

DRAFT REPORT (Not for Publication)

# **Assessment, Accountability and Independent Living**

Confirmation And Clarification Of A Disability Led  
Perspective, Coombe Abbey, Coventry 23/24 May 1995

Edited By Colin Barnes, Maureen McCarthy and  
Steve Comerford

# Contents

Forward: Colin Barnes  
(Yet to be written)

1. Independent Living, Legislation and Direct/Indirect Payments: Mike Ridout
2. Independent Living, Assessment, Accountability and Monitoring
3. Some Insights from the BCODP Research on Direct/indirect Payments' Cashing in on Independence' : Gerry Zarb
4. Disability and the Labour Party: Tom Clarke
5. Assessment2 Accountability and the Community Care Direct Payments Advisory Group: Jane Campbell
6. Personal Assistant Support Schemes; Fidelity Simpson
7. Resolutions

Appendix One: List of Participants

Appendix Two: The Department of Health's Community Care Direct Payments Technical; Advisory Group

# 1. Independent Living, Legislation and Direct/indirect Payments

## Mike Ridout

Independent Living is a major issue for the disabled people's movement. At present the Government are considering introducing legislation which will allow local authorities to make direct/indirect payments to enable disabled individuals to employ their own personal assistants (PAs). With this in mind it is important that the complex issues of assessment and accountability are clarified in order to inform any future policy developments.

There is no doubt that a great deal has already been achieved by the British Council of Disabled People (BCODP) (formerly the British Council of Organisations of disabled People) and its member organisations. Notable examples include the two independent living seminars held in 1992/3 (Barnes, 1993) and the recent research on direct payments (Zarb and Nadash, 1994). But a number of issues still need to be addressed. For example, how do users participate in aspects of policy making? What influence does this involvement have on general policy?

A starting point would be to clarify the debate surrounding the concepts, 'needs' and 'wants' in relation to services. Some professionals tend to confuse the issues by suggesting that you may 'need' a car but 'I want' a 'Rolls-Royce'. The implication is that basic needs can be satisfied but wants cannot. In terms of assessments and support packages to enable disabled people to live independently there is no difference; independent living is not a luxury it is a right.

To enable disabled people to live independently the Government must introduce legislation allowing local authorities to make direct/indirect payments. We must also ensure that limits are not placed on those payments. Such a policy sometimes referred to as 'maximum payments' would ensure that people with the most 'severe' impairments would be discriminated against. Under the 1990 NHS and Community care Reforms people whose support packages exceed £500 are liable to be committed to a residential home.

The Independent Living Movement and the Hampshire experience of user-led services have been encroached upon by the development of non user-led services. This was the experience in Coventry until the development of the Coventry Independent Living Group. The continued development of user-led services is important because institutionalisation can occur while living in the community if provision is led by service providers and not by users.

It is important to recognise that we all have different experiences; some people have been institutionalised by residential services, others by community based services. It may be that some people new to Independent Living are prepared to accept almost anything in order to escape institutionalisation.

Most of us have now moved on from that position and are beginning to recognise how controlling and disempowering the assessment, monitoring processes and accountability criteria can be; hence the need for this debate. We need to lay our cards on the table and bring these issues out into the open because the more liberated disabled people become through access to Independent Living, the more relevant the issues become.

We must recognise that once people have had the opportunity to experience Independent Living, the opportunity to self-determine their own lifestyles, they develop at an extremely fast pace as individuals. It is also true that Disabled Peoples' organisations are developing at an extraordinary speed. This means that we need to continue to network and communicate closely and recognise that we are on a sharp learning curve and that this will be an ongoing process.

## **2. Independent Living, Assessment, Accountability and Monitoring.**

Disabled delegates were asked to indicate on a continuum of 1 to 10 their individual experiences of involvement in the assessment process. A score of 1 would indicate no meaningful involvement whilst a score of 10 would indicate complete involvement or self-assessment. Those without personal experience of assessments were invited to comment on the type of practices within their local authority area.

Delegates were also asked to score on a scale of 1 to 10 the level of accountability criteria encountered in order to receive direct/indirect payments. A score of 1 would denote a situation where someone else is responsible for controlling payments; how payment is made and spent, for example. A score of 10 suggests a situation where the initial assessment is the only accountability criteria used, and where users are able to run their own services without interference.

Several delegates responded as follows:

### **John Evans: Hampshire Centre for Independent Living (HCIL)**

There ought to be no compromise regarding self-assessment; it is fundamental to the empowerment of disabled people. It IS critical in terms of the assessment process that self-assessment is the starting point in enabling disabled people to determine their own lifestyles. Although my own experience of assessment would score 8 out of 10 on the continuum, there is no uniform way of assessment in Hampshire.

Accountability criteria varies across Hampshire's 17 districts. Generally, reviews are held once or twice a year; but these are not always negative. They are kept simple with not much paperwork.

There is no means testing and this is encouraged. Overall it's not a bad system, you don't have people checking up on you all the time asking to see timesheets and so on. This makes sense because if you start getting tied up in bureaucracy, checking everything, for example, it means a lot of professional time. This costs a lot of money which inevitably comes out of the authority's Independent Living budget -hence there is less for PA users.

### **Ken Smith: Derbyshire Centre for Integrated Living (DCIL)**

In terms of self-assessment, the experience in Derbyshire is very varied. Where DCI is involved it can offer relevant peer support when needed. This can be crucial because of the effects of Institutionalisation whether formal or informal. I found assessment a very positive experience, but a lot depends on individual care managers. For other people in Derbyshire it has been a very negative experience. The continuum score would, therefore, range from 2 out of 10 to 10 out of 10.

The level of peer support varies across the County too, and there is an urgent need for more trained support workers.

The accountability criteria also varies. Some people are reviewed every three months while others are left alone. The care managers decide what level of intervention is needed. People have separate bank accounts but paperwork is not demanded, this is unexpected but welcome.

