

**FACING OUR FUTURE**  
**EXPERTS' SEMINAR ON INDEPENDENT LIVING AND**  
**DIRECT PAYMENTS**

Conference Report  
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# CONTENTS

INTRODUCTION

OUTLINE

ASSESSMENT

EXTRACTS

RECOMMENDATIONS

EDITOR'S NOTE

PAPERS AND DISCUSSION

Saturday 30<sup>th</sup> May

Presentation Back to Basics

*Philip Mason*

Workshop 1 Socially Based Self Assessment

*Stuart Bracking*

Workshop 2 Development of Future Centres for Independent Living

*Gordana Rajkov*

**Presentation** Future Roles of Centres for Independent Living -Promoting Direct Payments to a Wider Disability Community

*Adolf Ratzka*

**Workshop 1** Quality of Service

*John Roche..*

**Workshop 2** Users' Ability to Manage Direct Payments

*Simone Aspis*

Sunday 31<sup>st</sup> May

**Presentation** Involving the Whole Disability Community

*Arthur O'Daly*

**Listening Session 1** Independent Living and Personal Assistance for Mental Health Service Survivors

*Frances Hasler*

**Listening Session 2** Older People and Direct Payments

*Anne MacFarlane*

**Listening Session 3** JAG: Parent Controlled Personal Assistance Co-operative for People with Multiple Impairments

*Adolf Ratska*

**Workshop 1** Different Models of Support Schemes

*John Dunicliffe*

**Workshop 2** Training for Personal Assistance Users

*Anne Marie Flanagan*

Closing Session

Chair *Frances Hasler*

Appendix

## **INTRODUCTION**

Eighteen years ago some disabled people in Hampshire along with local government officers pioneered the use of payments to enable individual choice and control over the provision of personal assistance services. This sort of development took place in a number of European countries and came to be known as the payments option or direct payments.

It is from this background that, during the period of the United Kingdom Presidency of the European Union, we organised a European Experts Seminar on the subject in collaboration with the National Centre for Independent Living, London, Centre for Independent Living, Dublin and the Institute of Independent Living, Stockholm.

Participants were predominantly disabled people from countries familiar with the practice of using direct payments.

## **OUTLINE**

The event consisted of presentations followed by a series of workshops giving participants the opportunity to share experiences and learn from each other. It was one of two linked events called 'Facing **Our Future**', the other being organised by the National Centre for Independent Living in London.

## **ASSESSMENT**

Given the nature of the funding process, a speculative bid whose result is uncertain until six months before the event, it is remarkable that we achieved the quality of participation and debate recorded herein. Given more time and more certainty far better use of resources could be achieved, for example by securing more favourable rates for venue and accommodation as well as ensuring wider participation.

Another complaint is that funding is not paid until the event is completed in every detail. This characteristic mitigates against the participation of 'user-led' organisations who do not have the cash flow to accommodate such an imbalance. Despite these disadvantages it should be noted that the participants were predominantly disabled people most of whom were personal assistant 'users' as well as 'experts' on the subjects in question. Five European countries were represented. The fulfilment of the intended purpose 'to share experiences and learn from each other' is ably demonstrated by this report.

## EXTRACTS

'Disabled people wanted direct payments to enable them to buy and organise the assistance needed to access every day life as enjoyed by their non-disabled peers. The dream was to do with being enabled to be an active citizen at work, rest and play.'

'Direct payments are seen by central and local government as being another means of providing social welfare services. In this context direct payments do not enable independent living and should never be seen as doing so.'

'We need to say that enabling choice and control, for example through direct payment schemes, cannot be exclusively for one impairment group or age group in our society. What is good for one must be available to all.'

'The disability community has a responsibility to make it (*inclusion*) happen and the only way this will be satisfactorily achieved will be through our ensuring the centrality of people with learning difficulties in the development of the policies and practices of their scheme.'

'Our responsibility is to be open to and encourage these developments (*inclusion*) in ways that ensure that mental health service survivors are themselves at the heart of developing local policies and practices.'

'The first requirement for a high quality personal assistant service is that it should be consumer led and consumer driven, incorporating the concepts of self-responsibility, co-responsibility and accountability'.

'Direct payments enable people with learning difficulties to start pulling the strings. That is, they are now in control. We can resist the standard options, the status quo, and use direct payments to unlock opportunities previously unavailable.'

'We need to ensure that direct payments usage does not get stuck in one' model, one prescribed way of doing things. Flexibility and imagination should benefit all service users irrespective of impairment.'

(We) ..need to recognise that public opinion drives political decisions and not rational evidence. On the contrary, politicians are driven by a fear of public opinion and instruct local government officers to minimise risk.'

'If we are to influence the way in which elderly people are treated then we must change public attitudes -and this will be very difficult.'

'Instead of imparting the mechanics of using personal assistance it is much more important to ensure the development of self confidence, self worth, through self awareness and empowerment training.'

'None of us doubts the value of training for personal assistant users. The problem is convincing those who allocate funds. We all know that you only need to train one personal assistant user but many personal assistants for that user. Unfortunately it is easier to get money to train personal assistants.'

'It is worth developing our own economic model taking account of the broader and long term outcomes to demonstrate the value of 'independent living'.'

'We should also be prepared to exchange experiences with local and central government officers by way of educating each other as to our aims and objectives. The alternative is that we might be going along parallel tracks without communicating.'

## **RECOMMENDATIONS**

**Inclusion** -ensure that all 'groups' are central to the development of their own use of the payment option.

**Flexibility** -encourage the development of different ways of supporting the use of the payment option.

**Educating the public** -explain how we 'see ourselves' and how we fit into society.

**Educating personal assistance users** -more opportunities for personal development.

**Dialogue** -open exchange of aims and objectives with local government politicians and officers, 'parents' organisations and private or for-profit agencies.

## **EDITOR'S NOTE**

To assist a broader understanding of the text have not replaced words such as 'users' as in 'direct payment users' or 'service users' and 'care' as in 'Care Packages'.

# PAPERS AND DISCUSSION

Saturday 30<sup>th</sup> May

## PRESENTATION

### **BACK TO BASICS: Philip Mason (*Text*)**

I am privileged to be the first speaker in this conference. A conference which is looking at the future in respect of those well known phrases 'Independent Living' and 'direct payments'. It is a privilege and a responsibility because I need to strike the right note: to encourage and to challenge.

So where do we start? Do we talk about the past; look at the present or think about the future? We ought to do a little bit of all three and it is my job to start the ball rolling.

First the past. Let us congratulate ourselves on having moved things forward. We are here to talk about things that have already started to happen in many parts of Europe. In the first instance let us look around and pat ourselves on the back for having put the issue of independent living on the map. The concept of independent living, that is disabled people being enabled to lead active lives at work, rest and play is now beginning to be understood all over Europe.

*We have done this ... This is a major achievement.*

Of course, it is just not us alone. We have been aided, supported and encouraged by our allies. First we won the intellectual debate. Then the practical debate. And last but not least, the legislative arguments. At the beginning of my address I want us to be encouraged by where we have come from and what we have arrived at -of course not all of us, but a significant number. We are no longer trying to persuade people of the value of our convictions. Something worthwhile has been achieved. We have changed policies and practices, each in our own countries. And we have begun to change public attitudes.

Of course we have not arrived. There are still obstacles to be faced but at least the journey has begun.

in Hampshire our background was in nursing homes. If you were not looked after by your friends and relatives in the family home the only alternative was the nursing home. That was the prospect for disabled people sixteen years ago. In 1979 a group of disabled people in a local nursing home proposed to the local

government that instead of paying for them to be looked after in a nursing home they should give these people the money and they would look after themselves in their own homes in the community. That happened. That is our history. And that was a significant development.

We were not alone. Things like this were happening all over Europe. In different ways, in different circumstances, disabled people were challenging the accepted practices. Disabled people were seeing themselves as human beings and wanting to live as their non-disabled friends and relatives did. In other words we wanted to be able to access ordinary lives at work, rest and play.

In Hampshire we imagined that once we had shown that it could be done, this would open the door and many other disabled people would follow. That did not happen. Each of you in your own countries know the obstacles that seemed to spring up -it was almost as if each disabled person had to re-invent the wheel in order to make something happen. So it was for us; nonetheless we were eager to share our experiences. We established a local organisation to do this. This too was happening elsewhere in Europe.

Our local problems were to do with concerns over the legality of the payment process and the unavailability of suitable housing. Similarly elsewhere, disabled people were caught up in local and national legal and bureaucratic wrangles. Towards the end of the 1980s came a very significant development. A conference organised by disabled people met at the European Parliament in Strasbourg. The outcome of this was the Strasbourg Resolutions which asserted our desire to be given the means to enable equal opportunity at work, rest and play through funds to purchase personal assistance. The most important outcome of this meeting was the establishment of an international peer support organisation the European Network on Independent Living. We found allies each promoting independent living in their own country. We supported each other, sharing information and advice.

In Britain the most important matter was legislative -to legalise the payment of monies (instead of services) from local government to disabled people. Towards the end of the 1980s we began the campaign that ended with legislation in the mid 1990s. This was a major achievement. We had taken the idea of 'personal assistance' on to a national platform. It was debated in the national assembly. The idea of disabled people being enabled to exercise choice and control over who took them to the toilet had been put on the national agenda.



## **This brings us to where we are today**

In Hampshire we already had a payment scheme. In April 1996 there were some 500 people buying and organising their own assistance. The Hampshire scheme was simple and flexible. The arrival of national legislation meant changes as our old scheme had to fit into the new laws and regulations. We felt this was a price worth paying for two reasons:

- 1 the legislation encouraged all local governments throughout Britain to offer this choice;
- 2 we felt the law would make this choice more available to different people within our own areas -not just the physically impaired.

However, we were not prepared for what followed -the bureaucracy and the involvement of lawyers and accountants. So here we are today wrestling with the sudden onslaught of legal and technical details which have swamped what was once a simple and straightforward scheme. We dreamed a dream: the means to be enabled access to work, rest and play through funding to purchase and organise personal assistance. Along comes legislation which fits things into Government criteria and things turn out different to the dream.

