

**Disability Activism,
Independent Living and Direct
Payments**

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**Independent Living and Direct Payments:
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Disability Activism, Independent Living and Direct Payments

Anne Pridmore: Chair of the British Council of Disabled People

The Origins of the Independent 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 the restrictions placed on their lives by service providers. 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 the early 80's a number of leading and key individual disabled people from the UK raised money so that they could travel to the USA in order to look into the Independent Living possibilities in the USA, particularly in Berkeley California, which is where the first Centre for Independent Living was established.

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 universities, because they had a programme of personal assistants to support the disabled students. 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. You may ask "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.

The pioneers of this project were all based in a Cheshire Home in Hampshire. They then went about applying the principles of Independent Living learnt in USA which were about asserting control over 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. This was achieved by coming to a financial agreement with their appropriate Authorities who were sponsoring them to live in the institutions. 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.

The 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.

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 people's 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. The Independent Living Fund was a compensation based on the success of the Indirect Payment scheme which were being operated by some local governments.

My own fight for freedom was in the mid 80's – my partner of 20 years left and I was forced into using services. Not only was this a rude awakening but was my “coming out” as a disabled person. Having had no need for services I did not recognize myself as a disabled person. There followed 7 years of hell during which time I had no control over when I got up, when I went to bed, what I ate and more importantly I could have 10 or more different people coming into my home in one week. It was during this period that I was forced into having a hysterectomy because of lack of support for my personal hygiene. My first visit from a home carer was around 9 am and then my late call could be anything between 8.00pm and midnight. I was only assisted to shower once a week and if my bath nurses visit fell on a Bank holiday it was often two or three weeks before I was able to shower. I wrote to the Director of Social Services asking him if I could swap services for cash. I persuaded the Local Authority to let me be the pilot for a third party scheme. At this time Local Authorities were not allowed to pay money directly into an individual's bank account. I managed to get 35 people on what was then called the Independent Living Project whereby monies was “laundered” through a local organisation of disabled people. This took around 2 years because of the Local Authorities continually changing the rules and moving the goal posts. For the first time ever 35 disabled people in Leicestershire gained control and choice over their lives.

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 British Council of Disabled People (BCODP) which is the national, democratic, representative voice of disabled people in the UK. The Direct Payments campaign was initiated in order to change the legislation to make it easier for local authorities to establish Direct Payment schemes. This was because at this time the social security Act only allowed the Local Authority to provide services but would not allow Local Authorities to pay money directly into individual's bank accounts. This is why the Direct Payments Campaign, driven by disabled people, was so important in order to change the legislation and clarify everything in black and white. BCODP felt that the introduction of this Bill would bring disabled people choice and control over their own lives. Because the government was afraid of the cost implications BCODP commissioned 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 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. One of the main concerns of Local Authorities was their fear of "opening up the floodgates". In other words the cost implications. Outcomes proved that very few disabled people either needed or wanted high levels of support. How many of you here today would choose to live with 6 different people? Like other studies, it found that the highest level of user satisfaction existed where users had

advice from an organisation of disabled people. In the white paper Improving the Life Chances of Disabled People it talks about the need to have a CIL in all Local Authorities. It is interesting to point out that as I speak many user led organisation's are going down owing to their funding being cut or even stopped by government. In most cases these organisations are Centres for Independent Living, or Organisations of Direct Payment schemes. 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. 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.

What are direct payments?

The phrase 'direct payments' simply means that someone who has been assessed for 'community care' services is given a budget with which to choose how to buy the services they need to take control of their lives and live independently in the community. To achieve this people may need help with:

- **Personal services** such as getting up, using the toilet, bathing, eating etc,
- **Domestic services** like cleaning, washing, shopping, looking after children and so on.

- **Social services.** Such as visiting friends, going to the cinema, going to the pub, support to raise a family and other leisure activities.

For me personally this has empowered me (with the support of 6 PA's) to travel throughout the UK and Europe pursuing my work as Chair of BCODP and as an ambassador for Direct Payments whilst at the same time have an active social life.

Before the arrival of ILF and DP many disabled people were forced to rely on indirect services such as home helps, district nurses, bath nurses etc. This was far from satisfactory as my own personal history described earlier.