### **Anton Prantl -Wiltshire Independent Living Fund (WILF)**

WILF has the power to provide grants of up to £200 per week. Some peer support is available and a Development Worker is available. The assessment Process would score 9 out of 10 because it is virtually a self-assessment. Grants are based on a decision by a panel of disabled people.

Accountability would score 6 or 7 out of 10 because monthly returns and bank statements are required but support with PAYE (pay as you earn) and tax is given or offered. WILF funding is paid into a cheque account not a cash account. Personal assistants are paid by cheque not cash and 6 monthly reviews are standard practice.

Money is not provided for holidays abroad or for mobility; this is considered inappropriate, and because funding is available from other sources.

The WILF delegate was then asked several questions.

### **John Dunncliffe -West of England Centre for Integrated Living**

What happens if the self -assessment cost is above £200 per week? Anton Prantl

WILF refers application on to the Independent Living (93) Fund to top up to the £500 maximum. We can give grants of up to £10.400 per year.

### **Vicki Raymond -Disablement Association Hillingdon**

Is this ring-fenced social services money?

### **Anton Prantl**

Yes, it is a Community Care Transition Grant and is ring-fenced. The Social Services Department do not take responsibility for individual grants.

### **Suselle Boffey -Lothian Social Services Department**

Where do people come to WILF from? In Lothian we have found difficulty in increasing take-up, we have tried to improve this through using publicity and local authority workers.

### **Anton Prantl**

Social services put people on to WILF to save their own budgets, but some people are missed.

### **Suselle Boffey**

For the past 8 years Lothian has had Independent Living Schemes with built-in self-assessment procedures. But these are now threatened by local government and departmental reorganisation. If

the ring-fenced budget is - secure disabled people can receive direct payments, but to safeguard income support recipients' conduits can also be used.

Accountability is ensured by periodic 3 monthly reviews. However, as the scheme becomes more widely known the social work directorate want closer accountability.

### **Carl Ford -Shropshire Disability Consortium**

There is no current third party in Shropshire. Until 1993 the Social Services had considered direct payments legal. Self-assessment would score 10 and accountability would score 9 and a half. The care packages include funds for administration costs and paid holidays.

The accountability criteria requires records to be kept for 5 years; these may be checked. Because I was one of the first to have a scheme the pressure was on to keep records and be squeaky clean - in 5 years of running the scheme the books have never been checked. Since 1993 most schemes have been worked out on an ad hoc basis. Assessment forms have no user input so assessment would now score out of 10.

Accountability is very varied. Eight direct payment schemes still exist, but radicalism has been lost. Independent Living Fund take up in Shropshire has been very high but this has meant that central government funding has been reduced. Expectations have been raised by earlier success in terms of access to ILF but the Local Authority can no longer meet these expectations. Hence, we want a 3rd party user-led payment scheme in Shropshire.

### **Sue Bott - Shropshire Disability Consortium**

We should emphasise that assessment is about information and rights for empowerment. Living Options has involved disabled people reviewing community care procedures. There is a need to reach out to disabled people, how are we going to achieve this? we need to inform them about their rights but we can't rely on professionals to do this.

Professional attitudes vary -some are very good and committed but others aren't or just don't fully understand the issues. Either way the disabled person misses out; indeed, some people were unaware that they had even been assessed.

### **Barbara Vandamere - Norwich Independent Living Group**

Professional ignorance of conditions can be an advantage. As I know more about my 'illness' than they do. It takes 13 weeks to see a social worker which raises questions about who is sufficiently informed to do assessments.

### **Paul Kobryn - Hampshire P A Agency**

Development and support workers offer support to those on Self-Operated Care Schemes (SOCS). This attracts people to the schemes. But one disabled person was refused access to SOCS by a social worker, but they have now been awarded access funding.

### **John Dunicliffe**

Avon CIL (now West of England CIL) is a new scheme which has been running for less than a year. It seeks to help disabled people through the assessment process and complete a self-assessment procedure prior to contact with social services. How much these self-assessments are met varies greatly. Using specialist knowledge, the CIL can encourage social services staff into what is effectively a self-assessment process. This may become more difficult as the service expands. What we don't have presently is a user group who can offer support and advocacy, but the CIL does run a complaints procedure which offers advocacy support to challenge professional assessments.

As far as accountability is concerned, the local authority Finance Department initially demanded 4 pages of criteria, but this was negotiated down to about 25%. Now they require quarterly statements. Currently, they are not using these to reclaim funds. They also require signed timesheets and receipts for scheme associated spending. Records have to be kept for 3 years.

### **Carl Ford**

How well do you think the scheme works without advocacy? Will advocacy affect the role of the CIL?

### **John Dunicliffe**

Because of the level of funding available advocacy has not been necessary, but the problem is likely to increase. WE need to develop care management advocacy.

### **Mandy Kingwell - Norwich Independent Living Group**

Generally our Independent Living project is used as a buffer to social services in a similar way to Avon. People are supported in self -assessment and I haven't heard of anyone yet who has been refused a self-assessed need. In fact, quite often social services have come back to us where they have thought that people have under assessed themselves. We then go back and have another look -therefore the assessment score on the continuum would be 8 out of 10.

Accountability would score 9 out of 10 because the only accountability, once payment has been agreed, is an informal visit once a month by a scheme co-ordinator. Here receipts for PA's wages may be scrutinised, but it is very informal.

### **Jo Smith - Leicestershire Coalition of Disabled People**

The Leicester scheme is relatively new. Initially the social services department kept the scheme *very* low profile and quiet. Access to a self- assessment process was very difficult. Assessment by social workers was an awful process, they knew nothing about it. It was completed with support from Fairdeal -without this I would have given up.

Accountability consists of monthly timesheets provided by Fairdeal which in theory are signed by PAs.