## **Let me make something clear ...**

Direct payments are not independent living because they are a local government provision which meets central government legislative needs. Nowhere in our country does legislation contemplate the enabling of equal opportunity through the provision of personal assistance. Our dream was that disabled people would be enabled to fulfil their roles in terms of taking the opportunities society offers and meeting the responsibilities society requires. We believed that direct payments would enable this but that is not so. What has happened is that direct payments is seen as just another means of providing social welfare. At the basic level it is seen in the same category as attendance at the Day Centre, an auxiliary nurse getting you up and putting you to bed or two weeks in a respite home. It is not independent living. Direct payments is defined by local government to fit national government legislation. It is prescribed on the basis of eligibility criteria and the extent to which it can give support is determined by the tasks identified by legislation.

The dream was to do with being enabled to be an active citizen at work, rest and play. The fact of the matter is this is not available because nobody else is enabled to achieve these ends through social welfare provision. Instead eligibility criteria is seen in terms of the individual's vulnerability. The tasks that can be financed are to do with the simple facts of life, getting up, going to bed, eating etc. Issues to do

with social integration are little addressed. As for work, rest and play... the means to these ends are not available.

You see, the dream came up against reality and the dream has gone out of the window ...

**But...** it is not only legislation that has resulted in many more fingers in the pie. The identifying terminology has been stolen by others.

Suddenly the term 'independent living' became a catch phrase for social welfare professionals, for the orthodox charities and for anybody else... Suddenly 'independent living' became sexy and everybody climbed on the bandwagon, each with their own definitions and special interests, to the extent that the term 'independent living' is now avoided by many of those who originally identified themselves with the phrase!!!!

So now we see independent living bungalows, independent living aids and appliance centres, independent living homes, independent living advisers, independent living research ...and so on, and so on. It is just another com modify. We have lost control of the very creature we created. Each interest group has defined the term to its own advantage. The original concept and the aspirations of disabled people have been lost in the scramble.

But it not just that direct payments are not independent living and that the term 'independent living' has been stolen. It is that despite all the developments the underlying problems are still there. What we can and cannot do is still decided by others.

The fact of the matter is disabled people remain dependent in terms of what social welfare will enable them to do. The dream of being able to participate in all aspects of life has not been achieved despite the many claims to the contrary. And this is not because there is no local will to achieve it, but because much of our national legislation is built on the basis that by and large we are to be 'cared for' by friends and relatives.

We have made major achievements but these have not dealt with the underlying national understanding of the role of disabled people in society. It is still in terms of the old definitions. We are to be 'cared for'! There has not been the radical development we originally envisaged - disabled people being enabled to participate in all facets of society. The outcomes, though high on political rhetoric, do not materialise in practise.

In our country government have proposed the policy of 'welfare to work' but as disabled people already know, much of the financial infrastructure is such that the possibility of benefiting from earnings is ruled out by the fact that you would lose more than you would gain. The very means of independence and the ability to go out to work would be removed through financial penalties based on the income earned to the extent that it is not worth going to work in the first place.

These financial disincentives have not been removed. This is a supposedly caring society which talks about enabling individuals to fulfil their potential and so on. The reality is the very opposite. If you are a disabled person the financial incentives are still against you.

## **Having talked about where we have come from and where we are at today, we need to look to the future.**

I have already drawn attention to paid employment and the problem of financial disincentives. But this is only a symptom. We need to get to the heart of the matter and consider the question of why society should support its disadvantaged.

We all come from nations where people are voting to pay less taxes. Lower taxes and better public services are contradictory concepts. You cannot have better public education, better public social welfare, better public health with ever decreasing taxes. It is inevitable that the one affects the other. Our governments have all promised the electorate lower taxes and the consequence is lower funds for public services.

If we are to promote the case for better services for ourselves then we need to explain our position at the national level. We need to tell our fellow citizens why it is that they should contribute towards enabling our independence.

For people with a national background in social democracy, (those that accept mutual interdependence), this statement may come as a surprise. But even in your countries I suggest this mutual interdependence is being challenged. I would argue that the most important thing we need to do now and in the future is to explain to the public what we mean by independent living and why it should be funded from the public purse. **I think this the major challenge we face.**

Remember the dream. We need to challenge the persistent image of our being burdens on the public purse and in its place explain our desire to be fellow citizens being enabled to accept responsibility and make our own contribution.

**Next, to turn to a second challenge:** we need to say that enabling choice and control, for example through direct payment schemes, cannot be exclusively for one impairment group or age group in our society. What is good for one must be

available to all. And this too is a challenge: **how do we make sure that the choice and control payment schemes bring is made available to all?**

Traditionally the payment option was seen as being something for physically impaired people only. That is how many schemes started, although they never set out to be exclusive. We all realised long ago that direct payments were an enabling tool that would work in many *different* circumstances. It is to our deep regret that only now are we beginning to talk about ways in which this option can be developed. Only now are we talking about structures that can make direct payments more flexible and adaptable. Only now are we recognising that not everybody can hire and fire but most would like the choice and control this brings.

Our task is to make the payment option more available and to enable more choice and control for people who want the greater flexibility this option gives. How do we achieve this? **How do we structure things in such a way as to ensure these developments take place?**

Today and tomorrow and the following weekend these themes will be taken up and expanded. At the heart of it is our dream for our significance to be recognised and enabled.

In closing may I encourage you all: do not forget the dream whilst at the same time dealing with day to day realities. Keep your eyes on the horizon whilst taking one step at a time in the real world. Do not be disappointed if some of these steps may be backwards or sideways. Ultimately we will go forward to the horizon we have all have been working for.

And remember... we do this not for ourselves but for those who come after us, those who inherit what we have done. We owe it to them to leave things better than we found them.

# **WORKSHOP 1**

## **A SOCIALLY BASED APPROACH TO SELF-ASSESSMENT:**

*Stuart Bracking (Text)*

### **What is self-assessment?**

Self-assessment is a tactic which has been promoted by the Independent Living movement to enable disabled people to assess and articulate what services and assistance they believe they need in order for their needs to be met and to achieve a good quality of life.

Before their needs are formally assessed by their local Social Services Department disabled people are encouraged through publications, training and one-to-one support to think about the lifestyle they want, their aspirations and future goals, and then identify all of their personal, domestic and social needs, including their need for Personal Assistance.

By separating the assessment of need from the allocation of resources a disabled person is able to arm themselves with thought out, reasoned arguments to help them to resist the organisational, professional and financial pressures that often lead to resource-led assessments.

### **Barriers to self-assessment**

There have been significant and positive changes during the last twenty years in those laws and social welfare structures that regulate and organise the assessment and arrangements for meeting need. The idea that disabled people who need Personal Assistance are passive and dependent creatures who cannot organise and control their own lives and support has partly broken down. And funding opportunities have improved.

However, there are still significant barriers to independent living and needs-led assessments which mitigate against an individual's self- assessment being respected.

### **The Barriers:**

#### **i      Legal and Financial Pressures**

In Britain, the House of Lords ruled in the Spring of 1997 that local authorities could take into account their available resources when deciding what needs to meet and to whom to provide services. This removed the right of disabled and older people under a 1970 law to have their community care needs assessed and met

irrespective of available resources. This situation developed as a result of long-term central government under funding of Social Services Departments. It has in many areas reinforced the use of resource-led assessments.

## **ii Access to Assessments**

Assumptions are sometimes made about disabled people's access to assessments. Leonard Cheshire research found 8 out of 10 Social Services' Directors thought it was not difficult to get an assessment. A majority of service users surveyed disagreed.

## **iii Policies of Social Services Departments**

The nature of assessments and the 'Care Packages' that result vary enormously from one area to another. A reading of the figures for the numbers of disabled people who access monies for Personal Assistance via the government funded Independent Living Fund illustrates that many local authorities limit access to this funding. A disabled person in one area might receive a comprehensive package of £500 plus a week from their Social Services Department and the Independent Living Fund, but in the neighbouring district or county the same person may be limited to home based support which falls far short of the £200 of services a week needed to access the Independent Living Fund.

## **iv Structure of Social Services Departments**

Joseph Rowntree funded research published in March 1998 found that Specialist Disability Teams were more likely than Older Persons, Generic and Hospital Teams to acknowledge the legal entitlement of a disabled person to a comprehensive assessment and to offer a full assessment to everyone.

## **v Professional Assumptions**

Assumptions can arise about the ability of an individual to manage a 'Care Package' and assume responsibility for their own risks. Sometimes this results in an individual being given a low-level assessment and access only to the Social Services Departments own services. Also, access to new opportunities can sometimes be limited. For example, the patchy implementation of the Community Care (Direct Payments) Act 1996 reflects an over cautious (and sometimes disbelieving) approach by many local authorities to the issue of trusting disabled people with financial resources.

## **vi Qualifying for Funding**

Sometimes it is difficult for disabled people to access the Independent Living Fund because they cannot get the necessary passport benefit - the higher Care Component of Disability Living Allowance.

## **vii Fear**

Disabled people who live in areas where access to services has been limited and their local Social Services Department has developed a hostile culture and poor relationships with their local disabled community, can sometimes be afraid to ask for a comprehensive assessment for fear that they might lose those services they are already receiving.

## **A Socially Based Approach**

Because of the need to challenge and breakdown these barriers, the Independent Living movement needs to continue to promote and refine self-assessment.

For self-assessment to be effective it must be firmly rooted in the Social Model of Disability. To truly reflect an individual's needs, self- assessment must not be corrupted by assumptions about what services are likely to be given or can be afforded. Also, each individual disabled person who does a self-assessment has to be encouraged to regard it as their right to be able to ask for Personal Assistance and other community care services. As such, it is essential that Personal Assistance is promoted as a liberating tool. The idea is often promoted that independence means disabled people should do everything for themselves and regard it as a failure if they have to ask for another person's assistance. Self-assessment must challenge this notion.

