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## Edward V. Roberts

### Testimony on CIL, A.M. and P.M. Sessions of CIL Hearing

1/5/78

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#### A.M. Session of CIL Hearing

House of Rep Subcommittee on Select Educ. Hearing

1/5/78

Berk. Calif.

ED ROBERTS: Good morning. It's really a pleasure for me to be here this morning to see a Congressional hearing on Independent Living, to have it at the Center for Independent Living which has played such a large role in my own life, as well as many thousands of disabled and elderly people in this area.

I think about what CIL means to me and what it meant to me when I lived here, not as an Executive Director, but as a disabled person. Thru the times I had to find new help thru attendants, the times I had struggles with welfare agencies and other agencies; and how we began to learn together to make the kinds of changes in the system that allowed us to live as independently as possible, to make the kinds of choices that each of us has to make, not only about career goals, but about how we're going to have food the next day and basic survival kinds of things.

I moved two years ago away from Berkeley to Sacramento, the State Capitol, thru the request of the Governor, and found that I worked very well, but I had a hell of a time maintaining my employment because it was hard to find attendants, because problems - wheel-chair problems would come up because equipment is made so shoddily - often grounded me, and I wound up having to buy tremendously expensive duplicative equipment because I couldn't keep going each day. I knew that if I didn't back myself up it would wind up costing more than four thousand dollars to do that - I wouldn't be able to do my work day-to-day, that it was that critical to my existence. And you think about what's happening around the country

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and what's happening here in California. California's become literally a model of how even the most severely disabled people can become independent, can begin to learn how to take charge of their own lives; and this concept is so key - this movement has come directly from our experience; from experience of trying to survive away from the institutions, away from isolating experiences. So it becomes for me an even more powerful kind of argument. All across the country communities, and especially people with disabilities, are looking at how to import this concept to their own communities. We know it can be - we know these can be duplicated. When I became Director we began using rehab innovation expansion dollars, trying to set some additional models up, some additional programs, and we funded nine additional ones. Their share of this type of programming is community funding and the dedication of people with disabilities, and their friends, have founded five or

six others. There are many others in the planning stage in this state. I think it won't be long before we'll see, especially if we can talk later about additional resources, that each community, and I would hope within each of our districts, there will be this kind of resource, not only to rehabilitation, but to our regional centers to help mentally disabled with the basic philosophy that no one should be written off in this society, that the disability itself is not the prevailing factor. The prevailing factor, and the most difficulty that people with disabilities have, is the underdevelopment of our communities and of our society. Not only underdevelopment in terms of architectural barriers, or in terms of services, but the underdevelopment in terms of attitudes. The most paralyzing thing for most of us is that we're seen as much more limited than we really

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are, and the potential there, and we've learned now from a project called the California Project, which is working with the most severely retarded, those people whose IQ's are not measurable basically and often who don't speak, we are finding with new training techniques and with positive attitudes towards the future for these people, that they can learn the most complicated kinds of tasks. That once again because - maybe because we wrote them off, people jump up and let us know that you're wrong, that we do have abilities - and this project - and I think a new attitude in the State of California, a new look at the old myths. Myths are crumbling so the people are beginning to become more active in their own behalf. There are three important elements I think in this process-this independent living process. One is that people come together, all differing disabilities come together and learn in time from each other, so that we're not constantly caught in categorical kinds of aid - where you're aiding a cerebral palsy person, or a retarded person, or mentally ill person - but people come together and can talk for each other and about each other's experience. We need to respond to the needs of the disability, not to the category of the disability. That's a key concept, I think, because many of us have very similar needs, and it's not so difficult to build on elements for disabilities like the deaf or the blind that have special kinds of needs, special communication needs. Really, for me, this has got to be the beginning or middle course of a long - I guess you'd say a life-long project, first to free myself and then to help free all people with disabilities; and I think for the rehabilitation agency. We'll talk more about this later in the afternoon.