### **Anne Pridmore -Leicestershire, Fairdeal**

The problem with self-assessment is that my idea of Independent Living is so different to that of social services.

I think this is the real issue that we need to tackle.

## **Mike Ridout**

When the Coventry Independent Living Group was founded the first thing we decided to do was actually define what we meant by Independent Living. We looked at a lot of BCODP information and came up with the following definition:

*Independent Living is about the empowerment of disabled people and their ability to control their own lives. It is not the name of a particular service or provision but the objective of services and provisions; the furtherance of Disabled Peoples human right .*

*independent Living covers the whole range of practical solutions to disabled peoples' inclusion in mainstream society : personal assistance, information, benefits, housing, equipment & adaptations, access to environment, transport, education, training - employment. Independent Living is a concept that IS relevant to all disabled people, whatever their impairment'.*

This is the definition we came up with and we think it is a good starting point. Steve Vincent - Coventry Independent Living Group

## **Steve Vincent – Coventry Independent Living Group**

From 1986 there was a partially successful scheme in Coventry; people were given funding and left to get on with it. It was basically a direct payment with no formal accountability , It would therefore have scored 10 out of 10.

However, this situation was replaced by the Penderels Trust Fund in 1988 which responded to people's problems by imposing criteria and restrictions. The accountability issue became extreme and reactionary; this detracted from the earlier ethos of self-determination and independence. It would score about 3 out of 10.

Assessment would score 8 out of 10 because self-assessments were broadly accepted. But this only applied to people who had knowledge of the system and were articulate. It was a more negative process for people with little or no experience and limited communication skills.

## **Mike Ridout**

These examples illustrate the degree of inconsistency that exists in different parts of the country: people who are articulate and assertive have more chance of getting the service they want, whilst more vulnerable people receive a much poorer service.

## **Jane Campbell: Chair of the BCODP**

The Kingston scheme is more or less similar to some of those already mentioned. People have to provide bank statements and timesheets etc. but one thing Kingston doesn't have is a £500 limit. If you are assessed as needing I600 or £700 a week for personal assistance then you will get it. There are at least 3 or 4 instances on the Kingston scheme that have significantly higher costs; funding is provided over and above ILF and Local Authority combination money.

## **Frances Hasler -Greater London Association of Disabled People (GLAD)**



Is there a waiting list to get on the Kingston scheme?

**Jane Campbell**

Yes.

**Frances Hasler**

There is a link between assessment and rationing; assessment can be used as a tool for rationing. In my experience there are situations where there is a *very* strict eligibility criteria and rationing. The level of impairment determines the amount of resources provided -rationing is very explicit. *People* re only allowed a limited service in terms of weeks, days and hours. There needs to be a very different way of doing assessments.

How do we get away from this sort of rationing? If there has to be rationing, how can it be done more fairly? Rationing is often done covertly. Often, people are not told that budgets are limited and that they are divided according to certain criteria.

It would be much more empowering if people were told that there is a basic entitlement, this is the size of the cake, and that it is divided accordingly. This is a problem because when local authorities are trying to make savings or cuts they make their eligibility criteria tighter and tighter. Type and severity of impairment then determine access to funding. Alternatively, people are not considered able to manage the paperwork or PAYE etc. .These and other criteria often deter people from asking for support.

These are problems which must be addressed.

3. Some Insights from the BCODP Research on Direct/Indirect Payments ‘Cashing in on Independence ‘

**Gerry Zarb.**

Today, I want to talk about accountability as there are some potential problems with the new legislation. There are a lot of little traps at both the national and local levels which we will need to address and resolve so that they don't come back to haunt us.

The first point to make about accountability is that much of the talk on this issue focuses on the needs and concerns of local authorities; we hear a lot less about accountability towards disabled people themselves. obviously local authorities will have some kind of legal responsibility to account for the money that they have for payment schemes; the Treasury won't allow it to be any other way. But what is important is that we get a sense of balance between the needs of local authorities and the need to avoid unnecessary and disempowering intrusions into disabled peoples lives.

It's also important to keep a sense of perspective about the level of risk involved because we hear so much talk about the abuse of direct/indirect payments. Our research looked at lots of-different payment schemes around the country and the average budget IS around £100.000. It's a lot higher In Hampshire because they have a bigger scheme than most. Even the national scheme, the ILF, at its highest levels, is only paying out £97 million per year .

Now this sounds a lot but last year the Government spent £81 billion on social security. Now people receiving social security benefits don't have to keep receipts and they don't have to keep timesheets. In fact, apart from picking up their cheque they don't have to do anything. Yet, the level of social security fraud is probably higher than the total amount of money paid out on direct/indirect payment schemes. This is an important point to bear in mind when talking about relative risk.

A second point which came out of our research and which hasn't been mentioned yet is that disabled people receiving direct/indirect payments have a very powerful inbuilt personal incentive to ensure that direct/indirect payments are used wisely and prudently. This is because, quite literally, their independence and, in some cases, their very survival depends on it. Many people currently receiving payments are very concerned about the need to guard against abuse; some of their comments were as forthright as any made by even the most hard-nosed treasury official.

One of the things we did when I worked for the Spinal Injuries Association (SIA) Haringay On-Call Support Project was help to set up a user-led management committee. Here, decisions about the allocation of funds were made entirely by service users. Disabled people take their responsibilities very seriously when they are actually dependent on services or payments for their own independence. *So*, there is a very powerful incentive to guard against abuse.

However, you will always get, whether by accident or design, some people who either can't or won't use the money for the purposes it was intended. But in such cases their payments will eventually cease and they will have to make other arrangements. But there is little evidence that this actually happens. Up to now, there is little evidence that abuse of payment schemes actually exists: what evidence there is has all been in the opposite direction. You have to have some justification for the kinds of intrusions into disabled people's lives mentioned earlier, but I find it difficult to see where that justification comes from.

