

‘Independent Living - Right or Revolution’

Clair Hall, Haywards Heath

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Opening Remarks

Welcome to today’s Conference on Independent Living, which I hope will not only be interesting and informative, but will at the same time energise us all here in our firm belief to push the Independent Living agenda forward. Not only here in West Sussex but expanding our boundaries throughout the UK and Europe. It is a pleasure for me to be able to chair this Conference with you today, and I look forward to meeting some of you more personally later.

Independent Living

It is amazing that it is now 25 years since a group of us, young disabled people, then living in Le Court Cheshire Home in Hampshire decided that we were not prepared to spend the rest of our lives living in the residential home, and so embarked on our pathway to Independent Living. Then of course, Independent Living was unheard of, so in effect what we did was to challenge the whole notions of social policy at that time. 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 away from the main zest and activity of life. We also did not want other people making decisions about what we did with our lives, that we felt should be our decisions. This is the essence of the Independent Living philosophy.

Social Revolution

This was in many respects, the beginning of a social revolution in this Country, 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 revolution has indeed happened. What was a radical, grass roots initiative by disabled people to gain control of their lives over 25 years ago, has now become national mainstream policy. We now have Policy and Practice Guidance from the Government embracing the philosophy and language of Independent Living, where words and concepts like autonomy, self determination, control, choice, empowerment 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 video, promoting the notions of control and choice and the benefits of Direct Payments to users. If this is not a social 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.

Control and Choice

Without doubt, the most significant changes Independent Living has brought about is the element of more control and choice disabled people now have. Seven years on since the Direct Payments Act became legislation, 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. It is clear that the areas where this is happening there are more users on Direct Payments, than in places where there is little direct involvement of disabled people. Some of these areas being Essex, Hampshire, Kingston, Barking and Dagenham, Bristol, Coventry and more recently Surrey and yourselves, here in West Sussex. One of the challenges we have now, which NCIL is very involved with is developing Direct Payments in those areas where user involvement is sparse. I am currently a consultant on a piece of Direct Payments research being carried out by De Montfort University, Centre for Social Action, on behalf of SCIE, addressing this issue. This research intends to help fill the gaps for those areas slow on the uptake of Direct Payments, to learn from what good practice has already been implemented.

Changing Disabled People's Lives

Professor Mike Oliver once said that disabled people have come up with three big ideas – the Social Model of disability, Independent Living and Civil Rights for disabled people. Independent Living encapsulates all three of these ideas. I think there is no better way of seeing the social model of disability in action as reflected by the whole philosophy and practice of Independent Living. Independent Living has had an enormous impact in changing disabled peoples lives. Believe me, because I have witnessed this now for 25 years, not only in my own locality but throughout the Country and throughout Europe.

Right to Independent Living

What is exciting now is seeing the whole push forward for the right to Independent Living. This work is being carried forward by the National Centre of Independent Living, SCIE and DRC. It is encouraging that so much work is being done on this since the initial Conference run by DRC in March this year. NCIL have even submitted a clause on it for the new Disability Bill. We all need to keep working on this, lobbying hard to ensure the momentum is kept up. I have said for some time, that until Independent Living is enshrined as a 'Right', we are always in a precarious position in terms of future developments. It is also encouraging to see this Right for Independent Living being promoted in Europe too. At a major European Independent Living Conference last year, this issue was one of the key presentations.

European Perspective

In many respects I suppose I am fortunate in that I have experienced Independent Living internationally too, especially in Europe. It has been exciting seeing this happen, and being part of it through ENIL. What is interesting is that disabled people want Independent Living everywhere, and that we have the same problems, difficulties and solutions what ever Country we live in. The main differences being the cultural peculiarities for some of these Countries. This is clearly

reflected in the way that Independent Living was a movement firstly in northern Europe, eg. the Scandinavian Countries, UK, Germany, Austria, and now more recently being introduced into Southern Europe. This is because the family has had a much more dominating role and position in these Countries than those in Northern Europe.

Whilst this has been interesting in seeing these developments, I think we in the UK are still favourably placed in terms of our Direct Payments Scheme. The Scandinavian Countries probably have more money invested in Independent Living, but what is unique about us in the UK is that we are definitely pioneering the use of Direct Payments for other impairment group, e.g. people with learning disabilities, mental health service users, young and old disabled people etc. Europe has a lot to learn from us in this respect.

European Centre of Excellence for Personal Assistance.

Another exciting project which is worth pointing out to you, and is being funded by the European Commission, is the formation of the European Centre of Excellence for Personal Assistance. This project as it implies, is trying to develop strategies and policies for good practice that can be applied throughout Europe, particularly for those Countries who have struggled to get Independent Living going. The standards and policies they are drawing up for personal assistance users, are not prescriptive but are guide lines to help Countries. Most of the Organisations and Centres for Independent Living involved in this project are members of ENIL. It is not always easy to satisfy all European Countries, because there will always be those national differences and idiosyncrasies but this will always be the case because of the nature of our political and welfare systems.

I think it is very evident from my experience that the spirit of Independent Living is alive everywhere. Independent Living in this Country was created as a solution to overcome Institutionalisation. It is now a well established community based alternative, an innovative social policy empowering the lives of many disabled people. There is no going back. We have to go forward and share these opportunities to all who want to do it. Independent Living cannot be forced upon

people, it is something a person wants to do. I am sure this conference will have its impact.

John Evans, OBE
President of the European Network of Independent Living (ENIL)
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