A socially based approach to self-assessment must address the following issues:

i **Information:** Disabled people need access to information about what services and Personal Assistance funding they are entitled to. As well as this being provided in a range of accessible formats, information needs to be written in such a way that it conveys the positive benefits of assistance and illustrates all the ways that it can be used.

ii **Self-Assessment Check-Lists:** Many Independent Living projects produce check-lists of all those tasks that an individual might need assistance with. Check-lists allow an individual to record how frequently they believe they might need assistance with each task. They also act as a prompt to suggest tasks that an individual might not think of. It is important that regular consideration is given to how effective Self- Assessment check-lists are.

Whilst check-lists need to be as comprehensive as possible, there is a danger they can become intimidating if they are not presented in the right way. Check-lists need to be refined and thought should be given as to whether or not those using a them can understand what is meant by each task. Also, different individuals will require different levels of support when filling in a check-list.

iii **Peer Support:** When talking to someone about Personal Assistance and how it works in practice it can be difficult for them to understand in the abstract how it might be beneficial. This is particularly true if the services and support they have previously received have been low level, home based and structured using a care approach. Contact with other Personal Assistance users can give disabled people (who are about to or thinking of self-assessing their needs) a chance to talk through any issues or worries with someone who they can relate to and they know has succeeded. Peer support groups not only encourage this kind of support but also help to develop a sense of community amongst Personal Assistance users.

iv **Professional Advice and Support:** Professional advice and support provided through our own movement and organisations can be an important element of effective self-assessment. Whilst Personal Assistance Advisors should actively promote a disability rights culture, clearly they also have a duty to respect the aspirations and desires of the person they are working with. However, if an individual restricts what they believe they need in their self-assessment, believe it is right to challenge this in a positive way.

An Advisor must always strive to provide accurate advice and convey information in as simple and non-threatening a way as possible. More networking and training for Advisors is important so that we can learn from each other's experience. Also, the professional status of Advisors needs to be raised so that our advice and opinions are respected more by other professionals. But we must guard against Advisors become another elite.

v **Advocacy** Advocacy is *different* from advice. Although the boundaries between the two can sometimes be blurred, an Advisor who both advises an individual doing a self-assessment and then advocates for them when they have a formal assessment risks shaping their desires and the services they ask for. Advocacy is important since it takes a lot of confidence to promote and argue for a self-assessment when faced with a confident Social Worker or Care Manager who is not willing to listen or disagrees with what is being requested. Professional advocacy projects need to be developed, but equally as important is the promotion of advocacy skills and peer advocacy amongst Personal Assistance users.

vi **Definitions** Increasingly the term "Personal Assistance" is being substituted for "Care" by local authorities and other agencies, who understand it is perceived



more positively by the disabled community. However, this occurs without significant changes to the structure and culture of their services. Our movement must promote its own definitions and principles to prevent the term Personal Assistance from becoming diluted.

## **The Future**

In Britain, there are significant numbers of disabled people who have had their self-assessment respected at their formal assessment. Because a self-assessment is based on real needs that reflect the lifestyle a person wants, it is difficult to argue against. Where comprehensive assessments are promoted by Social Services Departments, there is no reason why a formal assessment should not be based on a self-assessment. Where they occur, those barriers that work against self-assessment and promote resource-led assessments must be undermined and actively opposed by our movement.

We must also be wary of trying to make self-assessments 'realistic'. If barriers exist, an individual will learn about them soon enough in a formal assessment. I believe our vision should be to create a society where disabled people can self-assess their own needs with support, and then go to statutory agencies and get the appropriate funding and services without being questioned.

## **Summary of Discussion**

There are a number of dynamics at work in the formal assessment process, ranging from the tendency of local government officers to fit people into existing services right through to budgetary restraints - restrictions imposed by resources. There is also tension between the natural aspirations of disabled people and the local government interpretation of its responsibilities. These differ significantly, resulting in frustration on the part of disabled people. Then there are the collective and individual preconceptions and prejudices of those taking part in the process. Our cultural, professional and personal baggage.

Self assessment is a journey, an awareness raising process. Time is essential for this to take place. For many it is a journey that never ends, the more you are enabled to do the more you want to do.

You cannot choose until you have seen all the options. However there is a tension between time and decision making. Exploring all the options can mean that a decision is never made.

The process might involve risk taking. Unfortunately society does not see this as being a legitimate ingredient. On the contrary, politicians are driven by a fear of public opinion and instruct local government officers to minimise risk.

The process should be guided by the principle, for example the process of 'self-direction' should result in practical action. That is if people need information then they should be enabled to gather it themselves, for example through them being given the money to 'find out' for themselves rather than them just being given the information. Information finding and using are valuable skills.

We need to recognise that accepting help is more difficult for some than for others, for example where people have extremely low self esteem. In other situations we need to question whether or not people are genuinely being allowed to make their own choices, for example where a family member is an advocate.

## **WORKSHOP 2 :**

### **DEVELOPMENT OF FUTURE CENTRES FOR INDEPENDENT LIVING: Gordana Rajkov (*Notes*)**

When considering the subject of developing future Centres for Independent Living we can assume this includes setting these up. Therefore, the next question is where? Firstly I suggest we should be trying to build on the existing network of Centres for Independent Living in Western Europe, and establishing a network of Centres in Eastern Europe.

From my experience I can give an example of what is involved in bringing independent living to Yugoslavia. Not just the philosophy of independent living but much more importantly, the practical workings- out. It is the practice that people see and which enables them to begin to understand what you are trying to achieve.

I was involved in setting up a Centre for Independent Living in Belgrade. In doing this I was able to build on my experience working at the Centre for Independent Living in Dublin. Although the circumstances were very different I already knew the areas that needed attention, which were basically the external political and social circumstances.

One of the obvious measures we took was to find out what people were doing in other Centres and for this we built on the experience of Dublin's and Vienna's Centre for Independent Living. We took every opportunity to put across the independent living message, including being involved in the training of staff who were to work in a newly opened residential home. This was an opportunity to discuss the use of resources during which it was possible to negotiate a pilot programme where instead of going into a residential home the individual disabled person would use money to organise their own care.

Another matter we had to resolve was whether or not the Centre for Independent Living would focus solely on issues to do with personal assistants. Among the services often found in the Centre for Independent Living are housing, access, transport, equal opportunities and peer support, so creating a self sufficient movement.

Among my concerns for the future is that in trying to become established we are forced to make compromises which water down the Independent Living philosophy. I am certain that new Centres for Independent Living should be cross-disability organisations and that we should avoid setting up Centres that do not deal with personal assistance issues. Peer support is an essential ingredient of the Centre for Independent Living. We -need to be sure that we understand who are

members of the Centre and recognise that the movement has been weak in not being representative of the broader disability community.

There is a real danger of Centres for Independent Living turning into another Social Services organisation and compromising the philosophy in order to gain and fulfil service contracts. Funding is a major problem, particularly funding for advocacy activities. We need to be clear about what we mean by independent living and argue clearly why this should be enabled through state funding. I think the latter is one of the main challenges. Direct payments are not independent living but they are an important demonstration of the philosophy because they give individual disabled people the finances necessary to enable important choices in their lives.

The term independent living has been stolen by commercial and professional interest groups. Not only do they use it to further their own ends but they use it and reinterpret it in order to support the acceptability of their own policies, practices and products.

When trying to promote independent living in Eastern Europe we need to be sensitive to the prevailing cultural, political, economic and social conditions and work for change within this context. We have to understand where people are coming from and interpret the practice of independent living accordingly. In many countries national legislation enforces and supports the accepted cultural view that disabled people should be cared for, usually by family, at low or no cost to the state. Furthermore nothing is expected of disabled people; they are not seen as being capable of any achievement. The idea of disabled people being enabled to participate in all areas of life and why this should be funded are radical concepts that need to be explained and promoted. We need to remember, that the disability movement is about rights and not services.

The question we all need to be asking ourselves is what can we do to support the development of new Centres for Independent Living. We need to accept the responsibility of making our own contributions to this purpose. However many difficulties we encounter we must not forget the original dream.

We are not as far forward as we think. We need to be providing more training opportunities for new users. We need to be more balanced in our presentations and not force our interpretation of 'independence' on our fellow disabled people. Perhaps we should concentrate on developing the basics -personal assistance, housing and transport rights, keeping the momentum of the social model going and working on disability awareness. We need to be aware of the tendency towards passive dependency and ensure that in all our practices we are promoting non dependency. We need to value the diversity of human nature and support the

development of Centres for Independent Living through the exchange of experiences.

## **Summary of Discussion**

Disabled people's organisations developed the personal assistance model and supported this through Centres for Independent Living. Subsequently these ideas and practices were increasingly imperfectly copied by private agencies and orthodox charities. To some extent this was inevitable, often because of an 'activist gap' at the local level; the absence of a local disability organisation.

At a time of rapid expansion in direct payments practice it is difficult to bring into being a local disability movement with sufficient depth to take control. Local disabled people do not have the infrastructure or resources to enable them to quickly develop in ways that will support independent living, even though it has long been accepted that peer support, advice, information and training are essential ingredients of a successful operation. Such developments take time; they cannot be rushed.

There are different direct payments practices between different countries and within countries. Some operate through an organisation such as a Centre for Independent Living while others pay directly to the disabled person, who can choose whether or not they want to be involved with the Centre for Independent Living. For good practice it was felt that there should be a formal link between the individual and the local Centre for Independent Living as this was in the best long term interest of the individual and the scheme. Only disabled people can provide the advocacy services sensitive to their common interests; choice must also remain important.

In the UK the local authorities have been strongly advised to involve local disabled people in the development of policy, practice and support for direct payment schemes. Whilst there is little or no guidance on the detail of how this involvement should be achieved, this advice recognises that successful schemes are more likely to develop where there has been good consultation and involvement with local disabled people from the start. The hope is that this will develop into a local Centre for Independent Living.

Unlocking resources for the Centre for Independent Living and direct payments is easier when there are existing, supposedly sympathetic institutions. In this situation one is challenging existing interests and practices and arguing for a different use of the resources, such as closing the nursing home. It is much more difficult where no resources are identified. Then it has to be an argument for the resources themselves.

Centres for Independent Living need to be rooted in independent living philosophy and the disability movement. Their support of individual payment users needs to be out of conviction. Once funding is involved the free enterprise culture enters the equation and a Centre for Independent Living can lose its way -as seen in the American experience. There is a danger we end up compromising our convictions in order to receive financial support. Nevertheless Centre for Independent Livings need money in order to develop and support one another. Where is this money to come from?

