

**How Disabled People are Excluded from
Independent Living.
Presentation for Madrid Conference
On European Disabled People.
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Introduction

I would first like to say how delighted I am to address you today at this significant conference on what I regard as one of the most important subjects for disabled people, which is Independent Living.

Firstly I would like to define what Independent Living is and why it is such a dynamic and important philosophy and practice in the lives of disabled people. However, what I will say regrettably is that the implementation of Independent Living practice is not carried out very comprehensively and effectively in many European Countries. When it is, very often this is only on a limited scale.

In my presentation I shall explore some of the issues of why I think this is the case.

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

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 Assistants Schemes. It has helped to politicise many disabled people.

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. 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 of many disabled people.

Direct Payments

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, 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.

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

Quality of Life

Independent Living practice through the use of Direct Payments, have without doubt enhanced disabled peoples quality of life, as well as improving their general health and wellbeing. A number of pieces of research work has shown this to be the case. In particular the work of (G.Zarb, 'Cashing in on Independence'). This work demonstrates very adequately the Users satisfaction in Direct Payments. These are some of the key areas that have positively changed the lives of disabled people.

Why is it then that Disabled People are still Excluded from Independent Living?

The answer to this is social, economic and political. This is because of the lack of implementing good social policy practice. This is ironic especially when we live in a time when the directives from the European Union and National Governments are towards social inclusion. This is meant to include disabled people in all aspects of life, social, political and economic, yet what happens sometimes is the opposite.

Disabled people find themselves victims of a system that disenfranchises them and keeps them at the poverty level, dependent on benefits, lacking opportunities in employment and training, and further isolated in their own communities because of inaccessible public transport systems.

From a social perspective much of it stems from bad social policy planning, but the root cause is through fear, ignorance and a poor attitude to including disabled people in the main stream of life. There is a lack of commitment, both by national and local Governments to address this problem.

This is clearly indicated in many instances where disabled people and their representatives and organisations are excluded from any real involvement in planning teams in developing appropriate services.

Many countries still have a problem fully understanding what real consultation and user participation is all about.

They neglect it at their peril, but unfortunately it is disabled people who are the real victims in the end by not getting the services they require. There should be a continuation from beginning to end in the planning and delivery of proper, appropriate services. This should work from the top down, from national government policy and legislative level to the regional and local government levels. In this process there should be forums, networks, planning and consultation groups, that constructively involve disabled people as real participants, planners and experts in their own affairs.

Social Exclusion on an Economic Level.

Social exclusion from Independent Living also exists on an economic level. Part of the reason why Independent Living practices are not instituted is because of a financial barrier.

For some reason Independent Living is seen as too high a financial cost to implement.

The questionable financial argument is used to avoid putting it into action.

Consequently disabled people are denied the right to live independently and therefore socially excluded in an isolated and inadequate life style.

The financial argument is used in a way that protects the responsibility of the state.

It is a shame that Independent Living is not seen as a cheaper option in the long term, as opposed to an expensive one.

This is because it improves the quality of life of an individual, which reduces the amount of medical treatment a person needs and avoids hospitalization and institutionalization, which comes at a higher cost to the State.

Let me give you an example of this comparison in the UK

UK Cost Comparison of Independent Living and Other Services.

Cost of hospitalisation:	1760 Euros £1,100 per week
Cost of institution/residential home:	1440 Euros £900 per week
Cost of Independent Living for 24 hour cover:	1280 Euros £800 per week

Bearing these figures in mind, most disabled people living independently in the community do not need 24 hour cover, many of them need much less which means the Independent Living figures would be much lower.

Even if you compare the delivery of direct services in the community, there is still in most cases a financial saving to the State.

Let us compare the cost per hour of support in the community, between receiving Independent Living or a direct service from the local community social services. These can be the rough average rates of pay:

Independent Living costs:	13 Euros £8.25 per hour
Cost of Direct services:	18 Euros £11.50 per hour

The reason for this is that somebody living independently does not have the same overheads as that provided by the State. This is because the person living independently does not have the costs of maintenance to the building, office, lighting, heating, IT technology, payment to the local government staff and all the other extra costs and overheads that go along with providing a local social services department. The person living independently only receives the hourly payment they pay their workers, plus a 15 –20 percentage addition for unsocial working hours, administration costs which should cover things like holidays, sickness pay, insurance costs of workers etc, and all national insurance and tax costs, recruitment and training etc.

There have been a number of studies on this as well. ‘Cashing in on Independence’ which I mentioned earlier also covered this subject.

Family and Informal Support

What are the reasons why many countries have not gone ahead with implementation of Independent Living schemes, or in some cases restricted their development to only a number of small pilot schemes? It is mainly because they think the care or support should be provided informally by the family, or other informal networks of neighbourhood support. This is because many countries still live by the traditional notion that a family should provide. They see this as the cheaper economic option. They are afraid of the floodgates opening. It also releases them from their state responsibilities of providing adequate support to enable disabled people to live richer and fuller lives. There is a neglect of family relationships and quality of life issues.

Many disabled people are actually trapped in their family’s and are socially excluded as a result of this.

Their lives are severely restricted in terms of freedom of mobility, equal opportunity and inclusion in main stream society.

In many cases these situations are often burdensome and put a lot of pressure on the families to carry out this support.

This is often at the detriment of members of the family and the disabled person.

It leads to breakdown in family relationships and the harmony within the family.

This cost is very high in the quality of life, user satisfaction, and social and family relationships.

A particular example of why this approach does not work is demonstrated by the inability of young adolescent disabled people to be able to grow up in a mature and independent way. Their adolescent development is often hindered through the over protection of the parent and the denial of the usual life opportunities that most adolescents have as they grow up. It is much harder for the disabled adolescent to become independent within their families and be able to access those opportunities.

Disabled People are Excluded because they have no Choice but to live in Institutions

As well as the reasons of bad social and economic policies which restrict the development of Independent Living, the other social exclusion, which all our countries perpetrate, is that of housing many disabled people in institutions. Unfortunately this is historical, and now because the buildings are there they have to be filled.

This is at a much higher cost to the State as shown above. It is the worst and most degrading type of social exclusion that exists in all our countries.

As long as Institutions exist, the spectre of a disabled person finally ending up in one is a fear that haunts most disabled people through out their 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 of their life, know 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 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 ones 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 chose 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

Some Scandinavian countries are now trying to address this by closing many of their institutions and opening up smaller ones that are more manageable, user friendly and community based. It is still important though even with these changes to ensure that the user still maintains control and choice over their situations, otherwise there will still be an institutional attitudinal approach.

The Future

If countries are really going to commit themselves to developing Independent Living and Direct Payment projects in their attempt to overcome social exclusion, then they will seriously need to financially support these schemes. There needs to be a political will, and an economic investment and a significant social policy change. The consequential difference will go a long way in liberating disabled people, freeing them of social exclusion, and at the same time providing them with more control and choice in their lives with equal opportunity in life, work and play.

For those countries who have struggled to implement Independent Living schemes there are many countries now providing some very good practice models to use. Many of the Scandinavian countries have good examples as do the UK, Germany and Austria. Smaller schemes are also operating in Holland, Belgium, Ireland, France and Italy. We must remember that this style of life is not for every disabled person, as the decision lies with the individual themselves. It is they who must decide and choose to do it otherwise this is not Independent Living.

**John Evans,
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