

DIRECT PAYMENTS CAMPAIGN IN THE U.K.
PRESENTATION FOR THE ENIL SEMINAR IN STOCKHOLM.
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INTRODUCTION

The Direct Payments campaign in the UK was started in 1989 by the BCODP IL Committee as one of its primary objectives. BCODP (British Council of Disabled People) is the national, democratic, representative organisation of disabled people in the UK. BCODPs Independent Living committee was formed as a result of the founding of ENIL (European Network on Independent Living) in Strasbourg in 1989 so that it could advise, develop, monitor, campaign and co-ordinate IL activities and developments in the UK and also feed into the European scene through ENIL. The Direct Payments campaign was initiated in order to change the legislation to make it easier for local authorities to establish Direct Payment schemes.

DIRECT PAYMENT SCHEMES AND THE LEGISLATION

The original Independent Living schemes were first set up in the UK in the early 1980s. Throughout the 1980s they developed slowly but they were still few in number and only operated in a limited amount of areas in the country. Most authorities were not keen to take on Independent Living schemes because they either considered them too risky or were wary of handing over all the control to disabled people. Direct Payment schemes represented for the first time a shift of power to disabled people. Most authorities who ran the schemes either did it because it was a new idea and way of providing services or had empathy with the Independent Living philosophy in terms of giving more choice and control in a disabled person's life. Other factors which restricted the growth and development of Independent Living schemes was the dubious and varying interpretation of the appropriate legislation.

After Hampshire had been running Independent Living schemes for three and a half years, the authority suddenly reviewed the situation when the county solicitor and treasurer became aware of the uncertainty of the legislation and were poised to stop the schemes. Fortunately, at the same time a report came out from the Audit Commission, which is an independent organisation that monitors the performance of local authorities. The report highlighted the Independent Living schemes in Hampshire as being innovative and good community care practice. This proved to be the saving grace and on hearing this the county solicitor and treasurer then changed their judgement and the schemes were saved and allowed to continue.

The reason for the confusion and the different interpretation of the legislation was because of a 1948 Social Security Act about Social Services provision. In this act, it states that a local authority can only provide services and cannot provide cash

payments, hence the stumbling block in the law. Even though Hampshire changed its mind there are still authorities who will not go ahead with Independent Living schemes which they regard as illegal. The situation was made worse in 1992 when the then current Minister of Health, Virginia Bottomley, sent out a circular to local authorities stating that Direct Payment schemes were illegal. This exasperated the situation and even authorities who had been running schemes up until then withdrew them. This is why the Direct Payments Campaign is so important so it can change the legislation and clarify everything in black and white. The way local authorities got around this was by paying the money into a third party ie. a disability or voluntary organisation for instance, and then they would pass the money onto the disabled individual. It was a kind of loophole in the law.

DIRECT PAYMENTS CAMPAIGN AND LOBBYING

The Independent Living movement believes that Direct Payment schemes should be as of right and that is why a change in the legislation is probably the second most important priority in the issues of disabled people after comprehensive civil rights legislation. In the early 1990s when BCODP IL group embarked on its Direct Payments campaign, it got together with the Spinal Injuries Association and its parliamentary officer Fidelity Simpson who was an expert in lobbying tactics and parliamentary affairs. This group then drew up a tactical strategy for bringing about Direct Payments legislation. Key disabled people from both these organisations with direct experience of running their own schemes worked together with Fidelity targeting possible key allies of Members of Parliament and politicians who would support and fight our cause. Many letters were written to local and national politicians seeking support. Numerous awareness raising and briefing meetings arranged and relevant publicity drawn up to disseminate in order to make the issue public and clear together with articles in both the mainstream and disability press.

LOBBYING AND THE PRIVATE MEMBERS BILL

Not long after the campaign started when the group found a very keen and influential advocate and supporter. He was Andrew Rowe, a conservative MP. He fully understood what we were trying to achieve as he had first hand experience with one of his constituents, a disabled woman who was running her own Independent Living scheme and at the same time running her own business. This left a deep impression on Andrew Rowe who then decided to put together a Private Members Bill on Direct Payments Legislation. In British politics, a Private Members Bill is another way of attaining legislation that is not part of the Government's proposed agenda. It is a difficult way of achieving success but over the years many innovative pieces of legislation have used this parliamentary procedure to achieve their results. It is long and arduous and prone to many pitfalls and political manoeuvring, especially if the government do not support it.

