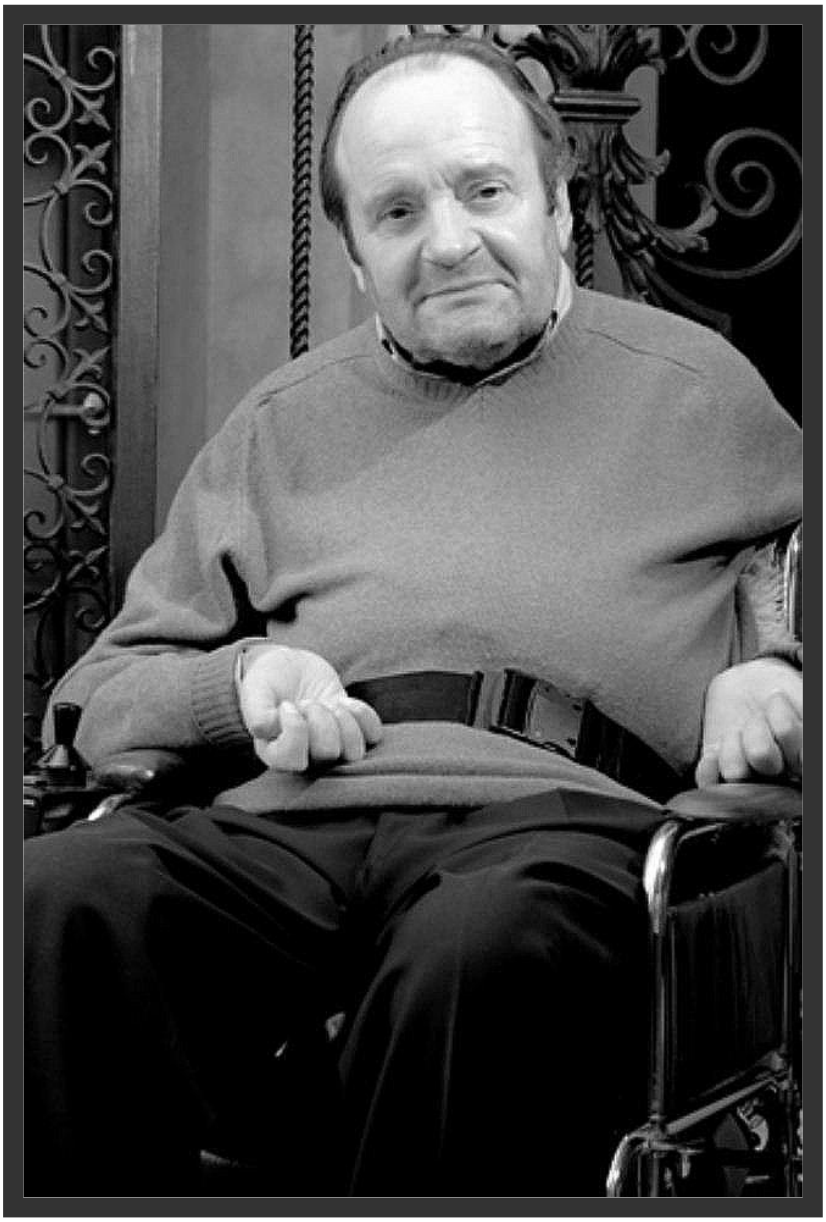
From Le Court to Strasbourg: Fighting for Independent Living for 30 years

A tribute to John Evans OBE



SPECTRUM
Centre for Independent Living CIC

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Foreword

It is a great personal privilege for me, and an honour for SPECTRUM to welcome you to this tribute to John Evans OBE; marking, as it does, the 30th anniversary of the Independent Living Movement in the UK.

John Evans is synonymous with the Independent Living Movement. His enormous contribution to the practical application of Independent Living is undoubted; his dogged commitment, passion and sheer hard work in promoting the cause, no matter what the challenges, is a constant inspiration to us all.

Having known John for nearly 20 years, I thought I knew his successes well. However, reading this tribute has blown me away, the depth and breadth of his achievements has re-motivated me, as it will do for everyone who reads it.

In the current hostile environment, we spend many hours worrying about the threats to the liberty of Disabled People. It is liberating to remind ourselves that John and his contemporaries showed us that we, Disabled People, can challenge the wisdom of the state and provide a better alternative. Let's remember what was achieved in 1983, and strengthen ourselves to fight harder to achieve John's dream for national legislation that embeds a right to Independent Living.

Above all, those privileged to know John, knows that, despite his achievements, he remains humble and understated; equally comfortable working at the grass roots as he is advising Government. John is simply a thoroughly nice guy!

On behalf of SPECTRUM, welcome to this tribute – a celebration of John Evans OBE.

Ian

Ian Loynes
Chief Executive, SPECTRUM CIL

Introduction and acknowledgements

In December 1983 John Evans left Le Court, a Cheshire Home in Liss, Hampshire (UK) to live in his own home, with support from paid Personal Assistants. This effectively marked the start of the Independent Living Movement in the UK.

Over the 30 years that have passed since then John Evans has devoted his life to promoting Independent Living and Disability Rights, throughout the UK and Europe, as well playing an active role in the movement across the world.

This document has been produced as a tribute to that work and to mark the 30-year anniversary of the hugely important events in 1983. It charts the journey that both the Independent Living Movement, and John himself, have made over those 30 years, from the early days in a residential care home at Le Court, where the seeds of Independent Living in the UK were first sown, to Strasbourg, where John and other activists from across Europe regularly gather to campaign for Disabled People's rights to Independent Living and inclusion.

While the document has been produced as a tribute to the central role that John Evans has played in the Independent Living Movement, we should also acknowledge and celebrate the contribution of other early pioneers that he was associated with. In particular, the other members of Project 81 – the group of residents at Le Court who determined in the late 1970s to leave residential care and live independently by 1981, which had been designated United Nations International Year for Disabled People. The Project 81 "escape committee", as they were dubbed by the celebrated singer Ian Dury, were: Philip Mason, Philip Scott, Tad Polkowski and Liz Briggs.

Other Disabled People who played an important role in the early days of Independent Living in the UK included Neil Slatter, Simon Brisenden, Vic Finkelstein, Rosalie Wilkins and, in particular, Ken and Maggie Davis whose collective 'Grove Road' scheme – which was truly innovative at the time - helped to inspire John Evans and the other members of Project 81. John Evans drew on their example, and that of a handful of other pioneers in Europe and the United States, to develop his own individual living arrangements with paid Personal Assistants. His determination to make this choice possible for everyone meant that his personal journey was also a political one. It marked the start of the Independent Living Movement as an integral part of the Disabled Peoples Movement in the UK.

The rest of this document contains speeches and articles John Evans has written on a variety of issues, including the origins of Independent Living in the UK, civil rights, Centres for Independent Living, the impact of Independent Living on national policy and legislation, and the impact of current austerity measures.

The material for this document has come from a variety of sources and particular acknowledgement is due to Adolf Ratzka at the Independent Living Institute, who has compiled an extensive and invaluable library archive of material on Independent Living over many years. (http://www.independentliving.org/library.html). Thanks are also due to the Secretariat of the European Network on Independent Living (ENIL), whose web site has also been an invaluable resource. (http://www.enil.eu/)

The document is a celebration of everything that the Independent Living Movement has achieved. It has been produced at a time, however, when those achievements are under renewed threat as a result of severe pressures on public finances in the UK and across Europe. John Evans and the other members of Project 81 always knew that freedom would have to be hard won and, once secured, involve constant struggle to keep hold of it. While the context might be different, their words back in the early 1980s could just as easily have been written today:

> “Project 81 naively believed that once they had "done it" the flood gates would open and new horizons and opportunities would open for Disabled People.
>
> Sadly this is not the case and indeed one would have to say that we live in an even harsher climate today. One in which even the hard-won gains of Project 81 are threatened and questioned.
>
> It was as if Project 81 had never happened.
>
> BUT IT DID. WE DID IT.
>
> Let us take pride and inspiration from that.
> The struggle goes on.”

The lasting legacy of Project 81 is that, while they may be still be at some risk, the “new horizons and opportunities” that they spoke of are now a practical reality for thousands of Disabled People. It is sometimes easy to forget that, at the time these words were written, most did not believe Disabled People could live independently as full and active members of their communities. A life of isolation and dependency in institutional care was considered to be ‘normal’.

Today the situation is very different and the ideas that were born at that time are now at the heart of national policies and Independent Living has itself become an expectation rather than just an aspiration. To have come this far in just three decades is really quite remarkable and a testament to John Evans and the other pioneers of Independent Living. We celebrate all their achievements and pledge to continue to build on their legacy.

Gerry Zarb, SPECTRUM Centre for Independent Living

Vic Finkelstein, John Evans and Etienne d’Aboville at ENIL Independent Living Conference, London, June 1998

Katerina and Adolf Ratzka, Arthur O'Daly, John Evans, Frances Hasler, Nick Danagher and Anne Marie Flanagan, Stockholm, June 1996

Virginia and Philip Mason, Stockholm, June 1996

Biography – John Evans OBE

John Evans is a Disability Rights and Diversity Consultant, Trainer and Researcher specialising in Independent Living and Disability Rights.

He was one of the first people to set up an Independent Living scheme in the UK with funding to organize his own Personal Assistance. He has now been running his own scheme for 30 years. He has been actively engaged with the Independent Living Movement in both the UK and Europe since their beginnings.

He commissioned the first piece of research demonstrating the cost-effectiveness of Direct Payments in the UK, when he was then with the BCODP (British Council of Disabled People). This was called ‘Cashing in on Independence’ - carried out by Gerry Zarb and Pamela Nadash at the Policy Studies Institute - and was influential in persuading the UK Government to legislate to allow Disabled People to receive Direct Payments.

He has been involved in the Disability Movement in the UK and Internationally for many years and was one of the founders of the Hampshire Centre for Independent Living (HCIL) and Hampshire Coalition of Disabled People (HCODP) in the 1980s, and the National Centre for Independent Living (NCIL) in 1997.

He was on the Board of Directors of the European Disability Forum (EDF) from 1997 to 2013, and the European Network on Independent Living (ENIL) until 2011. He was also ENIL President from 1996 to 2006 and is now an Expert Advisor to the Board. He has been a policy advisor on a number of different European Commission studies in particular the EU ‘Included in Society Project’, which carried out a study of Disabled People in Institutions throughout Europe which made a number of recommendations calling for more community based services in Europe. He was one of the founding members of the European Coalition of Community Living (ECCL).

He has lectured, led workshops and organised seminars in many different countries and writes on Disability Rights and Independent Living issues. He is also an editor of the International journal ‘Disability and Society’. He is an ‘Expert by Experience’ for the

Care Quality Commission and was formerly on their National Quality Board.

He is an Honorary Fellow of the Centre for Citizens Participation at Brunel University. At the UK Queens Birthday Honours List 2001 he was awarded the Order of the British Empire (OBE) for his services and work in Disability Rights and Independent Living.

He was also awarded the Silver Banner Award by the Tuscany Regional Government in Italy in 2003, the European Year of Disabled People, for his distinguished international work in Independent Living and Human Rights for Disabled People.

He is currently working with the 'Think Local Act Personal' partnership as part of the National Co-production Advisory Group.

Biography adapted from the Independent Living Institute
http://www.independentliving.org/

John Evans at ENIL's founding conference, Strasbourg, April 1989

Reflections on John Evans and Project 81

We have asked some of John Evans' friends and colleagues for their thoughts on the legacy of Project 81 and his hugely significant contribution to the development of Independent Living. This is what they had to say:

> "John Evans has played a key role in developing the Independent Living Movement in Britain and beyond. He is what the great Italian thinker Antonio Gramsci called an organic intellectual. If I can be forgiven for using an ambulist metaphor in this context, John not only talks the talk of Independent Living but he also walks the walk.
>
> I remember in the early days John talking the talk when he persuaded the Management Committee of the Spinal Injuries Association to part sponsor his trip to America to study Independent Living there when many of its members didn't even know what Independent Living was. Since then through his work with Project 81 and the European Network on Independent Living, John has been both a passionate advocate of, and a committed activist in the individual and collective struggles to achieve Independent Living for himself and other Disabled People.
>
> If more of the people involved in developing and providing our heath and social care services were organic intellectuals like John, then these services would be much more responsive to our needs and wishes and wouldn't be in their current state and heading for a possible meltdown."

Mike Oliver, Activist and Professor of Disability Studies

> "More than thirty years ago, John Evans and the other Project 81-ers invited me to Le Court to hear about their plans to go free. Their ideas helped to create not only Hampshire CIL but also the first ever user-controlled personal assistance agency in the UK, at the Spinal Injuries Association.
>
> Over the years that followed, I was lucky enough to go with John to some of the significant events in the Independent Living Movement – including the first ENIL Strasbourg conference in 1989 and the world summit in Washington 1999. Everywhere we went, it was clear how much respect John commands in the European Independent Living

> Movement. The reason for this, I think, is to do with John’s approach to life. He is not loud, or showy. He works through listening, talking and encouraging. He is supportive of others, tirelessly visiting all sorts of fledgling Independent Living groups in every corner of Europe.
>
> He’s not only inspired me, he has helped me to develop my work in the movement. But the most fundamental thing about Independent Living is that it is about having a life. So I am happy that these days I mostly see John in a pub somewhere, just nattering about silly things, and enjoying each other’s company.”

Frances Hasler, Co-Founder of the National Centre for Independent Living

> “The lasting legacy from Project 81 is invisible: it is the universal acceptance of the lifestyle aspired to: ordinary lives in ordinary streets doing ordinary things. This was what people wanted and it is what they worked for because they believed it was right. Simple as that.
>
> It is difficult today to imagine the degree of scepticism, negativity and hostility encountered in pursuit of this ambition. Two examples: a "friendly" civil servant from Whitehall stated that the Treasury would never allow a local authority to fund Disabled People to buy and organise their own support. From a slightly different perspective the Acting Chair of Rehabilitation Medicine at Southampton University stated that "severely Disabled People" could never live in the community and manage their own support.
>
> This last statement prompted the demand for John and Philip Scott to demonstrate their capabilities by staying a week in the Odstock Hospital occupational therapy bungalow where the severest challenge proved to be keeping themselves and their assistants in beer.
>
> In time not only did Elizabeth Briggs and then John Evans move into homes of their own with local authority funded support, they stayed there and very obviously thrived. These were major achievements of initiative and dogged determination. We all too easily forget the hardships and anxieties experienced along the way. People were expecting them to fail but they didn't, and the rest is history.

> We must not forget that in other parts of the country there were other Disabled People aspiring to and achieving similar ends: making their own lives in their own way with local authority support. The time was right.
>
> In the early 1960s the residents of the Le Court Cheshire home, skilfully led by Paul Hunt and Peter Wade used strike action and the Press to ensure that residents were included in the management of the institution. Project 81 took this achievement one step further by asking for and being given the means to manage their own lives.”

Philip Mason, Project 81 member and Co-Founder of Hampshire Centre for Independent Living

> I met John together with Phil Mason at a conference in Munich in 1982 where they presented their Project '81 - the plan to move out of the Cheshire Home by 1981. Phil was the first in succeeding, I understood, but he "cheated". He met his Virginia and with her help he was able to move out. John had to do it the hard way and, in the process, showed other people how to organise themselves for their liberation. Since 1982 I have met John numerous times in many countries. He has been an untiring travelling salesman for Independent Living, has written important ideological texts with powerful arguments for our right to live the way other people take for granted and has become a key figure in the Independent Living movement in the UK and Europe: he chaired the European Network on Independent Living, has been its representative on the Board of the European Disability Federation and is often invited to speak at international conferences. John has the ability to reach all types of audiences, from politicians to the grassroots. He touches them all. Hearing him speak about his gut feelings about residential institutions sends shivers down my spine. I'm sure that happens to anybody who's had similar experiences. When he gets fired up John is an impressively powerful public speaker. John is a remarkable person, a role model for many. Thanks to him and people like him de-institutionalisation is slowly beginning to win ground in a number of countries.

Adolf Ratzka, European Network on Independent Living

My first near sighting of John was in 1981 when I visited the Berkeley Centre for Independent Living two weeks after John! After that we met regularly and. with people from Derbyshire discussed the problems of setting up CILs. All three centres - Hampshire, Derbyshire and Greenwich were different but had the same principles. John has been a good friend ever since. He has a dogged determination to achieve IL for all - and his work in Europe has been magnificent. It was not easy to fight the influence of EDF and the power of the parent organisations. But John remained true to DPOs and helped ENIL to grow and be a force to contend with in Europe. His quiet perseverance has been remarkable. I am very proud to call him a friend.

Rachel Hurst CBE, Director, Disability Awareness in Action

John Evans and
Frances Hasler,
Bar Le Duc on route to
Strasbourg, April 1989

John Evans – A Personal Testimony

Why am I doing what I am doing? Why have I devoted my life to being a Disability Rights Campaigner advocating Independent Living in particular?

It is because I strongly believe in the right of every disabled person to be included in Society like everybody else, and to be able to have the same equal opportunities and chances as most people take for granted. Disabled People for far too long have been excluded and denied such opportunities.

This is why we need to be empowered and to be enabled to live independently in control of our lives and able to make our own choices. The importance of this was made clear to me when for 5 years of my life I had my freedom taken away from me and my life was in the hands and control of others. Yes, whether I liked it or not I had to live in an Institution, because at this time there were no other choices or alternatives.

This experience of living in an Institution is what inspired me to fight and devote my life to finding an alternative. This alternative is Independent Living. Such freedom of spirit is born from removing the chains of imprisonment. This kind of experience is unforgettable and enough to fire me up in our fight for freedom.

Independent Living has not only allowed me and other Disabled People our ability to regain our freedom and to be able to live our own homes and not in Institutions, but also enabled us to find meaning in life and more importantly, real status through paid employment. I was not able to do this alone. Independent Living is the cooperation, networking, and collective working together of Disabled People in order to be able to achieve our ultimate goals of being included in Society. Throughout this whole process it is Disabled People who created Independent Living, developed and guided it and will continue to do so.

Independent Living has provided us with a philosophy and practice of life. We still have some way to go and Independent Living has to be recognised as a basic Human Right and Politicians everywhere have to support it.

John Evans OBE, speaking at Official Launch of the European Year for Disabled People Ceremony, Athens 26th January 2003

Timeline of key events

1979	‘Project 81’ group formed
1981	International Year for Disabled People
1983	John Evans leaves Le Court to live in his own home
1984	Hampshire Centre for Independent Living established
1989	First European Network on Independent Living conference held in Strasbourg
1996	Direct Payments Act passed in the UK
1999	Washington Declaration at the first global meeting on Independent Living, in Washington DC
2001	John Evans awarded the OBE for his services and work in Disability Rights and Independent Living
2002	Madrid Declaration from the European Congress of People with Disabilities
2003	Tenerife Declaration from the European Congress on Independent Living
2013	John Evans inducted into the European Network on Independent Living Hall of Fame

Le Court and ‘Project 81’ …. where it all began

John Evans’ story: Extract from *Project 81 - One Step On*, HCIL, 1986

http://www.leeds.ac.uk/disabilitystudies/archiveuk/HCIL/one%20step%20on.pdf

EARLY DAYS

I broke my neck in December 1975 in New Mexico. I spent some time in hospital in the States and then flew back to complete my rehabilitation at Stoke Mandeville Hospital. When the time came for me to leave hospital I did not have a home of my own to go to because I had been living in the States.

The hospital administration insisted that I should go and live with my parents, but I felt this proposal was unfair and unreasonable. I was twenty six years old and had not lived with them for seven years. My care was too much for my parents to cope with. They were both ageing, and I knew that it would be both emotionally and physically difficult for them. In addition their house was very small and totally inappropriate for my needs.

A FIRST HOME

Fortunately some friends were willing to look for a different solution.

They found a cottage to rent in the New Forest, an area I had never seen before. I left Stoke Mandeville on a Friday afternoon and was driven to the little bungalow which was to be my home for the next eighteen months. It was all very pleasant and olde worlde, but obviously I had not researched the move, and was totally naive.

Nobody gave me any advice, information, or support of any sort. All I got from the hospital was a wheel chair, which arrived the day I left.

One of my friends was a nurse. The other had no nursing experience whatsoever, but he devoted himself to looking after me and trying to get me going.

When I moved in, an Occupational Therapist came to visit me and I asked her to make me some "plonkers" and straps, and to help me get some art materials, because I wanted to do some painting. That was the last I saw of her.

In order to give my friends a break I arranged to go to a local hospital twice a week for physiotherapy. It was pretty depressing because it was a geriatric hospital and all I could do there was sit around. I used to take a newspaper and a book to read in between the physiotherapy sessions.

For income one friend worked and we shared my Disability Pension and Supplementary Benefits. I was not assessed for my Attendance Allowance until I had been living in the bungalow for about two months. It was some nine months later by the time it came.

CHANGE IS FORCED

After about a year of this it became clear that things had to change.

One friend wanted to go back to London to work, and the other decided she had had enough and wanted to go back home to Holland. So I was left in an awkward position. I knew months beforehand that the arrangement was inevitably going to break down and I had tried writing to all sorts of different organisations, communities and such places, to see if people would take me.

THE ONLY OPTION - RESIDENTIAL CARE

The last option was a Cheshire Home. These represented imprisonment and institutionalisation, all the things I had been trying to avoid. Another factor against them was that at that time I was not too keen on mixing with other Disabled People. In the end I gave in and wrote off to the nearest Cheshire Home. It was sometime in March 1978. I wrote to the Head of Care, and she wrote back and said they were interested in my application and that I could come for a visit on April 6th.

APRIL 6TH, 1978

This was the day before our lease on the cottage expired! I was shown around the Cheshire Home and I decided to try and move there until I could find a better solution. I returned to the cottage and contacted my social worker. I explained that my friends were not able to look after me any more, and that I wanted her to apply for me to live at the Le Court Cheshire Home which I had just visited. Meanwhile I had to go and stay with my parents in Wales.

Three weeks later I had a further meeting with the social worker. She explained that Hampshire Social Services would sponsor me at Le Court and that I was to go "on assessment" there in a month's time. We did not discuss any alternatives. I think we both realised it was either Le Court or nothing. I did my probationary month and then after a two-month period back in Wales, I returned to live at Le Court.

These two months living with my parents were probably the most difficult period of my life. It was virtually impossible for me to get out of the house and our relationships became very strained. It was inevitable in such a small house. During this time District Nurses came in every morning to get me up. Putting me to bed at night was left to my mother, brother or father. They all had jobs and did this in addition.

Amazingly enough, I think we grew stronger as a family through having to deal with my disability, despite the difficulties I presented. I can look back now and laugh at those times and even feel a warm nostalgia. When families are put through such adversity it can deepen the bonds.

LE COURT

I came to Le Court in August 1978, and remained there until December 1983. Five years. It had never been my intention to stay that long.

When I arrived I made it plain to everybody that my stay was only' temporary and that I did not see myself spending the rest of my life there. I had a two-year period in mind I did not know how I was going to get out, but I was quite confident that I would find a way.

About a year after I arrived, a group of us began discussing the future. Well actually, we were always talking about "ways out" right from the beginning but we did not come up with anything until 1979. In the summer of that year I went to Taylor House, a small hostel for severely disabled students in Oxford. Something came alive from that experience.

A number of us went there separately, and we all felt that if four students could live in a house and be supported with unskilled care, so could we.

From then on there was no stopping us.

PROJECT 81

This was the beginning of Project 81. Our small group set out to discuss other ideas with numerous other people, both in and out of Le Court. It was the beginning of a long and hard learning process. At this time we tended to separate discussion of care needs from housing. This helped us to consider different ways of proceeding with each. So we never got caught up with orthodox solutions. We did not have any firm ideas of how, for example, the care could be arranged, but we could see that just as the students at Taylor House received care, so could we.

We floated the idea that: if the authorities would give us a fraction of what they paid to support us at Le Court, we could find another way of meeting our needs. This was the first thing we really latched on to. We saw it as a wonderful idea. The general reaction though was that it was totally unrealistic!

FIRST STEPS

Our first step in search of support was in October when we met with some of the Cheshire Foundation Trustees. Two were encouraging, but the remainder were extremely sceptical. The fear seemed to be that we would establish some sort of premises that would bring the name of the Cheshire Foundation into disrepute.

Later that year, we talked further with the Head of the Le Court Home, and the Cheshire Foundation Counsellor, Gill Corney. Both were encouraging. Gill was particularly supportive of the alternative living plans that we were putting forward. She agreed with our wish to live in the community and thought it was our right to do so.

EARLY IDEAS

Our idea was to have a home like Taylor House, where a small group of Disabled People could live together. We thought

Southampton might be a good location, because it was a big city with a university. We thought that might make recruiting staff easier as well as having some "life".

FORMAL RECOGNITION

Early in 1980 Peter Wade, a former resident of Le Court, joined our discussions, and we began to meet informally with Ann Parkes, the General Manager of the Cheshire Foundation Housing Association.