Clearly, both local authorities and disabled people share a vested interest in ensuring that payment schemes are not abused. So they should also have a shared interest in working out accountability measures that are doing to meet the concerns of local authorities and disabled people equally. If you have accountability measures that only meet the needs of the local authority, then the resulting payment scheme will be both efficient and unworkable.

I think user panels which allocate funding, such as the one in Wiltshire, although they will inevitably encounter problems, are basically a sound idea. It's important to remember too that the whole development of the Independent Living Fund in Wiltshire, the proposals which drove the project came from disabled people themselves. One of the first things Wiltshire Social services did when they said they were going to set up this fund was to get in touch with the Wiltshire users network and ask them to put a policy group together so that they could get the principles of the scheme right from the start.

There has to be accountability measures somewhere along the line, but it makes a big difference if people using the schemes are involved jointly with the local authority in setting up those measures in the first place - it's likely to provide a workable solution for everyone.

The Wiltshire experience also raises a number of important issues about accountability to users themselves. Local authorities don't just have an obligation to make sure that the money is not abused they also have an obligation to make sure that the money is used effectively. In the context

of direct/indirect payment schemes this means does it genuinely promote and facilitate Independent Living? In Wiltshire, they have used the expertise of disabled people not only for Independent Living but for other services too. Disabled people are involved in evaluating services in order to find out if they meet the expectations of the people who use them.

I think the Wiltshire model is a very good example. Perhaps the guide-lines coming out of this conference could emphasise this kind of arrangement and encourage people to adopt it in the future.

One of the problems with the proposed legislation is that what's on offer only going to be permissive. Local authorities will not be obliged to offer a payment scheme and even if they do have one they will not be required to advertise it. This worries me because we know that there are already marked regional variations in what is being offered. If you live in Greater London, for example, 80% of local authorities have some sort of payment scheme, whereas in the Northwest of England it's only 17%, and in Wales it's only 20%.

Clearly, the present system allows local authorities to provide some form of indirect payment scheme; but many don't. This raises the Question, why should we expect them to do this under the new legislation? it doesn't automatically follow that they will.

There's also the problem that John Evans eluded to about the Independent Living transfer money which is no longer going to be ring fenced after next year. I know a couple of authorities already who are actively abandoning their payment schemes rather than extending them simply because they have got competing pressure for that money now that it is no longer ring-fenced. And if you have got say, a local authority with a high population of elderly people, social services departments; however willing, are going to have problems securing budgets for direct/indirect payment schemes.

That is bad news, but it needs to be addressed now. Although the Department of Health (DoH) says it is committed to permissive legislation I don't think it is too late to continue pushing for direct/indirect payments as of right. I don't know if you will get it and you might not get it this time round but still do it because as long as it's permissive you are going to have the same kind of variations locally that there is now. You will have the same old problems if you want to move to another part of the country or change jobs; i.e. not knowing if you will get funding for Independent Living when you move. The levels of payment will be different, charging policies will be different, there are all these kind of problems that stem from having a permissive piece of legislation rather than one that is mandatory.

Next, I want to turn to the issue of needs and wants. I agree with the sentiments expressed earlier but I don't think it's going to be easy to get that point across. We don't know exactly what the arrangements in the guide-lines are going to be, but it seems fairly clear that direct/indirect payments as envisaged by the DoH are going to be part of community care. They are going to have to fit in with current community care arrangements.

That means that assessments for direct/indirect payments are likely to be part of the community care assessment process. I think this does actually raise some very serious problems which need to be addressed in any guide-lines you produce.

There is simply no models of assessment operated by local authorities that are suitable for independent Living or direct/indirect payment schemes.

Community Care assessments are about allocating or rationing pre-defined services. They are not about allocating resources to people so they can create and manage their own services which is what Independent Living is all about.

This raises the problem of regulation, although legislation is undoubtedly welcome, it will be accompanied by rules and regulations. This is one of the advantages of NOT having legislation. Legislation and regulation will bring payment schemes out of the closet. Up to now they have been quite small-scale ad hoc arrangements, and no-one has really looked at them too closely. It is likely that eligibility and assessment criteria will be very tightly controlled as other parts of the community care assessment process are. This runs counter to the whole principle of Independent Living.

It's all very well making a statement about needs and wants, and I agree with it, but local authorities are not going to accept it. They will argue that other service users don't get these kind of benefits so why should PA users? I think people will only be offered the option of cash instead of services.

What's happened in the past is that people have had payments from the ILF, for example, and then gone away and created their own service with the money. Sometimes in ways that the ILF trustees never thought possible; that was the beauty of the old ILF system. But the new regulations will be quite specific. So it's very important that any guide-lines for the DoH and local authorities must emphasise the plain fact that Independent Living is not the same as community care, and the differences must be clearly spelt out. It follows that there must be different models of assessment too.

My final point concerns the ceiling on payments. Again, we don't know what the ruling on this is going to be, but bearing in mind the changes that were introduced with the ILF 93 Fund, it will be surprising if the new policy doesn't suggest that local authorities impose a ceiling on payments. Again, in the past and because arrangements were quite informal, some authorities have been quite flexible - in Tower Hamlets, for example, there are at least two people whose packages cost well over the £500 limit. The question is that with regulation will such practices continue? If the new regulation put a ceiling on payments this could be a problem.

However, estimates from the Cashing in on Independence project show that there are only about 12,500 people in the whole of the country whose PA packages would exceed more than £500 a week. This is a mere drop in the vast community care budget ocean. Given this relatively small amount, and the inevitable negative consequences of locking these people away in institutions we must ask the DoH and local authorities: how can such a policy be justified?

Several points were made by delegates following Gerry's presentation. These were as follows:

### **John Evans**

I don't think we should stress that people everywhere should adopt the Wiltshire model. There is a danger in prescribing a single way ahead for direct/indirect payment schemes because it won't work everywhere. There are lots of different systems and local infrastructures. In some respects the Wiltshire scheme is quite restrictive. I'm not sure if individuals actually administer their own schemes, it all seems to be done through the one model. There is also a lot of paperwork and monitoring. We should not be too prescriptive, we need to allow for different options and different local arrangements.