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It is extremely difficult for us to work with the most severely handicapped. We have this tremendous pressure for substantial outcome and goals of the program. We need to talk about a dual system, one that assumes in the beginning, that every person who comes into the system has a vocational potential. If not full-time, then part-time vocational potential. If we don't do that - and you and I know from our own experience what work means. Work often means positive self-identity, it means something to commit yourself to and to do. For me, that continual services must start for the severely disabled with comprehensive independent living services. Without that, there is not that future for vocational goal. I've seen very few people in my experience in this state that cannot have the vocational goal, in one way or another. I wanted to begin with a philosophy and belief in people that comes from my gut, a belief that there are very few people in this society that should be written off, and we in California, working with Federal Government and CIL type programs, and other community leaders, intend to show that we have made a mistake in the course of these programs in that we have left out millions of people who lead lives on welfare and on dependants, who could lead productive lives, and be an important force in this society as a part of each of our communities. Thank you very much.

MR. CHAIRMAN: Thank you, Ed. John.

JOHN: Thank you, Mr. Chairman. Everything you said was interesting. One thing struck me and I'd like you to go back to that because we're always looking at programs, goals, and so forth. You indicated something, obviously in your experience, has led you to believe, properly I'm sure, that there's what you referred

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to, a pressure of achieving goals. Would you give me a little fuller explanation of that because I know so often in Washington we say if we're going to spend a million dollars and something doesn't happen right away,

something's wrong with it, and is there that type of urgency or goals that are achievable? Just what did you mean by that? That's an interesting phrase.

ROBERTS: I - I intend to elaborate on that later this afternoon, but just quickly - the rehabilitation program, vocational rehabilitation program, has been geared and sold to the Congress and the country based on the amount of money that it returns to the taxpayer. What we call cost-benefit. Well, when you have people longer in the program, let's say some people could be on this continual moving toward a vocational goal for ten years, as I was in my own rehab program. When you have many cases like that you get substantial pressure from the system to take easier cases, cases that can move through the system and keep up the high production rate. And it's - in many ways you've got to have goals and I really believe in outcome and in measuring outcome, but if that outcome is discriminatory towards the more severely disabled we have a national commitment to work toward deinstitutionalization and really freedom for these people. Then we need to take a hard look at the law and find out how we can make - how we can expand that continual, I think. Take some of the pressure off the rehab agencies by setting up a stream of - called independent living - because for many of us it is very difficult to decide on where you want to go vocationally when you don't know if you're going to survive day-to-day, when you're not confident that you can find that help you need or get that wheelchair repaired, or get to and

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from places you want to go. It would help rehab agencies tremendously to have equal mandate toward independent living and I would suggest that your cost-benefit in the traditional way would be - still be tremendously high, but that it will be a longer-term payoff, especially in terms of severely disabled, will be deinstitutionalization. In our state it costs \$22,000 a year to keep someone in a state institution. With programs like this and programs like the rehab program, we can do that - do the total job with a person in as much independence as possible for much less, perhaps half that.

JOHN: Are you saying then, I gather from your response that probably the traditional government outlook of, you know, taking the easy cases, you got five people and you take a look at the five and the one looks like he can - he or she can be rehabilitated, retrained, helped, put out independently in a year or so, that there's some preference to that person over the one who might take five, ten, fifteen years to achieve the same goal? Is that basically what you're saying?

ROBERTS: Oh, absolutely, absolutely.

JOHN: What - you said you were ten years. Could you give us a little bit of your experience? We've got a lot of witnesses, we don't want to take a lot of time I know, but I'm so anxious that your own -

ROBERTS: I confess that at the time my biggest fear was - I was 14 when I got polio, and when I was 14, 15, 16, my biggest fear was what would happen when my parents died. I was so totally involved in those kinds of survival issues that there was no way -

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even when I was 17 it was very difficult to think about vocation. I initially had to fight my way into the rehab program. Obviously rehab has been changing over the last few years. But it was difficult for a counselor to see me as vocationally feasible.

JOHN: See you as an end product somewhere down the line, is what you're saying.