If the Centre for Independent Living is an integral part of a local payment scheme they can use some of this money as core funding. The alternatives are to act as consultants and charge for services provided or forever be arguing for grants from charities and local governments. Whatever the case, providing local services and fostering the development of fellow Centres for Independent Living are very difficult, almost incompatible, objectives.

## **PRESENTATION**

### **FUTURE ROLES OF CENTRES FOR INDEPENDENT LIVING - PROMOTING DIRECT PAYMENTS TO A WIDER DISABILITY COMMUNITY: Adolf Ratzka (*Notes*)**

The purpose of a Centre for Independent Living is to enable ourselves to gain more personal and political power and promote independent living.

#### **Central issues or foundations**

- Clarifying and re-asserting our definition of independent living and promoting this.
- Establishing control over social norms as applied to disabled people's expectations.
- Sharing independent living experience amongst ourselves locally, nationally and internationally.
- Remembering our backgrounds, the history of Centres for Independent Living in the USA and how people worked together to establish these.
- The threat of vested interests particularly from professional bodies and orthodox institutions and charities.

- The need for our own organisations to be strong: clear in what they stand for, independent of funding sources and accountable to the community they represent.
- Building on and fostering personal and political power

### **Core areas of activity**

- Recognising the value of and promoting peer support as a foundation activity provided by genuine peers and not as a service provided by professionals.
- Advocacy, meaning enabling, supporting people to do things for themselves -promoting independence and not dependence.
- Other activities will depend on local conditions, local needs amongst the disabled community. These can include: housing, finding assistance and so on.

### **Core characteristics of a Centre for Independent Living**

- Need to be a cross-disability organisation built on the principles of cross-disability cooperation -working together to achieve mutually agreed objectives.
- Must be run by disabled people. Problems arise with non-disabled people as they are inclined to take over.
- In order to avoid making bad compromises keep measuring things against the original definitions and intentions.

### **The Future**

There is a great need to spread our concept further. Maybe we do not need Centres everywhere but we need to spread the concept further, not only in Europe but all over the world. This is needed as long as the general population can say that we should be happy because things could be much worse. In Sweden the public always want to be first in the world in respect of services for disabled people and they keep telling us how fortunate we are. But it is the gap between us and the general population that counts. We can also work and get our views across in politics.

In the beginning independent living was an extension of rehabilitation but now we are hungrier for life than that. We want the same as everyone else. Some of the services we have concentrated on help towards these goals but there is still a barrier. We still find discrimination. I think we have to work much more in the area of anti discrimination legislation. We need to push for more services that we can control but also anti discrimination legislation. We need to combine the independent living and disability rights movements; collective and private aspects together.

I see some dangers. If we depend solely on contracts for the direct payments projects then we will be vulnerable. Some places in the US have workers talking about 'case loads', 'case management', 'clients' etc. One Centre forbids its employees to mention that they come from the Centre when they lobby because they do not want to lose contracts. In the US the forefront of the movement is no longer with the Centres for Independent Living it is with ADAPT, the national lobby campaigning for a re-direction of Nursing Home funding.

The other danger is professionalism; dealing with individual 'clients' and forgetting the group aspect. Once an organisation has established its character it is too late to change it.

## **Summary of Discussion**

It is very important that Centres for Independent Living aim to be inclusive and not impairment specific. Despite the difficulties this may involve all the people concerned must learn to understand each other and work together towards commonly agreed goals.

Centres for Independent Living should resist the temptation of becoming dependent on non-disabled people. Employing disabled people should be a commitment in its own right as well as a means of ensuring that peer experience is utilised.

Apart from the value of their service and the important role they can play in raising the stature of disabled people within society, Centres for Independent Living will have the means to act in a political manner, listening to the grass roots and reflecting hopes and fears as well as generating the income to make this possible. There is a tension between service provision and advocacy; practical as against political activity. To overcome the potential for conflicts of interest some organisations have split into two -in Britain this is sometimes represented by the Coalition and the Centre for Independent Living.



We need to recognise that as a Centre for Independent Living develops and the employed staff become increasingly competent, or 'professional', the Centre for Independent Living can grow away from its 'roots'. The employed staff can become increasingly identified with the Centre for Independent Living and they can take over. The questions then becomes: how do you keep the Centre for Independent Living part of the disability community?

An equally difficult issue is that of the 'disinterest' of the average user of the Centre's services. Many, if not most people just want to get on with their lives and have little or no political commitment to or involvement with the Centre, the disability movement or the independent living philosophy.

Maybe instead of developing Centres vertically we should consider encouraging the proliferation of many Centres for Independent Living cells; more locally based small self-help-groups horizontally linked one to another for sharing information and the provision of balance. This would create a network of local Centres for Independent Living staying at the grass roots.

# WORKSHOP 1

## QUALITY OF SERVICE: John Roche (*Text*)

### 1. Principal Philosophy

Nothing About Us Without Us -Interpretation & Implementation: Consumer Led And Consumer Driven

#### 1.1 The Centre for Independent Living in Ireland

The 'Nothing About Us Without Us' philosophy is well demonstrated by the structure of the Centres for Independent Living in Ireland.

The Centre for Independent Living at the national level is driven by its membership, a number of whom are elected onto a Board of Directors. A large number of the membership are Leaders, that is, disabled people who have personal experience of independent living. This is considered the best method of keeping independent living 'pure', i.e. of the highest quality.

An Executive, consisting of a strategic management team and executive director, reports to the Board. The Executive is concerned with the day-to-day running of the Centre for Independent Living and has the responsibility for achieving goals and implementing policy of the Board. The operating structure is further broken down into six key Action Cells which perform the work of the Executive.

In keeping with Centre for Independent Living's philosophy, the involvement of Leaders (i.e. clients/consumers) at all levels is actively encouraged, as they have the greatest interest in ensuring that consumer needs are constantly borne in mind and that the independent living philosophy is properly adhered to at all times. A key component of its structure is that the coordinator of each Cell is a Community Employment programme manager from a local Centre for Independent Living. The structure therefore ensures that the independent living movement develops its strategy and philosophy uniformly across the country. The Centre for Independent Living is therefore both consumer driven and consumer led, with empowerment, accountability and ownership at many levels.

#### 1.2 Direct Payments in the United Kingdom

In the United Kingdom Self Operated Care Scheme or Personal Assistance Schemes are coordinated by Centres for independent Living which provide support to clients in terms of assisting with setting up one's own direct payments scheme, recruitment advertising, pay and tax management, etc. but at all times the responsibility of an individual's scheme (as an employer) lies with the individual.

In many ways, therefore, Self Operated Care Schemes and Self Operated Personal Assistant Schemes are both consumer led and driven and reflect the 'Nothing About Us Without Us' Philosophy.

Without the 'nothing about us without us' philosophy driving independent living, people with disabilities run the risk of adopting a passive dependency stance which experience shows has not been in our best interests. *Therefore the first requirement for a high quality personal assistant service is that it should be consumer led and consumer driven, incorporating the concepts of self to responsibility, co-responsibility and accountability*

### **1.3 The 'Nothing About Us Without Us' Philosophy -Why Personal Assistants Must Have a Say**

There are considerable fears which currently abound with respect to the organisation or unionisation of personal assistants. To form a union or be part of one is a right. Therefore personal assistants should be permitted to exercise this right. As we members of the independent living movement continually seek rights for people with disabilities, the first thing we should do is ensure we do not infringe the rights of others. Our greatest fear perhaps would be a strike by personal assistants. The questions arises as to whether or not this would be worse than the often daily fear of 'will my personal assistant turn up' anyway? The subtle difference is that if personal assistants 'get organised' their voice can become a lobby for a high quality personal assistant service. Allowing them to work alongside consumers and clients will give the independent living movement a strength and depth it has not seen heretofore.

What then is the best kind of personal assistant union? In my opinion, a union set up and owned by personal assistants would be the best kind to reflect the unique and flexible nature of the job. Affiliation to other unions would be acceptable but its rules and regulations should adhere to independent living principles with regard to client empowerment and unique interpretations of Health and Safety at Work Acts and similar legislation.

The basic improvements being sought are:

1. Improved (Realistic) Pay Structure for personal assistants -including provision of adequate Relief.
2. Improved hours accounting procedures.

3. Provision of formalised life-skills and independent living training for Leaders.
4. Provision of formalised Leader-driven Training of personal assistants leading to qualifications and loosely attached to pay scales to keep personal assistants motivated.
5. Career Structure (limited) for committed , reliable personal assistants - as personal assistant Co-ordinator's Assistants liaising with personal assistants and Leaders.
6. Development of Consumer-driven methods of assessment of potential future Leaders.

Self-assessment -taking on Responsibility - importance of High Personal Standards -setting and meeting Targets on an individual Leader basis -The importance of Political Motivation.

7. Networking of Leaders and Peer Consultancy

### **3.3 Employer Responsibility and Commitment To Equal Rights**

#### **3.3.1 *Equality of Treatment for personal assistants***

The Independent Living movement must be seen **to** advocate equality of treatment of personal assistants in the following areas:

1. Employment Law.
2. Health and Safety at Work Act -the need for some (Leader supervised) classroom training of personal assistants in this area for their own safety.
3. Provision of adequate Relief for personal assistants -Local Authorities or Health Boards or Local Government Bodies must adopt a fair strategy, such that for every personal assistant an individual client employs, enough Relief hours must be built into the hours assessment, such that the Statutory number of paid holidays (e.g. 7 hours off per 100 hours worked) and Bank Holidays (often as time-off in lieu) can be taken by personal assistants without leaving the client stranded.
4. **Keeping Up With The Private Sector - Is This The Greatest Threat Of Them All?**

Currently the private sector attracts personal assistants as their pay rates are one-and-a-half to three times the going rate for publicly funded personal assistants. Perhaps the Independent Living movement should endeavour to be the quality leader in the area of personal assistant training, whereby privately funded personal assistants must first attain a qualification through working in the public sector. How? Set up a high quality accreditation agency which is consumer driven that surpasses anything currently in existence. European Social Funding might be amenable to such a development. The aim would be to have private recruitment agencies seeking out personal assistants with an Independent Living Assistant's Certificate. With a realistic retention period of 1 year to 18 months per personal assistant, at least the Independent living movement could avail of this resource of personal assistant-power that otherwise would move directly to the private sector as is currently the case.

