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Independent Living in the USA

The Independent Living Movement started in Berkeley, California, in 1973 . It started on the university campus, because three severely disabled students were able to study there because of a special assistance scheme that was set up to support them during the period of their study. This scheme was organised by the Disabled Student Association and provided personal assistants for the three disabled students.

When they finally graduated they felt strongly that the personal assistance service that they had at the university should continue. This was obvious because they wanted to transfer their same lifestyles into the community and find jobs. Their lives had been transformed and they did not want to lose this new freedom and integrated approach to living which the personal assistance support had provided. They were successful in this transferring and hence personal assistance as a service in the community was established. It was probably the most significant, innovative service provisions in the lives of disabled people and still is. It would eventually have a far reaching effect world-wide.

This was a seed of enormous consequences, because from Berkeley the whole Independent Living (IL) movement flourished through California and finally spread throughout the entire USA.

In order to develop and build a structure for the growth of the IL movement they set up the first Centre for Independent Living (CIL) in the world. This CIL went from employing a handful of people when it first started to employing well over a hundred people in the early 1980s. At this time they had a very comprehensive variety of

different programmes covering diverse areas as housing, personal assistance support, wheelchair repair, outreach programme, employment, advice in rights, benefits and educational programmes etc.

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 organisation and the information, advice and services they wanted to provide and not traditional organisations, charity based being run by non disabled people. The Berkeley CIL established what has become the corner stone of disabled people's philosophy by setting up what is known as the five basic core services. 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. 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. 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. 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. 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. 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. Another factor I think 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 and also at a time close after the 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.

What is a Centre for Independent Living (CIL)

Let me briefly define what a CIL is. When it was originally set up in Berkeley, its two basic premises were that it was an organisation that was run and controlled by disabled people and secondly, that it should serve people with all sorts of impairments from all backgrounds. In other words it should not exclude anyone whatever their impairments or cultural background.

Independent Living in Europe

After having such an affect on the lives of disabled people in the USA it was not long before these ideas were being picked up by disabled people in Europe. During the early 1980s there were many disabled people from a number of European countries who visited the USA to observe first hand and to study and research the whole IL issues. Many of these disabled people on returning to their home countries were influenced so profoundly that they then started setting up the seeds of the IL movement in their own countries. In the early 1980s we saw the emergence of the IL movement and CILs in the UK, Sweden, Finland and Germany, which was later to be followed by Austria, Ireland, Belgium, Holland, Norway and Italy. The most developed and strongest of these IL movements are in Germany, the UK and Sweden.

UK Developments

I would like to concentrate on the UK and how the IL movement developed here. As in the USA, when CILs developed, they responded to the needs of the local disabled community focusing on the issues of the needs of local disabled people. The first two CILs in the UK were in Hampshire and Derbyshire. Both developed with different emphasis. In Hampshire, it developed around the issue of personal assistance and the empowerment of disabled

people, whereas in Derbyshire it developed around partnership approach with Social Services and focused on issues and services around employment, accessible transport, peer counselling and service provision.

An original definition of what a CIL is that came out of Derbyshire is

“Local services to meet local needs wherever possible under local control. A CIL is a central support resource and depending local initiatives by disabled people. A CIL is a resource to assist the redirection of help and Social Services toward Independent Living. A CIL is a symbolic consciousness raising beacon to assist the process of shifting attitudes and low expectations. A CIL is joint collaborative practical service as distinct from the watch dog pressure group role of the coalition itself.” This was an interesting point differentiating the difference between a CIL and a coalition seeing that a CIL is a service provider and a coalition as a political pressure group. This distinction however is not agreed by all disability organisations as some CILs still see themselves as being very political. This has been a source of conflict throughout the whole of the CIL movement both in America and Europe.

Another interesting difference in the UK was that in Derbyshire the CIL was set up by a coalition of disabled people, whereas in Hampshire the CIL was set up and the coalition came later. Again it was an example of disabled people responding to the different needs of the local community.

The setting up of the CIL in Hampshire was similar to what happened in Berkeley to some respect, in that it was set up by disabled people moving out of a residential institution to establish themselves in the community with the support of personal assistants as supposed to move out of a university community as they had done in Berkeley.

