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Creating Independent Futures: Conference Report, Preliminary Findings and Policy Implications

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Introduction

This Report provides edited highlights of the 'Creating Independent Futures' conference held at Lancashire County Cricket Ground, Old Trafford on 6th December 2001. The conference was staged by the British Council of Disabled People’s Research Unit, Centre for Disability Studies, University of Leeds, and the National Centre for Independent Living to mark the conclusion of the empirical component of the 'Creating Independent Futures' research project. This was a two-year study that set out to critically evaluate the development, organisation and services provided by Centres for Independent/Integrated/Inclusive Living and other user controlled services.

The following attempts to synthesise and reproduce as faithfully as possible the proceedings of this event without undue repetition, duplication or distortion of meaning.

Nick Danagher: Chair of the British Council of Disabled People’s Independent Living Committee.

Welcome to the ‘Creating Independent Futures’ Conference. First of all I'm going to mention the victory we had last week at the end of a long campaign led by 'Let us Work' and the 'National Centre for Independent Living' (NCIL). I'm sure many of you are aware that the Government in England has now decided against the means testing of community care services, and, equally the Independent Living Fund will follow suit, so we are on the crest of a wave. This was a campaign run entirely by disabled people and lots of you here are involved in direct payments and support services, so that will be particularly important. But of course the majority of disabled people continue to be charged, so the fight goes on.

I now have great pleasure in introducing Martin Pagel who is the Deputy Leader of Manchester City Council.

Martin Pagel: Deputy Leader of Manchester City Council.

Welcome to Manchester, that is an in-joke because, as with many parts of the country, the actual boundaries of Manchester do not relate to what the majority of people in the area actually think is Manchester. We are, technically, in Trafford, so welcome to Trafford on behalf of Trafford Metropolitan Borough Council. Next year Manchester is hosting the Commonwealth Games, the largest multi-sport event that has ever taken place in Britain and the first world integrated games, with both the disabled people’s games and the other games taking place simultaneously.

So I am very pleased that today's event is taking place here and I hope that, in time, it will be recognised, as one of the most important conferences on disabled people’s issues and, most importantly, independent living.

I was reminded when Colin (Barnes) asked me if I would come and welcome people to today's event of a conference that I Chaired a few months ago. This was a community conference on racial equality and organised in conjunction with the Commission for Racial Equality (CRE) entitled 'Beyond the Rhetoric'. The title is important because it relates not only to racism but also to the discrimination we face as disabled people. Over the last twenty years, what we've discovered and what the research you're about to discuss shows is that we're very clear about what we mean by 'independent living'. It's about disabled people having control of their lives, it's about disabled people controlling services and it's about disabled people delivering services. But often we have to work in partnership with non-disabled supporters and allies. I say that with my tongue firmly in my cheek.

This is because all they have learnt is our language and how to use our experiences and our knowledge to perpetuate their futures and not ours. If you look at most public agencies - councils, health authorities, and other service providers - we see, increasingly, recognition of disabled people and disability issues. We see references to independent living; we see references to empowerment, self-advocacy and self-organisation. But then we see the reality of the lives that disabled people lead. The language is there, and, on the surface, so is the support. But we know from experience that this hasn't impacted upon the quality of life for many disabled people.

Some of the reasons for this will become apparent as we go through the course of today. But some progress has been made; some of you may remember me as a very angry cynical young man. I’m now an old man, I'm not quite as angry, but I am still as cynical.

I am cynical because for the last twelve years I have been an elected member of Manchester City Council. For the last six I have been Deputy Leader. Before that I did four years as the Chair of Social Services. So for those people who recognise me as a sell-out reformist careerist, you're right, I am. But I am a pretty poor sell-out careerist. I am still much better as an activist and a campaigner. So I have failed in one but gained in another.

I hope that during today we look at what we have won because I think it is important that we celebrate success. It is not really acceptable to say that we have made no progress. It is not acceptable because that excludes those disabled people who think we have made progress. There are people who are now more in control of their lives than they were twenty years ago and that is something to be celebrated.

