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The Independent Living Movement in the UK

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European Network on Independent Living

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The Independent Living Movement in the UK

Abstract
[Excerpt] The origin of the Independent Living Movement in the UK go back to the late 1970s. Disabled People in the UK, like many other disabled people in other Countries were very disenchanted by the services being provided for them at this time. Disabled people felt the services were paternalistic, institutional, second class, too medically orientated and out of touch with their real needs As a result of this they looked elsewhere for solutions to overcome their restricted predicament and living conditions. This led to a number of disabled people finding out about Independent Living which consequently led them to visit the USA, researching into their Independent Living Movement in terms of how it started, what it did and how it developed. They felt the concepts, ideas and philosophy of Independent Living were very significant and appropriate, and would be helpful and innovative in the UK and point a way forward for disabled people in the future.

During 1980 and 1981 a number of leading and key individual disabled people were able to raise funds so that they could travel to explore looking into the Independent Living possibilities in the USA, particularly in Berkeley California, which is where the first Centre for Independent Living was established. These people included Vic Finkelstein, a radical activist, sociologist and founder of UPIAS, (Union of the Physically Impaired Against Segregation) which was largely responsible for the conception of the social model of disability, Rosalie Wilkins, a TV presenter of a disability programme and disability activist, and John Evans, one of the founders of Project 81, an innovative scheme to help disabled people get out of institutions and at the time living in an institution himself. These 3 were followed by many others in later years. It was not only disabled people from the UK who went to America, looking for answers and inspirations for their situation at this time, as many other European disabled people did so in their quest for Independent Living too.

Keywords
disability, Independent Living, independence, United Kingdom

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The Independent Living Movement in the UK

by John Evans, 2003

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John Evans was one of the founders of Project 81 that marked the beginning of the Independent Living Movement in the UK. Since 1996 he has been the chair of the European Network on Independent Living (ENIL). In this document he gives an overview of the origin of the Independent Living Movement in the UK, it's development and evolution, as well as the current situation.

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Chapter One

1. Origin of Movement

1.1 The Early Days

The origin of the Independent Living Movement in the UK go back to the late 1970s. Disabled People in the UK, like many other disabled people in other Countries were very disenchanted by the services being provided for them at this time. Disabled people felt the services were paternalistic, institutional, second class, too medically orientated and out of touch with their real needs As a result of this they looked elsewhere for solutions to overcome their restricted predicament and living conditions. This led to a number of disabled people finding out about Independent Living which consequently led them to visit the USA, researching into their Independent Living Movement in terms of how it started, what it did and how it developed. They felt the concepts, ideas and philosophy of Independent Living were very significant and appropriate, and would be helpful and innovative in the UK and point a way forward for disabled people in the future.

During 1980 and 1981 a number of leading and key individual disabled people were able to raise funds so that they could travel to explore looking into the Independent Living possibilities in the USA, particularly in Berkeley California, which is where the first Centre for Independent Living was established. These people included Vic Finkelstein, a radical activist, sociologist and founder of UPIAS, (Union of the Physically Impaired Against Segregation) which was largely responsible for the conception of the social model of disability, Rosalie Wilkins, a TV presenter of a disability programme and disability activist, and John Evans, one of the founders of Project 81, an innovative scheme to help disabled people get out of institutions and at the time living in an institution himself. These 3 were followed by many others in later years. It was not only disabled people from the UK who went to America, looking for answers and inspirations for their situation at this time, as many other European disabled people did so in their quest for Independent Living too.

1.2 From Institutions into the Community: Roots of the Movement

Some of these disabled people were also living in institutions trying to find ways in which they could move out into the community. This is where the roots of Independent Living in the UK started, by enabling disabled people to move out of institutions unlike their counterparts in the USA, who started Independent Living while studying in university, because the universities had a programme of personal assistants to support the disabled students. There were also some university based schemes in the UK which encouraged Independent Living through using personal assistants which I will refer to later.

The most notable group of these disabled people planning their way out of institutions at this time were a group known as ‘Project 81’. This was a group of disabled people living in Le Court Residential Cheshire Home at Liss in Hampshire in southern England. They

formed ‘Project 81’ in 1979 and used this title because 1981 was designated the United Nations International Year for Disabled People. They felt that this would be a significant year in helping them promote the cause of Independent Living and would be helpful for them in achieving their aims of moving out of the institution. Why were disabled people living in institutions at this time anyway? This was simply because if they did not have families to support them, or did not want their families to support them, or did not have the money to privately pay for the support they needed, they were left no other alternative but to be incarcerated in an institution as there was no other choice.

