

# **UNDERSTANDING OUR PAST AND CONTROLLING OUR FUTURE**

## **NCIL Forum Presentation**

### **12<sup>th</sup> July 2001**

#### **Introduction**

This paper is about where Independent Living and Direct Payment are today in the current social and political climate of constant change of local government, and the policies relating to the delivery of Social Services. More importantly it is a reminder of where we have come from in the heady days of the 1980s, when visions of Independent Living were beginning to be realised in this country. This paper also covers what we can do to ensure the survival and progress of Independent Living in these difficult times.

#### **Background**

Direct Payment has its roots from Independent Living. There would be no Direct Payments without Independent Living. We, disabled people believe that the purpose of Direct Payments is to enable Independent Living. In other words it is to ensure that disabled people are able to live like everybody else, with the equality of opportunity. We have planned, negotiated, lobbied and campaigned for this. We have done this from the outset, since we originally set up the first Independent Living support packages in the early 1980s in Hampshire.

Independent Living was started with the premise that it was to enable disabled people to have more control and choice over their lives. These are its two fundamental principles, which we have to safeguard in the modern market place where they are under threat.

#### **Self Determination, Citizenship and Rights**

Independent Living also started with the wish for disabled people to achieve self-determination and control over their lives. It was about moving out of institutions and into the community and graduating from university. It was a community-based approach, which endeavored to provide disabled people with equal citizenship. Its motto was to

ensure that despite the impairment of the individual and the restrictions which result from limited mobility and impairment etc., that a disabled person should still have equal access, facilities and opportunities to function equally in the world. Independent Living was all about challenging these restrictions.

Part of the process of an individual achieving self-determination was the introduction of Direct Payment schemes. A Direct Payment scheme is a means to an end, and the end is Independent Living. The Direct Payment scheme buys in the support that one needs in order to achieve this. This is the ideal, as long as the scheme enables the person to do this, and it ensures that Independent Living is the goal. Unfortunately what restricts this and the individuals needs led assessment is the system.

The system sometimes operates in a way forcing compromise upon the individual. It is the way that the service provider can maintain control. Independent Living practice enables disabled people to challenge the system, hence the power struggle. The only difficulty is when the allocation of resources is restricted, it can impede the Direct Payments scheme through not allowing enough funding for the individual for the whole amount of time required in their assessment. This can often have a negative and restrictive effect on the person. This is one of the many challenges we face in the modern climate of Social Services delivery.

## **Solution to Institutions**

We must remember that it was we, disabled people that came up with the solution to institutions by negotiating with our authorities to set up our own Independent Living schemes. Independent Living was born in the UK as an alternative to institutions when a group of us moved out of Le Court Cheshire Home in the early 1980s. As well as enabling disabled people move out of institutions it was also the solution to stop them moving into institutions, because until that time there were no other kinds of community care services in existence to enable disabled people to stay in their own homes.

Despite these tremendous advances as long as Institutions exist, the spectre of a disabled person finally ending up in one is a fear that

haunts most of us through out our lives. Institutional life denies a person, real citizenship and participation in the community. It also takes away ones freedom. For those disabled people who have already experienced institutional living and have tasted that reality and the loss of control over the basic decisions of their life, know too well, that it is a large price to pay, sacrificing ones own contribution and livelihood in the community.

As I speak I shiver at the thought that right now at this moment in time there are thousands of disabled people in institutions in every EU Member State. I dread to think of what the exact number of disabled people are in institutions throughout Europe. It touches me deeply especially as I have personally experienced some years in an institution myself. I was one of the lucky ones who originally pioneered Independently Living as a solution, in order that we could get out and escape from the imprisonment of institutional living.

Let us not forget that living in an institution is a violation of our basic Human Rights. It denies disabled people the right to have control over their lives and the right to make decisions and choices about the basic things that matter in their lives, among many other personal matters that most non disabled people take for granted.