We asked the Le Court Residents' Association to Support an application for our formal recognition by the Home's Management Committee. In April 1980 this was granted. Project 81 was established as a Housing and Care sub committee of the Le Court Management Committee. We had our first official meeting in May 1980. By now we had decided to work with Ann Parkes and the Housing Association to get our group home.

A WARNING

Later that year we met Ken and Maggie Davis, a disabled couple who lived in their own flat in Nottingham. They warned us against the group home idea as it had been something that they had thought about some five years previously, and found there was a real danger that it would end up just another institution. These warnings remained at the back of my mind from then on. However we still thought of Taylor House as a model and felt that what we were trying to do would not become another residential home because the people involved were aspiring to something different.

Also, I could not see any other way of getting a home through the Housing Association, as the cash guidelines appeared too restrictive. I did not consider Local Authority housing because I did not think they would consider me. Somebody else at Le Court had recently been turned down by the Local Authority on the grounds that they were already adequately housed, and it seemed that if I went that way I would have to wait forever.

WESTWOOD ROAD

Almost immediately after we started looking for property in Southampton a suitable house in Westwood Road came to our attention. We set about trying to purchase it through the Housing

Association: Exciting and hectic days followed as we worked on the planning and adaptions. I even went and lived in the area for a week to familiarise myself with the neighbourhood. All this was a learning process and I think each of us was slowly putting together what were at first just hazy ideas of alternative ways of living.

EARLY EXPERIENCES OF THE STATUTORY AUTHORITIES

We began meeting with the Health Authority in the area as we knew our plans would involve them. Some of them thought our scheme was not financially viable and that there was no way we could get the support to cover the amount of care that we needed. They only thought of care support in terms of medically trained staff. Some of them told us that many of our demands were quite selfish and unrealistic; others just thought that we would not be able to cope.

We worked hard at selling our ideas to these people, attending numerous meetings over a long period. It was tough having to go to such lengths to promote something which we were all sure was going to work but we needed the support. After each meeting it always seemed to take so long before we got to the next stage in our negotiations.

Fortunately we did not give in. Right from the start Peter Wade insisted that we should never compromise on the original vision. We never did really. We stuck to our guns right the way along and, in the end, we did achieve our objective.

THE FIRST SETBACK

Westwood Road fell through in October. Somebody else bought it while the Housing Corporation were still considering our application. That was a shock. It had represented in a physical form "the vision". To lose it was a real blow.

We renewed the search in Southampton travelling there and back, week by week, month by month, without any success. We must have looked at over 50 properties, and were inundated with houses from the estate agents which we had to sift through. It was a demoralising period, and I do not know how I would have kept going had I not had the idea of travelling back to the States.

BACK TO THE USA

I had wanted to return to the United States for a long time, and had already begun to find out about the American Centres for Independent Living (CILs). In the Summer of 1980 a friend suggested I apply for a Churchill Scholarship to enable me to make the journey. I applied in September, but this was unsuccessful. I was very disappointed and tried to find another way of raising the money. Then in February 1981 the Overseas Manager of the Cheshire Foundation contacted me to say that the Foundation had decided to pay for two air tickets. I was half way there. All I needed was to raise enough money to cover the living costs for myself and my care attendant for six weeks. From February until I left in August my time was mainly devoted to this project.

ASSESSMENT

But before that came a bit of "business". One of our meetings with the Health Authority had come up with the idea that a colleague, Philip Scott, and I should spend a week in the Independent Living Bungalow'. At Odstock Hospital. This was mainly because they were very suspicious, indeed sceptical, of our proposals and felt it was necessary for us to prove that we could live that way. So in May, shortly before my American trip, Philip and I went to Odstock for a so-called "Independent Living" week.

We were a bit insulted about the idea and the way it had come about. But we went along with it because we thought it would make the sceptics happy. We knew we never needed to do it. I guess this was one of the compromises that we did make, even though we knew that in the end we were not going to let the ball go completely into their hands.

In fact we had a lot of fun, our main problem was keeping our attendants in beer money! Also, we met a very helpful Occupational Therapist who has maintained an interest in our work and has been extremely valuable to us. This relationship still prospers and was a most positive, if unexpected, outcome.

OXFORD STREET – SOUTHAMPTON

At about the same time a large property became available in Oxford Street. It was planned as a group home for three people, but neither Liz, one of the other intended tenants, nor I, was madly keen on the house.

Soon after this Liz decided to go her own way. I felt that I was not going to go ahead either, so I pulled out of the project just before going to the States. I decided I was not going to live there and for me that marked the end of the group home idea. Philip took the scheme on.

In truth the whole of 1981 was dominated by my trip to the States. This journey to St Louis, Berkeley, Albuquerque and JW Boston, convinced me of one thing above all others, and that was that I had to go ahead and get this "living in the community" done.

The trip was an incredibly uplifting experience. Everything I dreamed of, everything I thought of, there it was going on in front of my very eyes. It cemented my approach to living independently and destroyed quite a few fears that were floating around in my mind. I knew for sure there was nothing to be afraid of.

PETERSFIELD

By the time I returned to England Liz had already found her bungalow.

This encouraged me to pursue my searches. I felt that if the Housing Association could help Liz in Cowplain then they could help me in my chosen area. Cost guidelines meant it was going to be harder to find a similar property in Petersfield, but I had decided that was where I wanted to be. I started looking for properties and put my name down on the Local Authority housing list.

A LEAN PERIOD

As 1982 and then part of 1983 passed without my finding any suitable properties, I incurred increasing criticism. Many people thought that I was not taking moving out of Le Court very seriously, and they suggested that I did not really want to leave. That really bugged me. I knew inside me what I wanted to do, but everyone seemed to think I was stalling, or being unreasonable in not accepting any old property.

There were more pressures when Philip found his bungalow. He was able to find a place so quickly because he could buy privately. People did not see that, and it annoyed me, as they questioned my commitment to moving out. I was pleased for Philip's sake that he had got his place and wished him well. Besides, I could learn from watching how he organised his care, the adaption of his property, and everything else he did.

FRESH DEVELOPMENTS - CARE

1982 saw the growth of the Project 81 group into Hampshire Centre for Independent Living (HCIL). This aimed to be a more broadly based self-help group for Disabled People in Hampshire.

In May, HCIL invited a team from the Hampshire Social Services to attend a discussion on Independent Living. That is when I met Lynn Kear, the local Occupational Therapist. Soon after that we decided to put together a Care Proposal for me, even though I did not have a house. I knew that Liz had done the same thing. Further, I was aware that Philip's proposal had taken nine months to receive approval. So, house or no house, I decided it was time I presented a proposal to the Social Services. I had been involved in talking to Liz's Social Services, and had helped Philip with his Care Proposal, so I already had a good idea of how to proceed.

WORK ON MY CARE PROPOSAL

My main aim was to show the authorities, in a presentable and appealing way, how I could live independently in the community. I worked very hard on it. Mostly on my own, with comments from my colleagues.

I was building on Liz and Philip's experiences. My vision was coloured by what they had done, but at the same time I knew that the details of my proposal were going to be quite different. I tried to imagine a system that would work for me. I realised that I was not going to be absolutely sure until I had tried living with it, but I had a pretty good idea of the kind of life I wanted and the Care Proposal was my way of asking for the help needed to achieve it.

THE DETAILS

My concern in preparing the proposal was to demonstrate that I really needed the amount of care that I was asking for. I split this up into three categories:

- the physical care, which is getting up, going to bed, and some additional attention;

- the domestic care, which is cleaning, shopping, food preparation, washing up; and,
- social care, like driving to places, visiting friends, attending meetings, conferences, etc.

I wanted a live-in care attendant, but did not necessarily want him or her to be the person who was to do all these things for me.
I never gave any details as to how I thought the duties might be arranged, the only things I described were the general tasks that had to be fulfilled. My idea was to have a live-in care attendant, who would perform some of these duties, but also to employ several back-up carers from the local community. I suppose the thing that was running through my mind was to have more than one care attendant to spread the load. Not the more the merrier, one can have too many, but as long as I had three, and an emergency list of people I could call on, I thought that was plenty of back-up.

In March 1983 I presented my Care Proposal to the Social Services, and in August, one of their senior officers rang me to say that I could go ahead with it. It took five months to be approved.

FRESH DEVELOPMENTS - HOUSING

As far as housing was concerned the outlook continued to look bleak. I had submitted a bungalow in Petersfield to the Housing Association at the end of 1982. It fell through before it even got started. I was still on the District Council housing waiting list, so I had that hope, though I never seemed I to get very far in my few meetings with the Housing Officer. Then, in the summer of 1983, I found out that there was a new Housing Officer, so I thought it would be a good idea to arrange to meet him. Within six weeks the new officer offered me a flat.

MY FLAT

I went to see the flat. It was damp and cold, and very difficult to see how it was going to be adapted to make me feel happy. I cringed and wondered if it could really be what I wanted.

Despite my fears, I accepted it almost immediately. The area seemed alright, reasonably flat, near the shops, the pubs and the library. I was able to keep the same doctor and dentist from Le Court, and, as I had shopped in Petersfield many times before, I was familiar with the town.

Additionally a disabled friend already lived in the same road and I knew that if I had any problems I could always consult him. His house was similar to mine, so I could also talk to him about adaptions and in fact he proved to be of enormous help to me.

GETTING THE SHOW ON THE ROAD

The necessary structural alterations were quickly established. I listed all the things I wanted to have done, and after I had signed the tenant's agreement the Works Manager came to see me and we agreed the work.

In the early discussions I was concerned to hear talk of phasing the building work. I wanted it all done at once so that it would be ready when I moved in. I did not want to have building work always going on around me. I was told I would have to let it be done in stages, but I was quite adamant that this should not happen. As I understood it they intended to pay for one adaption, then I would move in.

Later on, they would fund another adaption. All of which could have gone on for a couple of years. I feared being stuck with the place half adapted. The arguments were not about what needed to be done, but how. To me it seemed to make a lot more sense to do all that was necessary in one job. Fortunately this view was eventually accepted.

PAYING FOR THE ADAPTIONS

It took over two months to put a package together to pay for the adaptions. This consisted of grants from the Social Services, the Environmental Health department and the District Council's own Housing Department. Wessex area Health Authority supplied a hoist and rail for my bedroom and, after a year's wait, a "Steeper" environmental control system.

THE RENT PROBLEM

When I signed the rent book I had been given the impression that the rent would be paid by the Department of Health and Social Security (DHSS). At the time I did not know enough about the Social Security system to be able to assess whether this was correct, but it seemed right that they should pay the rent while the place was being adapted, as they would be paying it when I moved in.

The Housing Department followed this matter up with the DHSS and where they did not get satisfaction at the local level, they pursued the matter with the local MP and subsequently the Secretary of State. The DHSS insisted that as I was not in residence they could not help and that the rent problem rested with, the Housing Department.

I found myself caught between the DHSS and the Housing Department. All the way through October there was increasing pressure on me to move in, in order to try and get the rent paid, but I was not prepared to move until the flat was ready.

When it became clear that the DHSS would not pay my rent, a meeting of all the interested parties was arranged to try and resolve the issue. The Housing Department felt I might be able to pay off the debt myself, or get a charity to help. However no one was prepared to pay so we spent the time beating around the bush.

The pressures over the rent arrears were a great worry to me. The debt and the aggravation concerned me! Of course I wanted to move in and get the rent paid. Of course I wanted everything in order. The last thing I wanted was to generate ill will. But I felt all this was out of my hands and I was not prepared to move into a building site. It would have been impossible to cope in such a situation. I had learnt that from Liz's experience.

The pressure on me to move in increased. It was hinted that the mounting rent debt might force the Housing Department to give up the project. However, once the work started on the 1st of November, this pressure subsided. I think people realised that the whole flat was being taken apart and that no one could have lived in it during this time.

WORK BEGINS

Despite the fact that I had asked for the ramp to be built first, so that I could get into the flat easily, it was done last. This was annoying, as every time I came to look around I had to be bounced up two big steps. This meant that I had to be in my pushchair rather than my power chair, and this restricted my mobility. In fact the ramp was not built very well when it was done, and had to be rebuilt.

Apart from the ramp, the only other structural error was the positioning of some of the power sockets. These were the right height, but difficult to get at in a wheelchair because they were too neat - the corners of the rooms. Other than that, I was very pleased with the way things worked out.

FURNISHING MY HOME

All this time I was sorting out the household fittings; organising decorations; thinking of care routines; and generally preparing for my new life.

I had no help with any of the furnishings and had to provide these myself. There is a grant available from the DHSS towards these but I was not eligible for this, as I had just over £500 in the bank. We managed to raise £400 from various charities after writing 72 letters, but the bulk of things came as gifts from family and friends.

KITCHEN PROBLEMS

Just before I moved in a problem arose over the Environmental Health grant. I was told that my kitchen did not qualify. I had already gone ahead with the fitting-out on the basis of a verbal agreement and now the officials told me that they could not support it. They wanted to withdraw the grant on the grounds that they felt it was not a ‘disabled' kitchen, even though it was the one most suitable for my use. I think the real problem was that I was the victim of the cutbacks. Later on, after I had protested vigorously, they agreed to pay a proportion of the cost. I had to find the rest myself.

ADDITIONAL COSTS

Throughout the six weeks that the work was being done I was visiting the house at least twice a week. This meant hiring a vehicle, paying for the petrol and finding a driver.

Also, the various expeditions to collect and deliver furniture had to be organised and financed. In one week I remember covering a distance of 300 miles just in the local area!

There was also the cost of phone calls, and other correspondence. And, for the two weeks before I moved, I paid the attendant who was helping me £50 a week. All these expenses had to be met from my limited savings.

THE MOVE

When the time came I was able to call on a lot of help from friends who packed boxes for me, and transported things. In fact there were two momentous trips when everything was moved.

My attendant moved on the Sunday night, and I moved in on the following Wednesday, the 11th of December. There were no carpets, boxes were piled everywhere, and the whole place was covered In dust After a few days, we realised we were not going to be able to live without carpets, as the dust was getting everywhere. I arranged for someone to do the carpeting over the second weekend. That made an incredible difference.

HOME

Despite the difficulties, I felt at home straightaway, though looking back at it, there were certain stages along the way when the home became more of a home. Putting all the carpeting down was the first step. Then getting rid of all the boxes from the middle of the living room, and then when I got some lamps put up.

It didn't take very long to establish myself and with my friend living so near, many other details, like dustbin day, milkman, and so on, were easily sorted out. In fact, the weekend I moved in I asked my doctor to come and visit me to see my new home, which was just as well because I had some problems. I am quite sure this was the result of all the anxiety and the build-up to moving in. Fortunately everything soon sorted itself out.

MY FIRST LIVE-IN CARER - LOTTE

Lotte was my care attendant throughout this period of change and she was very important indeed. I had met her earlier in the year when she had been working at Le Court. She had agreed to come and help me move in and set up home. We had quite a good understanding and I had warned her that there would be lots of pressures, responsibilities, and long hours ahead.

All in all, although there were difficulties and pressures, we got on OK: as we were able to talk things through, and Lotte is a very tolerant person anyway. She stayed with me for six months, so she really established me. I will always remember her because of that particular period. She was a part of something that was very special. She realised how important it was and how much it meant to me. She understood what was happening in my life. It was my own home, my own place. She truly appreciated the significance of the move.

At first Lotte had to care for me as well as carrying out all the other household chores and the business of building up a new home. I had not yet organised my other carers and we were still trying to find things, unpacking boxes, and so on. I think that if we had not gone to my parents for a week at Christmas it would have been too much. That was a good holiday for us and we both had a good rest.

John Evans in his new home, Petersfield, 1983

BEING PART OF THE COMMUNITY

Until I moved out, I had never realised how isolated I was in Le Court. It was a very remote existence. The routines and timetables dominate and hide what is happening in the real world. In your own home you have to be much more yourself. You, as a person, are much more exposed. You cannot hide behind the organisation.

Now I find that my social contacts are extending and I feel part of Petersfield. People drop in on me all the time, it's an inviting home in an ordinary road. It is a lot easier to go to the town centre than I had imagined it would be, and if I need any help once I am there, I can usually find it.

My neighbours have all been very helpful. There are four or five I can call on who would willingly come and make me a cup of tea, or get something out of the fridge and put it in the oven. I think there was some jealousy when I first came because I was a single person, and I was moving into a flat that was big enough for a young family with children. But now, as people have got to know who I am, and what I am doing, I feel most of the barriers are broken down.

Perhaps some people may be critical of the financial help I am getting from the Social Services, thinking that could go to supporting some old people, or something else. But it is not my fault that there are limited resources allocated to Social Welfare and that those in need end up fighting each other, that is the consequence of a deliberate political decision.

VALUE FOR MONEY?

As for my response to someone who questioned the value of adapting my house I would point out that a special building would have cost a lot more. The fact is that this house has been adapted in such a way that able-bodied people can still live in it after me. Of course I would always like to see it kept as a dwelling for Disabled People, because there is such a shortage of suitable dwellings for them anyway, but it is not exclusive. This property can easily revert back to the general housing stock.

Another point is that the "giving" is not all one-way. Apart from employing people, I am an asset to the community in other ways. Society at large is able to benefit. I am able to share my experience with other people. Not that I think I have to do this to justify my new position. I do it because I want to.

OK, I might be regarded as elitist and somebody who knows the ropes, and that is why I got where I am. But I think: my doing it is only a stepping-stone for other people who now might think of trying something similar.

Another thing, if I had not done this for myself, where would I be now?

REFLECTIONS

Overall my life since my move has exceeded all my expectations. I do not regret the change in any way. There was a part of me which feared I could not cope with being by myself. I was a bit worried that I might have a bad spasm or something and fall out of my chair, but I have put all that behind me and I really enjoy the times when I am alone. Even lying in my bed I do not get worried, as I have my alarm system. It is quite a nice feeling actually being by myself.

The quality of my life has changed enormously. It is to do with control and choice. I can be myself. I do not have to worry about conforming to other people's standards. It is my house and I am the boss. I can choose what I do.

I feel secure in my own home. It is mine, and I can close the door behind me, close the curtains at night, turn the TV on and just wade into the bliss of being in my own place.

I have left behind the anxiety of being part of a clinical-smelling, urine smelling, bells-ringing, system, with all the petty jealousies and manipulations that went on there.

It is so peaceful in my own home, even though there are pressures and a constant challenge. That challenge will go on because, whether I like it or not, I live with the thought that for the rest of my life I am dependent on other people. I am always going to have to be employing people, changing them, and so on.

I have my experience in the New Forest cottage years before to compare things with. This is a lot better, less of a struggle. I have the ability to pay for what I, need, and I am not relying solely on the goodwill of other people. I am not dependent on so few people.

If I had complaints they would be about money. Lack of money is very restricting. More money would give me a bit more freedom, more flexibility, and I could feel free to use more care attendants as I need them, and to pay them better.

At present if I have to go away to a conference it is tough asking one person to cope with all the travelling and care work involved. It would be far easier to take two.

As for whether I have changed as a person, I do not know. I probably have, but it is something I do not think about. I have certainly changed from what I was like when I was at Le Court, but I think: that was because I changed as a person during my time in the Home. That was a matter of necessity: I had to go out to the pub regularly and do those sorts of things because they were all ways of expressing individuality.

Now I do not feel the need to do that so much, I am quite content to be at home. I think I became somewhat introverted at Le Court, as I was so intent on defending my privacy. Now this is not something I have to worry about.

When I first came here I could hardly sleep, just the excitement of being in my own place again. Instead of just one tiny room in which I had everything - my work area, my office, my living room, my bedroom - now I have five different rooms. It is really quite extraordinary. One of the things that amazes me is how much more I can do now. I am not confined by tea times, and going to bed times. I really can work until I have finished.

I still resent having had to go into care in the first place and I wish I had left earlier, but that is easier said than done!

INDEPENDENT LIVING - THE PRACTICE

CARE DEVELOPMENTS

To begin with I was able to get by with a very tight organisation of three people. Mainly Lotte, backed up by two local people. It was almost an ideal set up. I would like to have a similar one the whole time.

Later in the Spring, I went through quite a difficult time. Perhaps this was a reaction to the uncertainty and stress of the previous six months, or it could have been the fact that Lotte was leaving and I was going to really become independent.

There followed a time of an amazing number of changes. I had six different main care attendants in six months! I purposely put myself through this insecure period and it taught me that I can survive. I can organise something even at the last minute. The ability to cope with this gave me real confidence. During this time there were two ten day periods when I had no main carer at all! I had people coming in who had never worked with me before. I never knew how it was going to work out from day to day. It was a challenge, I relished it. This was a great experience in terms of understanding my care needs and how I relate to them, but, I must say that I would not like to live like that for longer than ten days! Indeed, I keep my carers for much longer as a rule! Sometimes with attendants you look forward to when they leave, not in a nasty sort of way, but you look forward to a new challenge, the variety, the change, but you always know you are going to have to re-establish your routine again.

The care aspect of my new life has worked out remarkably well. I now have a lot more confidence and have not really had anybody who has been negative, or any real hassles. There have been some minor incidents and personality conflicts here and there but overall the theory of the Care Proposal has worked well in practice.

DAILY ROUTINE

At present my live-in attendant works a five day week and is off for two days. He or she gets me up three days a week, and puts me to bed four nights a week. For the rest of the time I am covered by people coming in on an hourly basis. However these details are not rigid. I like to feel that I am able to change things. When people come to work for me I make it clear that things are flexible.

If my care attendant goes away for the weekend I have to find someone who can stay with me, or come and cook meals. I can usually think round two or three people, and ring them a couple of weeks in advance. It is something that I am constantly aware of even though I have a well organised schedule.

It is quite a hassle having to constantly organise care. If I need to get cover, it means a lot of phoning around. Every week I look ahead to next week and think: What will be happening then? Which days does my care attendant have off? What have I got covered?

My system works well for me and I will probably stick to it, because I find it is easier to have someone living in. I can be flexible about the time I go to bed, more so than when someone is coming from outside to put me to bed.

THE ENVIRONMENTAL CONTROL UNIT

I now have an environmental control unit, but it took a long time to be installed. A year. It is a comprehensive unit. I always have it in bed with me. It has an alarm on it so I feel safe. I do not mind sleeping by myself, as long as someone is around when I need turning in the morning. The unit is very convenient to make phone calls on as well. I have a bank of 10 pre-programmed numbers, my neighbours, my doctor, things like that. I can also make dialled calls and answer the phone from my bed.

STAFF HOLIDAYS OR SICKNESS

My live-in carer has holiday entitlement according to the Witley Scale, which is one week for every three months worked. I cover the time of his or her absence with casual labour. So I pay double during the holiday. Similarly, if my live-in carer is off work through illness, then I would call in some of the part-time people. This extra cost was not built into my Care Proposal effectively enough. I did mention the idea of sickness and holidays, but there were no figures put down. I have learnt from this and make sure it is built into all the Care Proposals that I help other people prepare for themselves.

Finding someone to come in at short notice means calling around friends, or casual staff. I have no formal arrangement with the local Care Attendant Scheme. I have met the Organiser a couple of times and she has said that if I ever get stuck I can get in touch with her, but I do not think I will ever need to do so, as I have my own emergency list.

If I am sick during the five days when my full-time helper is working it is not too bad because he or she is in the house anyway. However, outside those days, I would probably need somebody to come in during the daytime and would try to use my regular helpers for this.

MY HOLIDAYS

If I go away on holiday I take my live-in carer with me, and sometimes, if I am away for a while I take somebody else as well. It depends on individual arrangements really: who you take, where you are going, what you are doing. For example, if I am paying for the holiday then I would take a helper who has agreed to be paid less than the full amount. This is all I can afford and is the only way I can take a holiday.

Ideally I need two people with me to be able to go away on holiday, and of course I would like to be able to pay for two people. But that isn't possible on my income.

FINDING STAFF

All my live-in staff searches have been through word of mouth. I have never used Job Centres or newspaper advertisements. It is all through friends, previous contacts, current care attendants, and so on.

One day I may well have to try other methods, but so far this has been sufficient. I have not had trouble recruiting casual people this way either though I find the evenings are slightly harder to fill than the mornings.

LOCAL CARE STAFF AGENCY

At the moment I do not feel there is a need for a local care staff agency. I think I am perfectly capable of identifying possible staff. There again, if something like that existed, I suppose it would be helpful to some people. In truth, the more ways of finding potential staff, the better.

CARE AGENCY: THE SPINAL INJURIES ASSOCIATION

I have used the SIA Care Attendants from their Care Attendant Agency. On both occasions only for a limited period and of course I paid the Attendant. I helped set up the agency and wanted to have direct experience of it. This source of Care staff is one that I would always have at the back of my mind, but I would be reluctant to use it often because there are other people more in need than I am. It is definitely a very worthwhile resource.

CHOOSING STAFF -THE INTERVIEW

The selection of an employee is based on a gut feeling in the end, but I have a list of questions that I use to help me approach people, and screen them. I want to find out as much about a person as possible, and at the same time I want to let them know a bit about me. I can usually sense what sort of a person they are by noting the things they ask questions about. I observe their reactions to things I say and can soon tell if they are really interested and eager about the job.

