

Independent Living and Human Rights

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Introduction

During the recent history of the Disability Movement three main ideas have emerged which have become known as the “Three Big Ideas”.

These are: The Social Model of Disability
Independent Living
Civil Rights for Disabled People

All of these have had a considerable impact on the lives of disabled people in terms of our empowerment, the realisation of more control and choice over our lives and our fight against discrimination.

Today I shall be looking at Independent Living and Human Rights which inevitably involves all the “The Three Big Ideas”, because it is the interaction of how disabled people have used them which has enabled us to challenge the system and work towards achieving our civil rights legislation. We are not there yet but we are on our way!

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 ever 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 and social and economic oppression of the policy makers and the people who managed the institutions. Discrimination was rife and obvious 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 struggle for equality and life free of institutions. Independent Living has provided us with a powerful tool in order to achieve our Civil Rights.

To quote Rachel Hurst: “Independent Living is, in fact, the practical solution to ensuring self-determination and the free pursuit of an individual’s economic and social development – those empowering philosophies of the UN Convention on the Civil and Political Rights.

It should be impossible to break the link between Independent Living and human rights. The basic principles under-pinning Independent Living should be reflected in civil rights legislation for disabled people and in all policies and programmes that support our inclusion into society.”

Discrimination

However, whether we like it or not, even with the introduction in some countries of anti-discrimination legislation like the USA, Canada, Australia, Sweden and the UK, disabled people still face discrimination in many ways. Despite the positive developments towards our Civil Rights the picture remains bleak. To put it into context here are some examples of what still frequently happens today.

Disabled people

- 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 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 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

These are just some examples of what disabled people face on an everyday basis where their basic human rights and needs are violated and this list is far from being comprehensive. I am sure every disabled person here could add many more experiences.

The reasons for this as we all know too well is because governments have not implemented appropriate legislation and policies to support Independent Living despite their promises. Sadly Independent Living and civil rights remains low on their political agenda.

Key Developments

As well as the disability movement strongly demanding civil rights legislation to help change this situation, there have been a number of key developments in different countries over the years, which have helped push the civil rights agenda forward. These are important to mention, as they have had a wide reaching effect and are part of our history.

Social model

Firstly let us look at the social model. In the early 1970s a group of disabled people in the UK formulated the social model which ever since has been like a manifesto for social action and change. It offers a means by which disabled people can both question the norms, stereotypes and structures of society and at the same time put forward some positive and constructive images. It highlights that the problems that disabled people face in life are not as a result of their individual impairments, but the barriers they face because of the inaccessible structures of the world we live in. It is the environmental and attitudinal barriers, which restrict disabled people.

Civil Rights and Social movements of 1960s/70s

The civil rights and social movements of the 1960/70s also contributed a lot of influence and inspiration to the disabled peoples movement. After the black civil rights, peace, women, environmental and other movements gained momentum for themselves, disabled people felt that they could also benefit from uniting their forces in their fight against oppression and discrimination. Through democratically organising ourselves nationally and internationally we have been able to exert more authority, power and influence and contribute towards change. Great developments have happened world-wide over the last 20 years particularly since Disabled People International (DPI) was formed in 1981.

Vietnam veterans

Another important feature in strengthening the cause for disabled people was when the Vietnam veterans returned home from the Vietnam war. As a result of the injuries they sustained in the war, they expected that certain services and conditions would be made available for them. However this was not the case. They became disillusioned and frustrated by ending up being victims of the society they went to war for, so then joined the wider disability movement in order to protest about the inadequate conditions and to fight for change.

Berkeley and the birth of the Centres for Independent Living (CILs) in the USA

A hugely important development later, which had enormous significance and was really the birth of the Independent Living Movement, was when a group of severely disabled students in Berkeley were able to secure personal assistance in order to support them in their studies. This had such a profound impact on them and their life styles, that they decided that they would fight to maintain this support when they completed their studies, in order that they could live equally in the community and be contributing citizens like everybody else. This then led to the formation of the first Centre for Independent Living which was set up to support and enable disabled people to live independently in the community. This was done by setting up some basic core services like housing, personal assistance, access, accessible transportation and peer counselling and support which would provide a link to Independent Living.

Section 504

As the Independent Living Movement developed and became stronger disabled people were able to organise themselves more effectively and thus exert more influence through political demonstrations and lobbying. One of their outstanding achievements at this time during the late 1970s was the passing of the Section 504 of the USA Rehabilitation Act. They achieved this after a 40 day sit-in in the USA Government Health and Social Services building. This particular section of the Act had a clause, which forbid discrimination against disabled people in public services, buildings, transport and employment. It was the first piece of anti-discrimination legislation in the world, which would later prove to be very useful in the build up to the American Disabilities Act (ADA).

Independent Living developments

After the establishment of Berkeley CIL there was a rapid growth and flourishing of CILs throughout the entire USA. By the early 1980s there were over 100 spread across the majority of different States, but particularly strong on East and West Coasts and the Mid West. It was not long before European disabled people found out about this significant development and then began to establish their own

Independent Living programmes and CILs. During the early 1980s many European disabled people visited the USA on research and exchange projects learning about this Independent Living expertise in order to return to their own countries and put it into practice.