## **5. Accreditation To Quality Standards Applied To Personal Assistant Services and Schemes**

As a part of setting high standards for personal assistant services and schemes and all attendant supports in the fields of recruitment, training, management and auditing, an excellent means of demonstrating that our real abilities are 'beyond reproach' would be to seek Quality Assurance Accreditation in accordance with the International Standards Organisation.

That is: ISO 9000 = Quality Assurance = Steps towards Permanence

### **Summary of Discussion**

It is very important that disabled people who use personal assistants should value their staff and ensure that they treat them responsibly with good terms and conditions of employment. Employers need to be well informed about their responsibilities and duties. In addition they need continuing advice and information as well as the possibility of support particularly when things go wrong. Whether training and proof of competence should be a prerequisite to a disabled person joining a scheme is debatable. Whatever the practice, training is essential and the cost of this training and ongoing support should be part of the funding.

Some personal assistance schemes will cost more than others simply because some people need more assistance with recruiting and managing their assistants. Everyone should have the opportunity to exercise choice and control whether or not they can manage their own staff. However it is not certain whether these variations can be accommodated within one model of provision.

Different schemes have different practices for example in the recruitment of personal assistants. Some allow the employer freedom of choice, others are more prescriptive and identify a specific source such as a specific agency. Furthermore there are differences in opinion as to whether or not employees should hold a recognised qualification, be encouraged to attend a training programme or be 'trained' by the employer.

Centres for Independent Living could go some way towards meeting some of the concerns expressed by running personal assistants training programmes. These could address basic issues such as disability awareness and health and safety matters like safe practice and hygienic procedures.

More contentiously there was discussion around the interests of personal assistants: should they be enabled to meet together and develop mutually beneficial programmes -like their own 'support services'?

Finally we discussed the issue of standards in employment practice. We agreed that personal assistant employers should aim to have better standards than the 'similar' statutory services. However, the question arose: how do we ensure that these standards are met by everyone -can we really ask disabled people to police disabled people or do we leave this to the local government officers? We suggested that the answer depends on what is being policed: the proper treatment of employees or the proper use of public money?

## **WORKSHOP 2**

### **USERS' ABILITY TO MANAGE DIRECT PAYMENTS:**

**Simone Aspis (Notes)**

*(Simone accompanied her talk with illustrations which are available in a publication from the National Centre for Independent Living, 250 Kennington Lane, London SE11 5RD).*

Direct payments for people with learning difficulties can be seen as the ultimate chicken and egg situation: to choose direct payments or direct payments to enable choice? What comes first for people with learning difficulties if they have no real experience of making, choices?

People with learning difficulties are invisible. Why is this? Basically because they are hidden away within secure institutions: a private home with family; the group home with carers; the sheltered workshop or day centre with staff. They are smothered and their lives ordered within the confines of these settings.

Historically this has been the case, though changing attitudes within society have seen people with learning difficulties moving from asylums to ever-smaller units in the community, group homes. However, whatever the setting, their lives are identified by routines and activities of which they have little or no choice or control. The fact is, has anything really changed despite community care? Have independent living services brought more fulfilment to these people's lives to date?

We need to ask who makes the decisions on the services provided. Who controls the budget, who provides the service, who decides the risks, who decides who can take part? In answering these questions we see parallels between practices at the turn of the century and today. Not a lot has changed in service provision to people with learning difficulties despite the trappings of modern rhetoric.

What is 'the value of direct payments to people with learning difficulties and what will these bring? The answers must be the same for people with physical or sensory impairments and non-disabled people: payments open up a range of opportunities to suit the lifestyle of the individual. Payments bring a personal level of opportunity. People are no longer reliant on having to blame one of a group. Instead the individuals enabled to make choices about leisure, employment, holidays, education, friendship etc.

Direct payments enable people with learning! difficulties to start pulling the strings. That is, they are now in control. This seems a simple enough concept until authorities like Government start looking into whether or not people with learning difficulties are able to manage their own lives, manage money, control their own lives etc.

To discuss whether or not people have the ability to manage their own lives we need to recognise that this means making choices. And in the context of direct payments this means choosing and managing personal assistance. To explore this further we will split up into small groups and discuss:

- How do you manage money?
- How do you make choices or decisions?
- How do you go about employing someone?

## **Flip chart notes following discussion:**

### **Managing money**

Accountants  
pay-roll section at work  
Bank procedures  
Tax-saving ideas  
Can accountant help with everything?  
*E.g. insurance, other information*  
Can people make savings on their own?

### **How do we make choices?**

Daily routines often automatic  
Controls come from daily routines with work/family  
Information  
People's opinions  
Status quo  
Media

### **Employing staff**

Decide what is wanted to do  
Decide how to get them V  
Word of mouth  
Legalities  
Tax/National Insurance  
Get another organisation to do it  
Contingency plans/back up  
Different scenarios in mind  
Need the money

The conclusion was that the same issues, the same experience was common to all people. But is this really the case, for example for someone with Down's



Syndrome? Will there be other things that they need help with, for example concepts like counting?

The answer must be that advice, information and support are prerequisites and are used by all people in addressing these questions. The level of input necessary to enable informed choices needs to be gauged to meet individual circumstances. Therefore we are not dealing with a completely different set of issues for people with learning difficulties. People with learning difficulties need advice and advocacy but things can be set up in such a way as to enable choice and control. We can resist the standard options, the status quo, and use direct payments to unlock opportunities previously unavailable.

### **Summary of Discussion**

The 'management' of personal assistants is a skill which some people can develop whilst others for one reason or another are less able to do so.

The issue of using a personal assistant is much broader and more important than simply utilising direct payments. It is not just a matter of 'can you manage money?' but issues like how to relate to each other and not allowing one to dominate the other need to be worked through at the personal level.

Enabling people with learning difficulties to utilise the direct payment option can include the use of an advocate. In these circumstances how do we ensure that the individual is truly exercising choice and control? Perhaps it is important not to get too hung up on the mechanics as long as sensitive support results in equal opportunity coming to individual people. This needs to be done in an enlightened manner being aware of all the potential pitfalls and all the time leading to the ultimate goal of enabling the individual to exercise more choice and control in his other life.

Having said all that it does not just happen! The disability community has a responsibility to make it happen and the only way this will be satisfactorily achieved will be through our ensuring the centrality of people with learning difficulties in the development of policies and practices of their scheme. 'He who wears the shoes knows best how they fit.' Our duty is to support, encourage and foster this development.

**Sunday 31<sup>st</sup> May**  
**PRESENTATION**  
**INVOLVING THE WHOLE DISABILITY COMMUNITY: Arthur**  
**O'Daly (*Note*)**

In the early days in Ireland there was uncertainty within the disability community about the practice of independent living. We knew it did not exist at home and so we looked elsewhere for examples. These enquiries helped us to clarify our thinking and develop our own proposals.

At this time there was little or no dialogue between people using statutory services and the officers providing them. A Forum of people with disabilities developed in 1990. This was not resourced and existed solely on the collective determination to make things happen. There were a number of issues we wanted to discuss including anomalies around whether or not one was fit to vote in elections.

Our endeavours were supported and enhanced by political changes and political allies. After 1990 a Coalition Government came into power with a leading Government Minister, Dick Spring, having a personal interest through his daughter. The result was the setting up of a separate Ministry for 'Mental Handicap'. This was subsequently changed to the Ministry for Equality and Law Reform with an identified Minister.

As a result of the campaign by the Forum a Commission was established looking into every aspect of life in Ireland. This sat for three years and involved service providers and people receiving services. There were many tensions throughout these enquiries with the establishment trying to maintain the status quo whilst people with disabilities argued for changes.

The report was published in November 1996. It was received with great excitement. It addressed all aspects of life: social, legal, health, training, employment etc and indicated the need for legislation. Among the recommendations was the importance of disability awareness and that training in this should be given to civil servants amongst others. The recommendations were to be adopted as resources allowed. The Minister said, 'This is a whole new world for people with disabilities'.

Now we have had the Commission, its report and recommendations. In the 1970s we had a Green Paper. Between 1981 and 1984 there were various moves to put disability issues on the public agenda. In each case nothing happened. Now the 1996 report -the hoped-for dream -and nothing is happening. The fact is that it

needs decision makers to make things happen. We need to focus on implementing individual recommendations, not on discussing the whole philosophy yet again. Ministers have spoken about new horizons. How about working to implement the recommendations, for example addressing simple needs like training that will lead to employment and a salary? Training for disabled people is an obvious and achievable target.

One of the issues that needs to be addressed is the well-known poverty trap that people with disabilities find themselves in once they start earning money. I am sure many of you are familiar with systems that reduce pensions at the appearance of earned income with the result that people end up worse *off* than when they started. Other groups in society such as students are encouraged to earn money through schemes which disregard earned income up to a certain level. This could and should be done for disabled people.

Another issue is that of public attitudes toward people with disabilities. Some of these are patronising and most are the result of ignorance and can be quite comical, like 'We must not deprive disabled people of their leisure'. That is, that we need to be free to spend our days sat in front of the TV!

A tension has arisen over definitions. Basically this is between people with disabilities and organisations of parents such as the National Association of Mental Handicap. Legislation involved a change in language but non-disabled people felt that terms like 'handicap', meaning 'cap in hand', helped with fund raising and should be retained. There has been an attempt to establish a general coalition, but people with disabilities and parents' organisations have different views about the purpose of this body. One sees it as a means of protection, whilst the other a channel for protest. One is arguing for more residential places and a carer's allowance, whilst the other argues for further independent living resources. One consequence of the parents' lobby was an increase in the carers allowance, rather than money being given to independent living.