For a live-in carer I look for somebody who is responsible, trustworthy, respectful, flexible, physically able to cope with the lifting involved, able to drive, and preferably able to cook reasonably, although I can always help people with that. I also like them to be self reliant and able to get on with their own lives.

With part-time people I am more tolerant. You are not going to find the abilities I mentioned in everybody. Each person is different, some are more reliable, some are more responsible, clean, tidy, and so on.

AGE

Up until recently my live-in staff have been aged between eighteen and twenty five, but the present one is thirty. I do not think age is very important.

PREVIOUS EXPERIENCE

If somebody has done care work before, the training process tends to be quicker, but previous experience can mean people come determined to tell me how things are done. It is usually better if possible carers have had no previous contact at all with care work, so that they start on the basis that I am responsible for myself. This applies particularly to live-in staff.

TRIAL PERIOD

When somebody comes to work for me, even though I may have known them before, they have a month's trial period. This provides a safeguard for both parties. The situation has never arisen, but if somebody did not get on well here, I think I would try and agree to make it even less than that. If somebody is not very good then hanging around too long would not be helpful, because it would make life unpleasant for both of us.

STAFF: LENGTH OF STAY - LIVE-IN

Six months I think. Maybe a bit longer, depending on the type of person, and how well you get on. But I find six months a happy medium.

Anything less than six months can be a bit too changeable, although change and variety is quite nice. Anything more than six months, then obviously that person needs to be fairly amiable.

LENGTH OF STAY - CASUAL STAFF

Some of my casual staff have stayed longer and it is no problem because they only come when I need them and do not stay in my home.

I have had two for eighteen months. There is no reason why casual staff cannot stay longer, provided they want to, and that I am happy with them.

LIVE-IN STAFF COSTS

The live-in staff and I share the cost of food. He or she also pays towards heating, and wear and tear, and so on. I do not think this covers the real cost, especially in winter when the heating is high, but even If I was living by myself I would have the heating on anyway. Obviously phone bills are something we detail separately.

COPING WITH NI AND PAYE

My live-in carer and I usually deal with NI (National Insurance) and PAYE (Pay As You Earn) together. I am quite happy as long as I know what is going on. I get him or her to fill in the forms and then I check them. It is a lot easier getting people to learn how to do it for themselves, and it saves them an idea about something they probably never have anything to do with normally. At the beginning it was confusing, with things taking more time than necessary. Even now it is a lot of paperwork. It takes 20 minutes or so to fill in the forms. Every now and again we might need to look up something. I have *a* number of helpful documents, also if necessary, I can ask a colleague, Liz, for advice.

INSURANCE

I have an addition to my home insurance, which covers me for negligence if someone is working for me, and also protection for myself from other people and vice versa, for injury. It is an extra premium of £20. Something else I didn't put in my original Care Proposal!

RELATIONS WITH SPONSORING AUTHORITY

My "case" was "reviewed' for the first time earlier this year by the Social Services. It was done through my Occupational Therapist. I was formally invited to discuss a number of aspects of my needs and their funding. It was a good opportunity to show my Occupational Therapist many of the things I had missed in my original proposal, like holidays, sickness, etc. I was able to introduce these onto future calculations. Hopefully this procedure is going to be repeated every year.

Le Court, the body responsible for transferring funds from the sponsoring authority to me, have no other role in my life. They just handle the money and that is it. Obviously they retain a friendly interest but nothing else. They respect my privacy.

My arrangement with Le Court is like an agreement between two people who know and trust each other. Their role is necessary because of a law forbidding Social Services departments from making Direct Payments to clients. It is all rather silly really and everyone concerned would like to see a change in the law. In the meantime I would not have been able to leave residential care without the willing, co-operation, of a body like Le Court.

Independent Living Movement in the UK

John Evans in Alonso, J. Vidal Garcia. *El Movimiento de Vida Independiente, Experiencias Internacionales* (The Independent Living Movement: International Experiences), 2003

Chapter One

1. Origin of Movement

1.1 The Early Days

The origins of the Independent Living Movement in the UK go back to the late 1970s. Disabled People in the UK, like many other Disabled People in other Countries were very disenchanted by the services being provided for them at this time. Disabled People felt the services were paternalistic, institutional, second-class, too medically orientated and out of touch with their real needs As a result of this they looked elsewhere for solutions to overcome their restricted predicament and living conditions. This led to a number of Disabled People finding out about Independent Living which consequently led them to visit the USA, researching into their Independent Living Movement in terms of how it started, what it did and how it developed. They felt the concepts, ideas and philosophy of Independent Living were very significant and appropriate, and would be helpful and innovative in the UK and point a way forward for Disabled People in the future.

During 1980 and 1981 a number of leading and key individual Disabled People were able to raise funds so that they could travel to explore looking into the Independent Living possibilities in the USA, particularly in Berkeley California, which is where the first Centre for Independent Living was established. These people included Vic Finkelstein, a radical activist, sociologist and founder of UPIAS, (Union of the Physically Impaired Against Segregation) which was largely responsible for the conception of the social model of disability, Rosalie Wilkins, a TV presenter of a disability programme and disability activist, and John Evans, one of the founders of Project 81, an innovative scheme to help Disabled People get out of institutions and at the time living in an institution himself. These 3 were followed by many others in later years. It was not only Disabled People from the UK who went to America, looking for answers and inspirations for their situation at this time, as many other European Disabled People did so in their quest for

Independent Living too.

1.2 From Institutions into the Community: Roots of the Movement

Some of these Disabled People were also living in institutions trying to find ways in which they could move out into the community. This is where the roots of Independent Living in the UK started, by enabling Disabled People to move out of institutions unlike their counterparts in the USA, who started Independent Living while studying in university, because the universities had a programme of personal assistants to support the disabled students. There were also some university-based schemes in the UK which encouraged Independent Living through using personal assistants which I will refer to later.

The most notable group of these Disabled People planning their way out of institutions at this time were a group known as ‘Project 81’. This was a group of Disabled People living in Le Court Residential Cheshire Home at Liss in Hampshire in southern England. They formed ‘Project 81’ in 1979 and used this title because 1981 was designated the United Nations International Year for Disabled People. They felt that this would be a significant year in helping them promote the cause of Independent Living and would be helpful for them in achieving their aims of moving out of the institution. Why were Disabled People living in institutions at this time anyway? This was simply because if they did not have families to support them, or did not want their families to support them, or did not have the money to privately pay for the support they needed, they were left no other alternative but to be incarcerated in an institution as there was no other choice.

After returning from the United States with the ideas and expertise learnt from the USA’s Independent Living Movement, Disabled People in the UK were able to apply Independent Living ideas and principles within a British context. This meant that as the political and social policy systems of the Countries were different, Disabled People in the UK had to adapt an Independent Living system to fit into the Social Welfare State Model. What is interesting is that even though the political and social structures are different the principles of Independent Living are the same. Disabled People worldwide have a remarkable affinity with each other, especially those within the Independent Living Movement.

The pioneers of ‘Project 81’ were Philip Mason, John Evans, Philip Scott, Tad Polkowski and Liz Briggs, based in the Cheshire Home in Hampshire. They then went about applying the principles of Independent Living, i.e. asserting control about the decisions of their lives, empowering themselves, taking more responsibility about what was happening to them and developing their choices. They were then able to successfully negotiate a financial package which enabled them to move out of the institutions and into the community. They struck a deal for their freedom! This was achieved by coming to a social and financial agreement with their appropriate Authorities who were sponsoring them to live in the institutions. In other words their authority provided them with the amount of money, agreed through an assessment, which they could then use to pay for the support they needed through employing their own personal assistants. This enabled this group of people to move out into the community in the early 1980s. This was the start of Independent Living in the UK. It would change the lives of generations of Disabled People to come.

This was a huge achievement that took almost 3 years for them to convince their Authorities about the validity of making this possible. At this time there was a lot of paternalism around decisions being made about Disabled People’s lives by non-Disabled People, either in Local Authorities, Charities, or National Government. The process of changing minds and breaking down the existing patterns of social conditioning, organisation and habitual planning for a more forward thinking and alternative approach did not prove to be too easy. The Project 81 group went about it in a painstakingly methodical but pioneering spirit in order to influence and change the mind-set of the sceptics and the policy makers of that time.

At the same time when the ‘Project 81’ Group were attempting to come to a negotiated settlement to enable them to live independently in the community, they also embarked upon an intensive exploration of what other Disabled People were doing around the UK. They discovered that there were other groups of Disabled People with similar aspirations and ideals, around the importance of developing the Independent Living ideas and philosophy, in order to empower and transform the lives of Disabled People in the UK.

One of these other groups were based in Derbyshire, who had also been successful in moving out of residential care and establishing a shared living scheme in the community with the support of a Housing Association. This was called the ‘The Grove Road Scheme’ based in a mining village called Sutton-in-Ashfield. It was set up in 1976 by a couple called Ken and Maggie Davis. Their living arrangement was a complex of flats, with 3 flats for Disabled People downstairs, and 2 flats for non-Disabled People upstairs. Part of the agreement for living in these flats was that the non-Disabled People living upstairs would help and assist the Disabled People downstairs. There was some payment – but as benefits were small, payments were also small. This was a shared arrangement which enabled Disabled People to move out of residential care, but in the end the Disabled People realised that it did not always satisfy their needs of living completely independently in the community, so this group then later moved into their own individual homes. Ken and Maggie Davis later became two of the key players in establishing and developing the Derbyshire Centre of Independent Living which went on to become known as the Centre for Integrated Living. They were also key figures and instrumental in developing the national Disability Movement.

1.3 The First Centres of Independent Living (CILs) in the UK

As a consequence of the achievement of ‘Project 81’, this group of people then naturally felt that they wanted to share their experiences and change of life style, with other Disabled People seeking similar solutions to their lives. They then got together with a number of other Disabled People in the community, some of whom were students, and included Neil Slatter and Simon Brisenden from Southampton. In order to organise, structure and develop this process, they founded the Hampshire Centre for Independent Living in 1984, which was the first of its kind in the UK. This CIL was founded on similar lines to those in the USA incorporating the basic “Independent Living Principles”. This meant that the services provided would be available for all Disabled People regardless of their impairment, gender, sexual orientation, age, ethnicity and background. Secondly that the organisation should be run and controlled by Disabled People. This would ensure that it would have the right emphasis and focus to empower Disabled People to manage and develop their own organisation, and have its expertise around Independent Living issues which could easily be passed on to other Disabled People through advice, information, peer support, self help, sharing and training.

Two of the main focuses of attention at this time, were ensuring that housing and personal assistance were the two main core services that needed to be provided to help and enable Disabled People to live independently. The problem about accessible housing was particularly pertinent, because Disabled People needed an accessible housing environment in order to be able to live in the community. Personal assistance was also important because this was the essential support component the individual needs to be able to live and survive in the community.

The Derbyshire and Hampshire Disabled People involved in the development of CILs felt it was important meeting each other as regularly as they could arrange, so that they could keep the ideas and momentum going. This was as well as networking by telephone, correspondence and faxing, as at this point there were no e-mail communications as yet. This collaboration enabled both groups to prosper and develop a cross-fertilization of ideas. This helped them support each other strengthening their will and determination to secure a firm platform for their infrastructural development and to look at creating a national network and movement. Both Derbyshire and Hampshire established their Centre for Independent Living in 1984 and then started encouraging others around the country.

It is important here to highlight some of the key differences here between the Hampshire and Derbyshire CILs. As it was in Hampshire where Disabled People were first successful in negotiating their way out of residential care to live individually and independently in the community, this element of personal assistance and support became the focus of the HCIL. This was the area in which Hampshire would focus on, developing its expertise over the years, providing advice, information and support around personal assistance and Direct Payments issues. They also produced a Video, a number of articles and publications on the subject, and were the first to provide and publish a regular Newsletter covering the main topics. They also produced the first “Source Book Towards Independent Living in the UK”, which was the ‘blue print’ for Independent Living until superceded by other publications.

In Derbyshire their development was quite different. They based their approach on the 5 basic core services which were developed by the original CIL in Berkeley, in California. These were housing, personal assistance, mobility/transport, access and peer counselling. They also added to these, information and technical equipment including support. These became known as the ‘Derbyshire Seven Basic Needs’, which became a blue-print in the development of many of the CILs and Disabled Peoples Organisations in the UK. Later in 1989 the Seven Basic Needs were superceded by the ‘Eleven Basic Needs’ adapted by the Hampshire Coalition of Disabled People. These included employment, education and training, income and benefits together with advocacy.

During this time there were also a number of students trying to live independently whilst they did their studies. Taylor House in Oxford was a good example of this, as it was a communal home where 4 disabled students shared with 4 non disabled students, who in turn for living there provided the support and assistance needed by their fellow disabled colleagues. This model was later used by other universities and projects to help Disabled People study in university. There were other examples of universities that provided on site personal assistants to support disabled students. These universities included Essex, Southampton, and a few others.

1.4 Volunteer Schemes and Student Schemes

CIL developments were all based on Disabled People using paid personal assistance. Parallel to these schemes were a number of schemes using young volunteers to provide personal assistance. The best known of these was the Community Service Volunteers “One to One” scheme which started in the London Borough of Islington. Although this provided round the clock support, Disabled People did not get a choice of who worked with them, they had to accept whichever volunteer was assigned to them. For a number of Disabled People, volunteer assistance was a route out of residential care. This scheme was designed and set up by non-Disabled People. Later, Disabled People set up their own volunteer schemes (for example Independent Living Alternatives in London) where users had control over the scheme.

Some Disabled People were enabled to attend higher education through the provision of volunteer assistance. In the 1970s a handful of universities built specially adapted accommodation for disabled students, and provided volunteer assistance (e.g. Taylor House at Oxford) or limited paid assistance (e.g. Kulukundis House at Sussex). This gave some students their first experience of living independently, an experience they wanted to continue when they graduated.

Although these other schemes were not originated or controlled by Disabled People, they were providing support for Independent Living. This swelled the numbers of people in the UK who knew they had a choice, and were demanding the right to Independent Living.

1.5 Initial European and International Networking

What was interesting, as Disabled People in the UK were trying to develop Independent Living and CILs, was that they linked up very early in this process with their counterparts in some other European Countries, particularly Sweden and Germany, who were also trying to establish Independent Living. This reverts back to as early as 1982. This was a significant year in that there was the first International Conference on Independent Living in Europe staged in Munich. This was the first time that European and American Independent Living activists were brought together. This proved to be extremely valuable for future networking and the development of Independent Living on both sides of the Atlantic. It was particularly relevant for the European development as much was learnt from the experiences already practiced in many parts of the USA.

What was fruitful about this Conference in Munich, was the way that contacts and networks developed between European Pioneers of Independent Living. This is where Philip Mason and John Evans met up with Adolf Ratzka, a disabled German living in Sweden who had studied in Berkeley. There was a great affinity between activists from UK, Sweden and Germany in particular at this time. Between 1983 and 1985 there was considerable contact between Adolf Ratza in Sweden, who was at that time setting up STIL which was their first Centre of Independent Living based in Stockholm, and the instigators of Derbyshire and Hampshire CILs, together with other emerging groups around the UK. This led to Ken Davis from Derby and Neil Slater from Hampshire attending the first Conference on Independent Living in Sweden in 1983.

This was reciprocated in the UK with its first Conference on Independent Living and attended by Adolf Ratzka and Judy Heumann, who was then the Director of the CIL from Berkeley, California. After these two Conferences there was a very close liaison and relationship between the UK and Swedish Independent

Living developments, which would form the basis for the beginnings of an European movement.

During these early developmental years a number of other CILs started emerging in different parts of the Country, which helped focus and develop Independent Living based Organisations. These included Southampton, Nottingham, Bristol, Islington, Lambeth and Greenwich in London and Lothian based in Scotland. Most of these developed around the local needs of the local Disabled People, and used the social model of disability and Independent Living principles to plan their development.

Adolf Ratzka speaking at first ENIL Conference, Strasbourg, April 1989

Chapter Two

2. Development and Evolution of Independent Living in the UK

In terms of the development of Independent Living in the UK, there were two other significant early developments, which led to an increase in the numbers of Disabled People running their own form of Independent Living schemes that are worth highlighting. These were the introduction of the Independent Living Fund and the formation of the British Council of Disabled People (BCODP) Independent Living committee.

A technical note on support for Disabled People in the UK
Since 1948, two sorts of support have been available – “care” for those in need and welfare benefits for those in poverty. Care is administered locally and benefits are administered nationally. The 1948 law made it illegal for local authorities to offer cash instead of care. Much of the struggle for Direct Payments in the UK was a struggle to overturn this bit of the law.

2.1 Independent Living Fund

Firstly the introduction of what is known in the UK as the Independent Living Fund (ILF). This is a national fund set up by the Department of Social Security, which is the provision of money specifically for enabling Disabled People to live independently. This Fund came about because of a major change in the benefit system in the UK. Between 1984 and 1986 many Disabled People who had begun to live independently, were able to do it as a result of using money either from their Local Authority or from the State Benefit called the ‘Domestic Care Allowance’, or in many other cases, a combination of both. When the Benefits System was changed in 1986 the Government decided to withdraw the Domestic Care Allowance. This outraged Disabled People in the UK, as this reduction in benefit threatened to restrict the development of Independent Living Schemes. The Disabled Peoples Movement then organised a campaign to challenge this. This campaign was extremely successful and the Government announced in 1987 that it would bring about the introduction of the new Independent Living Fund which would replace the previous allowance.

When the Independent Living Fund started in 1988 it was slow to get going, but after a while there was a big increase in those subscribing to it. This was partly due to the reason that it also helped some of those Disabled People living in areas where the authorities were not prepared to run Independent Living schemes, because they still felt they were illegal. The Independent Living Fund ended up being a great asset, because it provided more flexibility and money for the individual in organising their support. The Independent Living Fund also helped some people who already had an Independent Living scheme, by providing more money as a supplement to their existing arrangements. This allowed them more flexibility and choice in how they operated their schemes.

The Independent Living Fund was a compensation based on the success of the Indirect Payment schemes which were being operated by the Local Governments around the Country. The ILF is a national fund provided by DSS, national Government, and a Direct Payment is provided by Local Government. An individual can receive a combination of both.

The development of Independent Living schemes which now are more commonly known as Direct Payments schemes, was probably one of the most crucial developments in strengthening the infrastructure to mould the schemes into the framework of the social policy systems of the Country.

2.2 BCODP Independent Living Committee and the Direct Payments Campaign

The second significant development was the formation of the BCODP Independent Living Committee. This was a group set up particularly to focus on Independent Living issues. Its primary objective was to change the law in order to make Independent Living schemes more available to all Disabled People.

The Direct Payments campaign in the UK was started in 1989 by the BCODP Independent Living Committee as its primary objective. BCODP (British Council of Disabled People) is the national, democratic, representative organisation of Disabled People in the UK. BCODPs Independent Living committee was formed as a result of the founding of ENIL (European Network on Independent Living) in Strasbourg in 1989 so that it could advise, develop, monitor, campaign and co-ordinate Independent Living activities and developments in the UK and also feed into the European scene through ENIL.

The founding of the European Network on Independent Living, ENIL was one of the most significant events in Europe for the Independent Living Movement. ENIL 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 and hence for the first time there was a co-ordinated approach for Independent Living at a European level.

L'Ancienne Douanne, Strasbourg, April 1989 (From left: Frances Hasler, Rachel Hurst, John Evans, Etienne d'Aboville, Carl Ford)

The Direct Payments campaign in the UK was initiated in order to change the legislation to make it easier for local authorities to establish Direct Payment schemes. The other reason why this campaign was started was because many Disabled People in the UK at this time who were running Independent Living schemes, felt that it was very unfair that many other Disabled People in other parts of the Country were not having access to these schemes. This was because they lived in areas where the Authorities saw these schemes as being illegal. This was precisely the reason why Disabled People felt so strongly about changing the legislation.

2.3 Direct Payments Schemes and the Legislation

The original individual Independent Living schemes were first set up in the UK in the early 1980s in Hampshire. Throughout the 1980s they developed slowly but they were still few in number and only operated in a limited amount of areas in the country. Most authorities were not keen to take on Independent Living schemes because they either considered them too risky or were cautious about handing over all the control to Disabled People. Direct Payment schemes represented for the first time a shift of power to

Disabled People. Most authorities who ran the schemes either did it because it was a new idea and way of providing services or had empathy with the Independent Living philosophy in terms of giving more choice and control in a disabled person's life. Other factors which restricted the growth and development of Independent Living schemes was that the legislation was unclear and open to varying interpretation which is why some LA did not provide IL schemes.

After Hampshire had been running Independent Living schemes for three and a half years, the authority suddenly reviewed the situation when the county Solicitor and Treasurer became aware of the uncertainty of the legislation and were poised to stop the schemes. Fortunately, at the same time a report came out from the Audit Commission, which is an independent organisation that monitors the performance of local authorities throughout the Country. The report highlighted the Independent Living schemes in Hampshire as being innovative and good community care practice. This proved to be the saving grace and, on hearing this, the county Solicitor and Treasurer then changed their minds and judgement and the schemes were saved and allowed to continue, much to the relief of the Disabled People on these schemes.

The reason for the confusion and the different interpretation of the legislation was because of a 1948 Social Security Act about Social Services provision. In this Act, it states that a local authority can only provide services and cannot provide cash payments, hence the stumbling block in the law. Even though Hampshire changed its mind there were still authorities who would not go ahead with Independent Living schemes which they regarded as illegal. The situation was made worse in 1992 when the then current Minister of Health, Virginia Bottomley, sent out a circular to local authorities stating that Direct Payment schemes were illegal. This exasperated the situation and even authorities who had been running schemes up until then, suddenly withdrew them. This is why the Direct Payments Campaign was so important in order to change the legislation and clarify everything in black and white. The way local authorities got around this was by paying the money into a third party i.e. a disability or voluntary organisation for instance, and then they would pass the money onto the disabled individual. It was a kind of loophole in the law to enable the authority to provide cash to the individual instead of services.

2.4 Direct Payments Campaign and Lobbying for Change

The UK Independent Living movement believed that Direct Payment schemes should be as of right, and that is why a change in the legislation at this time was the second most important priority in the issues of Disabled People, following the first priority which was the introduction of comprehensive Civil Rights Legislation. In the early 1990s when BCODP Independent Living group embarked on its Direct Payments campaign the Independent Living committee got together with the Spinal Injuries Association and its Parliamentary Officer Fidelity Simpson, who was an expert in lobbying tactics and parliamentary affairs. This group then drew up a tactical strategy for bringing about Direct Payments legislation. Key Disabled People from both these organisations with direct experience of running their own schemes, worked together with Fidelity Simpson, targeting possible key allies of Members of Parliament and politicians who would support and fight our cause. A huge mail shot campaign was embarked upon, and many letters were written to local and national Politicians seeking support. Numerous awareness raising and briefing meetings were arranged and relevant publicity materials drawn up to disseminate publicly in order to make the issues clear. To support the campaign many articles were published in both the mainstream and disability press.

Not long after the campaign started, the group found a very keen and influential advocate and supporter. He was Andrew Rowe, a conservative MP. He fully understood what we were trying to achieve as he had first hand experience with one of his constituents, a disabled woman who was running her own Independent Living scheme and at the same time running her own business. This left a deep impression on Andrew Rowe who then decided to put together a Private Members Bill on Direct Payments Legislation. In British politics, a Private Members Bill is another way of attaining legislation that is not part of the Government's proposed agenda. It is a difficult way of achieving success, but over the years many innovative pieces of legislation have used this parliamentary procedure to achieve their results. It is long, arduous and prone to many pitfalls and political manoeuvring, especially if the Government does not support it.

Anyway, Andrew Rowe attempted this approach twice in three years and both attempts failed. During this time when Andrew Rowe was trying to progress his Direct Payments Bill, the campaign group organised a number of meetings with key politicians to try and influence them about the issue. These included the then current Minister of Health, and the Minister for

Disabled People. Both of these politicians expressed how much they appreciated Independent Living schemes, but neither were prepared to take serious action and publicly support them. Our understanding of the situation then was that the Treasury Department were not in support of this kind of legislation because of the economic argument of costing too much. They also felt that if these Direct Payments were extended the floodgates would open and the demand would increase dramatically which never happened. These developments exasperated the campaign group and the Independent Living movement and the BCODP Independent Living Committee then felt another course of action was needed to promote the Direct Payments campaign and develop its strategy in order to succeed.

However, all was not lost during this period as we were able to gain a lot of support from a number of important National Statutory organisations, in particular the ADSS, the Association of Directors of Social Services, who passed a motion at their annual conference, supporting the need for Direct Payments legislation.

