

**“Who Will Care when We are not There?”
International Conference, Milano
25th November 2004**

Direct Payments As One Way Forward

**Presentation by John Evans, President of European Network of
Independent Living**

Introduction

I am very pleased to be able to talk at this very important Seminar on a subject that is of both great concern and interest for us all. It is something that we all have to face at some point in our lives and I have much admiration and appreciation for you in organising this seminar with its challenging notion. I admire you for having the courage to seriously look at this issue, giving yourselves time to address it and to be able to come up with some ideas or alternatives in terms of what you can do as families of disabled individuals in the future. Yes, who will care when you are not there? This is a very big question for you and I know is very much in your hearts.

We live in a time of an ever increasing ageing society and a potential demographic time-bomb, so time is of the essence to us, so that we can allow ourselves enough thinking time to plan ahead. Society still has many questions to answer in terms of the future of social care in all of our countries throughout Europe, and your Conference is dealing with one of the big issues. I must say I pay tribute to Parent Organisations who have in the past been pioneers of Social Care. Your experience in many instances is that nobody would care if you did not care. I say this because your contribution in this field should not be undervalued.

Time has often shown that those who come up with the right solutions for these kinds of questions are indeed the very people who are most affected by them. In this case it is you. You will see from the alternative I shall be putting forward that it was disabled people, who

originally came up with the idea of Independent Living as a solution so that they could move out of institutions and live in the Community to realise their dreams. I hope your dreams become realised and this Conference is a step in that right direction.

An Alternative Solution

In my presentation I would like to put forward one possibility as an alternative to the family providing the care and support for disabled relatives. This alternative is indeed Independent Living and the way it can be achieved is through something called Direct Payments, which is one of the new personal budget schemes that enables disabled people to pay for their social care. This development has emerged in a number of different countries over the last 15 – 20 years. I know this way forward may seem difficult for some of you, but it has proved to be the answer for many disabled people and their families since it was introduced. It certainly changed my life and many other disabled friends and colleagues. For many families, it has helped to relieve them from some of the pressures of the caring role. However it does mean that the approach will be different, and for some this could be painful, relinquishing some of the responsibility of the caring role.

I know that sometimes there can be a difference from the way that a family can perceive the needs of the disabled member as opposed to that experienced by the disabled person themselves. This is the nature of the social interaction of the family relationship. However, I think the main point of both is the same, which is the health and wellbeing of the disabled person, particularly in terms of how their needs are met, either by the support of the family or the services provided by the local Government or through some other means.

Role of the family

In this discussion we need to be clear that the role of the family in supporting disabled people in their everyday needs is not always consistent and definite. In other words there are many variations of how support is provided by families. We must also recognize that within Europe this role of the family can vary a lot from country to country, and from the North to the South of Europe. I know in Southern European Countries the role of the family in supporting

disabled relatives is much stronger and is more culturally the accepted norm.

Whilst the family can on the one hand provide a life saving role and be the pivotal centre in a disabled persons life, on the other hand family relatives can also be a huge barrier to the disabled person. The whole caring role is subject to a variety of different emotions and forces. In many respects there can be exceptional stress and pressure. This is not always healthy for the family, and we need to bear this in mind looking at this situation.

Direct Payments Can Support the Disabled Person and the Family

I believe that the provision of Direct Payments, which is the money a disabled person receives from the state to pay for all the personal assistance the person needs, can help support the family situation very positively. If an individual receives this funding for support it can help relieve the family from some of those stressful pressures that can often have a negative effect on the interpersonal relationships.

Receiving a Direct Payment can also help disabled individuals within the family in gaining their independence which could assist their personal development. Sometimes individuals can be inhibited and restricted within their families and many times overprotected. It is important that disabled individuals do not become institutionalized within their own families and limited in the scope of opportunities available to them.

I know that there is not a clear cut answer to the family providing support for their disabled relatives, but the autonomy and self expression of the individual must be taken into account. This can be healthier psychologically and emotionally for all.

There is also a great difference regarding different impairments, and sometimes people might have extensive disabilities with complex dependency needs, as well as learning disabilities and mental health difficulties. Even amongst this group I believe that the provision of direct payments and personal assistance can improve the situation both for these individuals and their families.

Let me quote the Minister in the UK Government on this subject, who has responsibility for Social Care and Direct Payments, Mr. Stephen Ladyman:

“You cannot restrict your ability to make decisions based on an individual’s circumstances by having blanket policies, for example excluding people who have complex and intensive support needs, whose care costs are above a certain threshold, and you certainly cannot exclude direct payments from particular groups. If someone is not receiving a direct payment that must have been a positive choice they have made.”

I feel strongly that we should not be stereotyped in seeing the role of the family in black or white terms but must be open for innovation and flexibility in order to bring about the best of this relationship. The more we can avoid compulsion and force the better. In the end each individual is different and so is the family, so one has to make the best of the situation in order to get the most out of it.

What are Direct Payments?

Direct Payments are the way that disabled people have been able to achieve Independent Living.

Direct Payments is the money, which the disabled person receives from their Local Government or the State so that they 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 on a day to day basis, as opposed to getting direct services from their Local Government services in which they will have very little control or choice over.

Direct Payments is a means to an end, and the end should ultimately lead to Independent Living.

What is Personal Assistance?

Personal Assistance is all the necessary and required support and assistance a disabled person needs in order to live independently and equally in the community. It is self directed, organised and managed by the disabled person who chooses to employ their own personal assistants to carry out all the necessary tasks, duties and skills needed to support them. Some disabled people also have advocates and others to help them in this process of management. It does not necessarily mean that the disabled person has to do everything themselves.

What is Independent Living?

“Independent Living is the ability to decide and to choose what a person wants, where to live and how, what to do, and how to set about doing it. These goals and decisions about a persons life and the freedom to participate fully in the community have been and will continue to be the essence of what Independent Living is.

