

# The Right to Live in the Community

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## How Disability Activists Create Possibilities for Independent Living

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### Introduction

In my presentation I want to show how Independent Living has not only transformed the lives of disabled people but has also systemically changed the nature of the way disability services are delivered. I want to point out how the main principles of Independent Living are now incorporated into mainstream policies and practices and how Independent Living exemplifies good social care practice and innovative community living, through schemes like Direct Payments and Personal Budgets which are opening the possibilities for other Community Living Options. Independent Living has also been instrumental in pushing forward the Human Rights agenda for disabled people.

### Independent Living

It is amazing that it is now 30 years ago since a group of us, then young disabled people, living in a Residential Home in the UK decided that we were not prepared to spend the rest of our lives living in the residential home, which to us represented "institutional living", but wanted to come up with an alternative solution. We managed to successfully negotiate an agreement with our authorities to transfer some of the funding we were receiving to live in the home to be reallocated to support us to live in the community.

We opened up new horizons as we embarked on our pathway to Independent Living. At that time, Independent Living was unheard of, so in effect what we did was to challenge the whole notion of social policy as it was then. In other words **we** wanted to decide what we wanted to do about our lives in order to have more control over what we did, and quite simply to be able to do what we wanted to do. This was to live in ordinary streets with ordinary people as citizens in the community, and not to be excluded, living isolated in the countryside in a residential home, institutionalised, away from the main zest and activity of life. We wanted to be a part of society **not apart from it**. We did not want other people making decisions about what we did with our lives, which we felt should be our prerogative and under our personal control. This is the essence of the Independent Living philosophy. In other words we wanted to create our own service, as well as breaking down the conditioning of institutionalisation of disabled people being focused in institutions. It was the first time that disabled people were demanding their basic Human Right to live just like everybody else despite their impairments.

### Social Care Revolution

This was in many respects, the beginning of a social care and Human Rights revolution in service provision. It was when disabled people wanted to seize back power over their lives from the policy makers. If we look back to these early beginnings and see where we are today, a

social care revolution has indeed happened. What was a radical, grass roots initiative by disabled people to gain control of their lives over 30 years, has now become national mainstream policy in many European countries. Disabled people simply wanted equality of opportunity in order to overcome the discrimination they experienced on a day to day basis, which sometimes involved the violation of their Human Rights, particularly if they lived in Institutions.

We now have Policy and Practice Guidance from Government's embracing the philosophy and language of Independent Living, where words and concepts like autonomy, self determination, control, choice, empowerment, human rights and living in one's own home as long as one wishes, are now common place in Government documents. We even have Government Ministers on videos, promoting the notions of control and choice and the benefits of Direct Payments to users. If this is not a social care revolution, then I do not know what is! The general thrust about social policy these days, is about user control, participation and planning. The question is how much is it being put into practise. We still have to overcome the policy making rhetoric and make sure these policies are put into practise.

### **Control and Choice**

Without doubt, the most significant changes Independent Living has brought about are the elements of more control and choice disabled people now have. Control and choice is now well documented in many pieces of research and writings by disabled people and their organisations. What I feel is important now, is that disabled people not only have control over their own lives and how they live it, but they are also directly involved in the development, planning and delivery of Direct Payments and other community living social care services. It is clear that the regions where this is happening, there are more users on Direct Payments, than in places where there is little direct involvement of disabled people. One of the challenges we have now, which NCIL in the UK is very involved with, is developing Direct Payments in areas where user involvement is sparse.

### **Creating Services around Individuals**

#### **Self Determination**

Let us look at some of the reasons why this has had such an impact on changing disabled peoples lives.

- Direct Payments schemes have liberated disabled people from being passive recipients of inappropriate services, to being active citizens and employers, leading creative and productive lives.
- Direct Payments have enabled disabled people to move out of institutions,
- given them more control and choice over their lives,
- contributed to a better quality of life with more flexibility, satisfaction and real empowerment.

I say real empowerment purposely, because empowerment has become a very fashionable word in social care circles recently and as it has been so overused, its real meaning has seriously been undervalued and flawed. In this context of Independent Living 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.

More significantly, these schemes have helped disabled people move away from their lives being dominated by the medical profession and the negative dependency and restrictive practices of the medical model of disability, into the more vibrant, realistic and dynamic mode of the social model, reflecting the true values of the world we live in.

### **Self Assessment**

One of the primary and philosophical premises of Independent Living is self-assessment. This is based on the notion that the individual disabled person best knows ones own needs. We are the experts in this and experience it directly, and if necessary together with the support of our disabled peers, are best at arriving at an accurate and more appropriate assessment and appraisal of their situation.

Obviously in order for the scheme to be accepted by the Social Services authority, it then needs to be agreed in partnership by the social worker or Social Services representative so that it can then be put through the system. We believe that if the assessment is right from the start there should not be any problems. It is of our belief that the early Independent Living advocates were in fact the first 'care managers' in the organisation of community support. It was the first time that disabled people had become involved in the organisation of their own service.

### **How Control of Personal Assistance Services Enable Full Participation**

#### **Being an Employer**

This is the area where we have seen the biggest changes. What a contrast on the one hand disabled people, either being in institutions or dependent on fragmented unsatisfactory local services, in a very passive role, to being a responsible employer having to take on all the many tasks and responsibilities that go along with this, which is like running a small business. As well as keeping abreast with all the administrative and financial aspects like keeping records, doing the Tax and National Insurance of the employee, getting adequate insurance cover, drawing up job descriptions, contracts and conditions of employment. There are also the practical aspects like advertising, interviewing, employing, training, supervising and directing etc. Some people have these qualities naturally, but others need to develop these skills and this is where the disabled peoples' movement is valuable in providing this type of training, advocacy and support.