2.5 The Way Forward through Direct Payments Research

After the failure of Andrew Rowe's Private Members Bill and the tactic of trying to influence prominent politicians, BCODP felt that the best way forward now would be to commission a piece of social policy research to come up with some good evidence about the cost implications and effectiveness of Direct Payment schemes and how they improved user satisfaction and quality of life. BCODP drew up a workable proposal to carry out this research and was then awarded a grant from the Rowntree Foundation to do this. The next step was to contract the Policy Studies Institute who are a very notable and influential research unit to do the work for us. We felt that by using the Policy Studies Institute the research would have an impact on politicians and other important policy makers because the Institute was highly regarded for its social research and independence.

Our research compared Disabled People using services with Disabled People using Direct Payments to employ their own personal assistance. It looked at the quality of support, at costs and at user satisfaction.

It found that Direct Payments offer Disabled People a higher degree of choice and control, and were more reliable than service provision. Service users reported much higher levels of unmet need than payment users. They were four times more likely to have difficulty in obtaining back up for regular support than payment users. They were less likely to have assistance delivered in the manner they wanted. These findings are probably not news to most people in the Independent Living movement, but it was useful to have them documented by an independent research agency.

On costs, our research found that support financed by Direct Payments was on average between 30 and 40 percent cheaper than the equivalent service based support. At the time of the research the average hourly cost for Direct Payments users was £5.18; for service users it was £8.52. There was a marked difference in overhead costs: payments schemes had between 20 and 30 percent overheads. We must remember that this piece of research was concluded in 1994, so these figures are now inaccurate because they have increased, although the percentages and differences and still roughly the same.

The research also found that people receiving Direct Payments had markedly higher levels of overall satisfaction with their support arrangements than service users. This was mainly due to the increased choice, control and reliability offered by Direct Payments. Like other studies, it found that the highest level of user satisfaction existed where users had advice from an organisation of Disabled People. In most cases these organisations are Centres for Independent Living, or Organisations of Direct Payment schemes.

Our research was the first study to combine the issues of cost and quality. It showed that on both counts Direct Payments are preferable, both cheaper and better. Information from our research was used by our allies in persuading the politicians to bring in Direct Payments. (We could not always get direct access to the Minister, but we had strong allies in the British Parliament and among Directors of Social Services who pressed our case.)

2.6 Government’s Official Announcement and the Movement’s Success

Interestingly enough, a week before the BCODP/PSI launch of the Direct Payment research findings, called "Cashing in on Independence", the Minister of Health announced that it was the

Government's intention to bring about Direct Payments legislation in the next parliamentary year. We were ecstatic! After five years of campaigning vigorously, we had achieved the beginning of our main goal. We were more than pleased that the research and the lobbying had the impact that we were hoping for. This announcement led to an intense flurry of activity around the whole issue of Direct Payments and a proliferation of seminars and conferences were organised by both policy makers and the Independent Living movement. Also, numerous research projects on Independent Living issues were instigated. At one of these conferences organised by the SSI, the Social Services Inspectorate, a number of Independent Living advocates met up with some key civil servants, who had been delegated the task by the Department of Health to research and work on implementing the Direct Payments change. From now on this association with Civil Servants was crucial in our deliberations and strategies.

The Government then set up a body called the Technical Advisory Group to work on the research and implementation of the Direct Payments legislation. This group then invited participants from a number of professional, statutory, voluntary and disability organisations to be part of this group. BCODP obviously, because of its expertise in this area, was one of three disability organisations invited onto the group. Jane Campbell, the representative from BCODP, was the only Personal Assistance user who had been running her own Direct Payment scheme that was on the TAG. The TAG group started in June 1995 and looked at all the key issues involved and worked on drawing up guidance for the appropriate Civil Servants and Government Ministers. It eventually drew up the Government's consultation document on Direct Payments, which was distributed out for comment. The Direct Payments Act 1996 was finally implemented 1st April 1997. This was a huge achievement for the disability movement who must take credit for this major shift in national policy, bringing about change and empowering legislation.

There were a number of issues in the Direct Payments Act which the disability movement were not very happy with. First we were keen Direct Payments would also be available for older people, but in the original legislation this was not the case. However, as before we fought the campaign and were successful in changing this legislation, and since 2000 older people have access to the Direct Payments. Another success about the Direct Payments Act was its inclusiveness right across the board so people with Learning

Difficulties, Mental Health users, people with HIV and Aids, Disabled People from ethnic communities and older people are now able to use it. I think including these groups was an important step forward in principle but unfortunately in practice the number of these people using Direct Payments is still very low.

The Government did not propose to set cash limits for how much can be paid. They proposed that authorities must give people enough to meet their legal obligations, such as paying National Insurance. However, this was not a very big concession. Workers in the UK have very few employment rights until they have been with an employer for two years.

The Direct Payments Act was originally "permissive" when it started in 1997 but now it is "mandatory" and Local Authorities must now implement Direct Payments legislation in law.

Other aspects we were concerned about were:

- support services, on which the Government are not making any directives and
- who may be employed as a personal assistant - the Government want to prevent people from employing close relatives.

The campaign was on two levels. We have worked with Parliament, allying ourselves with paid lobby workers from other organisations. We have also worked through our networks, getting our members to approach their Members of Parliament. Working with paid lobbyists has been a new venture for us. In the UK there are a large number of charitable bodies concerned with disability. Although they do nothing to promote Independent Living, they all wanted to comment on the Bill and to influence the Government. So we had to educate them about Independent Living at the same time as trying to influence the Members of Parliament.

Our biggest victory was to convince the Government that people with learning difficulties (intellectual impairments) should be included in the scope of the Bill. The organisation controlled by people with learning difficulties, People First, did some very effective lobbying on this subject.

During the campaign we kept our supporters fully informed so that they could contact their Members of Parliament to press our case for change. We wrote lengthy briefings to assist Opposition MPs.

Our research was helpful here, as it gave us good background material, but being in regular touch with Personal Assistance Users was vital, too, to get new quotes and up to date facts. This was our strength.

Throughout the whole campaign we responded not just to the Government but to social work and charity professionals who were concerned about Direct Payments. Some of them supported the Government approach, of making Direct Payments available to a small elite group. We had to argue the case for full eligibility over and over. We had to explain the principles of Independent Living over and over. We were helped by having very clear principles and a united Disabled Peoples Movement.

The Direct Payments Act 1996 was implemented on 1 April 1997.

The Direct Payments Act is a continuation of the Community Care Act 1990, which preceded it. This Act is very significant because it was the first Act of Law in the UK which seriously addressed the issues of support in the home, assessing the individual's needs and trying as much as possible to meet these needs. For the first time it focused on the individual's needs, and emphasised the importance of enabling Disabled People to stay in their own homes. This Act was a major breakthrough in UK Legislation.

2.7 National Centre for Independent Living

The National Centre for Independent Living was started in 1996. It was a project set up by the BCODP Independent Living Committee in order to promote and develop Direct Payments. It is funded by the Department of Health, and it is seen as a flagship for Direct Payments and for promoting good practice. Since it started it has had an enormous impact on the growth of Direct Payments through out the UK. This is because it has advised, informed and assisted many local authorities to implement Direct Payments. It is based in an office in London but it has many Consultants working all over the country, all of whom are Disabled People, and most of whom have first hand experience in Direct Payments. In this way they can target areas of the UK, particularly in the North of England, Wales and the South West, who have been slow in the uptake of Direct Payments in order to support them to do so.

The NCIL has its roots firmly based on the principles of Independent Living. This means it is an organisation run and controlled by Disabled People, and is inclusive of all impairment groups. It has an equal opportunities policy, which ensures that it inclusive of gender, ethnic group, disability, sexual orientation and age etc.

NCILs role in terms in helping to implement Direct Payments throughout the Country has been immense. It has assisted numerous authorities with Direct Payments Schemes, help set up Direct Payment Support Groups, run and controlled by Disabled People through out the country. It has also set up a Direct Payments Co-ordinators network which brings together all the different schemes around the Country twice a year. This provides a forum for constructive discussion and debate and allows for the interchange of good ideas and models of good practice. Over the years, the co-directors Jane Campbell and Frances Hasler have been engaged with numerous discussions, meetings and working groups with Government Officials, in helping the development of documentation on good practice guidelines, policy issues, and legislative matters on Direct Payments and related subjects.

Through its managing group the Independent Living Committee has also been instrumental in networking not only nationally with disabled organisations, but internationally, and particularly in Europe. It has been involved in a number of EU projects with other European Countries, and has liaised very closely together with ENIL and its member groups. It has been a web of hyper-activity and networking . It has set itself very high standards, and as a result has developed a high profile which has been highly regarded by the UK Government, particularly the Department of Health, which provides it with most of its funding.

Due to its ‘Breaking Barriers’ Project, NCIL has been responsible for blaze trailing Direct Payments to other user groups. This project has opened the door to people from black and ethnic minority groups, older people and mental health service users. These groups previously had very little access to Direct Payments support. This project has not only addressed the issues at a grass roots level, but has also involved the users themselves in the development of the project. It has also produced the first kind of documentation on Direct Payments for these groups. As part of the project it has also organised some Conferences for these different groups, which have been extremely successful and oversubscribed, showing that there is a great deal of interest in these new developments.

This is a point worth noting that the UK is probably the only European Country that is now advocating and implementing Direct Payment Schemes to these other user groups other than Disabled People with physical and sensory impairments, which is what the usual concentration of most Countries focus on.

NCIL was a logical development, which built on many years experience of Disabled People using payment schemes through out the country. It did not come out of the blue, but built on a wealth of expertise which became its focus, and consequently a repository for the further development and promotion of good practice around Direct Payments.

2.8 Funding Independent Living

The funding of individual Independent Living and Direct Payments Scheme is mainly organised from the Department of Health. However, each Local Authority has the duty and responsibility of delivering this. This means that the money will come out of the budget that is allocated for its Social Services. This budget covers all the services provided by other user groups as well, which includes not only Disabled People but people with learning difficulties, older people, mental health service users, HIV and people with Aids, and all other voluntary sector support. As well as this there is also the Independent Living Fund mentioned earlier, which is managed by the Department of Social Security.

The funding of Independent Living Organisations and Direct Payments Schemes can come from a number of different sources, Local Authority, National Lottery Community Fund, and different Trusts and Charities, and sometimes Private Organisations. The funding of these organisations has often been precarious and as a result of a recent research project, by the NCIL and the Disability Studies Unit of Leeds University, called ‘Creating Our Own Independent Living Futures’, highlighted that many of the Centres of Independent Living and Disabled Peoples Organisations were struggling financially, which is not an optimistic sign.

2.9 Seminars and Conferences

During the development of the Independent Living Movement, there have been a series of Conferences, that have occurred which have all played their purpose in enabling the movement look at what it has been doing in order to try to monitor and evaluate its progress, and at the same time looking for different ways forward for its future. The first CIL Conference of its kind held in the UK was in 1987, and this provided the first forum to look at what the different CILs throughout the Country were doing. Its main outcome at that time was to generate more enthusiasm and initiated in order to consolidate the movement to that it could continue to grow in the true spirit of Independent Living. This was a key time too, because exactly at the point when the Benefits System was in flux and the discussions about bringing the Independent Living Fund were originating.

The next important Conference of Independent Living was in 1993, in Hereward College in Coventry and Peterborough. This Conference was organised by Colin Barnes and Paul Lindoe, under the management of the BCODP IL Committee. The twin aims of this Conference were to develop further the principles of Independent Living and to introduce newcomers to the disability rights movement and in particular the operation of Personal Assistance schemes.

The need for this Conference emerged mainly because of successive British Government failures to introduce policy which would enable Disabled People to achieve meaningful Independent Living within the community. This meant Disabled People were still characterised by a life style of unrelenting poverty, social isolation, enforced and unnecessary dependence on support systems provided by family, friends and loved ones. For many it still meant a life style accompanied by the insidious fear of incarceration of residential institution in the event of break down.

The main outcomes of this Conference was more of a concentration and thrust on Equal Opportunities Issues, highlighting the main themes and difficulties for other groups accessing Independent Living, i.e. women, people from black and ethnic minorities, and disabled Gay people and older people.

Chapter Three

3. Where are we now in the UK with Independent Living and Direct Payments

In terms of where the UK has reached in its Independent Living development to date, is multi faceted. From those few early beginnings there are now approximately 5,500 individual Disabled People on Direct Payment schemes. There are very few of these who would regret this or would choose to go back to direct services being provided for them by another agency.

There are also about 45 organisations, who would either define or consider themselves as Independent Living Organisations. As well as these there are many other Coalitions of Disabled People who would see themselves as embracing the overall Independent Living Philosophy as prescribed by the 7 or 11 Basic Needs. There are also over 90 Direct Payment schemes operating in the whole country whose purpose is to implement and develop Direct Payments for users. All of these combine to create a strong infrastructure and network. Some authorities have individuals on Direct Payments, but do not have a Direct Payments scheme for support. In these areas people can often be isolated.

The Government has now quite a definite commitment to Direct Payments, and its Department of Health places a high priority on this and is carefully monitoring how the different Local Authorities are developing and increasing their Direct Payment schemes. What is also interesting is that one finds in the Government Policy and Practice Guidelines, that are issued and circulated to Local Authorities or published as National Documents, much of the language used one could say has its origins in the Independent Living Philosophy and definitions There is much mention on providing Independence, enabling people to live in their own homes until they die, developing choice and control of a persons life style, user involvement and participation in service delivery and planning, to mention a few.

3.1 Successes and Strengths

One of the key successes of the UK Independent Living and its outcome through the provision of Direct Payments, is the fact that it is now available to people with learning difficulties, people from ethnic backgrounds, mental health service users and older people. This is something we should be proud of, and it is a direct result of the focus the Independent Living Movement started to push for in the late 1980s early 1990s.

One of the strengths of the Independent Living Movement over the years has been its united spirit of the people involved in being able to work cohesively and harmoniously together. Interestingly enough it is surprising that there have been so few conflicts amongst this group, as it is not the case with the wider disability movement and its groups where the struggle for power has often taken precedence over the main core aims and purposes. The other strengths have been the clarity of its aims and objectives, which have been agreed and shared with common purposes in order to deliver its targets and achieve its ultimate aims.

3.2 Difficulties and Weaknesses

Its weaknesses have been lack of funding, conflict between being a campaigning Organisation or a service delivery one. This is a universal problem of the Independent Living Movement particularly in terms of its role and organisational priorities. Many CILs have laboured and debated through the problems involved in this dilemma.

Many of the CILs have been unable to function as effectively as they would want in terms of delivering the variety of services and meeting the demands of the local disability community, because many of these organisations have been under-funded. The lack of sources of funding and the difficulty of obtaining them has become a major stumbling block in terms of how the CILs can develop. We have also encouraged over the years that the organisations should not restrict their funding supply to just one funding agency, and should attempt that funding comes from a number of different sources. Many organisations have had to cut back staff and services after they have had their funding withdrawn. This has even closed some organisations down.

3.3 Challenges

As a philosophy I believe Independent Living is both inspiring and powerful. I believe that we have to use this powerful practice to help us keep control of our own Independent Living schemes and organisations. As always our strength lies in our unity. If we work together in this we can succeed, but we need to build more infrastructures and support schemes first to succeed, despite the challenges that may come from various authorities.

Let us remind ourselves of some of those threats and challenges:

- Firstly there is the Direct Payments legislation, while on the one hand it has spread Direct Payments into new areas, on the other hand it has made everything more bureaucratic. This means that there is more monitoring, reviewing and more paranoia about accountability about public money.

- The now common trend of cut backs in services due to tight budgets. Unfortunately Disabled People always seem to be the first to be hit by this. It often used as an excuse.
- Authorities who are insistent on a service resource led assessment approach, as opposed to a needs led approach, which hinders the development of Direct Payment schemes.
- The use and practice of rigid accountability criteria, which is applied as a controlling mechanism to ration service delivery.
- The dreaded introduction of charging policies in order to try and claw back more money from users to cover the cost of services. This has been one of our biggest challenges now for some time, and we still have a way to go to counteract this.
- The constant reorganisation of local authorities and the way they provide Social Services. We have been inundated with many legislative changes recently with local government reform, modernising Social Services and Best Value, to mention a few. All of these have been disruptive in developing Direct Payments because they have diverted attention, policy and finance.
- The lack of continuity of Care Managers, which has also been worsened recently by the current shortage of Social Workers. This has meant that we have lost key allies in Social Services when they have moved on. It has also meant that the assessment process in many areas has lacked consistency by the high turnover of Social Workers, long waiting times, and the incompetence of others.
- The recent development of the market place economy of Social Services provision of purchasers and providers. This has meant there has been more competition of providers of support services, which has often meant a deterioration in the quality of services. It has also made it more difficult for Disabled People to have control when run by other agencies.
- There has also been the development of the “consumerist” view of Direct Payments, as seeing it as “just another service”. This is usually from those, who did not experience the pioneering days and do not identify with the movement. We need to spread the message.
- There is also the apathy of our fellow Disabled People. Many do not want to commit themselves or get involved. Are they content? Have we failed to communicate effectively with them. It seems we need to redouble our efforts here.
- There is no requirement to provide advocacy or other

support for people who need assistance to manage Direct Payments.

- Last but not least, because Independent Living and Direct Payments have become fashionable there has been a proliferation of independent providers, which has meant Disabled Peoples Organisations have been competing for tenders to run Direct Payments schemes. This has become one of our battle grounds where we have seen many of our organisations lose out on the Contracts.

I do not think this list is exhaustive, but it does show what we are up against in terms of maintaining control over the very service that we created and developed from Independent Living.

The other difficulty there has been over the years is the tension of our understanding of Independent Living and what it means, and that of the service providers, as they do not always meet eye to eye. Our understanding of Independent Living is enabling a holistic and meaningful life of equal opportunity and not just an existence in ones own home, which sometimes can be an isolating experience. A service provider’s understanding is often based on a resource led approach which is more about hands on, getting up and going to bed, and these kinds of tasks which Disabled People would some times refer to as the ‘bed and breakfast syndrome’. In other words, basic survival not ‘quality of life’. We firmly believe that Independent Living has to be based on the principles of quality of life issues.

3.4 What Happens now and Where Do We Go in the Future: Maintaining Momentum and Control

In some respects from what I have just written, it appears to be an uphill struggle and there is much against us. What’s new! This has been the history of Independent Living. A history of challenges, negotiations, campaigning, lobbying advocating change and finding solutions. It is never easy trying to be innovative and positive in a system where Independent Living does not always fit smoothly because Independent Living brings into question many of the notions of the status quo and the question of power. Authorities have never found it easy handing power over to Disabled People. Our primary task now is to maintain control for the continuation of Independent Living.

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 to lose and 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 Direct Payments have 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. As well as this we are lucky to have NCIL as our central focus in the UK. NCIL needs to develop further in order to inspire other regional organisation and networks so that they can support their own local Disabled People through more Personal Assistance Support Schemes.

We also need to professionalise the Direct Payments Support Workers role by expanding them and keeping them in a peer support/counselling role and accountable to the disability community.

Over these last 20 years we have seen big advances in Independent Living and Direct Payment in this UK 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.

European Congress on Independent Living, Arona, Tenerife, April 2003 (Back, from left: Colin Barnes, Gerry Zarb, Frances Hasler; Front, from left: John Evans, Adolf Ratzka, Judy Heumann, Manuel Lobato)

John Evans and Judy Heumann speaking at European Congress on Independent Living, Arona, Tenerife, April 2003

Independent Living, Direct Payments and Civil Rights for Disabled People in Europe

John Evans – Speech at European Congress on Independent Living, Tenerife, Spain, 24th April 2003

Introduction

I am delighted to be with you here today at this very significant Congress which is the first of its kind in Spain. Indeed it is an historic day for the Disability Movement in Spain, particularly for those engaged in the development of Independent Living. We should see today as a celebration of the work Disabled People are doing pioneering Independent Living in Spain and throughout Europe. There is now a great sense of solidarity about what Independent Living is and its future. I think it is also significant that this Congress on Independent Living is in the European Year for Disabled People.

Independent Living is a civil rights issue and we must not forget it. Today we are asserting those rights and the struggle to develop Independent Living goes along with our struggle in achieving our full Civil Rights. We need stronger legislation in all our countries and at a European level to be able to achieve this. This will be one of the main focuses for ENIL in these coming years so that we can strengthen this link.

In my talk I want to cover why Independent Living is so important and why the development of direct payment schemes is a crucial part of transforming the Independent Living movement's philosophy into practice. I also want to briefly say a little about ENIL and the situation in Europe with a particular emphasis on the UK, because that is where I come from and have done most of my work. My presentation will highlight some of the key aspects of Independent Living and Direct Payments.

Independent Living

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 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 and choice for all Disabled People, the Social Model of Disability and the civil rights perspective, which makes it both practical and appealing. The key is that Disabled People uphold ownership of Independent Living, especially as it has become so fashionable for professionals. 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 life in the world and not 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 20 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.

Direct Payments

Now I want to say something about Direct Payments. Why are Direct Payments schemes so important? Direct Payments are the practical expression of how we put Independent Living into action. They are the means which help us achieve our goals. What exactly are Direct Payments?

What are Direct Payments

“Direct Payment is the money, which the disabled person receives from their Local Authority or the State. Direct Payments is a means to an end, and the end should ultimately lead to Independent Living, so that the disabled person can buy in the appropriate assistance and support, which they need. This means employing their own personal assistants who will provide them with the necessary support they require, as opposed to getting direct services from their Local Authority in which they will have very little control or choice over.”

These kinds of schemes have transformed the lives of thousands of Disabled People worldwide. In the USA, Canada, Australia, South Africa, Brazil, Europe and many of the developing countries. I know we are mainly concerned here today with the situation in Spain and Europe, but it is worth bearing in mind this international perspective when we are looking at the importance of these schemes. This is because when the original pioneers of Independent Living in Europe in the early 1980s were planning their schemes they were not alone in their endeavours, because at that same time Disabled People world wide were trying to establish Independent Living lifestyles in their struggles for inclusion into their own communities and control over their own lives.

In the UK and Europe generally we were certainly influenced a great deal by the Independent Living developments in the USA and in particular Berkeley, California, where the first CIL (Centre for Independent Living) was set up to help people with advice and support in Independent Living. We forged many links with our counterparts in the USA and in other countries and these exchanges proved to be invaluable in our initial stages in Europe. I personally was fortunate in spending sometime in Berkeley as did a number of other European Independent Living activists.

The formation of ENIL the European Network of Independent Living in Strasbourg in 1989 was a milestone for us. A European organisation that would champion the cause of Independent Living in Europe and thus able to network and exchange good practices, and help enable other countries establish Independent Living. We shall look at this more later.

Disabled People Moving Beyond the Medical Model

Direct Payments 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.

More significantly these schemes have helped Disabled People move away from their lives being dominated by the medical profession and its 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. As far as Direct Payments are concerned the proof I think is in the pudding and its successful track record everywhere clearly demonstrates this. It is also a far better use of public money.

In the UK now the Government has made the Direct Payments Act mandatory, which means that all Local Government Authorities must provide Disabled People with this opportunity if they are both willing and feel able to run it themselves. So we can see how well developed the infrastructure is now as a result of the Direct Payments Act 1996.

Where did Independent Living and Direct Payments come from?

I think it is important to put this issue into context and remind ourselves how and why these schemes started. It is significant in terms of individual Disabled People taking control of their own lives, as well as Disabled People collectively organising themselves in a unified voice, to improve their lot in their struggle for their full civil and human rights. This means not only the right to have control over basic daily living tasks - such as when to get up, go to bed, go to the toilet, when and what to eat etc., but also the right to have personal relationships, to be a parent, to have equal access to education, training, employment and leisure activities and the right to participate in the life of the community. The development of the Independent Living Movement is inseparable from that of the Disabled Peoples' Civil Rights Movement. Independent Living is a totally holistic approach to life: personal, social, economical, political and philosophical.

The unique and indisputable feature of Independent Living and

Direct Payment schemes is that they were created, designed, established and developed by Disabled People and not by professionals - hence the reason for their success. Disabled People are the experts in this field and always will be. They were created to enable Disabled People to have more control and choice in our lives, and to be involved in all the major decisions about our lives, with the ultimate aim of living intrinsically in the community with everybody else and not segregated in institutions. This is where it started. The situation has moved on from here but institutions are still a threat. Independent Living was and still is an equal opportunities issue. It should be for all Disabled People who want and choose it. There should be no distinctions regardless of disability, gender, ethnic background, sexual orientation or age.

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 for Direct Payments schemes and through the Independent Living Movements' network, a continuity for developing and improving them. As well as this and with the development of Centres for Independent Livings (CILs) and other organisations run and controlled by Disabled People, it provided an ideal infrastructure and framework to help support, inform and advise potential and existing users with their 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 best knows their own needs, 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 the scheme to be accepted by the Local Government Authority it then needs to be agreed in partnership with a social services representative so that it can then be put through the system. 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 the individual and the authority is a good basis for developing the schemes in a positive way.

