

# **“Disabled People in Europe are Demanding the Right to Independent Living”**

**Presentation by John Evans, President of ENIL**

**(European Network of Independent Living)**

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## **Introduction.**

Firstly I want to say how delighted I am to be able to address you here today at your significant Conference. In this presentation I want to share with you a very important development which has transformed and changed disabled peoples lives in many European countries and at same time improved the quality of their lives. This way of life is called Independent Living, and one of the means to achieving this is through something called direct payments. I shall define both of these concepts shortly, because I think it is important that they are clear in your minds.

Disabled people in Europe and around the world are now insisting on inclusion and the right to equal opportunities in all aspects of life. Advantages in the development of organisations of disabled people, delivery of service provision, involvement of disabled people in planning and policy making and changes in legislation are enabling this to slowly happen. The consequences of this are Independent Living in action and disabled people are quite sensibly becoming more involved in all the decisions that affect their lives.

I hope in this presentation that I can reveal to you the essential aspects of the importance of Independent Living in empowering disabled people to becoming true and active citizens in our society.

## **What is Independent Living**

Firstly let me explain what Independent Living is for those of you who might not be familiar with it. Some people might have some ideas as to what this is, and to others it might be an entirely new concept. I think the important thing to say, is that:

Independent Living was started by disabled people in order to overcome social isolation.

It is also a way of moving out of institutions, and a way of being able to participate directly in the community in not only the decisions that affect ones lives, but also in overcoming unemployment and finding meaningful and valued work.

### **Let me Define What Independent Living is.**

“Independent Living is the ability to decide and choose what a person wants, where to live and how, what to do, and how to set about doing it.

These goals and decisions about a persons life and the freedom to participate fully in the community, have been and will continue to be the essence of what Independent Living is.

It is also the taking and establishment of self control and self determination in the total management of a persons everyday life and affairs.

It is about ensuring that all disabled people have the equality of opportunity in the chances and choices of life like everybody else.”

This is a quotation I made in 1989, but is still relevant today.

### **Some Principles of 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 services and involves disabled people in the planning of these services.
3. Disabled people should be fully integrated into the community with equal citizenship.
4. Independent Living applies to all disabled people, regardless of their impairment, gender, ethnicity and age.

## **Independent Living: A Blue Print for Change**

Independent Living has been a catalyst for the Disability Movement in the struggle for our Civil and Human Rights. It has provided us with a framework with which we can both challenge and monitor the structures of society. Independent Living touches upon the nerve fibres of everything we do in our every day lives. This is why it is so important in highlighting our needs and aspirations, and at the same time it significantly provides us with a direction to progress our overall movement

Independent Living has provided us with many answers and solutions to the problems and discrimination we face. It has become our blue print for survival and liberation. Through the philosophy and practice of Independent Living, disabled people have been able to regain more control and power over their lives. We have been able to organise and develop our own organisations, and at the same time operate more control and choice over our life styles by setting up our own Independent Living, Direct Payments or Personal Assistance Schemes. It has helped to politicise many disabled people, and in many cases it has enabled disabled people to find meaningful work.

This is in blatant contrast to our past history where disabled people were incarcerated in workhouses and institutions, with little or no control over their lives and at the mercy and whims of the policy makers and the people who managed the institutions which resulted in the social and economic oppression of disabled people. Discrimination was rife and disabled people were denied individual expression, autonomy and freedom of movement. Many disabled people still live in their homes but are dependent on the goodwill of their families and partners for their support and assistance irrespective of their wishes.

Independent Living and the struggle for our Civil Rights has begun to address these problems in our search and demand for equality and a life free of institutions. Independent Living has provided us with a powerful tool in order to achieve our Civil Rights.

Independent Living has been one of the most liberating aspects in disabled peoples lives.

It has transformed us from being recipients dependent on services which have not always met our needs, to becoming active citizens in the community, and at the same time employers of our own personal assistants and support workers.

There has been a dramatic shift in the balance of power. As well as this, it has improved the quality of life and health, and user satisfaction of many disabled people.

### **What are Direct Payments?**

Direct Payments are the way that disabled people have been able to achieve Independent Living.

Direct Payments is the money, which the disabled person receives from their Local Government or the State so that they can buy in the appropriate assistance and support, which they need.

This means employing their own personal assistants who will provide them with the necessary support they require on a day to day basis, as opposed to getting direct services from their Local Government in which they will have very little control or choice over.

Direct Payments is a means to an end, and the end should ultimately lead to Independent Living.

