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CENTRES FOR INDEPENDENT LIVING IN THE US AND UK - AN AMERICAN VIEWPOINT

Report of a Seminar held at

King's Fund Centre

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King's Fund Centre
126 Albert Street
London NW1 7NF

INTRODUCTION

During November 1983 Judy Heumann was on a 'whistle stop tour' to meet disabled people in Hampshire, Manchester, Nottingham and London, where Centres for Independent Living are being developed. We suggested to Judy that she might like to spend her last free afternoon with a small invited audience of representatives from the physical handicap world, to tell us something about the American Independent Living movement, and to share with us her views on the present 'state of the art' in this country.

The Long Term Care Team would like to extend their thanks to Judy for a very lively thought provoking afternoon.

CIL - AN OVERVIEW

Judy Heumann is currently with the World Institute on Disability, a US policy organisation which works on both national and international issues.

She taught in New York for three years and then took a masters degree in public health at Berkeley, California before working for three years for a senator in Washington. She joined the staff of CIL in Berkeley in 1976 and has been involved in its work ever since.

Here is her talk to the seminar:

CIL - the context

There are many more similarities between disabled communities, irrespective of political structures, than there are differences. Whether in Japan or Africa, Mexico, Canada or Europe, I find the same theme recurs. Disabled individuals feel that they are not receiving appropriate services, that they are outcasts from the community, that services are frequently provided in a custodial, 'do unto us' fashion, and that we have very little say in their methodology. Charitable organisations, established for good reasons years ago, have not in many cases kept up with the times. Many of those organisations have not begun to work together as effectively as disabled people ourselves are wanting to work together.

For instance, I had polio when I was one and a half. I couldn't get into school until I was 10 years old, because the segregated classes to which I went were only for children with cerebral palsy. I was the first post-polio in these classes, which was a major victory. But the polio foundation really did very little with the cerebral palsy association, which did very little with the muscular dystrophy association........
On the political level, a number of consortia have since evolved where these groups are at least discussing civil rights and education legislation, and monies to be appropriated. But on a service delivery level, they still don't really collaborate to provide services based on functional need rather than the label of disability.

In New York in 1970, we established Disabled in Action, which was and is run by disabled individuals - and began discussions in the US about 'for' and 'of' organisations, the first being those which are 'doing for' us and not usually controlled by us, the second being controlled by the constituency of disabled people.

Disabled in Action grew out of a lawsuit I brought against the New York schoolboard when I had been denied a job because of my disability. In those days, there was a lot of discussion around the job discrimination issue and we had publicity for a solid year every week, in major newspapers, TV and radio, all across the country. It was the right time. I don't know whether today would be, but in 1970 we were in a real liberal upswing. So a disabled person being denied a job when there weren't enough teachers to fill vacancies was the right cry. When I got my credentials after going to court, it was a very powerful experience for us as disabled people, because we felt we had all had an arm in what had gone on. And what we did with all the publicity was to begin to talk about overall discrimination against disabled people and their overall problems.

We worked with our local governments, with traditional agencies. We were basically young, inexperienced people, trying to deal with the New York city system of 7 million people - which is a big system even if you're experienced! We began to develop coalitions with many different kinds of groups. Disabled in Action was not a group just for physically disabled people. It was for people with disabilities, and although it was primarily made up of people with physical disabilities in those days, it was a 'first' for many of us to acknowledge that we wanted an organisation that dealt with issues of discrimination in disability as opposed to a specific label of disability. We began to become actively involved in what we defined as civil rights issues - and of course received a lot of impetus from the anti-war movement, and the development of the women's movement and the black and other racial minority movements.

Many of us in the disabled community were very middle-class people. We'd really been brought up to believe that the American dream was attainable for us and that if we worked hard and studied hard - and maybe a little bit harder, because we were disabled - things were going to be OK. But as many of us started growing up, it became quite apparent that that was not true; many of us had had parents who were very active and assertive, and that was the reason that we were where we were. In the late 1960s, it was becoming more common for disabled people to go to universities; it was becoming more common for disabled people to be in the schools, even if that was in a segregated class rather than a completely segregated school. So as we were getting older and recognising that we wanted to take more responsibility for what happened to us, DIA became very effective for us.