## **Gerry Zarb**

The important point I was trying to make about Wiltshire was the principle involved; the fact that decisions were made by people who have real vested interests in service outcome - disabled people themselves.

## **Carl Ford**

We have to be very careful about promoting one kind of model because some authorities are using disabled people's expertise and, at the same time, almost stifling it because those very same people have been given the job of rationing the budget. Local authorities can stifle disabled people's initiatives and control them by restricting resources - I have a real problem with that.

## **Gerry Zarb**

That is a very good point and this is a big issue -there is a great difference between disabled people being consulted and involved in the setting up and provision of user-led service, and disabled people being used as gatekeepers to limited resources. I think these issues need to be separated

## **4. Disability and the Labour Party**

Tom Clarke. (This presentation was also attended by Geoffrey Robinson, the Labour MP for Coventry)

There are 2 major Bills in Parliament at the moment the Government's Bill which is now at the House of Lords, and the Harry Barnes Bill; the only Civil Rights Bill, which has been talked out but is still in Committee.

The Labour position is to build on the Harry Barnes Bill and by keeping it in Committee we are keeping Mr Nicholas Hague, the Conservative Government's Minister for Disabled People) fully occupied. We are doing some important preparatory work for *a future Labour Government and we are fully committed to introducing a full Civil Rights Anti-Discrimination Legislation Bill as made clear by Gordon Brown's pledge in his speech to 1994 party conference and this remains our objective and our priority (emphasis added).*

My role is to prepare a comprehensive policy framework and this involves consulting with the widest possible range of disabled people in the country . Of course I am consulting with the disability organisations in London such as RADAR (Royal Association of Disablement and Rehabilitation) and others. In fact I would like to state that we are immensely grateful to the BCODP for their help over the various Bills and in other activities. But above all I want to prepare a policy document on disability where I can say that I have really gone out there to the grassroots.

As you know, there are some 6 and a half million disabled people in Britain which means there are an average of 10.000 in every constituency and the London organisations don't always reflect the values and problems that I see in my own constituency. It worries me when I look at some of the statistics and I keep trying to remind myself that we are not talking about statistics, we are talking about people. I was shocked for example to look at the employment scene and remember how this affects constituencies like mine in Scotland and Geoffrey's here in Coventry.

It is 3 times more difficult for disabled people to get a job and even if they do a man who is disabled earns only 78% of the national average wage and a woman who is disabled earns only 72% and *they* work longer hours *too*. For disabled women *it* is a double discrimination. *The bottom line for the Labour Party even at this stage of policy formulation is that we want, indeed demand the introduction of a government Civil Rights Anti Discrimination Bill to which Gordon Brown and the whole Shadow Cabinet are committed (emphasis added).*

Back to the issues of *this* conference, I managed to read about 40% of the document *Cashing in on Independence*. The thoughts and views that put forward in this document do, in a sense, offer a manifesto for all of us in a democratic society to consider. I am sure that every department in Tony Blair's Government will be influenced. I hope this week will have a big impact on our discussion of these matters.

Independent Living is an important way of empowering disabled people with a culture of independence and freedom whilst also recognising the duty of the community to the individual. It gives people choice about how and where they live and the option not to depend on residential care. Advocacy is also crucial in making those choices and central government should be properly involved in promoting and resourcing those choices.

Local authorities also have a pivotal role to play in providing the framework and Support that disabled people need in making choices of how best *to* use the opportunities for themselves. But I have got to convince a Parliament which is very cynical, frankly on both sides, but once they are convinced they will be with us so I want *the best* possible arguments from you this morning because then my advocacy will be all *the* greater when we vote for the policy in the House of Commons.

The issue of direct/indirect payments are part of this, the document makes this clear. From the perspective of disabled people using such Support *it* offers the best quality and most cost-effective way of meeting their needs and, more importantly, It enables them to lead full and independent lives. My major worry is that whilst a Labour Government might have a national policy, it will be dependent on local authorities up and down the country which might not always be Labour, and some of them may have different attitudes, views and priorities towards care in the community and disability.

That is why I was particularly interested in the final chapter of this excellent document which demonstrates these differences -for example, 80% of authorities in Greater London make payments compared to only 17% in the Northwest and 25% in Wales. Not surprisingly the exception to this trend is Scotland where legislation permits local authorities to make cash payments.

The argument I saw elsewhere in the document that the administration costs accompanying direct/indirect payments, are much less than in those accompanying the normal system of delivering services in local government and public services leads me to say that there is something wrong with the latter and I want to put that right.

I want to turn briefly to the wider issues and the role of central government. Currently there is a Crisis in government funding for local authority services, we are seeing a crisis in education, a reduction in resources, we are seeing unjustified restrictions on housing initiatives, and the break up of the National Health Service, all through the folly of privatisation.

This crisis has a direct/direct impact on disabled people which threatens access to work schemes etc. The campaign against the Hague Bill has had cross party support and this has forced changes on transport and integration to education. The experience of this campaign has illustrated the Government's failure to provide sufficient resources to allow local authorities to provide adequately for the various groups entitled to support under care in the community .

So our approach in developing a policy between now and the next election must recognise the need to see disability in a very comprehensive perspective. Independent Living may only apply to 2% of the population, but it is a very important 2% . Disabled people should have as much involvement as is practicable in the assessment of need which should be beneficial to both users and providers.

Accountability should be seen as of mutual benefit not about checking up as viewed by Peter Lilley (The Conservative Government Minister for Social Security). People don't get into wheelchairs for the sole purpose of cheating the Department of Social Security (DSS). I want to see a genuine partnership between central and local government both experiencing a degree of priorities which disabled people want to see. I want to see a partnership between public service providers as representatives of the whole community and the individual disabled person who must be recognised at both local and national level as being absolutely unique.

