

ED ROBERTS.

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

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

I think the founders - as we envisioned DPI just could play a very significant role, changing the course of a lot of brutality and a lot of prejudice and our stereotypical responses to disability. Right now on the council we have two people from each continent. In the main the leaders are from Canada, Ireland, Sweden, USA, Singapore, Costa Rica, Argentina, Zimbabwe and French Mauritania, all representatives are disabled. The Council by bringing together people from round the world will begin a process that should bring all people in the world with disabilities closer together. Building on the strengths of the already worldwide organisations. Deal in the main with specific disabilities, on deafness, blindness, mental retardation etc., but the key to DPI is that it must be a coalition of all disabilities, by disabled and for the future of all disabled people. It is clear that our role as disabled people in each country is to begin to reach out, for example, in Zimbabwe our delegate needs used clothing, so any group that would like to take up a collection of clothing, they sell that and use the income to support their organisation. There are so many things that we can do together if we learn more about each other. The main job in the next few months is to spread the word about DPI and to join with us. Read our draft constitution and provide input. Two of the very specific tasks we have taken on are a lawsuit in Germany that allowed people to get money back on a package tour of another country because they were depressed by the presence of disabled people among them. The other issues have to do with airlines, just being able to move about and all the different regulations and problems with electric wheelchairs and white canes and all the patronising treatment that disabled people get in general from international carriers, so we have a lot of work to do together. This will be an organisation where we set the priorities, our dream really is to do something in many areas, one is prevention. The number one cause of disability in the world today, and there are estimated 1/2 billion disabled people in the world today, the number one cause is malnutrition. It means

that as we get involved in organisation we will be also providing a lot of technical assistance to help prevent disability. It means that the vision is not to gain more for people over and above those who live in a society but to gain an equal opportunity within a society, so if everyone is poor you are not going to make a disabled person rich, but equal.

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

Well, we have been very seriously thinking, we realise that it is the first and many people will want to attend who will not be able to, from all around the world and we hope to have money for scholarships for people from developing nations, at least for some from each country, depending on population, we hope to get that from the UN, but we are expecting in the developing nations people to go to their governments and talk about becoming a part of this because the government is not going to send somebody, that is not how we work, we work within organisations but the government could participate and be supportive in the UN and also provide transportation, so I would think you all would want to get this organisation legitimised, contact your Irish colleague and he will, I am sure, help out.

The Irish representative's name is Liam McGuire and I will give you a list of people, because we are just the first year people, the organisers, and there will be elections for regional representatives, we hope to follow this and immediately set up regional offices and have the real strength in the regions as well as in the central, we have talked about differing places as a kind of central headquarters, but we have not come to any real conclusions on that. We have thought a lot about it and the more we think about it the more excited we get, the more people we can get involved with us, the more perspectives, the richer the diversity, the stronger we will be and I think politically we will address an issue that applies to the right and the left. Disability is such a chancy thing and so many of us have a chance to have it in our overall lifespan that the future, what we see needs to happen, a way be prepared for all of us. Our American coalition of citizens with disabilities is in the process of becoming directly involved with DPI and I am also on the board of our ACCD so I have become a good link to the international movement. There is a wealth of diversity out there and a lot of things are happening. In a few weeks I am going to Japan and the responses to disability, or lack of response in any society is very culturally based and one of the things that we know very little about is how in differing cultures, what are the cultural effects on disability. In India you may be a chosen one, but you also may be chosen to beg for your livelihood. There's a lot of things, it's a fascinating area. In Japan a Quad who is a member of the Japanese parliament is going to be a representative on our committee, so there are some very interesting people around the world involved already.

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

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

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

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

Independent Living Movement.

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

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

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

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

terrifically sorry for us, we knew we could get what we wanted, because we could exploit those stereotypes and often we don't exploit what we have, we have a lot of strengths in the way people view us, so you have to really exploit those kinds of stereotypes. At the same time you have got to bring people along and laws along and we are a very rights orientated and law orientated society.

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

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

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

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

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

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

JE: That's just California

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

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

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

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

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

JE: But there is no choice ....

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

JE: I notice that you train your own physiotherapists

Absolutely. Take them out of the institutions and bring them out into the community with us. A difficult system, but we are finding, even with the most severely retarded person, it wasn't that they could not learn, it's that we did not teach. Now we are learning how to teach and we can teach people with profound disabilities a job and how to work and you can teach a person vocational as well as living skills. People have a right to their fullest potential, whatever that is, and to be seen as having potential. We did some experimentation here with severely retarded people on assembly lines, and what

you do is you do a task analysis of an issue, you break it down into smaller learning units and you teach it, once a person learns it, which can be relatively quickly, they don't make mistakes and they don't get bored at it so they just turn out great work, so they may do a lot fewer, but their productivity in terms of the numbers that go through are passed on, and then the old attitude thing comes in because people don't want to be compared with the work of a retarded person, because they are not worth much. That's why I work on all the issues, because I believe a retarded person is equally or more oppressed than I am. We have a new organisation called 'People First' here in California, it is an organisation of the mentally retarded speaking for themselves, so frank, so honest, such an honesty, a willingness to speak up, this is a very positive thing. In DPI that's it 'speak for yourself'.

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

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