things we had to face from the beginning was that we were not in the business to change cultural things or personal values. We offered alternatives, and if people accepted those, fine, if they did not it was their business, but we would keep a window extended, so if at a later time they wanted help, we were available, regardless of when it occurred

JE: This thing I am talking about is a cultural thing too, he was Welsh .... Some people want help but can't get it, and other people just don't want help.

That is interesting to hear you say that, because that kind of verifies where we are. .... This is the very first form that is filled out, this just gets kind of name, address and serial number, just very basic kinds of information, this is the very first thing that we do. Then, if the client needs more services, that is if we don't satisfy them on the first go round, we need to know more about them ....+TAPE OVER!.......

.... who is he and what are we doing with him, what are his plans and everything. This is the way each client contact sheet is written up. We try to design them so that they are easy check lists, very quickly they can be checked off. .... It is the same deal as the client contact, if you are going to go out contacting social service or some other agency you need to know who it was you contacted and have some record and again, it is very simple to fill in, we don't want anything that is time consuming. Now, on the basis of collecting this data we can tell you how many blind Hispanics we are serving in Mora County who wear ear rings in their right ear. We can get very detailed as to what our statistics are by this simple method of data collection, but it is important that everybody keep up with these sheets. I will point out the statistics to you a little bit later on, but in a nutshell we have documented data of contacts with 462 clients, and we have contacts of about 1000 community agencies. If anybody says, how do you know this, we have got stacks of these sheets, we can show them our records. Confidentiality is extremely important to us and we are very careful that we do not divulge client names or the business of the clients, we hold this as sacred. To get any information about a client, we insist that they sign a release form, to give out any information we insist that they have to sign a release form, so this is the form that we use

JE: In England the problem is not being able to gain access to files about yourself. Who wants this information over here

You would be surprised, insurance agencies have badly abused people, they have written and tried to find out information. I don't know how it is in England, but over here there are some prejudices, say if a person has received a lot of psychological help, an employer can say, I don't want him on the staff, he is crazy. They give them a hard time, so with confidentiality nobody knows about these contacts with a therapist or anyone except the individual himself, and it really protects the patients, the clients, from being exploited. I am more concerned about protecting an individual's rights to privacy than I am worried about being sued, it works both ways. It is important to respect that privacy. I think the United States has just been grossly negligent in that area, they have just thrown open people's lives and really demolished them as the result of things that they have said or done, information that has been for example given by DVR to an insurance company or to a physician and vice versa. There has been a lot of problems with physicians, at one point in time giving information from one doctor to another, from one agency to another, without the client having permission.

Gene: If you were my client, there is no way anybody outside this agency would know anything about you. In order for us to tell them you would have to sign one of these forms, that way we could say, sure, you told us to

If a friend of one of our clients came in and said, hey, I heard that Jo is attending your support sessions every week, it seems like it is really doing him good, how is he reacting in the classes, we can't even acknowledge that he is a client, we don't discuss it. In a nice kind of way we would suggest to the individual, maybe it would be best to discuss this with your friend rather than coming to us ......

...... in so many counties needing such and such a service, housing or transportation, and we can prove it, and this helps us to support our needs so that we can go after different kinds of grant money

JE: Do you have an expert on grants too

We are just getting into this area now. With the federal cut backs that we have had, I am sure you have been hearing about them

JE: What about what Reagan did last Thursday

We are not sure how that is going to affect us. The last word we had is that we are going to get our full funding, and we are just hoping and praying that that does not change, but we don't know for sure yet. If we don't get our full funding we will receive the same amount of money that we received this past year, that is the worst thing that can happen. When you consider the increases in staff salaries, you are still talking about operating on a lower amount.

Public relations, Community services, advocacy, national resources, funding, those are all the areas we had to look at as components. National resources is what is available in the United States in this area, IL centes and so forth. Then we go on to number 7, where we hired the IL consultants. That was Max Starkloff, that is what that is referring to. We paid Max, they were a delightful couple, they were really very helpful to us because, interestingly enough, the staff's first day of work was the day that Max came as a consultant to the progrmme. It was kind of neat that everybody kind of got the same introduction to IL at the same time. It was a good way of starting. They were pointing out lots of things to us, it was really helpful to have them at the beginning of the project, because they pointed out pitfalls, things for us to look out for. The data collection was one of them, they were going back and still trying to find statistics that they had lost a long time ago. They really were very helpful in telling us what to avoid as well as giving us suggestions. There were some of the things that they went over that we just really did not get into with them because there were some things that would not work in New Mexico, if there is any place that is different it is New mexico, there are just certain things that will or won't work here, and we had to realise that in what they were advising us, we had to sort it out to see what would work here. Coming from a town and then trying to put it into practice is sometimes difficult

Gene: The differences are mostly cultural, respect for the extended families. There are some political issues too, you really have to know this area

Number 8 is the data collection system, which we have already talked about. Number 9 is client confidentiality guidelines, we have very specific rules that we go by on that, we handle the files in a certain way, very cautious with the files, so that files don't remain out on desks. Number 10, we shaped our project philosophy, which recognises the needs for every disabled person to make his own life decisions and participate in the determination of events surrounding him, and recognises the needs of non-disabled and their plight to overcome apprehension, ignorance and discomfort in dealing with handicapped friends or strangers. Emphasises a positive gentle approach towards awareness and involvement of the non-disabled community. We talked about that a little bit the other day, we are prepared to go to whatever lengths we need to in applying pressures in order to advocate for services.

But we do believe in starting gentle, building up, because of the type of environment that we are living in. The people here usually respond better by starting gentle. The next point emphasises the teaching rather than giving approach in providing services to disabled, so that a disabled person actively participates in securing his needed services. I don't know how this is in England, but the welfare system here has worked some real disasters on our population. We literally train people to extend their hands, for handouts all the time, and our philosophy is we need to work people through the process of obtaining it, rather than just handing it to them on a silver platter

JE: Disincentives, do you mean, or the charity ethic, do gooders

Right, very degrading.

Gene: It is easier for so many people to be on welfare and accept those ethics, rather than go out to work. They might even lose some money by doing that

You hear this all the time, I can only make $75 a month or I lose all my benefits, which is unfortunate. But what we are talking about here extends even beyond the money, it might be, say, a person says, my wheelchair is broken, repair it. We don't just walk out and do a repair on a wheelchair, to begin with we don't have the money. We work with that individual, to raise the money if necessary, contact some civic groups or something to get some money for wheelchair repair, we help the person make the contact with a repair person, and then we are willing to work however we need to in between, as a liaison person, maybe even in carrying a chair to the place that it is going to have to go, whenever we are making a trip that direction, but we don't just pick up a wheelchair and deliver it back on the doorstep, we feel that people need to be a part of securing services. That way they can go back if we are not around, if anything happens to us and know how to do it next time around, we won't just leave them high and dry. A lot of people in this state don't know how to obtain services, and they have so many run arounds with red tape, it is too much for them, and so we are trying to make this a teaching, training process.

Avoids duplication of services by other agencies, promotes a co-ordinating supportive role wherever possible and attempts to fill gaps in current community services delivery. We are not into doing any service that any other agency can provide. What we will do is refer a person to another agency. Now if that person has a gripe with that other agency, and says I don't like Mary down at social services, I'm not going over there, that is his tough problem, because I am not setting up a separate agency, so we are very careful that we don't duplicate services that are available other places

JE: What areas does duplication occur in

Gene: .... helping a person become employed or getting social security benefits. People who become disabled and are unable to work because of disability, you find social security may not be getting him benefits right away or not at all. He says, how can you help me out, so we will see if they have looked at it ... .

We have what we call professional door knockers, who know how to play the agencies, not a bad business.

OK number 11. Explore the possibilities of trade off services with other New Vistas projects, there is expertise in the other branches of New Vistas, so we try to find ways and means of trading off some services and facilities in order to broaden our spectrum.

Number 12. Conducting the following in service workshops, this is what I alluded to earlier, you could look down and see all the things that we have provided in service to this point in time. I am going to call your attention to something, at the very bottom down there, task analysis, are you familiar with this. Task analysis is taking any task that you do, like picking up this pencil, breaking it down into its very simplest component steps, so that you can teach another person to do it, so that you can determine what part of that task it is that the person can't do. Maybe the part that the person can't do is grasp the pencil, with the pencil in his hand he can lift it all the way up, we have isolated then where the problem is, the problem is not picking up the pencil, the problem is grasping. Task analysis is breaking anything you do into its simplest parts. We do specific staff training in this because it applies to everything youdo in life. If you are going to design a new project, then you need to do a task analysis, say the first thing I have to do is ... contact so and so, then I have to rent the room, then I have to do such and such. This process that we have just been through is a form of task analysis, and I highly recommend a staff understanding that concept. If they do, then they can plan anything in the world and be successful with it, but if they don't know and understand that process they will always have difficulties. You will find people who don't think far enough ahead of consequences, and they will find themselves in hot water because they did not think the task all the way through to the end, to say well if I do this it means that I am going to cause myself trouble down the road here. That is what that is in there for.

13. We have not heard any outcome of this. This is the inter agency living initiative, description and plans. This is some money from Washington that was coming and apparently dried up before it ever got here.

Then, to go on to number 14. We have served 462 clients, received 462 referrals. You can see how this is broken down, the type of disability, the number of clients served,again, all this came from our data collection system. By the way, we are getting a computer, and Gene is the one responsible for this MIS system. The information was there but he had to go through and hand count it, with a computer it will take no time at all.

Gene: If we handle the stuff by computer it will take no time at all. The computer system will keep track of all our clients, the type of disability they have, the counties they are in, which .... is working with the person. The systems we are down to are IBM and the Apple computer

We are encouraging Gene to undergo some professional training

JE: that is an area of employment

That's a big thing in the United States

Gene: .... there's so many community agencies working in that county, we have been able to do a lot of outreach. The other counties are so rural

JE: Which one is that

Right next to Tulse

JE: Why are you getting so much from that one

Gene: Partly because of the size, and partly because of the community programmes .... they have really been helpful. A lot of them have really good records too. Some are just excellent, it is really a pleasure to go through their records

We do have access to DVRs records, because they are sub contracting out of their agency, therefore we are under the same umbrella and can have access to their records. This is a real advantage for us. At that meeting I attended in Houston, the majority of people there had just .... to get DVR agencies to co-operate. Here our agency is just really bending over backwards to help us

JE: That would be very difficult in England

Gene: As far as the community contacts go, the organisations that we are working with .... end of tape. ....

Gene: ..... We offer a number of different services, we would like to do that, but there is one particular client, and they are going to court, and we provide an interpreter to make sure that the client got all the rights that he was entitled to, made the court aware that the person was deaf, so we have been dealing with a number of cases like that

Caroline: The courts officially assigned him to us, to do communication skillsand something else. He is supposed to learn how to use a TTY

JE: Do you have many sign language interpreters

Gene: One of our staff can do sign language, but we do keep in touch with the deaf registry in Alberquerque and they will have a list of people all over the stte that can do this sort of thing, so if we need someone we just give a call

Caroline: They are available, their services are free, any time anybody is gong to a PTA meeting, that is a parent meeting at school, or anything like that, there is a service that is available to them there. We kind of act as a catalyst to get those services sometimes. So many people in the deaf community don't understand what is available, and how much their lives can be expanded by taking advantage of some of these things, they are I think a little reticent to be involved

One person lives by herself and has nobody, no friends, no one to really relate to. It was really quite an experience for her to get out and talk with people, other people who were deaf

OK. Organise and initiate publicity for the project. We have done some on publicity, we have got a lot more we have got to do. This is an area that Tom is responsible for. Tom is responsible for our community, he is a community resources co-ordinator so he is responsible for coming up with some directories, for coming up with publicity contacts and so forth

Tom: What I have not dealt with, is radio stations. We have had one radio station come and interview our staff. We just pretty much went over our programme, they interviewed Gene, myself and Caroline, and then they aired it on the weekend three or four times Saturday and three or four times Sunday. I don't know if I told you that I have gone to one State Senator and one state representative and talked to him about the programme, and what is real interesting about that, is I go and I explain to them what we are doing and talk a little bit, and at the end, when it is about time that I should go, they say, well, how can we help now, what is coming up in the next session of legislature that I should support, is your programme .... I say, no, we don't need your help, we just wanted to let you know that we were there, and they really get excited on that, it is a real pleasant surprise, then they sort of relax

Caroline: By the way, in these contexts Tom, if this is not happening, one of the things you could tell them, is that if any bills do come forward and they have questions about the validity of them or the need, to please call us and we will supply any information we can, let them use us as resources,instead of us always approaching them. We could supply them with statistics on a bunch of things

Tom: One of the things that I was telling Gene, he was calling some agencies yesterday for referrals, and what I suggested is, instead of just asking these people for referrals, ask them if we can go talk to them, be an in service. That is kind of the way I have beenn doing it, but sometimes we think of a certain agency, we have not contacted them. The initial thing is get a hold of some referrals, we could be a little more impatient about it and schedule some things, he and I will probably be doing an in service together. I usually go out and do it myself, but occasionally Gene and I will be going to do it. Now Jeanette and I have been doing it as a team, in Los Vegas we did an in service for a nursing home and that was real positive. Jeanette had a client in the nursing home, so we went in and heard the staff side of the problems, so we are sort of acting as an in between, and we made a good enough impression that they want us to go back and do some more staff development, they want us to do a sexuality awareness thing, and she now will be doing some of that and some of the other .... we will be doing one Nov 7th. That is really a good combination of a disabled person, an able bodied person, Hispanic Anglo Male, and that has worked out real real well.

Caroline: Why don't you speak a little about territorial rights, he may run into this

Tom: I guess that is another big reason why we go about it the way we do, because for example, Gene called ....

Gene: I called the Social Security Disability Termination Unit, Alberquerque, they get advocates for Social Security, they have a medical examiner, and this unit will determine whether or not a person does qualify for Social Security, and a number of the people are disabled, they could really use our help. So I called down and asked them if they could give us some referrals, and they said, well we don't give referrals to anyone. It is kind of strange, because I was looking through some records and DVR get a lot of their referrals from you, and they said, Oh, well, we have done that in the past, but you would need to speak to someone else about that

Tom: The initial reaction is they are ours, we don't do this. That is the reaction I am sure a lot of them have, and that is why you should sort of leave it wide open at the beginning, and just tell them a little bit about your programme, then you sort of work around into the referrals, make yourself available and sort of ask, when can I come down and talk to you, and once you get there and they understand that you are for real ...... I don't know if I told you that we are very slowly starting to get into the state penitentiary, that came about in an interesting way. Before I came Gene sort of made some contacts and mailed some stuff out, and he mailed some information out to the warden, with a letter that was written by people before I came, telling them that we would be doing a follow up later on. I was going through the list and I came to the state penitentiary, and I thought that is not priority right now, they are not going to have anybody that is severely disabled in a penitentiary, so I went on to the next one, and it turned out that an inmate wrote to Caroline and she was gone, so I saw the letter and I thought it was important that I go ahead and do a follow up to that, so I wrote the guy and I have corresponded with him a couple of times by mail. I am going to go see him tomorrow now, he was transferred to the minimum security place near Alberquerque, but in the meantime I went out and met with the community resources co-ordinator at the State Pen, and they have several disabled inmates, a couple of them are the result of the riots they had there a couple of years ago, really a pretty nasty thing, so there is a couple of people that came out of that with permanent disabilities. So what I am going to do is do an in service for all the case managers, so the case managers will have a place to refer their disabled clients

Caroline: We were surprised to find out how many disabled persons were in the State Pen

JE: It is the same in Berkeley. Somebody who left the CIL has now become director of the disabled inmates programme, there are 800. Some had gone into it disabled, but a lot had become disabled since they were there, a lot through injuries inflicted upon them by other inmates, you never hear about that

Tom: In PVA newsletter there was a little advert for a motorised wheelchair out of Arizona, what happened is this guy who is severe enough to need a motorised wheelchair got convicted of something and they don't allow his motorised wheelchair in this prison, so he was trying to sell it. There is good and bad, the good is that they are not discriminating, the bad is that they have kind of put someone in a pretty vulnerable position. I asked the guy out here if that was the case, what if I did something and I was rolled in there, would they gang up on me, I can't defend myself. He said no, in fact it would probably be somewhat the opposite, they would look out for you, because he said they have a fellow there who is on the second floor, he uses crutches, he got his ankles blown up during the riots, and they carry him down the steps. He said if you mind your own business, serve your time and keep out of people's hair, they will leave youalone. If you have got a big mouth and open it too often, they will do something. I am not sure if I believe all of that yet, but it was interesting

CAroline: Anyway, how we got into this was the fact that there are a lot of agencies who are very possessive of their clients, very suspicious of our service, look at us as if we are getting ready to put them out of business, trying to be in competition. So that is why we try to explain to people that we take a supportive role to what is already going on, we will refer our clients to their agencies for services. if needed services do not exist then we will try to encourage appropriate agencies to develop the services, rather than us doing it. If that does not work, then the final step is that we will try to be the ones that fill that gap, for at least long enough to get something going, and then hopefully another agency will pick it up. So we are always in the process of moving on to something else, leaving other people tending the fires in other places, this again helps us get mileage out of our staff, it keeps us from stagnating by providing one kind of service.

Now there might come a time when that would be inappropriate thinking, maybe we should be just operating a housing facility or something like that. Right now that is not our purpose, we have got to be all things to all people.

JE: Do you speak Spanish yet

You will see further down here, we have sent some staff to take Spanish lessons, that is another area where we need a lot more.

JE: What about the indians

We do provide services for them, we are making some pretty strong contacts with the agencies. In fact I just got a call from Diane a while ago, she will still be in medicinal services, the health service will be providing for the indians, so we will be doing a co-operative thing with the Puablos

Tom: I did some in service with some of the field nurses that went out, last week ....

JE: That must be really difficult

On 17. Gene is the one that has been doing this review of DVR cases, which we talked about a little bit earlier, and he is going county to county doing that. Then on 18. This study is just about at completion, actually there is just one book to be turned in then this will be finished, there are a lot of volunteers that were involved with this project, and we are real pleased that we will be able to put out a guide to Santa Fe, through co-operative efforts, the Governors Committee on Concern for the Handicapped will be publishing the guide, making them available.

JE: It is tough getting around

19. Assisted in launching a work activities programme for developmentally disabled adults, this is in Las Vegas, this is in connection with another part of New Vistas, we arranged for a travelling display of adaptive appliances, we talked about that earlier, we began provision of IL evaluations for clients and their families. We are finding that there are a number of people who want to leave home, particularly we find this among the developmentally disabled, and the family are very much afraid because they don't feel they can make it on their own. By doing some systematic evaluations, whether the problem is retardation or some other type of disability, we can sort of determine what they can and cannot do, or are going to have to learn how to do if they do wish to move out. We may be able to recommend, well this individual is certainly not ready to be totally independent but could function very well in a group home. You have got some concrete evidence there, both for the disabled person and the family, so that it gives them something tangible to work with. So evaluations have becme a very important part of our work here

JE: Sometimes the family should be evaluated as well

That is right. I think this is helping us to get to the family a bit better, to say, hey let go, be supportive instead of holding the person back.

Made arrangements for an interpreter to provide TV news. this again has not happened, the arrangements are all there, it is a matter of a go ahead for this to become a reality. You have seen the TV screens with a little interpreter in the corner, this is supposed to be full screen, interpreter has full screen, the narrators voice in the background. It will be a first for New Mexico.

We talked about Spanish classes. We have been ordering materials like crazy for our IL library.