That is why I support advocacy and will continue to do so. This will be based on a perspective of freedom of choice and consumer rights. Disability cannot only be seen as a medical condition because solutions depend on a social perspective.

Subsequently, delegates put a number of questions to Tom Clarke.

### **Steve Vincent**

What will the position of the Labour Government be on Incapacity Benefit?

### **Tom Clarke**

This is a social security issue and I will provide a written answer if contacted after the conference.

### **Frances Hasler**

Could I point out that the concept of Independent Living is a collective response even though it is often portrayed as being mainly individualistic. It is important to keep hold of this communal tradition when thinking about Independent Living.

### **Tom Clarke**

I think in many ways that gets to the heart of the problem. I was responsible on the (Labour) Front Bench for care in the community that's when I discovered the wide variation in attitudes. There is a need for a national audit because we should be able to say centrally what is going on. I mean the Tories are so keen on league tables with education I see no reason why we shouldn't be doing that with disability and care in the community .

When we have got a Labour Government I want us to remember that we have got a mandate. and we are going to tell local authorities that this is the way that they are going to do it. And that means asserting minimum rights for disabled people and maximum consultation to ensure that those rights are delivered.

### **John Dunicliffe**

In Bristol the local Labour party thought that Self-Operated Care Schemes (*SOCS*) smacked of privatisation -eventually they were convinced that this was an issue of rights and collectivity and not privatisation and individualism. It is important to remember that Independent Living was developed by groups of disabled people pushing for direct/indirect payments and that it is about civil rights and collectivity; not about privatisation. We need to make sure that people in the Labour party understand this because it can be misunderstood.

### **Tom Clarke**

This is undoubtedly a problem and there's no point in trying to disguise it. Some people in the Labour party will say: is this Thatcherism? is this giving people a voucher and saying go and do your best?

In the main the Labour Party will see it that way but it's not the first time the it has changed its views and adapted itself to modern times. So I would simply ask you for your help as the debate goes on, in making sure that Labour MPs and Labour members of the European Parliament are made aware of the difference. If people like yourselves exercise your right to be assertive then there can be a change in attitudes. You have got to be seen to be arguing your corner. Lobbying and education will be crucial, and necessary at all levels of Government.

### **Fidelity Simpson**

Can I just add to what John said earlier. It will need very strong disability organisations to do this and not all areas of the country have them. So we need to convince the Labour Party so that they can then educate local politicians and councillors that this is what disabled people want.

### **Tom Clarke**

I think that is a fair point. If the Labour Party ultimately decides on that point of view on policies, we will have a responsibility to sell it. We are obviously hoping for as much support as we can get from yourselves.

### **Paul Kobryn**

Are the Labour Party going to get rid of state segregation in education?

### **Tom Clarke**

I can firmly state that a policy of integration will be introduced. But this will need gradual implementation to ensure proper facilities and staff training are in place. This does not mean unnecessary delay but will ensure that a lack of resources doesn't undermine the policy.



That does not mean we are going to remove schools or places of education which are appropriate. For example, for children with profound difficulties, physically or intellectually. I have seen so many cases where the principle became discredited because preparation and resources were not made available, so we will approach It in that way

**Gerry Zarb**

Can I just say that leads to segregation not inclusion.

**Tom Clarke**

If you want us to move on to inclusion then get all the organisations you are involved with to write to us and we will consider that and consider our policy. You see I'm prepared to commit myself to integration but I have not yet accepted the word inclusion.

**Paul Kobryn**

Inclusion should replace integration as a concept.

**Tom Clarke**

I am still to be convinced of the importance of a shift from integration to inclusion.

**Martin Smith - Hillingdon, Social Services Department**

What is the Labour Party's view on funding regarding the end of the Community Care Transition Fund?

**Tom Clarke**

Tax and spending will continue to be a key issue;... but I have always found the shadow Treasury team approach fair. The new visibility Department must use its weight to find its corner. The creation of a shadow cabinet disability team has improved access to the party leadership.

**Sue Bott**

Even without direct/indirect payments what we have at the moment is privatisation because what happens is that people have to rely on care agencies. Many local authorities don't provide services anymore. What we have is lots and lots of private care agencies and these are difficult to control and difficult to impose quality standards. At the moment some of these agencies are getting away with standards that are not acceptable and dangerous to the people they are supposed to be caring for. We need to watch out for the private agencies lobby.

**Gerry Zarb**

One of the reasons that service provision is more expensive than the payments option IS because of the high costs of care agencies. Many northern authorities are very proud of their traditional role of providing public services. It's part of their Labour culture and when they hear about direct/indirect payments they don't want to know about it because they see it as renegeing on their public

responsibilities. I admire their sentiment but they are wrong - because if you don't make direct/indirect payments mandatory you are actually creating a system of apartheid.

For example, if a PA user living in a part of the country which has a payment scheme gets offered a job in another part of the country which does not offer that service, then they would have to refuse it. Their civil liberties will vary from one part of the country to another.

### **Tom Clarke**

I want the Labour Government to see this practice as being minimum .... we are responding to the unique individual rights of every disabled person. That may well mean a cold shower for some of our Labour authorities but that it has to be done.

I think the Labour Government will set minimum standards and will call for if the new care reports to be made available centrally and we will work to ensure that the legislation means that regulation for the Secretary of State will be carried out.

But the greatest contribution we can make to increasing standards everywhere and consultation is the (Disability) Commission consistent with Race and Gender which I am determined the Labour Government will introduce. One of its principle responsibilities will be to report to the Secretary of State and to Parliament on how parliamentary legislation and regulation are actually carried out. I believe in representative parliamentary government. there is a role for central government to ensure best practice. I will not hesitate to engage any local authority pursuing a policy which excludes disabled people.