### **What is Personal Assistance?**

Personal Assistance is all the necessary and required support and assistance a disabled person needs in order to live independently and equally in the community. It is self directed, organised and managed by the disabled person who chooses to employ their own personal assistants to carry out all the necessary tasks, duties and skills needed to support them. Some disabled people also have advocates and others to help them in this process.

I hope these key definitions are now clear to everybody in order that we can fully understand what Independent Living, Direct Payments and Personal Assistance really mean so we can proceed together.

### **How Does A Direct Payment Scheme Work?**

A Direct Payments Scheme works quite simply in that the disabled person receives the money directly from his local Government or Authority, in order to buy in the support the person requires. Obviously the disabled person would initially need to go through what we call in the UK a “Community Care Assessment” which means that the disabled person would need to verify that they require this kind of support and scheme. The money will go into a bank account singularly for the purpose of managing this scheme. This way it can easily be monitored and reviewed by the Local Government. It is usually the procedure that a disabled person would be reviewed annually, and this might be more frequent in the earlier stages of running their own schemes.

One of the important principles of direct payments initiated by disabled people is that of self assessment so that they are well prepared for this process and situation. This is based on the fact that disabled people know what they need and know how they want their support and assistance provided.

### **What Do We Mean By Compensation and Adjustments?**

Disabled people are demanding the right to compensation and to be duly recognized as citizens like everybody else. Independent Living practice provides us with a framework for disabled people to be compensated in terms of being able to live like anybody else. Disabled people have shown that adjustments need to be made within society in order to be truly included in every day life. To achieve this, the barriers that restrict disabled peoples equality of opportunity have to be broken down. This means that the compensation of a direct payment that enables a disabled person to live in their own home and organize their lives, must also incorporate the wider outside world by having accessible transport systems as well as a barrier free designed environment. It is no good enabling a person to live in their own home if they become isolated and

estranged from the rest of society, by not having the freedom of mobility in order to be able to move and travel around like everybody else due to inaccessible transport systems and a hostile environment.

A disabled person can take control of their lives and develop choices in order to manage their own Independent living life style through direct payments, but they still need the support of planners and policy makers in making inclusive adjustments to society at large.

The problem that disabled people have is not so much their own individual impairments but the social construction of society, which disables them from being full and active participants in every day life. It is the barriers of access and mobility which restrict them from being equal players in main stream society. This is basically known as the social model of disability.

### **What is the Place within the Framework of Equalisation of Opportunities?**

Independent Living is one of the central focuses of the principle of equalisation of opportunities. One of the many definitions of Independent Living is to enable disabled people whatever their impairment, to have equal opportunities to life, work and play. It is not only about ensuring that disabled people have equal opportunities in access to leisure, but also to be able have decent education and good access to jobs and family life and their role in it, without the barriers of attitude and structural design.

As well as having equal opportunity to the structural world, it is also a question of all disabled people regardless of their impairment, having the opportunity and chances that are taken for granted by non disabled people. What I mean by this is that the compensations that come from Independent Living and direct payments, should not only be available for physically disabled people but for people with sensory impairments, learning and intellectual disabilities, mental health service users, people with complex dependency needs, older people and young disabled people.

This equalisation of opportunities can also be seen within the framework of the UN Standard Rules. In particular Standard Rule

No.4, which requires the right to support services and all that this entails. UN Standard Rule 5 the right to an accessible environment. UN Standard Rule 6 the right to education. UN Standard Rule 7 the right to work. UN Standard Rule 18 that organisations of disabled people should be encouraged and supported by the State to fulfil an active role in the development of services for disabled people. UN Standard Rule No1 also requires that information is needed at all levels for disabled people and should be provided in all the necessary formats. As we know, information is power so this should not be underestimated. The more a person knows about the system the more they are able to use it for their own means and ends. For those of you who are interested in finding out more about the UN Standard Rules and their application to your local community, there have been two excellent documents produced over the years. Firstly "The Toolbox" which was produced by the Finish National Council on Disability in 1997, and more recently "Agenda 22" produced by the Swedish National Disability Council.