Support Services

It is extremely important that disabled people receiving Direct Payments receive good support. This can be about advertising, recruitment, interviewing skills, managing a budget, employment law etc. It is very important that any support service should be based in a Centre of Independent Living which is managed and run by disabled people. It is also crucial that CIL's are funded properly in order that they can buy in any expertise they might be lacking. This can be extremely critical in relation to employment issues especially as many disabled people have never been employed themselves so to find themselves employers can be very frightening. Disabled people who employ Personal Assistants as employees. To date if you are an unwaged employer you are unable to join a union and have no right to legal aid. The result of this is that if you find yourself facing an employment tribunal you will have no legal support unless you have the personal funds to pay for this.

Where are we now in the UK with IL 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 22,500 individual disabled people on Direct Payment schemes.

At the present time we are finding that many CIL's are competing with the contract culture. This means that where in the past tenders were firmly placed with CIL's they are now being placed with organisations who do not embrace the overall Independent Living Philosophy of what Direct Payments mean to disabled people and in many cases are not run by disabled people. These agencies have the benefit of "capacity" which many organisations' run by disabled people do not have. In the worst case scenairio like my own our support has now gone over to the Local Authority. The disabled peoples movement must campaign to make sure that user led organisations such as CIL's fight to secure their funding for the future benefit of disabled people.

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. However the reality for many disabled people is small care packages resulting in difficulties in recruitment and retention of staff.

The Future

Throughout its history the disabled people's movement has campaigned for the rights of disabled people to have choice and control over their lives. This would in theory support the political goal which sees a society that facilitates and supports an independent lifestyle. In this struggle, user controlled organisations have been accorded a crucial role. This is also the philosophy of the Improving Life Chances White paper which has at its heart the philosophy of Independent Living and Direct Payments. It talks about every Local Authority having a Centre for Independent Living run by disabled people. However the present climate of government departments failing to support service user led organisations, whilst at the same time asking them to input into their consultation documents, bodes ill for disabled people's autonomy. Perhaps there is a need for disabled people's organisations to do some joined up thinking! Unless we are prepared to do this service user led organisations will no longer exist.

Disability Activism, Independent Living and Direct Payments



By Anne Pridmore, Chair
of the British Council of
Disabled People.

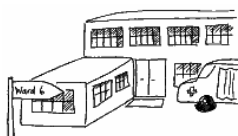
Introduction.

In the UK, the Independent Movement started in the late 1970s. Disabled People were unhappy with the services being provided for them. Many people thought that the services didn't meet their needs and didn't take into account their preferences and ideas about how services could work for them.



People started to look for other ideas about how services could be better. Some people had heard about the **Independent Living Movement** in the **USA**. A few people visited to find out more and liked the values and ideas behind Independent Living. The visit included Berkeley California as this is where the first **Centre for Independent Living** was established.

From Institutions into the Community: Roots of the Movement



Many people in the UK were interested in Independent Living because they were forced to live in institutions, rather than in the community.

The Independent Living Movement in the USA started in a very different way. There, the Universities provided personal assistants to support disabled students and this was their first experience in Independent Living.



Project 81.

One of the first groups of people in the UK to use the ideas of Independent Living to take control over how they lived were known as

Project 81.

They lived at Le Court Residential Cheshire Home at Liss in Hampshire, southern England. Feeling that they wanted more choice and control over their lives, they negotiated the move out into the community in the early 1980s.

This was the start of Independent Living in the UK.

The Development and Evolution 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. These were:



1. The introduction of the Independent Living Fund.



2. The formation of the British Council of Disabled People (BCODP) Independent

Living committee and the Direct Payments Campaign.



1. Independent Living Fund (ILF)

This is a national fund set up by the Department of Social Security. It is money to be used by disabled people so they can live independently.



This Fund came about because of a major change in the benefit system in the UK. In 1986 the Government decided to stop the Domestic Care Allowance. Many people had used this money to gain Independent Living. This change meant other people may not get the chance to create Independent Living Schemes.



The disabled people's 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 instead.

My own fight for freedom

My own fight for freedom was in the mid 80's – my partner of 20 years left and I was forced into using services.

Not only was this a rude awakening but was my “coming out” as a disabled person. Having had no need for services I did not recognize myself as a disabled person.