Number 25. We established care givers support group, which meets weekly. This has been a rather successful group. Families many times need some support and help, they also, again, through counselling and all, need to feel able to start turning loose in some areas, and give their disabled family members a little more freedom, this has been a way to build up the confidence to do that. We began work on a disabled volunteers group. We would really like to see a well organised volunteer organisation here in town that is made up primarily of individuals who are disabled. We have one person who is coming in regularly, a person with MS

Gene: There is a new person, one of Jeanette's clients

Number 28 is important. Organise a comprehensive survey team, made up of a local person from each of the 9 counties. We are here, the counties are all away up there and there is a lot of travelling involved. Who is there, what do they need, what is going on, what is not going on, what are the resources, this is really quite a task. To help get us started in that we put on a team of consultants, part time people, and we paid them a package amount of money to find out certain kinds of information for us, we gave them the forms we wanted filled out and so on. They went out and collected the data for us. By the fact that each of them was a native to his county,knew the people who were there, he knew the resources to go to, and it really helped us out. Now these people have set up speaking engagements for us, they are referring clients, and they have just really proved invaluable. They only work part time, we paid them a small salary todo that, and the benefits that we are getting from that are really tremendous, it is one of the best things that we did. So you might keep that in mind

29. We initiated arrangements to provide follow up services to clients discharged from rehab hospitals. There has not been a great deal of follow up, on certain needs anyway, of individuals coming out of rehab hospitals, and we are trying to fill in some gaps

JE: What are the rehab hospitals here

Gene: Rosswall, St. Josephs ....

We organise classes in money management, sexuality, personal grooming and hygiene, job seeking skills. Those are on going classes, we will be providing a lot more of those as more group homes open. There is a great big project that is getting ready to open a series of group homes operating on different levels, all the way from persons who have a great deal of independence to people who are very dependent

Then we have already talked about in service training to rehab hospitals, sexuality. We told you about the court referral. Gene is responsible for the rough draft of an attendant training manual

Gene: There's is two or three sections to be rewritten ....

We arrange for placement of college interns in IL. Then we made the commitment to the group homes to organise the classes in IL skills. That pretty well takes us to the point where we are. You have got to realise all of this occurred during six months of time, starting March to right now. The staff has really moved, I feel so proud of everybody, they have really sunk their teeth in and moved fast, very independently, they are living up to the word independence, and that makes everybody feel good.

Then, under project plans. There is so much we have got in front of us, really what is listed here is just some token information, because there are so many things that we want to do and we need to do. One of the biggies that we are concerned about is the security of our future. What are we going to do in order to obtain contracts to keep us surviving, that is going to really be a challenge, or we are not going to be in business. This is us, this is kind of where we are, can you guys think of anything else ....

Gene: One thing I was thinking about, in the case of the interns .... We have got a graduate school programme, we are going to teach counselling with an emphasis on IL. The students that go through this programme will be .... so they will get jobs as rehab counsellor, they will most likely find work in areas where someone needs a lot of education in IL, because of the straight tasks involved, how to set up an IL programme.

JE: What has been your main source of inspiration

.... we have set out first to satisfy needs, and then later to compare what we are doing with other centres

JE: You can learn from their weaknesses as well, particularly in management and organisation, but the services work in some places and not in others ..... what about wheelchair repair

It is a real problem. We see about the places that will do at least minimal work, changing tyres, things of that nature. A lot of firms do their own repairs, do their own welding ....

JE: If I came in and asked about hiring an electric wheelchair, what would you do

.... there is a firm that does that, R & R

Everest and Jennings, that is another bad thing in this country

Tom: A possibility for the future is to get some of the civic organisations involved in that kind of thing, Rotary Club, Lions Club or whatever, wheelchair repairs or even just providing the transportation to get the chair to Alberquerque for repair. Another thing to be involved in in the future is acquiring materials for ramps. If a person is discharged from St Josephs to an isolated house up steps, perhaps these clubs would donate the time and materials to make it accessible

Gene: going back to the problem of wheelchairs, we do have one that we can loan out, they can use for a couple of days

And we have access to others. I ran ours out last week and it did not work.

JE: In England you can't hire a powered wheelchair

Are you familiar with the Amigo, it looks like a little gold cart that you ride around on. those things are really neat for people who have enough movement to be able to use them, so much more versatile than wheelchairs

JE: a van would be useful here

There is a transportation service here in Santa Fe, which we have really been tapping. It has helped us out a great deal. It is not taxis, it is a sort of a taxi service, something between a bus and a taxi

Gene: You call 24 hours in advance .....

If you know you have an appointment or something, they are available. We are getting our own van. Ours is almost finished, they are modifying it so that Tom will be able to drive it as well as the abs. That is real exciting, that is going to really help us out, that is going to greatly expand what we are doing

Tom: The taxi service here, we are training the drivers to transfer, they asked us to put a business phone in the van, if we have any trouble within a 70 mile radius we can call them 24 hours, they will come out and help

We are just so pleased with the way people are joining in. It is as if they are waiting to be contacted

JE: Do you think IYDP has anything to do with that

Tom: There is a lot of awareness

A lot of things are happening I think, within the last year there has been a lot more awareness, all over the United States.

Tom: We are just waiting for a real rich person to come by and say we really want to help you out

We have a lot of commuters, they actually live in California but they come here to Santa Fe during the week, and have lots of money, but they are not into giving out money, they prefer to remain anonymous ....

One thing I would still really encourage in any project in England is, this is speaking from an ab standpoint, plan the project to adapt to the needs of the abs as well as the disabled population. that is the key, if you can get over that fear, apprehension, whatever it is that there is with the abs .... there are some very genuine sensitive needs there to be recognised ....

END

.... there is no room for old people, let alone handicapped. Monthly I get what they call a supplemental social security, $264 a month. My son gets what they call Aid to Dependent Children, which is $124. Then together we get food stamps, coupons, $45 between both of us. I know to institutionalise me the latest statistics are $1200 a month to keep me in a nursing home and about $200 to put him in a foster home. So they could be paying almost double what they pay right now, at least $800, and still be hundreds of dollars below what it would cost to institutionalise me annually. So, right now my attendant gets paid $450, and in the past I have had couples, and the woman did attendant care and housework and the man did the hard work. But my problem there was giving people time off, then I was depending on friends, for ever hustling to get someone to come over the weekend so the attendant could have the weekend off. That just became a total source of stress. So, last year Zoe and another lady,.I said would you be interested to be my attendant, it is time, the time is running out for the one that has been here a year and I need to find someone else. But Oscar came up with the idea of sharing this job between the two of them, one would do five days, then the other would do five, and rotate it back and forth. It has changed my whole reality, it has taken a whole lot of stress off my life. Now if they were just paid more, it would be a real liveable situation. What I would like to do, is to fly into Washington to testify to Congress in committee and open hearings, what is really going on, they have no idea of what is really happening. They live up there and they make those decisions and they think what they are doing is what is cracking. I said to him, you want to get people off welfare, start with the disabled, they don't want to have welfare, we are not charity victims. We are people with an enormous economic reality, we don't belong in nursing homes, we don't belong in hospitals, we belong in our communities. Then an alternative that is real positive that is developing in this country is the small group homes for single disabled people, living and sharing expenses

JE: How many

Three or four, five at the most

JE: We visited one in Watsonville, near Santa Cruz, but it was based on the old ethic, two people shared the same room ....

There is one in Denver, called Atlantis, that is working. That is a real viable alternative for single people, who are going to school, or have a job and are living in an urban area

JE: Atlantis was set up by a CIL

My real belief is that people should live urban or rural, in a home, as normal as possible, close to normal as possible, doing whatever anyone else would do, and that it is cheaper to live independently. It is the world cry, I am sure disabled people are realising all over the world, unless you are living in India, where you sit on the streets all day long

JE: In the third world it is very different

So, it is not going to be easy. I have got the ear and I am trying to twist it. He may finally decide that I know what I am talking about, decide he owes something to me, or he may just decide I am bonkers and write me off. I am pretty much ready for it to go either way. I don't understand their logic. I don't understand where, in God's name, they figured out that what they are doing is what happens. In this country, one of my biggest frustrations is that disabled people themselves are some of the biggest enemies. Why was I the first person to sue my respective state for trying to put me away and take my children away from me. I know of innumerable situations where women lost their children because they were disabled. Nobody wanted to fight the system. Like one of the things that overwhelmed me was that I was the first in this country to do it. That was in 1978. I did it on the basis of 504, because I was a recipient of HEW they were discriminating against me and saying I was unfit because I was disabled (Health Education and Welfare, which has now changed). Regan is of course going to do away with the education department

I went to a conference in St Paul about a year ago, it was the national conference for the legal rights of the handicapped, sponsored by legal services office at Washington DC. I was real amazed that my case has become famous, because I guess it is initiating some inspiration in other states. What I was most overwhelmed about was that I was the first, I thought surely someone would have fought the system before me, I said I am capable of maintaining my own life, I just need help. I understand in California attendants get paid maximum $700 a month, no nurses. Here I get visiting nurses to come in and do all the bowel and bladder care and all that, so some of the responsibility is shared. The way the state guidelines read for this programme that was initiated by me is that the attendants are not supposed to do that. They are supposed to do laundry, cooking, child care

JE: In England we are trying to define an attendant, we say they should do anything ....

I feel like if my attendants were really paid well I would just as soon not deal with the nurses, but as it is, considering they are only paid $450 a month, that means $225 for each of them, I feel like any extra we could get I like to put it into the house. But if I was able to pay each of them $500 a month, split the job, and I ws putting out $1000 a month for my care, then I could think in terms of that. Because as it is we really have to schedule my life around when the nurses come. It would be more flexible if that was not true. I won't get off that until either the pay goes up. I would live that much more independently if I was not tied into the nurses

JE: The nurse system does not work in England .... In England you have got to be rich or find someone who will work for nothing

It is the same here. As far as I am concerned $450 is next to nothing, the only in between is to be rich or to try to survive on this pittance they give you. I think it is criminal. I have really shoved it in the faces of the American medical, you guys think you are such hot shots keeping us alive, then you thrust us out into a society that is not in the least ready. If that is what you want to do, why don't you just line us all up and polish us off with a firing squad, it would be just as humane

JE: They are not concerned about anything like that ....

If you are a war connected veteran in this country, if you are a glory boy, not to say that those boys did not deserve it. I will tell you what they get, $3,500 a month, all their medical expenses paid, a loan to totally pay for a house etc.... ...... if that is how I ended up like, damn well the government better b e treating me like a king, that is a hell of a reason to break your spinal cord, it is hard enough to do it in a car, or a diving accident, but if you are just some young kid who got sucked into the glory of the war, and got your spine blown up, I think the government owe you a special, I don't begrudge them anything. What really blows my mind is the difference between $2,500 a month and ....

JE: But the veterans don't do anything to help the disabled movement. Alberquerque are probably the best ....

$800 of that money is supposed to be allowed for attendant care, and then you live off the other $1700, so you could possibly spend $1000 on attendant care. At that rate you could be putting money into your home to make it accessible, but they already have programmes for that. There is no national programme to make your house accessible. The people in this country that are really in trouble from disability are like blue collar workers, labour force, married when they were at high school, they have four or five kids, father breaks his neck on the job, and after that they can't get any assistance because the wife is expected to be the attendant, go out and work, raise the kids, three jobs in one

JE: Santa Fe CIL have a lot of problems

What kind of transfers do you do. Do you do one person transfers

JE: When there is another person around we get two people, it is easier. I get a lot of spasm

Did they give you valium

JE: I refused to take it

I said, what happens if I don't want to take those big blue pills any more. The doctor said, you have to. I said, Oh no I don't. Years later I said, Oh I used to take those, three or four a day, and this person went, what were you taking all that valium for. I said, valium, they did not tell you what they were giving you

JE: I had a big argument about that once

..... he is a vet, who has just come back in a wheelchair, big funky VA hospital in Souther California, he has got his urine bag on the side, and she runs into it and spills it all over, and he flips out ...... and he gets his crutches out ..... and the guys in the hospital run, get him out of here, quick, rush him off to his room and give him an injection, knock him out, because what he has been trying to do is get his bag emptied for two hours. So this diddle brained volunteer at the VA hospital, she is married to a glory boy, and it is a really incredible scene. The evolution of Wight's personality, his own struggle in dealing with disability, they way they regressed him, the way he looked in the beginning of the year, the way he looked in the middle of the year, how he was looking towards the end. He falls in love with her, which also flips her out, she is the real classic 60s woman, real oppressed. It was a wonderful movie.

Speaking of glory boys, he has got a bunch of war gods working for him. They would just love to pull us out of our economic troubles by putting us in the third world war, whether they get away with it or not remains to be seen.

I am going to go out trying with my philosophy in dealing with the system, in the meantime I just have to get along .... I am a quadruple minority, a single parent, disabled, a woman, Hispanic. So I just have to make little arrangements if my family gives me a little money or I sell a painting or ..... I have them put the cheque in someone else's name

JE: You need support to get established

I am somewhat established, by virtue of my own fights, and then my own political outlook, who I ran against for the state senate, a very old established political crut patron, he is a real godfather, everyone owes their soul to him, he has been known to try to off people, everyone got real worried that I was really putting my life in jeopardy. I was kind of the one person he could not touch, it would have been too risky. Imagine getting caught for picking on a disabled woman, the scandal would have ruined him, so he left me alone. I gained a lot of political clout for doing that. I ran on a third party ticket, because I am native spanish, and always felt a real kinship with the Chicano movement

JE: What did this guy represent

He is a democrat, county manager, made his way up as a goon sheriff, thugging people who got in the way, just playing games. He has got a hold on everyone around here, all the jobs inn this area come through him

JE: I assume he is still in there

Yes, he won. I got 10% of the vote, I got an endorsement from the capital newspaper, which is a very conservative paper, never endorsed anyone as radical as me, and I went in for a really scrutinising interview with the editorial board, it was a total fluke that they decided to endorse me. It came out three days before election day, that I was fighting for the rights of the disabled nationally, for the underprivileged, and that they just felt that my vigour and my desire to make things better and change things would follow through in me being senator, and they decided that as a result of a much needed change in this area they would go ahead and endorse me. We never expected that to happen. So we made our own sort of political victories, and it gave me a little clout. Like when I called Washington, I made sure that he knew I was the woman who had opposed him, because that is his lingo, politicians speak nothing but their own lingo, they are so tied up in their reality, if you start talking in those terms to them, all of a sudden they listen to you. My feeling is that I will try everything I can, if I have got a hold of his ear I will hang on to it as long as I can. See what I would like him to do is change the federal law. Give me help to pay my enormous medical expenses annually, pay my attendant, let me go ahead and work. I don't want the $264 cheque a month, and I don't want the $45 worth of free stamps. I told him that as nicely as possible, it is not the $264 I am hanging in there for, it is the white medical card which pays the nurses, ensures that I get an attendant, pays for the ascorbic acid, catheter ...... That is it, that is the only reason I hang on to it. One of my personal dreams, because I am an artist and I like to work with Hispanic culture, I want to restore the old town plaza in this village, and have a Hispanic gallery and like a little cafe that serves native pastries and coffee, and then restore the plaza where people used to stroll. I would like to be the director, it has been my dream for years to pull this off, that is the thing I lean on, I have got a real viable thing I want to do. The way those federal guidelines are set up I can't do it, and those guys don't even know what they are doing. They sit up there and they make their laws and the states go along with them, it is crazy. They were horrified when I talked to Senator Dominici, I said since I have been disabled I have been America's second class citizen, just because I happened to be in a faulty car, a Volkswagen that was on recall and went out of control. Incidentally, on that, I sued Volkswagen in the days when people were not getting big settlements after accidents, had I sued them today I would probably have got easily a quarter of a million dollars. I got $25,000, that is how I bought this house, and I bought a car. I was married at the time of my accident, my husband left me after, par for the course, for a lot of good reasons and a lot of bad reasons, we left the relationship totally unresolved, it has haunted him more than me all these years. I went ahead and remarried many years later, and had Daniel since I had my accident, which was another thing that horrified everybody. Daniel is 9. And it has just been nothing but a struggle for every morsel I have ever gotten. The only time I ever had any money at all was that 25,000 and you can imagine how quickly it went

JE: Just to get a house is getting more difficult

....

JE: On that particular issue you would not have stood much chance in England

Unless the woman was an unfit mother before her accident, there is no reason in the world that she can't be a mother and manage a home and work. I don't understand their thinking, you were human before, you were a person before, and now you are not, you are no longer a person. In counselling disabled people, one of the things I have hounded on their head is, because as I said earlier I feel like uttering obscenities sometimes, is to believe in themselves. One of the ..... you get into, you begin to put yourself in a place where you think you are different, you are not different, you have got the same problems everyone else has, you have got to live. Physical reality is magnified, you have to go to the bathroom like everyone else, but your reality gets magnified, and therefore you allow yourself and other people to think you are different. You are not any different and you must make them understand. That is where disabled people go wrong, they feel sorry, why was it me. I went through that, the first couple of years were hideous, I just wanted to die, what was there to live for, my life was over, how come I lived through this horrible accident, only to be this worthless person for the rest of my existence. It is very hard. A lot of people kicked me in the butt and said, you are going to have to get better, you are going to survive. A combination of that and prayers and the spiritual attitude. I was in the indian church before, about a year before

JE: A lot of people who become disabled turn to some kind of spiritual trip, like Joni

That is alright though, if it enables her to survive. I have always wanted to meet Jill Kinman, they made a movie .... I would be interested in meeting her, but you see she is making a lot of bucks off that movie, the royalties at least supplement her income on some basis. She married, and I think her husband has a decent salary

JE: What is she into

I get the feeling she is not real radical.

I am a political creature. Right now I am committing myself to working through more straight laced politicians, but he is one of the more creative and inspired, if he becomes governor the state has a chance. There is a design to put an enormous nuclear waste dump in this area, this has been declared by the government, they say the area has poor people, low incomes, high unemployment, desert ..... There is uranium, most of it is on land that was originally part of the spanish land grants and indian reservations, so there is a big Chicano/indian movement to keep them off the reservations and reclaim the land grants, to not allow uranium mining to take place. So I am real involved. The spanish and the indian used to own everything from the river basin to the mountains, all the cattle and the ditch irrigation systems had big associations, and they were very politcally powerful people, and very well run, and everyone got a piece of the pie, their land, their grazing area, their timber rights, their water rights were run by the old heads of the villages. Right before statehood enormous amounts of well to do Anglos moved into this area and began to buy a vast amount of the land and when statehood came into being, what happened was, the Fire service took the mountains and the BLM took everything from the base of the mountains to the river basin. So now the spanish people own about this much of the river basin, little acreages, then there is reservations here and there, indian reservations.

So what happened is, all the indiginous people lost their rights to all the land, predominantly just a little area off the river basin up to the mountains, and they lost with it their grazing rights, their timber rights, their mineral rights. It was a burning economy, everyone made it that way, and it has been, from that time on the Hispanic people have been selling their land and moving to California or Dallas and giving up. It was the beginning of the end of the culture. The transition was guys like the fellow I opposed for political office last year got everyone on welfare, no one could make it any more, that is how he controls them. What the Cicano movement wants to do is claim the land grants, which is all the BLM land and be part of the regulation, a lot of people don't understand the land grant movement, they just think the Cicanos want it back, but what they are really vying for is to have say so and control back over all that land. Right now the forest service is selling most of the timber and grazing rights out of state, these big lumbur companies are coming in from Texas and California, buying up these enormous expensive timber licences from the forest service and going in and cutting it all out, then they are giving the native a hard time to go out and get his winter firewood. Same with the grazing rights. In the old days the little ranchers used to have small herds and graze them up in the mountains, these days you have to be a major rancher with enormous amount of cattle to get grazing rights. They have completely eliminated the small time rancher. The BLM land is totally off limits to everyone, so that is what the land grant issue is all about. They want the San Rocee land grant back, which covers an enormous amount of their natural resources

JE: Is there any uranium around here

A lot. Of course, their approach is, it will be a boom town, you alleviate economic oppression in New Mexico, cheap short nine years, but completely denude the whole area of all the uranium, leave the area full of radioactivity. Give everybody $9 an hour jobs for four to nine years, and then move out, and all the miners develop lung cancer, the land will be completely depleted of uranium

JE: Where are the main areas

All over northern New Mexico, south of Santa Fe, and north west of Santa Fe and north east of Santa Fe

JE: Are they starting to go ahead

Economically it is not feasible. We brought a law suit against the forest service for allowing them to drill on forest service land, we brought major law suits against Anaconda and Philips Uranium and we have kept them literally at bay, at gun point almost. If the uranium companies moved in some of the more radical men in the movement were going to just dynamite the uranium companies' out of the county, mentioning no names. They would do anything. One of the Cicano movement's ideas around here is to redevelop native industry. It used to be vineyards all through the north, a wine country. You could easily again turn it into vineyards and have a native wine industry, which would be preferable to uranium, and a native textile industry, because it is still vastly rural enough to have sheep herds and collect wool and have a native textile business. Who needs uranium, it will kill us. This county I am in right now is the most radical, Rio Ariba ....(big gap in tape) ....