We also need to recognise the contributions that people who are not in this room have made to our struggle for equality, and especially to those disability activists who are no longer with us. If we do not do that we betray their memory and we betray the legacy that they have left for us. So I think it is important that we start on a positive note and that we accept and acknowledge that some progress has been made, that some disabled people are in control of their lives and are living independently. And for that we salute everyone who has played a role in our movement.

However, there are also people whose situation has not changed one jot. There are many of our brothers and sisters that are in institutions, not by choice, but by force. They are there because of assumptions made by people in power and authority. These people have decided that disabled people’s quality of life is best served in an institution. I do not accept that there are any circumstances in which people should live in an institution unless they have broken the law; then they should be an institution called prison.

Our place is in the community. Our challenge to the community is either accept us and embrace us or come out and say that you don't want us, that you don't like us and that you're not prepared to support us. That is the only choice that I am prepared to offer to professionals and to politicians, including myself.

I would like to say that after twenty years of being involved with many campaigns and organisations, and some of the leading figures within the disabled people’s movement, across our region that we have achieved a great deal. I would like to say that the Council's policies on independence, on ensuring that disabled people are integrated into the community, and that disabled people have direct control over their lives, have been delivered.

If I believed that then I would be deluding myself on a grand scale because we haven't. We've got the policies, we've got the vision, we've got the Mission Statement, we've got all the things on paper but we have not yet managed to effect the quality of many disabled people’s lives. That is a challenge I must accept as Deputy Leader of the Council. It is a challenge that anyone must face who is prepared to accept public office.

Public office is not just about the titles and the status; it is about the responsibility that goes with it. That responsibility is to ensure that things on paper become a reality. We need to move away from simply asking have we got the right policies. I am tempted to say ignore the policies because they do not actually deliver what they are supposed to, but they are a start.

I believe it is important that we get the right policies in place. But the next stage, ensuring that they're implemented, is just as important. We must remind people that just because they have discussed 'disability' last year or the year before we have not answered all the questions yet, and that we certainly have not delivered the quality of life that disabled people have a right to expect. We must make sure that we have got our policies in place. But we must also ensure that they are an effective means of delivering change.

This is the challenge: we need to keep reminding policy formers and service deliverers at each and every opportunity that change is not something you simply want, change is something you have to work for. Too many people seem to think that we have won the argument about disability and independent living, that we have got the policies, and that is the end of the struggle.

This is only the start of the struggle. The real struggle is to make sure that what we have won in principle is actually delivered in practice. The work that has been produced by the disabled people’s movement, the studies, the reports, they are very important. They show us the way; they get us to the starting line. We now have a choice. The choice is, do we cross that starting line and begin the race, or do we stay at the starting line and just accept the fact that we have won the argument.

I want to give a challenge to every person in this room. The challenge is that the struggle involves everyone. Too often we look to organisations and we look to leaders. The only leading figures in the disabled people’s movement are you and the people that you come into contact with directly. Everyone in this room has to become equipped to carry the argument to people day in day out. We have to support each other. This does not mean that we should never disagree, there will always be disagreements. But to bring about the changes we want we must find ways of supporting each other so that we can continue the struggle.

I do not expect to see the kind of changes that I want, changes that will guarantee a good quality of life for all disabled people, in my lifetime. This is a society that is truly equal, a society in which everyone's contribution is recognised and valued. I would dearly love to be proved wrong. But the world is not as I would want it to be. So the challenge is the struggle for something better and that it is important that we are part of that struggle.

It is important that we continue to support each other and recognise that if we do not that there are plenty of vultures - politicians and professionals - out there waiting to pick us off. Over the last twenty years, we have spent far too much time disagreeing amongst ourselves than pursuing a common agenda. Twenty years ago disabled people had little evidence to support the arguments about the need for change. Today we have that evidence. Now, not only do we know that we are right we can now prove it. The real challenge for all of us is to find ways of taking this knowledge forward.

