

"The Importance of CIL's In Our Movement"

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Introduction

I am very pleased to talk to you to day on the importance of CIL's in our Movement. We should see this time as a celebration of the work disabled people are doing, pioneering and advocating for Independent Living throughout Europe. There is now a great sense of solidarity about the significance of Independent Living and its future. It is also now exciting that Spain especially, is embracing Independent Living and striving to open up new frontiers and demands for this important practice and philosophy for disabled people. I know this has not been easy for you with the present political climate and the new disability legislation in Spain.

I am sure I do not need to tell many people here about the importance of Independent Living and CIL's, because we are an unique gathering of activists and pioneers of Independent Living who already know this. In fact, this is our strength, the fact that we all come from different CIL's around Europe, and we are here to learn from each other in order to develop and expand our diverse movement. Let us see this occasion as a great opportunity to move forward. We must ensure that we use our time here well, so that we can all return back to our own Countries refreshed and reenergised, to continue our fight to make Independent Living a right and a reality for all those who aspire to it.

Independent Living is a Civil Rights issue and we must not forget this. Today we are asserting these rights by having this conference. In order to achieve our Civil Rights we need stronger legislation in all our countries and at a European level. This is one of the main focuses for ENIL, trying to enshrine Independent Living as a right in the laws of our Countries and Europe. Now more than ever, we are in a stronger position to achieve this after the successful and significant signing in August of the "UN Convention for the Protection and Promotion of the Rights of Disabled People", and in particular for us, Article 19, which is the

relevant article for Independent Living. Let me quote this to remind us:

((UN Convention for the Protection and Promotion Of The Rights Of Disabled People [Art. 19 Living Independently And Being Included In The Community]))

“The Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs”.

This convention should be ratified in December, and we should use this conference as a starting point to work towards implementing this Article in all our countries. In this Convention we have a very powerful Legal Instrument now which we can use to promote Independent Living.

I know in many countries our movement is trying to get Independent Living into our Laws. In the UK for instance, we are currently trying to get an Independently Living Bill passed through Parliament. This work is being led by the National Centre of Independent Living, NCIL in cooperation with the Disability Rights Commission. The important thing is that WE ARE in control of this process and not the Disability Rights Commission.

Independent Living has been one of the most dynamic influences for disabled people in changing our lives and developing disability politics. It has also provided us with a pro-active philosophy. It continues to inspire us and gives us a positive image and direction in addressing the main issues of this time. It also provides us with a definite way forward for the future and is an on-going process of empowerment, both individually and collectively.

The proliferation of interest in Independent Living and the development of CIL's, Independent Living projects and initiatives seems to be striking at the heart of many different countries in many different ways. It is because of its **strong foundation based on the principles of control, choice, a sound social model of disability, and Civil Rights, that makes Independent Living both practical and appealing.** The key is that **Independent Living gives disabled people power over our lives,** Independent Living reflects the social model of disability in its most comprehensive expression and firmly eradicates the medical model as a way forward. The Social Model is about our life in the world, and not about being separated and excluded from it as in the institutional and medical model approach.

Independent Living undoubtedly has had more impact on the lives of disabled people over the last 30 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 lives and opportunities.**

Our CIL's have given us an organisational structure in order to take our struggle onwards. Many of us are still inspired by those stirring early beginnings at the Berkeley CIL California, where our whole movement started. As Judy Human, one of the founders of Independent Living in the USA said, "**Independent Living is about being proud of ourselves and using this to empower us. We have to believe in ourselves in order to achieve our Independent Living goals**". This has to be our motto and strength for this Conference.

Since those early Berkeley beginnings, we have been developing our own European models of CIL's, in order to empower and support disabled people in our quest for Independent Living.

We have developed a variety of different models now in Europe to do this. These have been the **cooperative models as developed in some Scandinavian and Northern European Countries**, the **Direct Payments model in the UK**, the **Personal Budget schemes in Holland and Belgium**, and the **currently thriving Functional Diversity approach of the Spanish Independent Living movement**, not forgetting the ever surprising, **instinctive Irish** way that always seems to find its own Independent Living rules and ways.

It is these different approaches that have reflected the richness of our unique Independent Living movement. It is a movement based on self determination, self direction, control and choice, and with the notion that we know best our needs and how best to achieve these. It is an expertise and knowledge that has been developed over 30 years, and by working together through our CIL's we have been able to sustain it. This is why our CIL's are so important to us, and this must be one of the key messages and themes for this Conference and our networking together. By working together we can strengthen each other, and we all know that we have only been able to achieve what we have until now by doing this.

Blue Print for Independent Living

The Independent Living Movement has its roots in the struggle to liberate people from institutions during the 1970s and 1980s. Those early negotiated arrangements by disabled individuals with their respective authorities, formed the basis for a workable model through the Independent Living Movements' network, and a continuity for further development. As well as this together with the development of Centres for Independent Living (CILs) and other organisations run and controlled by disabled people, it provides an ideal infrastructure and framework to help, support, inform and advise potential and existing users of Independent Living schemes. This is undoubtedly one of the main reasons for their successful record.

Self Assessment

One of the primary and philosophical premises of Independent Living is self-assessment. This is the starting point. It is based on the notion that the individual knows best their own needs and are the experts in this and experience it directly and if necessary together with their disabled peers are best at arriving at an accurate and more appropriate assessment and appraisal of their personal situations. Obviously in order for Independently Living schemes to be accepted we have to **convince Local Government Authorities** and **develop partnerships**. I do not use partnership too lightly here either, because there have been cases where professionals have taken the lead and it has often led to schemes going wrong. We believe that if the assessment is right from the start there should not be any problems. A partnership approach between disabled people and the authority is a good basis for developing IL schemes in a positive way.

Disabled People Moving Beyond the Medical Model

Independent Living schemes have liberated disabled people from being passive recipients of inappropriate services, into being active citizens and employers of personal assistants, leading creative and productive lives. They have enabled disabled people:

- to move out of institutions,
- given more control and choice over their lives,
- contributed to a better quality of life
- provided more flexibility and satisfaction
- enabled real empowerment.

I say real empowerment purposely because empowerment has become a real buzz word recently, and as it has been overused, its real meaning has seriously been undervalued. In this context though it fully represents and reflects the full meaning of the word, because here we are seeing peoples lives change and grow immensely as their confidence and control increases.

Effects of Independent Living

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 on enabling people to work by having the support and assistance in doing this.

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 has control and management of the whole process. This also enables one to create opportunities and chances and as a result it makes common sense and leads to a healthier lifestyle. This is one of the **Key roles of CIL's in supporting Disabled people setting up their Independent Living schemes**

Today, we can see Independent Living thriving throughout Europe in different ways, particularly in the UK, Sweden, Finland, Norway, Ireland, Italy, Spain and Germany and many other Countries. I say this with some reservations because the Independent Living movement and philosophy is thriving, but in a number of other countries there are still many restrictions due to inadequate funding of Independent Living schemes and initiatives, as well as some bad planning and social policy.

ENIL, the European Network on Independent Living, is not only a network for countries who are active in the Independent Living movement, but tries to attempt to address some of the main issues in promoting Independent Living. ENIL is also helping those Countries who are struggling to get Independent Living developed.

The Future

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 nothing to lose, as 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 Independent Living has 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 30 years we have seen big advances in Independent Living and Direct Payment in Europe through our work. 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. The importance of CIL's in our Movement is to ensure this happens and our solidarity grows.

This conference is yet another reflection of the strength and growth of the Independent Living Movement.

John Evans, ENIL
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