Anyway, Andrew Rowe attempted this approach twice in three years and both

attempts failed. During this time when Andrew Rowe was trying to progress his Direct Payments Bill, the campaign group organised a number of meetings with key politicians to try and influence them about the issue. These included the then current Minister of Health, and the Minister for disabled people. Both of these politicians expressed how much they appreciated Independent Living schemes, but neither were prepared to take serious action and publicly support them. Our understanding of the situation then was that the treasury department were not in support of this kind of legislation because of the economic argument of costing too much. These developments exasperated the campaign group and the Independent Living movement and the BCODP Independent Living Committee then felt another course of action was needed to promote the Direct Payments campaign and develop its strategy.

However, all was not lost during this period as we were able to gain a lot of support from a number of important national statutory organisations, in particular the ADSS, the Association of Directors of Social Services who passed a motion at their annual conference, supporting the need for Direct Payments legislation.

THE WAY FORWARD THROUGH DIRECT PAYMENTS RESEARCH

After the failure of Andrew Rowe's Private Members Bill and the tactic of trying to influence prominent politicians, BCODP felt that the best way forward now would be to commission a piece of social policy research to come up with some good evidence about the cost implications and effectiveness of Direct Payment schemes and how they improved user satisfaction and quality of life. BCODP drew up a workable proposal to carry out this research and was then awarded a grant from the Rowntree Foundation to do this. The next step was to contract the Policy Studies Institute who are a very notable and influential research unit to do the work for us. We felt that by using the PSI the research would have an impact on politicians and other important policy makers because the PSI was highly regarded for its social research and independence.

DIRECT PAYMENTS RESEARCH

Our research compared disabled people using services with disabled people using direct payments to employ their own personal assistance. It looked at the quality of support, at costs and at user satisfaction.

It found that direct payments offer disabled people a higher degree of choice and control, and were more reliable than service provision. Service users reported much higher levels of unmet need than payment users. They were four times more likely to have difficulty in obtaining back up for regular support than payment users. They were less likely to have assistance delivered in the manner they wanted. These findings are probably not news to most people in the Independent Living movement, but it was useful to have them documented by an independent research agency.

On costs, our research found that support financed by direct payments was on average between 30 and 40 percent cheaper than equivalent service based support. At the time of the research the average hourly cost for direct payments users was £5.18; for service users it was £8.52. There was a marked difference in overhead costs: payments schemes had between 20 and 30 percent overheads.

The research also found that people receiving direct payments had markedly higher levels of overall satisfaction with their support arrangements than service users. This was mainly due to the increased choice, control and reliability offered by direct payments. Like other studies, it found that the highest level of user satisfaction existed where users had advice from an organisation of disabled people.

Our research was the first study to combine the issues of cost and quality. It showed that on both counts direct payments are preferable, both cheaper and better. Information from our research was used by our allies in persuading the politicians to bring in direct payments. (We could not always get direct access to the Minister, but we had strong allies in the House of Commons and among Directors of Social Services who pressed our case.)

OFFICIAL ANNOUNCEMENT

Interestingly enough, a week before the BCODP/PSI launch of the Direct Payment research findings, called "Cashing in on Independence", the Minister of Health announced that it was the Government's intention to bring about Direct Payments legislation in the next parliamentary year. We were ecstatic! After five years of campaigning vigorously, we had achieved the beginning of our main goal. We were more than pleased that the research and the lobbying had the impact that we were hoping for. This announcement led to an intense flurry of activity around the whole issue of Direct Payments and a proliferation of seminars and conferences were organised by both policy makers and the Independent Living movement. Also, numerous research projects on Independent Living issues were instigated. At one of these conferences organised by the SSI, the Social Services Inspectorate, a number of Independent Living advocates met up with some key civil servants, who had been delegated the task by the Department of Health to research and work on implementing the Direct Payments change. From now on they were crucial in our deliberations and strategies.