My understanding of events in the USA taught me that they get things done by making them happen. Even if they get it wrong initially the US reaction is to do something. From this I have learnt that we need to stop discussing and start implementing by setting priorities and giving resources. In America the view is that if they have a third done that is progress. Our first priority is to establish an Independent Living Fund and to resource that now.

# **LISTENING SESSION 1**

## **INDEPENDENT LIVING AND PERSONAL ASSISTANCE FOR MENTAL HEALTH SERVICE SURVIVORS:**

**Frances Hasler (*Notes*)**

I am speaking at rather short notice in place of Gloria Gifford and I am reminded of our often-repeated dictum: nothing' about us without us! However, I feel this is one of those subjects that needs attention and if no people are around to discuss it then no talking gets done. It is on this basis that I will proceed in the hope of stimulating attention.

When considering direct payments for mental health service survivors it is very difficult to grasp exactly what the money would be for. For example, going through the standard Assessment Check List would prove it to be irrelevant in this context because it is focused on physical needs. Obviously we need to re-conceptualise the meaning and purpose of support.

For mental health service survivors their experience is of support at times of crisis and then nothing until the next crisis occurs. Perhaps support should be available on a continuing basis? We would then need to ask questions like what would be supportive on a daily level, and what would be the continuing measure necessary without waiting for a crisis? Then the support would be informed and available if a crisis arose although the intention would be through its availability to avert a crisis.

For example, in parenting responsibilities there are times when it is difficult for a parent to fulfil this role. In these instances it is all too easy for the children to be labelled 'young carers' and in some instances even removed by the local authority. Surely there is a role here for flexible support that will keep the family unit together and enable the parent to continue in their role.

Times when people are in a crisis are the times when they are not 'self-directing'. Yet these times could be accommodated by establishing a pre-directive for just such occasions when the individual is unable to manage. In other words, making allowances for such eventualities; sharing responsibilities in advance.

It is imperative that in developing independent living policy and practices mental health service survivors are included and attention given as to how they wish to participate. We need to be open to the probability that mental health service survivors will not necessarily adopt current practices and require alternative arrangements. For example, in Essex one scheme has found that mental health service survivors do not like the peer support meetings so they do not attend..1

They are instead involved by videoing these meetings and passing around the resulting recording.

We need to question our very structures, the way our organisations are established and function. These can be uncomfortable and unwelcoming to many people including mental health 'service survivors. For example, in America the US Survivors Network is very non- hierarchical. We need to make sure that the way we operate does not exclude people.

Another aspect of this subject is the environment in which mental health service survivors find themselves, both in public perception and professional practices. In the UK mental health services are very patchy and largely focused on risk management. They are often very custodial and invariably compulsory. Mental health diagnosis can result in involuntary incarceration and fear of this eventuality is very real for some people. The independent living movement needs to connect more with this reality, with these fears.

Gloria would have said things in a different way. I hope I have managed, in some small way, to draw attention to mental health service survivors and the need to include them in the movement and, in particular, to enable them to speak for themselves about using direct payments.

## **Summary of Discussion**

It is not for us 'outsiders' to make assumptions about what needs are or what assistance is most helpful to mental health system survivors. The disability movement's experience teaches us that the 'end user' is the person who best knows what they want and already has good ideas about how this could be achieved. We should build on that principle.

For example, where assistants are expected to assume responsibilities or exercise some initiative, this means a reconsideration, re-definition of their role and training by mental health system survivors. And we must not forget people with more than one disability, for example a mental health service survivor with a physical impairment.

The difficulties in developing local programmes are not just those of prejudice but also those of entering new areas of discipline' dominated by totally different professional cultures. Areas dominated by medical practitioners complete with their own well established hierarchies, theories and practices.

Our responsibility is to be open to and encourage these developments in ways that ensure that mental health service survivors are themselves at the heart of

developing local policies and practices. We can do a lot by using our credibility and organisations to insist that this happens. Furthermore we can make our experiences available to mental health service survivors as they consider how to go forward.

In the meantime we need to be encouraging more flexibility and imagination in the use of direct payments for example by showing that the availability of an average quarterly budget can help an individual cope with fluctuating needs. We need to ensure that direct payments usage does not get stuck in one model, one prescribed way of doing things. Flexibility and imagination should benefit all service users irrespective of impairment. We should resist the temptation to segregate people and practices into impairment groups.

A warning: we need to be aware of public opinion, the media and its influence on politicians and policy makers. Economics and rationality rarely apply in the public debate. For example in New Zealand a family assessment and response to the whole family was shown to have better outcomes both in quality and economically for the community, the family and the individual, yet the practice has never been successfully applied. Rationality may point to known successes but that is not the factor that guarantees implementation or adoption. Public perception, often shaped by the media, drives politicians.

Once again we are back to public opinion and the need to influence this. We need to recognise the importance of educating the public.

## **LISTENING SESSION 2**

### **OLDER PEOPLE AND DIRECT PAYMENTS:**

**Anne MacFarlane (*Text*)**

Over the next two years 30 million people will be invited to have their say in a debate entitled the Millennium Debate of the Age. This consultation is being co-ordinated by Age Concern who recognise that longer life-spans and falling birth-rates mean the structure of British society will be transformed over the next 20-30 years, with fewer young people and more older people to support. The key themes will cover health, money, family life, jobs, homes and transport. The Debate of the Age provides an opportunity for individuals, public and private organisations together to become the architects of future policy that will influence the quality of life for all in the new Millennium. It will be an informed debate that will involve people of all ages irrespective of circumstance. People will be involved through local and regional conferences and will be able to give their views in many different ways.

By the year 2051 the over 60s will outnumber the under 20s by 3 to 2 and this pattern is emerging world-wide. A vital strand of the Debate called the Voice of Experience will target older people. Age Concern is having the first of a number of conferences on the 30th June entitled 'A Life Worth Living'. We need to ensure that the social model of disability perspectives permeate every discussion within these Millennium debates.

The numbers of older people living independently and alone in their own home is set to increase considerably. By the year 2020 19% of the population will be over 65 and by 2040 there will be 15 million older people, making up just over 25% of the total population. Community Care policies and a general recognition that older people want to remain in their own homes for as long as possible, mean that older people will be more likely to be living independently in the community than in institutions or even in sheltered housing. One of the fundamental issues is the ability of older people to manage physically in their own homes as their situation changes with reducing mobility, sight and/or hearing. It is obvious that much of our existing housing stock in this country fails to meet the needs of older people and disabled people. This situation is going to continue for many decades and already presents serious physical barriers to independent living. While grants are available through the local authority Disability Facility Grants system it is known that many older people do not know how to access this system they are loath to ask for financial assistance and, even when they do break through the red tape, the wait for an occupational therapy assessment can be as much as twelve to eighteen months. During this waiting period a person's condition may deteriorate making it impossible to stay in their own home or they may die, often as a result of an accident, before a decision has been made for a grant. In any case, adaptations may

only be part of the solution to independent living or no solution. The older person may require personal assistance and they should have access to this option from the outset of their need.

Six months ago the National Centre for Independent Living called a meeting inviting organisations representing older people to come together. Two significant issues were for discussion, the first concerned the exclusion of older people from the Community Care (Direct Payments) Act and the second was the difficulties in getting younger disabled people and older people to come together to discuss issues of mutual interest and concern. From the discussion it appeared that those groups representing older people, for example, Help the Aged, Age Concern, Greater London Association of Older Women and Pensioners Forums had felt that so much campaigning effort was needed to focus on financial benefits and financial assessments that the Direct Payments Act had not appeared on their agendas. This is one of the common issues which the disability movement and the older peoples' networks could work together on. The British Council of Disabled People recognises that it has not spent time on including older people and their issues but this had not been because of lack of commitment, interest or acknowledgement of the importance of doing so. This factor, as well as the ongoing struggle for a core grant to deal with the many issues that confront our national organisation means that older disabled peoples' issues do not get any quality time on agendas. Equally, older peoples' organisations have not seen the relevance of the British Council of Disabled People for its membership.

What is recognised is that for years older people have been purchasing the services of personal assistants through advertising, by paying neighbours and family members or they have gone without and struggled through each day.

Those of us who have been working with local authorities on setting up direct payments schemes know that whenever we invite people to meetings there are always older people in the group. Older people want the option of direct payments. Research by the British Council of Disabled People has shown that the numbers of older people wanting direct payments is not high but this is probably because they have never had experience of support in setting up an independent living scheme. There is no evidence to suggest that older people have any more difficulty in setting up an independent living scheme than younger people. All the same issues arise: How will the money be paid to me? What will have to do to account for it? How do I pay personal assistants? How will know the person I am employing is genuine? What happens if I am let down by a personal assistant?

One of the significant differences and difficulties surrounding older people having the option of a payment lies in the fact that Government community care policies still divide people by impairment rather than addressing service provision by



tackling barriers. Older peoples' service provision are unequal when compared to provisions for younger people. Care packages for older people have lower financial ceilings than for younger people. Most local authorities pay no more than £300 per week for a 24-hour care package for an older person whilst the majority will receive far less than this even though they may require 24 hour support. These differences have serious implications for younger disabled people reaching the age of 65 and who are having to transfer to older peoples' services.

Not only are the financial awards less but most senior managers within older peoples' services have not begun to understand the direct payments legislation or have any procedures in place.

### **What recommendations can this conference put forward?**

- There is a need for older people to be represented on all the direct payments schemes.
- Disabled peoples' and older peoples' organisations need to come together to debate direct payments.
- Older disabled peoples' issues must feature on every British Council of Disabled People agenda, not necessarily as a separate item but included in all relevant agenda items
- All local authority joint planning groups should ensure that direct payments are on every groups agenda.
- Campaigning for the inclusion of older people and direct payments needs to continue.
- Direct payments should appear on relevant health authority and community trust agendas.
- General Practitioners should be made aware of direct payments legislation and its relevance for disabled patients.

### **Summary of Discussion**

Why is there less social welfare money for older people? Is it a question of volume or the fact that living longer is a more recent phenomena which has not been catered for because it did not used to exist or is there a more cynical explanation?

