

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 our 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 and 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 you owe Uncle Sam, Uncle Sam says I want my 20k and they can't get you on a repayment plan, they shut you down.

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 or 500 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 don't 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 irrelevant. 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 don't you see one of the greatest differences is that you are the Commissioner... I don't 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 sparsely populated areas... Santa Fe, around that whole northern part, and not Albuquerque. Albuquerque is outside it which it seems like if something was going to be started up in NMexico it should have been there where there is 14,000 people and there is quite high percentage of dab people cos I met it 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 political decision that they wanted to split up and the only way they could get the money was to make out they were being unique by being rural so you've got a kinda dilemma there

I think its the way you have to go after the money, they've created that dilemma there... they figured the best thing they could do to make it unique was to make it a rural one... so they find this project and once you get the money 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 to be our agencies (??) 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 (over BU??) 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 similar, 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 expertise 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 Organizations of the Handicapped which today is kind of 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 organized .. and something...???back.. One of our problems in the Disability Movement is that we have got so many of the 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 our disability groups don't know what to do.. so its kinda falling apart. Theres (R?)evolution that start with defining a set of problems and 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 lot of 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 the disability movement for a long time. A lot of the rabble-rousers of a few years ago we are now responsible for running it. You will have to decide if thats the way you want to 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 Machievelli 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 do the job, and I thought, hey, thats a helluva thing to do. I was in the 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 40 million 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 Governor 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 qualifications required?

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 and I think that document is going to be good for another three or four years, because we are not going to make enough 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 are just 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

U 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 mentioned 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 you ought 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 get it 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 fact he 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 consensus 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 identities, inhibitions etc.

You can be the catalyst for that. You have a certain credibility with the people that sent you over 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

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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 organize 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 with others 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 ancillary 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 front 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 install 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 a disabled 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 do the 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 organization, 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

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