

Independent Living and its Development in the USA and Europe

Lograno, 25 May 2002

John Evans OBE, President of the European Network of Independent Living

Introduction

I am really pleased to be with you today and to be able to talk to you about the origins and development of Independent Living and Centres for Independent Living (CILs) in the USA and Europe. I think Independent Living is one of the most exciting developments in the lives of disabled people recently. It has helped transform our lives. Firstly, however I would like to define some key words and concepts about Independent Living. They are:

What is Independent Living?

What is a Centre for Independent Living?

What does Personal Assistance really mean?

What are Direct Payments?

These are key terms, which have been created by the Independent Living Movement and it is important to see them in that context. I say this because it is disabled people who came up with the idea, practice, philosophy, definitions and development of IL. I would also like to look at the importance of Direct Payments in giving disabled people the buying and consumer power in order to take control of their lives. In other words our road to freedom. This is a development that has happened in some European countries.

Independent Living

It has been said that there are as many definitions of IL as there are people living independently and to a certain extent this is true. So here is one.

“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 person's 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.”

Centres for Independent Living

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.

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 services.
3. Disabled people should be fully integrated into the community with equal citizenship.

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 to help them in this process.

Direct Payments

Direct Payments is the money, which the disabled person receives from their Local Authority 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, as opposed to getting direct services from their Local Authority in which they will have very little control or choice. Direct Payments is a means to an end, and the end should ultimately lead to Independent Living.

I hope these key definitions are now clear to everybody in order that we can fully understand what Independent Living really means.

The Alternative

Disabled people over the years have been very inventive in finding solutions to the problems that they encounter. In the early 1970s in the USA when disabled people started Independent Living, they did so by ensuring that the personal assistance that they had in the university could also assist and support them in the community. In the early 1980s in the UK, disabled people came up with a blue print of how to move out of institutions into the community. They did this by cleverly negotiating with their sponsoring authorities, a deal which ensured their freedom and liberation from institutions. They negotiated to receive some of the money that their authority was using to keep them in the institution, so that they could use it to make their own arrangement to live in the community. This was the start of what is now known as Direct Payments. It provided them with direct access into the community. It was the ultimate escape and alternative to institutions, which has now become the norm for many disabled people.

It became such a successful transition into the community - living like every one else in ordinary houses in ordinary streets that the idea and practice spread quickly.

In order to maintain their survival in the community, and also to help avoid other disabled people from going back into institutions they decided to pool their expertise that they had developed into a safeguard for the future. This expertise was channeled into establishing Centres for Independent Living. Disabled people had successfully integrated themselves into the community through Direct Payments but felt strongly that Independent Living was not only about the individual empowerment and personal liberation but was also about the collective emancipation of disabled people, as an oppressed minority group.

Centres for Independent Living

The Centres for Independent Living provided an infrastructure to develop an inclusive approach that would enable disabled people to maintain their survival and participation in the community. This was achieved by providing some basic core services that supported disabled peoples maintenance in the community. The services met the local needs of disabled people at a grassroots local level. These basic core services provided a holistic approach. This ensured that disabled people leaving institutions would not then set up their own institutions in their own homes and back-yards by living in isolation, because of the lack of access to local facilities and services, and the inability to move about because of the lack of accessible transport.

Five Basic Core Services or Principles

When the Independent Living movement was first established in the USA, it had two fundamental premises from which it operated, and these were control and choice. It was disabled people for the first time running and controlling their own organisations and providing the information, advice and services they wanted and not that provided by traditional organisations, charity based being run by non disabled people. The original CIL which started in Berkley California, established what has become the corner stone of disabled people's philosophy by setting up what is known as the five basic core services:

Housing
Personal Assistance
Transport and mobility
Access
Peer Counselling and peer support

Housing

The first of these core service being housing which makes sense, because when you start out like everybody else you need a home or some form of shelter to exist from.