Some organisations have refined this knowledge, expertise and training to a fine art. This is an area where the support factor is crucial and with many disabled people it can be an on-going process, where the role of advocates and administrators can be an integral feature of some disabled peoples schemes. This peer support was absolutely crucial when we first got our schemes going originally in the UK. We would often help each other out in advice, practicalities and trouble shooting with any problems that might occur.

Many Independent Living and Direct Payment support organisations and schemes provide advice, information, support and training that can assist disabled people in acquiring better management and financial skills in order to help them run their own schemes more efficiently and effectively. Disabled people's organisations have developed strong infrastructures and networks to support this.

### **Independent Living and Citizenship**

Independent Living has enabled many disabled people to become more actively involved in their local community. They have been able to do this because they have had the support of their

personal assistants to assist them in these activities. This has meant they have been able to become involved in local groups, doing voluntary work and in many cases finding paid employment. In many countries now disabled people who are personal assistance users find full time employment.

Independent Living has emancipated and politicized many disabled people who work, as a direct consequence after achieving an Independent life style. They have also become more politically involved through disability organisations, in working towards change and improving the existing conditions. These organisations have tended to be Centres of Independent Living. In a recent report in the UK from the Strategy Unit of the Cabinet Office of the Government called "Improving the Life Chances of Disabled People", recommended that each area in the country should have a Centre of Independent Living to promote and develop the chances for disabled people fulfilling the aims of the report.

### **Improvement of Quality of Life and Health**

The improvement in the quality of life of disabled people has been one of the main findings in pieces of research done recently in the UK. This is the work of Morris, Kestenbaum, and more significantly by Zarb in "Cashing in on Independence". This was a work commissioned on behalf of the main British disability organisation called British Council Of Disabled People (BCODP). One of the main features of the findings of the Independent Living research, was undoubtedly the high quality of life and satisfaction experienced and gained by disabled people. Improvement in the quality of ones life not only means more personal, social and vocational satisfaction, but also usually means peoples health and general well-being tends to be better due to the improvement in their situations.

It has other advantages like a more positive approach to life generally, and good personal and social relationships, which can also be helpful in ones attitude and relationship to ones assistants.

The research also showed that disabled people are much happier running their own schemes as opposed to receiving services directly from the State. This was due to

- organising the support they needed, and not having to wait for it when arranged by a local authority,
- having more freedom of flexibility, to do things when they want,
- getting on with their lives as they want, as opposed to waiting for some one to come to assist them in their own homes,
- eating better quality meals, chosen and arranged by themselves and not somebody else.
- Being able to organize their social lives instead of fitting into boxes like day centres etc.

The list could be endless. This is why it is so important this treasure of Independent Living must not be lost, and should be developed further as part of social policy.

### **Good Practice of Best Value**

Can I reiterate that one of the best examples of best value and practice is Independent Living and Direct Payments. In other words, this is the scheme that provides money for the disabled person who then uses this to buy in the support which is required. When disabled people were carrying out their campaign to change the law for Direct Payments to make it legal in the UK, the research they carried out at this time emphatically showed that not only were these schemes cost effective, but they provided much more flexibility and user satisfaction than other

direct services. These schemes were highlighted as good innovative practice by a number of independent monitoring and reviewing organisations. Today in the UK Government Officials often express their support for these schemes because of their good practice and best value.

Independent Living and Direct Payments demonstrate how disabled people can come up with their own solutions which provide more satisfaction and flexibility, control and choice, and at the same time relieve social services departments of providing it itself. There are no administrative overheads for social services departments and their main role really is to ensure that there are effective monitoring systems in place, in order to ensure that there is no abuse of the public funds, and they can justify their financial packages.

## **Overcoming Social Exclusion**

### **Inclusive Approach – Social Exclusion Agenda**

It has been interesting watching the development throughout Europe over the last five to eight years, on policy relating to social exclusion. This is policy, which is directed at supporting minority groups and ensuring that they can have the same opportunities as others in society and hence the inclusion.

It has been interesting from the disabled people's movement perspective, because disabled people had been pointing out and identifying this exclusion for a long time before European governments and the European Union developed it as a main policy.

This again demonstrates how governments have got their best value approaches and ideas about exclusion and inclusion from existing groups within society. Disabled people in the UK and other European Countries throughout the 80s, were showing that disabled people are the poorest in society, the majority of whom are on benefits, that discrimination occurs in the workplace, that much education is segregated, as sometimes is housing when it is 'ghettoised' or even specialist. Access is also restricted and limited in public buildings, and disabled people cannot go where everybody else goes because the transport infrastructure in many areas is inaccessible. These highlight just a few of the examples of how disabled people are excluded from main stream society, disenfranchised from the norms that other people take for granted, and have their human rights violated every day.

However, it is encouraging now and positive to see this inclusive approach is impinging upon most things, but we still have a long way to go to put this into practice. Exclusion still exists in many facets of life, and we cannot be complacent until these barriers are broken down.

There are many positive examples of how this inclusive approach is now being put into practice, but it still needs to be further developed in social services department structures and the organisations of local government as well as national Government and European Institutions. Disabled people and their organisations need to be used more in constructive partnerships that are not conciliatory. This way, best value can again be put into practice in order to improve the quality of services, the planning, management, and policy development, as well as developing a more human rights approach to social care delivery.