After returning from the United States with the ideas and expertise learnt from the USA’s Independent Living Movement, disabled people in the UK were able to apply Independent Living ideas and principles within a British context. This meant that as the political and social policy systems of the Countries were different, disabled people in the UK had to adapt an Independent Living system to fit into the Social Welfare State Model. What is interesting is that even though the political and social structures are different the principles of Independent Living are the same. Disabled people worldwide have a remarkable affinity with each other, especially those within the Independent Living movement.

The pioneers of ‘Project 81’ were Philip Mason, John Evans, Philip Scott, Tad Polkowski and Liz Briggs, based in the Cheshire Home in Hampshire. They then went about applying the principles of Independent Living, i.e. asserting control about the decisions of their lives, empowering themselves, taking more responsibility about what was happening to them and developing their choices. They were then able to successfully negotiate a financial package which enabled them to move out of the institutions and into the community. They struck a deal for their freedom! This was achieved by coming to a social and financial agreement with their appropriate Authorities who were sponsoring them to live in the institutions. In other words their authority provided them with the amount of money, agreed through an assessment, which they could then use to pay for the support they needed through employing their own personal assistants. This enabled this group of people to move out into the community in the early 1980s. This was the start of Independent Living in the UK. It would change the lives of generations of disabled people to come.

This was a huge achievement that took almost 3 years for them to convince their Authorities about the validity of making this possible. At this time there was a lot of paternalism around decisions being made about disabled peoples lives by non disabled people, either in Local Authorities, Charities, or National Government. The process of changing minds and breaking down the existing patterns of social conditioning, organisation and habitual planning for a more forward thinking and alternative approach did not prove to be too easy. The Project 81 group went about it in a painstalkingly methodical but pioneering spirit in order to influence and change the mind-set of the sceptics and the policy makers of that time.

At the same time when the ‘Project 81’ Group were attempting to come to a negotiated settlement to enable them to live independently in the community, they also embarked

upon an intensive exploration of what other disabled people were doing around the UK. They discovered that there were other groups of disabled people with similar aspirations and ideals, around the importance of developing the Independent Living ideas and philosophy, in order to empower and transform the lives of disabled people in the UK.

One of these other groups were based in Derbyshire, who had also been successful in moving out of residential care and establishing a shared living scheme in the community with the support of a Housing Association.. This was called the 'The Grove Road Scheme' based in a mining village called Sutton-in-Ashfield . It was set up in 1976 by a couple called Ken and Maggie Davis. Their living arrangement was a complex of flats, with 3 flats for disabled people downstairs, and 2 flats for non disabled people upstairs. Part of the agreement for living in these flats was that the non disabled people living upstairs would help and assist the disabled people downstairs. There was some payment – but as benefits were small, payments were also small. This was a shared arrangement which enabled disabled people to move out of residential care, but in the end the disabled people realised that it did not always satisfy their needs of living completely independently in the community, so this group then later moved into their own individual homes. Ken and Maggie Davis later became two of the key players in establishing and developing the Derbyshire Centre of Independent Living which went on to become known as the Centre for Integrated Living. They were also key figures and instrumental in developing the national disability movement.

1.3 The First Centres of Independent Living (CIL)s in the UK

As a consequence of the achievement of 'Project 81', this group of people then naturally felt that they wanted to share their experiences and change of life style, with other disabled people seeking similar solutions to their lives. They then got together with a number of other disabled people in the community, some of whom were students, and included Neil Slatter and Simon Brisenden from Southampton. In order to organise, structure and develop this process, they founded the Hampshire Centre for Independent Living in 1984, which was the first of its kind in the UK. This CIL was founded on similar lines to those in the USA incorporating the basic "Independent Living Principles". This meant that the services provided would be available for all disabled people regardless of their impairment, gender, sexual orientation, age, ethnicity and background. Secondly that the organisation should be run and controlled by disabled people. This would ensure that it would have the right emphasis and focus to empower disabled people to manage and develop their own organisation, and have its expertise around Independent Living issues which could easily be passed on to other disabled people through advice, information, peer support, self help, sharing and training.

Two of the main focuses of attention at this time, were ensuring that housing and personal assistance were the two main core services that needed to be provided to help and enable disabled people to live independently. The problem about accessible housing was particularly pertinent, because disabled people needed an accessible housing environment in order to be able to live in the community. Personal assistance was also

important because this was the essential support component the individual needs to be able to live and survive in the community.