Self-Organisation and Decision Making

Independent Living is all about taking control of ones life and developing more choices and options. This happens because the individual takes on the responsibility in all the decisions that affect ones life. The main notion here being the aspect of self-operated and self-directed. In other words all management, direction, organisation, supervision, training etc. resides with the disabled person, and all the decision-making processes that go along with this.   It was once said that Independent Living is about identifying choices, and being able to come up with alternative solutions when needed, and sometimes this requires the ability to be able to think fast and be well organised, especially in the case of an emergency situation arising this is of even more importance. It is the self-development that occurs in this process which is what real empowerment is about. Also the skills that are developed can ultimately help Disabled People into real and gainful employment as well as giving them more socially interactive life.

Quality of Life and Flexibility

The improvement in the quality of life is one of the main findings of research done in the UK by a number of researchers and in particular Gerry Zarb. In a piece of research called “Cashing In on Independence”, they found that one of the main features of Independent Living is undoubtedly the high quality of life and satisfaction which is 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. It has other spin offs like a more positive approach to life generally and good personal and social relationships which can be helpful in ones attitude and relationship to ones assistants. However people are people with an impairment or not, and we should not expect Disabled People to be more saintly than others, so they will have the occasional inter-personal and communicational difficulties and problems like everyone else, and hopefully will deal with them accordingly.

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 becoming a responsible employer and 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 of being an employer, like keeping records, doing the tax schemes, getting adequate insurance cover, drawing up job descriptions and contracts and conditions of employment for one’s personal assistants - there are also the practical aspects like advertising, interviewing, employing, training and supervising and directing employees 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 people it can be an on-going process and where the role of advocates and administrators can be an integral feature of some people’s schemes. This peer support was absolutely crucial when we first got our schemes going in the UK and still is. We would often help each other out in both advice and practice. It is not surprising that the highest numbers of people on direct payment schemes are where there are active organisations of Disabled People where there are Personal Assistance Support Schemes (PASS)

Empowerment

Already in what I have said I have outlined a number of areas where Disabled People have directly become empowered by living independently e.g. taking control of their lives, creating choices, being decisive and assertive, articulating their needs, being an employer, and being an advocate just to mention a few. As well as these more individual qualities there is also empowerment in terms of raising ones awareness and becoming committed to a cause and the politicisation that goes along with this process. This is certainly the case with Independent Living advocates and activists who are not only running their own schemes, but are committed to the objectives of the Independent Living Movement which is inextricably tied up with the campaign for equal rights, which as you know is gaining momentum everywhere.

I think there is more than enough positive experience and evidence to support the whole Direct Payments issue and campaign and personally I do not see any problems. The usual ones of accountability, abuse, exploitation of workers, irresponsibility, inability to cope, risk factors and so on will continue to prevail but as I said earlier the proof is in the many success stories and the numbers that have achieved it, both quality and quantity and at the end of the day it is still only up to those who choose to do it and that is how it should stay. I look forward to the day when Direct Payments are the norm for all who want them.

Independent Living in Europe

I would like to briefly end up by summarising the situation of Independent Living in Europe. After the inspiration which European Disabled People gained from the initial developments in the USA, in the late 1970s/early 80s small beginnings were made in Europe. From these early beginnings in the early 1980s we now see an extensive and varied picture of Independent Living with its different models and initiatives throughout Europe.

The first countries to develop Independent Living and Centres for Independent Living in Europe were the UK, Sweden and Finland. This was then quickly followed by Germany, Denmark and Austria, and later the Independent Living Movement became established in Ireland, the Netherlands, Norway, Italy and Belgium and now also in France, Spain and Portugal. The only two member states of the EU that as yet have to develop Independent Living schemes are Luxembourg and Greece, although Greece is currently part of a EU trans-national Independent Living Project, so hopefully we will see some progress here.

Obviously there are great variations in the level of developments in these countries and in some there is very little alignment with the overall affiliation and activity with the European Independent Living Movement through ENIL (European Network of Independent Living). In the case of Denmark, there are a number of personal assistance schemes in different cities, particularly in Arhus, but the Danish Disabled People have very little to do with the overall involvement in developing Independent Living through ENIL or the European Community. Recently we have also seen some interesting and exciting if small and significant developments in some of the central and Eastern European countries, e.g. Hungary, Bulgaria, Slovakia and the Czech Republic, and attempts are now being made in a number of others.

The reason why I have tried to briefly outline Independent Living developments in these countries is to demonstrate how widespread Independent Living is throughout Europe, albeit only on a small scale in a number of countries and operationally on many different levels.

John Evans at the 2009 'Freedom Drive', Strasbourg

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 in 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 is in control and management of the whole process. This also enables one to create opportunities and chances and as a result makes common sense and leads to a healthier lifestyle.

Today we can see Independent Living thriving throughout Europe in different ways, particularly in the UK, Sweden, Finland, Norway and Germany and many of the other Countries above are pushing forward. 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 Direct Payment schemes and Independent Living initiatives, as well as some bad planning and social policy.

ENIL tries to attempt to address some of these issues and is not only a network for countries who are active in Independent Living, but also tries 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 to lose and 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 Direct Payments have 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 20 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.

This conference is yet another reflection of the strength and growth of the Independent Living Movement. I am sure it will have its effect in influencing other Independent Living initiatives throughout Spain. I wish you well in your important work.

John Evans, ENIL
February 2003

John Evans with the Minister for Social Affairs, Valencia 2006

The Importance of CIL’s In Our Movement

John Evans – Extract from speech at ENIL Conference, Puerta Valencia Hotel, Valencia, Spain, 2nd November 2006

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 a 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 re-energised, 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 recognises 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 Independent Living Bill passed through Parliament. This work is being led by the National Centre of Independent Living, NCIL in co-operation 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 Heumann, 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 moto 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.

John Evans, ENIL
October 2006

John Evans, Valencia, November 2006

Independent Living in the UK - Developments, Accomplishments and Impact on Government Social Policy and Legislation

John Evans – Speech at 25 Years Independent Living in Sweden conference, Stockholm, 28th November 2008

Introduction

In this paper I would like to provide you with an overview of Independent Living (IL) in the UK since its formation in the late 1970s. I will highlight some of the significant times of this development but I would like to concentrate on the latter years from 2003 until today, as before 2003 much has already been recorded. I think the last five years of the IL movement are important because these are the years, which reflect the coming-together of the philosophy of the IL movement and the national Social Care Policies of the current UK Government. I believe, this experience is unique not only in Europe but probably throughout the world. In doing this, I hope to show you some of the accomplishments of the IL movement in terms of how it has been a decisive factor in the country's development of thought, policy and practice in the disability field and how this has also impinged upon the academic world and received public recognition in mainstream culture.

The History of the IL Movement

The origins, history and development of the IL movement in the UK have already been documented in detail in a paper (1) I wrote in 2003 for a Spanish publication (2) on the IL Movement worldwide. In order to come to an understanding of where the IL movement is today and how it has achieved this, it is worth highlighting some of the key strands, themes, events and attainments of the movement. This will also reflect how the legislation has changed and adapted as a direct result of IL.

Its beginnings can be traced directly back to a group of disabled individuals living in institutional care who refused to accept that they were destined to spend the rest of their lives excluded from the rest of society. This group was known as Project 81.

Project 81

The roots of IL in the UK are firmly embedded in creating an alternative solution to institutional care by Disabled People demanding control over their lives and all the decisions that go with it. It was a vision which at that time was not understood or accepted, but the Project 81 (3) group through their determination was able to decisively convince the social administrators of the day that it was possible to live independently in the community with everybody else. The late Rock singer Ian Dury named this group the “escape committee”. In the end, this group proved their critics wrong as IL began to spread rapidly throughout the UK.

The Project 81 group was able to live in the community because they successfully negotiated with their Local Authorities to receive a grant which they would use to pay for their support in the community. At this time, there were different interpretations as to whether Local Authorities could do this legally within the existing law. The problem, believe it or not, was due to the National Assistance Act 1948, as this Act stated that Local Social Services could only provide Care and not Cash. The way Project 81 and the Local Authorities overcame this dilemma was by channeling the money through a third party, e.g. charity, housing associations or voluntary organisations. The Third Parties would then transfer the grant into the individual’s bank accounts. Surprisingly enough, this arrangement would remain until the Direct Payments Act of 1996.

Independent Living activists were always uncomfortable about this because they felt it to be unjust. This meant that those Disabled People who lived in areas that did not have a Local Authority that was innovative, daring and willing to take risks were not able to live independently. These Authorities did not see the benefits which were gained through an independent lifestyle in terms of the improvement of the quality of lives of the individual.

Threat to Funding of Independent Living

This situation demonstrated the courage, the Independent Living advocates had in sticking to their principles. This all came to a head in 1986, when the county treasurer and solicitor of Hampshire got cold feet about the scheme and decided that it was illegal. By a stroke of good fortune, at exactly the same time the Audit Commission, which is a national body monitoring the services of local authorities, published an influential report, “Making a Reality of Community Care” (4), that praised Hampshire's approach and questioned the legal objection to it. As a result of this, the County Treasurer and Solicitor withdrew their threat and the scheme continued.

Some years later, in 1992, there was another fright when the Department of Health issued a circular instructing councils to stop all Direct Payments. Many councils did so, but Hampshire held its nerve. Thankfully, there were other councils in the UK who still persisted with their support for Independent Living despite the Government’s warning. I think these incidences show that by keeping their nerves, the local authorities were able to ensure the survival of Independent Living in the UK. It was not easy for the activists at this difficult time, being aware that their futures were precarious because of this legal uncertainty.

I think there are some other key areas worth highlighting which are fundamental to the Independent Living Movement and its development in the UK.

First Centres of Independent Living

Firstly, I think the other area that is worth pointing out is the emergence and founding of the first Centres for Independent Living. These organisations were able to provide an infrastructure of support, advice and information which could promote further Independent Living initiatives. They were endowed with an invaluable expertise, which was essential in supporting a sustainable framework to enable the movement to flourish. It was a collective approach which soon developed a dynamic network of different models of exchange, ideas and practices throughout the country.

The Derbyshire and Hampshire CILs were the first to be set up in 1984. These CILs were founded on similar lines to those in the USA incorporating the basic “Independent Living Principles”. This meant that the services provided would be available for all Disabled People regardless of their impairment, gender and background. These emerging years of CILs were an inspirational and challenging time because these organisations were run and controlled by Disabled People which ensured the right emphasis to empower them to manage IL. At this time, Disabled People in the UK gained much encouragement from their disabled colleagues in the USA.

Regular meetings were arranged between the Derbyshire and

Hampshire CILs and other Disabled People interested in developing projects in other areas, which kept the momentum going through the positive exchanges of ideas and strategies. This collaboration enabled both groups to prosper and develop a cross-fertilization of ideas. This helped them support each other in strengthening their will and determination to secure a firm platform for their infrastructural development and to look at creating a national network and movement.

The two CILs were different in terms of the models they established for themselves. However, this formed the basis of a framework in which other CILs were able to use when they were setting themselves up. It was not long until there were many CILs throughout the country as they developed quite rapidly throughout the 80s and 90s. There are now over 50 CILs or similar types of organisations operating within the UK. Over the last five years in particular, many have struggled due to severe financial cutbacks in many areas throughout the UK. Since the introduction of Direct Payments in 1997 most CILs managed contracts for Direct Payments support workers and schemes but again over recent years they have lost out in the tendering process to more commercial organisations and charities that are not run and control by Disabled People. There is a growing movement now to redress the situation and establish more User Led Organisations (ULO) in order to regain control of Direct Payments schemes and the new radical Personalisation Transformation of Social Care Policies of the UK.

The Independent Living Fund

The introduction of the Independent Living Fund (ILF) was absolutely critical in enabling Disabled People to have decent packages of support. This was because this National Fund provided extra money over and above what Local Authorities could provide. It was ideal for people with high support needs. The ILF was introduced in 1988. It came about because there was a big change in the Social Security Law in 1986. At this time Disabled People were outraged; as a benefit called the “Domestic Care Allowance” was removed. The reason for this was because many Disabled People used this benefit to top up the money they received from the Local Authorities. It meant that without this, many Disabled People who had established their IL schemes throughout the UK were faced with a crisis of survival. A movement of many different disability organisations was formed to protest against these Social Security changes. In 1986 London had its biggest ever Disabled People's demonstration to protest against these changes. Following this demonstration, there was a lot of political lobbying and direct action highlighting the adverse effects it was having too many Disabled People, who were suffering more poverty and struggling to maintain their support systems.

The Government then finally realised that it had to put something in its place to avoid further hardship. The ILF was established and immediately made it a big difference to how Disabled People organised their IL schemes. The ILF now provides support for approx. 19,000 Disabled People. The reason why it is so essential is because Local Authorities have a ceiling of how much they can contribute towards to somebody’s Direct Payments which is usually £ 250 per week and this does not cover people with high needs of support.

We are keen to maintain the ILF, with all the current new Social Care changes happening in the UK at the moment. We do not want this budget to go to the Local Authorities because we know they would not provide enough funding alone due to the restriction in their resources and eligibility criteria which they use to assess a person’s needs. These eligibility criteria are often service- and resource led and not led by an individual’s needs. This is the big battle of the IL movement to achieve a self-assessment approach which will overcome this difficulty.

This has proved to us the importance of a National Fund. We were not always convinced about this at the beginning. The main reason for this was because we had to go through two different assessments. Now with the current Social Care Personalisation transformation going on and introduction of something called Individual Budgets, it is even more crucial to receive this. The intention now is to put all the different strands of funding together. The main thing we have to ensure is that there are Disabled People who do not lose in their packages.

The more I think about this, the more I realise how big an achievement the ILF was, particularly now when we are going through such a radical Social Care transformation.

Disability Discrimination Act (DDA) 1995

I think it is worth pointing out the success of finally getting the DDA passed. This was a long painstakingly process which amazingly enough took fourteen years. It started in 1981 and every year until 1994, we had a bill trying to go through Parliament and each year it failed. At that point in time, the Government refused to accept that discrimination existed and always said that the best way forwards was not through legislation but through education. The disability movement refuted this situation knowing it was not realistic as this is what has been said for many years.

The DDA became law in November 1995. It was one of the fastest pieces of legislation that the Government has brought in. The Government was politically forced into bringing in some kind of legislation around discrimination because of the amount of publicity that was being generated by the demands for civil rights legislation and the embarrassment it was causing the Government because of this public exposure. It was a political compromise to counteract the more radical Civil Rights Bill sponsored by the Rights Now campaign that was going through Parliament at the same time. The DDA took only 6 months from beginning to end in becoming law which indicates how rushed a piece of legislation it was. This rush was due to the fact that the Government was getting very embarrassed by the demand of direct action which was occurring at this time which included the famous news broadcast scenes of Disabled People bringing traffic to a standstill in Central London, chaining themselves to the gates outside Downing Street and pouring red paint over themselves and the pavements as well as chaining them to the Parliament building.

Unfortunately the DDA was flawed from the start as being a weak piece of legislation which was unenforceable and was considered a drop in the ocean, as it was certainly not going to protect Disabled People from the many forms of discrimination which existed. It outraged the Disability Movement because it denied them the fully comprehensive civil rights legislation which they had worked so hard campaigning for, and consequently they refused to have anything to do with it.

The DDA, however over time, has had considerably impact on British society and has protected Disabled People from discrimination in the fields of employment, provision of goods and services, access to public buildings and services, more accessible transport including taxis. Disabled People's rights are now far more protected as they were, and it is probably the best "Anti-discrimination Legislation" than in any other European country.

Campaign for Direct Payments

We started the campaign to get Direct Payments legislation in 1989. This was because the movement felt uneasy about Disabled People not being able to access funding for IL, if they lived in certain parts of the country and did not have support of the Local Authorities. We call this the “Postcode lottery” in the UK. We wanted a law based on equality of need and not based on what part of the country you lived in.

It was surprising how quickly we achieved the Direct Payments Act in terms of how long it can take to get legislation through the Parliament, especially Disability and Human Rights Legislation. At least it did not take the fourteen years which it took for the Disability Discrimination Act (DDA). It was a great relief to us when the Minister of Health announced the introduction of Direct Payments Legislation in 1994. It did not come easy though. It took much campaigning, lobbying and hard work but the IL movement and our allies. We had four attempts of getting this new bill through parliament before it was finally realised.

It was surprising that some of our main supporters for the Direct Payments Act were from the professional social care fields, e.g. Association of Directors and Social Services (ADSS), Metropolitan Authorities (AMA) and Local Government Organisations (LGO). They proved a great ally, and together with the convincing piece of research done by the influential Policy Studies Institute (5), which came up with the findings that Disabled People were far happier having their own Direct Payment schemes, as opposed to having direct services from their local areas. It also showed that Disabled People had more control and choice over their lives, more flexibility and satisfaction and they were also cheaper to provide direct services. This research is what I think made the final impact on the Government in changing its mind to call for Direct Payments legislation.

Direct Payments in the UK

The Direct Payments scheme in the UK is seen as one the main successes of the IL movement. The reason for this is that it meant that Direct Payments was made available for all Disabled People regardless of their impairment. It did start with physically Disabled People but now is open to people with learning disabilities, Mental

Health users, older people and any other impairment group. It has made a huge difference to all these groups in providing more appropriate services for individual needs. The only group that has had difficulties is Mental Health users as there has been a lot of resistance from mental health professionals in supporting them to do this.

The fact that we were able to have Direct Payment legislation meant that there was a legal entitlement for this service. When the Act was first implemented in 1997, it did not force the Local Authorities to do it, so there were still many areas that went ahead with it. In 2001, this changed with the Social Care Act because then the Government specified that every local authority in the country had a duty to provide Direct Payments. The Disabled Children and Care Act 2001 then made Direct Payments available to sixteen to eighteen year olds and parents of disabled children as well as carers.

The success of Direct Payments has led to what is known as Individual Budgets. These are pretty much the same except Individual Budgets are intending to use other sources of funding, e.g. health, access to work and the ILF.

National Centre for Independent Living (NCIL)

The formation of the National Centre for Independent Living in 1996 also had considerable impact on the IL movement. It meant that we had a national centre to coordinate actions, meetings and the work of the IL movement around the country. It became a great groundswell of ideas. It organised regular meetings a few times a year which brought people from the different parts of the country together who were able to exchange ideas and practices about how each CIL or Direct Payments scheme did things. This forum became an action and learning group in helping different CILs focus on what strategies and directions they wanted to go in. This way, they were able to monitor quite carefully, how Direct Payments were being delivered around the country and the various differences of approach there were. As a result, bad practice was quickly shown up in some areas, which they were able to resolve. The NCIL was also able to put pressure on the Government in trying to influence change.

NCIL became a vehicle with which we could work with Government in helping develop Direct Payments and the IL philosophy. Regular meetings with different Ministers, helped to keep them informed with what was happening and was of an extreme importance in getting the Government on our side. We were able to get key Ministers to speak at major conferences and events throughout the UK. NCIL is still trying to fulfill this role and is having much greater influence. The only problem now which many other CILs and disability organisations are also facing is the lack of funding which it has. This immediately affects its capacity to be able to do everything it needs to.

John Evans with Tony Newton, Minister for Social Security and Disabled People, at NCIL Launch, 31 January 1997

Disability Rights Commission (DRC)
The Disability Rights Commission also had a key role in its brief existence from 1998 to 2007. In this time it achieved a lot in terms of developing policies and campaigns, especially on IL. It was influenced much by the movement and the work it did with NCIL.

We had key allies in the Independent Living policy unit, as well in the campaign and political departments of the organisation. The Parliamentary political team was very instrumental in working with the Independent Living movement through NCIL in drawing up for the Independent Living Bill. This has now gone through the Parliament for 4 years running and we will continue to push for this. Unfortunately at the moment the Government is not very supportive as it feels the IL Strategy which it released this year in 2008 is the way to go forward.

The DRC were also helpful in monitoring the DDA in terms of individual Disabled People experiencing discrimination in one form or another. Since the DRC has now merged with the Commission for Equality and Human Rights (CEHR), this momentum monitoring discrimination has slowed up. This is unfortunate. We can only hope it is temporarily phase when the new organisation is finding its feet, but I personally have my doubts. It is now the responsibility of CEHR to fulfill this role. The Commission has a Disability Committee that is supposed to cover this area. Only time will tell how effective this will be. The CEHR now consists of the three old Commissions, Disability Rights Commission, Racial Relations Commission and Equal Opportunities Commission. As well as these three areas it does cover Age, Sexual Orientation and Religion.

In its lifespan, the DRC were very good in drawing up many policies. There is a general feeling in the UK now that we have lost a key ally in protecting our rights and working along with this for the benefit of improving policies and good quality services. The same positive relationship has yet to develop with the new commission. However we do have people like Jane Campbell and others on the Disability Committee who are fighting our corner. The problem with the commission is that it covers all the areas of equalities so disability issues have been watered down. Exactly the same thing happened in Europe, with the horizontal approach to discrimination. When the new non-discrimination, programme developed with the European commission, disability NGOs, missed out on funding in the way that they were used to prior to this and the disability specific areas of discrimination were not adequately covered. I hope the same does not happen in the UK with the new commission.

Significant Advances in Terms of Influencing Disability and Social Policy

In the UK the Disabled People's Movement has always been political. It has tried influencing the Government whenever the opportunity has arisen. What has helped us is that the IL philosophy makes obvious sense and shows a way forward for Disabled People generally whether they are signed up to it or not. I think we have a rich history in the UK of disability politics of IL and an IL movement, which has constantly looked for answers and come up with creative solutions.

The IL movement’s lobby started in the UK as the Independent Living Committee of BCOPD, the national democratic representative of Disabled People’s Organisation. It was later continued by the work of the National Centre for Independent Living. It is this thread that has led us into interesting times now in terms of the Government using our language and ideals in many of its own policies. This was not an accident. I think, it clearly shows the power and common sense of the core values of IL and how it can now be included in mainstream policies.

One of the key disabled activists, who since the mid-90s have engaged in working for the Government on a consultancy basis in a number of different areas and departments, was Jenny Morris. Jenny has a long history in the Disability Movement and has written many books and articles on these issues as well carrying out significant works of research. She led the Independent Living Strategy developed by the Office for Disability Issues, which leads on the Independent Living strategy in the Department of Works and Pensions.

John Evans, Sue Bott, Frances Hasler and Gerry Zarb at ENIL Conference, Alicante, May 2007

Improving the Life Chances of Disabled People Report 2005

She worked for the Department of Health on a number of different projects during the 90s and was instrumental in formulating some key policy documents. The most significant change came when she was commissioned to do some work with the Cabinet Office directly under the Prime Minister in his Strategy Unit.

This Unit did an extensive study of disability in the UK, and one of the key areas, Jenny pushed for was IL. As a result of the considerable research and consultation in her work within the Department, the study concluded with almost a revolutionary policy document called “Improving the Life Chances of Disabled People” (6). I think this document was fundamental as being a catalyst for change, and the drawing up of the new current social care policies. It was greeted by the IL movement with excitement because of its wide ranging recommendations and potential beneficial outcomes to the disability community in the future.

The report highlighted a vision for Disabled People in the UK up until 2025. Amazingly enough, one of its main recommendations is to set up a Centre for Independent Living in every locality throughout the UK. This Report set out a vision for Disabled People to have full opportunities and choices to improve their quality of life, and to be respected and included equally by 2025. This is where the original proposal to have Individual Budgets was also introduced as one of its main recommendations, along with the setting up of CILs or User Led Organisations (ULOs) in each local authority locally throughout the country.

It also recommended the improvement of advice services available to Disabled People, and that the existing problems with suitable housing and transport should be addressed. This is also where Equality 2025 came from. Equality 2025 is a group of Disabled People which was set up by the Government to monitor and review policy and make reports. It was meant to be inter-departmental and would cover a number of different of key Government departments. It would be based at the Office of Disability Issues which was another recommendation from this report. This was part of the Labour Government Third Way of joined up thinking between the different departments. The Life Chances Report made 60 recommendations.

The Report gave a commitment that:

- Government Departments would model good practice in involving Disabled People. This led to the development of the Office of Disability Issues (ODI).
- User involvement protocols would be developed by public bodies in consultation with Disabled People, e.g. Association of Directors and Social Services (ADASS) and NCIL.

It also highlighted two other key issues which were transition and employment. This was quite a radical change, as it took disability out of the Department of Health and into the Department of Works and Pensions, as well as including other key departments. It wanted to achieve full equality for Disabled People by the 2025.

In many respects, this was quite a powerful vision, which has come from the Government. I think it is important to know that it would not have come without the direct involvement of key activists from the movement like Jenny Morris and her colleagues.

Baroness Jane Campbell speaking at the Butterfly Ball, London, May 2013

Jenny was not alone, as were many other activists playing the role in influencing and lobbying Government for positive change. Another figure was Jane Campbell who is now Dame Jane Campbell of Surbiton, who has a seat in the House of Lords, which means she is directly involved in working on all the major debates of Parliament. We also have a few other Disabled People in the House of Lords, who are working with her.

It is a very important position, as she is able to make amendments and comments on all the Acts of Parliament. She obviously concentrates on the key issues around social policy and disability legislation. Jane was also the first Chief Executive of an organisation which was set up to research and to highlight good practices that were going on in the social care field in the UK. This was called the Social Care Institute of Excellence.