...... I just could not figure it out, because .... sometimes I get tired of fighting

JE: I know the feeling well

I have been fighting the system for fifteen years on way and another, I have won two or three court cases, and I get weary of fighting the system for every little morsel, which are not luxuries but necessities. I mean I don't often put that out, because I am not going to feel sorry for myself, but I do occasionally put out just what my reality is. In my case, because I am so active, people forget I am disabled, which is OK, but when some phenomena of my physical limitations or mydisability catches up with me, if I have to go to bed for two days, it freaks people out,because they are used to seeing me, go get em. From time to time I am wiped out, I can't do any more, and people say, ... they don't handle it, they are so used to seeing me on top of it, that when I finally succumb and say I have got to stop or I can't deal with this ...... It is almost like they don't want to see me that down. Another problem I get into, people put me up on a pedestal, I don't like that either .... (changes tape) ....

I have spent years trying to elevate the counties. For the most part I have felt like I was butting my head against the wall ....

JE: There are a lot of architectural barriers in Santa Fe. I suppose the Cicanos want to take care of their disabled in the family

Traditional thing about God punished them or .... Needless to say it took this community aback when I decided to oppose the big boy for the throne. He has run the county for 50 years, a disabled woman doing that. I really was given the courage to do it by the founder of the ...... party in those areas, incredibly liberated man, politically, on the subject of women, children, his own people, the Cicano movement, he is a real visionary. He said, do it, he said I think you will never know what the consequences will be, but I think they are all going to be positive, this county will never be the same if you do it, because they will never think about it quite the same again. Because everyone has lived in fear of this man for years. I was not hideous to him, but I sure exposed his corruption on the campaign. I could live in Berkeley, I could do it, and sometimes I even entertain and fantasise, it would be so much nicer to have things easier, but the need is so much greater here and I have such deep roots here, family wise, and in my own beliefs, that every time I entertain it it is just a passing fancy.

JE: Why should you uproot your roots just because you are disabled

I met Judy Hewman at that conference, she said, ah, I have been wanting to meet you for years, she said, you are that lady that took New Mexico to court. She said, gosh, are you as famous in New Mexico as you are in California, no not really. Berkeley is a radical town and always has been

JE: They all come from somewhere else in Berkeley

I get sick with heat sometimes, I broke down and got an air conditioner this summer. The last three or four summers I was getting so ill from it, so at least now I can go in my room and kick on the air conditioning in the heat of the day. I get violently ill from heat, I pass out ...... When I go places in the summer I carry cold water with me, if I start getting too hot I just have them pour it on me. People have thought I have lost my mind, big jug of water going all over my clothes, it does bring my body temperature down in the heat. Aside fom that the only thing I have to watch is, thank God I have never had a bedsore. I have a thin quad woman friend who gets bedsores all the time. I have to watch kidney infections, my lungs, I had a case of pneumonia last spring, I had double pneumonia in 75, it almost killed me. People get pneumonia real easy round here, we get these cold dry winters. My lungs are susceptible anyhow. I lost half a kidney in 76 ......

JE: Do you go for regular check ups

Yes. Not more than once a year unless ..... What I don't mind is having them flush out my bladder and getting rid of all the stones and debri, I hate it but it seems that I have less trouble if they do that

JE: That is an American phenomena

Orange juice is supposed to make your bladder alkaline and create more infections, so I don't drink a lot of citrus juice, I drink cranberry juice because it does keep your bladder acidic.

JE: Phil Draper drinks cranberry juice, he is C5/6 and big

You C5/6

JE: Yes

Me too.......... (Asks how Jane got involved ...... John explains .... asks how they came to America .... John explains)

Have you read about the two fellows that are crossing the United States in their wheelchairs. They left LA in May, they have been through here, their goal was to be in Yankee Stadium by around now. Not electric ones, they are pushing themselves. They were both placed in the Boston marathon last year. One of the other things that caught me up was the four disabled people that climbed Mount ...... , there was a blind person, a person in a wheelchair, one on crutches, and one other disability, four of them climbed Mount ....., which is a reasonably tall mountain and put a flag up for disabled people.

JE: There are a lot of those things going on

I cried when they did that, and I am really moved by those guys going across the United States, they are doing it all on their own money, and they are doing it to protest to the government that not enough is being done on spinal injury research and also to commemorate the IYDP. The years whisk by and not enough has been done

JE: We have all been cut back in the international year ....

I have a doctorate in quadraplegia

JE: there are a lot of spinal injury hospitals going inthe wrong direction .... Is it normal to get money to pay for attendants in New Mexico, is it because you have a child

One of the reasons, that makes me a priority on the list, but seeing as how I initiated the case and I was the first one anyhow. 100 people are being served by the programme now and there is 40 on the waiting list. My thinking is if there were 200 on the waiting list, they would all be served. Nobody should be waiting in line to get attendant care. That is in the whole of New Mexico. It is the only state besides California that has any form of attendant care

JE: I gather it is difficult to get suitable attendants ....

I don't feel free to live alone. Too many things can go wrong, particularly if something goes wrong with my catheter. I live in a really ethnic neighbourhood, it is already hard enough for me to be living alone as a woman, as it is it could be real dangerous. I have an intercom between my room and there is a little one roomed house out there, my attendant has that.

JE: Do the attendants stay with you for a while

No. Ablosta got interested in my political campaign, she is real active in the feminist movement, has been for years, and was real ecstatic to support my candidacy, and she started coming over and visiting with me and I liked her, we had a real instant rapport, and so I said, I will ask if she is interested in being my attendant. I think rotating the jobs is the answer. I have tried everything else

JE: In California they said you have got to have three or four ....

These particular ladies I have a really nice relationship with, nothing we have not been able to work through, they are real supportive of me politically, they even go to native american church meetings with me, which I have never expected any of my attendants to do. Eating peyoti as part of a religion is kind of ....

JE: Where do you sit when you go there

I make up a seat with cushions and sheepskins and have a backboard that supports my back when I lean on it. I tell you, it helps my health too, it is a real medicine and it keeps my kidneys and my body from getting real ....

JE: So what do you think of the place in Santa Fe

We incorporated a bunch of disabled friends and made a bid for the contract. It was real political. I applied for the directorship and to be part of the initial committee and they just did not want me. I have a good friend working there now and he is right on, did you meet Tom Holden, and if they keep hiring people like him, he is a good old friend of mine. As it turns out I would not have wanted todo it. I entertained the idea because I wanted to be in the initial putting together of the policy for the centre, and the approach to the disabled of the centre. I knew that it was important to have radical disabled people initiating the whole thing, that is why I decided to at least do it for a year.

JE: A disabled person should be the director of a centre like that

I was not educated, and I was too politically radical, that was part of it. Ralph was in on that, he was part of the ones that bid for the contract

JE: He said it should be in Alberquerque

I know of one of the men, because he is a good friend of a friend of mine, he lives in Berkeley, his name is Mike Muldane, and he is hard to get hold of. He is one of the originals that worked with Judy and Carmen Lapaz etc. She is an outrageous person

JE: I heard some terrible stories about Carmen

She has a Cleopatra complex.

JE: Her coming to Berkeley, there is only one good thing, she managed to train a lot of attendants, because they moved on so fast that other people were getting them afterwards

I was up and around when I met CArmen, and she was on crutches from her first auto accident. As a Puerto Rican she is gorgeous, really pretty. She went through dancing school in New York, then she went to work in a big time Mafia night club as a professional latin dancer, then one of the Mafia boys got her into Chicago and she was one of the original Playbody bunnies, she went from Chicago to Hollywood and was on her way to sign her contract with Paramount pictures to be a dancer and had a head on collision in LA freeway, cost her her pelvis and her lower spine. When I met her it had been years since that accident, she could not professionally dance any more, she was on crutches and getting around ws real .... and had just married. I was up and around. I did not see her again for a year and during that year Ihad my accident, and she was off the crutches, walking on her own, and I ws totally disabled, and then as luck would have it, she had her second car accident, which killed her husband and disabled her. She ran guns into Cuba when Castro was overthrowing the Batista government, with some cousin of hers. They had been off the plane 5 minutes and the cousin got killed and Carmen got shot half an inch away from the heart. she has got quite a story, she is outrageous. She and I get along well, she has a real legitimate respect for me, she has always admired the way I stuck to it and made it like I did. They don't really like to give her a lot of credit at CIL, she was a thorn in their sides and a real hustler and there was a real personality conflict between her and Judy and a few other people, so I think they don't give her the due they ought to. I know Carmen real well, pro and con, I don't hang out with her, I don't care to smoke dope or anything like that, but she calls me a couple of times a year, always got some scheme she is up to

END

Consumers here have a great deal to do with how the organisation is run. Their input into policy and procedures, in hiring practices, in programs, the30 day review and comment period on everything that we do. They really are an asset.

JE: How does it work day-by-day? Do people just come in and get together with a co-ordinator?

We have a list of individual consumer-consultants, we also have advisory councils staffed by consumers. They meet state-wide level, they meet here .. areas, regions, district. We have advisory councils in the regions and districts and they advise at that level.

JE: So you cover the whole state?

Yes. And he works with the local units. The minutes from my meetings pass through him to the localities and the localities deal with it and they pass their recommendations back up through him to me and then through me to the Commissioner. Minimum two week response period for the commissioner to respond to the advisors.

JE: Are there any key issues that dominate..

Yeah order of selection which is one of the things we are under right now.... This is the manager of consumer involvement Laural Flemming...

Yeah. We met in the lift.

Did he offer you any crisps??????...... Maybe we better get on our way.

This is the office of affirmative action ... is that part of Federal part of ..... that forces us to act affirmatively on the part of those who have been treated rather negatively in the past. Minorities, women, handicappers ... so we have regular goals that we have to meet with every agency..... This is the labour relations conference room... unions and management. I know you know about unions and management?!!! Mr Sparrow on that side of the wall runs the personal care attendants program. He works for the independent living director... BCIL are under contract to us. All the ILCs in the state are under contract to us.

JE: Does that mean there is an attendant referral system here?

Yes. Actually they are organised at the Centres... we just pass the money through and make sure that the blokes meets the needs of the person that hires them.

JE: How does that work here?

Its a sliding scale. He runs the state program which takes over after the federal program .. you know the federal program... you can only have it if your on SSI or something like that. This program takes over when all those benefits are finished, when a person is employed or employable and theyre not eligable for that anymore.. then our state PCA program takes over on a sliding scale depending on how much money the person makes they contribute to the salary of their PCA.

JE: So what youre saying then is any disabled peerson in Mass. should be able to get money for thei independence... I mean, in some places they don't get that..

Yeah... either federal or state. This is our public information gallery. You know, when I go out you really gotta have an exhibit... you just slide this across here, fold the legs, throw it in a case and carry it across town.

JE: You dont have one of those? Programs, Statement and Planning in

Consuumer Involvement?

Yeah. And this grey one is our Annual Report.?

JE: Can I have one? (YEAH).... I'll never read all this before I go this afternoon..

Sure, but you still have it all. Down here ... its not very visual ... but its all part of client services .. keeping track of whose in the workshops, how much moneys going....

JE: What kind of workshops?

Sheltered workshops.

JE: The dreaded word..

Right. And housing, and vehicle modification.. is down here, planning is down here, where we plan quarterly and annual (?) state plan .. and things like that.

JE: The vehicle modification unit as well? You don't get that in many rehabilitation services do you? in different state?

Actually we have more demand for it than we have money. But the consumers refused us to allow it to close down, they allowed us to cap it. But its not a federally mandated program. Its a program that got started here because there was a need, so of course we don't get a lot of money for it. We have to pull it out of the basic VR dollar and the consumers said Yes, we need those programs. People cant go to work.. they cant get in and out of their homes... they cant get to their jobs and back... they cant have transportation at their convenience to use. Nobody wants to be sitting there waiting for a cab to come and get them if they have if they have a $15000 van in the driveway they cant drive .. so we take them to the hospital at Braintree, we get them out there, get them evaluated and trained to deal.. the way they deal best .... vehicle.

JE: Thats tremendous. The only other place I saw that was Berkeley but the CIL was doing that there... its most unusual of voc rehab services .. do you know of any other States doing that? New York?

No. Then our CILs here are set up a little differently in that the VR Agency holds the contracts so they do have to fit in to some of our demands .. that we have to fit it into to get the Title 7 Independent Living moneys from the feds

JE: Yes. Cos thats (or Mass.) one of the important ones...

And the State matches us.

JE: Are you going to be affected much by this thing Reagan did...?

The latest word is that it could hurt. They wont know until Monday or Tuesday of next week. And then we will immediately have to increase or decrease our budget.. One or the other. It won't be the same... and chances are 9 out of 10, decreased. Means we'll have to cut in half. And its hard to do that as we are already squeeking. We've dropped from 750staff to 630staff you know, and trying to keep your counselling staff up....

JE: Why was that...

Funding. Congress decided an entitlement was just for show, it didn't matter..

JE: And your an Agency... you cant do without that ..

It falls into the mould of tthings now really. Theres not a lot of money going into Education .. to me its sad .. but...

Now we go around the other side we have the other side of the Paul Head staff development .. where we have all the training back-up, word processing... legal council and just the executive staff is up there... the real interesting stuff is on the third floor - thats where our electronic data processing system is where we process client tracking, financial data, and everything with the fastest turnover for money... we started it here..

JE: There is a lot of activity... we got out of the 3rd floor by mistake at first..

The information centre for individuals with disabilities, .. covers the nation. People just call here from everywhere to get information, to get assisstance and to find out where to get an advocate.. to find a bowel (?) form.. the Mass Office of deafness has an electronic registry of deaf, hard of hearing and hearing impaired persons in the commonwealth (?).. and everyone that goes to an autologist gets registered and we fought a battle and won it about sixty days ago with MaBell (?) and got reduced rates for TTD users... across the State with night rates.. We have a mass media library .... extensive rehab library....

JE: Yes. I wish I was staying longer. How many staff did you say?

Statewide. 630..

JE: Down from ...

750

JE: Are many of those disabled

It was all done through attrition, we did not fire anybody, people retired, moved on to other jobs, nobody got fired. In order to reduce that staff we just did not backfill the positions. According to our affirmative action update that we had at about 9.30 this morning we are doing grand in terms of social security and minorities and the real sticky thing now is women in the administration. You are looking at one, no there's two, pardon me, one in the general council, but they don't do very well at getting above grade 21 in the agency. So that is the only issue there is now, but as far as minorities and disabilities, we are pretty well covered. We are beginning to look at whether we should do an assessment of how many of us with disabilities are actually functionally limited. I mean I could tell you I am a disabled person, and I mean its dandruff or anything, so we are considering how you could go about figuring out how many people are functionally disabled and how many are in reasonable accommodation. Records would show that on our administration the disabled are about 50%, but we would look and see if that is really the truth or is it just people with allergies, stuff like that. We have a lot of people who have disabilities and that is probably, they know this ..... but then a lot of folks do

JE: It's a community activity, is this a kind of outreach thing

Yes, it is basically the responsibility of every district office to do the very same thing, to get involved in every health fear, every handicap, every educational fear, library, whatever is going on in the district and have somebody on hand with information. To stay visible we do public service announcements, radio and television, articles in the newspapers and I shift my brochures out, the yellow one I leave in the supermarket

JE: In terms of disability groups there is a lot going on here.

It is a very strong lobby. I have to sit on the board of a group today, and as a child I was a doughnut girl, when I was a child you realise there were .... The only way to deal in this situation is to be part of the consumer groups, they have to know you, they have to believe you, they have to trust you, or they will destroy you. So we survive because ....

This is Charlotte Lijier and she is the grants manager

Well hello

Regularly brings in all the money

I spend it

This is John Evans, this is Jane, they are here from England, doing a little research and what have you. They have visited St. Louis with Gini Laurie

JE: And Berkeley and San Francisco

Did you get to see Ed Roberts

Very nice to meet you and I hope you enjoy your time here

This is the man who runs the programme for adapted vehicles. John Evans, Jane.
JE: I've heard about that programme. It seems like everywhere else I have been no one is doing a programme like that, except Berkeley

It is a pretty progressive programme

John tells me that in England it is unheard of to have a disabled executive

JE: Yes, but we don't even have the vehicles, we don't have the vehicles that can be modified, we have small cars and they are alright, but if you want to stay in your wheelchair, the only time you can stay in your wheelchair is if you have some one who is going to drive you

What level are you John

5/6

You'd be driving

JE: Yes, I can drive, but it is a matter of getting the right vehicle where I can stay in my chair, so it is a hassle

How long are you here

JE: We are only here until Tuesday, we have been in the states almost six weeks now

We have some vans I'd show you

JE: I've seen a lot around, any information you have. The agency that is sponsoring me to come here, the SIA, have said that they want to aim for American type vans adapted, so they are interested in that idea, so whatever information I can take back to their head office, this is the next move, the next thing is we want to try and bring those sort of vehicles over, as I said we don't have them

I can get you a whole package, I can send it out to you, and how we set it up here and the type of equipment, the cost and all that. We have been in touch with Caltran of California, which is a testing agency. We have recently issued .... We have got a lock down now which holds your chair, and a belt which holds you in a thirty mile crash, it is like you were not in an automobile

JE: That's quite something. Tina will have my address. That is their next project, they want to go ahead and do something, the quicker we can get them moving on that, we want to get them moving fast, it has been too long anyway. The other thing is, somebody told me about a Scotmobile, do you know about that. Have you got information about that right now, because I have been trying to get hold of that to take back with me, I want to go back armed and say this is it...... No... What is the name of the firm that is doing that, I almost got to see it in Berkeley and then the person who was driving it, I missed him by seconds

The man's name is Charlie Scott, and it is Mobility Products and Design Inc., right now he is, I believe, in New Jersey and is trying to set up a factory on the East Coast for producing the car

JE: But you do not know the exact address

I can find out. He was supposed to come up here and show one of these systems to Elmer, he was supposed to be here September but for some reason he has been delayed.
You would not need something as complicated

JE: I am only interested in that because it is revolutionary, for somebody who is really severely handicapped, that is what is so fantastic about it. No, I was not thinking in terms of myself on that one, it is just a breakthrough

I don't know if you have seen them, but it's just power clamps on the floor .... What we used to do is cut into the chassis, 4", the frame itself, with the Dodge and the Chevvys, rest right on the chassis, but we did not really like doing this, because we don't really know what it does to the stability of the van but it was the only way we could do it. Now the floor is 4" above where the frame is so you can put a car in there without even touching any part of the vehicle and we have no problem in operating the hand controls

JE: We are way behind on vehicles, all over Europe

You know what, it is 2.30, I am going to take them down and show them where they can get something to eat and then at 3.15 or so they are going to meet with Elmer

END...

Next interview with Elmer Bartels.