It is also the taking and establishment of self control and self determination in the total management of a persons everyday life and affairs.

It is about ensuring that all disabled people have the equality of opportunity in the chances and choices of life like everybody else.”

This is a quotation I made in 1989, but is still relevant today. However, it has been said that there are as many definitions of Independent Living as there are people living it.

I hope these key definitions are now clear to everybody in order that we can fully understand what Independent Living, Direct Payments and Personal Assistance really mean so we can proceed together.

How Does A Direct Payment Scheme Work?

A Direct Payments Scheme works quite simply in that the disabled person receives the money directly from his local Government or Authority, in order to buy in the support the person requires.

Obviously the disabled person would initially need to go through what we call in the UK a “Community Care Assessment” which means that the disabled person would need to verify that they require this kind of support and scheme through an assessment process. The money will go into a bank account singularly for the purpose of managing this scheme. This way it can easily be monitored and reviewed by the Local Government. It is usually the procedure that a disabled person would be reviewed annually, and this might be more frequent in the earlier stages of running their own schemes.

One of the important principles of direct payments initiated by disabled people is that of self assessment so that they are well prepared for this process and situation. This is based on the fact that disabled people know what they need and know how best they want their support and assistance provided.

Direct Payments developments

Since the Direct Payments Act was implemented in April 1997 there has been a considerable increase in the users of Direct Payments in the UK. In a survey carried out in 1997 of all the local government authorities in the country amounting to 180, it found that about half of these governments were running Direct Payment schemes and almost all the other half said that they would do. Only 4 local government authorities in the country said that they would not run Direct Payment schemes. A recent survey carried out shows that the majority of these authorities are now all running Direct Payments schemes.

This clearly shows that the Direct Payments Act has had an enormous effect in the UK, in encouraging local government authorities to implement Direct Payment schemes. This has been particularly significant in those areas of the country, which never had them before. Before the Direct Payments Act came into force, there was a predominance of schemes in the South of England and the London area, but now this has spread to include the northern parts of the country and Wales. The NCIL (National Centre for Independent Living) has played an important role in this process in helping Local Authorities implement Direct Payments.

The Government has also held great importance in expanding Direct Payments. I quote Stephen Ladyman again:

“ Direct payments really do change lives. Direct payments really do make a difference. These aren’t just my views they are the views of people I’ve spoken to and corresponded with from all around the country.

I’m not saying they are the only way to deliver services, I’m certainly not saying that top quality, well planned services can’t be provided directly because they can. What I am saying is they can, for many people with care needs, put real power in their own hands and genuinely put people in control of their own lives, sometimes for the first time in their lives.

These stories speak volumes and show us the power of direct payments. They are why I am passionate about wanting to expand their use.

People have to be at the centre of their own care. People's personal ambitions, their desires and hopes and dreams, should be the centre of planning the support they need; in that way we liberate people, we transform lives, we make things possible that previously seemed impossible.”

What are the advantages?

The main advantage is that the individual is in control of the situation and can organise their own support when it is needed, employ the people one wants and has flexibility in being able to do this. It means that users are not subject or dependent upon on receiving services at times when you do not need it and by people you are not happy with working for you.

It also means that you have the control so that if something goes wrong you are responsible for overcoming it. So, for example, if someone is not able to come to work, you are not left without anybody at all, you can arrange for an alternative by engaging somebody else who works for you to cover the difficulty.

The other advantage as well as providing more control and choice is that it allows for much more flexibility. This is one of the reasons why there is so much more user satisfaction experienced than through direct services provided by Social Services.

Positive Outcomes of Direct Payments

It is said that Independent Living has as many definitions as there are people living independently. It is a very individual thing and Direct Payments clearly reflects this in the way that individuals express themselves running their own schemes. It is difficult to highlight all the positive outcomes, which Direct Payments have had on the lives of disabled people, because they are so varied and individualistic. However, I think it is important to identify the main ones.

- More choice and control
- More user satisfaction and flexibility
- Cost effective
- Healthier
- More freedom
- Self worth and self esteem
- Confidence building
- Enable disabled people to find work
- Help disabled students at university
- Experience as employers and running small businesses
- Improving the quality of life
- Enhancing ones social life
- Providing more personal opportunities

The Future

If countries are really going to commit themselves to developing Independent Living and Direct Payment projects in their attempt to overcome social exclusion, then they will seriously need to financially support these schemes. There needs to be a political will, and an economic investment and a significant social policy change. The consequential difference will go a long way in liberating disabled

people, freeing them of social exclusion and dependency, and at the same time providing them with more control and choice in their lives with equal opportunity in life, work and play.

In the UK the Government has now relaxed some of its regulations regarding disabled people being able to use the Direct Payments for their families. This has also helped to improve the situation for some. I quote Stephen Ladyman finally:

“We have relaxed the regulations on close relatives – councils now have the discretion to allow a direct payment to be used to pay spouses or close relatives living in the same household, where it is necessary to meet the individual’s care need. Relatives living outside the household can be paid as part of normal practice.”

For those countries who have struggled to implement Independent Living schemes there are many countries now providing some very good practice models to use. Many of the Scandinavian countries have good examples as do the UK, Germany and Austria. Smaller schemes are also operating in Holland, Belgium, Ireland, France and Italy. We must remember that this style of life is not for every disabled person, as the decision lies with the individual themselves. It is they who must decide and choose to do it otherwise this is not Independent Living.

I leave you with this thought that the choice is with you and should be at the heart of the disabled persons future. I hope Independent Living can be a way forward for many of you in helping you to overcome your dilemma about the future care of your disabled relatives. I hope I have been helpful. Thank you.

John Evans, OBE
November 2004