The Derbyshire and Hampshire disabled people involved in the development of CILs felt it was important meeting each other as regularly as they could arrange, so that they could keep the ideas and momentum going. This was as well as networking by telephone, correspondence and faxing, as at this point there were no e-mail communications as yet. This collaboration enabled both groups to prosper and develop a cross-fertilization of ideas. This helped them support each other strengthening their will and determination to secure a firm platform for their infrastructural development and to look at creating a national network and movement. Both Derbyshire and Hampshire established their Centre for Independent Living in 1984 and then started encouragi ng others around the country.

It is important here to highlight some of the key differences here between the Hampshire and Derbyshire CILs. As it was in Hampshire where disabled people were first successful in negotiating their way out of residential care to live individually and independently in the community, this element of personal assistance and support became the focus of the HCIL. This was the area in which Hampshire would focus on, developing its expertise over the years, providing advice, information and support around personal assistance and Direct Payments issues. They also produced a Video, a number of articles and publications on the subject, and were the first to provide and publish a regular Newsletter covering the main topics. They also produced the first “Source Book Towards Independent Living in the UK”, which was the ‘blue print’ for Independent Living until superceded by other publications.

In Derbyshire their development was quite different. They based their approach on the 5 basic core services which were developed by the original CIL in Berkeley, in California. These were housing, personal assistance, mobility/transport, access and peer counseling. They also added to these, information and technical equipment including support. These became known as the ‘Derbyshire Seven Basic Needs’ , which became a blue-print in the development of many of the CILs and disabled peoples organisations in the UK. Later in 1989 the Seven Basic Needs were superceded by the ‘Eleven Basic Needs’ adapted by the Hampshire Coalition of Disabled People. These included employment, education and training, income and benefits together with advocacy.

During this time there were also a number of students trying to live Independently whilst they did their studies. Taylor House in Oxford was a good example of this, as it was a communial home where 4 disabled students shared with 4 non disabled students, who in turn for living there provided the support and assistance needed by their fellow disabled colleagues. This model was later used by other universities and projects to help disabled people study in university. There were other examples of universities that provided on site personal assistants to support disabled students. These universities included Essex, Southampton, and a few others.

1.4 Volunteer Schemes and Student Schemes

CIL developments were all based on disabled people using paid personal assistance. Parallel to these schemes were a number of schemes using young volunteers to provide personal assistance. The best known of these was the Community Service Volunteers "One to One" scheme which started in the London Borough of Islington. Although this provided round the clock support, disabled people did not get a choice of who worked with them, they had to accept whichever volunteer was assigned to them. For a number of disabled people, volunteer assistance was a route out of residential care. This scheme was designed and set up by non disabled people. Later, disabled people set up their own volunteer schemes (for example Independent Living Alternatives in London) where users had control over the scheme.

Some disabled people were enabled to attend higher education through the provision of volunteer assistance. In the 1970s a handful of universities built specially adapted accommodation for disabled students, and provided volunteer assistance (e.g. Taylor House at Oxford) or limited paid assistance (e.g. Kulukundis House at Sussex). This gave some students their first experience of living independently, an experience they wanted to continue when they graduated.

Although these other schemes were not originated or controlled by disabled people, they were providing support for independent living. This swelled the numbers of people in the UK who knew they had a choice, and were demanding the right to independent living.

1.5 Initial European and International Networking

What was interesting, as disabled people in the UK were trying to develop Independent Living and CILs, was that they linked up very early in this process with their counterparts in some other European Countries, particularly Sweden and Germany, who were also trying to establish Independent Living. This reverts back to as early as 1982. This was a significant year in that there was the first International Conference on Independent Living in Europe staged in Munich. This was the first time that European and American Independent Living activists were brought together. This proved to be extremely valuable for future networking and the development of Independent Living on both sides of the Atlantic. It was particularly relevant for the European development as much was learnt from the experiences already practiced in many parts of the USA.

What was fruitful about this Conference in Munich, was the way that contacts and networks developed between European Pioneers of Independent Living. This is where Philip Mason and John Evans met up with Adolf Ratzka, a disabled German living in Sweden who had studied in Berkeley. There was a great affinity between activists from UK, Sweden and Germany in particular at this time. Between 1983 and 1985 there was considerable contact between Adolf Ratza in Sweden, who was at that time setting up STIL which was their first Centre of Independent living based in Stockholm, and the instigators of Derbyshire and Hampshire CILs, together with other emerging groups around the UK. This led to Ken Davis from Derby and Neil Slater from Hampshire attending the first Conference on Independent Living in Sweden in 1983. This was reciprocated in the UK with its first Conference on Independent Living and attended by

Adolf Ratzka and Judy Heuman, who was then the Director of the CIL from Berkeley, California. After these two Conferences there was a very close liaison and relationship between the UK and Swedish Independent Living developments, which would form the basis for the beginnings of an European movement.