In Massachusetts we are still not totally covered with independent living centres, we are still trying to build up the western part of the state, our rural counties. We have been serving them in a partial way, we have staff out there that do a little rabble rousing now and then, but there is no comprehensive programme and we are trying to get that established, even then not very much, it will be about $60,000 this coming year

JE: But you have very high goals and objectives, I think, all the same. Here and California and other places, you operate very differently, but you are still covering a lot, quite a good area

One of the fortunate things, I think we have a lot of committed people in Mass. independent living programmes running. Many of the disabled people are on the staff, on the board, a lot of energy. The dollars that are spent are spent pretty effectively.

JE: In terms of how, you were one of the originators of the CIL, how do you see from the time it started to where it is at now in terms of its development, is that how you saw it was going to develop

When we started we were so much in the middle of trying to get the damn thing started that we did not spend much time thinking where's it going. Bootleg operation of trying to get something done with a little bit of federal money, and a welfare dept. to pay for medicated DCAs. Did we have any long range picture? Each of us probably had out own, but we never wrote it down, but where it has gone, I am certainly very comfortable with that, it has evolved very nicely. I think the biggest problems we have had in the independent living movement is the fiscal responsibility and the financial soundness of the non-profits, because the people getting into the programme, the people have now become responsible for the books and for the financial viability of their organisation and people usually are not very good at that, it is actually the exception that is good at that. That has been our biggest problem. In two of the small centres that we have going here we have a contract with one of the management corporations to go in and stall their books for them. We feel that it is that important to get them on a good fiscal footing, give them a good set of books so that when they go up to the rate setting commission they can get their rates quickly and without a lot of hassle, because they do it with finances

JE: Is that something that has come out recently because of the economic situation

No, it has been there since the beginning

JE: In Berkeley, my impression was that that was always very loose

They have exactly the same problem. I understand the feds are in there wondering what did you do with the money. The feds might even ask for some of it back. They can do that if the non-profit can not justify what they did with the money. They can ask for it back. Can they get it back? Probably not, because there is no money there anyway.

JE: So what you are trying to say, is that everything has to be accounted for. So that should be inbuilt to any independent living programme

One of my mottos in doing business is "You gotta do well, before you do good", well in a financial, fiscal sense. You have got to do that well before you can be around to do good in some other way, otherwise, if you don't do that you won't be there. Somebody will come in an shut you down, for tax purposes or whatever, many non-profits have had that problem, they find they have got to pay their staff and they have got to pay Uncle Sam, federal tax that goes with it, they don't have the money to pay Uncle Sam so they say, well we'll pay him next week and we'll pay the staff, because the cash flow is not right, the books are not set up properly and they don't know where the hell they are anyway. Then they keep paying the staff and they postpone paying Uncle Sam and when you build up a bill of $20,000 youowe Uncle Sam, Uncle Sam says I want my 20k and they can't get you on a repayment plan, they shut youdown.

JE: So, as well as that record keeping, finance keeping and accounting, there's the other end of it too, looking into the future and trying to acquire funds to maintain the ongoing procedure of that centre. All the directors in the centres I have been to so far, 80% of their time is spent doing just that, just getting into businesses, into other areas where they can get more funds because no one knows where the next grant is going to come from or how long the next programme is going to last. In Berkeley their staff has been cut in half in one year.

We have the potential, our grants we have now, we have about $600,000, technically it runs out 30th September next year, all of it, now we think we are going into a competing continuation to be able to maintain at least some of that, whether it is 600 or500 or 400 I can't say, some level of programme. At the same time, the programmes out there are establishing their fee for service with the welfare dept., the medicated, to provide independent living, ECA services ...

(tape turned over...)

One of the problems I have seen in Voc Rehab around the country .. if they were to take a stronger interest in ILCs that are developing .. that relationship creates a sounder ILC. Where the relationship has gone well you have a stronger CIL movement ... where do you see that, .. in Massachussettes they have a very close link.. the executive of each CIL and the IL Project director (John Rowledge) sit on the Executive Committee - as they call it - and it is the Exec Committee is the one that drives IL in Mass. as a group. They deal with Tuft, they deal with policy, they get together on how to approach the Welfare Commission, PCA Services, how to get after the Rate setting Commission, how to deal with other State Agencies - so that that group is a good planning and consensus getting group and they are the ones defining what IL is and what its going to become in the context of our outside world.

I dont see that model anywhere else other than Mass. Its a kind of a Management model... one of my favourite topics is Managed positions.

JE: I suppose the whole social climate is so different that you have got a Dir. of Rehab Services who was one of the originators of the CIL Movement who is still in touch, that you can have that kind of co-operation between them .. throughout. Is that because the way California is... a very loose State?

Its that the IL Movement got started at a period of time outside of the Voc Rehab agencies - and really the IL Movement does not consider the Voc Rehab agency is theirs and that they should relate to it and need to relate to it. They think the Voc Rehab agency is kind of irrelevent. They are going to do their things and voc rehab doesn't improve or whatever and so they kind of give up on them. I was at San Diego a few years ago talking to the guy at the CIL and I asked him how close his relationship with the office of the local voc rehab agency - do you meet him often? Talk to him? ... "No, not much. He really doesn't deal with the same things as I do." I think its vitally important. What I encourage is that our CIL Directors and our regional people meet/work together. We started.. a couple of the CILs in this state out of our regional offices .. keep the rent down. But I was trying to achieve two things. 1. keep rent down, 2. get the thing started with our staff so that people get to know each other and you build a bridge right from the beginning.

JE: But dont you see one of the greatest differnces is that you are the Commissioner... I dont know of any other States where the Commissioner...

There is a disabled Director who left in this past June.. but he had an opportunity to do it that way..if he chose to.. Ed Roberts in California, he can do it that way if he chooses to..

JE: But I suppose he is limited because of areas.. its split up into smaller areas there isn't it?

You can develop that, even though he's got 20/30 CILs supposedly in California, .. you can develop it on a Regional basis.. enforce it that... and it depends on how you want to run it. I choose to run it that way because I think its important.. somebody else can choose to run it a different way. I think we've got to (Bank with the buckhouse??).

JE: Its interesting you should say that for I've just come from Santa Fe and they have just started one up there . I dont know if you know about it, but that seems to have been started .. that started from.. it seems the impulses came from voc rehab, and there was some money available and they were given the money to set up a centre so it was given to certain people to set it up . The Director happens to be a lady who has been involved in a number of Social Welfare programs over the years and, you know, a little bit of experience with disability and she has been given the job and has drafted in quite a few other disabled individuals . the staff is about half and half now. But it seems that they started from an entirely .. it seems like it was almost a political thing almost to make it unique and to try and make it rural, because they are trying to cover a lot of New Mexico, and they are very sparcely populated areas... Santa Fe, around that whole northern part, and not Albequerqui. Albequerqui is outside it which it seems like if something was going to be started up in NMexico it should have been there where there14,000 people and thereis quite high percentage of dab people cos Imet ip with a PVA director - Ralph Markwood, one of the co-ordinators - and I was astonished at the amount of people they were dealing with that are not Veterans ad he said, "We have been doing this job for a while and we could have gone onto that quite easily but it seemed to be a politial decision that they wanted to split up andthe only way they could get the money was to make out they were being unique by being rural so you've got a kinda dilema there

I think its the way you have to go after the money, they've created that dilema there... they figutred the best thing they could do to make it unique was to makeit arural one... so they find this project and once you get the moey you have to do it that way

JE: Seems like they've got a lot of area to cover... I mean I'M sure they'll do it .. they seem to be doing quite well now although they have only been going six months

It is tobe ouragencies (??) willing to give it away so to speak to the disabled community but yet keep a close ownership to it .. and thats a trust relationship. How much are you willing to give away... dollars or whatever for building.. folk rehab .. but also to be around when the small non profit needs you .. its like raising a child .. very much the same .. sometimes its a love/hate relationship

JE: In each CIL ..... the problem with us is in England .. coming back to what sort of implications all these ideas and experiences that we've had since we've been over here is that there isn't that kind of set up there. You wouldn't get the support.. or it'll be very hard to sell it to them from a disabled consumers point of view.. and this is how it has to be done and this is the model in the States .. this is how it developed.

We did it 10 years ago. Back in '72 we came to this agency which was rather introverted and disinterested and began to do it.. a little seed money and started something (overBU??) with the Boston Centre and slowly grew it and then title 7 came along and that kinda the culmination of it ..

JE: Yeah at the moment we don't have something similar to that. I'm sure if there was it would make a lot of difference. At the moment people are trying to change.. there was a law made in '71 that all public buildings should be made accessible, and transportation systems and so on and so forth .. it was very siilar, but it wasn't an enforced law thats what was different, so people didn't take it too seriously.

I would say then that the disabled people then have got to use some of their political clout to get some of these things taken care of .. back in '68 we created the Architectural Barriers Board that oversees the implementation of regulations on accessibility of State owned buildings. It got expanded to buildings open to and used by the public, the Board's got the clout to force people to do it. In '74 we passed a law that requires curb-cuts. Whenever the streets or side-walks are redone, curb-cuts have to be put in at the corners, and you see the results of that now . a law passed in '74 and now you go around here and you see them on just about every corner.

JE: Yeah, well we've only just got here and haven't been around, but I know in Sante Fe it wasn't clear, it was hard. After going there from Berkeley it was like going from heaven to hell.

The difference is in how the disabled people have used the political process to get a job done. You have to have a political organisation to do it and its got to be broad based. It cant be the SI here and the CP there and the MS here .. its got to be all together girls. We're going to go after a piece of legislation, we're going to go to the right place, we're going to do our homework, we're going to plan out exactly how to do it, who makes the decisions and how they are made, and then we're going to dance on their heads.. one by one by one, until it gets done. And it happens, and you don't need a lot of people. 4 or 5 people in wheelchairs can do one hell of a lot of things... if you get your act together, do your homework and go do it and stay with it until it gets done, because non-disabled people get very intimidated by a group of wheelchairs and they'll do almost anything as long as its reasonable.

JE: Yes. Its beginning to happen now. I just cannot understand why its taken so long. I mean, its ten years later than it is in the States. As I say, its been going on, people have been doing it as individuals, they've been doing their own thing basically and not organised on a level. We've had no Coalition of Citizens with Disabilities or anything like that.. and thats the sort of crux of the matter. The only thing we've got is the UPIAS. Have you heard of that? (No) Thats a sort of very radical, Marxist, left wing organisation.

Don't get involved in that stuff because they're raising a whole mess of red herrings that you don't get nothing done.

JE: Exactly. Thats the reason why they haven't got anything done. Thats why you need a more middle of the road thing sort of like what happened over here just Citizens with Disabilities coming together. I think the attitudes are different. I mean the English psychological barriers are much stiffer to break down .. people tend to kind of stick within their own kind of groups much more and thats why these kind of groups have tended to sort of perpetrate and keep it together. I mean the SIA are probably amongst the most progressive in the sense that when they asked me what was I going to do when I came out here and what kind of implications did it have in the UK I said, first of all before you give me any money and support me I'm going to the States to study independant living and to look at the IL movement as a whole .. as a severely handicapped person. Not just as an SCI person.... even though that is my own experteese and in terms of my own experience what I know I can do and can't do and be counselling. And they accepted that and they said Yeah thats fine and if you see that thats a question thats got to come up...

That broad base is so important here. We have had in Mass. the Mass

Council of Organisations of the Handicapped which today is kindof defunct, but it existed 10 years ago and it helped to get a number of the laws enforced. Then the Mass. Coalition came along in the last three years.. and it is somewhat organised .. and something..???back.. One of our problems in the Disability Movement is that we have got so many ofthe things done .. the laws been created, we have Architects Law, Transportation Law coming along even though it hasn't gotten off, but at least its on. We've got some housing, not enough, but some. IL program thats reasonably comprehensive and now ouur disability groups don't know what to do.. so its kinda falling apart. Theres (R?)evolution that start with defining a set of problemsand people say we are going to go after them. And I was part of that back in the late 60s and early 70s and in the outside world. I spent a lotof time up on Beacon Hill getting laws passed National Spinal Cord Injury Foundation, National...... and working on those national issues and opening those particular concepts. And as a group of us both in Mass. and then nationally we were pushing those issues and some of us have gotten into positions of responsibility. I am running this agency, another guy is running the Transit Authority taking care of the transportation of h/capped people here in Boston. The Architectural Barriers Board has some of the old folks on it that we were involved with years ago ... he's on the Board making AD rates, making those decisions. We have an office of h/capped affairs that has people on it that have been with thedisability movement for a long time. A lot of the rabble-rousers of afew years ago we are now responsible for running it. You will have to decide if thats the way you wantto go. Its a perfectly reasonable place to go or do you want somebody else to do it for you and you tell them what to do

JE: No no. Thats the way to go, its just a matter of getting there. In England there is nobody at all, there's no disabled director of social services which is the equivalent of rehab services.

Do you have any qualified disabled people to do the jobs?

JE: Oh yeah they are around. You find them on campuses or Universities earning their livings there, or directors of Spinal Injuries Assoc and so on or so forth... or housing projects.

Directors of things have got to be encouraged to go after State jobs and be responsible for ..... in England. They have got to apply for the job and use the political clout to get there.

JE: Yes, its almost like changing the system in England. Its a long drawn out process.

You have got to get in it. And you gotta use that. I'm on the inside and I do what I can do when I can't do anymore, I make sure the people on the outside that want the same thing done know what it is, and then they can go up on the Hill and lobby an issue when I can't go up there, I can't do that. So its Inside/Outside. Good guy/Bad guy. Whatever approach you want to use. Rather Machieveli but it all works.

JE: When did you consciously decide to get into the position you are in now? Was that in the early days? I mean, how did that come about?

I had no idea in the early days that I wanted to do this job. In the Summer of 76 this job was vacant and they were looking around for someone to fill it. They wanted somebody who was disabled and after some discussion with people responsible for filling the job - I went in and talked to them to see if they were interested, and they started courting me and asking me to dothe job, and I thought, hey, thats a helluva thing to do. I was inthe computer business, running a department for systems development for Honeywell. I thought it was a tremendous opportunity to come and manage something big, its a 40million dollar agency, and deal with budget issues, personel, labour relations, the voc rehab program, consumerism, IL, the political aspects of running an agency. Its been helluva learning experience for those reasons I give. Did I ever think I was going to do it, ten years ago? No. I always thought of myself as a computer programmer and manager and stay in the computer business .. its a great business, someday I'll go back.. maybe.

JE: So it just happened like that .. the job came up and you decided, thats where I want to be.

Ah. Yeah, maybe I wanna do that. I did some deep thinking and I talked to some folks up on the Hill and the then Govenor and his Secretary of Human Services came after me and asked me if I'd do it. And I thought about it a bit and then said I would. I got leave of absence from Honeywell.

JE: What does it take to do something like that in the States - do you need a degree? What are the qualificationsrequired?

I have a Masters Degree in Nuclear Physics.
The point is, the qualification for a political appointment are not terribly relevant

JE: You mean just a Masters degree

No, you would not need to have a masters. You need to have a reasonable experience to be able to do the job. For some one who has not been a manager to come in and manage a $40m. agency does not make sense. For me it made sense. I had been a manager in data processing for about three years, where I had been responsible for a department of 40 people, data processing, pretty complex stuff, budgeting, controlling and discussing and all the stuff you do at management. Those are the things that made it viable for me to think I could run this place. Not the degree I had.

JE: Did you have that after your disability?

I was injured in 1960. BCIL started in 72. So I have been around for a long time.

JE: Do you think that there is a place in the independent living programme for management training

Oh yes, we are training an awful lot of disabled people to run things. That is part of the challenge and the responsibility of independent living. So the people come out of the independent living programmes and it is now viable for them to say, I'm going to go for a Yale programme, it is something I could do

JE: So one step leads to another

Did you meet Max Starcroft? That guy in another year or so, two, he is a bright guy, it is going to be reasonable for him to take on a high level position in government, given he wants to do it.

JE: I was very impressed by him. The whole St. Louis paraquad centre really stems around him and his organisation

He is bright, he is young, energetic, learning how to manage things, people

JE: So how do you see the independent living movement now, at this stage intime, when you think about the cut backs that are going to happen

It is a period of consolidation. Consolidate the gains, document what we have done, and try to hold it properly

JE: Do you think there is enough documentation

No. Definitely not. We have been guilty of that here and I have an activity going on presently, somebody writing up the history of independent living, paying money to have it done. Documentation of what we have done, cost effectiveness of programmes and all that stuff

JE: When do you think that would be ready by

A couple of months. Did somebody give you the Stirbridge Report?

JE: That's the Gurven de Yung book. Yes, I got that off Gini Laurie

That document for me is one of the contemporary documents of the day that turns to the future, and defines some of the problems and the approaches to them andI think that document is going to be good for another three or four years, because we are not going to makeenough progress to obsolete that book for a few years. The problems are significant enough and deep enough so that they will continue to be problems, especially when some states, like Mass. are way ahead and others, like Mexico arejust beginning to deal with the problems, you've got those differences and you will have those for a while until we bring everybody else up to speed, so the Stirbridge document is going to be very helpful for the new boys in the block, that is one of the reasons we did it, to help the new boys in the block

JE: It was a criticism I had of Berkeley, I said there is very little documentation about the centre. There is Hail Zukass' CIL History, which is alright but it does not really cover the details of what they had to go through to get that place organised, yet they still think there is a lot written on it, just small articles written by various people within that movement that have done things, like Grees Curtis, Debby Caplan, the directors etc. I suppose they are not going to admit it, but it is not there, that kind of documentation of how they began. They were so significant, being the pioneering group, at least on the West Coast, I mean here it is different ...

East Coast, West Coast. It has been very interesting. You've got a competition going as to which state is going to have the better statewide independent living programme

JE: If you went back to the beginning now, how would you see yourself documenting that as you were doing it, because as you say, at the time you just want to get the thing going

You have got to put it in the budget. Put $2000 or whatever you want to put into the budget to put a report at the end of the year of what you have done in the year. You put a little money aside to write a good annual report. You get somebody good. It's a programmatic description what you are looking for. You can get your bookkeeper to tote the numbers up

JE: You mentionned the Stirbridge Report, what other things do you see as vital reading

Maybe what you ought to do is ask Lex to send you a bundle of stuff, what he thinks youought to have, get one of everything he has got. He has got a whole list of media stuff that you can use, buy it all. It will cost somewhere near $200 to getit all, buy it. He has probably got the most written stuff of anybody.That is why you missed an opportunity, not going down to see him.

JE: The impression I got on the West Coast. People were a bit suspicious of people who wrote too much

We've had a very close relationship with Gurven here, as a matter of facthe wrote up the Stirbridge conference. We were very lucky to have somebody as skilled as Gurven to write up that conference. It was also the message of how we put that conference together, that you may want to use over in England, get together some work groups, questions and topics, and ask ...

JE: Beforehand

Yes, we organised that thing to the hilt before anybody came in through the door. We trained our workshop leaders and put people through two days of intensive brain storming and tried to get concensus and recommendations, issue dealing, and deal with some futuristic stuff. Look at the structure that went behind that, you might want to use that in England as an approach, to find out, where the hell are we, where do we want to go

JE: It is a matter of getting people together to do that

Get a grant from somebody to pull people together for two or three days, a brain storm, where do you want to go,develop a coalition, an organisation to deal with it, to pull people together, maybe each one of these organisations would put up some money, SIA, DIG, all of them, put up some money. Structure it, what do you want to get out the other end of that conference, what do you want to achieve, what do you want to leave behind, ask those questions, make sure you know what you want to accomplish, not just get people together to talk, they will talk anyway, but you want a result out of the other end, a nationwide organisation, you want to put together a structure, an executive committee, an agenda, dialogues

JE: Just hope they will be able to loosen up their individual identies, inhibitions etc.

You can be the catalyst for that. You have a certain credibility with the people that sent youover here and you go back and become the catalyst for the next thing that is going to happen, decide what it is. Surprising what a person can do.