Over the last twenty years we have made important gains. We now have a law to outlaw disability discrimination and other legislations such as the Community Care (Direct Payments) Act. But we have had legislation against racism for thirty years and black people still are kicked to death by racists and Fascists purely because of their identity. Policies and legislation are only the start. If we want a society that is truly equal, just and fair, then each and every one of us is charged with the responsibility of working for it.

I hope that today's conference will lead to better services for independent living by stimulating discussion and debate and that it will also contribute to the on-going campaign for change and justice. I hope we can finally cement the bonds between independent living services and campaigning and that in uniting those two together we can continue the crusade for our liberation. Let's move beyond the rhetoric and start to deliver the just and equal society that we demand and have a right to expect.

***(**Participants were invited to ask questions or comment on the presentation).*

Question A: ***Y**ou began to talk about your background and you talked about being an activist and being involved in many things as an elected member for the last twelve years. But you mentioned you valued being involved with disabled people, you valued working together and you said 'they've learnt, they've experienced, they've shared our experiences'. You say 'they've shared our experiences' how do you clarify that because I'm fed up of people saying yes we can offer you this service, we can work with these people. For example, a non-deaf person has experiences to offer, they have things to share with us, I would say hang on a minute, we also have things to tell.

Martin Pagel

I think part of the problem when I use the word 'we' is that as well as being a councillor I am a disabled person. I do completely agree about working together, between ourselves and other people. The point I wanted to make is that we need to unite as disabled people.

First, because without unity we get picked off by people who will find a disabled person to give them the answer they want. Whether that person does it deliberately and maliciously or whether it's done through ignorance or fear I don’t know. But many people agree with professionals because they have little choice; they either agree or lose their services or support. That's what I meant about working together and sticking together. Without that unity of purpose we will continue to be divided by professionals and other people who determine on our behalf what services we should have and what quality of life we enjoy. I hope that clarifies the point.

Question B: Can you clarify what you meant about ‘winning the argument'?

Martin Pagel

I still do not believe we have won the argument completely. People are being taught the answers to the points we have made but don't actually buy into the concept of an equal and just society. Nor that we have the right to independence. This was confirmed at a conference for social workers I recently attended.

What really scares me is that in the world of teaching and training people are being taught how to respond to our arguments, but don't necessarily have to share or sign up to that view. There are still people that think we need to be looked after and protected. There are still people that think we are a danger to ourselves.

I can certainly assure you that I am a danger to others, but I do not think I am that dangerous to myself. That is why I think that we haven't yet won the argument. What we have is a more sophisticated group of responses to the points we make. I say that because I do not see the recognition of what independence or independent living actually means.

We have acceptance that there should be some services. We have acceptance that there needs to be integration within education, but I do not see anything that pulls all that together nor is there a true declaration of civil rights ensuring our role and place within society. This is a major obstacle to our liberation and our inclusion within society. That is why I do not believe we have won the argument. If we had the framework for change would be firmly in place.

I do not expect us to be fully integrated into society tomorrow. I would love it, but it's not going to happen. We have won only half the argument about the extent of the exclusion and discrimination disabled people face. I cannot stand up today and say that every director of social services, every council leader, every parliamentarian, every purchaser, deliverer of services and every teacher accepts that we are equal and that we have a role to play in our society. Unfortunately I meet too many of them; they have learnt the language of inclusion but not the practice.

I hope that I'm wrong. When we have the total package, total recognition and a better commitment to inclusion, then I'll believe we've won the argument, until then I do not think we have'.

3. Background to the Creating Independent Futures Project

John Evans: Member of the BCODP Independent Living Committee and Chair of The European Network on Independent Living (As John was admitted to hospital the day before the Conference, Frances Hasler read his presentation.)