During these early developmental years a number of other CILs started emerging in different parts of the Country, which helped focus and develop Independent Living based Organisations. These included Southampton, Nottingham, Bristol, Islington, Lambeth and Greenwich in London and Lothian based in Scotland. Most of these developed around the local needs of the local disabled people, and used the social model of disability and Independent Living principles to plan their development.

Chapter Two

2. Development and Evolution of Independent Living in the UK

In terms of the development of Independent Living in the UK, there were two other significant early developments, which led to an increase in the numbers of disabled people running their own form of Independent Living schemes that are worth highlighting. These were the introduction of the Independent Living Fund and the formation of the British Council of Disabled People (BCODP) Independent Living committee.

A technical note on support for disabled people in the UK
Since 1948, two sorts of support have been available – "care" for those in need and welfare benefits for those in poverty. Care is administered locally and benefits are administered nationally. The 1948 law made it illegal for local authorities to offer cash instead of care. Much of the struggle for direct payments in the UK was a struggle to overturn this bit of the law.

2.1 Independent Living Fund

Firstly the introduction of what is known in the UK as the Independent Living Fund (ILF). This is a national fund set up by the Department of Social Security, which is the provision of money specifically for enabling disabled people to live independently. This Fund came about because of a major change in the benefit system in the UK. Between 1984 and 1986 many disabled people who had begun to live independently, were able to do it as a result of using money either from their Local Authority or from the State Benefit called the 'Domestic Care Allowance', or in many other cases, a combination of both. When the Benefits System was changed in 1986 the Government decided to withdraw the Domestic Care Allowance. This outraged disabled people in the UK, as this reduction in benefit threatened to restrict the development of Independent Living Schemes. The disabled peoples movement then organised a campaign to challenge this. This campaign was extremely successful and the Government announced in 1987 that it would bring about the introduction of the new Independent Living Fund which would replace the previous allowance.

When the Independent Living Fund started in 1988 it was slow to get going, but after a while there was a big increase in those subscribing to it. This was partly due to the reason that it also helped some of those disabled people living in areas where the authorities were not prepared to run Independent Living schemes, because they still felt they were illegal. The Independent Living Fund ended up being a great asset, because it provided more flexibility and money for the individual in organising their support. The Independent Living Fund also helped some people who already had an Independent Living scheme, by providing more money as a supplement to their existing arrangements. This allowed them more flexibility and choice in how they operated their schemes.

The Independent Living Fund was a compensation based on the success of the Indirect Payment schemes which were being operated by the Local Governments around the Country. The ILF is a national fund provided by DSS, national Government, and a Direct Payment is provided by Local Government. An individual can receive a combination of both.

The development of Independent Living schemes which now are more commonly known as Direct Payments schemes, was probably one of the most crucial developments in strengthening the infrastructure to mould the schemes into the framework of the social policy systems of the Country.

2.2 BCODP Independent Living Committee and the Direct Payments Campaign

The second significant development was the formation of the BCODP Independent Living Committee. This was a group set up particularly to focus on Independent Living issues. Its primary objective was to change the law in order to make Independent Living schemes more available to all disabled people.

The Direct Payments campaign in the UK was started in 1989 by the BCODP Independent Living Committee as its primary objective. 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 Independent Living activities and developments in the UK and also feed into the European scene through ENIL.

The founding of the European Network on Independent Living, ENIL was one of the most significant events in Europe for the Independent Living Movement.. ENIL was founded in 1989. It started when over 80 disabled people, most of whom were personal assistance users, from 14 different European countries, congregated at the European Parliament in Strasbourg to discuss issues of concern on Independent Living. This ended up being an historic event because the main outcome of this meeting of minds was the establishment of ENIL and hence for the first time there was a co-ordinated approach for Independent Living at a European level.

The Direct Payments campaign in the UK was initiated in order to change the legislation to make it easier for local authorities to establish Direct Payment schemes. The other reason why this campaign was started was because many disabled people in the UK at this time who were running Independent Living schemes, felt that it was very unfair that many other disabled people in other parts of the Country were not having access to these schemes. This was because they lived in areas where the Authorities saw these schemes as being illegal. This was precisely the reason why disabled people felt so strongly about changing the legislation.

2.3 Direct Payments Schemes and the Legislation

The original individual Independent Living schemes were first set up in the UK in the early 1980s in Hampshire. 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 cautious about 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 that the legislation was unclear and open to varying interpretation which is why some LA did not provide IL schemes.