JE: As long as you have got a few people working together with the right objectives

P.T.O. 9 + 10

Going back to the beginning, we never thought of this being so structured as I am describing it, we were doing it by the seat of our pants. We got together and moved the issues and we were going to go after this and after that and I was sitting in the middle of this with a friend and both of us were feeling even though this was not terribly sophisticated at the time we would really organise things, and we would scheme together how we would go after this and that

JE: You had no idea where you were going. Were you concerned with yourselves or were you concerned withothers as well

We were interested in pushing the movement, pushing the set of issues and getting something done for disabled people

JE: How do you see the Coalition of Citizens with Disabilities helped that process along, independent living movement

They helped politically, they helped in some of the ancilliary issues like rights for handicapped people, voting rights, impact in Washington, which was a significant part of the job. Frank Bow, running ACCD did a beautiful job. He too had a problem with trying to do good without doing well, the financial house within ACCD is a rats nest, so he is spending an awful lot of time trying to fix it up, I'm not sure whether they have got it fixed up yet. Frank was way out froont with a lot of programmatic stuff, but the house back here, rotten apple

JE: So the inbuilt weakness is the business side

Every single time. One thing you take away from our conversation, make damn sure your bucks are in order

JE: I would have thought if anybody had it together on that level it would have been the Americans, maybe it is because there is so much availability of bucks in certain areas, it is something that is taken for granted more, the materialistic level I think

I would not put it that way, I would put it that there was programmes, with people trying to run a business and programmes with people who don't know how to deal with bucks

JE: So how do you overcome that

The way to overcome it is to deal with the issue head on, to get somebody who knows the books wherever, a good accountant, a good accounting firm, to instal a good set of books in your organisation and start it right, make sure you stay with it, don't change it along the way

JE: Do you see any difference in whether that person should be a disabled person

You need a bookkeeper, you better get yourself a damn good bookkeeper, if he is that's nice. It's true of an executive director running independent living, if you put it in the hands of adisabled person who is not competent for the job, you are going to kill him. You want to get people that are disabled that have the abilities to dothe job, maybe they are not quite there yet, but very quickly they will rise to the occasion, but you cannot afford to take somebody from ground 0 up to that at the same time you try to start a programme from scratch, because it is beyond the ability of the person to do it. We saw a couple of times in BCIL that the directors of that in the early days did not have the capabilities of building that and that is why the BCIL has gone to a non-disabled director, but on the staff there are many disabled people. Now it is worked out reasonably well. In Worcester, the director of that started off disabled, and he did a nice job getting things started, then he moved on to other things and since then there has been two non-disabled directors.

JE: Do you find any sort of dichotomy in your experience in being a commissioner and a consumer at the same time

I am not a consumer

JE: You are not a consumer, you must be. I mean, in some ways you are receiving the services that you are providing

I am not

JE: No? How do you overcome that, I mean I can't quite see that

I don't receive services of a vocational nature or a community service nature from anybody. I am not a service receiver in that sense

JE: Why, because you provide them

No, because of where I am with my disability

I don't conceive of myself as being a consumer. I am an administrator of a Voc. Rehab. Agency that happens to have a disability. Hopefully that makes me a little wiser, to be able to run this place a little better than somebody else, and you can't wear the two hats, be a consumer and an administrator at the same time, inside one organisation, you can take that hat and go outside, but you better be careful when you do it and who you do it with. You may represent the consumer community, I do that as an administrator of Voc. Rehab. but I am not a consumer, fine point, but important point

JE: I think I have got it

What are you trying to change on the other side. I don't know what Disabled International is trying to do, who is it trying to impact on, who is it trying to change, where, how, how much. Generally, I think, it is a good idea, but what is it really trying to do. Is it information sharing. Even of itself, that is fine, if that is what it is for, they can bring other countries along, give them ideas. If that is what it is for, that is good even of itself. But, is it trying to do more, I don't know, are you part of it?

JE: No, I am not part of it, just trying to find out myself. I just talked a little bit to Ed Roberts and he seemed to feel the need for

END.

This side of the idea was bad from a liability point of view, they were going to get rid of the monkeys, so I says to one, I was friends with one of the people who was going to do this, so I says, listen, if you are going to get rid of the monkeys, I would not mind having one for a pet, I did not know it was illegal to have one at the time, so .... You can't own a monkey in this country, so, but I took it on

JE: Was it that in the beginning they thought it was alright, or was it under scientific research it was acceptable

Well, that's kind of how I got it, I said, well why don't I do this, I will work with the monkey, then actually everybody looked the other way mostly anyway, so I lived with the monkey for about three months training just basic, come when you are called, this and that and basic obedience, we used to have terrible ... it was fun though, and

JE: So, you could not control it

Oh, yes I could. She understood after a while, because monkeys are very sociable that way. I once saw acouple of documentaries about gorillas and apes and how they interact with each other and Jane Goodall as a matter of fact, and I got a lot of helpful hints out ofher, in terms of establishing dominence and that kind of stuff, so I was kind of the head of her little monkey colony, and that is basically the way, although I think she thought it was a human colony because she did not go with any monkeys

JE: Did you call it that, or is that just the name you put intoit, a colony. Did it get known as the colony

That's kind of the way I treated it, that's about the best way to do it. I always kept her on a leash, she was never off leash, that was the other secret. As long as she knew I had the other end of the leash, you know, the minute she knew that I did not, then I ran into problems. It was funny though, about a year after going through all that training, I sitting down in the lobby, and there were some truck driver friends, she was making a round, saying hello to all the people and I don't know how, but the leash had come off of the collar and she did not know this yet, I saw it and I say, oh God, so I called her back and tried tgrab a hold of her and then she took a leap and she looked and she says, I am not on the leash and she started dashing about the lobby and I said, oh boy, I'm in trouble now, we had visions of her, because we used to have plants hanging from the ceiling, like in the coffee shop, and I said, she is going to be here for ever, and I sat here and called her and one of the truck drivers was going to go try to call her, because one bite from that thing can put you in hospital, so I told everybody to.. and she just was getting more frightened and more frightened, so I got the idea, just headed for the elevator and got into it and she just bounced along back inside with me and just jumped on and then I went back into the room and opened the door to the cage and she got in. You know, by that time it was home, so everything was good, but until all that had been established, she would probably still be down in there now, but you see that is the thing where you can not train them in a separate centre, because they develop social, personal relationships that are not transferable.

JE: Is that what they were trying to doin Tufts, train her there, or what

There, the idea of the psychiatrist and, well I had very bad ... with her, because her ideas were cuckoo. You know she wanted to implant sharp devices on her and take out all her teeth and I says, listen, this monkey is leaving in the same way it came, and I finally kicked her out after about a year. She just wanted research money and all that kind of stuff. But anyway, that is when we split up, I told her to go our separate ways and kept Crystal with me, we kept on trying to work on different things, you know, on our own and we were having a ball and she was more or less just a friend. But, the problem was, I work, and she stayed in the room allduring the day and I just did not think it was fair and I could not bring her to work either because there was no portable johns that you could bring along. By that time I had her trained so that she would just go in the cage. If she was ever out in the room and she had to go, she whipped back into the cage

JE: So she wasn't shitting and pissing in your room, but everywhere else

No, no, just in the cage, well when you are down in the lobby and she has to do it, she doesn't have much trouble

JE: I always thought about that when I read that article

You have to lead a very controlled environment, the minute you ... also controlled as far as people are concerned and that is where I was mainly concerned, like in terms of PCAs and ... you bring a new PCA in, that the monkey is not used toand the monkey may not like it or may, you know, God help you PCA

JE: Did you have any problems there

No, because I did not go through a change in PCA at that time. No, I did, I had one change.

JE: Do you want a beer by the way

No thanks, maybe at another time

JE: You are famour the world round. Everybody thought you were crazy, but I think it is great youhave done that. It never got beyond that stage. Everybody was thinking of you, but no one was thinking of the monkey

Well that is what I finally reached the stage at. In order to adapt the monkey to do what you needed I just thought it was, you know I am very strong for animal protection and all that, and I just did not think all these things that they were planning to do were right so we told the researcher to go. Because I owned the monkey from the very beginning, I bought it off of Tofts for $1, because they just wanted to get rid of it. I let them use me because in the beginning I thought it was an idea with potential, but then I saw that it was not. They did not buy that, because they wanted to alter and adapt, but I said no, that is where I am going to have to go

JE: So you went with the monkey. What did they do, did they go ahead with any other experiments or no

They got a couple of other monkeys and took all their teeth out and took out all their sexual organs, then strapped little shock devices on their backs, where if they misbehaved you could press a button. But even with that, once youget out of a controlled environment like I am in, if there is any chance for freedom, I don't care how many times you shock them or what, he's gonna split, I know I would. But it was a lot of fun, we got along well. She is now, I put her in a monkey refuge, because I felt badly about leaving her, it isjust not good for her to stay alone all the time. I was getting home and then some nights when I was tired and I did not take her out of the cage she would really let me know about it. She definitely had a personality ofher own, and it was like saying, listen Bob, I've been in here all day and you are not going to take me out, and she would start throwing things around in the cage and rattling the door and causing all kinds of uproar and I finally got the hint that maybe this was not the best lifestyle for her. She would still be around today if I had worked something out. It was either staying in all day and taking care of her, which was not really my cup of tea, or it was put her some place where she would be happy. Some day I will have to go up and visit her

JE: Where is she

She is close by, I don't know exactly. I called up this old lady that takes care of monkeys and she came down and whisked Crystal away one weekend and I know the address, but I have not got a chance toget up there. It isout of the state and up north some place

JE: How did you get into it

You know the hospital, I work over there, you know they tack up like there is going to be a seminar like open heart surgery or something, and then I saw that some one was going to give a talk about the idea of monkeys helping with disabled, this was just going to be for the OTs, so I says, hey, would you mind if I sat in on this, and so I sat in and there was a little slide show, and I said to the person involved, the psychiatrist, you know, I would be willing to try it if no one else will. Tufts never followed through on it though, in fact we got a lot of publicity on it but they never backed the project from the very beginning. Nobody did, I bought a monkey and supported it all on my own. They refused her. She still worked for Tufts and she needed that name to get her into other places, so after the monkey had stayed with me for about three months, since I live in the hotel and all, one of the newspapers in town here got wind of it and said they would like to do a story, so I said sure, so one little reporter came by and put it in a local newspaper and within the span of two weeks, I had literally had like three interviews a day, for three weeks in a row, TV crews, and I have a friend who lives in London and he sent me one of the inserts from the London Times, and I said how on earth did that even end up over there. I learned a lot about newspapers and reading and all and very disillusioned, I was very disillusioned about the newspapers. Towards the end I was saying, listen folks, because I was getting a lot of letters from disabled people saying listen, we are going to go out and buy a monkey, and also there was letters from parents thinking they were going to go and buy a monkey and they were going to have it serve their kids. They are wild animals and I was concerned about this. When I started getting that kind of mail I told the reporters, listen this is something you can not treat very lightly, and would you put this warning in and tell people that it is not a good idea, and I told the researcher that, and they did not listen, they just wanted a cute little story that would sell. So after a while I turned down four TV shows in the States, because I said you can do it this way, and they said no, so I said see you later. Well I had to draw the line, if I had kept it up I probably could have wheedled it into a ..... but I was not interested.

JE: So for a time she did things for you

No, she never ever did. She never did one thing for me. What would happen would be, the reporters would come, and it would be like putting a circus animal through tricks, the reporters went ooh and aah and think that this happened morning, noon and night. You try to tell them that these are just tricks and all that. I had been working at Tufts for seven years before any of this happened and people would stop me on the street and say, how on earth can you work without your monkey, they were all concerned about me because I did not have my monkey, and I was saying wait a minute, you guys are getting the wrong idea about what is going on.

She never hurt anybody while I had her, which was good. What she would do if she ever got angry, she would run to the other side of the room and she would bare her teeth like she was going to charge at me and she could be a very intimidating little thing, but what I do is I charge at her with the wheelchair and she would take off the other way. What you can not do is show any fear, so whenever she did naything like that I just gave it back to her and fortunately if worked. I knew I was playing with fire a little bit. It was something that I would probably do over again just for the experiences. Of course, I still own her so if I ever get a good living situation again I could get her back I suppose, depending upon how wild she had become. One in which she would have a little bigger open space and some company during the day. So when are you folks going to have some free time while you are up ...

Bill Powell - Second Interview

JE: ..... so many, is it just because you had not got your scene together, I mean it must be pretty hard right after to get things moving

Not just that, but Independent living did not its act together

JE: So the whole PCA thing had not started

Right. I don't think it has got its act together to my satisfaction yet either

JE: There is a lot of empty spaces

Yeah, they are so easy to fill but people are not willing to do it. I have come up with several suggestions that are ... but you need some kind of commitment from the people to ...

JE: Do you have anything to do with the CIL at all

Yeah, I am the chairman of the CIL

JE: What is that, the Chairman of the Board

Right. So I don't spend toomuch time over there

JE: You just have monthly meetings or something

Right. I make sure I am there

JE: You mean you can't get your ideas in or they wont accept them or what

With the economics of everything and also with the staff and all heading in one direction and for some reason the clients, there is not really a good sense of community

JE: You mean they are just into taking, we came across that in Berkeley, they were just into taking what they could get and when CIL Berkeley is staggering around trying to find out where they are going to go next and where the money is going to come from, nobody seems to be helping out

Precisely. The staff is worrying about keeping their jobs, the members are worried about getting their cheque every month and nobody is concerned about putting together a comprehensive programme thatwill ensure everybody's future being good

JE: You get the idea from outside that there is a comprehensive programme and people's needs are being met, but that is not really the case

No, it is not.
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..... disability groups. It is really a distressing situation

JE: What kind of groups

Like the department of mental health, for example, trying to ... there was a law passed in 1972, they would have to pay expenses, so they are under legal commitment to pay expenses for de-institutionalising clients, whereas spinal cord injured or others, they are not under any legal commitment to do so, so if you get into mental health programmes you are guaranteed the funds, if the department of mental health has some. Also it is time to draw everybody together, all these 70 different organisations, but trying to break down those barriers, because everyone wants their own little empires

JE: You mean like the CILs and the Coalition of Citizens with Disabilities

Also with the deaf people and the blind

JE: That is the problem in England, that they are all into their own things. I was under the impression here that people all worked together, Elmer Bartels told me that, you've got to get the disability groups together like we have done here

They will meet like once a month or something, but they are not together on any other basis though. What we are trying to do is move in that direction and how are you going to co-ordinate you services, and whether it should be under one organisation or under several different ones, each buying services from the others. My attitude is now is when we should sit down and do the planning for it. Not wait till we die, because at the end of this year, the independent living funds go. It was a four year pilot project funded by the ...

JE: What BCIL

The basic independent living funds from the federal government

JE: All of them

The chances of them renewing that grant are slim to none and that grant supported the staff of centres

JE: And that is from the beginning of next year

This October, no next October, October of '82 is when that grant gives up and so better find alternate money some place, that is the other thing that is happening this year that is so crucial

JE: Finding the money from alternative sources

Yeah, and fund raising

JE: Everywhere we have gone, people are into fund raising, 80% of the time, and they are not able to put their energy into planning the programmes

That's where I think the Board should play a more active role, let the Board people do that, traditionally that is not necessarily so either, there has always been an intermingling, not really a clear cut definition. Just on my own personal basis that has been difficult to deal with. To say listen people, you do this job and it has been difficult. But if we don't do anything about it we are going to be in an interesting situation. I don't see how the Feds can justify just leaving all the people they are helping out. That is why it is so important to try and bring the members together so that they can talk in a voice when this is going to happen, you see the more people you have screaming and saying listen, you see that is the only way they are going to listen. If they stay out there still waiting for their cheque to come, 12 people on the board is not really effective. Keep our fingers crossed

JE: So you get attendants coming in to help you in the morning and evenings

Yeah, that is it

JE: Other than that first year

It has kind of settled down. Well I made a promise to myself that I would

... I was literally hiring people off the street, up by the sidewalk

JE: Yeah, well you gotta be careful

I met up with some quite bizarre people. That was the one advantage of living in the hotel, because I knew the hotel people very well and they are very, it is like a family atmosphere, they were fairly protective of me, so if anybody come in they knew not to mess with me, which was good. If I had been living in an apartment it would have been a different atmosphere

JE: Do you get a special rate for living here

Oh yes,

JE: Would it cost you more to live in an apartment

Well actually it is costing me less to live here than in subsidised housing, but I came here when rents were quite low, in fact the only business the hotel did was hookers and strippers. This whole area round here is infinitely better than it was. It was quite sleaze bags, that is how I got a good room down here

JE: I suppose meeting people in the streets you can pick up all kinds of weird folks

Sure. But in a strange sort of way too, the weird ones were the ones that protected me most, they were the ones that would do the crazy things

Bill Powell & Otto - Interview 3

JE: It is still a necessary part of rehab to try and help it along its process I suppose, just having other people around going through it

When I was in ..... General, I suggested to them that they have a resident cripple on the staff, because I know when a doctor came round and told me stuff I did not believe it was so, when I saw somebody in a wheelchair that I knew had been through this stuff, that is when I learned, watched how they did things

JE: What did you mean when you said the CIL could be doing a lot more, things like helping to take care of different needs, which they don't seem to be doing

Well it is a question of independent living philosophy. Basically the philosophy has been, if you want to live independently you are out there on your own and we do not want anything to do with you, you have got to take care of it all yourself. But even a person without a wheelchair does not do that. Sometimes you have to go to a lawyer or a doctor or somebody who assists you, people in wheelchairs sometimes have to deal with wheelchair type issues and I think independent living centres should be a resource for that kind of issue and offer assistance and ..., kind of a specialised type of approach. They have refused to do that at all. Their attitude is more we will mail you out the PCA cheque and that is all we will do. That is the most level of contact most of our members have with the CIL, not even getting the attendant, getting the pay cheque. They do not think it is their role to get attendants. I think they could do a lot of screening of individuals ... because I think a disabled individual just hiring through the newspapers is at an insufferable disadvantage. You get some weirdo coming off the street into your apartment, he can rip you off. Think of female disabled people, males coming in, a lot of ugly things which need not happen.

JE: So what do you think is a way of avoiding that

Have the Attendant technically hired by the member but also at the same time on staff at the CIL, you can work it out very nicely legally, I talked to an attorny about it. But that some other responsible authority - if you will - besides just the disabled person, that can bring pressure to bear on anybody that does something nasty.

....

Its much more that the non-disabled person has very little to say ... I think its a two sided coin too. Its kinda like a circle. The client and the members aren't brought into decision making so they don't make any decisions, so the other people do and then they feel more cut off. Its just like a revolving ... .to survive, we might as well get together and find ways to do it in an easier fashion.

JE: Yes. That is what I see as the main purpose of a CIL ... that and bringing together, it enforces the end bit. Because in the future people are going to have to find ways to get around the economic hassles that are going to happen because the cuts are going to affect them. When I saw Elmer Bartells I asked him does he have a conflict inside himself between being a consumer and being Commissioner and he said he wasn't a consumer he was the Commissioner. What do you make of that?

Elmer thinks of himself as Elmer. He doesn't really identify with wheelchairs at all.

JE: Yes. I picked that up. When I asked that question he looked right through me as if I should never have asked it.

JANE: It really was very embarrassing...

OTTO: Elmer told me that his wife was his Attendant. She does everything.

JE: There's a lot of dedicated wives around...

BP: Oh yeah. If you were to take Elmers wife away from him I honestly don't think ... I don't know what would happen to him.

JANE: He has no other Attendant?

BP: Nothing. He has been married ever since he got hurt.

JE: Thats a very unusual situation. OK I mean, its great, the dedication, but you take his wife away and it all falls in. I know this applies to quite a few people .. I mean, just small things like someone else driving you somewhere, or getting you up once, twice a week or helping with a bath.. little things that take some of the pressure off. It must be enormous pressure on his wife. What does his wife do? Does she have a livelihood?

