

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 in 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 Hewmann 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 scary 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 on 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 Hewmann 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 Cincinnati 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 to become public, so the 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 to build 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 a job, 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 get through 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 you are 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 you another \$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 not 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 community orientated projects, he had four of these people living with him, 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 to turn to, we have to convince the professionals, the social services, the AHA that it is going to work. That is our 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 into the community. 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 I think 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 them all day long, but you bring people in here and they will hang around for a while

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