Namely that the easiest thing to do is to wait for them to die and that in the meantime they are no vociferous or organised enough to make a collective fuss? In some countries social welfare practices specifically exclude older people. For example in the UK direct payments are not available to people over 65 and in Sweden direct payments are not available to people needing under 20 hours assistance a week - which is the category into which most older people fall.

There is also the issue of tradition. Many societies still have the unwritten rule that 'older people' are the responsibility of family and friends. This unwritten rule is often more apparent in rural areas but nevertheless it is the sentiment that underlies many social welfare practices. Furthermore people themselves are creatures of tradition and many elderly people are liable to conform to stereo-typical expectations. However this situation is changing and more and more elderly people are questioning current attitudes and practices. This trend will continue -we are the first generation of disabled people likely to reach old age having been accustomed to personal assistance services. This eventuality is a challenge both for ourselves and for society.

As in many of the workshops a persistent theme has been that of public attitudes: the fact that in western society elderly people are not valued. By and large they are seen as a nuisance or a burden. If we are to influence the way in which elderly people are treated then we must change public attitudes - and this will be very difficult. We should not be naive about the challenge: there are reasons why euthanasia for example is a persistent topic in the media.

Another recurring theme in the workshops is that of equity between the treatment of one group and the treatment of another. Recipients of direct payments are seen to be receiving a better quality service than that available to people receiving directed services. We all agreed that rather than 'equalising down' we should encourage the raising of all standards.

**LISTENING SESSION 3**  
**JAG:PARENTCONTROLLED PERSONAL**  
**ASSISTANCE CO-OPERATIVE FOR PEOPLE WITH**  
**MULTIPLE IMPAIRMENTS:**  
**Adolf Ratska** (*Notes from JAG presentation*)

The word "JAG" in Swedish means "/" or "me". The users of personal assistance who are members of JAG are subjects and individuals; not, as before, objects of care. The word "JAG" is also formed from the first letters of the Swedish words for Equality, Assistance and Fellowship, immensely important words for JAG's members.

JAG is a personal assistant cooperative specialising in 'independent living' for very severely mentally and usually physically disabled people. JAG drew its inspiration from the Stockholm Independent Living Co- operative model of personal assistance supply and in the space of a few years has become the largest personal assistance cooperative in Sweden. It is very different from the Stockholm Independent Living Co- operative model in the sense that although JAG tries to achieve direction and control by the users of personal assistance for obvious reasons, this has to be facilitated in a specific way.

### **Organisation**

One part of JAG is an association which works with issues related to personal assistance and disabilities. The other part of JAG is a cooperative of users of personal assistance. Ideologically, JAG claims to belong to the Independent Living movement. The association JAG and the cooperative JAG are both organized in the form of national, non-profit associations.

### **Membership of JAG**

Only a person with multiple severe disabilities, including some kind of intellectual disability, can become a member of JAG. Others can become supporting members, without the right to vote. Only a member of the association JAG can be on its Board of Directors. JAG's members are, with few exceptions, represented by their legal guardians.

Due to their intellectual disabilities members of the cooperative JAG cannot be 'burdened' with the responsibility of being on its Board of Directors. To risk making the members personally responsible for decisions concerning large amounts of money would be unethical. To achieve the closest connection possible between the members and the management of the cooperative, the Charter of the

cooperative JAG stipulates that only a legal guardian to a member of JAG can serve on the Board.

For the same reason, JAG's members are unable to work at the central office. Some of the staff at the central office are parents of members of JAG, and thus bring valuable experience and knowledge of JAG's members' situation and needs. Among JAG's members are persons with developmental disabilities, as well as persons who have had a head injury caused by an accident or by illness. With few exceptions JAG's members also have extensive physical disabilities. Most of JAG's members have no speech but communicate in their own very personal way. The nature of the members' disabilities presents problems to achieve user-control of personal assistance. JAG has undertaken the difficult but not at all impossible task to provide personal assistance of high quality to its members. The JAG-model will be presented further in the following.

## **Guardian**

What JAG does is that each disabled person will appoint a Guardian, a legal entity, who acts as the member of the cooperative and makes decisions along with the other Guardians. In practice the Guardians tend to be parents, other family or spouse.

## **Deputy Supervisor**

The other person in the equation, apart from the ser, is the Deputy Supervisor. This is someone who works with the individual disabled person to fulfil the responsibilities of selecting, organising, training and directing staff on a daily basis. In fulfilling this role the Deputy Supervisor has their expenses reimbursed and a small monetary compensation as a gesture of the time commitment involved in being available twenty-four hours a day to ensure that the user's needs are met. The Deputy Supervisor undertakes all the administrative roles in terms of ensuring needs are met on a regular basis including, if necessary, covering in the event of a breakdown in services.

There is an agreement as to what the Deputy Supervisor will do. This is written in a contract between the disabled person and the Deputy Supervisor so that areas of responsibility are clearly identified. The Deputy Supervisor also has an agreement with the co-operative as to what their role is.

## **The Co-operative**

The Co-operative undertakes all the financial and legal responsibilities to the employees as in the Stockholm Independent Living Co-operative model.

## Summary of Discussion

This co-operative is unique and separate. Although it espouses the independent living philosophy many in the disability community remain critical. The question we need to ask ourselves is why? Many of us come from a background where we have seen young disabled people being inhibited by their parents. Parents, with the very best intentions, can end up adding to the disadvantages of their children by making them dependent to the extent that they fail to develop any life skills. Such a career is one of dependency on parents and then dependency on institutions. It is a familiarity with this experience that prejudices our consideration of organisations like JAG.

The question we should be asking ourselves is, 'why are we surprised that these parents have such concerns for their children?' Who else would make the sacrifices, take collective actions and make long term plans except the parents? There is almost an impudence in our questioning the validity of the parents' motives -as if our record of concern was any better?

Maybe we should be asking ourselves why our organisations have not done more to include these people and to act to develop ways of meeting their needs. We should be asking ourselves: how can we encourage these parents to become part of our organisations and how can we enable them to accept independent living philosophy? How can we develop independent living practices that promote the independence of their offspring?

Stockholm Independent Living Co-operative includes these parents and young people. We need to encourage practices like this whilst at the same time questioning and influencing the 'parents organisation'; for a start by asking them to employ disabled people in their infrastructure.

# **WORKSHOP 1**

## **DIFFERENT MODELS OF SUPPORT SCHEMES:**

**John Dunicliffe (*Notes*)**

First of all some nuts and bolts: the Independent Living Scheme Support and Advice Service is part of the West of England Centre for Independent Living. It is an organisation of disabled people with all members of management and most of the staff being', disabled people. The organisation comes from the Social Model perspective and tries to put Disability Equality principles into practice. ,

The scheme we operate is called the Self Operated Personal Assistant Scheme. Individual disabled people receive local authority funding through the scheme; they take the responsibility of employing their own staff and we provide advice, information and support: Cash Payments and Support. In explaining how the scheme works, I will focus on three main areas: Support; Funding; Accountability/Collectivity.

### **Support**

We give one-to-one support through advisers to people coming on to the scheme so enabling them to make an informed choice and thereafter. We have produced a handbook giving very detailed information and offer a pay-roll service which people can use. We organise peer support and training sessions, both being part of the collective nature of the organisation.

### **Funding**

We support disabled people in drawing up a self-assessment of their needs for assistance. They are then assessed by Social Services and needs are measured in a number of hours per week. These hours are turned into an amount of money using established guide-lines based on how much is needed to pay an assistant plus 30% for National Insurance, holidays, administration etc. It is essential that we enable people to be reasonable employers so that they can recruit and retain staff.

Once they have funding the disabled person can then choose how they organise their scheme, rates of pay etc. They have to account for funding by keeping time sheets and receipts and submitting a quarterly financial statement.

The Independent Living Scheme Support and Advice Service receives per capita funding for each person on the scheme which enables us to maintain the level of support to each payment receiver as the scheme grows.

## **Accountability**

The Independent Living Scheme Support and Advice Service is accountable to the Personal Assistance Advisory Sub-Committee with one representative on the main board. There is a danger of direct payments recipients becoming isolated. By operating within an organisation of disabled people recipients are given the opportunity to develop contacts through our activities.

The scheme has been running for four years with one hundred disabled people on it. The scheme is successful and hopefully it will grow as direct payments become better known. We know that this is a relatively small number and that many disabled people do not come on to the scheme because they are unwilling or unable to manage the level of responsibility. This takes me back to revisit the fundamentals of independent living, three of which are choice, control and responsibility.

As well as developing Independent Living Scheme Support and Advice Service-type schemes, we need to look at other schemes that can run in parallel. These other schemes might not involve direct payments.. My own feeling is that in the UK some of us have been carried away with direct payments as the be-all and end-all. This is not to underestimate the political achievement but it must be put into its correct context as a tool. What we wanted to achieve was choice and control. These are measures that we can use to judge any new model.

We need to move on from direct payments. The West of England Centre for Integrated Living is working to develop a new scheme to run in parallel with the Independent Living Scheme Support and Advice Service: Partnership Operated Personal Assistance (POPAS). The idea is a scheme in which the individual works in partnership with the West of England Centre for Integrated Living in order to achieve the desired end. The Centre would not act as the employer; the disabled person would be enabled to be actively involved in recruiting and line managing staff etc. Obviously there is a continuum along the line of choice and control. If this model works it increases the choice available to the disabled person.

It is important that these models are developed and run from organisations of disabled people based on the Social Model of disability.

Direct payments was an important political victory and is still an important political tool. Within the direct payments movement we need to be sure that we are thinking beyond direct payments and refer back to the fundamentals of choice and control and develop schemes that offer these to disabled people.

## **Summary of Discussion**

Providing support to people in four different local authority areas with their four different practices involves considerable complications. Among the difficulties were those of maintaining confidentiality, keeping good relationships with local authority officers and dealing with referrals.

Different practices operate in different countries. Although the moral case for direct payments has been won there remains some scepticism about the business case and whether or not 'disabled people can cope'!

Means testing appears increasingly common, with various practices being implemented in different countries and within different countries. There does not seem to be very much consistency other than the resistance of disabled people! Means tested charges are a major disincentive to paid employment and must be objected to on the grounds that they discriminate against disabled people.