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 throughout the Country. 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 minds and judgement and the schemes were saved and allowed to continue, much to the relief of the disabled people on these schemes.

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 were still authorities who would not go ahead with Independent Living schemes which they regarded 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, suddenly withdrew them. This is why the Direct Payments Campaign was so important in order to 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 to enable the authority to provide cash to the individual instead of services.

2.4 Direct Payments Campaign and Lobbying for Change

The UK Independent Living movement believed that Direct Payment schemes should be as of right, and that is why a change in the legislation at this time was the second most important priority in the issues of disabled people, following the first priority which was the introduction of comprehensive Civil Rights Legislation. In the early 1990s when BCODP Independent Living group embarked on its Direct Payments campaign. The Independent Living committee 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 Simpson, targeting possible key allies of Members of Parliament and politicians who would support and fight our cause. A huge mail shot campaign was embarked upon, and many letters were written to local and national Politicians seeking support. Numerous awareness raising and briefing meetings were arranged and relevant publicity materials drawn up to disseminate publicly in order to make the issues clear. To support the campaign many articles were published in both the mainstream and disability press.

Not long after the campaign started, 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, arduous and prone to many pitfalls and political manoeuvring, especially if the government does 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. They also felt that if these Direct Payments were extended the floodgates would open and the demand would increase dramaticly which never

happened. 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 in order to succeed.

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.

2.5 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 Policy Studies Institute the research would have an impact on politicians and other important policy makers because the Institute was highly regarded for its social research and independence.

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 the 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. We must remember that this piece of research was concluded in 1994, so these figures are now inaccurate because they have increased, although the percentages and differences and still roughly the same.

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. In most cases these organisations are Centres for Independent Living, or Organisations of Direct Payment schemes.

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 British Parliament and among Directors of Social Services who pressed our case.)

2.6 Government's Official Announcement and the Movement's Success

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 this association with Civil Servants was crucial in our deliberations and strategies.

The Government then set up a body called 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 to be part of this group. 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 looked at all the key issues involved and worked on drawing up guidance for the appropriate Civil Servants and Government Ministers. It eventually drew up the Government's consultation document on Direct Payments, which was distributed out for comment. The Direct Payments Act 1996 was finally implemented 1st April 1997. This was a huge achievement for the disability movement who must take credit for this major shift in national policy, bringing about change and empowering legislation.

There were a number of issues in the Direct Payments Act which the disability movement were not very happy with. First we were keen Direct Payments would also be available for older people, but in the original legislation this was not the case. However, as before we fought the campaign and were successful in changing this legislation, and since 2000

older people have access to the Direct Payments. Another success about the Direct Payments Act was its inclusiveness right across the board so people with Learning Difficulties, Mental Health users, people with HIV and Aids, disabled people from ethnic communities and older people are now able to use it. I think including these groups was an important step forward in principle but unfortunately in practice the number of these people using direct payments is still very low.

The Government did not propose to set cash limits for how much can be paid. They proposed that authorities must give people enough to meet their legal obligations, such as paying National Insurance. However, this was 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 Act was originally "permissive" when it started in 1997 but now it is "mandatory" and Local Authorities must now implement Direct Payments legislation in law.

Other aspects 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 campaign was on two levels. We have worked with Parliament, allying ourselves with paid lobby workers from other organisations. We have also 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 the Members of Parliament.

Our biggest victory was 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.

During the campaign we kept our supporters fully informed so that they could contact their Members of Parliament to press our case for change. We wrote 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. This was our strength.

Throughout the whole campaign we responded not just to the Government but to social work and charity professionals who were concerned about Direct Payments. Some of them supported 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 had to explain the principles of Independent Living over and over. We were helped by having very clear principles and a united Disables Persons Movement.

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

The Direct Payments Act is a continuation of the Community Care Act 1990, which preceded it. This Act is very significant because it was the first Act of Law in the UK which seriously addressed the issues of support in the home, assessing the individual's needs and trying as much as possible to meet these needs. For the first time it focused on the individual's needs, and emphasised the importance of enabling disabled people to stay in their own homes. This Act was a major break through in UK Legislation.

2.7 National Centre for Independent Living

The National Centre for Independent Living was started in 1996. It was a project set up by the BCODP Independent Living Committee in order to promote and develop Direct Payments. It is funded by the Department of Health, and it is seen as a flagship for Direct Payments and for promoting good practice. Since it started it has had an enormous impact on the growth of Direct Payments through out the UK. This is because it has advised, informed and assisted many local authorities to implement Direct Payments. It is based in an office in London but it has many Consultants working all over the country, all of whom are disabled people, and most of whom have first hand experience in Direct Payments. In this way they can target areas of the UK, particularly in the North of England, Wales and the South West, who have been slow in the uptake of Direct Payments in order to support them to do so.