This group of people in Hampshire who moved out into the community and set their IL schemes up then wanted to draw upon

and build upon the experience and expertise that they had developed. As a result of this they founded the Hampshire Centre for Independent Living (HCIL), so that they could then work together with other disabled people in their community in order to avoid other people going into institutions and helping others to get out. HCIL made its focus around personal assistance issues and as a consequence has become known for its work in developing training, resources and publications on this area.

Seven and Eleven Basic Needs

In Derbyshire however, it was quite different. Here they based themselves very much around the five basic core services as in Berkeley and then developed another two services. These were information, which is paramount in enabling disabled people to acquire what they need and information can be power itself in equipping people with the information they need to do what they can. The second service is technical assistance. This is enabling disabled people to live independently through the application of their necessary technical assistance.

As other organisations in the UK have developed they have added an extra four basic needs or core services to the seven. These are employment, which obviously is as important to disabled people as to everybody else, education and training, because without these disabled people are denied the appropriate opportunities. Thirdly, that of income and benefits, because this goes without saying that when over 700/0 of disabled people are on benefits, it is a major issue. And lastly but not least, that of advocacy, which has recently emerged as a very important function in empowering disabled people.

In the UK now there are CILs in Hampshire, Southampton, Derbyshire, Bristol, Greenwich, Glasgow, Lothian, Leicester, Lambeth. As well as the CILs there are a number of other IL projects in other parts of the country.

In other countries e.g. Sweden, the CILs have also developed around personal assistance schemes in Stockholm and

Gothenburg. The situation is also similar in Finland and Germany, although in Germany the CILs have taken on a similar model to that in the USA by having a variety of different other programmes as well as having a focus on peer counselling.

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 and at the same time has organised a series of seminars and meetings since it started in various European locations which has enabled it to have considerable impact. It has meant that at regular occasions over the last eight 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 European nations to look at setting up IL in their countries.

In the last eighteen months ENIL has begun to play an important role in disability politics at a European level. It has started to receive 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.

Challenges to the European Independent Living Movement

Whilst there are innumerable examples of good practices of IL happening in many European countries now and other interesting schemes emerging in other countries, the whole situation still needs to be consolidated. Despite these exciting IL developments we need to be aware, ready and cautious because there have been a number of concerning developments in a few countries after the introduction of new legislation which have created some backlashes, e.g. bringing in charging policies into direct payment schemes and restricting the criteria. These developments are now challenges to the IL movement in Europe to find solutions as ways forward from the se difficult situations.

Two of these concerning developments have been in the UK and Germany as a result of introducing new legislation. Ironically, in the UK this was after the new Direct Payments Act (1997) came into effect. This was an act that was in effect legalising direct payment schemes, because previous to this they had always existed in a dubious legal frame work, so in order to overcome the uncertainty and the loopholes which authorities were using to operate such schemes the new law. This was also as a direct result of the campaign mounted by the disability movement to improve the legal position and make IL schemes more available to disabled people.

The problem that arose was that in the guidance that came along with the act, which tells authorities how to implement it, it stated that local authorities could introduce charging to direct payment schemes. This has become a hot potato as far as the IL movement in the UK is concerned, because it feels that they have been unfairly treated. By bringing in charging it not only acts as a double taxation, but also becomes a further financial disincentive going against helping a disabled person find work. Other than this

disabled people are very angry that they are being charged for a service that they themselves are actually organising and providing for free. They do it in their own time, with their own resources and do not get paid for it. Obviously, this situation is being challenged vigorously, both in the local way in many different areas, and also at a national level. In Germany the introduction of a new social care insurance legislation in 1995 again proved to be very controversial and having negative affect on the lives of disabled people. After the introduction of this new law all disabled people who were on direct payment schemes were reviewed and many lost a number of hours of support they were previously receiving. This set back took disabled people back to the medical model where they were disadvantaged even further. The long term care insurance that was introduced meant that people needing personal assistance could only claim assistance from social welfare if they could not cover the cost of daily care with their incomes or financial assets. This reduces people who require personal assistance to recipients of 'pocket money' , and this despite the fact that many were part of the labour force contributing to the insurance funds. German disabled people are challenging this in order to get a more positive approach to direct payments again. It is also a question of defending the social model of disability developed by disabled people as a positive construct and approach to spread good practice around disability issues based on the notion that the problem for us is not the individuals impairment but the structure and decision-making processes of the society we live in. This again is one of the reasons why ENIL is so important in that by working together through its framework IL activists can help support each other as well as trying to find solutions to their problems regardless of what country we come from.

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