There are considerable variations in what is deemed reasonable for personal assistants to do, what is regarded as a 'need'. In some countries personal assistants can enable social activities, in others enabling employment, whilst others find that support is only available on the basis of keeping people at home -a bed and breakfast service.

There are variations in the level of pay allowed to personal assistants. All present felt that the personal assistant role was undervalued and that in many instances the funding did not allow reasonable reward for the services provided. A prime example of this was the United Kingdom's Independent Living Fund. It was for organisations of disabled people to work hard at improving the terms and conditions of personal assistants. In particular looking at things like paid holidays, working conditions, etc.

Are direct payments being accepted as the norm? Direct payments are only being used by a minority of disabled people. We are a long way from this option being seen as the norm. Many more models of support and practice need to be developed in order to increase availability and accessibility, for example partnership schemes.

The issues of discipline, regulating both personal assistants and personal assistance users. Abuse of funds or abuse of staff is recognized as a possibility and various monitoring practices operate within different countries. In some instances it is the local government who will act; in others it is the Centre for Independent Living, the cooperative or civic authorities. In each case it is a painful matter and it is better to take measures that try and avoid this eventuality.



What is the role of the private, profit-making agency and how do organisations of disabled people relate to them? What about the orthodox charities and their encroachment into this field? Do we ignore these developments or should we try and find ways of ensuring that whatever 'the system' they adopt that it serves the ultimate interest of disabled people?

## **WORKSHOP 2**

### **TRAINING FOR PERSONAL ASSISTANCE USERS:**

**Anne Marie Flanagan (*Notes*)**

This is an important subject to me and I know that it is important to many other people as well. Part of the dream of independent living was being given the opportunity. Opportunity also means responsibility and that is where the training we provide comes in. We want to take absolute control and exercise absolute choice over our own destinies in our own lives.

If we look at the Irish experience and the In Care programme it has to have a training element in it. We had to identify the training needs. With the help of other people we developed training modules for Leaders and at the development stage we were very Leader focused. It was a wonderful and exciting time. It was very empowering particularly for people who had been institutionalised.

We looked at the philosophy of independent living and how people could fulfil that in their lives. We looked at communications; with each other, with personal assistants and the broader communications. And we recognise the need to train support people looking at issues like seeing disabled people as people.

When later on the Centre for Independent Living in Dublin wanted to broaden the independent living message to other groups in the country, and their Centres for Independent Living, we were forced into the position of looking at training. This time it was for personal assistants and this is where I think we were knocked off track. The only way we could get funding was for a programme to train personal assistants. We tried to make it a condition that Leaders came along as well but unfortunately it was not a scheme primarily for them.

Subsequently the funding came to an end and we lost the contract. When a different organisation took it over we lost a certain amount of energy as a result. The consequence of this development has been that new Leaders are not trained or supported.

I was interested to hear how in some parts of the UK direct payments come through the Centre for Independent Living, whereas in our case Centre for Independent Living clearly says that independent living is a philosophy and you do not have to subscribe other than subscribing to the ethos. We can focus on how we support each other. Unfortunately that has got lost with the contract going over.

Today we feel that very few people have moved on in their lives and

in their ability to contribute to the overall movement. And there are very few who on a daily basis are active in campaigns. I think this goes back to the lack of support and training.

My concern is that we focus too much on direct payments and think that this is the way forward without recognising all the other aspects that need to be put in place. I can see direct payments becoming just another means of delivering social welfare and so losing the independent living philosophy that gave birth to it. My question is how can we make sure that direct payments funding includes training that covers these broader issues?

We are trying to refocus the scheme in Dublin so that it becomes Leader-driven again and we are trying to develop a Leader forum. We feel that the organisation that has the funding should see this as their role but that is not the case at the moment. The present organisation recruits, organises and trains personal assistants. They feel they are doing a good job but it is disempowering for new Leaders. They are chronically disempowered. We are hoping for an independent evaluation that will demonstrate clearly that training of Leaders is the issue.

We need to get back to looking at what training Leaders need and what support we should be giving them. I feel that we need to look at programmes that ensure that Leaders are enabled to develop in a meaningful way. We also need to recognise that for some people receiving funds in order to employ their own staff, is not a possibility -they just do not have the energy for it.

We need to look at training in terms of who am I, where have I come from and how do I fit into society. I think an approach like this will help people to look at themselves and where they are and understand why they are the way they are. This will help people to see how they fit into a broader family and society. There are Leaders who once they are given the opportunity will begin to participate and recognise the power of choice and control. However these same people can still find difficulties when negotiating with the family. Another aspect is that of burn out. Some of the original group put so much energy into the movement that they became exhausted and now are no longer able to contribute. These now have their own lives and are resentful of the efforts they had to make to get where they did whilst they see people today getting personal assistance without the sacrifices. Once again we have failed to support each other and to learn that what we do we do for the future.

Because of the lack of training new Leaders have no confidence and are easily persuaded that it is the personal assistants that need the training, the organising, the advice, information and support. These Leaders expect assistants to know what they want and how to provide it as soon as they walk into the house. When this

does not happen they become disillusioned and give up and go back into residential care. These Leaders have been given no opportunity to, develop the skills necessary to take control of their own lives.

I work with long term unemployed people who have limited formal training. One of the things we do when thinking about the necessary support for people who want to become self employed is to study the culture around long term unemployment. There is a lot of public finance for Enterprise Boards. Government recognises the need to provide professional training to people becoming self employed. If it is important for people in this context surely it is important for people becoming Leaders?

I am worried about the push for direct payments because we can lose the emphasis on the need for training and the importance of training Leaders. And we can lose sight of the need for continuing support for example for people who will always need help with recruiting and interviewing staff. There are issues around formal support and peer support which we have not talked about -another aspect of training!

### **Summary of Discussion**

Before we talk about controlling what happens we must recognise the need to be in a position to exert influence. The experience in Ireland was that the impetus was lost because we lost control of the personal assistance programme. This was a very disempowering experience. Before we discuss training programmes and their purpose we need to ensure that local and central governments understand why disabled people must be involved in this process. We need to be central to the process in order to promote independent living philosophy and practice.

When it comes to training support for personal assistant users we need to recognise that people come from different situations and that these individual differences need to be taken on board without prejudice and prescription. Instead of imparting the mechanics of using personal assistance it is much more important to ensure the development of self confidence, self worth, through self awareness and empowerment training.

We also want to challenge the accepted norms for example the definitions of success and failure. When judgements are made on orthodox principles the consequences can be traumatic and stigmatising. Where else are people condemned when they 'suck it and see' and it does not work out? Trying something new should be seen as a natural process, part of learning and not something that differentiates one person as a 'success' and another as a 'failure'.

None of us doubts the value of training for personal assistant users. The problem is convincing those who allocate funds. We all know that you only need to train one personal assistant user but many personal assistants for that user. Unfortunately it is easier to get money to train personal assistants. In some countries creative use of this budget has provided training for personal assistance users.

We need to persuade those who allocate funds of the importance of funding organisations of disabled people that provide training and support to personal assistant users. We need to repeat the message 'invest in disabled people' in order that the truth sinks in.

The best schemes are those that have training and support provided by organisations of disabled people familiar with the policy and practice of independent living built into the programme.

Whether some sort of training should be a prerequisite of entering a scheme is something that each organisation needs to think about. We do not want to be prescriptive but we do want to ensure that good employment practices are taught and used.

We need to be proud of what the payment model has achieved and boast of its empowering consequences. We should question those statutory services that use our language and consider themselves to be agents of empowerment. It would be helpful to identify simple characteristics or outcomes expected of a Centre for Independent Living, guide-lines which will define the genuine article. There are many interest groups eager to steal our clothes and make sure we do not challenge their access to funding and authority. The independent living philosophy behind direct payments is seen by many orthodox establishments as subversive.

## **FEEDBACK AND CLOSING SESSION**

*Chair Frances Hasler*

### **Summary of Discussion**

It is worth developing our own economic model taking account of the broader and long term outcomes to demonstrate the value of independent living'. It is worth identifying the characteristics of a genuine Centre for Independent Living in order to ensure that others do not 'steal our cloak'.

One of the criteria we might include would be the outcomes, for example is this process empowering the individual?

We need to revisit traditional practices, unlock the resources from these and divert them into 'independent living programmes'. This is how the Stockholm Independent Living Co-operative started: not a fresh slice of the cake but using the same slice in a different way.

Whatever we do we must be inclusive. Our record is not good in this area.

We should encourage exchange programmes between Centres for Independent Living and between different countries. These would share expertise, help us to re-evaluate what we are doing and promote mutual support.

We should also be prepared to exchange experiences with local and central government officers by way of educating each other as to our aims and objectives. The alternative is that we might be going along parallel tracks without communicating. Developing this relationship is particularly important when we are trying to promote the consultation of disabled people in programme development and implementation. Always remembering our different agendas and the importance of representatives of disabled people remaining accountable to disabled people and not becoming a new class of 'professional representatives'.

We need to remember that, despite the day to day compromises that we have to make, the reason we started out along this path was that of establishing the support necessary to enable disabled people to lead 'ordinary' lives. This remains an eminently reasonable aim. Our dream is not just getting out of bed in the mornings but being enabled to get on with life thereafter: to boldly go where everyone else has gone before. We are ordinary people wanting to do ordinary things.

## **APPENDIX**

### **Hampshire Centre for Independent Living**

Phone/Fax [+ 44] (0)1420474261

### **Hampshire Coalition of Disabled People**

Phone [+44] (0)1428-712 067; Fax [+44] (0)1428 714347

### **Southampton City Council**

Phone [+44] (0)1703 832630; Fax [+44] (0)1703 832424

### **Hampshire Social Services**

Phone [+44] (0)1962 847270; Fax [+44] (~)1962 877681

### **National Centre for Independent Living, London**

Phone [+44] (0)171 587 1663; Fax [+44] ~O)171 582 2469

### **Centre for Independent Living, Dublin**

Phone [+353] 1872266; Fax [+353] 187 30998

### **Institute of Independent Living in Stockholm**

Phone [+46] 874 04200; Fax [+46] 874 01500