The NCIL has its roots firmly based on the principles of Independent Living. This means it is an organisation run and controlled by disabled people, and is inclusive of all impairment groups. It has an equal opportunities policy, which ensures that it inclusive of gender, ethnic group, disability, sexual orientation and age etc.

NCILs role in terms in helping to implement Direct Payments throughout the Country has been immense. It has assisted numerous authorities with Direct Payments Schemes, help set up Direct Payment Support Groups, run and controlled by disabled people through out the country. It has also set up a Direct Payments Co-ordinators network which brings together all the different schemes around the Country twice a year. This provides a forum for constructive discussion and debate and allows for the interchange of good ideas and models of good practice. Over the years, the co-directors Jane Campbell and Frances Hasler have been engaged with numerous discussions, meetings and working groups with Government Officials, in helping the development of documentation on good practice guidelines, policy issues, and legislative matters on Direct Payments and related subjects.

Through its managing group the Independent Living Committee has also been instrumental in networking not only nationally with disabled organisations, but Internationally, and particularly in Europe. It has been involved in a number of EU

projects with other European Countries, and has liaised very closely together with ENIL and its member groups. It has been a web of hyper-activity and networking . It has set itself very high standards, and as a result has developed a high profile which has been highly regarded by the UK Government, particularly the Department of Health, which provides it with most of its funding.

Due to its 'Breaking Barriers' Project, NCIL has been responsible for blaze trailing Direct Payments to other user groups. This project has opened the door to people from black and ethnic minority groups, older people and mental health service users. These groups previously had very little access to Direct Payments support. This project has not only addressed the issues at a grass roots level, but has also involved the users themselves in the development of the project. It has also produced the first kind of documentation on Direct Payments for these groups. As part of the project it has also organised some Conferences for these different groups, which have been extremely successful and oversubscribed, showing that there is a great deal of interest in these new developments.

This is a point worth noting that the UK is probably the only European Country that is now advocating and implementing Direct Payment Schemes to these other user groups other than disabled people with physical and sensory impairments, which is what the usual concentration of most Countries focus on.

NCIL was a logical development, which built on many years experience of disabled people using payment schemes through out the country. It did not come out of the blue, but built on a wealth of expertise which became its focus, and consequently a repository for the further development and promotion of good practice around Direct Payments.

2.8 Funding Independent Living

The funding of individual Independent Living and Direct Payments Scheme is mainly organised from the Department of Health. However, each Local Authority has the duty and responsibility of delivering this. This means that the money will come out of the budget that is allocated for its Social Services. This budget covers all the services provided by other user groups as well, which includes not only disabled people but people with learning difficulties, older people, mental health service users, HIV and people with Aids, and all other voluntary sector support. As well as this there is also the Independent Living Fund mentioned earlier, which is managed by the Department of Social Security.

The funding of Independent Living Organisations and Direct Payments Schemes can come from a number of different sources, Local Authority, National Lottery Community Fund, and different Trusts and Charities, and sometimes Private Organisations. The funding of these organisations has often been precarious and as a result of a recent research project, by the NCIL and the Disability Studies Unit of Leeds University, called 'Creating Our Own Independent Living Futures', highlighted that many of the Centres of Independent Living and disabled peoples organisations were struggling financially, which is not an optimistic sign.

2.9 Seminars and Conferences

During the development of the Independent Living Movement, there have been a series of Conferences, that have occurred which have all played their purpose in enabling the movement look at what it has been doing in order to try to monitor and evaluate its progress, and at the same time looking for different ways forward for its future. The first CIL Conference of its kind held in the UK was in 1987, and this provided the first forum to look at what the different CILs throughout the Country were doing. Its main outcome at that time was to generate more enthusiasm and initiated in order to consolidate the movement to that it could continue to grow in the true spirit of Independent Living. This was a key time too, because exactly at the point when the Benefits System was in flux and the discussions about bringing the Independent Living Fund were originating.

The next important Conference of Independent Living was in 1993, in Hereward College in Coventry and Peterborough. This Conference was organised by Colin Barnes and Paul Lindoe, under the management of the BCODP IL Committee. The twin aims of this Conference were to develop further the principles of Independent Living and to introduce newcomers to the disability rights movement and in particular the operation of Personal Assistance schemes.

The need for this Conference emerged mainly because of successive British Government failures to introduce policy which would enable disabled people to achieve meaningful Independent Living within the community. This meant disabled people were still characterised by a life style of unrelenting poverty, social isolation, enforced and unnecessary independent on support systems provided by family, friends and loved ones. For many it still meant a life style accompanied by the insidious fear of incarceration of residential institution in the event of break down.