“Our Health, Our Care, Our Say” 2006

Another key policy document which has a wide-ranging potential for the future of disability policies, is “Our Health, Our Care, Our Say” (7) which came out in 2006. The Consultation responses to this White Paper confirmed that people wanted access to support when they need it and they expect it to be available to them quickly, easily and able to fit into their lives.

Most of the main points of the previous Green Paper “Independence, Well Being and Choice” (8) which preceded it are included in the White Paper.

It also confirmed that the seven outcomes from “Independence, Well Being and Choice” would provide the central features for a social care model. These being:

- improved health
- improved quality of life
- making a positive contribution
- exercise of choice and to attempt and control
- freedom from discrimination or harassment
- economic well-being
- Personal dignity

“Putting People First” Concordat 2007

The importance of a holistic approach to Social Care policy is recognised and underpinned by “Putting People First” (9) This landmark Concordat was launched by the Minister of Health, Alan Johnson, in December 2007 where he emphasized that this was the most radical change in social policy for thirty years. He said now that we have to see social care as the individual being in control of his support and not the state intervening. This is a shared vision and commitment to the transformation of Adult Social Care. It is a Concordat which establishes a collaborative approach between central and Local Government. It sets out the shared aims and values, which will guide the transformation process of adult social care.

It was signed by six Government departments: the Treasury; the Department of Health; Department of Works and Pensions; Department of Communities and Local Government; Department of Innovation, Universities and Skills and the Department of Children, Schools and Families. It was also signed by a number of key organisations like the ADASS, CSCI, Social Care Institute of Excellence and Local Government Organisations (LGAs).

It seeks to be the first public service reform programme which is co-produced, co-developed, co-evaluated and recognizes that real change will only be achieved through the participation of users and carers at every stage. It recognizes that sustainable and meaningful change depends significantly on our capacity to empower people who use services and to win the hearts and minds of all stakeholders', especially front line staff.

In future organisations will be expected to put citizens at the heart of a reformed system. Incentives will include the new focus of the local performance framework, putting guidance on commissioning for health and well-being, Human Rights legislation, and any international obligations such as the new UN Convention on the Rights of Persons with Disabilities.

Independent Living Strategy

The IL Strategy (10) was the end result of two years of research, study and consultation among many stakeholders. It was led by the Office of Disability Issues and was guided by a panel of experts in IL which was chaired by Dame Jane Campbell.

The main points of the strategy are the following:

- We want to create a society where everybody is treated with dignity and respect and has the chance to fulfill their potential and unlock their talent. We need to ensure that Disabled People are a full part of this agenda.

- The Government is therefore committed to delivering on full and equal citizenship for Disabled People and sees IL as being part of the way we advance this. IL enables Disabled People to fulfill the roles and responsibilities of citizenship.
- This Independent Living Strategy sets out a strategy to improve Disabled People’s experiences and life chances. It is a cross-Government strategy because it is only through all Departments working together can we really deliver for Disabled People.
- It is the Government’s ambition that by 2013, Disabled People have more choice and control over how their needs for support and/or equipment are met. We also need to make significant progress in tackling barriers to Disabled People’s access to health, housing, transport, and employment opportunities.
- The personalisation of services is one element of the wider cross-Government Strategy on IL. Giving Disabled People greater choice and control over the support they need and the resources available to them is important, not just in social care, but across mainstream services as well – housing, transport, health, employment, education and training – and across all age groups, including young Disabled People in transition to adulthood and older Disabled People.
- We acknowledge that there is a gap between national policy and people’s real experiences. This Strategy will begin to fill this gap.
- The Strategy has been developed in partnership with Disabled People to ensure that it reflects their knowledge and real life experiences of the barriers to IL.
- The Strategy includes new investment from Government, and is also about using current resources in more effective and empowering ways.
- This is a five year Strategy and we will look every year at what progress we are making. We believe that this change can be achieved without new legislation but, we are committed to reviewing the situation if delivery does not happen.

The Role of User Led Organisations (ULOs)

The term ULOs was derived from the Government’s policies following the “Improving Life Chances” Report which recommended that CILs should be in every locality in the UK by 2010. Somehow, in the Government rhetoric CILs became ULOs even though a ULO is supposed to be modelled on a CIL!

User-led organisations can play a fundamental and important role in assisting transformation through Peer Support. There is nothing better than the direct experience of Disabled People, sharing their understanding and views of how things can change for the better.

ULOs can provide training in order to bring users up to speed with the new transformation process into Individual Budgets etc.

ULOs can provide an array of different expertise for new ULO's in their development of providing good quality services and support in local areas.

ULOs can ensure a good mix of different user groups and organisations, so they can support each other. This would mean including people with learning disabilities, mental health service users, older people's organisations and carers.

Used led organisations must have a crucial role in a new vision of IL. They can play an essential role in transforming social care so that services are driven by the needs and wishes of those who use them to deliver real IL. When resourced adequately, local User Led Organisations have been found to be the most effective and efficient means of delivering a range of services including advocacy, self-advocacy, peer support and supported decision-making. Services can be greatly improved by the people who use them, having a leading role in delivering, monitoring and evaluating services. User Led Organisations can play a key role in consultation processes because they have the knowledge base about issues around local service provision. They can also advise on practical issues on how to involve marginal groups in consultation.

Inter-agency Group of Statutory and Voluntary Organisations, representing the Third Sector, can also play a fundamental role in partnership with Disabled People's Organisations in bringing about positive changes in the Transformation agenda.

The new system of Individual Budgets is about promoting self determination, information, advice, advocacy and peer mentoring services will be an important part of enabling people to self assess their needs, apply for and use an individual budget. The new system needs organisations that understand the barriers to self-determination and are committed to helping people have control over their lives.

User Led Organisations are the right organisations to do this and the pilot areas are working with CILs or similar organisations where they exist. However, if the implementation of Individual Budgets is to be done in an empowering way for all groups of people with support needs then user led organisations representing all these groups need to be given a clear role. This is why there is a need for a network of User Led Organisations working together in each area.

User led organisations can also assist in the following:

- Involving people who don't usually get involved
- Increasing involvement of people who use mental health services
- Promoting user involvement to bring about change in local social care services

I think it is clear that if the Personalisation Transformation is going to be successful it will require true co-production and co-development with User-Led Organizations. If not, we will find ourselves going backwards instead of forwards into a positive future.

Conclusion

In the UK, we now have a rich and diverse amalgamation of key Government social care policies. The question is now, whether these will deliver real change at a grassroots' local level truly affecting the lives of individual Disabled People and carers. This remains to be seen. What I do know is that the IL movement is actively engaged in this process and committed in doing what they can in making this a reality. This will be one of our big challenges in the coming years.

Notes

(1) www.independentliving.org/docs6/evans2003.html.
(2) Alonso, J.V. (2003): "El Movimiento de Vida Independiente, Experiencias Internacionales". Madrid.
(3) "One Step On", HCIL publications, 1986. http://www.leeds.ac.uk/disabilitystudies/archiveuk/HCIL/one%20step%20on.pdf
(4) "Making Reality a Community Care", Audit Commission, 1986.

(5) Zarb, G. and Nadash, P. “Cashing in on Independence”, Policy Studies Institute, 1994.
(6) “Improving the Life Chances of Disabled People”, Cabinet Office Strategy Unit, 2005.
(7) “Our Health, Our Care, Our Say”, White Paper, Department of Health, 2006.
(8) “Independence, Well Being and Choice”, Green Paper, Department of Health, 2005.
(9) “Putting People first” Concordat, Department of Health, 2007.
(10) “Independent Living Strategy”, Office of Disability Issues, Department of Work and Pensions, 2008.

John Evans and PA at Rights Now rally, London 1994

Development of the Independent Living Movement

An interview with John Evans by the NCDP, a leading DPO in Greece, June 2011

http://www.enil.eu/news/3014/

1. Would you kindly describe the definition and the principles of Independent and Community Living?

There are many definitions of Independent Living which have developed over the years through the pioneering work of Independent Living activists of ENIL and other worldwide Independent Living organisation representing the different continents.

I think they are all united in the definition “that Independent Living is all about the disabled person taking control of their lives and being involved in all decisions that affect one’s life. It is deciding what you want to do, when and how, and how you go about doing it. It prescribes that the disabled person is in the position of self-direction and self-determination about what affects their lives. It is about Disabled People becoming empowered and being in power. The main principles are being in control and having a series of choices and opportunities in one’s life in order to enable the disabled person to live the life they want. It is also about equality of opportunity and equality of citizenship.

Independent Living means that Disabled People want exactly the same as non-Disabled People in having the opportunities for decent education, access to jobs, accessible transport system, a barrier free environment and being able to live in communities with others with appropriate accessible housing.

2. How long have you been involved with the Independent Living Movement and with ENIL?

I have been involved in Independent Living for a long time but not long enough yet! No seriously, I pretty much became involved with the Independent Living Movement at the outset of its origins in the UK even though it had already been established in the USA some years earlier in Berkeley California during the civil rights movements developments during the early 1970s.

I became involved in the late 1970s when I ended up living in an institution and decided that I wasn’t going to spend the rest of my life there. This was part of the story of the beginning of Independent Living in the UK. We developed a project called Project 81, as 1981 was designated as the International Year for Disabled People by the UN. It was a project we created to help liberate us from the institution and establish ourselves through Independent Living in our local communities. We started it in the late 1970s and by the early 1980s five of us were already living in the community by 1983. We felt that by using the UN International Year as a lever not only to promote the cause for Independent Living but to be able to show what Disabled People were able and capable of achieving as an example of good practice and how this good practice could change Disabled People’s lives for the better.

Following this success we then started developing networks throughout the UK with other Disabled People who had similar ideas and aspirations as ourselves. Those were extremely exciting times and can still send chills down my back. We had a vision and in a sense a mission to complete. We believed in what we were doing and we knew we were right and on the right path and wanted to take others with us. It did not take long until the movement started developing quite rapidly both in the UK and Europe.

Interestingly enough, it did not take us long to link up with other Independent Living activists in Europe and the USA to start establishing an informal network already in the early 1980s. I remember well many of us travelling from all over Europe and the USA to attend the first European and International conference in Munich in 1982.

3. How do you see the development of the Independent Living Movement in UK and in Europe? How should EU involve? Have you experienced different approaches in other countries?

We have come a long way in the development of Independent Living Movement in both the UK and in Europe, but we still have a long way to go. We cannot allow ourselves to be too complacent and we certainly cannot sit back and let others do it for us because

Independent Living is about self-determination and Disabled People taking control and planning our own future actions and development.

I think we can be quite proud of the development of Independent Living in the UK. I think we can be proud in a number of different ways. I think we have widely established Independent Living throughout the whole country. Obviously there are certain areas which are not as developed as others but this is often down to whether there are active Independent Living or disability organisations present or not.

I think we can put down that success of such diversity and practice of Independent Living in the different regions because of the introduction of Direct Payments as legislation in the 1990s. It did take us over 10 years to achieve this but it did break down the barriers of Independent Living only being available to certain groups of Disabled People. It also provided a duty to Local Government and local community areas to implement Direct Payments whereas before they could choose not to. The law until that point was always debatable and open to interpretation and only the more innovative authorities chose to provide Independent Living services. This meant it was extremely unfair because it depended on where one lived as to whether one received Independent Living services or not. The achievement of Direct Payments in theory then meant Independent Living could be available to all who wanted it regardless of impairment or where one lived. I think another reason why we can be proud is because we fought to make Independent Living available to all groups of Disabled People regardless of their impairments. This includes people with physical and sensory disabilities, people with learning disabilities, mental health users and both young and old Disabled People as well as people with long-term health conditions. This was a great achievement.

The other area which I think in the UK we have made enormous progress is by influencing Government. Again this took many years of lobbying and campaigning but it has had its effect. I believe we now have some of the best disability policies around Independent Living and personalisation, in other words the person being the centre of their lives, than in any other European country.

Independent Living now is central to Government and social care policy in the UK. I think it has also had its impact on other aspects of social care services. We have seen some really progressive Government programmes over the last eight years. However now, we have come to a crossroads following the banking crisis and the current economic situation we now find ourselves in. We have some great challenges facing us now to ensure that we do not go backwards after the great progress we have made over the last 30 years and more.

I think in Europe as well Independent Living has progressed substantially. ENIL has obviously played an extremely important leadership role in developing networks throughout Europe. However, I think the whole philosophy and practice of Independent Living has been strong in many European countries for a long time. There are obviously great variations between North and South European countries and ENIL is committed to trying to help develop and support Independent Living in Central and Eastern European countries as well. We would like to spread it as far and as wide as possible.

As far as the European Union (EU) is concerned it certainly took them a long time before they fully took Independent Living on board as a serious policy and strategy issue for Europe and the European Commission. ENIL worked extremely hard, in fact since 1989, trying to achieve this and it is only in the last six years or so when Independent Living was finally introduced into the Disability Action Plans of both the European Commission and the Council of Europe we have started to see some serious changes for the better. There is now a much stronger sense of it being inherently included in the wider disability strategy. I think there is also more understanding within both the European Commission and the European Parliament. Of course, we still have more work to do here with the ever-changing faces and personalities of people working within the Commission.

I do still think they could do much more in helping to influence and bring about more Independent Living developments in those EU Member States where Independent Living is still struggling. We will certainly be working on this over the next years as we have been now for some time as we are fully committed in making Independent Living available throughout Europe and this is beyond the EU as well. We do not have EU boundaries in our work.

4. How difficult is it to enforce a transition from institutions to community-based alternatives? In which states are there

examples of good practice?

I can assure you that trying to bring about alternative community-based structures as opposed to institutions is not easy. ENIL has been working on deinstitutionalisation since it was set up and this has always been one of our primary targets. In the last eight years or so ENIL has worked collaboratively in partnership with other European disability NGOs and helped set up the European Coalition of Community Living in 2005 to help drive this work forward.

It is hard bringing down institutionalised thinking and changing policy-making as it is a question of changing the hearts and minds of politicians, social care policy makers and sometimes local communities trying to understand the issues of inclusion. This does not always come easily when people have often been conditioned into certain set patterns of behaviour and living historically for long periods of time.

I think the best examples and practices of good models on deinstitutionalisation can be seen in some of the Scandinavian countries in particular. I would highlight Norway and Sweden in this. You also have to be very careful not to believe that everything is okay in our own backyard in both Western and Northern Europe and that the main need for deinstitutionalisation is in Central and Eastern Europe because this is not always the case.

Over the last few years we have seen some terrible conditions of abuse and violation of Disabled People rights in institutions in Holland, Belgium, France and the UK to mention a few. Only months ago in Holland it emerged that a mental health user was chained like a dog in order to inhibit and limit his movements. As you can imagine this caused outrage and had major publicity on Dutch television. I do not think any country is sacrosanct here in how they treat Disabled People in institutional living. This is why we are so determined to do something about it. The work of ECCL (European Coalition of Community Living) is still continuing under the work and leadership of ENIL. There is a need for much more progress in Europe in this. We have recently highlighted in a publication “Wasted Lives, Wasted Money and Wasted Opportunity ” (ECCL 2010) how European Structural Funds money has been used or rather misused for the building of new Institutions and worse still for renovating existing Institutions.

5. What kinds of initiatives have been taken, or are on – going, in order to put deinstitutionalisation on the European Agenda?

I said earlier that ENIL following its inception in 1989 embarked upon the process of challenging institutional living because it was exactly the opposite of what Independent Living was. Institutional living often denies Disabled People some of their basic human rights and basic decisions about their lives in what they do. Independent Living has always been the alternative and answer to institutions.

Recently we saw the founding of the European Coalition of Community Living which as I mentioned earlier has been working extremely hard trying to help bring about good practice and highlight bad practice about institutionalisation. This involves a number of other key players and stakeholders particularly the main European disability NGOs. However, ENIL has taken the lead in this work of ECCL thanks to being supported by MHI (Mental Health Initiative) of the Open Society. ECCL has managed convincingly and effectively to keep deinstitutionalisation and the desperate need for developing community-based services on the agenda at a high level with the European Commission and European Parliament. I think the main point here is that the initiative originally came from grassroots Disabled People and their organisations and ENIL was at the forefront of this before others even thought about it.

We shouldn’t forget either that the European Commission has also funded a number of important studies in this field over the last eight years which has helped make progress in identifying the situation of Disabled People institutions in Europe. These major studies have transformed thinking on this. These studies were the “Included in Society” 2003 and the previous Commissioner for Employment in and Social Affairs, Commissioner Spidla, also lead an initiative by setting up an European Expert Group to do a report on how best to go about deinstitutionalisation. This group has been continuing to work together over the last three years and is still engaged in the process. ENIL/ECCL and other European Disability NGOs are an important part of this group.

I think we can also say that over last few years the European Fundamental Rights Agency (FRA) are also taking an interest and have now started funding projects to do some research and studies in this area. They are also keen to include deinstitutionalisation and the development of community-based services in their future Annual Work plans and programmes.

6. In the midst of the economic crisis, is political commitment the only necessary prerequisite for a State to enforce the transition mentioned above? Could you describe what the consequences are in UK and in Europe, due to economic crisis, in Independent Living?

I do believe that in such an economic crisis which we are going through right now a political commitment is essential and a necessary prerequisite for the State to enforce transition to community living. I do not think it would work without a political commitment both on a national and local level. It is hard enough anyway to achieve and usually it is only progressive policymakers who are prepared to try and put their ideas into action as a direct result of being influenced by the Independent Living and disability movements on the importance of community living particularly through Independent Living.

I think the consequences in Europe and the UK right now due to the economic crisis for Independent Living are extremely serious and should not be under estimated. We are at a crossroads of development of either entering a new phase and going forward or struggling to avoid going back. The Independent Living movement in the UK and throughout Europe now needs to be united more than ever to challenge the cuts that are now being implemented by many EU Governments. ENIL has a role now in this in order to organise regional partnerships so that countries can support each other in combating the loss of Independent Living services. Last week we had over 10,000 Disabled People and the supporters marching and demonstrating through the streets of London past the Parliament buildings in protest against the cuts. It was a huge turnout and showed the solidarity now of Disabled People from all parts of the UK. I think over the next months and years we will have to keep up the momentum and keep on lobbying and campaigning to counteract the negative aspects of the economic crisis. Disabled People should not receive a disproportionate amount of cutbacks to services compared to the rest of the population.

We will also need to organise ourselves more on a European level through EDF as the main representative umbrella organisation.

We have to act quickly with an effective strategy and make sure we get the European Parliament and the European Commission on our side. At the moment we need all the support we can in bringing about effective strategies and partnerships challenging these inhuman cutbacks. They are a threat to our basic human rights. As a colleague of mine recently said, “we are not just concerned about the cutbacks, we are bloody terrified”!

7. ENIL’s purpose is “to build and co-ordinate a European Network on Independent Living”. How close you think you are so as to achieve this purpose?

We have come a long way in developing a co-ordinated network throughout Europe for Independent Living. However, we still have some way to go.

I think we have moved on considerably during the last few years by organising our regional groups throughout Europe. This has enabled ENIL to focus attention on certain areas particularly Central and Eastern Europe and also Southern Europe. It took us many years galvanising momentum and encouraging countries in Southern Europe in developing Independent Living services. I think this had much to do with the Mediterranean culture, which was very much dominated by the thinking that the family always take care of their disabled members. It was difficult breaking down some of these stereotypes. Even when many of the Northern and Western European countries started developing Independent Living some 30 years ago this was also the case then. It was still assumed that the only option available to Disabled People to live independently was either through the support of the family, being rich enough to buy in your own support or last but not least having to live in residential institutional care whether one wanted to or not!

I think these next year’s because of the economic crisis we hope to see much stronger regional development of our Independent Living network throughout all parts of Europe. I hope I am correct in my assessment but what is for sure is that we are certainly a lot closer in achieving our purpose than we were a few years ago. Independent Living is not going to go away. It is too powerful a philosophy and way of life to be dismissed. It has changed the lives of thousands of Disabled People over the last few decades and I believe it will continue to do this. I know I am committed to the cause as are many of my colleagues and what is reassuring these days is that we do finally see younger Disabled People and new faces coming in and taking over.

John Evans
May 2011

John Evans at the 2003 ‘Freedom Drive’ in Strasbourg
(with Berni Vincent, Cathal O’Philbin and Ian Loynes)

The 10th ‘Freedom Drive’, Strasbourg 2013

The Impact of Austerity on Disabled People and Independent Living

Rights and Responsibilities or Cuts and Social Exclusion

Speech at ‘Europe's Way out of the Crisis: The Disability Rights Perspective’, European Day Conference for People with Disabilities, Brussels, December 1st 2011

http://www.enil.eu/news/john-evans-from-enil-speaks-to-europe-about-the-devastating-effect-of-the-cuts/

Introduction

We are currently living through an unprecedented time. How things have changed over the last 4 years since 2007. It seemed like then we were going through the dawning of a new age when the UN CRPD was launched at the UN in 2007. It felt like finally we had an international legal instrument which recognised our absolute rights as full citizens. It was a breath of fresh air. We had waited a long time to have such a legal capacity with the potential of enabling us to realise all our rights like non-Disabled People. However, the utopia was not to last as we were brought to the brink of an incalculable economic banking disaster. Four years later we are now paying the price of this.

The European Commission should be applauded for choosing the impact the austerity measures are having on Disabled People in Europe as a central theme of this conference. It is essential now that we address this situation and have a constructive debate looking for a way forward together.

It is unfortunate that Disabled People seem to be disproportionately experiencing the brunt of the savage cuts being made to their benefits, frontline services and funding for our organisations. Economic recessions usually follow certain cycles and it is clear from recent events that we are not through the worst yet as these effects could get worse.

What is clear is that we need to find solutions fast before the situation gets any worse and our hope is that this debate can initiate this.

Background

Since the crisis began EDF and my organisation ENIL have been receiving many complaints and requests for support from concerned members struggling to maintain their quality of life and rights. I can assure you Disabled People are right now terrified of what is happening and what might happen next.

No countries are exempt from austerity measures, even those who have been seen as leaders in services and legislation for Disabled People. The UK was once seen as one of the pioneers in Independent Living and now we find ourselves struggling to maintain what we have built up over the last 30 years.

In many countries disability organisations have been uniting to protest and challenge the cuts that are being made nationally. We in ENIL have been very active and have devised a Resolution on the impact of the crisis for the European Parliament. EDF has been working hard collecting information which has been coming in from many EU Member States. In June 2011 EDF established its EU Observatory to monitor the crisis focusing on what specific measures were being taken at national levels. It has focused on the direct effect on the social inclusion of Disabled People and the violation of the UN CRPD.

Complaints of the situation have been received from Sweden, the Netherlands, UK, Belgium, Bulgaria, Slovenia, Italy, Spain, Portugal, Ireland and Greece. From the basis of these responses received by the survey, my presentation will cover the main areas affected by the crisis which include the social, economic and political participation of Disabled People in the community.

Economic effects.

Disabled People already experience numerous barriers to social and economic participation and employment is particularly problematic. The crisis has worsened the situation. Unemployment rates have increased dramatically and the average percentage of Disabled People in the workforce is less than half compared to non-disabled workers. It goes without saying that this lack of employment leads to further poverty and social exclusion for many Disabled People. In some countries over 70 per cent of Disabled People are on benefits.

Employment plays a crucial role not only for financial security, but also for providing status, a sense of community belonging and participation.

In the UK alone 400,000 Disabled People will lose out on work support through the reform of the employment support allowance. Many countries expressed their concerns on the lack of working opportunities for Disabled People.

The worst consequence of the crisis is being seen in welfare systems. Welfare reforms and cuts in public expenditure have been indiscriminate and drastic. When introducing new pension and social protection systems, Governments must be aware of the fact that the majority of Disabled People already live below the poverty threshold. Therefore any further reduction in income would increase more hardship.

Several studies have proved that poverty rates have increased at least 50% for the disability community population. This is a very sensitive and important fact to consider, when trying to apply the targets for poverty reduction in the EU 2020 Strategy.

In Belgium over 550,000 people are still waiting for their personal assistance budgets. It is said that in the Netherlands by 2014 117,000 people will lose their personal assistance budgets. In the UK the Independent Living Fund is also being targeted for closure in 2015. This will have devastating effects for supporting Disabled People and severely limit the possibilities to fully participate in society. It seems like Governments are now only looking at budgets and cost cutting and not the long-term impact the cuts will have on the quality of life and well being of Disabled People in the future.

Social Participation

As a result of the crisis there are particular concerns about access to services, mobility and social relations getting worse, as often social and public services are not always that accessible for Disabled People already in many countries. Availability and access to services to enable Independent Living in the community and to actively participate are crucial for an inclusive society.

Deinstitutionalisation

Cut backs in public expenditure could seriously deteriorate the possibilities for the development of Independent Living and community based services. This could mean that it could reverse the positive trends towards deinstitutionalisation which has advanced considerably in Europe over recent years through the work of a number of European disability NGOs. This development is already being seen in Greece and Poland and not far off in many other countries. Institutionalisation is again a real threat!