ROBERTS: Yeah, right, right. And I respect that opinion because 10 years ago, 20 years ago, most quadriplegics were written off as not feasible in any way. But we began to demonstrate over a period of years that as we begun to include more people, more of these people became successful, many more. Then we began to develop some models, people who were successful, and that experience is snowballing now in California, especially. But the critical thing is the comprehensiveness of the programs like this, because we see around the country many transitional living or housing arrangements, that is a community-based program that goes out,

that can help find housing for someone so they can begin with independence. We'll talk a little bit more about some of the state programs also, like homemaker chore, which make this possible and feasible to do.

JOHN: Thank you.

ROBERTS: You're going to hear more about this this afternoon.

JOHN: Thank you. I know I speak for George when I say how pleased we are and I think everybody's pleased that there are trend-setters and pace-setters and trailblazers like you. Thank you very much.

ROBERTS: Thank you very much.

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## **P.M. Session of CIL Hearing**

ED ROBERTS:

As I sat here for most of the day listening to the testimony, it really makes me feel good that you all are here, that the hearing is here, and that you all get first-hand information from people who are actually developing the Independent Living Programs. It also pleases me that the Department of Rehab has had a lot to do with helping to set up these programs, but I'll tell you, it's not been done easily and there were real times when I wondered whether RSA was gonna tell me that I was illegally using the innovation expansion monies. I think you need to clarify for them the things being used around the country now to help start Independent Living Programs, and you need to clarify the intent of Congress when the development of new programs, innovative programs, in that whole pile of money - I think we also need to be clear that the '73 Rehab Act is one that was written to have growth and to expand and to be a living thing, and there are times when I think or I will say that other governmental agencies, especially, are very limited to an innovative state like California. When I came in two years ago we really wanted to change and open up and meet the mandate and challenge of the '73 Rehabilitation Act and with the help of the Regional Office we've been able to do some of that. But I think the vision of the '73 Act is yet to be unfolded. I mean, right now we're serving about 55% of our active caseload of severely disabled. It's a very high amount. At the same time we are caught in a tremendous dilemma because we don't have the resources in the community to full serve those people with the most

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severe disabilities. We've tried and we've made a major effort to create new community resources, to build our communities with Independent Living Programs and other kinds of services that will allow our counselors to purchase the kind of Independent Living services that are necessary. And that's really what Rehab does. We do vocational counseling and placement as a part of individual flexibility, but we purchase the kinds of services we need for individual clients and the community development aspect becomes critical. I would suggest that you look seriously at putting some money aside for community development. You may want to mandate some of the community development money that's there to go into this kind of community development for the disabled - that there is a need for ongoing development money, and I submit that the rehab agencies across the State, across the country, have good experience in the development of new agencies to serve its newly emergent needs.

I think its critical that we look at two kinds of funding. The one kind has to be the direct funding, whether it's through Rehab or another agency of Independent Living Programs, such as you just heard the Directors before me. It's our estimate that if we funded - we have 26 districts - if one can be funded per district across the State that it would cost three-and-a-half million dollars. It's not terribly much money to get what I would consider a fairly strong system. I think from that you can spin off branch type operations. But it's critical that that money come into the system soon - the Coke Bill for example - what's the number -HR 8153, is acceptable but the funding is much too low - at least 13 million. I think we need more like 30 to 50 million.

It's not a tremendous investment if we can guarantee that Rehab and the movement of people along a continual through these Independent Living Programs.

The second stream of funds needs to come through the Rehab Act and that is fee-for-service money, and to mandate - to open up Rehab Programs to Independent Living goals. Right now it's very difficult - the words Independent Living, while very popular, is very difficult for rehab agencies to move into what we might call Independent Living Plan. There's no mandate for that. There's a tremendous need to get away from this fight that we have to go through each time about whether or not we will take a certain client. My belief is that all the people who come to us have potential, the potential to move, to become more independent, to become partially employed even. It tears us apart, it tears me apart, and it tears our counselors apart to have to turn people away that they know could be helped; that as long as we continue to say that our primary goals, vocational rehabilitation, can not recognize that Independent Living is integral to a vocational goal, can not recognize it in law, its equal status to the vocational goals, we are gonna have such tremendous tension developing within these programs and RSA saying you know your production is falling, it's falling — more severely disabled people. They take longer and they cost a little bit more money. This dilemma has not been solved. You have to help us do that by writing in the Act of Independent Living, by mandating, and not by saying use the funds you've got, because I think we're stretched thin as it is. I think it's important, that we serve everyone, all people with disabilities, but when we set priorities for the severely disabled