The main outcomes of this Conference was more of a concentration and thrust on Equal Opportunities Issues, highlighting the main themes and difficulties for other groups accessing Independent Living, i.e Women, people from black and ethnic minorities, and disabled Gay people and older people.

Chapter Three

3. Where are we now in the UK with Independent Living and Direct Payments

In terms of where the UK has reached in its Independent Living development to date, is multi faceted. From those few early beginnings there are now approximately 5,500 individual disabled people on Direct Payment schemes. There are very few of these who would regret this or would choose to go back to direct services being provided for them by another agency.

There are also about 45 organisations, who would either define or consider themselves as Independent living organisations. As well as these there are many other Coalitions of disabled people who would see themselves as embracing the overall Independent Living

Philosophy as prescribed by the 7 or 11 Basic Needs. There are also over 90 Direct Payment schemes operating in the whole country whose purpose is to implement and develop Direct Payments for users. All of these combine to create a strong infrastructure and network. Some authorities have individuals on Direct Payments, but do not have a Direct Payments scheme for support. In these areas people can often be isolated.

The Government has now quite a definite commitment to Direct Payments, and its Department of Health places a high priority on this and is carefully monitoring how the different Local Authorities are developing and increasing their Direct Payment schemes. What is also interesting is that one finds in the Government Policy and Practice Guidelines, that are issued and circulated to Local Authorities or published as National Documents, much of the language used one could say has its origins in the Independent Living Philosophy and definitions There is much mention on providing Independence, enabling people to live in their own homes until they die, developing choice and control of a persons life style, user involvement and participation in service delivery and planning, to mention a few.

3.1 Successes and Strengths

One of the key successes of the UK Independent Living and its outcome through the provision of Direct Payments, is the fact that it is now available to people with learning difficulties, people from ethnic backgrounds, mental health service users and older people. This is something we should be proud of, and it is a direct result of the focus the Independent Living movement started to push for in the late 1980s early 1990s.

One of the strengths of the Independent Living movement over the years has been its united spirit of the people involved in being able to work cohesively and harmoniously together. Interestingly enough it is surprising that there have been so few conflicts amongst this group, as it is not the case with the wider disability movement and its groups where the struggle for power has often taken precedence over the main core aims and purposes. The other strengths have been the clarity of its aims and objectives, which have been agreed and shared with common purposes in order to deliver its targets and achieve its ultimate aims.

3.2 Difficulties and Weaknesses

Its weaknesses have been lack of funding, conflict between being a campaigning Organisation or a service delivery one. This is a universal problem of the independent living movement particularly in terms of its role and organisational priorities. Many CILs have laboured and debated through the problems involved in this dilemma.

Many of the CILs have been unable to function as effectively as they would want in terms of delivering the variety of services and meeting the demands of the local disability community, because many of these organisations have been under-funded. The lack of sources of funding and the difficulty of obtaining them has become a major stumbling block in terms of how the CILs can develop. We have also encouraged over the years that

the organisations should not restrict their funding supply to just one funding agency, and should attempt that funding comes from a number of different sources. Many organisations have had to cut back staff and services after they have had their funding withdrawn. This has even closed some organisations down.

3.3 Challenges

As a philosophy I believe Independent Living is both inspiring and powerful. I believe that we have to use this powerful practice to help us keep control of our own Independent Living schemes and organisations. As always our strength lies in our unity. If we work together in this we can succeed, but we need to build more infrastructures and support schemes first to succeed, despite the challenges that may come from various authorities.

Let us remind ourselves of some of those threats and challenges:

- Firstly there is the Direct Payments legislation, while on the one hand it has spread Direct Payments into new areas, on the other hand it has made everything more bureaucratic. This means that there is more monitoring, reviewing and more paranoia about accountability about public money.
- The now common trend of cut backs in services due to tight budgets. Unfortunately disabled people always seem to be the first to be hit by this. It often used as an excuse.
- Authorities who are insistent on a service resource led assessment approach, as opposed to a needs led approach, which hinders the development of Direct Payment schemes.
- The use and practice of rigid accountability criteria, which is applied as a controlling mechanism to ration service delivery.
- The dreaded introduction of charging policies in order to try and claw back more money from users to cover the cost of services. This has been one of our biggest challenges now for some time, and we still have a way to go to counteract this.
- The constant reorganisation of local authorities and the way they provide Social Services. We have been inundated with many legislative changes recently with local government reform, modernising Social Services and Best Value, to mention a few. All of these have been disruptive in developing Direct Payments because they have diverted attention, policy and finance .
- The lack of continuity of Care Managers, which has also been worsened recently by the current shortage of Social Workers. This has meant that we have lost key allies in Social Services when they have moved on. It has also meant that the assessment process in many areas has lacked consistency by the high turnover of Social Workers, long waiting times, and the incompetence of others.
- The recent development of the market place economy of Social Services provision of purchasers and providers. This has meant there has been more competition of providers of support services, which has often meant a deterioration in the quality of services. It has also made it more difficult for disabled people to have control when run by other agencies.