But one of its big problems was that it wasn't linked to any service organisation. So if we didn't drive, if we needed help to get out to meetings, we were dependent on other people. There was no attendant care system that anyone knew about in New York; health and other benefits were there - but not there.

I moved to Berkeley because I needed an advanced degree to maintain my teaching certificate and had been called by Ed Roberts - a severely disabled post-polio person who became Director of the State Department of Rehabilitation - the largest State rehabilitation agency in the US, for seven years under the previous Democratic administration. He said they were looking for young, progressive disabled individuals who were interested in studying in Berkeley and getting involved in a programme called the Centre for Independent Living - of which I had never heard.

I was very scared about going to California. I had this whole system set up for myself in New York. Although I lived in an apartment with friends and didn't have any attendants, I certainly used my friends to the maximum and they, my parents and my brothers would drive me, and I was able to be very active in the community. But when I went to Berkeley for a visit, I was incredibly impressed by the community that was evolving there. What was happening in Disabled in Action was going on there too. But the Centre for Independent Living had gone one step further and begun to develop services. And those services were really allowing people to get out who were not yet able to do that in New York.

CIL - The History

The Berkeley programme in 1972 was really a second step. The first had been 10 years earlier, when Ed Roberts - who sleeps in an iron lung and uses a respirator during the day and can move one finger on his left hand and a toe on his right foot - attempted to get into the university. They were, to say the least, a bit distraught. But he wasn't going to go away, so they allowed him to live in the wing of a hospital, whose doctor had had experience with polio and so wasn't afraid of the disability.

Between 1962 and 1972, more and more severely disabled people - quadraplegics and paraplegics - began enrolling at the university and living in this segregated setting, which of course was not satisfactory for them. After they developed an organisation called the Quad Squad, they were successful in getting Federal funding to set up a disabled students programme at the university. (The college I had gone to in New York was developing its own programme at about the same time - there were parallels through the States).

Berkeley set up its service organisations as a disabled-controlled programme - so the first director was disabled and so were the majority of workers. They provided services such as advocacy, to let people know what federal and state financial and medical benefits were available, as well as traditional services like helping people enroll, decide on their majors and so on. They also set up a wheelchair repair service and helped people find attendants and places to live in the community. All the services were very oriented to what disabled people were interested in getting.

The problem was that these services were only available to students. Other people were hearing about them and wanting to set up something similar. And that is really how CIL started - from a group of people, some of whom were students, some of whom had dropped out of university and some of whom never went there at all.

There was a very clear discussion about whether or not the organisation would be a coalition of different disabilities and whether it would offer a residential programme. It was clearly decided that it would be an activist organisation, not made up of a single disability group, and that it would specifically not be a residential or 'transitional living' programme. The people in the group were quite severely physically disabled and could do very little for themselves - I would be at the 'moderate' end of those involved in setting up the programme. So the fact that they concluded that they did not want any form of residential programme is very significant. A number of people had lived in county hospitals and other types of institutions, or had been taken care of by their families for longer than normal. So it was a very risky proposition to start an organisation like this. But they felt very confident about it.

So CIL started as a non-residential, disabled-controlled, inexperienced group of people - inexperienced in as much as we'd never run a business. And that is what CIL is in part: it gets money, it hires people, it pays them, it fires them, it provides services, it has to do planning and work in the community. There was no money for CILs at the time, and it was through sheer nerve of people selling themselves in the community, to foundations and government agencies, that they got a grant. This ran out in a year, and they hadn't raised any more money. So people worked on very little money and none at all, out of an apartment.

CIL was then a coalition only of physically disabled and blind people, but that includes severely cerebral palsed people, so issues of communication difficulties and so on were involved from the beginning. It picked up some of the services that the disabled students programme had run. In housing assistance, it identified which apartments were available, whether they could be ramped and bathroom doors could be made wider. It asked: what do people really want? Do they always want completely accessible houses? We found that many people who can't do certain things didn't really care whether their kitchen and bathroom was accessible, and although that was not true for everybody, we began to be able to use a lot more of what was available in the community. We built all kinds, sizes and shapes of ramps, so we've got into housing that from the outside looks completely inaccessible.