we have to have a new stream of funds for Independent Living; and with those funds we could then purchase future services through future service arrangement, through the Independent Living Programs, to contract to do part of the work. That could be part of our base support, and we could figure it out and figure how much that would be. So those two funding streams are extremely important. One without the other becomes - it becomes very difficult to maintain or to even bring these programs into - make them go on, I guess you'd say. I'm thinking about my.

It's important that we - the grants be for minimum - for grants, that they be for a minimum for five years. I've got to give people time with a funding base so that they have time to develop their own community contacts and other kinds of funding can come into the program. One of the key aspects that has not been mentioned here today, although you can see by looking around CIL, is that we have to, whether we collect from the Department of Commerce or other Federal Agencies, we have to build in a business component or a small economical development component, so that these centers are constantly in need of State and Federal money, that they can begin to become self-supporting. And I think when they are, or if they are, the advocacy efforts become even stronger because they have the kind of independence. So it's critical that we learn and be able to do some of the work through the Department of Rehab. We think of this as a wholistic concept, Independent Living, that we build in the kind of units that can keep these programs going. They are - I don't know if you went out to look at the CIL something like 20 thousand dollars a month.

So in delivering a service it is critical to the maintenance that people in wheelchairs move around and in other kinds of equipment, so you can see that you can provide a business service which will support your free services or other services which will maintain the momentum of your project, and you can build. You can build yourself a very strong program through that, and there are many other kinds of things that I know people can get into. Soft hardware, which includes all kinds of products that disabled people need day-to-day, which could be sold even cheaper - Rehab Engineering kinds of - for instance, a kind of wheelchair which CIL is considering and marketing it and involving several people in the manufacturing operation. That can all become a part, and should be a part of the whole concept of an ILP. We are just beginning to realize how many in the ILP's are involved heavily in developing other sources of phones. Community block funding grants, for

example, I understand are in process now for the three Los Angeles Independent Living Programs, large city grants San Diego. They're beginning to learn how to use other resources that have been passed by Congress, especially manpower programs, but they're limited and it's very difficult when you bring a staff in to get them to keep it growing after the year or after a year-and-half, or however long it is. So maybe we need to think about the use of these kinds of funds in a more stable way for development of ILP's.

Independent Living Programs obviously are only part of the answer. There are broad, a broad concept that transitional housing and half-way types of situations are extremely important for certain populations. It seems to be the mentally ill, some a

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little more severely mentally disabled people, and some severe physically disabled people are in real need of this kind of transition to the community. Out of the - they provide and they create real alternatives to state institutions and nursing homes, and we can do that, hopefully through the new Office of Independent Living and HUD by getting people to begin to work together with a vision of how a comprehensive system like that would work. You know what it comes down to here, the bottom line, is that somebody has to begin to lead in the Federal Government, somebody has to begin to take - play a role as our Department is in California, begin to set up what has to be done and then bringing the other agencies in to do their part of it. I don't see a lot of that happening right now, but I see a lot of it happening in what role in this process eventually moves a person towards, hopefully a vocation. There's a real need of - once we - obviously once we create these Independent Living Programs, one of the things you hear is now we need money to keep them going. That's equally true of rehab workshops and other rehab facilities. They have constant pressure to take clients, they often have insufficient fee-for-service money and are constantly on the edge of collapse. The irony is that there is no long-term funding available really for people with very severe disability to move forward through that system, and the more money we can put into an Independent Living stream of rehab the more we will be able to pick up long-term people, people like myself and others. The severely mentally retarded, for example, who could move into independence given time and aggressive kinds of training and a positive attitude that they are going to achieve, what their end goal is.