### **5. Assessment and accountability and the Community Care Direct Payments Technical Advisory Group.**

#### **Jane Campbell**

We have two important but inter-related tasks today. One is to identify and clarify what we think are the key issues around assessment and accountability . The other concerns a body of which I am a member called the Community Care Direct Payments Technical Advisory Group.

As you all know we have been trying to get direct/indirect payments legislation on to the statute books for at least 5 years. And, at last, Virginia Bottomley (the then Minister for Health) has set up the Community Care Direct Payments Technical Advisory Group to advise on the best way to introduce such a Bill. But as mentioned earlier the legislation will not be mandatory, it will be permissive. It would be nice if we were going to have mandatory direct/indirect payments legislation - but that's not to be. But it will be legal for local authorities to make payments if they choose to do so.

How that will be done will be determined by guidance produced by this Advisory Group. So these guide-lines will be critical as they will contain, first, key principles on how to implement the new Act and, second, what level of support should be made available to disabled people following implementation.

There are at least 5 areas which we are going to have to deal with on the Advisory Group which will prove unacceptable to many disabled people. However, I think that by focusing on

assessments and accountability we can also look at the 5 areas and come up with some resolutions which I can then put the Advisory Group.

This is important because it is the first time that a BCODP representative has been invited on to an Advisory Group of this status. And the Advisory Group is quite large and includes people with differing agendas from a variety of background and organisations {see Appendix Two). So we are going to have to lobby very hard in order to influence what is actually put in the guidance.

To date the Advisory Group has met only once. But already there are 5 areas where there is potential for conflict.

### **i. The floodgate scenario**

This is the fear that too many people will want access to direct payments and, therefore, the schemes will prove too expensive. Some people argue that this can be resolved by limiting access to payments with tight eligibility criteria. Payments would be available only to those considered able to control and direct their own services.

### **ii. The abolition of third party schemes**

Some elements of the Advisory Group are unsupportive of third party schemes. Again this is based on a concern over finance: the argument is that paying a third party to manage an individual's P A package will increase costs. Again it is argued that this can be resolved by limiting payments to only the most able.

### **iii. Tight eligibility criteria**

It follows from the above that the majority of the advisory group want eligibility criteria to be limited by age and impairment. No one on the Advisory Group, apart from Jane Campbell, wants payments to go to people over 65. They also wish to exclude people with learning difficulties, and people with HIV or AIDS. It has been suggested that these people should get support from elsewhere? There has been no discussion yet on a lower age limit.

### **iv. Direct payments as a substitute for benefits**

Are social services department going to become benefit agencies and will there be regional differences? This needs specific discussion in the workshops

### **v. Direct payments and the 1990 NHS and Community Care Act**

Some people on the Advisory Group see payment schemes as conflicting with local authorities' role under the 1990 National Health Service and Community Care Act. Under this legislation local authorities were given the responsibility of managing locally based services. On several different levels direct/indirect payments are said to undermine that role.

These are important issues which concern us all. I hope we can come up with appropriate resolutions to take back to the Advisory Group.

## **6. Personal assistant support schemes Fidelity Simpson**

I am currently writing a handbook of advice on setting up PA support schemes. It's based on my work with the Spinal Injuries Association (SIA) and the BCOBP. We felt that there was a need to draw existing good practice together. The final draft will be completed later this year and will form the basis of a DIG policy document on this issue.

Our research shows that there is a variety of third party schemes which makes it difficult to unify these experiences.

However, findings suggest that successful third party schemes require:

- i. An equal partnership between social services departments and disabled people based on a shared knowledge, which recognises a disabled person's life experiences and knowledge, and the validity of this.
- ii. Attitudes- the perspective needs to be WITH disabled people and not FOR them.
- iii Information is crucial, and needs to be clear, concise and comprehensive.
- iv. Funding irrespective of amount needed to be secure to set solid foundation.
- v. Training for all parties was found to be significant - to run schemes for disabled people, training for PAs and also for all associated divisions of social services departments and local authorities. The issue of training kept recurring .

The research also shows that third party schemes are constantly evolving and are responsive and reflective of individual user need. And that this offers a good model for other areas of social services provision. There are possibilities for joint local authority/health authority partnerships through joint care planning teams, and influencing community care plans. Some steps in this direction have already occurred in Hampshire, Wiltshire and Norwich.

## **7. Resolutions Introduction**

Over the course of the two days delegates discussed at great length the various issues raised at the conference. Indeed, on the second day participants were divided into 3 groups. Over two sessions, one in the morning and one in the afternoon, these workshops were asked to comment on: first, assessments and accountability and second the five areas raised by the Community Care Direct Payments Technical Advisory Group. The following is a summary of the outcome of those workshops.

### **Assessments**

The assessment process must be preceded by the provision of comprehensive and accessible information about maximising user options and choice.

Assessments should be needs-led and there should be no distinction between needs and wants. The goal of assessment must be to empower disabled people to control their own lives.

Assessments must be user-led but where appropriate support may be needed to enable people to do self-assessments. Here partnerships between local authorities and peer support/advocacy services are vital.

Since many people involved in the assessment process will need appropriate training and support. This should be provided by user led organisations; notably, those already providing third party support services.

Assessment reviews should be subject to negotiation and should not take place without the consent of all concerned.

## **Accountability**

People receiving direct/indirect payments should have the appropriate information and, where necessary, support to use funding wisely and effectively.

Independent Living involves a recognition that risk-taking is part of the process of empowerment. Disabled people must have the right to make mistakes.

Hence, a clear distinction between fraudulent abuse of payments and mistakes resulting from lack of experience or inappropriate advice must be included in all direct/indirect payments monitoring systems

The former should not be tolerated, but the latter should be addressed constructively through the development of appropriate reviews and support procedures.

