

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 Medicaid. 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

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wants to give me the option to do it, the other method is, I would be authorized \$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 counselors 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

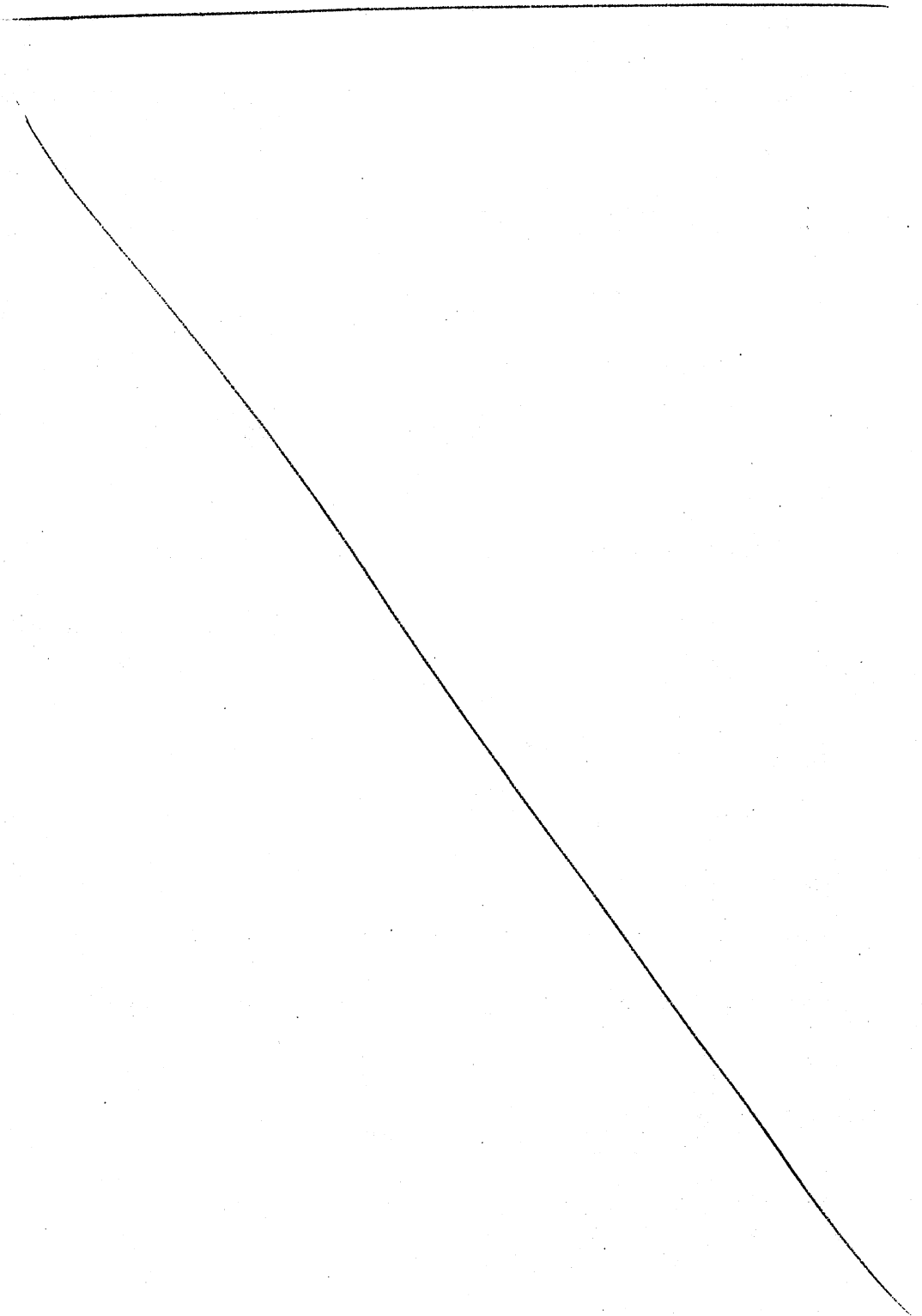
JE: She was not making any progress statewide, because they have real funding worries, they are federally funded

I am real interested in them, because we surfaced out of the state that

already had supportive services.

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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 ...

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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 we drop 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 organization can mould national policy, but afterwards 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 that's the problem with a Civil Rights Movement that's so emotional, the first easy step is to go out on the streets and yell, or to go 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 to have 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 to be 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 affiliated with anybody.

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 be great 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 I think 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 knowledgeable 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 the 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.

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