Health and Well-Being

We are also witnessing how the crisis is affecting social and health services which are key factors in Disabled People's lives. A recent EU study by FRA (Fundamental Rights Agency) revealed the findings that people with intellectual disabilities and mental health issues had much more difficulty accessing medical services than others. These are real serious issues for the health and well being of Disabled People.

In the UK and Spain the crisis has had negative effects on the health conditions of Disabled People psychologically, causing more anxiety disorders, stress and depression. In an extreme example two Disabled People recently committed suicide in the UK. I can honestly say that this last year has been very depressing witnessing the hardships Disabled People have been exposed to. It is important during such traumatic times we are able to have escape mechanisms to protect our health.

Six Major Trends from the Survey

1.Reassessment

A worrying development has emerged around the reassessment of disability status. This has been through a dangerous distortion of the reality in order to recover millions of Euros from many EU countries. Unfortunately, this has been supported by the media who have portrayed Disabled People as scroungers, not wanting to work, cheating, and people abusing the system to claim disability benefit. The media has been blatant in the UK in this respect.

In countries like Belgium, Greece, Italy and the UK it is perceived that there are too many Disabled People claiming benefits. The State's way of dealing with the situation is to reassess disability status in the hope that this might lead to lower levels of support needs and therefore decreasing budgets.

In Sweden reassessment has resulted in the decrease in the number of hours of support people are granted. In Italy a new Law assessing the needs of disabled students must be made in the presence of a doctor and requests made through the Internet. This is incredible, as it seems after years of fighting to develop a Social Model of Disability we are now facing the threat of returning to the medical model full of restrictions and barriers.

The development of these stereotypes is a dangerous phenomenon, as it will only increase social exclusion with the concrete risk of further poverty.

2. Cuts in Disability Allowances

Universal cuts have been made to disability benefits, allowances and other special benefits for Disabled People in nearly every EU Member State. It is a sad consequence when public expenditure cuts are being made Disabled People are often easy targets.

3. Increased Taxation

The third tendency has seen several national recovery plans involving increased taxation. This again aggravates the heavy economic burden for Disabled People and their families already trying to meet the high cost of disability in order to maintain a reasonable standard of life. Fewer resources means it is more difficult to participate in the social, economic and political life.

4. Reduction in Local Authority Budgets

Cuts in Disability services have been universal throughout Europe over this last year or so. Local Authority budgets have been reduced significantly. In the UK each Local Authority has had a 25% cut for the next 4 years. This means that frontline services, which are the support systems for Disabled People, are being reduced despite challenges from national and local organisations. In many countries local public funding to disability organisations has been reduced substantially, which again could make more Disabled People unemployed as these organisations can often employ numerous Disabled People.

5. Review of Funding Resources for Disabled People’s Organisations

Many countries have seen the funding resources for Disabled People's Organisations being reduced significantly. In Ireland a major national cross disability organisation funded by the Government was ended. This organisation was during valuable advocacy work both nationally and at a European level with EDF.

The capacity to participate in the policy making process for organisations has been diminished. In Slovenia there has been a review of the funding procedures without any consultation with Disabled People's Organisations. This resulted in the reduction of the financing capacity to support Disabled People in the community.

6. Austerity Measures being made without Consultation with Disabled People's Organisations

This detrimental development is in violation of the UN CRPD. Article 33 of the CRPD recognises the obligation to consult representative Disabled People's Organisations when measures are taken which affect their rights. The absence of consultation and dialogue between public authorities and their organisations has resulted in a negative impact on the lives of millions of Disabled People.

In Conclusion.

Many European disability NGOs are very concerned that EU funding will not be reduced like it has in many different countries. Otherwise this will further diminish the support Disabled People could receive from these organisations both nationally and a European level.

It seems evident to me that a combination of the EU legislative framework and more concrete implementation of the UN CRPD could go a long way in helping to address the situation by highlighting to Member States their legal obligations. I think it is also important that we work together with other Social NGO Networks during the crisis in order to support innovative change. The European Commission has an important role here.

Recommendations

It is true that in the EU we need a strong legal framework that protects Disabled People from discrimination. We also need an effective legal apparatus enabling Disabled People to fully participate in social, economic and political aspects of the societies. In order to achieve this EDF calls for:

1. Awareness raising of the needs of Disabled People to ensure appropriate portrayal of Disabled People in the media and other relevant stakeholders to avoid social stigmatization.
2. Freedom of movement for Disabled People to have the right to live independently and be included in society. Social protection reforms must support this. Personal assistance and other community support systems should not be undermined by the austerity measures.
3. The right to work and employment must be protected. Measures for full inclusion should include reasonable accommodation and innovative work schemes.
4. Education for Disabled People to be respected in all reforms. Mainstream education should be priority and not be reduced through cuts.
5. Access to health services for all Disabled People.
6. High quality social services should remain a precondition for respecting the human rights of Disabled People.
7. Family life should be respected through appropriate policies.
8. Adequate living standards and social protection should be maintained to avoid social exclusion, reduction in income and poverty.
9. Appropriate statistics and data are collected to assess properly the situation of Disabled People in Europe.
10. Organisations representing Disabled People should be consulted of any actions that could have an impact on their rights.

I finish by calling upon all EU Institutions, the Commission and the Parliament and the Council of Europe to support us in alleviating this situation.

John Evans OBE
December 2011

European Parliament of Disabled People Statement (ENIL)

http://www.enil.eu/news/the-3rd-european-parliament-of-people-with-disabilities-success/

Right now as we privileged Disabled People sit here debating important issues of the European Parliament, 1.2 million of our fellow disabled brothers and sisters are imprisoned, isolated and forgotten in institutions throughout Europe. They are not free like us to participate in whatever activities they want or even choose what to wear, what to eat and drink and when to get up and go to bed most days of their lives.

Most of the EU Governments have blatantly ignored and denied implementing the UN CRPD and in particular Article 19 which begs Governments to enable and allow their disabled citizens to be free of institutions. They are deprived of the choice of choosing where to live, who to support them to live in the community. This situation has been made worse by the austerity measures many countries are taking which are decreasing the funding in Independent Living and other community-based services. This is a blatant violation of the UN CRPD.

We call upon the EU Parliament and institutions to address this issue immediately and call upon EU Member States to put into action their responsibility in implementing UN CRPD to protect and improve the rights of these estranged Disabled People. FREE OUR PEOPLE NOW.

John Evans
ENIL, December 2012

John Evans at 3rd European Parliament of Disabled People, 2012 (Photo: Lukasz Michalak)

Induction into the ENIL Hall of Fame

http://www.enil.eu/news/hall-of-fame-john-evans/

ENIL are honoured to induct John Evans, OBE into the Hall of Fame.

In this interview, John tells us of the importance of Independent Living in his own life and why in these times of austerity it is even more important to advocate for Independent Living for all people across Europe.

Could you tell me a little about your background?

I am originally from Swansea in South Wales which is where I was brought up and had my basic education. I left Swansea when I was 18 and never returned to live again except to make frequent visits to my family and Welsh homeland. I consider myself very rooted in the Welsh culture and background. I am proud to be Welsh as well as being a disabled person, but I am certainly not nationalistic. I see myself as an internationalist which has remained part of my character since the 60s which was a time that expanded my views about people in the world we live in and the importance of breaking down rigid and stereotype conditioned barriers and boundaries of modern society.

I spent most of my earlier years following my departure from Wales in London and travelling so this is when I started developing a wider interest in the wider world and other people's cultures. I continued to travel to the Middle East and Europe and finally in New Mexico to complete a peace project we had started in Jerusalem in 1973. Six months after arriving in New Mexico I broke my neck and became Tetraplegic and was then paralysed from the shoulders down. This is when my life changed dramatically in many ways.

Following my recovery and rehabilitation in the US, I then returned to the UK to start a new life and direction. After probably two years or so I managed to get my feet back on the ground in trying to sort my life out. When I was in hospital in Albuquerque in New Mexico recovering from my spinal injury, a friend introduced me to a disabled person they knew who worked at the Centre for Independent Living in Berkeley, California. This encounter and exchange never left me and it was when the first seeds of Independent Living were planted in my spirit. Following this, Independent Living became an integral thread in my life. It would change my life dramatically until I felt I had fully achieved this goal and ambition. I was passionate in exploring and researching as much as I could to discover what Independent Living was and how it started and why it remained a dynamic force in the lives of Disabled People in Berkeley, the USA and Europe. It felt like a quest for a vision.

How did you become involved in the Independent Living Movement?

I suppose in a sense I became involved from the onset of my injury when becoming disabled from being non-disabled even though in the beginning I didn't realise it. I think the moment when it became reality was when my situation broke down after being supported by friends and I ended up going to live in a residential institution home which not only did I regret but terrified me. It meant that I was going to lose my freedom and end up being imprisoned in a place in a home with other Disabled People which was not my choice at all but I had little option but to accept it temporarily. My loss of freedom was what concerned me most and the fear of isolation and estrangement.

As soon as I moved into this new home my adventure in pursuit of Independent Living started. I wanted to regain my own life and re-establish my roots in the community again as opposed to being isolated away in a beautiful rural setting. I immersed myself in this search for a solution vigorously.

I knew I wanted to maintain the freedom which I had developed from my life over the last decade. This is when I remembered the phone call I had from Carmen Anderson in Berkeley Centre for Independent Living when I was in hospital. I knew I had to find out more about what Independent Living was as I felt this was going to be key to my future despite my ignorance of it. It was clear to me inside that Independent Living was the answer.

What do you think was the most significant moment of the Independent Living movement (e.g. Project 81)?

I think for me personally Project 81 was certainly one of the most significant moments to me personally in the development of Independent Living in my own life and in the UK generally. There are other numerous significant moments in our rich history since then but Project 81 had its specific relevance for us in the UK. Project 81 provided us with a vision and a blueprint towards developing Independent Living although we had to convince many policy makers and professionals about how we were going to achieve it in reality. It made sense to us and was a very exciting time to embark upon this. We were all thirsty in trying to make this a success despite the amazing amount of scepticism there was towards us.

We learnt a lot in a short period of time through networking with many other Disabled People and their supporters both in the UK as well as the US and Europe in particular. I was fortunate to be able to return to the US in 1981 to travel, work and research how Independent Living started in the US and how different regions embraced it and implemented it. It was an extraordinary inspiring trip which convinced me that what we were doing was right when we really have to push on more to make this a reality in the UK.

In the UK and for us on a local and regional level it clearly reflected the unique difference of us as individuals in the way that we worked out the different solutions in the mystery of all our lives in our search for Independent Living. It is very moving to look back to realise how much we did accomplice together by coming up with such a revolutionary idea and practice that would change our lives forever. We were pioneers and knew we had to take risks and had to be strong not to let the criticism wear us down and diminish our passion to achieve change.

What is your vision for Independent Living at present and for the future?

At present considering the economic situation of most of Europe our main priority is to ensure further consolidation of Independent Living in all our countries in order to survive through these years of austerity measures. Many countries now are faced with going backwards ten to thirty years and losing a lot of the creative infrastructure which took us long to develop. These are unprecedented years and demand the Independent Living movement to be firmly strong and resolute in our defence of our basic core principles and beliefs in order to sustain our future for all.

In the future I would like to see all EU Member States having national legislation protecting the right for all people who need it to live independently so that Independent Living is enshrined by law. This way it can help us to protect and sustain its longevity.

I would also like to see the UNCRPD and in particular Article 19 which is the relevant article covering Independent Living and personal assistance fully implemented by all the EU member states who have implemented and signed the convention and the optional protocol. It is important that the CRPD is put into action, tested and tried. The European Union and the Commission should support in this along with the European Parliament.

Ultimately it would be nice to see in the future that Independent Living can survive on its own accord without all the bureaucracy and legislation and it is accepted as the mainstream.

You will be speaking at the Strasbourg Freedom Drive, can you tell me a little about what you will be speaking about at the Strasbourg Freedom Drive?

I will not go into any detail about my presentation at the Freedom Drive this year but only to say that it would concentrate on celebration and challenge. I would like to highlight the celebration and successes of ENIL over the last decade since the Freedom Drive began. I will also call upon the European Independent Living movement to grow closer together in supporting each other in the big challenge we have facing us over the next years counteracting the impact of the austerity measures and encouraging solutions and creative thinking to help overcome some of the burdens from the cut backs of the last few years. We have to work together to stop Independent Living and our successes going backwards in these difficult times.

Why do you think the Strasbourg Freedom Drive is such an important event?

The Strasbourg Freedom Drive is an extremely important event as it creates a focus to bring together many of the different Disabled

People together from many of the EU Member States every two years to celebrate the exciting new lifestyle of Independent Living. As well as the hard work involved in what we are trying to achieve over the four days, it is also important that we can come together to have some fun as well and really celebrate our achievements and our wonders.

The Freedom Drive has become a focal point for the European Independent Living movement over the last ten years I think for those who have attended and participated in it, it has become one of the main highlights of the ENIL activities and the feelings of camaraderie and unity are very uplifting. It has been symbolic in ENIL's campaign to free Disabled People from institutions throughout Europe in their quest for freedom.

I think this year's Freedom Drive in 2013 takes on a much more significantly symbolic role being ten years celebration since it began. This year also comes at a time where we have seen the devastating impact, which the austerity measures are having in different EU member states which are now beginning to restrict Independent Living possibilities. We must remain steadfast in defence of our belief and vision of Independent Living to ensure our sustainability.

John Evans OBE
August 2013

John Evans with Bente Skansgard and Björn Hecter, *Turin, April 1999*

Independent Living in the UK in 2013

Transcript from *Disability Now* Podcast, broadcast on 9 December 2013

http://disabilitynow.org.uk/article/download-great-escape-and-old-school

Paul: Hello I'm Paul Carter and I'm joined by Victoria Wright for this episode of The Download.

Victoria: The great escape. John Evans, the pioneer of the Independent Living Movement in the UK liberated himself from a Cheshire home to establish his own Independent Living scheme. But do Government cuts threaten to return us to the dark days?

Paul: As well as John Evans we're joined by Sue Elsegood from Greenwich Association of Disabled People who uses the Independent Living Fund. Now let's start out as we always do by finding out what disability-related matters are on your minds at the moment.

Sue: I've had lots of things on my mind. One of the things has actually been reflecting since the passing of Nelson Mandela on the sort of parallels there has been for our movement and the segregation that exists still for Disabled People. And I've been thinking about people that are in residential homes against their will. That's been on my mind as well as other more I suppose more fun things related to Christmas coming up and sorting out somewhere accessible to go for a meal with my PAs. So yeah lots of things.

Paul: And John, Sue mentioned Independent Living there which is something we are going to talk about in a little while but what kind of disability things are on your mind at the moment?

John: Well today being December the 9th actually is quite a significant day because it is exactly 30 years since I broke free of Le Court Cheshire Home in Hampshire and established my own Independent Living scheme in my own place in Petersfield in Hampshire. So yeah I'm in celebratory mood. And I think it's good to be in a celebratory mood because the last five years given the kinds of austerity measures we've been going through and the cuts we've been facing and the attacks that we've been having by this

Government I think it's good to celebrate something and I think we need that kind of thing.

Paul: The right to choose where and how we live is a right we take for granted today but as recently as the 1970s the best that many of us could have hoped for was being locked away in institutions with no control over when we got up, who we socialised with and what we ate.

Victoria: The fact that we have escaped from that kind of existence has got a lot to do with John Evans who was in a Cheshire Home, as he said, but who emancipated himself and used council funding to organise his own support.

Paul: So before we get on to that, John, can you just tell us a little bit about that Cheshire Home; how did you end up being there and how would you describe a typical day there?

John: It was unfortunate how I ended up being there to start with. I broke my neck in 1975 and for three years after that I managed to survive at that time when there was no community care and no support in the community really, I managed to survive through the support of my girlfriend and another friend. And then when that relationship broke down I was faced with the prospect of going into that Cheshire Home which I despised. I mean I was a 25 year old man and I cherished the freedom that I'd had. So when I went into the home I was absolutely fearful of what that meant. It just represented imprisonment to me. But from the moment I went into that home I met a person I said I'm not going to stay here for the rest of my life. And I was told, well that's possible but it might be very, very difficult. And so when I was in that home it was quite inspiring because I met a couple of other Disabled People who also felt similar to me and we got together and formed something called 'Project 81' which is the scheme we put together to enable us all to get out. And so from that respect I was lucky even though I was in a home and I had to get up at certain times in the day and I never had choice over what I was eating and when I could go out or whatever; even though I managed to somehow always find ways of doing it.

Victoria: So, John, how did you become first aware of the concept of Independent Living?

John: Interestingly enough it was when I was lying in bed in a hospital in Albuquerque New Mexico having broken my neck, and a friend came in and told me about somebody he knew in Berkeley California who was at something called a Centre for Independent Living which I didn't know anything about at the time. And he said I think you should call that woman. And I didn't call her because at that point in time I was still very much confused as to what I was doing, where I was going. And about a week later she rang me and had a, what I can describe as a very explosive conversation and said to me, "Look" she first of all said to me, "You can't go back to England because it's no good. They don't have anything going over there for you. You've got to come here to Berkeley California and stay with us because we can tell you how to live your life and how to recover from your injury and get your life back on track again." And after a long discussion we left it at that. Then of course I was left in a kind of position as to what I could do it sounded very appealing but I knew I had to somehow return to the UK because from a visa perspective I wouldn't have been able to have stayed there anyway.

Victoria: Do you regret though, do you sometimes wish that you had stayed there?

John: No I don't but that conversation stayed with me and two years later when I did end up in Le Court Cheshire Home that's when it came alive, then I started thinking right I've got to find out more about this, what this Independent Living is, what these centres for Independent Living are, and that's really the beginnings of a few of us putting our ideas together and trying to contact ((them. We have to remember those were the days before the Internet, before fax machines and so communication was very slow; it was through letters or if we could afford it telephone calls.

Paul: Sue I'm intrigued how and why did you get involved in the Independent Living Movement?

Sue: I first got involved back in around '89 when I'd finished university and I moved back to the Borough of Greenwich and I got involved with GADP, Greenwich Association of Disabled People. And they had an Independent Living scheme. They had a worker who was supporting people to begin living independently in the community. And they had like a mentoring system where we would buddy up with someone in a similar situation. And I luckily palled up with Katherine Araniello who's quite a well-known disabled artist. And so she'd already been living independently before I moved there. So I guess we learnt from each other and could explore how to live with assistance. At that time it was with volunteers but all the same we could have a life.

Paul: And Greenwich Association of Disabled People emerged quite early in the Independent Living Movement what kind of challenges did you face early on?

Sue: I think it was established in 1975 but as I say I got involved in the late ‘80s. There were a lot of difficulties around funding for the organisation and for it to be taken seriously locally and nationally. But I think it did establish quite a reputation of challenging the Government. And we also established quite a good training project for people who were employing their own PAs so they could learn all the skills around that.

Paul: John, how quickly did the movement develop once it had been established; was there quite a lot of pace about it or was it slow, tell us a little bit about that?

John: Yeah at the time I think it seemed slow, but when I look back it was actually quite fast because as soon as we knew what we wanted to do and how we wanted to go about establishing our Independent Living we also did a lot of research trying to find out about whether other people in the country were doing it. And we slowly started making a lot of good contacts with Ken and Maggie Davis in Derbyshire, some people in Manchester, Rachel Hurst in Greenwich, which is the person who set up the Greenwich Centre for Independent Living and a number of others, and before we knew what was happening we were really developing a network. Again a network without the Internet and everything else so it was a very organic process, which felt very lively, it was very exciting because we felt we were on to something that was very special.

Victoria: And how does it make you feel that in many ways we still have to campaign to preserve the support for Disabled People to live independently?

John: I find it very disheartening because I think after 30 years of Independent Living being so successful changing dramatically people’s lives, enabling many to get jobs and work and others to just have good, meaningful lives that it is extraordinary that we now have a Government that’s brought this into question in terms of trying to close the Independent Living Fund. And I wouldn’t have thought 30 years ago when we started out we would be facing these kinds of difficulties now. But I still feel confident, and I still believe in Independent Living, it is so strong and it is so important that it can't be dismissed and it certainly can't be taken away from us. And there's going to be a big fight on to make sure that doesn't happen.

Paul: And a question for both of you against that backdrop of the closure of the Independent Living Fund etc. what do you think the outlook is for Independent Living?

Sue: Well of course we did win the appeal at the high court. We said it was actually unlawful of the Government to have closed the fund. So we've won a battle. But we still need to pull together to ensure that the Independent Living Fund stays open and the funding is protected for those already on the funding and opened up very importantly to new applicants.

John: Yes we have some struggles in front of us as Sue has quite correctly pointed out. But I think the court of appeal win was a big plus and I think that will make the Government stop and start to re-look and rethink about what they're doing and hopefully see some insight into the importance of Independent Living. But I still believe that what we need in this country, and we've been trying to get it for some time, is a right to Independent Living. And we did have a number of private member bills that went through going back 10/15 years. But now I think we have an international legal framework that fits so well in terms of the Article 19 of the UN Convention that we need to be able to try and implement that in our country with national legislation that will embed it and give us the right to Independent Living which is so importantly needed.

The Strasbourg Freedom Drive

Celebration and Challenge for Our Independent Living Movement

Speech at ENIL Freedom Drive Conference, Strasbourg, 9 September 2013

Dear Colleagues, Friends, Freedom Drivers and Supporters.

I am delighted to be able to address you all here today at this significant ENIL Freedom Drive conference celebrating our 10th anniversary of holding this event here in Strasbourg, the 2nd home of the European Parliament. In 2003 we started the Freedom Drives with less than 100 Disabled People and our supporters. Every 2 years this has grown and our numbers have grown into the hundreds as the inspiration for this event captured the imagination of Independent Living activists throughout Europe. The Freedom Drive has now become a rallying call for action where we can come together and unite to campaign for our right to Independent Living to be respected in Europe.

We should all stand and sit proud of the achievements of our movement throughout Europe over this last decade. If it wasn't because of your efforts in your different countries the opportunity and chances to live independently would not be possible. This is a huge achievement. We must celebrate this over the next few days when we march and rally together and when we meet the MEPs in the Parliament. The Independent Living Movement Is about both Action and Lobbying. We need to act to defend our rights and to spread the practice of Independent Living. At the same time we need to stick close to our principles in order to be able to lobby and argue our case effectively to try and influence politicians and policymakers.

These next few days are some of the most important days of our lives. We need to be sure that the European MEPs listen to our demands so that they can work in the Parliament trying to meet our needs and wishes within the framework of the European political dimension. We must educate them to understand the politics of Independent Living so they can support our struggle for equality and human rights.

We are living through unprecedented times and unprecedented times require unprecedented actions and we should not be afraid of challenging the status quo and the Government in charge to put forward our case. In these times of austerity we cannot allow our politicians to push us aside cheaply, stereotypically labelling us scroungers, living on the benefit system and not wanting to work. We cannot accept this disproportionate and false attack on our people and our humanity. Our budgets are being cut, our benefits are being cut and to make matters worse our services are being cut. We must demand that this stop immediately. Despite these grave consequences and the dire situation we must not forget to be proud to celebrate as this is our way of overcoming this negative situation.

UK has been seen as one of the pioneers in Independent Living in Europe but now this very achievement and existence is being threatened by a Government, who see Disabled People and the welfare system as an easy target. This is why we have to consolidate our energy as much as possible in challenging these cuts and defending our rights. In the UK last week there was a week of action and protest by disabled activists challenging the attack on Independent Living and Disabled People's rights. It was called the Freedom Drive campaign to reclaim our futures organised by the DPAC (Disabled People against Cuts). It seems like our Government has no interest in recognising the important values and changes in Disabled People's lives for the better through Independent Living, but is only seeing it now as another budget that can be cut to meet their severe austerity measures. We must show them how they are failing in their obligations under the UN CRPD to protect our rights. The UN CRPD is not about cutting services and budgets, it is about building a structure to support Independent Living as specified by Article 19.

We are living at a crossroads and these next few years are crucial for our survival and the survival of the Independent Living movement. This is the biggest challenge we have had to face since we pioneered Independent Living from the 1970s until today. We cannot accept or allow this threat to Independent Living. We know how important Independent Living is for Disabled People. It is what gives us our life to do what we want to do and in the way we want to do it. We want to continue to make this positive contribution in the world we live in, whatever society it is and whatever country we live in. Our vision, our belief and our lifestyle are far too important to be brushed aside by ignorant politicians who are obsessed by budget cuts. We must protect our principles and our way of life. I call upon all of you to fight to protect and defend our right to Independent Living in whatever country you are from in order to give it more sustenance for it to grow in the future. We want a stronger Independent Living movement and not a weaker one. We are not weak. We are strong.

During these days of the conference, the meeting with MEPs in the Parliament and on our great Freedom Drive march and rally remember these qualities and attributes. Celebration, strength, unity, belief and finally challenge so that we can protect and maintain the advances we have made in bringing Independent Living from the grassroots of local communities and sharing in expanding our collective approach throughout all our countries and Europe. We must share our creative ideas and find inspiration from each other so that we can return to our countries stronger and more confident.