I went on staff at CIL in 1976 for very specific reasons. I wanted it to start serving the deaf community and children and to start providing services for mentally retarded people. I wanted us to have a much stronger civil rights, legal arm.

I had these interests, I think very significantly, because of my background in segregated education and involvement in segregated camps with friends with all different kinds of disabilities. As I and my physically disabled friends were getting older, we were the ones who were able to move into the universities. Maybe we weren't getting the jobs, because of discrimination, but at least we had better opportunities than many of our other friends who were not even making it into high school but going to sheltered workshops. Yet we didn't see any distinguishing factors, because these people had been our friends. And now all of a sudden there were these artificial divisions, which many of us were wanting to remedy.

Many of us who joined CIL's staff came from New York and had been friends for years and years. We had to persuade the older people who had become disabled later on and had no experience of dealing with disability at a younger age and had a lot of immediate needs that they wanted dealing with. It wasn't that they didn't want to provide services to a younger population, but they saw no real relevance in it. And from a planning point of view we needed to make sure we had enough money to continue what we were doing now.

Anyway, we were forceful. The Democrats came in in 1976. We had good connections with them and were able to get lots of grants to begin to provide some very creative programmes.

CIL today

Between 1976 and 1983, CIL has evolved significantly, as a community-based programme where disabled people can get services, which advocates on their behalf and whose goal is to ensure that they can receive services from any agency in the community. While the largest percentage of people who use CIL are 14+, probably 15-20% are over 60 and we are beginning to reach below the age of 14 because we feel strongly that we want to provide a programme 'from birth to death'. We serve all disabled groups - people with all physical disabilities, blindness, deafness, mental retardation, mental illness; there isn't anybody who comes to us with a label of disability to whom we deny services because of that label. The staff reflects the population served - so our deaf services have deaf staff, our blind services blind staff and so on. And our Board of Directors reflects the population of the organisation too.

There have been many problems in producing this integration, because we didn't know about each other and had to learn a lot and get in touch with the prejudices that exist within the disabled community towards each disability group. That in the long run has been very positive and one of the most important factors of the independent living movement in the United States. We as disabled people will fight for the rights of disabled people - not 'polios for polios', 'the mentally retarded for the mentally retarded' and so on.

Our services increased significantly between 1976 and 1980, when we went from a staff of about 50 to one of about 200. In 1980, we had a state election and they decreased; by 1982, the staff were down to about 45. (Berkeley's total population is 120,000). Our funding has always been mostly governmental, from as many sources as possible - housing, education, health and various other pots. We did not go after money that was specifically designated for disability because we very much feel that all government money should be providing services for disabled individuals. So we have been successful in getting funding that had traditionally not gone to disability groups.

The kinds of services we had begun to establish in the early 1970s were the kinds that I could successfully use: I could go and get a list of names of attendants and do my own interviewing, hiring and paying. But as we got into working with more severely disabled people, who were either living in institutions or at risk of that, or were living with their families (which we define as institutionalised living when it's beyond the time that you would normally want it), we needed to begin to provide a different kind of service, which would truly allow them to move out of those settings. So we have been going out to those places, trying to meet disabled individuals and to make them aware of some of the services that exist. We have a reasonably accessible rented apartment in the community - not labelled in any way - and in that there are classes for two days a week, taught by severely disabled individuals. People come there to learn such things as money management and mobility. There is a lot of peer work - disabled people talking to each other about problems and experiences and learning anything and everything they need in order to be more successful. Then they can really start using the services available at CIL, and the people at the Centre can learn how to work more effectively in a co-operative way with those who receive services.

We are also working in the schools, which has been an interesting experience, because it has been seen as threatening - as has our work with traditional organisations and many of the governmental agencies. We come in as disabled people saying "We believe that disabled people, irrespective of the severity of their disability, are capable of making decisions". We've also very strongly instilled within disabled individuals their right to say 'No, we do not want to receive certain things the way they are given". So that's a very threatening situation.