UN Programme of Action

After the UN International Day of Disabled People, the UN decided to set up a UN Decade Programme for Action, which started in 1983. At this time disabled people and their organisations had very little involvement in the decision and policy making, but at least the equal opportunities of disabled people and their integration and participation in events was mentioned. However, this was not long after the world-wide disability movement had started in 1981 through DPI and the various national assemblies around the world. So it was not long before they made themselves street-wise about what was going on and began to learn how they could start influencing policy direction by getting involved. This obviously took some time before their impact started having effect, but during the course of the 1980s it became stronger and stronger. By the end of the UN Decade of Action disabled people particularly through DPI were actively engaged in the planning and decision making processes of this programme. This culminated in the end with the formation of the UN Standard Rules, which would lead to have many benefits and significance for disabled people and their organisation, which we will see later.

European Network of Independent Living (ENIL)

During the 1980s Independent Living slowly developed through out many European countries. This all came to a head when over 80 disabled people from 14 different European countries met at the European Parliament in Strasburg in 1989. After a few days of intense discussion, debates, meetings and deliberations, the European Network of Independent Living (ENIL) was formed. This was a tremendous development and enabled disabled people who were working on Independent Living to network more with others from other European countries in order to improve the scope of the projects. Through out the 1990s ENIL has provided a structure and forum for the exchange of networking of experts and grass-roots

disabled people in Independent Living in order for the movement to develop.

American Disabilities Act (ADA)

Without doubt the biggest and most effective achievement and way forward for disabled people in their fight against discrimination world wide was the signing and establishment of the ADA in 1991. This was a milestone not only for the disabled people in the USA but for disabled people through out the world. This is because we now had a proto-type piece of legislation which we could all look to for guidance in order to develop similar kinds of legislation in other countries and continents. It has had a big effect particularly in Europe where many of us have been engaged in our own countries trying to establish civil rights legislation. It has been an inspiration and a model for us to build on.

UN Standard Rules

In 1991 the UN published a special report called Disability and Human Rights, where for the first time, the systematic violations suffered by disabled people were recorded. Independent Living was not mentioned in this Report, but it was significant that many references were made about the horrors disabled people encountered in institutions which was seen as a solution to their exclusion.

The emergence of the UN Standard Rules on Equalisation of Opportunities for Disabled People in 1993 was another significant land-mark in our struggle for civil rights. It states that “the purpose of these rules is to ensure that girls, boys, women and men with disabilities, as citizens of their societies, may exercise the same rights and obligations as others.” The Rules are very holistic and cover many of the areas of Independent Living. It even goes as far as Rule 4, which includes personal assistance and interpreter services as important measures to achieve equalisation of equal opportunities.

Disabled people in many countries have used the example of the UN Standard Rules in order to help influence and develop civil rights legislation in their countries. The Standard Rules have been used as

a stepping stone in this process. A number of areas throughout Europe have made public and policy commitments in signing up to these Rules. My own area in Hampshire signed up to the Rules in 1997 after we had a successful European Disability Rights Conference in Southampton.

Amsterdam Treaty

Astonishing enough up until 1992 there was no mention of disabled people in any of the European Union legislation and no policies regarding disabled people, except those relating to rehabilitation. Both the European Union and the Council of Europe talked about integration in their rehabilitation policies but there was no real promotion of the concept of self-determination or the freedom of the individual, nor any duties for the member states to legislate for any empowering disability legislation. However, since then with the introduction of the Amsterdam Treaty and its clause on discrimination, together with the inclusion of disabled people in advising on EU disability policy the situation has begun to get better. Even though this is the case, disabled people in Europe cannot become complacent because we still need to ensure that the Article 13 of the Treaty is fully implemented and seriously confronts discrimination at a European level. We know that discrimination occurs in all our countries.

Disability Rights Commission (DRC)

In order to ensure that our rights to Independent Living and the fight against discrimination is advanced we need to work on a European and National level. To give you an example of what we are doing in the UK in order to promote our push for civil rights. The Government has recently set up a Disability Rights Commission whose purpose is to monitor and combat discrimination. It is not as strong as we would like but it is a step in the right direction and will be interesting to see what happens. We shall be monitoring the situation very, very carefully.

I hope that these examples of the key developments of what has happened over the last 30 years or so in our struggle to achieve Independent Living and Civil Rights Legislation, will put into perspective the advances we have made. What is significant is that

all these developments and solutions have been a direct result of disabled peoples actions. We can gain strength by this in our push towards fully comprehensive Civil Rights 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 leave you with. Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living.

Finally and to let you know that DPI and ENIL are just starting to work jointly on a research project whose aim is to arrive at a new, disabled people's, millenium definition for a human rights approach to independent living. You shall no doubt be informed about this when it is completed.

John Evans
ENIL Chairperson
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