Personal Assistance

The second was personal assistance because if disabled people are going to live independently in their own houses in the community they need the appropriate support to be able to do this.

Transport

Thirdly, accessible transport. Disabled people do not just want to live independently in their own homes and be isolated, but they also want to move around, participate and do things, visit friends, have jobs etc.

Access

Fourthly, that of access. They want to be able to move around in the community freely with places to go, places to study, and have jobs. In other words, an accessible environment in which they have freedom of movement and access.

Peer Counselling and Support

Fifth and finally, the important core service of peer counselling. The purpose of this service is to support disabled people at all levels, be it emotional or through providing appropriate advice and information, or

whatever.

Some CILs have added other core services and needs to the original. These are: information; employment; education; technical assistance; benefits and income and advocacy.

After the initial start in Berkeley, within ten years the IL movement in the USA flourished to the extent that over 200 CILs were established. It was a major development that had enormous impact on the lives of disabled people throughout the USA. I think another factor, which helped the strong development of IL in the USA, was that when it started in the 70s it was at the time, when there was considerable social change. There was an emergence of a number of other social movements, e.g. peace movement, womens' movement, the gay movement, and the environmental green movement. Coming after these other significant social movements gave it a tremendous impetus, and the attitudinal climate at this time was also right and receptive.

As you can see since the beginnings of Independent Living this Movement has now flourished through out America, Europe and the World. Now in many European Countries we have active and flourishing CILs that are providing invaluable services, which are not only an alternative to disabled people living in institutions but are ways of enabling people direct access into their communities and employment. These services and facilities, which they provide, enable disabled people to overcome social exclusion. This inclusive approach has been operating much longer than the recent policies of many of our Governments and the European Union about social exclusion. Disabled people came up with this idea a long time ago in order to protect its people from isolation, and at the same time providing a meaningful system of support and self-help.

European Network on Independent Living (ENIL)

As well as the encouraging IL developments throughout many European countries, one of the most significant events in Europe has been the formation of the European Network on Independent Living

(ENIL) which 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.

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. At the same time it has organised a series of seminars and meetings in various European locations which has enabled it to have considerable impact. It has meant that at regular occasions over the last 12 years it has been able to bring many European disabled activists in the IL field together debating the relevant issues and helping to promote and encourage IL 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 newer Central and Eastern European nations to look at setting up IL in their countries.

It has begun to play an important role in disability politics at a European level. It received some funding from the European Commission and is now being taken very seriously by the European Union as a major player in the development of overall disability policy in the new mood of the European Union as a European NGO. As a result of this funding, as well as organising seminars and workshops it now will hopefully produce important publications and resources on IL issues. It has also begun to use the Internet by creating its home pages and placing its various information, reports and other resources on the world wide web.

Independent Living Developments in Europe

I would like to briefly end up by summarising the situation of Independent Living in Europe. 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, Denmark and Austria, and later the Independent Living movement became established in Ireland, the Netherlands, Norway, Italy and Belgium and now also in France, Spain and Portugal. The only three member states of the EU that as yet have to develop Independent Living schemes are Luxembourg and Greece.

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. In the case of Denmark, there are a number of personal assistance schemes in different cities, particularly in Arhus, but the Danish disabled people have nothing to do with the overall involvement in developing Independent Living through ENIL or the European Community. Recently we have also seen interesting and exciting but small and significant developments in some of the central and Eastern European countries, e.g. Hungary, 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 and 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.

Today we can see Independent Living thriving throughout Europe in different ways, particularly in the UK, Sweden, Finland and Germany - where it first started - but also in Austria, Holland, Ireland and Italy. I say this with some reservations because the Independent Living movement and philosophy is thriving but in a number of these countries there are still restrictions due to inadequate funding of direct payment schemes and Independent Living initiatives.

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 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.

The Independent Living Movement over the years has gone from strength to strength and will continue to do so in order to eradicate social exclusion, institutional living and poverty.

John Evans OBE
ENIL
May 2002