These procedures should offer a range of options which enable local authorities to strike appropriate balance between their own accounting requirements, and the need to avoid unnecessary intrusions into the privacy of disabled people's lives.

Where necessary, reviews should be an ongoing process conducted at appropriate intervals negotiated between disabled people and local authority staff.

It should not be overlooked that all service providers are accountable to users. Consequently, all reviews and monitoring processes must take account of local authorities and support services responsibility to users?

## **The five concerns of the Community Care Direct Payments Technical Advisory Group.**

### **i The floodgate scenario**

The main concern here should not be whether payment schemes are too widely used but whether they accurately reflect the needs of disabled people.

There is no evidence to suggest that all disabled people will want access to payment schemes. Despite widespread publicity, where schemes are currently being offered, for example, in Kingston and Leicester, local authorities are not being swamped by potential users.

Payment schemes are fully compatible with the current community care policy in that they offer enhanced user choice and empowerment.

Payment schemes are therefore, simply a different and, in many ways, a more effective way of using existing resources. Research from a number of sources, including the casting in on Independence project, shows payments schemes are both cost effective and user friendly.

## **ii. The abolition of third party schemes**

Experience shows that the most effective payment schemes are those which are supported by user-led support networks.

Besides enabling more disabled people to manage their own support networks and thus reduce local authorities administration costs, user-led networks generally provide other essential services too. These include advocacy, peer counselling, consultancy and information services.

Investment in user-led support networks, therefore, is an efficient and cost-effective way of using Community Care funding.

## **iii. Tight eligibility criteria**

This is fundamentally a human rights issue; all disabled people have the right to independence and the resources needed to enable them to live full and productive lives.

Everyone eligible for support under the present community care system should have access to the payment option should they want it. Eligibility should not be determined by age or impairment - whatever the cause.

Experience suggests that areas which offer payments and do not restrict access on the grounds of age or impairment do not have a disproportionate high take up.

Additionally, restricting access to payments in this way would create more problems than it would resolve. Besides contradicting the principle of equal opportunities, to restrict access in this way will enshrine discrimination in law.

It would also require the creation of difficult, contentious and, inevitably costly, legal definitions.

## **iv. Direct/indirect payments as a substitute for benefits**

Direct/indirect payments are an essential part of community-based support services - they enable people to employ PAs to help them live independently in the community. They are not and should not be seen as any form of income maintenance or compensatory benefits.

Where schemes are currently in operation they are part of the community care system. The amount payable is decided by various assessment procedures (see above) and for a specific purpose, there is no reason why this should change following the introduction of legislation.

Current community care arrangements will ensure that the direct/indirect payments option is simply an alternative to traditional locally based services. Because not everyone will want to manage their own support system there is no reason to assume that local authorities will become a substitute for the Benefit agency.

If the concern is that payments will be absorbed within the family budget rather than on the employment of PAs then appropriate criteria and monitoring systems can be introduced to prevent this. Experience shows that these systems can be developed by mutual agreement between users, user organisations and local authorities.

## **v. Direct/indirect payments and the 1990 NHS and Community Care Act**

Payments schemes are a vital means of enabling local authorities to discharge their obligations under the NHS and Community Care Act more effectively. This is especially the case for the development of user-led services -a major Government concern since the early 1980s (see for example, the 1986 Disabled Persons (Services, Consultation and Representation) Act.

Payments schemes offer genuine opportunities for disabled people and local authorities to build meaningful and mutually beneficial partnerships in the , community care' enterprise.

When viewed in relation to existing practices; assessments, care contracts, and the development of care packages, for example, they are only another way of doing what is already being done.

They do not represent a major threat to existing services because self operated personal assistance schemes will not be the first choice of all disabled people, and there will always be a need for some form of back up service should this type of provision break down.

The addition of the direct/indirect payments option to the range of services provided by local authorities can only add to their responsibilities under the Community Care Act.

## Appendix One: Participants

Sue Bott	Shropshire Disability Consortium
Suselle Boffey	Lothian Social Services Department
Tom Clarke	Labour MP and Shadow Cabinet Minister for Disabled People
Jane Campbell	Chair of BCODP
John Dannicliffe	West of England Centre for Independent Living
John Evans	Hampshire Coalition of Disabled People
Carl Ford	Shropshire Disability Consortium
Mandy Kingwell	Norwich Independent Living Group
Paul Kobryn	Hampshire Personal Assistance Agency
Anne Pridmore	Leicestershire, Fairdeal
Anton Pronti	Wiltshire Independent Living Fund
Francis Hasler	Greater London Association of Disabled People
Vicky Raymond	Disablement Association, Hillingdon
Mike Ridout	
Fidelity Simpson	Disablement Incomes Group
Jo Smith	Leicestershire Coalition of Disabled People
Ken Smith	Derbyshire Centre for Integrated Living
Martin Smith	Hillingdon, Social Services Department
Barbara Vandamere	Norwich Independent Living Group
Steve Vincent	Coventry Independent Living Group
Gerry Zarb	Policy Studies Institute



## **Appendix Two: The Department of Health's Community Care Direct Payments Technical Advisory Group**

J. Allen	(Welsh Office)
M. Baldwin	(Independent Living Fund)
J. Campbell	(British Council of Disabled People)
R. Campbell	(Finance)
D. Ellis	(Social Services Inspectorate)
H. Farren	(Department of Health)
G. Flavor	(Law Society)
M. Gallagher	(Department of Health)
H. Jones	(Department of Health)
J. Kemp	(Royal Association of Disablement and Rehabilitation)
B. Mathews	(Department of Social Security)
M. McCaron	(Scottish Local Authorities)
A. McNaughton	(Scottish Office)
D. Platt	(Association of Metropolitan Authorities)
D. Walden	(Department of Health)
C. Spicer	(Association of County Councils)
R. Taylor	(Department of Health)
P. Thompson	(Disablement Incomes Group)
K. Wright	(Department of Health)