John Evans OBE
ENIL Freedom Drive 2013
Strasbourg

John Evans in Strasbourg for the 2011 ‘Freedom Drive’

Appendices – Strasbourg Resolution and Washington, Madrid and Tenerife Declarations

The Strasbourg Resolution

In April 1989, the first European Independent Living Conference was held at the European Parliament in Strasbourg, France. The meeting's theme was Personal Assistance. The conference resulted in the founding of the European Network for Independent Living, ENIL. This is the resolution adopted at the conference.

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Preamble

We, Disabled People from the Netherlands, UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, Federal Republic of Germany and Norway have come together from April 12-14 1989 at the European Parliament, Strasbourg, France. This conference has focussed on Personal Assistance Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence.

We, Disabled People, recognizing our unique expertise, derived from our experience, must take the initiative in the planning of policies that directly affect us.

To this end we condemn segregation and institutionalization, which are a direct violation of our human rights, and consider that governments must pass legislation that protects the human rights of Disabled People, including equalization of opportunities.

We firmly uphold our basic human right to full and equal participation in society as enshrined in the UN Universal Declaration of Human Rights (extended to include disable people in 1985) and consider that a key prerequisite to this civil right is through Independent Living and the provision of support such as personal assistant services for those who need them.

The recommendations of the UN World Programme of Action (Paragraph 115) specifically state that "Member States should
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encourage the provision of support services to enable Disabled People to live as independently as possible in the community and in doing so should ensure that persons with a disability have the opportunity to develop and manage these services for themselves".

Resolution 1 of the 43rd United Nations General Assembly (1988) reaffirms the validity of the World Programme of Action, and Resolution 2 stresses that "special emphasis should be placed on equalization of opportunities". Considering these and similar recommendations from both the European Community and the Council of Europe and to ensure that Disabled People within Europe should have parity of equalization of opportunities we stress that these objectives must be achieved.

In support of the international movement of Disabled People in Disabled Peoples' International which has a special commitment to setting up a network of initiatives for Independent Living as part of the implementation of equalization of opportunities, we call on governments and policy-makers to enforce the following principles:

1. Access to personal assistance service is a human and civil right. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need irrespective of personal wealth, income or marital and family status.

2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give legally informed consent.

3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure and travel and political life. These services shall enable Disabled People to build up a family and fulfill all their responsibilities connected with this.

4. These services must be available long term for anything up to 24 hours a day, 7 days a week, and as a short term, or emergency basis. These services shall include assistance with personal, communicative, household, mobility and other related services.

5. The funding authority shall ensure that sufficient funds are available to the user for adequate training of the user and the

assistant, if deemed necessary by the user.

6. Funding must include assistants competitive wages and employment benefits, and all legal and union required benefits, plus the administrative costs.

7. Funding shall come from one guaranteed source, and to be paid to the individual wherever he/she chooses. Funding shall not be treated as disposable taxable income, and shall not make the user ineligible to other statutory benefits of services.

8. The user should be free to appoint all personal assistants, whoever he/she chooses, including family members.

9. Lack of resources, high costs, substantial or nonexistent services shall not be used as a rationale for placing an individual in an institutionalized setting.

10. There shall be a uniform judicial appeals procedure which works independently of the funders, providers or assessors, and is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.

11. In furtherance of all the above Disabled People and their organizations must be decisively involved at all levels of policy making including planning, implementation and development.

Washington Declaration

The first global meeting on Independent Living was convened in Washington DC September 21-25, 1999. Over 100 leaders evaluated the movement's 30-year old history and set the agenda for the future.

The Declaration set out to “celebrate the achievements of the Independent Living Movement around the world; accept the responsibility for our own actions and lives; and reaffirm the global philosophy and principles of Independent Living.”

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We, the leaders of the Disability Rights and Independent Living Movement from 50 countries participating in the Summit, " Global Perspectives on Independent Living for the Next Millennium," September 21-25, 1999, in Washington, DC, USA:

> celebrate the achievements of the Independent Living Movement around the world;
>
> accept the responsibility for our own actions and lives; and reaffirm the global philosophy and principles of Independent Living:
>
> > that all human life has value and that every human being should have meaningful options to make choices about issues that affect our lives;
> >
> > that the basic principles of Independent Living Philosophy are human rights, self-determination, self-help, peer support, empowerment, community inclusion, cross-disability inclusion, risk-taking and integration,
> >
> > that the Independent Living Philosophy recognizes the importance of accepting responsibility for our own lives and actions, and at the same time, the importance of community to foster Independent Living;
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that we recognize the importance of equal and inclusive education, employment opportunities and entrepreneurship, assistive technology, personal assistance, accessible transportation and a barrier free environment to promote Independent Living;

that the Independent Living Principles and Philosophy have applications on a global scale and are to be implemented on the local, national and international levels without regard to disability, sex, religion, race, language, ethnic background, political affiliation, age or sexual orientation.

We commit ourselves to the following Action Plan to ensure the continuation and promotion of Independent Living and the dissemination of Independent Living Philosophy:

1. to promote comprehensive Disability Rights Legislation and policies in each country in order to create a worldwide environment to foster Independent Living, inclusive education, accessible and affordable housing, transportation, health care, personal assistance services, a barrier free environment, accessible communication, and assistive technology incorporating universal design features;

2. to continue to act locally, nationally and internationally to promote Independent Living;

3. to promote inclusiveness for Disabled People of all backgrounds and ages--including disabled women, minority groups, children, and elderly persons--in the Independent Living Movement;

4. to network among ourselves and others

through the Internet, e-mail, teleconferencing and videoconferencing, faxing, phone and written communication to share our knowledge, expertise and ideas with each other;

5. to promote exchange programs and training opportunities;

6. to build partnerships with international disability organizations such as Disabled Peoples’ International, World Blind Union, World Federation Of The Deaf, and Rehabilitation International to promote Independent Living;

7. to influence governments, funding bodies, development agencies and overseas development assistance programs to support the goals and philosophy of the Independent Living Movement in their activities;

8. to promote partnerships with universities and academic institutions to incorporate Independent Living Principles, create greater access for students and professors with disabilities and initiate courses in disability studies;

9. to utilize the media to promote equality, positive images and the Independent Living Philosophy;

10. to establish working groups that will develop discussion papers on such areas as: definitions of Independent Living, Independent Living Philosophy, peer support, personal assistance services, advocacy, and the cross-disability focus of Independent Living; and encourage these groups to work closely with Disabled Peoples’ International and other international disability organizations;

11. to explore the feasibility of follow-up, face-to-face, international conferences on a regular basis.

We congratulate the efforts of United States governmental agencies in collaboration with the leaders of the Independent Living Movement in the U.S. for taking the initiative to organize this summit and express our appreciation for their support as well as to all the individuals and organizations that helped organize this event, and

We call upon all participants to continue to promote Independent Living Philosophy in their own countries and invite Disabled People around the world to become part of the Disability Rights and Independent Living Movement.

John Evans and Sandra (PA) at the first global meeting on Independent Living, Washington DC, September 1999

Madrid Declaration

In March 2002 the European Congress on Disability met in Spain and adopted the Madrid Declaration, which set out a plan of action for a partnership approach to “advancement of the disability agenda.”

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We, over 600 participants in the European Congress on Disability, meeting in Madrid, warmly welcome the proclamation of 2003 as the European Year of People with Disabilities as an event, which must act to raise public awareness of the rights of more than 50 million Europeans with disabilities.

We set down in this Declaration our vision, which should provide a conceptual framework for action for the European Year at European community level, national, regional and local level.

PREAMBLE

1. DISABILITY IS A HUMAN RIGHTS ISSUE.
   Disabled People are entitled to the same human rights as all other citizens. The first article of the Universal Declaration on Human Rights states: All human beings are free and equal in dignity and rights. In order to achieve this goal, all communities should celebrate the diversity within their communities and seek to ensure that Disabled People can enjoy the full range of human rights: civil, political, social, economical and cultural as acknowledged by the different international Conventions, the EU Treaty and in the different national constitutions.

2. DISABLED PEOPLE WANT EQUAL OPPORTUNITIES AND NOT CHARITY.
   As with many other regions in the world, the European Union has moved a long way during these last decades from the philosophy of paternalism towards Disabled People to one of attempting to empower them to exercise control over their own lives. The old approaches based largely on pity and perceived helplessness of Disabled People are now considered unacceptable. Action is shifting from an emphasis on rehabilitating the individual so they may 'fit in' to
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society towards a global philosophy of modifying society to include and accommodate the needs of all persons, including people with disabilities. Disabled People are demanding equal opportunities and access to all societal resources, i.e. inclusive education, new technologies, health and social services, sports and leisure activities, consumer goods and services.

3. BARRIERS IN SOCIETY LEAD TO DISCRIMINATION AND SOCIAL EXCLUSION.
   The way our societies are organised often means Disabled People are not able to fully enjoy their human rights and that they are socially excluded. The statistical data that is available shows that Disabled People have unacceptable low levels of education and employment. This also results in greater numbers of Disabled People living in situations of real poverty compared with non-disabled citizens.

4. DISABLED PEOPLE: THE INVISIBLE CITIZENS.
   The discrimination Disabled People face is sometimes based on prejudice against them, but more often it is caused by the fact that Disabled People are largely forgotten and ignored and this results in the creation and reinforcement of environmental and attitudinal barriers which prevent Disabled People from taking part in society.

5. DISABLED PEOPLE FORM A DIVERSE GROUP.
   As with all spheres of society, Disabled People form a very diverse group of people and only policies that respect this diversity will work. In particular, people with complex dependency needs and their families require particular action by societies, as they are often the most forgotten among Disabled People. Also, women with disabilities and Disabled People from ethnic minorities are often faced with double and even multiple discrimination, resulting from the interaction of the discrimination caused by their disability and the discrimination resulting from their gender or ethnic origin. For deaf people the recognition of sign language is a fundamental issue.

6. NON DISCRIMINATION + POSITIVE ACTION = SOCIAL INCLUSION.
   The recently adopted EU Charter of Fundamental Rights acknowledges that to achieve equality for Disabled People

the right not to be discriminated against has to be complemented by the right to benefit from measures designed to ensure their independence, integration and participation in the life of the community. This synthesis approach has been the guiding principle of the Madrid congress that brought together more than 600 participants in March 2002.

OUR VISION

1. Our vision can best be described as a contrast between this new vision and the old vision it seeks to replace:
    a. Away from Disabled People as objects of charity and towards Disabled People as rights holders.
    b. Away from people with disabilities as patients and towards people with disabilities as independent citizens and consumers.
    c. Away from professionals taking decisions on behalf of Disabled People and towards independent decision making and taking responsibilities by Disabled People and their organisations on issues which concern them.
    d. Away from a focus on merely individual impairments and towards removing barriers, revising social norms, policies, cultures and promoting a supportive and accessible environment.
    e. Away from labelling people as dependants or unemployable and towards an emphasis on ability and the provision of active support measures.
    f. Away from designing economic and social processes for the few and towards designing a flexible world for the many.
    g. Away from unnecessary segregation in education, employment and other spheres of life and towards integration of Disabled People into the mainstream.
    h. Away from disability policy as an issue that affects special ministries only and towards inclusion of disability policy as an overall government responsibility.

2. **INCLUSIVE SOCIETY FOR ALL.**

Implementing our vision will benefit not only Disabled People but also society as a whole. A society that shuts out a number of its members is an impoverished society. Actions to improve conditions for Disabled People will lead to the design of a flexible world for all. "What is done in the name of disability today will have meaning for all in the world's tomorrow".

We, the participants in the European Congress on Disability, meeting in Madrid, share this vision and request all stakeholders to consider the European Year of People with Disabilities in 2003 as the start of a process that will make this vision a reality. 50 million European Disabled People expect us to give an impulse to the process to make this happen.

OUR PROGRAM TO ACHIEVE THIS VISION

1. LEGAL MEASURES.
   Comprehensive anti-discrimination legislation must be enacted without delay to remove existing barriers and avoid the establishment of new barriers that Disabled People may encounter such as in education, employment and access to goods and services and which prevent Disabled People from achieving their full potential for social participation and independence. The non-discrimination clause, Article 13 of the EC Treaty allows this to happen at Community level, thus contributing to a real barrier-free Europe for people with disabilities.

2. CHANGING ATTITUDES.
   Anti-discrimination legislation has proven to be successful in bringing about changes in attitude towards people with disabilities. However, the law is not enough. Without a strong commitment from all society, including the active participation of Disabled People and their organisations in securing their own rights, legislation remains an empty shell. Public education is therefore necessary to back up legislative measures and to increase understanding of the needs and rights of Disabled People in society and to fight the prejudice and stigmatisation that still presently exists.

3. SERVICES THAT PROMOTE INDEPENDENT LIVING.
   Achieving the goal of equal access and participation also requires that resources should be channelled in such a way as to enhance the disabled person's capacity for participation and their right to Independent Living. Many Disabled People require support services in their daily lives. These services must be quality services based on the needs of Disabled

People and must be integrated in society and not be a source of segregation. Such support is in accordance with the European social model of solidarity - a model that acknowledges our collective responsibility towards one another and especially towards those who require assistance.

4. SUPPORT TO FAMILIES
   The family of Disabled People, in particular of disabled children and people with complex dependency needs unable to represent themselves, plays a vital role in their education and social inclusion. In view of this, adequate measures for families need to be established by public authorities, in order to allow families to organise their support for the disabled person in the most inclusive way.

5. SPECIAL ATTENTION TO DISABLED WOMEN
   The European Year has to be seen as the opportunity to consider the situation of disabled women from a new perspective. The social exclusion faced by disabled women can not only by explained by her disability but also the gender element needs to be considered. The multiple discrimination faced by disabled women has to be challenged through a combination of mainstreaming measures and positive action measures designed in consultation with disabled women.

6. MAINSTREAMING OF DISABILITY.
   Disabled People should have access to the mainstream health, education, vocational and social services and all the opportunities, which are available to non-disabled persons. The implementation of an inclusive approach to disability and Disabled People requires changes in current practice at several levels. First of all, it is necessary to ensure that services available to Disabled People are co-ordinated within and across the different sectors. The accessibility needs of the different groups of Disabled People need to be considered in the planning process of any activity and not as an afterthought when the planning has already been completed. The needs of Disabled People and their families are varied and it is important to devise a comprehensive response, which takes into account both the whole person and the various aspects of his or her life.

7. EMPLOYMENT AS A KEY FOR SOCIAL INCLUSION.
   Special efforts need to be made to promote the access of Disabled People to employment, preferably in the mainstream labour market. This is one of the important ways to fight against the social exclusion of Disabled People and to promote their Independent Living and dignity. This requires, not only the active mobilisation of the social partners, but also of the public authorities, which need to continue to strengthen the measures already in place.

8. NOTHING ABOUT DISABLED PEOPLE WITHOUT DISABLED PEOPLE.
   The Year must be an opportunity to grant Disabled People, their families, their advocates and their associations a new and expanded political and social scope, at all levels of society, in order to engage governments in dialogue, decision-making and progress around the goals for equality and inclusion.

   All actions should be undertaken in dialogue and co-operation with the relevant representative disability organisations. Such participation should not only be limited to receiving information or endorsing decisions. Rather, at all levels of decision-making, governments must put in place or strengthen regular mechanisms for consultation and dialogue enabling Disabled People through their disability organisations to contribute to the planning, implementation, monitoring and evaluation of all the actions.

   A strong alliance between Governments and disability organisations is the basic requisite to progress most effectively the equal opportunities and social participation of Disabled People.

   In order to facilitate this process, the capacity of disability organisations should be enhanced through greater resource allocation to allow them to improve their management and campaigning capacities. This also implies the responsibility on part of the disability organisations to continuously improve their levels of governance and representativeness.

SUGGESTIONS FOR ACTION

The European Year of People with Disabilities 2003 should mean an advancement of the disability agenda and this requires the active support of all relevant stakeholders in a wide partnership approach. Therefore concrete suggestions for action are proposed for all relevant stakeholders. These actions are to be established in the European Year and continued beyond the European Year; progress should be evaluated over time.

1. EU AUTHORITIES AND NATIONAL AUTHORITIES IN EU AND ACCESSION COUNTRIES
   Public authorities should lead by example and therefore are the first but not only actor in this process. They should:-
   - review the current scope of Community and national legal frameworks aiming at combating discriminatory practices in the fields of education, employment and access to good and services;
   - initiate investigations into those restrictions and discriminatory barriers that limit the freedom of Disabled People to fully participate in society, and to take whatever measures are necessary to remedy the situation.
   - review the services and benefits system to ensure that these policies assist and encourage Disabled People to remain and/or become an integral part of the society wherein they live.
   - undertake investigations on violence and abuse committed against Disabled People, with particular attention to those Disabled People living in large institutions.
   - strengthen legislation on accessibility to ensure that Disabled People have the same right of access to all public and social facilities as other people.
   - contribute to the promotion of the human rights of Disabled People at world wide level by participating actively in the work to prepare a UN Convention on the rights of Disabled People.
   - contribute to the situation of Disabled People in developing countries by including the social inclusion of Disabled People as an objective of the national and EU development co-operation policies

2. LOCAL AUTHORITIES.
   The European Year must really occur firstly at the local level, where issues are real to citizens and where associations of and for people with disabilities are doing most of their work.

Every effort must be made to focus the promotion, resources, and activities at the local level.

Local actors should be invited to integrate the needs of people with disabilities in urban and community policy, including education, employment, housing, transport, health and social services, bearing in mind the diversity of Disabled People, including, among others, older people, women and immigrants.

Local governments should draft local plans of action on disability in co-operation with representatives of Disabled People and set up their own local committees to spearhead the activities of the Year.

3. DISABILITY ORGANISATIONS
   Disability organisations, as representatives of Disabled People, have a major responsibility to ensure the success of the European Year. They have to consider themselves as the ambassadors of the European Year and proactively approach all relevant stakeholders proposing concrete measures and seeking to establish long lasting partnerships when these not yet exist.

4. EMPLOYERS.
   Employers should increase their efforts to include, retain and promote Disabled People in their workforce and to design their products and services in a way that these are accessible to Disabled People. Employers should review their internal policies to ensure that none of these prevents Disabled People from enjoying equal opportunities. Employer organisations can contribute to these efforts by collecting the many examples of good practice that already exist.

5. TRADE UNIONS.
   Trade unions should increase their involvement to improve the access to and maintenance in employment of Disabled People and ensure that Disabled People benefit from equal access to the training and promotion measures, when negotiating the agreements in the companies and professional sectors. Also increased attention should be paid to promote the participation and representation of disabled workers, both within their own decision making structures and those existing in the companies or professional sectors.

6. MEDIA.
   The Media should create and strengthen partnerships with associations of people with disabilities, in order to improve the portrayal of Disabled People in mass media. More information on Disabled People should be included in the media in recognition of the existence of human diversity. When referring to disability issues, the media should avoid any patronising or humiliating approaches but focus instead on the barriers Disabled People face and the positive contribution to society Disabled People can make once these barriers have been overcome.

7. EDUCATION SYSTEM.
   Schools should take a leading role in spreading the message of understanding and acceptance of Disabled People's rights, helping to dispel fears, myths and misconceptions and supporting the efforts of the whole community. Educational resources to help pupils to develop a sense of individuality with regard to disability in themselves and others, and to help them recognise differences more positively should be developed and widely disseminated.

   It is necessary to achieve education for all based on the principles of full participation and equality. Education plays a key role in defining the future for everybody, both from a personal point of view, as well as a social and professional one. The education system has, therefore, to be the key place to ensure personal development and social inclusion, which will allow children and youngsters with disabilities to be as independent as possible. The education system is the first step towards an inclusive society.

   Schools, colleges, universities should, in co-operation with disability activists, initiate lectures and workshops aimed at raising awareness of disability issues among journalists, advertisers, architects, employers, social and health care-givers, family care-givers, volunteers, and members of local government.

8. A COMMON EFFORT TO WHICH ALL CAN AND SHOULD CONTRIBUTE
   Disabled People seek to be present in all spheres of life and that requires that all organisations review their practices to

ensure that they are designed in a way that Disabled People can contribute to them and benefit from them. Examples of such organisations include: consumer organisations, youth organisations, religious organisations, cultural organisations, other social organisations that represent specific groups of citizens. It is also important to involve places such as museums, theatres, cinemas, parks, stadiums, congress centres, shopping malls and post offices.

We, the participants at the Madrid congress support this Declaration and commit ourselves to disseminate it widely, so it may reach the grass roots, and we will encourage all relevant stakeholders to endorse this Declaration before, during or after the European Year of People with Disabilities. By endorsing this Declaration, we organisations state openly our agreement with the vision of the Madrid Declaration and commit to undertake actions which will contribute to the process that will bring about real equality for all Disabled People and their families.

John Evans and other conference speakers at the European Congress on Independent Living, Arona, Tenerife, April 2003

Tenerife Declaration

The Independent Living Congress was held in held in Tenerife from the 24th – 26th April 2003. This was one of the biggest conferences on Independent Living ever held in Europe, and the first of its kind in Spain. Over four hundred participants from many European countries as well as delegates from the USA, Mexico and Argentina attended this two day congress. The ENIL, (European Network of Independent Living) hailed the congress as a milestone in the development of Independent Living and pronounced its long awaited arrival in Spain in the hope that it would spread throughout the rest of Southern Europe.

The main outcome from the congress were the Tenerife Declaration, which was a comprehensive statement outlining the importance of Independent Living, and calling upon the EU Governments, the EU Commission and Institutions to support its further development throughout Europe. The declaration was the culmination and work of many of the delegates present at the congress.

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Tenerife Declaration

Promote Independent Living -
End Discrimination against Disabled People

We, four hundred participants from many European countries gathered at the 1st European Congress on Independent Living, held in Tenerife in the framework of the 2003 European Year for Disabled People, urge that the Canary Island and Spanish Governments take the lead in advocating for the implementation of this Declaration in European Union policy, specifically in the work for the upcoming Non Discrimination Directive on Disability, and the European Action Plan on Disability.

Principles of Independent Living

We, Disabled People, must have the means to take responsibility for our lives and actions in common with non-Disabled People. Most of the problems that Disabled People encounter are not medical but social, economic and political.

After a history of marginalisation and exclusion, Disabled People are NOW demanding the right to choose how we live our lives in
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the community. We demand the same opportunities and choices and the same degree of control and self-direction over our everyday lives that non-Disabled People take for granted.

Our full and equal participation in society will enable us to reach our maximum potential as human beings, and in so doing contribute to the economic and social life of community. This has historically been denied us.

Disabled People must be viewed as the experts on their lives. As experts, we have the right and responsibility to speak on our own behalf. Furthermore, Disabled People need to control our own organizations.

Independent Living is a fundamental Human Right for all Disabled People regardless of the nature and extent of their impairment. These include People with Learning Difficulties, Mental Health System Users and Survivors, Disabled Children and Older People. All life and diversity should be valued. Every human being should have the right to make choices about issues affecting their lives.

We Affirm

In all activities of the public sector such as infrastructure planning, education, transportation, employment measures and other services, the needs of Disabled People must be fully taken into account through Universal and Inclusive Design. Service design and implementation must follow Independent Living principles and center on a person's individual needs.

Personal Assistance enables persons with physical, sensory, intellectual, and other impairments to live a self directed life in the community, enabling fuller participation in all human activities. Examples include, parenting, sexual activities, education, employment, environmental development, leisure, cultural and politics.

Disabled People should have maximum control over disability and Independent Living related services. These should include public financing, advocacy, training, and peer support for people who may not be able, or wish, to take full control of their lives.

It is unacceptable that European disabled citizens are still kept in residential institutions, because of the lack of appropriate living alternatives in the community.

We stress that Independent Living support services are essential in order for Disabled People to enjoy basic freedoms and must be funded by all Governments. We, Disabled People from all over Europe, do not accept any funding limitations in regards to our basic freedom. If necessary we are ready to challenge these assumptions about the lack of resources.

European Union

We urge the European Union (EU) to continue to expand its human rights policies to improve the quality of life of Disabled People through freedom of choice and higher quality of services.

We condemn any type of segregation and institutionalisation that are a direct violation of our Human Rights. Governments must implement and enforce legislation that protects the Human Rights and equal opportunities of Disabled People.

We urge the EU to adopt measures that will guarantee and prioritise community based, over institution typed solutions in the area of disability support services.

Disabled People must be given the choice to convert disability related support services, that are currently received in kind, into the equivalent amount of direct payments.

In compliance with the Treaty of Rome we demand the EU governments to adopt a minimum level of direct payment for personal assistance services in all EU countries in order to promote freedom of movement. Furthermore, in promoting standards for interoperability of goods and services the needs of Disabled People must be fully taken into consideration.

We demand the EU require governments to fund the development and support of organisations controlled and run by Disabled People to promote Independent Living.

We demand EU to adopt the necessary measures to prevent discrimination against Disabled People in future advances of genetics, science and technology.

Arona, Tenerife
April 26th, 2003