One of the panels before I came out talked about Title 5. Title 5

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is critical to the success of this new movement, Independent Living Movement and Civil Rights Movement, and you have to help us assure that the kind of enforcement that we need to move will be forthcoming. I think the suggestions for some changes given by the panel were good ones. I'd like to see - I'm on the Advisory Committee, for example, for the Architectural Transportation Barrier Board. It's a laugh, almost. I mean it's almost not worth my time and I had to make a decision about it, whether to go to those meetings and watch almost every suggestion that we made be turned down by the Board itself. Some of us have just begun to wonder whether it's worth our time to participate in that Board at all, or whether we should resign and protest of how ineffective it is and how little we're listened to by them. And yet we probably have some of the - I mean, if the Advisory Board was the Board, I think we'd have action. It's very difficult the way it is. One of the things that is paralyzing to the severely disabled that we've attempted to work on in this State, is the various and many disincentives to work for the more severely disabled that we built into so many of our major programs; and, Ralph, are you here? I would like Ralph just for a minute or so, to lay out some of the things that could be happening and things that are in process that all of us could help with.

I just - I wanted to point out with Ralph's testimony that as hard as we work to move people towards independence, the major barriers in the Federal system itself, the law, the system of law, almost across the board that we need to systematically work out and change so that we could provide an incentive to work, and I'm fearful that the new - the new - the President's package

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on Welfare Reform, is not going to include them and that in fact we are going to regress, and I mean, Congress has to use vigil on this point. We don't build any more disincentives, to remove the ones we have. Jim has been my, at Rehab, my principle advocacy in a rehab agency, I think, because we - I think we understood the mandate of the '73 Act. Go ahead, Jim.

I think it's important here to point out that a Rehabilitation Department under this '73 Act has an obligation to always deliver direct services in the service of the severely disabled, to provide primary advocacy for the disabled within State government, and I think all too few rehab agencies have taken advantage of that provision. Someone has to begin to move the ball in the State to serve all people with disabilities. Someone has to begin to provide through leadership within the State so that all people with disabilities begin to have a potential, can fulfill their own potential, whether it's work or whether it's learning how to control their own lives.

Recently we had - the Governor sponsored a conference on services to the severely handicapped. We invited a gentleman from Sweden, to come over and who is the architect of Swedish services. We saw a system that was comprehensive, that met people's needs, that wasn't exorbitantly expensive, that guaranteed those rights that we've just recently won. We also found that it's not that difficult to begin to pull together the kinds of resources that are already available from those State and Federal Governments to have them work closer together, to make the money more effective. We also found that the Swedish

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State Insurance Company made a study of the probability of disability for Sweden's 20-year-olds. They projected that at some time in their lives, the 20-year-old's lives, that their was a 60-to-70% chance that they would have a disability that was severe enough to limit their mobility or their ability to get around. So when we begin to think about it this, and I believe it, as we begin to prepare people to live independently we are preparing it for not for just those of us that are here now, but for the future, when many people that have no idea who will become disabled. As we begin to learn how to prevent diseases more we need to spend an equal amount of energy or more energy on developing the kind of systems that assure that anyone with a disability can achieve their own potential.

I thank you very much for coming here today and for listening, and you were listening intently, through a long series of speakers. We want to offer to you the California State Department and I speak now for the ILP's and Consumers as well, continued assistance. If there are any questions as you look at the Act, if there's any areas you'd like us to work on to help you develop language, we are here, we are available. We look forward to a new day in Rehab, one that legitimizes Independent Living as a primary goal, and one that recognizes that without strong Independent Living Programs we're not going to serve the more severely disabled in this country.

SPEAKER: Thank you. Let me just ask you one question because there's some indication, and I don't - let me just ask you if we can talk about this at some other time - but two things appear to

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be happening. One in regards to 504. There seems to be an awful lot of inflated estimates by institutions as to what they have to do and I just wondered in your advocacy as you're starting to pin these people down, what you're finding in terms of their original estimates and what it would take to make their facility acceptable and what it wouldn't. Some of the educational institutions are starting to lobby in Washington now and suggesting that there's not enough money in the world to do it.