BP: She used to be a nurse and now she doesn't work anymore. Anyone that is married and disabled takes an enormous amount of pressure..

JE: You meet so many whose marriage has broken up.

BP: I was married for a while after I got hurt and then I wasn't. The difference is really quite amazing now.

JE: Would you consider getting married again?
(General laughter.)

BP: If I was to be struck by lightening, yeah! She would definately not have to be the PCA. That would be the worst thing of all. Thats where I see what went wrong with the other one. There is a lot of confusion of roles, but the other side of the coin is that you get strangers coming into your lives a lot. There is really not too much privacy there .. we are used to it, but... There's difficult logistics there... I don't know.

JE: Do you have much ongoing involvement with people at CIL, other than going to the monthly Board meetings? You had said you weren't very happy about...

BP: Yeah I do. To start they are definitely tending towards er.. well, I would take exception to the work, proffessional, because I think you can have a consumer run organisation. I would say its definitely developing a non-disabled middle management structure which I think is very unhealthy.

OTTO: Yeah. Its not as open as Berkerley is. They have structure and they work at the structure.

JE: But Berkerley gets criticism for lack of organisation!

OTTO: I tell you... something between Berkerley and Watts. I have a feeling that this is structure and in structure it works, but there is no change in Boston, its hard to change the system.

JE: Have you been to Berkerley?

BP: No.

JE: Its a crips paradise. No one comes from Berkeley, they all move there. You see a dozen new people in wheelchairs everyday. The frequency of seeing wheelchairs is just extraordinary.

BP: What are they doing?

JE: I don't know, that is what I would have liked to have asked, where are you going, what are you doing. There are a lot of people that go to work, some people are hanging out. A lot of people doing voluntary work, because if they earn over so much, they lose their benefits

A thing that they are doing in California and here in Massachusetts that is nice, you can earn up to so much and still get benefits, they take some of it out of your pay, but in most states the day you start working ... it's a real lousy world ... the PCA is not allowed to be a family member. Often 17, 18 year olds, who are not ready to leave home, the mother and father can do the work, but they won't get reimbursed for it. It is also wrong to break up the family. In any really successful organisation the families, parents, are involved. But here the CIL tends to tear families apart, so they really look upon the CIL as a beast

JE: There's only one place where I know the family is quite strong. That is St. Louis, where the director's wife is involved with the care attendant training programme and referrals, at the same time, his mother seems to hang around the place. There is a family set up, and that is probably quite unique

Otto: No, there is the same in Buffalo, Tony Sara's family are involved in the CIL

BP: Is it Nepotism or, how about other members of the St. Louis or Buffalo group, were their family members involved

Otto: No

Well, that is what I am talking about, 'cos Nepotism is easy to produce, but that is not what I was talking about

JE: One of the most amazing things about CILs that I have come across are things like wheelchair repair, van modification and transportation, getting people around, getting drivers, that kind of thing

That is what I would advocate for, even job training, having other disabled people to teach others different skills

JE: So what do they do then

Nothing

Otto: At .... they do advocacy, I asked Buck Williams and he said this is one of our famous programmes and it runs very well. I asked him, do you have any problems between your board of directors and your staff members and he answered like a politician, well these are the day by day problems you have, no concrete answer, so he just jumped away to another topic.

You see, the very active disabled people like to exert themselves, but the staff does not want this

JE: Why is that, is it an able bodied staff or have they got self righteous over a period of time or

Well I think they want to move in a direction other than what the disabled people want. I think staff people, especially non-disabled, want to keep their jobs. Now if independent living monies are going to run out at the end of this year, they could not care less about that, all they want to do is keep their salary, so they want the organisation to go off some place where they can keep their salaries

Otto: For professionals it is very hard to say, you can live without me as a professional, so Buck Williams answered me that they had a programme for mentally retarded people and that those people need much more structure and much more organisation than physically handicapped people, which I agree with in some cases

JE: They take a lot of stick, Berkeley, but they do try almost anything that goes, even if they fail

Otto: But professionals take the self reliance away from handicapped people

Precisely the problem you were talking about in Europe, the doctors want to keep hold, once they lose control they lose their money, control is money. Then you get back to philosophy, should the CIL be there for the disabled people or should it be there for the professionals

JE: It is there for the disabled people, that is where it started

Otto: The medical doctors, they see the money, but so many therapists, I don't know whether they see it at first point the money, but their feeling about being a professional and if they have to consider what they are doing, and it is something they are doing is not necessary, they have to change their whole image of professionalism and this is a problem for many professionals

But what the CILs could be doing, they could be doing their jobs. Right now we have 6 disabled people, I mean mentally retarded in Boston and about 14 others, and those 20 people consume almost 80% of the resources of the Boston centre, of the monetary and of the staff

JE: That is bad management

Not only that but you just can't say to that programme go away, because that is the local CIL, you see it has been very cleverly managed to be that, that is the other side of the coin, because you can't get rid of it either

Otto: That is another impression I have, that the centre in Boston works like the big hospitals, you get paid while there is a patient in the bed, so you have to make sure there is always a patient in the bed. If he needs the service or not, he has to be there. That is the first centre where I had the feeling well that is the same way they are financed on their services they provide and if you are financed this way you have to provide services and then you can't say try it by your own

Did BUck Williams tell youhis salary. What would you think it would be. Do you know about the other CILs around the country. The average around the country is around $20 and he gets $35. Then we have got four middle management that are all earning over $20,000 a year, those are just programme managers

JE: It sounds like it is a bit of a waste of time going round there tomorrow

Otto: No, see it

The other side of the coin is most important, you can understand, you have got all this money tied up, you can't just say go away

Otto: That is the way the Europeans would run centres, that is the European approach

It is good to know about it in terms of avoiding letting it happen to your own centres

Otto: It always depends who runs the centre, if there are too many able bodied on the top levels then it goes in this direction

We don't have any disabled ... we have a guy by the name of Peter Leyton, but I don't even know what he does there myself

JE: But the board has 50% disabled

For what it is worth, but like I say, the money is so tied up, there is really difficult decisions that you are going to have to make. It all happened rather insidiously and that is why I believe it is such a strong board that know what directions you want to go in and moves the organisation in that direction. The board the last couple of years that I have been on it, I just recently became chairman, is totally managed by crisis. The director somes in and says we have a decision that has to be made tonight, nobody had any time to consider the ramifications, that is another thing to watch out for, management by crisis, that does not have to happen and should not happen. When you have got a director that does that to you, he is going to manipulate you into ... it is very sinister

Otto: It gives no time for the process to run and find its way

And no time for the board members, by the time they get home from this three hour meeting they are so spent that they don't want to start trying to figure out what the CIL is going to look like three years from now. They just try to get through today, that's a very bad way to be

Otto: Get rid of the professionals

JE: That's what we've got to do, definitely, not get rid of them, but get in with them, direct them

Otto: A good relationship, but that is so hard to adopt

Well that is where a person like ... is so valuable, if you get an .... on your side, he is so valuable

JE: Yes, that is happening in England, we have got one guy and he is so so good

What about that place Stoke Mandeville, isn't there anybody there

JE: Forget it, the place needs to be blown up, I mean really, they mend people physically and that is it, there is no counselling and what the doctor says goes. They are not interested in what happens to you, they just want to get you out into a hostel, hospital, charity home, anything, so long as someone else can get into your bed

Otto: The same in Germany

JE: That place's reputation is going completely, mention the word sex there and the doctors would fall through the floor

That is a touchy subject really. That's something a person can learn on themselves too, I've been shown films about that. Down at ... they have a course every year, it's a whole week for disabled people to go and they have sessions, groups encounter workshops and they start the whole thing off with explicit sexual scenes of every kind of sex manageable, just to get you in the mood that sex is alright

JE: No, the thing I was getting at was in Stoke Mandeville, the psychiatric social worker told a guy who was married that he could never have sex again and that area is just. ... he almost ruined their marriage

Psychiatric social worker, that is the two worst combinations. I don't even want to see a psychiatrist and a social worker, there was only one in my entire life that I even struck up any kind of relationship with, you could talk to her, all the others told me how I was going to run my life

JE: It is unbelievable what goes on

I didn't know that, I had glowing visions of Stoke Mandeville

JE: That is one good job I've done in America, just telling people Stoke Mandeville stinks, it's just not on

Otto: That is the same as Heidelburg

JE: They will prepare you, they will give you physiotherapy, two hours a day and Occupational therapy three hours a day and you will leave there in fairly reasonable shape rehabilitation wise, but in terms of your head and in terms of your life

I think if you develop strong CILs and have them communicating with these centres I think that is where you could break down a lot of this

Otto: They fear that you are trying to put the patients off the centre

Or try to tell them how to do their jobs, yes, still over here, they are afraid of the independent movement. They are afraid of somebody that they are supposed to be taking care of telling themhow to take care of you. They just cannot deal with that

JE: There is an interesting development in the South of England, where I live, there is a new spinal unit being set up and there is a doctor there in Southampton who is very keen on all the independent living ideas and he is ready to go along with us almost

Otto: This afternoon when you asked me to tell you something about your trip and what you have learnt and the first moment I was so tired and sorry I can't tell you anything

JE: It's a terrible thing trying to force a situation, I believe in spontainaity. We read the BCIL report and thought that looked like the basis for ...

Well I think conceptually that is the basis of it, it just has not been put into practice

JE: It seems like it has gone a bit off the beaten track

Well, Elmer likes to look the other way. He knows what is going on but he does not want to face up to it because if people found out about what is going on, the joke that would be around the country, so he is maintaining a standoffish attitude. In a way it is justified because really his job is rehabilitation for all disabled people and he can't spend all his time with independent living, but I do think he has not exerted as much pressure on the CILs to live up to their philosophy as they could

Otto: What is the difference between Ed Roberts and a Mass. commissioner

There is none, who is Ed Roberts, oh, the name strikes a bell, the Berkeley guy, oh, there is a world of difference. I never met Ed Roberts, just knowing what he does, I mean he lives the disabled life, Elmer lives the professional life.

JE: I stayed with Ed Roberts in his house

Otto: Bill told me he is more a symbol than a commissioner who wants his office

JE: He is prepared to get his head chopped off for the disabled, he would go out there and he would not care what anybody thought of what he said, he would say it, in public, he has taken an incredible amount of criticism in the California conservative press. There was this amazing article tyrannising him because, it was a big thing 'Disabled Director of Rehabilitation Services Pours Money into Independent Living Centres and Anti Klu Klux Klan factions and things like this, because they know he is political, that he is a radical and they will get in on him in that

The CIL is a radical animal

Otto: He is a politician, he knows how to play the game

The other side of the coin is if there is a lot of disabled backlash, people see the disabled and the money they are getting and they are slowly building up an anti disabled lobby

JE: Because of the radicalism you mean

Not the radicalism, they are getting all the money, the economic conditions in this country are diminishing rapidly. The average person with a family ... and when you see the disabled people fighting to get money tosurvive plus taking over jobs that possibly he could take over too, the sentiment is not one of .... I would say even five years ago people would be willing to help, now they are so busy just trying to survive themselves that help isout of the question

JE: It is not going to get easy

I would think in England that could be a big problem, the level of unemployment over there

JE: But you see in England disabled people have not got out in the forefront of things very much, it is only just beginning to happen. In terms of welfare they say well the disabled are taken care of

Otto: Which possibilities have CILs to finance themselves by their own

If you develop a good corporate structure, have the members of the centre coming in and have little places of business, people like running, oh the classic example would be a computer, you know consultant business, have another group running another kind of consultant business and they could sell their services and finance the centre that way, and I don't see any reason why they could not, and those members could be teaching other members who would be interested in whatever type of business is around, they could be teaching them and bringing them along too, so they could support themselves very well, for the whole community. Instead of having people as just an agency that absorbs, give something back

Otto: Tony Sara is thinking of building up a radio station in Buffalo

That is another good idea, a radio station. That requires a lot of initial overheads

Otto: He has the whole equipment. He thought you must pay $100,000s to get the permission, but it costs you about $5 or 10 to get the permission to put up your own radio station

Depending where you are. In Boston here it costs quite a bit more than that, but still on a reasonable level

Otto: I think this idea is great, it was the first time I realised that there are possibilities to finance themselves

JE: That is no good for Europe though is it

Otto: Well I don't know, but if you tell people in Europe that in the States they try to do this and this, they have other background information to find out a way to do it, but providing services might be one of the most important possibilities. If we start something which depends on the money of the government, forget it, it is not possible in England and no more possible in Germany, there is nomoney

You could even do it on a smaller town thing, be an accounting consultant, I mean itt is just a question of making the right connections

JE: It is a possibility

I think in terms of survival it is important, you have to figure out a way to become self sufficient. That could run into intersting political ramifications later on, the politics that might be involved in terms of people develop their own little power groups. That is where you need strong managers

JE: But I know one of the most active and articulate people in England, he is a quad, but a very able one, a C7, he can virtually push himself all through the day ..

Oh, I call those frog quads

JE: Right, but he's not a bad guy, a superquad, and heis a real Marxist and he said when I talked to him about coming round the CILs, he did a research programme last year, he said we don't want CILs, it is imperialistic, American, he is more into a Union of disabled people all coming together to fight against segregation, so there is political games going on even among the disabled people, it is a bit hard when youthink there is so much energy and resources available and they could change the country ...

The problem is you can't unionise a group of people that don't have any skills, I mean a union such as that is totally powerless, it means nothing

Otto: That is one of the most important facts in my opinion for the start of the whole independent living movement at Berkeley and even in Boston. Many people had the chance to get a university level of education and without this nothing would have happened and as long as it runs the way it does in Germany or in Europe now and only a few people go to universities, and they are not able to get into contact with other disabled people, and after ten or fifteen years hospitalisation, and they fear to get in to contct and nothing will change

Here again, education is controlled, getting back to the same thing, if you don't educate the people, you control them, and you are right, that is one of the big complaints I have had about, the rehabilitations centres of most all the, not the centres, the commissions of most all the states, they will finance you through school, just up to college, but the person coming out with just a college education these days, he can't make enough money, you've got to get at least a master's level education and to me it is just a waste because they pour all this money on somebody to get him through school and he's got a Bachelors degree of some sort and then the state gives him more money so he can survive, knowing that he can't find a job to be able to support himself, the whole idea is ludicrous. As long as a person graduates OK and wants to continue on, I think it is essential thathe does, that is how I was able to survive. ' I was down in Virginia, not Mass. as a matter of fact, it wasmy social worker down there who put me through masters graduate school

END

JE: Thats been the whole.... area too. to me.. I mean the California ... I felt much more at home there as a person within that enviroment. Even though when you really had to ask around ..

Thats right. You have to be very self-directed in order to make it in California its that unstructured. I have always said that very structured people do well in unstructured enviroments so you have to be very self-directive, but non-structured people need structured enviroments in order to put them together. And I really believe too that you cannot lead a successful life, however you define what successful is, you cannot be productive unless you have a lot of structure in your life. If you don't have structure your time will just wither away, blow to the four corners of the world with nothing to show for it. And I believe that can also be said for enviroments, if they are not structured all the energy gets dissipated in all different places.

JE: So how do you see that in Berkerley?

Well, Berkerley is relatively unstructured, it is a very flat organisation, a few people at the top and everything else is horizontal and I think, for the size of its organisation, it is probably too horizontal and I think it could use some more structure that way, but there again you don't want too much of that because then you get too much administrative overhead, so you want to minimise that too

JE: But the philosophy in Berkeley I think is not an anti leaders philosophy, but an anti authoritarian figures, that is why I think it is more horizontal

Yes, probably anti authoritarian, and possibly anti elitist, but on the other hand we see some elitist ideas and mind set in California, they have never felt the need to publish and one of the things that has struck me for example is that their attitude is, well you have got to come here to see it, you have got to do it here. That is OK, I am just more or less amused by it, I think one of the shortcomings of that approach has been the fact that Berkeley has never developed a real strong technical assistance, has not developed strong literature, has not developed a lot of other things that would help other programmes in other parts of the country to get going. I think they are good in terms of offering a model, saying come out here and see us and what not, but I don't think they have quite done the job in terms of helping others in other parts of the country replicate that model and I think perhaps Lex Freedman in Texas, in Houston, perhaps has done a better job in that regard

JE: He seems to be setting out to do that

That's right, that's his corner of the market, he's thrived on that and he has been able to get the funding and I think he is to be commended for that. I personally like the people out at Berkeley. I like Judy Hewman and I like all the other folks out there, I think they are vibrant people, they are articulate and I just love to hear it when they give the Establishment hell

JE: They don't mess around

No they don't, they are really straight, they shoot straight and they tell it like it is

JE: They don't care what they say, like Ed Roberts, in the position he is in he would say things, and he could get his head chopped off and he is prepared to accept that

Well, the risk of Judy Hewman or Bob or Ed Roberts, their chances of getting their head chopped off are actually quite minimal, because they represent such a threat, I think, to the vocational rehabilitation set up in particular. I think the reason why people like Ed and Judy can get away with that is that those are people who have made it despite the system and they made it not because of vocational rehabilitation, but in spite of it and now Ed is heading the very organisation that he managed to do without and I think the professionals are so much on the defensive, they just don't know how to come back at that, they have not got any good arguments and so I really think that people like Ed and Judy can continued to say what they want to say and never have to worry about the repercussions.

JE: What I meant when I made that statement was he takes a lot of stick in the local press and things like that, because I think particularly now he is getting more politicised, people see him as a sort of left wing commie, this article we read in the Sacramento papers about how this man who was the originator of the CIL in Berkeley, director of rehabilitation, was pouring all this money illegitimately into the CIL movement, and also anti Klu Klux Klan things, and on that level, he was totally misrepresented

We are to the point now where there is possibly a backlash of some sort, I shall be a little bit more cautious in my tactics I guess, but never compromise my belief, or my philosophy or my outlook. Sometimes it is not what you say, it is how you say it, how you couch it, maybe they just need to couch it in somewhat different terms

Tell me, John, what is your involvement in England, what precipitated you trip and what has been your main interest

JE: Well, there is a group of people in England very keen to get a more organised sort of set up going, comparable to a CIL. My commitment in England has really been to try and set up alternate housing, attendant care schemes, there is a project we have initiated, we are trying to get professional support and also monies from various rehabilitation and social service agencies, so it has been one big hassle after another just to get it accepted. So it is on that level, but that all fits in with the independent living movement, because when it gets doown to it housing and care are the two basic

You can't do one without the other

JE: We have been concentrating on that, a small group of us in Hampshire, most of the people are spinal cord injured. I have been interested inthe independent living movement for so long and this year being the international year, I thought, this is the year I want to try and do something

Are you part of a nucleus in London

JE: In Hampshire, yes. There's a number of small groups round the country, and people slowly beginning to see a need for a coalition, because in England people are into their own thing, spinal cord injured here, cerebal palsy here and there is incredible fragmentation because of that

Well there is a lot of that fragmentation in this country too, disability wise, but I think the independent living movement and I think, some of the other coalition movements have managed to get away from some of that, but still independent living in this country too has what I call a very spinal cord injury bias. In fact spinal cord injured persons are to a large part in the forefront of the ledershipof the movement and the more senior members of the movement are persons with post polio, people like Ed Roberts for example, and I believe Judy is a post polio too. The East coast is very definitely spinal cord injured.