For a disabled person living in an institution, here are just a few of the sacrifices that one makes in terms of losing ones basic Rights:

- Are denied their rights by having to live in institutions
- Do not have the right over decisions that affect their lives
- Are often denied choice and control over their lives
- Do not have the right over who gets them up and puts them to bed
- Do not have the right when they can get up and go to bed
- Do not have the right to chose their own personal assistance
- Do not have the right to basic services
- Do not have the right to decent housing
- Do not have the right as to when and what they can eat
- Do not have control over their own money – as many institutions withhold their pocket money and benefits which they receive from the state
- Do not have the right to leave an institution when they want to because they do not have access to their own or public transport

- Do not have the right to take a holiday when they want or go to cinemas when they want or have access to leisure pursuits when they want
- Do not have the right to have decent relationships like everybody else and are denied their rights to set up their own families and to be able to adopt children
- Do not have the right to have access to jobs and education
- Lose their privacy and often their own sense of dignity

This paints a bleak and gloomy picture, which makes one realise why disabled people are fearful over the spectre of ending up in an institution. This is without even touching on the bad conditions they live under and the potential physical and sexual abuse and victimisation they experience. This again reminds us that such potential threats need to be countered by disabled people and their organisations to remain in control of Independent Living and Direct Payment services.

### **Principles of Independent Living and CILs**

Let me reiterate again the important principles of Independent Living because it is essential that we maintain ownership over these. As I said earlier, the most important thing is having control and choice over one's own life, because when one has this we are involved in all the decisions that affect our lives. This means we have the power and control, it does not rest in the hands of the authorities.

As part of developing this control system, to both protect and develop Independent Living schemes disabled people set up Centres for Independent Living as an infrastructure to support and strengthen Independent Living services.

When Centres for Independent Living were first set up in the USA there were two basic precepts:

Firstly that a CIL should be run and controlled by disabled people. Secondly, that they should serve all disabled people regardless of their impairments, gender, age, culture or backgrounds. There should be no exclusion of any particular impairment or minority group. This now coincides with the inclusive approach which our Independent Living movement has embraced.

The Centres for Independent Living (CILs) then developed some “Strategies for Independent Living”:

1. Those who know best the needs of disabled people and how to meet those needs are disabled people themselves
2. The needs of disabled people can be met most effectively by a comprehensive programme which provide a variety of appropriate support services.
3. Disabled people should be fully integrated into the community with equal citizenship.

This makes sure that Independent Living includes everything, and is not just about enabling people to live in their own homes, with the possible consequence of isolation, but is a collective approach to inclusion.

### **Gaining Control over our Lives**

Gaining control over our lives has been without doubt one of the most powerful factors in empowering disabled people, not only to take control of their own individual lives, but also to be able to do this on a collective basis with other disabled people. It has enabled us to set up our own organisations like CILs and Coalitions, and at the same time develop support structures to support us in the community. This has been in the shape of PASS (Personal Assistance Support Schemes) in order to provide appropriate advice and support to individuals living independently. These kinds of organisations have had similar aims and goals in the emancipation of disabled people.

This is where we have seen a distinct difference in the success of Independent Living and Direct Payment schemes. In places where there are PASS schemes the success rate is much higher than the places without them. We have seen numerous instances where professionally guided Direct Payment schemes have often gone adrift because of the lack of appropriate support and advice and direction.

### **Fighting for our Legislation**

In our attempts to extend the control choices and opportunities for other disabled people to be able to run their own Direct Payment

schemes, we did have a huge success in being instrumental in changing national policy. This was in the bringing about of the Direct Payments Act in which we were highly influential together with the ADSS (Association of Directors of Social Services) and other supportive groups. We worked on this so that we could extend the opportunities of Direct Payments to other disabled people, living in areas that had previously not provided any other Independent Living service. This was very significant because of how rapidly schemes developed in many of these other areas post the Direct Payments Act.

### **Backlashes, Threats and 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 seems a cop-out.
- 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 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.
- 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, 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.
- 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 you what we are up against in terms of maintaining control over the very service that we created and developed from Independent Living.

## **Maintaining Control**

In some respects it is a gloomy picture from what I have just said, there is much against us. However, having said this I really do believe that 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. 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. 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. 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 PASS schemes.

We also need to professionalise the Direct Payments Support Workers role by expanding it and keeping it in a peer counselling 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 country 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 leave you with. Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living.

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