ROBERTS: I think we have to be very clear, all of us, that this is not a lot of money, but a right, and we talked about intergrating schools in the South, we did not talk about how much money it was going to cost; and every time we discuss this issue we should discuss it in a positive way by recognizing there's a lot of paranoia out there, these are people reinventing the ramp, people who are

SPEAKER: That's my real concern, is that what they literally want is to design the whole front of the building instead of putting in a wooden ramp.

ROBERTS: Well, that of course, that kind of problem - look at California Corporation - can't fit in. These kinds of embarrassments are embarrassments to us all, I think, and that's why we just got permission from the Governor to provide the kind of information and expertise to corporations, local school districts, and entities, there has to be a central source. Right now there's an awful lot of confusion about who's gonna do what from the Federal system, and everyone's coming to the rehab agencies in

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almost every State, and since that's happening maybe we should encourage RSA to take on an informational role and a role of providing technical assistance, and let the office of Civil Rights do the enforcement - because right now there's a struggle going on that's just gonna hurt the disabled in the long run. If we allow too many of these inflated figures, and they are tremendously inflated, to continue to be bantered about without pinning down some of the actual cost. It's interesting in the school districts and the university of California, for example, they're beginning to pin down their cost and they're much less than they originally estimated. The original estimates were in the hundreds of millions of dollars. They've got them down much lower than that, a quarter of that, and they're even looking at those now as to see how realistic. It doesn't mean filing for it, doesn't mean that every building has to have a ramp. It means that programs have to be accessible to the disabled. It could mean you move the class if that's what it is, to a building where everybody can get in. But the thing that - the kind of misinformation and fear that's out there could be very damaging in Congress this next year, and I, you know, I urge people here and yourself to - these figures and question where they got them and were there disabled people involved in the process of the costing and what was the technical help they got in getting these figures. Cause I - I think they could be used to minimize the effect of 504 and, I think that's some people's intent.

SPEAKER: The other one - are you saying I guess, really basically the same answers. Obviously the assault by - is on transportation.

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I mean, I've had a number of people from New York already come to me with horror stories in their minds of what the potential cost is, what's gonna happen, nobody's gonna write it. I mean these myths and these fears and these inflated figures were -

ROBERTS: You know when we began CIL, we were - I remember the city and the county and others said "Why are you beginning this project? We don't see any people." And I think that's exactly what's going to happen with transportation. People don't go to the bus lines because they - obviously many of them can't get on. In California we estimate it's seven-hundred-and-fifty-thousand people who can't with physical disabilities and other disabilities, late stages of pregnancy and other reasons people cannot use those buses. I think that's an extravagant figure to pay. It's often what it costs to put a two-way radio in. Often transit authorities making a decision between radios and ramps, and that's a very difficult decision to make. If I was making it, I know which way it would go. I think the Federal Government is now mandating the trans bus. You have to be sure they don't back away from it. There's obviously tremendous pressure from the industry itself. General Motors and others have developed buses that they think are perfectly adequate, even though very few people with disabilities can get on them, and those are the pressures we have to resist. I think every speaker, almost every speaker that came up here today reiterated the needs in transportation. You just can't underestimate them at all. It's not gonna be a panacea (sic), but I'll tell you, when we can get our clients to and from work, the work of their choice, that's gonna be a real triumph, and not have to purchase for some people 15 or 20

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thousand dollar vehicles because there is no way they can ride public transportation. I just hope - I hope we



can open up highway tax money to begin to look at some of these problems, right, like rapid transit and others.

SPEAKER: I don't know - you know Bella is running for the Congress again so she'll come back and start that argument with him again.

ROBERTS: There's a couple of other things I think that could be very helpful to the program like Rehab in California, Rehab's program. One is the allocation formula. The formula that allocates Rehab dollars to the States. California is the most penalized of all the States in terms of the amount of dollars it gets. You compare West Virginia and California for example, they get ten times as much.

SPEAKER: But they have the chairman.

ROBERTS: I know, I understand. But there are formulas and ways we can break out of this problem and begin to equalized the money. We can't serve as many people as we'd like because of the allocation formula. If it was a formula based on what a lot of today's bills are, we would have an additional 20 million dollars, which would make a vast difference to Rehab in this State. We could do Independent Living on 20 million.