

**Independent Living and Direct Payments in
Europe
Rethink Disability Annual Conference, Ipswich
7th November 2003**

Introduction

Firstly I would like to say that I am delighted to be able to address you today on the subject of Independent Living in Europe, which I think is of extreme importance for disabled people. In my presentation I want to also cover Direct Payments which provides a means of achieving this aim. Independent Living has transformed and improved the lives of disabled people everywhere. I want to say a little about ENIL (European Network on Independent Living) and the situation generally in Europe to give you a flavour of the different approaches in different countries.

I feel that we have reached a very critical point in the development of Direct Payments and now is the right time, not only to extend the schemes on a national basis, but also acquiring more recognition at an European level. We certainly have the commitment of the UK Government in extending Direct Payments, but this is not the case in many other European Countries. It is also important for us within the Independent Movement to ensure that the principles and ethos of Independent Living are preserved. European disabled people can benefit and have their lives enhanced by Direct Payments.

As the representative organisation ENIL has a significant role and responsibility in bringing this about. In our work we are monitoring and networking the introduction and development of Independent Living schemes in different countries. The uniqueness of ENIL in all this is that we have member organisations in each country who are at the cutting edge of these developments. These organisations are proactive in developing Independent Living and Direct Payments schemes and have been doing so for some time and are constantly evaluating their situations. They are lobbying

and campaigning, attempting to bring innovative changes about that empower disabled people. This is our work in which we are committed in achieving good practice. It is our prerogative to get the best results. Disabled people have set themselves high standards in order to get value for money and good quality schemes. There is no better example of best value in action than through a Direct Payments scheme. These schemes are about changing peoples lives and the social infrastructure of service delivery. We have done this in a partnership approach with our different authorities.

What is Independent Living?

Firstly, let me describe what Independent Living actually is, because this is where direct payments came from and is important for our overall understanding in order to put things into perspective and in the right context. I am sure many of you are familiar with this term but there are a number of definitions and I think it is important to establish the original one which has developed through the Independent Living Movement. In simplistic terms, it is doing what you want, where you want, how you want, when you want in the way you want to go about doing it. In other words a very liberating statement.

Here is a definition I came up with some years ago: "Independent Living is the ability to decide and to choose what a person wants, where to live and how, what to do, and how to set about doing it. These goals or decisions about a person's life and the freedom to participate fully in the community have been and will continue to be the essence of Independent Living. It is also the taking and establishment of self-control and self-determination and the total management of a person's every day life and affairs."

I think this is clear. The main confusion with Independent Living is that people often assume that there is some sort of physical independence involved, i.e. one is independent through the tasks one performs. It is more about the control and choice one achieves in life, and the decisions that affect one's lives. There is no doubt that the philosophy and practice of Independent Living has had an enormous effect on disabled people's lives.

Independent Living undoubtedly has had more impact on the lives of disabled people over the last 20 years than anything else. It has stretched boundaries, broken down stereotypes, pioneered alternative sources of provision, empowered disabled people, redirected services, established control and direction for users, provided choice and transformed disabled people's self worth, health, and provided satisfaction and opportunities.

What is Personal Assistance?

I think it is also important here to explain a little about what Personal Assistance is, because that is what Direct Payments are all about. Personal Assistance is an integral part of what Independent Living is. In other words, for those who are not familiar with this, Personal Assistance is one of the means which enables disabled people to achieve Independent Living. Personal Assistance is the support and assistance that an individual needs in order to live equally in the world, hence overcoming the restrictions that one experiences through one's impairment.

What usually happens is that the individual disabled person receives a grant from the local authority, this is the Direct Payment. This can also be increased by the Independent Living fund and through this the person buys in the necessary support needed. The individual employs different personal assistants to carry out all the tasks and duties necessary to achieve this. The whole emphasis is around self-direction and management. There are some very important support structures which have been set up by disabled people's organisations to help guide and support people setting up their direct payments schemes. The National Centre for Independent Living (NCIL) based in London is one of the best models of this kind of service. It is funded by the DOH, but also generates some of its own funding through consultancy work.

Over the last 20 years from a small handful of disabled people operating their Independent Living schemes there is now widespread practice of people running these schemes throughout the UK and Europe. Recent figures from the DOH show how widespread they are. So we can see how well developed the infrastructure is and as a result of the new Direct Payments Act the legislation is already having quite an effect. This legislation was brought about because previously there was a question mark over

the legality of such schemes because under the 1948 National Assistance Act it said, "that a local authority only provides services for individuals and not cash payments." Disabled people in the UK were not happy about this so we set up the successful campaign to bring about direct payments legislation.

European Network on Independent Living (ENIL)

Now I want to say something about ENIL, the European Network on Independent Living. The founding of ENIL was one of the most significant events in Europe for the ILM. 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 a co-ordinated approach for Independent Living at a European level.