### **What Happens in Other European Countries?**

Independent Living and Direct Payments are now fairly well developed in a number of European Countries. However, there is a distinct difference between the northern and southern European countries in terms of how this has progressed. In particular, in the Scandinavian Countries Independent Living and direct payment and other similar schemes are well established, especially in Sweden, Norway and Denmark. This has a lot to do with the social welfare system of these countries. Let me give you an example, in Norway an organisation which pioneered Independent Living called Uloba was formed in 1992 by five people in Oslo. Now this scheme, which runs as a cooperative, provides direct payments for over 4000 people throughout the whole of Norway. Sweden probably has the longest running and most successful scheme of all and is again a cooperative model. This was started in 1985 by STIL (the Stockholm Independent Living Centre), I do not have the up to date figures on this but they now provide direct payments scheme to people throughout the whole of Sweden, but it must be between 5000 to 6000 people. We must remember that both of these countries have low populations of 6 and 8 million people.

Outside of the Scandinavian countries, the UK has a well developed direct payments scheme which now includes about 6000 people. The difference in the UK is that the direct payments schemes are also available to all disabled people, and not just physically disabled people. The Government is keen to encourage these schemes for people with learning disabilities, mental health service users, people from black and ethnic communities and older people etc. I think this is quite unique throughout Europe targeting such a wide variety of disabled people. As well as the UK, there are schemes in Germany, Austria, Holland, Belgium and Ireland. Recently there have been some introductory schemes in France too.

As far as Southern Europe is concerned, there is a great lack of Independent living schemes. Italy is the most developed and now Spain are trying hard to make things happen, but both Portugal and Greece are still struggling very much, mainly due to the social and economic conditions of the countries. They are trying to make a start, and a number of pilot projects have been set up to support this development. Obviously I have only been referring to EU Member States but now there is a great interest in developing IL in Central and Eastern European countries.

### **Are There Restrictions to Direct Payment Scheme due to different Impairments?**

As I said earlier, in the UK there is a push to include people with many different kinds of impairments, but this is not the case everywhere. However, it does not mean that people with severe disabilities or learning disabilities should be excluded from this process of compensation. What will be required though for people with this impairment and back-ground, will be more support and advocacy to help these people run and manage their own schemes. Many physically disabled people are able to do this, but even among this group some prefer to have people to help them in the running of these schemes. This could involve doing the accounting, record keeping and general or financial management etc.

What we have to bear in mind about this is that people who run their own direct payment scheme are employers, and have all the responsibilities which go along with this. This means they have to



comply with all the relevant employment legislation required to run these schemes. It can be like running a small business.

### **Is Legislation Necessary?**

I think appropriate Independent Living or direct payments legislation is essential in order help develop the practice of Independent Living. It provides a legal base which can avoid inequality in terms of some disabled people being able to have it and others being left out and in the long term it can protect IL . This was certainly the case in the UK before we got the Direct Payments Act in 1996. Previous to this some areas were running schemes, and others were not, because they interpreted the schemes as being illegal. Other countries now have such legislation like Sweden, Norway the UK and some regions in Italy. Legislation also helps change public attitude. A good example of this is the sex discrimination act. It is also a good way of getting the support of policy makers otherwise change is impossible. Another way is by using the argument of – what would you like if it happened to you?

### **Have Direct Payments been Successful?**

I think in the countries where direct payments have been widely developed, there is no question that they have been hugely successful. This is not just in terms of the sheer numbers of disabled people running these schemes, but also the amount of research that has proved the huge user satisfaction attained by disabled people living independently.

As well as the user satisfaction, disabled people have improved the quality of their lives, gained more control and choice, acquired more flexibility in their life style, become healthier, created better life styles, more personal self-fulfilment, enabled them to find jobs and decent education and improved their social interaction and social relationships just to mention a few. In the end only society can gain and prosper through integrated housing, transport, education and employment. There are also less ‘special’ solutions which are more expensive and less flexible.

In my own personal experience it has transformed my life from somebody being dependent on services and benefits to somebody who has become an employer and set up my own disability consultancy business. Without my Direct Payments Scheme and the personal assistants to help to support me over the years, this would not have been possible.

## **The Vision and Future 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.

Over these last 20 years we have seen big advances in Independent Living and Direct Payment in Europe through our work. We are confident Independent Living is here to stay – helping people do what they want in life works. It is a robust model founded on satisfying human nature. 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.

This is why I do what I do, because I want to share the opportunities of Independent Living with disabled people and other supporters. We should celebrate our achievements because the freedom that Independent Living brings is a direct result of the cooperative networking, creativity and determination of disabled people aspiring together for our equal rights.

The message I want to leave you with today is a warning. If there is to be a real future for Independent Living in Europe and a life for disabled people free from institutions, then policy makers and politicians seriously need to support, plan and finance this inclusion in our communities throughout the whole of Europe.

**John Evans OBE,  
March 2003.**