TECHNICAL ADVISORY GROUP (TAG)

The Government then set up the Technical Advisory Group to work on the research and implementation of the Direct Payments legislation. This group then invited participants from a number of professional, statutory, voluntary and disability organisations. BCODP obviously, because of its expertise in this area, was one of three disability organisations invited onto the group. Jane Campbell, the representative from BCODP, was the only Personal Assistance user who had been

running her own Direct Payment scheme that was on the TAG. The TAG group started in June 1995 and since then has been looking at the key issues and drawing up guidance for the appropriate civil servants and Government Ministers. It was later partially responsible for drawing up the Government's consultation document on Direct Payments which was distributed out for comment.

PRESENT SITUATION

Since the Direct Payments Bill was announced in the Queen's speech (which is the Government's annual statement of what they intend to legislate for the next parliamentary year) last November, there has been a tremendous amount of activity on the political scene. BCODP has been extremely busy lobbying and briefing the Members of Parliament with a tremendous amount of success. The Bill has progressed very well up until now and only has its final stage to go through. We hope that this Bill will be passed before the end of July which is the end of the parliamentary year.

THE LOBBY FOR DIRECT PAYMENTS

The Government Bill for direct payments is very short, what they call "enabling legislation". All the details are to be put into regulations, which are published after the Bill becomes an Act. The Government has published a consultation document setting out the sort of regulation they have in mind.

The most important things to be decided from our point of view were:

- eligibility
- amount
- availability

The Government planned to restrict eligibility to people with a physical disability under the age of 65. This was clearly discriminatory and we had to oppose it.

The Government do not propose to set cash limits for how much can be paid. They propose that authorities must give people enough to meet their legal obligations, such as paying National Insurance. However, this is not a very big concession. Workers in the UK have very few employment rights until they have been with an employer for two years.

The direct payments Bill is a "permissive", not "mandatory" legislation. That means that it allows authorities to make payments but it does not compel them to. Each local authority can make its own policy to this. We wanted the Government to set national rules.

Other items we were concerned about were:

- support services, on which the Government are not making any directives and

- who may be employed as a personal assistant - the Government want to prevent people from employing close relatives.

THE PROGRESS OF THE CAMPAIGN

Our campaign has been on two levels. We have worked with Parliament, allying ourselves with paid lobby workers from other organisations. And we have worked through our networks, getting our members to approach their Members of Parliament. Working with paid lobbyists has been a new venture for us. In the UK there are a large number of charitable bodies concerned with disability. Although they do nothing to promote Independent Living, they all wanted to comment on the Bill and to influence the Government. So we had to educate them about Independent Living at the same time as trying to influence Members of Parliament and Members of the House of Lords.

Our biggest victory so far has been to convince the Government that people with learning difficulties (intellectual impairments) should be included in the scope of the Bill. The organisation controlled by people with learning difficulties, People First, did some very effective lobbying on this subject. And then, during the "Committee Stage" of the Bill (where a small number of MPs go through it in detail) the Government were defeated on key vote over eligibility, meaning that all disabled adults, whatever age or impairment, would be covered by the Bill.

We have not managed to shift the Government on the same areas. They will not make the Bill mandatory. So local authority can choose whether or not to have Direct Payments.

On other areas, such as employment of relatives, we are still in discussion.

Throughout the campaign we have tried to keep our supporters fully informed so that they can contact MPs and Lords to press our case for change. We have had to write lengthy briefings to assist Opposition MPs. Our research was helpful here, as it gave us good background material, but being in regular touch with Personal Assistance Users was vital, too, to get new quotes and up to date facts.

Throughout the campaign we have had to respond not just to Government but to social work and charity professionals who were worried about direct payments. Some of them support the Government approach, of making Direct Payments available to a small elite group. We had to argue the case for full eligibility over and over. We have had to explain the principles of Independent Living over and over. We have been helped by having very clear principles and a united Disabled Persons Movement.

THE FUTURE

Right now we are waiting to find out what further changes the Government proposes

to make to the Bill before its final stage in the House of Commons. We expect the Bill to come into affect next April. That will be the end of stage one of our campaign, to make direct payments legal. Stage two will be to make sure that all local authorities use their power, and bring in Direct Payments in their area.

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The Direct Payments Act 1996 was implemented on 1 April 1997.

John Evans and Frances Hasler.

June 1996