JE: I think it is going to be the same in England, it is unfortunate but I think a lot of those people who become injured in their lives, there is certain ground that they have trodden before, even though they have to go over it as a disabled person, they have a certain way ofapproaching it, whereas somebody from birth has a harder time doing that. I think we will have to accept it and work along with it. But this is what we aretrying to work on at the moment, while I am away, people are trying to bring groups together

Would yousay there is the same kind of awareness in England right now that there is in the United States about disability rights

JE: Oh yeah, but we've got lesslaws to make it enforced and that is our problem, we don't have a rehabilitation act, there is a Chronic Sickand Disabled Persons Act, made in 1971, that was pretty well based on similar lines to the rehabilitation act, in that all public buildings should be made accessible etc., but because it is not an enforced law, you can't really fight against it, so that is another area that needs to be developed, to try and get a disabled rights movement going in a stronger way

If I were to echo only one, not really criticism, but observation of the independent movement in this country that I think has been unfortunate and that is that it has not developed much depth. Individuals in the movement have a lot of depth, but I think that it has been able to thrive primarily on its ability to attrct media attention, because certain groups of people have been able to pull together, but in the long run you need a philosophical base, you need a tradition, youneed a whole ... there is not much theoretical, analytical depth to the movement at this point of time, because I think the movement, its whole outlook can significantly reshape the whole approach to disability and we need to articulate what that is and how that can be done, and the movement up to this point in time has not done that very well. It think it ismainly because people who are involved in the movement have been so preoccupied with their own survival needs, they don't have time to deal with issues of theoretical or empirical attitudes

JE: Is that where you see your role, you arelike the scribe of the movement

Yes, some one else has used that term too, the scribe, and that has been more or less my role, but I am only one individual

JE: How did you get into it in the beginning

Strictly by accident. It was the result of a year long study that I have just completed, dealing with attendant care issues. I was prepared to go on to the next study after that, then I was recruited by Tufts medical centre in the research training centre here to carve out a niche in the area of independent living and I said to myself, I don't want to take a leadership role in the movement, I don't want to take over, but I did feel that I was hearing things, seeing things, feeling things I had not read, and I really felt that I needed to find some way of putting that into words, and a lot of people I began to find had ideas on the tip of their tongues, but could not get it out, and I really felt that with the training that I had, maybe the insight that I had couldtake it from the tip of the tongue and put it on paper, and that is essentially what I have done and I have basically tried to reflect what I hear and direct whatI hear

JE: What was your background beforehand

My formal training is in the area of economics and public policy studies, believe it or not, most of my work is actually in the area of income maintenance, income assistance programmes, also health programmes. I think my background is quite interdisciplinarian in the sense I don't have allegiance to any one discipline, but I do think I am sufficiently well acquaintedwith the theoretical frameworks of different disciplines, and bring those frameworks tobear on disability issues for example. No rehabilitation background, I didn't know anything about disability prior to four years ago and in some ways I think that was an asset, because if I had been trained in rehabilitation thinking I don't think I would have seen the issues as clearly as I did. The other reason why I think I saw it as clearly as I did is because when I was involved in the attendant care study, dealing with attendant care particularly, self directed attendant care, consumer directed, you are dealing with some very basic needs, you are dealing with an issue with a service that is pretty fundamental to the whole independent living movement, so I began to see the independent living movement right at its most elementary level and then be able to go from there, that was my entry into the disability scene, and had my entry been vis a vis some kind of professional identification I never would have, so I did not have that handle of baggage to take with me. In fact if you look through mywritings youwill also see a lot of anti rehabilitation, a lot of that comes from knowing a lot of consumers. Basically everything I know about disability I have learned from consumers, I have not lerned it from professionals. I learned something from professionals who knew consumers and knew the consumer outlook, I would not want to deny that, I think there have been a few professionals that have been able to do that, but not very many and so I would have to say that what I have learned has been from consumers, in fact the professional literature in this area is so bad, the journals on rehabilitation are so bad, they are shallow, they stink, they don't say much at all ..

P.To.

END

(This follows other text) the professional who said, hey, this is not working, but who was willing to rise above his professional self interest and see the fact that there has got to be something else out there. He is very much committed

JE: It is extraordinary how our two paths crossed ....

He is just a refreshing person, period. He has been the perfect guest. He knew when to be involved, he knew when not to be involved, just rolled with the punches

JE: He is very sensitive

Yes he is. That is one time when sometimes I do disagree with people like Ed and Judy, as if nothing good can come out of able bodied people, and I would say that for 99% of the time they are alright. I have met a few people who are what I would say, severely able bodied, who have got advice and who have learned from other consumers. There are some people who are able bodied who want to take over the movement,that is such a mistake, there is so much todo besides being a leader of the movement. Three quarters of what you do is how you frame the debate,how you frame the issue and I think Ihave been a lot more effective in terms of framing the issue than in trying todo anything in terms of occupying the leadership positions, I don't want that, I have not had that role and I have shunned that role

JE: Do you find that some of them are still suspicious of you

Oh, I have had a couple that have been suspicious with me on the first few encounters, after that it is alright. Ihave never had to apologise for being severely ablebodied, for me it has never been a liability, because frankly I know my place, so for me it is not a problem. I must tell you about one thing, I propose that about 1.00 we adjourn to my office, there is a fellow from Norway coming.

JE: I was concerned that Elmer said he was a commissioner, not a consumer

He is not, you pin him down. You take his wife away from him, his whole support system would fall apart and I think ... he is sensitive to consumer issues, but Ithink he has also been insulated from the day to day hardships consumers have had because he has this built in support system, that he has been able to rely upon

JE: I know lots of people in that situation would not want their wives to be .. they would get their roles mixed up ....

It leads to a lot of resentment and a lot of other things. I would agree with that, but that is not to detract from Elmer. There is a very thin line sometimes between being a consumer and not being a consumer, maybe he is not a consumer at this given moment, in that he does not consumer any publicly subsidised services, but that is not entirely true either, because he has an attendant around the office, who takes care of getting him a hamburger at lunchtime, empties his leg bag and provides him transportation, and that is provided I presume at public expense, I don't know, but that invariably puts him in a consumer position. I have enjoyed working with Elmer, he can be a bull in a china shop sometimes, but he likes to get to the bottom of the issues if possible, he does not care for bullshit, and I like that, I can respond to that. And I think Elmer has been trying to make a dent in the IL movement, his own brand of impact. I think he sees Voc rehab agencies as being salvagable, agencies that can be redirected to meet the needs of people with severe disabilities, and he has really directed a lot of the agency's resources in the direction of IL, which has been good. But I think nationally there has been a real tension and conflict between Voc rehab and IL, with the Voc rehab agencies and the old line professionals still wanting tohave control, to determine where the funds are going togo, and to call the shots and decide what proposals are going to be funded. I just feel that puts a lot of Voc rehab people still in the drivers seat. I think Elmer has been able to redirect the agency sufficiently so there is not that kind of conflict, but if you take Elmer out of there, you still leave the agency with all the power, I just wonder whether that conflict would still resurface in some fashion and I am sure there are certain disability groups in this state who resent the fact that energy and resources are going in the direction of IL and spinalcord injury in particular, but that to me is just redressing a historical imbalance anyway, so I don't worry about that at all

JE: It has been interesting getting out of a structured environment and not knowing where you are going

You learn more that way because I think that if you go at it serendipitously and just absorb whatever hits you you learn a lot more than if you go at it in a very structured manner, you probably would never see things

JE: Doyou know Ralph Hodgkiss and Debbie Caplan .... Do you know about DPI

I was supposed to gothere originally, but I guess they found me too able bodied or something, but that is alright. Debbie used to live in Washington DC, I have not kept up with her for the last year or two, she is an attorney right ...

I don't care when the revolution comes, someone is still going to have tokeep the books and I would say just the element of fiscal accountability has been the breaking point of so many ILPs, because they have serious cash flow problems, they are spending money faster than they are getting it, or sometimes what happens is that state or federal agencies make commitments for outlays, but the money does not come in until three months later, in the meantime they have got a three month gap to cover. I think the whole problem of cash flow, fiscal management, from a very pragmatic point of view is the most serious problem ILPs have had, just from a strictly administrative point of view. I think the other serious problem, and it is not something that ILPs can do much about, I think is the lack of people with training in human service programmes, admin, management, and I really think that main line universities could do a lot more in terms of training people with physical disabilities to become effective managers. I think the answer to that is within the universities. Other problems that I see, I think those are the two big ones, and documentation. I think people have had a sense ofurgency in terms of getting programmes started but never looked at what programmes have done or what effect they have had and this has become a serious issue now, because money is being threatened and with this new admin that we have in Washington, but there is not a documentation yet to show what has been done, and different people have different ideas about how todo that. Trouble is the people with the ideas tend to be professionals and are not always in tune with consumer views, and values. I really believe that an evaluation of effectiveness should define what is effectiveness, what are the outcome measures, what the outcome measures are are in large part shaped by your values, what is considered to be a desirable outcome. That a person should be employed, that a person should be able to live outside an institution, that a person should be able to go to shcool, that a person should be able to participate in active leisure activities, what is it. I don't think you can convince a policy maker or funding source that self direction is an appropriate outcome, you can say, yes, it is an outcome, but how do you measure self direction, how do you measure whether a person is more self directed, how do you measure that aspect of independence. I would argue that most policy makers and funding sources really are not concerned about self direction or self esteem, they are mainly concerned about two overriding issues. 1. can a person become a more productive member of society, not only in terms of gainful employment, but also through other contributions that a person can make to community living and 2. can a person live in a less restricted environment than they have been accustomed to, can they live outside an institution, can they live outside a group home, can they live in some kind of independent setting. It is very interesting to note that when consumers go to the state legislature, or if they go to congress, those are the two issues they will always cite for justification of their programmes, they say we want more money for IL because that way people can become more productive, that way people can live a less restricted life, and that is what seems to filter down in the minds of policy makers. Now what we need todo is operationalise what that means, find ways of measuring that, and that is something that has not been done. If youlook at the law itself, Title 7, look at the language, what is an IL service, it is those services that will enable a person to live in a less restricted environment and become more productive. Another mistake ILPs have made is IL is whatever the person chooses for him or herself, in other words, we should not make any value judgements about how a person is living. I would say, yes on one hand, that is fine, onn the other hand, if I am paying you $1M a year to run a programme, I want to know what that programme is doing, and to say well the programme is enabling people to do whatever they want to do, is not going to satisfy me as a funding source, it is not going to satisfy any public officials

Norwegian: .... how is the coalition between these judgements and the policy makers

Well you have to consider the fact that first of all the forty two members on this group, my contention is that outcome is like beauty, the value of which is in the eye of the beholder. The question I ask is, who is doing the beholding, who is making the value judgements. So I turned to a group of 42 people, which at one time was known as the Inter Agency Council on IL, they are made up of state administrators, providers of human service programmes, a number of consumers, 6 of whom had no institutional affiliation, they were raw consumers, and a number of others, including reps of ILPs. It is also interesting that approximately 40 or 45% of the 42 people had a disability of one kind or another, the interesting thing was that there was a very high level of agreement between the different parties, about what would be desirable outcomes, how they should be ranked and how they should be weighted. I looked at it in terms of age, sex, disability status. First of all whether older people had different values, secondly whether being male or female made any difference, and third whether or not you had a disability made any difference. Age did not make much difference, sex made a little bit of difference, women tend to give more weight to home making activities, and disability status, whether youwere disabled or not, was the least discriminating variable. so, on the basis of that, I expected to see a lot of difference of opinion that would have to be averaged out somewhere, but it turned out that there was a high degree of consensus

Norwegian: Would you say the judgements were derived from an ideology

Yes. This is very important. The IL movement I would say has not done a whole lot in terms of whittling all of this out, and torealise that outcomes, effectiveness and accountability have a lot of value judgements that are shaped like ideology and my concern is that the consumer community has not been expressive as to what their ideology is and how that can be translated into outcome and be suitable for programme evaluation. I think that isvery important. I don't care who the technician is, whether able bodied or disabled, but I do care who is making the value judgement. The more consensus you can find, the more legitimacy you can get for the value judgements. The lack of consensus may be troublesome for some, but it is something I could live with if it was there, but I think in fact that there is a high level of consensus

Norwegian: The problem is to define normalisation

Yes. There is a whole lot of literature you may want to look at ... there is a lot of literature beginning to develop on the cost effectiveness of health care programmes, where this whole business of how do you value effectiveness .....

JE: Cost effectiveness is something we are trying to show ....

I think if you start from scratch, I don't know if those would be the most important, I would say the issue of finance and cash flow is most important, and effectiveness and evaluation follows that

JE: Elmer emphasised the importance of accounting and documentation

I think programmes went through kind of an evolutionary process. They first started out as advocacy organisations, trying to address a felt need, eventually some money starts to come in, so programmes begin to start, and pretty soon you have a little bit of a staff, office space, and eventually you have a mature human service organisation which did not exist before, and then that transformation from a consumer based advocacy organisation to a mature human service organisation is a pattern that you see going on all over the place, but many organisations have not realised that, have not seen it in themselves becoming such, and when you become this sort of organisation, then fiscal ability and programme evaluation become very important issues. I think there has also been some resistance in the movement to becoming a mature organisation, because then it has all the trappings of professionalism, the system that you are fighting against. I really feel that what you need in these programmes is almost two sets of organisations, one as a service providing organisation and the other as ....

All the energy is going into developing programmes and there is no energy left to do advocacy, there should be some separation of those functions, I think it is really important

JE: Berkeley is a bit loose about the edges .....

.... Yes, well it is not really the next phase so much

Norwegian: Are you following the same general design

Well, we are re-evaluating it. One of the people I was supposed to meet with this afternoon was a person who has a real specific interest in this and he and I were going to work through this, but how it will actually shape up I don't know for sure yet. It is interesting that when you deal with cardiac rehab, you ought to dealwith whole other sets of issues, compared with for example spinal cord injuries ....

Norwegian: Perhaps you have to redefine your whole approach to disability

The interesting thing is that a cardiac rehab for example, you are not concerned about bowel and bladder ... and with mental retardation you deal with a whole other set of issues that never get touched on by people withphysical disabilities

Norwegian: To what extent do you look at the sociological conditions around the person

Well, there is two ways of looking at that, and this is only half the answer, and that is that in some ways you could say labour markets, lets use public transportation and lets use architectural accessibility as an example, because I think it is a pure example. If public buildings are made accessible, they in a sense will benefit all people who are mobility impaired within that community, so whether or not a town's buildings are accessible it is very hard to assess whether it will help explain any variants of individual outcomes, because all individuals benefit soto speak. It is also, I think, similarly the problem with job opportunities, if the unemployment rate is 8% as it is here, it is in some ways going to adversely affect disabled people equally without explaining any additional variants among people, but on the other hand, some people have interests in specific segments of the job market, computer programming, teaching, sales work, switchboard operating, secretary, whatever, and in those cases you look at specific segments of the labour market. But how you measure that I think becomes difficult. I think what you want to do is explain as much of the variants outcome as you possibly can, if you can explain 60,70,80% of it you are doing very well, the other 20% is sometimes so idiosyncratic, so unique to each individual, that it is not really worth collecting the information.

Norwegian: In Scandinavian countries it is very evident that the possibility for IL is very much dependent upon both the structure in the specific community where the person lives, so there is great differences between different communities as regards the proportion of people who are employed, from north to south it may be something like 10 to 60%, then it becomes very important todescribe the situation of work in the specific area

JE: It is also important not to overemphasise the work ethic, first there must be attendant care, housing ....

I think if you look at the history of IL movement and look at the rhetoric, what the advocacy has been, you see a focus on half a dozen environmental factors, which have been very significant, housing, attendant care, transportation, the degree to which the person accepts the patient role, and also what the movement calls 'unmet service needs', a service need that might be considered very critical by the individual, but they do not receive that, whatever it may be. I would like the IL centres to set a kind of rank theory as to which factors are most important and to take those first, and I think the next step in the IL process is to look at labour markets, but I think that being concerned about labour markets is in some ways premature, when all these other things are not yet in place

Norwegian: But there is a strong correlation between the development of labour and transportation systems, so it adds up to what philosphy the researcher has .....

Well, I think a Marxist perspective which really emphasises the role of work, I think is a very useful outlook to evaluate. I have problems, not with the Marxist position, but we all like to have a very wholistic view of things, but the more wholistic we are, the more variables we have to take into account, and we that intervene and want to be successful can't take on the whole environment, so we focus our energies on those few variables that seem to contribute most to our understanding of our problems, once that is solved, we go on to the next layer, so to speak. Even in traditional multi-varied analysis, you put all those variables in the computer, only half a dozen of them are going to beaccepted, the rest are not going to be statistically significant. Maybe the model is deficient, but statistically that is the way it works itself out. Very seldom do you have as many as 20 or 30 variables being statistically significant, it is usually 6 or so, the questinn is, are those 6 the same ones that IL talks about. My argument is that they are

Norwegian: Everything adds up to the selection of the outcome issue, but it can be selective, what I mean to say, from different frameworks, from policy making, from political frameworks, it is important to define the values

To be conscious, forthright, and to make it as explicit as possible, so that everybody knows where they are coming from. You would be surprised how often people talk about outcomes as if we all assented in accepting those outcomes, we all had the same values,but we don't

Norwegian: finally people must decide democratically what is important

If you get consensus through a democratic process you will also gain support for the outcome, and you will gain some agreement that this in fact was a good way by which to measure the outcome. Somehow if you just impose outcomes on a programme, they say why should we abide by these outcomes, they are of no value to us, but if youget people to participate in the development of those issues, you will then also achieve much greater support, resulting in research and evaluation that flows from that

END

JE: Attendant care and housing, as far as I am concerned are the two basic services for handicapped people, without those you have got a lot of problems, so if you could tell me a little about how those two services operate

Housing is pretty much done by linkages that we have established with the housing industry. What has happened is that over a period of time we have developed quite a bit of credibility with corporations that develop housing, state and federal agencies, which are mandated to provide housing for low and moderate income people, which includes a certain percentage of housing for people with disabilities. Public housing authorities which provide public housing, a percentage of that also has to be allocated for the use of disabled persons, and mentally disabled persons as well. So by forming these relationships and building some credibility with the people who actually do the housing development and the tenant selections, we have been able to place a number of people in housing. The outstanding single reason why we have been successful in doing that is because the housing people strongly feel that they are not well equipped to deal with particular problems that might arise pertaining to people that have a physical or mental disability, so they have arrived at the logical conclusion that they need, if they are going to be mandated by federal law to provide housing for these individuals, they have to have some backup, some resources in the community who can assist them in analysing and reaching an equitable solution to those problems and as a major agency in the city of Boston for people with disabilities, a lot of them seem to have identified us as that resource. So it works out very nicely, even though it is a closed circle, somebody develops some housing and they identify a management firm to do tenant selection, the management firm calls us and says we have just constructed 100 units of housing, 10 of them we want to have occupied by physically disabled persons, can you help us in our tenant selection process. So we have the entree from the ground floor. A major piece of philosophy that may provide a bit of a problem for how other areas may approach this is that the definition of independence is the maximum freedom of choice comes from a community base, not from an institutional structured base, so even along with our programmes, the goal is to move a person into his own living environment, where they have got all the care and responsibility, self directed by the individual. What comes after that is really to a large measure is really dependent on the choices made by that individual, whether it is work or education, or some kind of activity, or no activity at all, which is too often the choice, but that is the way the system works, that means a type of on your own type situation.

JE: In housing there is the problem of having to accept what is available

Problems really come more in the rural and suburban areas. Somebody for some reason came up with a selection where they wanted to live in a rural or suburban setting, what we find is that the house market is much tighter, for reason of cost, property taxes, and also the fact that most suburban communities have exercised very tight control over the number of subsidised units allowed, so by and large the vast majority of subsidised units are produced in urban areas. Boston has the most housing produced of anybody. So to this point we really have not had a housing problem, we have always been able within a reasonable amount of time to identify the housing allocation for individuals that wanted to live independently

JE: Is it all subsidised housing, or do private landlords contact you

We have had that happen, it is not a common situation. The cost of living independently is such that there are very few people who come to us, who need our services, who have the financial wherewithall to pay $600 $700 or $800 a month in rent. Because of that I would say 95% of the cases, they really do need a unit with a subsidy.