But in the last 10 years, we've been able to develop a much more friendly atmosphere within our community. The schools are actually letting in disabled people who are running independent living skills classes. We are also working with the parents of these children and have found that helpful not only because we can give them information on the kinds of services that are available, (which the government may not do), but also because we can let them know what they should and shouldn't be accepting.

We also have a job placement programme which is very important. Although we do not see CIL as an employment agency, we have found that as people become integrated into the community and begin to live like anyone else, employment is one of the natural progressions. And although we certainly have similar problems to yours around the social security system and its built-in disincentives to work, we have been able to have some State legislation passed which means our benefits are not so severely cut off as yours are here.

We've been incredibly successful in placing at least 800 people in jobs over the last five or six years. They don't have to be university people - we'll run classes for anyone who is interested in work and help them write resumés and so on. And I'm talking about people who have anything from moderate to severe disabilities. We also have a computer training programme that has placed another 110 people in jobs. This very intensive programme serves people who are blind and deaf and physically disabled and is very highly respected in the industry - so people are getting entry level jobs worth between $18,000 and $23,000, which is a very good wage by anybody's standards.

Berkeley's CIL is still the largest. But there are now about 150 others of varying sizes and although New York and California have the most, there is at least one in each State. Some are State-funded. Many are federally-funded, and since 1979, $18m - worth of federal funds have been available to them.

The problem is that they are still not taken as seriously as they should be. It has not been decided, for instance, how many centres there should be in each state and what they should be doing. They still tend to be set up by politically active groups.

But what is clear is that where there is not a CIL, disabled people are far less assertive. Where there is a CIL, there is an appreciable change in the quality of life of disabled people. And there is also more change among traditional charitable and non-profit organisations, which are sometimes hiring disabled people and putting them onto their boards.

CIL: A MODEL FOR BRITAIN?

For some participants in the seminar, there seemed no question at all that it is - and that the sooner Centres are set up, the better!

But there were questions, too. Our system of welfare is very different from the American self-help ethos; consumer self-determination is as little part of our service traditions as it is central to CIL. Judy Heumann had certainly been interested to see just what a range of provision we take for granted; from her American perspective, the social services system in the States is so much more lacking. Britain has too, she thought, a degree of co-operation that is still unusual in the States; it would be difficult to set up a seminar drawing together the sort of bodies represented at this one.

Yet does the British system provide what disabled consumers really want and need? For one participant, who has visited Berkeley, the issue of ramps summed up the contrasting approaches of CIL and British welfare provision - and Britain didn't come out well. In Berkeley, ramps come in all manner of shapes and sizes, handily made of wood for easier removal if necessary and inexpensive too; it's the individual needs that matter, not the byelaws. Here, ramps come in concrete, and only after discussion and delay. For CIL, it's a question of getting on with the job rather than observing professional niceties; as Judy Heumann said, it's a matter of knowing a good carpenter rather than getting into the 'phys.dis.biz.'. She'd certainly been struck, as she went about England, by how often people had told her how old and inaccessible everything was. "But unless there's something magical going on inside your buildings, you have a lot of facilities that are very easily made accessible - much more easily than in, say, New York or San Francisco".

So, as she said, it's possible for services to become too structured and so lose sight of their original intentions. They can also, in their efforts to offer 'special' provision, work against the opening up of ordinary opportunities to disabled people. For Judy Heumann, the Dial-a-Ride services offered a specific instance of that. In Berkeley, CIL had also ordered its special vans. But it cut that order down from 16 to 5 when it realised that the more 'special' transport it provided, the less likely government would be to provide an integrated, accessible public transport system of its own. It took five years, a demonstration and two lots of litigation. But now all the new buses in the city are accessible and there's para-transit (subsidised taxi-vans) as well.

Sometimes, too, British provision can militate quite actively against individuals who rely on it. Judy Heumann, who was herself 21 before she got the electric wheelchair that enabled her to go out unaided, picked this particular provision as an example of how the aids on offer can actually handicap individuals. "I think its a very poor policy that people are only allowed to get in-house electric wheelchairs with DHSS funding. This system is potentially, unconsciously, building in a lot of dependency, and there's a major contradiction when you are saying that you want a population to be more independent, but are basically establishing a very dependency-oriented system. That sets up all kinds of problems for the individual on how they can begin to assert themselves".