- There has also been the development of the “consumerist” view of Direct Payments, as seeing it as “just another service”. This is usually from those, who did not experience the pioneering days and do not identify with the movement. We need to spread the message.
- There is also the apathy of our fellow disabled people. Many do not want to commit themselves or get involved. Are they content? Have we failed to communicate effectively with them. It seems we need to redouble our efforts here.
- There is no requirement to provide advocacy or other support for people who need assistance to manage direct payments.
- Last but not least, because Independent Living and Direct Payments have become fashionable there has been a proliferation of Independent Providers, which has meant disabled peoples organisations have been competing for tenders to run Direct Payments schemes. This has become one of our battle grounds where we have seen many of our organisations lose out on the Contracts.

I do not think this list is exhaustive, but it does show what we are up against in terms of maintaining control over the very service that we created and developed from Independent Living.

The other difficulty there has been over the years is the tension of our understanding of Independent Living and what it means, and that of the service providers, as they do not always meet eye to eye. Our understanding of Independent Living is enabling a holistic and meaningful life of equal opportunity and not just an existence in ones own home, which sometimes can be an isolating experience. A service provider’s understanding is often based on a resource led approach which is more about hands on, getting up and going to bed, and these kinds of tasks which disabled people would some times refer to as the ‘bed and breakfast syndrome’. In other words, basic survival not ‘quality of life’. We firmly believe that Independent Living has to be based on the principles of quality of life issues.

3.4 What Happens now and Where Do We Go in the Future: Maintaining Momentum and Control

In some respects from what I have just written, it appears to be an uphill struggle and there is much against us. What’s new! This has been the history of Independent Living. A history of challenges, negotiations, campaigning, lobbying advocating change and finding solutions. It is never easy trying to be innovative and positive in a system where Independent Living does not always fit smoothly because Independent Living brings into question many of the notions of the status quo and the question of power. Authorities have never found it easy handing power over to disabled people. Our primary task now is to maintain control for the continuation of Independent Living.

However, I really do believe that as the spirit and vision of Independent Living was born out of the minds of disabled people in order to gain equality and a decent life, this is where it must remain. These beliefs and principles in themselves are so strong that they can still provide us with the possibilities and chances to come up with further solutions.

More importantly we know what we have to lose and a life in an institution is not what we want to end up with again. I certainly do not, after spending almost 5 years of my life in one Neither do we want Independent Living and Direct Payment services to return to the professionals. It is now very hard to imagine what life would have been like without Independent Living.

Our strength lies in our unity to be able to work together, lobby together and campaign together to maintain control. We are the experts and we have to keep putting that into practice. Many of us have our roots in Independent Living and we are not going to give it up too easily. Our investment and ownership in Direct Payments have to be constantly strengthened. We can only do this by being vigilant and resourceful in ensuring that we strengthen our organisations, and increase our networking. As well as this we are lucky to have NCIL as our central focus in the UK. NCIL needs to develop further in order to inspire other regional organisation and networks so that they can support their own local disabled people through more Personal Assistance Support Schemes.

We also need to professionalise the Direct Payments Support Workers role by expanding them and keeping them in a peer support/counseling role and accountable to the disability community.

Over these last 20 years we have seen big advances in Independent Living and Direct Payment in this UK through our work. We have to keep on tapping into the spirit of Independent Living and make sure that Independent Living is enshrined as an Equal Right in legislation.

I do believe that it is essential that we get Independent Living as a Right enshrined in Civil Rights Legislation because until we do get this we will always be at the mercy of the legislators and the policy makers. Independent living has to be put into a legislative framework that everybody can understand including the Judges! This is the main message I want to end with. Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living.

Parts available in English from the forthcoming English version of: Alonso, J. Vidal Garcia. 2003. "El Movimiento de Vida Independiente, Experiencias Internacionales." ("The Independent Living Movement: International Experiences.") Internet publication URL: www.independentliving.org/docs6/alonso2003.pdf (In Spanish, PDF, 1.46 MB).

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