JE: How many clients have you serviced with housing

We have identified over 300 apartment units and we have directly used about 150 of those units, in other words people have come to us and said I need an apartment, I would say about 150 over the last 3 years. during that time we have identified a number of other apartments that we have not been able to use, but passed on to other agencies

JE: I suppose Voc Rehab use some

They have some, Mass. Commission for the Blind, they come to us too, one or two tracki units, Dept. of Public Welfare, Dept of Mental Health uses quite a few units too. So we try to share

JE: How much have things changed since the BCIL Report of 76. Is it still based on three stages, the transitional, the cluster, and then the total IL

Yes and no. I think there have been some significant changes. When I started as director in 78, we were serving 35 individuals and we had a staff of three full time people, 5 or 6 part time people. Now we are serving 300 people, three and a half years later, and we have a staff of over 60, and about half of those are full time and about half are part time. so there has been a tremendous growth and I think probably the most significant point of departure is that we have begun to serve people who are more severely disabled. In the report that you read reference is made to people who had suffered a recent traumatic injury, most often what that means is that they had broken their neck, spinal cord. Another thing that you read was that by and large the population was young, in their 20s. The fourth premise was that, because of the nature of the injury and the rehabilitation process, it was felt that some kind of transitional phase was needed for people to accommodate their injury, and also to rethink through their own lifestyle. By and large what has changed is that most people who come to us now who have a spinal cord injury do not need a nine month transitional programme. The rehab process has advanced to the point where people can come to us who have lived independently before, they know a lot of the things that we would transmit to them. So by and large, unless there is really some serious problems of confidence or a person has not been exposed to any formal education,or needs some intensive training in financial management or something else, spinal cord injured people would not have to go through a nine month programmes, so why put them to that test. The people who are presently applying for and receiving transitional services are really multiply disabled, congenital disorders, brain injured, people who really have never lived independently, from state institutions, hospitals, these are the people we feel best match up with a structured training programme, intended to impart skills and confidence needed to live independently. So the population to be served has really changed in character somewhat, we still serve the spinal cord injured population, but as far as the structured transition programme is concerned, no. The second change is that we found that because of regulations which were in place, people who were designated as living in a cluster situation were actually being penalised, because of the resources that were being made available to them to live independently, because the premise of cost of living was that it could be shared facilities, shared attendant care, shared transportation etc. As a result, the way the state and federal government worked was that they offered less money because of this co-operative economics. I guess at some point we arrived at the conclusion that that was basically not fair, if anything people should be given a premium for agreeing to co-operate at this sophisticated level, sharing PCAs and all that. Well, neither side would really budge on that issue, so we dropped the designation, so we no longer have that. However, as you might have discovered, most of the housing that is made available to us is made available in clusters. All these developments that are sponsored by the federal and state government are together, they are building units of housing in one building, apartment buildings, and for that reason usually we find that we are continuing to place people in clusters, we are continuing to give people a cluster philosophy, in terms of 'look, it is good for you to know each other, it is good for you to know what resources each other has, because in a crisis you ought to have a buddy down the hall, who you can call, who might be able to help you out.' So philosophically I think the thing still works, but as far as being an identifiable programme in the BCIL, it is not there. Community living is still the cornerstone of BCIL and that is the goal for everyone. Now we are beginning to think more in terms of the Berkeley model, that perhaps community living itself should not be the sole end goals, that perhaps BCIL should consider other ancilliary types of services or programmes ....

... disabled people have a history of wanting .... and, on the one hand we are saying to this population, if we can get you out there, we can get you ...... on the other hand we are beginning to recognise that they are unequal partners, because there has not been proper attention given to what Gerben de Jong would call productive activities. So I think that eventually we are going to see agencies such as ours begin to offer those services on a voluntary basis

JE: In what areas do you see that happening

Employment, I think. 70% of the population is now living independently in the community, basically not doing very much. They have reached that plateau, but there is no movement from there. We don't know all the reasons why. In terms of 100 people who are spending the majority of their lives in their apartments or in very limited activities, I could not, neither could any of my staff tell you why that has happened, but I have got a pretty good feeling that the reason it is happening is because first of all managing one's lifestyle when one is a quadraplegic is difficult enough in itself.

It requires a lot of time and attention. Number 2 is that nobody is providing any impetus, nobody is providing any spark, nobody is providing any incentive for people to look at themselves in terms of productive activities. I think that should happen, so I think that is something we should be getting into. Another thing I should mention is that when somebody comes into Boston, we don't take the approach that they have to live in the city, but we do point out the relative advantages of living in the city as opposed to living in another, ie, suburban or rural setting, and we have come to believe, rightly or wrongly, that there are tremendous advantages for our clients, for the members of Boston centre, to live in or immediate to the city of Boston, tremendous availability and quality of the medical services that are available, for an example, is an advantage. The fact that there is a subsidised transportation programme is an advantage, the fact that there is a strong lobby for accessibility in the city is an advantage, the fact that people can more easily band together and lobby ontheir own behalf is an advantage. All of those things seem to me argue very well for the urban selection as opposed to the other

JE: What other services do you provide

We provide IL skills training. Individuals will come in and they will want to live independently but they have never managed their own attendant care before. So, if a person has the basic capability of living independently in the community, in other words there are no apparent critical flaws, then what we would do is provide IL skills training to train the individuals to hire, train and manage their own attendants. For example, training the individual how to respond to an emergency, not so much what is wrong with them, how to get in touch with the police, how the emergency system works, that is another thing. ADL in terms of we will go to the person's apartment and try to assist them in planning their activities of daily living so there is a minimum of discomfort, and also so there is some plan to introduce additional adaptations, which may make their life more manageable within that particular environment. Also because one of the problems of living in the urban centre is that there is a plethora of resources available, we have a number of skill sessions that we provide just to help people become acquainted with the community as best possible, transportation, finances, social skills, we have a social club and we hold activities there. Some of the housing, in terms of tenant management problems should they occur, those kinds of areas. Much of that training is provided at the community level, we don't put anybody in a programme. What will happen is that when a person is evaluatedfor the PCA service, we have to do that because of Medicaid requirements, we will also have an in depth interview with one of our peer counsellors, and at that time there is an effort made to identify areas where the person may need advice or assistance. The counselling sessions, the skill sessions as we call them, can be scheduled in, there is a little work plan drawn up. We also do a great amount of advocacy, it is becoming a growing component of the Boston Centre. Brought on mostly I think by the fact that there are some critical times in the budget presented by the new administration, and a lot of programmes throughout the country felt the need to really share information with each other, begin to get information to the congress so hopefully decisions would be weighted on their behalf, which it turns out at this point anyway, they were. It was a lot of lobbying that went into that, lobbying in terms of getting information to the membership, lobbying in terms of asking the membership to contact their congressmen, that kind of thing. Then, of course, Boston is the capital of Mass., which provides another arena for lobbying, that is finding areas which are critical to IL, which are not being met by the federal programmes, by the state programmes, and trying to get some legislative solution to the state legislature, that also goes on. Then there is a third kind of advocacy we have had from the beginning, but now I think we are trying to change to a more sophisticated level, and that is what we call self advocacy, which is really problem solving. What it is is trying to work with a member of the Boston Centre to provide them with the tools and techniques needed to be as assertive as possible in terms of solving any given problem, a housing problem, or a problem of Voc Rehab, or a medical problem, whatever. The gimic is to try to give any individual the resources and the confidence they need to solve their own problems. Not to have a manual type force coming from BCIL to make everything in the world right. What I mean by more sophisticated level is what we are trying to do now is organise groups of disabled individuals around their particular neighbourhood environment, whether that be an apartment building, or a section of the city of Boston, or the particular living situation they might have outside the city. We are trying to get groups of disabled individuals to articulate their common needs, whether they be transportation, or housing,or employment, problem they are having with the management of the housing project, whatever those problems might be. The change in our approach will be that, once those problems are identified by the groups, we will ask those groups to design the solution, but we will provide the staff assistance necessary to help implement that solution, but the group will be responsible. It is going to take a year or two, it is not something that is going to happen overnight, but using that approach what we hope to do is build a community based strength into the membership, one that is not centred in BCIL, one that the membership does not see as being dependent on how

BCIL is able to react, but rather one that sees the membership growing in terms of its own confidence and ability to address problems. The idea behind it is really to give the membership a sense of responsibility in terms of running BCIL and in terms of being able to act politically, in terms of what is important to them

JE: Advocacy seems to be important in all CILs. Is there living accommodation attached to this

This is just the administrative office of BCIL, there are people who live in this neighbourhood, which we call Back Bay. The only housing that is connected with BCIL, we have four transitional programmes, and we are responsible for the housing for those four programmes. All together those programmes include 38 people, outside of that everybody else is responsible for their own housing

JE: What about attendants

Mass. is kind of in a favoured position, it works a lot like California, with one important distinction. Mass. is one of six or seven states who applied for and received permission to run a care attendant programme under existing federal programmes. This is what we call the state option. Mass. exercised the option of PCAs, under the Medicaid programme the federal government agrees to participate by paying 51% of the cost of the PCA programme, and the state pays the other 49%. So basically, the way the programme works is that, because it is a medical service under Medicaid, we are required to evaluate individuals such as yourself for the PCA programme, using such criteria as the Medicaid agency in Mass. might prescribe. Very simple criteria. The evaluation must be conducted by a nurse and an OT, which gives it the medical flavour, which in turn makes it eligible for the Medicaid reimbursement. The evaluation must be signed by your physician, because that is the only way a medical service can be ordered and paid for. We don't like it, but it is the only way we can do it. Then that evaluation goes to Medicaid, they approve it and you are then eligible to receive the amount of PCA hours for which you are evaluated, from that point you are really in charge, you hire your attendant, train your attendant, use your attendant as you best see fit. Every four weeks, you send us a bill for personal care expenses that you have incurred and we put that together with all the other bills that PCA users send us, we send them on to the state, and about four or five weeks later we receive a cheque for all those services and we reimburse you for the services that theoretically you have already paid for,this is a reimbursement to you for services already provided. It does not work out very well, it really gives people a lot of hardship, because they are required really to come up with two months expenses for their PCA, that is if they want to have a good working relationship. More often than not that means somewhere between $1600 and $2000 has to be put in the kitty to make the service work the way it should. Before you see any reimbursement. One of our priorities for the last few years, and one which the membership has really advocated very strongly, is to change that payment system so that when you were in fact designated as eligible for the PCA service, we would be able to pay you immediately the service had been provided. Hire an attendant, the attendant works for you for two weeks, then you call us, send us a little time sheet or whatever, we would be able to pay you immediately, so you would not have that cash flow problem. The way the system works now is not adequate, we are trying to change it. There is also another programme

JE: What does one pay an attendant for an hour

Right now the rate is $4.25 an hour. In comparison to other states which have an attendant care programme we probably should be $5.00 an hour. Things work differently here in Mass. and it has taken us a little while to establish an equitable rate for PCAs

JE: It is $3.75 in California

It is $5.00 in Maine, and I think it is $5.00 in Rhode Island, and another state that I talked to recently is $5.00, Texas Ithink. That seems to be the more accepted figure. Last year it was $3.50. There is also another programme which I think is really worthy of mention because it is funded 100% by the state, with no federal involvement at all. That is, if an individual receives PCA services as part of their Voc Rehab plan, in other words, they are in a job, or they are in a job training, or they are in an educational situation which is going to lead to a job, then they leave the medical programme, and they go with the Mass. Rehab Commission's PCA programme, that programme is funded 100% by the state.
This means the money comes a little quicker. One of the barriers to IL, which I found when I came here in 78, was a lot of people were afraid to leave their medical coverage to go into a work situation. So part of the state PCA programme we have also a state medicaid programme, which continues the medicaid coverage after a person has gone to the MRC PCA programme. So that barrier, that disincentive, has been broken down. We now have 35 people in that programme and what I would like to see is the number of medicaid people decrease and the number of Mass Rehab people, people who are in some productive activity, increase. That is really what we are after, when we talk about employability and productivity, that is what we mean. We would like to see more people in that situation, using the MRC programme, and fewer on the medicaid

JE: Do you have an attendant referral system

Yes we do. We have an attendant pool here. We advertise, mostly in schools and universities. We get quite a number of people who come in and they are interviewed, and they present their credentials and there is some follow up to be sure they are not ...... and if they meet that test. Usually what we try to do is find them assignment work, if somebody needs an attendant just for a couple of days because their attendant has gone home, kind of a test situation, and we send them out to work with one of the members of BCIL, then the member will call, say he did a good job, or did not do a good job. If they were good, then we put them in what we call a PCA pool. The PCA pool is to be used in emergencies and also when an individual has exhausted all other means of finding a PCA, they can call this office, they can get some names of people to interview, people who have been through this process

JE: I was going to ask about emergency back up

Yes. We have a 24 hour service. If somebody phones we can get somebody for them at least that morning. Then what we do is follow up, one of the staff will call and say, what is the problem, what times do you need an attendant. They will look through the pool, if they can't find anybody there, they will try to hook up with somebody in the community to provide some interim coverage until it is sorted out and they find a permanent attendant. The one flaw in the pool is that there is now a strong feeling among the membership and some staff too that we really ought to have a formal PCA training programme, we ought to have some kind of basic training, so that when we have 10 new people come in, students for example, say I want to do PCA work, we ought to be able to provide a structured basic training programme for those attendants. So regardless of what kind of disability disabled person they are referred to, they do have basic kinds of knowledge of what PCA work is, rather than just going in cold to try it out. Another thing the staff is going to put together this year, which I am excited about, is a little travelling kit, which has a basic training programme for PCAs on slide show type thing. If you were living in the community and you had the same attendant for six months or a year, you might need a little refresher as to how to hire and train a new attendant. What you would do is just borrow this kit from BCIL and show it to yourself, show the slide show. Something might come up as to really just a problem area, transfers, some techniques you might have forgotten

JE: The problem is that each disabled person is so different. Do you find that people tend to have more than one PCA at the same time

Yes. I think they have to. An attendant is like any other job. First of all it is an intensive relationship, not like a boss and a secretary. This is a very personal and intense relationship, everything gets involved in it, what kind of food you eat, what time you get up in the morning, what time you go to bed at night, the way you are handled personally, the way your body is handled. It is very very personal and intense. All the things you might expect come up in that relationship, what people like and don't like about each other, just in ordinary course of events, let alone when there is one person taking care of another. So it is just unrealistic to assume that any individual can carry on that kind of activity for five hours a day, seven days a week, week after week. It is just not going to happen. The people who arrange their attendant care the best are people who have two or three attendants, and people who also do some careful planning as far as resident care is available. In other words, having somebody, a relative or whoever come in for a week or two at a time, so the attendant can have a little break now and then. It is definitely vital. Most people now do have different attendants on weekends than they use during the week

JE: Or different morning and evening attendants

That is right

JE: How much of the counselling here is peer counselling, and how much is done by professionals

Well, it is hard to break that down. We have had the same peer counsellors now for well over a year. Right now I would say 70 or 80% of the counselling that is offered can be delivered by peers. Now at any point in time, it may be that peers can only do so much, it may be that the nurse or OT has to come in and provide some sort of instruction. There are also some areas of training where it is important that the medical staff, as we call them, the nurses and OTs become involved because, again, it is a regulatory problem, some of the services simply cannot be reimbursed unless the nurse signs, so there are some things with which they have to become involved. In the transitional programme I would say the nurse probably provides 25 or 30% of the counselling, and the rest is provided by peers. It is more and more coming towards a peer situation, right now I think the percentage is preponderant

JE: Do you have regular decision making meetings

Peter is the director of programme operation. We have a situation in which each programme has a programme director, somebody responsible for that area of activity. He meets with those programme directors on a regular basis, so he keeps track on that one. then every month we have what we call a Cabinet Meeting, where all the programme directors and Peter meet with me and with the fiscal officer, and at that time we adjust agency issues, problems which programmes may be having with each other, or even solutions where each programme might play a role, and we discuss those on a monthly basis. And, of course, in an agency like this there are alwys the daily situations that come up. What we try to do is structure the agency so that there is open access, if somebody has a problem they can come in here and discuss it, rather than scheduling an appointment or calling me on the telephone. In an agency like this, with this kind of population, it is very important to have an open system of administration

JE: You have a staff of about 60. what is the ratio of disabled and non disabled

Of the 60, 30 are pretty much part time people who are living with some form of attendant care in a structured programme, so I don't think I would really count them. But in terms of the rest of the population, about 40% are disabled, and the majority of people who work here in the core administrative staff are disabled. We have adopted and pursued a policy of preferential hiring, no bones about it. If we have a job opening, we write the job description and we send it out to our membership first, and they have first refusal on the job. If any disabled person who is in our membership thinks they can do the job, they come and get an interview right away. In the second round, after that is through, we do have a policy where we send the information out to other agencies that serve disabled people, and again, if a disabled person thinks they are qualified, they get preferential treatment. So the trend is towards really giving the agency a .... with regard to disabled people, and that is the way it should be

JE: Budgeting often seems to be a weakness with CILs

I have not been to Berkeley, they have done some things as good as they can be done, yet I guess as a practitioner I have some problems, but in order to really do justice to those problems I would have to go out and see for myself what is going on. Finances was our major problem. When I started here in 78 the CIL was bankrupt, they not only did not have any money, but they owed $16,000 that they did not have. So, certainly, one of my first priorities as director was to find sources of revenue which could make up that deficit. .... various people come and have a discussion about transporting John's luggage .... We also drummed up business with the agency that serves blind people, visually impaired people, and we also went to the private sector and asked for foundation grants, and other agencies, to get some money from them. That was really what pulled us out of the hole. Now we are kind of on a pay as you go basis. One big flaw in most of the newer programmes that are starting right now in the United States, they rely on a single source of funding for their existence, and that is Title 7, IL programmes, and that is almost asking for disaster, because if they cannot use that money over the short three years period for which it is available, and find other sources of income to replace and supplement that, then God knows what is going to happen. You are only going to be able to do so much. The other basic flaw in the way most IL programmes structure themselves is that, the way our government works is that it pays you money only after you have provided a service,and in business terms that may make a lot of sense.

But if you were starting a business for example, you would probably draw your own assets together and others who wanted to share in this venture with you, and you would put together a proposal of some kind to sell stock, approach a bank, and borrow a sufficient amount of money, so you could establish this business. Well, non profit service provider organisations can't do that because they have no collateral, we are not going to produce clocks or carpets or anything else, we are trying to help people, and that is not a definable product, it is not something banks will use as collateral. So these smaller agencies, the ones that are starting right now, are starting with no money and they are only being paid for what they do after they do it, and you can imagine the negative factors. One of the things I always make it a point to mention is to be sure you have some source of funding that can help yu establish whatever it is yu want to get into, help yu hire the qualified staff, pay for your office expenses, and so forth, because without that you will constantly be in a hole and trying to dig yourself out, the more you dig yourself out, the deeper you find yourself in. That was the problem of the Boston Centre. If we had been any bigger than we were, with only 30 people, we would have definitely gone out of business. Those 30 people would have run out of services, and the 200 that came after them would have received nothing. So, thank God it did not happen that way, but a lot of planning up front is required before you start any enterprise, whether it is a private business venture, or something even more important, like what we are doing. You have got to have money.

JE: It seems directors of CILs spend 80% of their time trying to get fund raising sorted out, particularly now

One advantage IL has, and I don't know, it has been 20 years since I have been to England, just the very concept of independence goes hand in glove with the culture of America. It is, in fact, a saleable product in the right circles. What you have to do, it may be repugnant to some extent, is figure out how to package and sell it to people who have money, so they will give you money, rather than somebody else. that can be done, like I say, some aspects of it may be distasteful, and if your goal is survival and growth and quality services, you find a way to do it with as much taste and class as possible

JE: The systems are very different, but you have still got to sell it

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