Despite the slow start by ENIL and the constant lack of decent funding to support the organisation, ENIL has continued to play an extremely important role as an exchange network for ideas and at the same time has organised a series of seminars and meetings. It has meant that at regular occasions over the last years it has been able to bring many European disabled activists in the Independent Living field together debating the relevant issues and helping to promote and encourage Independent Living initiatives in other European countries as well as strengthening their own schemes and structures. In particular it has recently had an influence in helping some of the Central and Eastern European nations to look at setting up Independent Living in their countries.

In the last few years ENIL has begun to play an important role in disability politics at a European level. It is now being taken seriously by the European Union as a major player in the development of overall disability policy. As well as organising seminars and workshops it also produces important publications and resources on Independent Living issues. We also have an active web-site, providing various information, reports and other resources.

We were recently in Strasbourg again lobbying at the European Parliament for a European wide policy on Personal Assistance.

Independent Living Developments in Europe

Lets look at the overall situation of Independent Living in Europe in terms of how Independent Living developed. After the inspiration which European disabled people gained from the initial developments in the USA, and in particular Berkeley, California, in the late 1970s/early 80s small beginnings were made in Europe. From these early beginnings in the early 1980s we now see an extensive and varied picture of Independent Living with its different models and initiatives throughout Europe.

The first countries to develop Independent Living and Centres for Independent Living in Europe were the UK, Sweden and Finland. This was then quickly followed by Germany, Norway, Denmark and Austria, and later the Independent Living movement became established in Ireland, the Netherlands, Italy and Belgium and now also in France, Spain and Portugal. The only two member states of the EU that as yet have to develop Independent Living schemes are Luxembourg and Greece. However there is a pilot project for older people in Greece now.

Obviously there are great variations in the level of developments in these countries and in some there is very little alignment with the overall affiliation and activity with the European Independent Living movement through ENIL. Recently we have also seen interesting, exciting and significant developments in some of the Central and Eastern European countries, e.g. Hungary, Slovenia, Bulgaria, Slovakia and the Czech Republic, and attempts are now being made in a number of others.

The reason why I have tried to briefly outline Independent Living developments in these countries is to demonstrate how widespread Independent Living is throughout Europe, albeit only on a small scale in a number of countries.

Independent Living is probably the most important development for disabled people in that it has had a great influence on individual lives and it has also had a considerable impact on social policy-making in general in Europe. Independent Living has shown how

fulfilling and satisfying lifestyles can be attained through its practice. Not only is the quality of life improved in one's home and social life as a result of directly controlling one's own personal assistance service but it has also had a great bearing in enabling people to work through having the support and assistance in doing this. However there are often problems with disabled people receiving personal assistance at work in terms of having to overcome bureaucratic obstacles.

The uniqueness of personal assistance lies in the fact that disabled people can choose who they want working for them, how they go about organising it and at the times when that they need it. The person is in control and management of the whole process. This also enables one to create opportunities and chances and as a result makes common sense and leads to a healthier lifestyle.

Comparisons 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, Finland and Denmark. This has a lot to do with the social welfare system of these countries.

Norway

Let me give you an example, in Norway an organisation which pioneered Independent Living called Uloba was formed in 1991 by five people in Oslo. Now this scheme, which runs as a cooperative, provides direct payments for over 2000 people throughout the whole of Norway. ULOBA is now a large organisation employing 30 staff and covers a the whole of Norway. It is seen as a large organisation making a lot of money but it is still providing Personal Assistance effectively. Norway has experienced tensions with the unions like Sweden and this is still to be resolved.

Individuals still have to fight with their local authorities to get the Personal Assistance they want during the assessment process. Local authorities do not provide training to the users and ULOBA is

not always able to fill this gap either, so it is a problem. Norway is currently going through the process to establish anti-discrimination legislation.

Sweden

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 about 3500 people. We must remember that both of these countries have low populations of 6 and 8 million people. Having said this, there is much complacency amongst its disabled people who no longer feel the need to fight for their rights. As a fellow Swedish disabled activist said, they have grown too fat on the riches provided for them. As a result there is not a big momentum to push things forward. Sweden has also found it difficult to involve younger disabled people.

The original organisation STIL now makes a lot of money from the services it provides, but unfortunately it has lost much of its original pioneering spirit.

They have a law on Personal Assistance and have developed an anti-discrimination law which is not very strong. Disabled people were not very involved in drawing up the legislation. As in other Scandinavian countries the money for Direct Payments schemes has been provided from the social welfare system helped by the high taxation of the country.

UK

Outside of the Scandinavian countries, the UK has a well developed direct payments scheme which now includes about 7500 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.

Ireland

The spirit of Independent Living in Ireland is very strong but over the years they have had very little funding to develop a strong infrastructure. Despite this they have developed their own infrastructure creatively and innovatively. They now have throughout the whole of Ireland 20 CILs with an extraordinary amount of variety and enthusiasm. They are almost like the heartbeat of the European movement. Dublin CIL remains the central focus but there is a tremendous amount of decentralised diversity.

