

Independent Living and Centres for Independent Living as an Alternative to Institutions

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Introduction

I have been asked to talk about Independent Living and Centres for Independent Living (CILs) as being an alternative to living in an Institution. Firstly, however I would like to define some key words and concepts which are important in my presentation so as to avoid any later misunderstanding e.g. These keywords 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. Then I would finally like to look at the role Centres for Independent Living can play as well as their historical perspective and also 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 their road to freedom.

Independent Living

“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.

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 Spectre that haunts Disabled People

As long as Institutions exist, the spectre of a disabled person finally ending up in one is a fear that haunts most disabled people throughout their lives. Institutional life denies a person, real citizenship and participation in the community. It also takes away one's 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 one's 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 in the UK as a solution, in order that we could get out and escape from the imprisonment of institutional living.

For a disabled person living in an institution these are just a few of the sacrifices that one makes in terms of losing one's 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 choose 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.

To add to these we have other structural and attitudinal barriers

- As they exist they must be filled and funded – this then deters innovation about service provision and the transfer of resources to alternatives
- Buildings tie up resources, as they must be staffed and maintained which means resources are not flexible
- Bricks and mortars do not empty bed pans, assistance is provided by people

- The edifice complex. In other words, they are seen so it looks like society is acting and doing something good for disabled people but in truth it is not what disabled people want.
- As there is vested interest in the institutions it means there is a resistance to change because of the bureaucratic professionalism.
- They are seen as being economical but this is debatable and still has to be proved.
- It makes residents dependent on a routine and system that leads to apathy, dependency and often ill health

The Alternative Way Out

Disabled people over the years have been very inventive in finding solutions to the problems that they encounter. In the early 1980s disabled people came up with a blue print of how to move out 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 IL movement was established, 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.

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.

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