British approaches can militate against individuals in more general ways as well. If, as one medical participant said, social services accused her of trying to 'throw people out' every time she tried to start discussions on finding them more appropriate accommodation than that offered by her own health agency, how near are we to achieving that 'multi-disciplinary co-operation' that is meant to make services work together for the good of the consumer? A clear advantage of CIL, as Judy Heumann saw it, was that it could look at each person as a whole and then work to ensure that they got all the services they needed, whoever provided these. CIL also got round another common disadvantage of statutory welfare systems - the divisive planning for groups by label rather than for individuals by functional need. So, for instance, instead of busying itself thinking up provision for a group called 'the frail elderly', it could recognise that in fact an 80 year old individual might have the same functional needs as a 20 year old with severe brain damage, and plan for both accordingly.

For her, the distinction between the situation here and in the USA was not, in the end, so very great - except that we have, through our existing services, a stronger basis for development. But there are statutory services in the USA as well, and CIL in Berkeley works with these as well as providing its own - through, for instance, its monitoring of the performance of the social services department (at that department's request) on affirmative action in employment.

So although the balance of any CIL work here might be different from in Berkeley, the components of that work would be the same: providing services and influencing those provided by other agencies. Its own services could be short-term 'pilot' ones, to be handed over to statutory services if they worked and abandoned if they didn't; what we need to do to become more creative is to free ourselves of the idea that just because a service exists now, it must always continue. Or perhaps CIL services wouldn't be handed over at all: "my guess would be that as the work increases, more disabled people will want to provide their own services, because those services will be of better quality".

Whatever the eventual mix, many participants seemed to have no doubt that a far greater consumer input to services is what we need, whether in general terms, or very specific ones, like peer-counselling. As one participant said, she couldn't see how this could not be in the interest of statutory service providers as well as disabled people. Just as architects were discovering their 'real clients' and housing authorities were actively encouraging tenants' associations, so disillusioned workers in the caring professions could only be helped by developing services which respond to the consumer.

HOW TO DEVELOP THE CIL MODEL?

In the last two or three years, the demand for places in Cheshire Homes has been falling. Yet four new Homes are planned and three more are to have purpose-built replacements.

What to do, when disabled people are often saying clearly that they do not want residential care, and yet lack the means to set up house and find the individual care they need to live in it? Participants underlined the dangers of turning too hastily from our present systems at a time when there's a danger to look to 'deinstitutionalisation' as providing a cheaper option and simply to leave people either once more dependent on their families or to the often grossly inadequate private market.

Judy Heumann saw two main things to be done. The first was for agencies worried about their current provision to start discussions with the consumers about possible ways forward. "I'd venture to say that the caring professions are not controlled by disabled people - who don't even influence the provision of care. If people would speak to those of us who do use care, it would be so helpful".

The second thing to do was to take on the whole issue of providing a national care attendant scheme - something which Britain, just as the USA, had so far failed to do. Yet Judy Heumann knew from her own experience when she first moved to Berkeley and starting using this CIL service, just how central the business of care attendants is. "Life was becoming 'normal'. When I lived either with my parents or in the apartment in New York, it was partly my schedule, but it was certainly partly the schedule of the people who were voluntarily helping me. But now none of that mattered. I had to make the decisions about when I wanted to get up, where I wanted to live, buying food, where I wanted my clothes put - all those things that I had never really had complete responsibility for. I did my own hiring, my own paying and my own firing. I did my own directing completely. I consider myself a fairly intelligent, independent person. And here I was, at the age of 25, feeling very adolescent because there was just so much that I had never done myself".

If more disabled people in Britain are to find the opportunities for self-determination that CIL offers, then there are questions to be resolved - not just of organisation and finance, but of attitude.