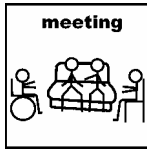
There followed 7 years of hell during which time I had no control over when I got up, when I went to bed, what I ate and more importantly I could have 10 or more different people coming into my home in one week.

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I managed to get 35 people on what was then called the Independent Living Project whereby monies was “laundered” through a local organisation of disabled people. This took around 2 years because of the Local Authorities continually changing the rules and moving the goal posts.

For the first time ever 35 disabled people in Leicestershire gained control and choice over their



2. BCODP Independent Living Committee and the Direct Payments Campaign

The second important development was the formation of the **BCODP Independent Living Committee**. The Committee was set up to think about Independent Living issues.



What is the BCODP?

In 1989 the Committee started the **Direct Payments** campaign and tried to change the law and make it easier for disabled people to use Independent Living Schemes.



Before then, Direct Payments were difficult to get because Local Authorities were not allowed to give disabled people the money to pay for their own services. Getting the money to pay for a service meant that disabled people would have more choice and control over their lives.

Direct Payments research

The Government was worried about how much money Direct Payments would cost. Local Authorities were worried that a lot of people would want Direct Payments were also worried about how much this would cost.

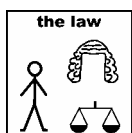
The BCODP asked Policy Studies Institute research unit to do some research and find out:



- how Direct Payments would work and
- how much they would cost.
- Whether they improved people's lives.

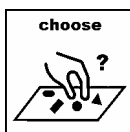
The results

The research found out that very few disabled people either needed or wanted high levels of support. Like other studies, it also found that the highest level of user satisfaction existed where users had advice from an organisation of disabled people. Like from a Centre for Independent Living.



The Direct Payments Act 1996 was finally implemented 1st April 1997.

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The phrase 'direct payments' simply means that someone who has been assessed for 'community care' services is given a budget with which to choose how to buy the services they need to take control of their lives and live independently in the community. To achieve this people may need help with:



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Before the arrival of ILF and DP many disabled people were forced to rely on indirect services such as home helps, district nurses, bath nurses etc. This was far from satisfactory as my own personal history described earlier.

Support Services

Getting good support to use Direct Payments is really important. To use Direct Payments, you have to think about advertising and interviewing people, dealing with money and employment

law.

It is important that any support service should be based in a **Centre of Independent Living**, which is managed and run by disabled people.

CILS also need to get enough money so they can provide good support. Sometimes this means 'buying' in experts to give advice.

Getting and using Direct Payments can be frightening because you have to do and learn new things, like becoming an employer. You have to understand your rights and the rights of the person you employ and this can be complicated.

Where are we now in the UK with IL and Direct Payments?

Many things have happened to develop Independent Living in the UK – some are good, some are bad.



There are now approximately **22,500** individual disabled people on Direct Payment schemes.



CILs are having to compete with other organisations, to provide Direct Payments support. Some of these organisations are not run by disabled people. Sometimes the Local Authority itself now provides the support – this has happened for me.



The disabled peoples movement must campaign to make sure that user led organisations such as CIL's fight to secure their funding for the future benefit of disabled people.



The Government says it is committed to Direct Payments. The Department of Health looks at Local Authorities to see how well they are doing with Direct Payments.



The Government now uses the language of Independent Living. Policies and documents includes phrases like 'providing Independence'....'developing choice and control' 'user involvement and participation'



In reality, Direct Payments for a lot of people means a small care package and difficulties in recruitment and retention of staff.



Future

The Government says that's it supports Independent Living. But what the Government does sometimes damages the Independent Living movement.



The Government says it wants a society that facilitates and supports an independent lifestyle for everyone. The Improving Life Chances White paper talks about every Local Authority having a Centre for Independent Living run by disabled people.



However Government departments are failing to support service user led organisations. The Government also asks service user led organisations to help with consultations which affects their independence.

Perhaps there is a need for disabled people's organisations to do some joined up thinking! Unless we are prepared to do this service user led organisations will no longer exist.

Anne Pridmore Chair, British Council of Disabled People

Images taken from CHANGE Picturebank, Mencap picture library, Through The Maze symbols pack, Department of Health Easy Guide to Direct Payments.