

# **MAKING CHOICES. TAKING CONTROL**

## **A Direct Payments Event for Users/Survivors of the Mental Health System. Woburn House, London. 7<sup>th</sup> February 2002.**

### **Introduction**

Today I want to set the scene for this exciting event and talk about where Independent Living and Direct Payments came from in this country, as its history and philosophy is important for us. I shall finish by highlighting some of the issues which have particular relevance to Users and Survivors of the Mental Health System but this will be covered much more extensively by our main speaker Pauline and Tina who will briefly outline the National Pilot project. Direct Payments for Users/Survivors is an exciting development and I am sure today promises to be an invaluable day for all of us in terms of exploring some of the issues. It is also important for us to ensure that the progress of Independent Living continues in these difficult times.

### **Background**

Direct Payment has its roots from Independent Living. There would be no Direct Payments without Independent Living. We 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 hard for this. It has not come easy. 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. It is a philosophy and movement that has developed over the years based on support and collective self-help. It originally started in Berkeley, California in the 1970s.

## **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, graduating from university and being included in main stream society. 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 that occurred from this, that a disabled person should still have equal access to 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. 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 over the service user. 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 restrict 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 limiting 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 disabled people that came up with the solution to institutions by negotiating with the authorities to set up our own Independent Living schemes. Independent Living was started in the UK as an alternative to institutions when a group of disabled

residents moved out of Le Court Cheshire Home in the early 1980s. As well as enabling disabled people to 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 support 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 throughout 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 about their lives, know only 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 there are thousands of disabled people in institutions throughout the world. 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.

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 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**

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 ones 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.

Other principles of Independent Living, is that it should be run and controlled by disabled people.

Independent Living should also 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.

Other Strategies for Independent Living are:

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 of the country 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.

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.

### **Maintaining Control**

To maintain Direct Payments, we will need to be vigilant in the present social and economic climate of a culture of cut backs, charging, resistance by Care Managers and the different interpretations, policies, and practices of Social Services Departments.

In some respects it is a gloomy picture, there is much against us, however, 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 investment and ownership in Direct Payments have to be constantly strengthened. We can only do this by being resourceful in ensuring that we strengthen our organisations, and increase our networking.

As well as this we are lucky to have organisations like NCIL. NCIL has been working hard in order to involve more, those excluded groups who have had difficulty in accessing Direct Payments. They have been pro active in their work with people with Learning Difficulties, people from black and ethnic communities, and more recently, for users and survivors of the Mental Health System.

Also in many areas there are Direct Payment Support Workers who work in supporting individuals. We need to professionalise the Support Workers role, by expanding it and keeping it in a peer counselling role and accountable to the disability community. In order to develop Direct Payments more for survivors we need Support Workers who are aware and experienced in Mental Health issues.

Before I finish I want to highlight some of the main issues for users and survivors which have been identified by the National Pilot Project so that we can focus on some of these in our discussions today.

## **Main Issues**

- Credibility – fears about service users accountability around money and organisational issues
- Different interpretations of “willing and able”
- Mental Health Act – those sections of the act that bar people from being able to receive Direct Payments
- Hospital admission after receiving Direct Payment
- Individual confidence to take up Direct Payments

- Making sure that users are “good employers” because of their fluctuating mental states
- Personal assistants – what expectations are there of them at times of crises
- Advance directives – training and induction – information provided – communication/relationship building
- Innovative ways of using Direct Payments – in lieu of ‘day care’ – respite – help around the house – support in a crisis
- Money management – banking – record keeping
- Lack of support
- Lack of understanding
- Getting the support of the Consultants
- Local authority charging
- Medication – support and responsibility – keep Health out of it
- Getting the right information about Direct Payments
- Information and support for people from black and ethnic minority communities, and people whose mother tongue is not English.

Over these last 20 years we have seen big advances in Independent Living and Direct Payments in this country through our work.

I do believe that if this is to continue, 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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