Questions of organisations and finance

For disabled people

How are disabled people to be strongly represented and start providing services of their own? Greenwich Association of the Disabled, as one participant pointed out, already acts in some ways as a mini-CIL. Yet how, without decent funding, can it help the many people the social services department sends its way as well as it would like? And where should the funding come from? Nascent CILs in different parts of England are grappling with the issue of establishing true independence while seeking funds from, perhaps, statutory bodies. It's an issue in the USA too, where some CILs have a quite autonomous board of management, but others are under the wing of traditional non-profit organisations. One possible way ahead is for those organsiations to provide set-up funding and support - as one has done in New York - but on the understanding that after a year or so the CIL become quite autonomous. But the question of long-term funding still has to be resolved. For one participant at least, the responsibility here must fall to DHSS and social services departments, and the independence of the CILs must be guaranteed.

On Care attendants

DHSS participants gave little hope of any foreseeble resolution of this central issue. "It's a long haul", was one comment - and they made clear that anything that cost more money was simply out of the question.

Yet, as more than one participant pointed out, the solution for people now in residential care who want to leave depends not so much on more money overall, but a transferring of existing funds from institutions to individuals, so that they can hire care attendants if they need them.

So should the residential institutions be able to use the money they receive as they wish, channelling it to individuals who want to leave? Why not a cash benefit direct to the individuals? But if this were simply for people now in residential care, then that, one participant thought, would discriminate unjustly against the many disabled people already 'in the community', living perhaps in equally unsatisfactory conditions with their families.

So the issues both of funding organisations which might become CILs and assuring care attendants for people who need them remain unresolved as well as critical. Lack of cash is clearly important. But will that cash ever be found until enough people believe that it must be?

Questions of attitude

Among service providers

How much do they believe in the potential of disabled people?

When Judy Heumann was asked how many people now in residential institutions she thought could benefit from the sort of services CIL provides, she was clear: potentially 100% - depending on the quality of the alternative services: "if the independent living movement continues to grow here, institutions will hopefully become a thing of the past".

For one service provider, though, that seemed to stretch credulity; he knew Homes where "half the people were in bed, just waiting to die". For another participant, it was his attitude that needed attention as well as those people: there was no reason at all, she thought, why anyone should be lying in bed waiting to die and if they were, it was simply because they weren't getting the sort of service they need.

But was there, some people wondered, at least a case for the 'half-way house', or opportunity for 'transitional living' between institution and independence? Judy Heumann was emphatic about Berkeley CIL's feelings on this one: it saw no place at all for what was in effect another institutional placement, but insisted that what people needed was an apartment and whatever support in living skills they needed to live there. This was true even for people who are mentally ill and traditionally thought to 'need' a half-way house. That was her prejudice too, until she heard mentally ill people saying they didn't want it and had to let the prejudice go.

For her, service providers had a clear responsibility to help disabled people assert their wants and needs. "One of the problems in disability is this continual fear that what little you have - and it doesn't matter how little it is - will be taken away from you. So very many people are frequently very afraid of demanding more, because they are afraid of losing what they have. As workers and professionals, if you're progressively-minded you use that positively; if you're regressive, it's a very, very easy way of holding something over somebody's head. Because you really do know fear that exists in people's lives when they are dependent on others - and if you don't, as professionals you should".

How far are service providers prepared to go?

Say there were something called a 'wheelchair allowance'. Do we recognise the right of disabled people to receive it and then spend it on drink? For one participant at least, this is a preoccupation in all our debates around the future of services - but concealed, rather than brought out, acknowledged and discussed.

And how far are the organisations 'for' disabled people prepared to co-operate with disabled people and their own organisations? Judy Heumann knew that in the USA, traditional non-profit organisations have often seen any newcomers as competitors; the 'old boy' network tends to keep them out.

Among disabled people

For Judy Heumann, what marked our laws governing provision to disabled people was their lack of specificity, their many 'as much as possible' clauses. Nevertheless, she found it incredible that there hadn't been 'massive suits': "you should definitely have lawyers trained in the States!"

"Muscle is what's needed at this stage. 'We want - you must provide'. Get people out, get petitions going, enroll your friends to drive you around!

"I'm not saying that everything will change in five years. But if there are not significant plans to change over 10 or 15 years, there will be a whole host of other problems".

Ann Shearer
November, 1983

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