In Ireland the Independent Living movement has struggled in establishing strong disability legislation over a succession of different governments. They do not have any Direct Payments legislation or Direct Payments schemes as such but have some pilot projects trying to bring this about. Even without these schemes the Irish Independent Living activists have been very resourceful over the years in developing Personal Assistance schemes. Much of this was originally on a voluntary basis but now they have developed an ingenious scheme over the last 4 or 5 years by bringing young Bosnian people over to work as personal assistants.

The ENIL office operates from Dublin and we get a tremendous amount of support from them. They were very instrumental in organizing the Strasbourg Freedom Drive and making it such a success.

Germany

The German Independent Living movement receive their money for Independent Living through their social insurance system. The amounts of money available are limited, but German disabled people have developed a number of Independent Living schemes throughout Germany. They have also used the civil service system as a way of providing Personal Assistants when young people decide to do community work instead of joining the army.

Germany also has around 20 centres for Independent Living spread throughout the country. They are all united under an umbrella organisation called ISL.

Germany is hoping to get an anti-discrimination law in place next year but it has not been easy. The official Ombudsman is also very keen on the German disability movement and wants to assist on legal issues. Disabled people are still struggling in getting Personal Assistance schemes stronger.

Southern and Central/Eastern Europe

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.

Italy

Italy has been an active member of ENIL since the beginning. There is a big interest in Independent Living by the Italian activists. They are very political, keen and do much lobbying with their politicians. Direct Payment schemes though are not well developed and are only in some areas. This is because the regional governments have the responsibility of developing regional services. So you find Independent Living developed particularly in Florence, Turin, Venice, Sicily and a few other areas. There is a Personal Assistance regional law in Tuscany. The Italian disabled people do struggle to get these schemes going. The unions in Italy are very strong and this does not always help. I was once told after I made a presentation at a conference in Italy that Direct Payments were not possible because they only have collective contracts and not private individual ones.

Much of the Personal Assistance in Italy is provided by friends and family on a voluntary level. Independent Living is seen as a basic right and not a human right.

Spain

In Spain the Independent Living movement has only recently started during the last few years. However, it is strong in spirit and

have a number of key figures and groups spread throughout most of the major cities in Spain. They have few Direct Payment schemes but are fighting desperately hard to develop this more. Disabled people in Spain cover their Independent Living through a combination of benefits and their own income. The traditional charities and disability organisations in Spain are really powerful and this has made it difficult for Independent Living to develop. Personal Assistance schemes are little understood and support is still provided by the traditional model of the family.

Despite this Spain has been at the forefront of two major developments in Independent Living this year. Spain received a considerable amount of money for the European Year For Disabled People and the Spanish Independent Living Forum were able to use this in partnership with others to stage the biggest ever Independent Living Conference that has been held in Europe. This was in Tenerife in spring and was hugely attended and very successful. This demonstrated that there is a lot of interest for Independent Living in Spain. Its major outcome was the Tenerife Declaration which was wide ranging in its demands and already has had quite an impact throughout Europe. Copies are available. The other significant outcome from Spain this year was the publication of the first major book on Independent Living in Europe. Its content covers the origin and development in Independent Living in the USA, South America, Canada, Africa, Sweden, Spain and the UK.

Challenges

It is shown that Direct Payments legislation has helped the process of encouraging countries to proceed in extending schemes. However, there have been some instances when legislation has provided some restrictions for disabled people which we need to be aware of. Independent Living is a very definite philosophy of empowerment for disabled people that does not always live well with prescriptive legislation. This presents the disabled peoples' movement with a dilemma. Such legislation creates tension between the needs lead approach and the service lead approach. It is because the basis of Independent Living philosophy is based on the self-assessment of the disabled person's needs because the disabled person is the expert. The tension exists because local authorities often use a service lead approach which often involves resource levels and this is used as

an excuse not to introduce schemes, or when schemes are introduced, to restrict the level of assessed need which they will support. This is the big challenge for the disability movement in finding a solution to this kind of dilemma.

Other difficulties that can arise from legislation are eligibility criteria, accountability, means testing and charging, lack of continuity of knowledgeable care managers, insufficient or inadequate training for social services professionals, and bad organisation of reviewing and monitoring procedures etc. In some areas disabled people have felt that the introduction of legislation has created more problems and confusion than before. Different local authorities often come up with different interpretation of legislation.

What is needed for the future is a civil rights based approach. The right to direct payments should be firmly enshrined in civil rights legislation. Independent Living covers all aspects of life and should not be restricted to a social services department or approach. It has clearly shown how it has improved the lives of disabled people worldwide. Its future developments need to be pursued with vigour.

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November 2003