‘This research has taken a long time coming. It is the kind of research that some of us in the disabled people’s movement felt should have happened a long time ago. For a long time many of us have felt it's so important not only to have an in-depth look at how organisations have developed, but also to try and get a feel for the position we are currently in right now. It gives us the opportunity of getting an overview of our historical trend and development and at the same time to have a look at how we fare now in the current, social and economic climate.

One of the criticisms of the disability movement has always been that we were never good at documenting our main developments and history. To a certain extent this is true and many of our organisations never recorded the key roots, origins, ideas and developments, except in an ad hoc way.

This denied us any insight to the origins of how some of our organisations emerged. Many of us had this knowledge and were able to share it, but only a few had recorded it, and even fewer in practical or documented detail.

The main point is that this project has addressed some of these issues. We conceived it, thought it up, went to the Lottery Fund and successfully received the funding and developed it. Now we are in a position to let you hear our findings. As well as this we can have this conference where we can look at some of the key issues together which can hopefully help form new strategies for the future.

Research is an area which has always been dominated by professional academic researchers who have always been keen to study disabled people, their lifestyles and organisations. That is why this piece of research is so unique because it is we ourselves this time who are looking inwards at what we have done in an attempt to come up with our own solutions.

Our movement has established a social model of disability, independent living and the struggle for civil rights. This work is a combination of all the aspects and ideas which we hope will fire us up again for more new ideas at a time when the odds seem against us within the current economic climate, ever tightening budgets, charging policies and service cut backs'.

It's not my job to tell you about the findings of the work, this will come later from Colin, I just want to finish by saying I wish you all a constructive and enjoyable day and look forward to reuniting with some old friends and making some new ones in this radical movement of ours'.

(Participants were invited to ask questions or comment on the presentation).

Question A: Who is John Evans, can you give some background?

Frances Hasler: Director, National Centre for Independent Living (NCIL), London

John Evans is a founder member of the Hampshire Centre for Independent Living (HCIL). I first met John in 1980 when he was a very unwilling guest of Group Captain Leonard Cheshire and was plotting his escape. I'm happy to say that he succeeded and became one of the first people in the country to use direct payments to employ his own personal assistants.

That was in about 1983. So John, along with some of his friends and colleagues from 'Le Court' (the Leonard Cheshire Home from which he escaped) decided to share what they had learned about how you get the money from the authorities to employ your own personal assistants. They set up the HCIL as a way of sharing the knowledge they had acquired with other disabled people.

Even at that early stage they knew that they were part of a wider movement. John is a great internationalist and had contacts with disabled people from around the world. There were people in other parts of the world doing the same kind of thing. He is also the Chair of the European Network on Independent Living, which was founded in 1989. That brought together people from all over Europe who were trying to do the same thing, achieving a right to personal assistance and independent living.

So John has been working with the independent living movement for more than twenty years and sharing what he knows as widely as he can. Recently, he's been working in Eastern Europe, working with some of the countries that are really beginning to develop an independent living movement.

Frances Hasler

I would like to say something about why the National Centre for Independent Living (NCIL) is involved in this work. Many of you know NCIL, but for those of you who don't, NCIL is part of the British Council of Disabled People (BCODP). We are an organisation controlled by disabled people. The Department of Health provides the bulk of our core funding to promote independent living and direct payments.

We also wanted to validate the work of Centres for Independent/ Integrated Living (CILs). Our roots come from the CILs. It was some of the early CILs such as Greenwich and West of England that asked us to set ourselves up. We were also aware that as direct payments was developing across the country more and more organisations were getting involved. There are a number of charitable and private sector bodies that are jumping on the direct payments bandwagon and we wanted to remind ourselves that it was the independent living movement who actually developed the idea and made it work.

All sorts of organisations and groups are now using the term independent living for all sorts of completely unrelated activity. For example, some charitable organisations have things that they call independent living bungalows. We also wanted to seek some clarity about understanding of independent living is.

We made the decision to work jointly with the Centre for Disability Studies (CDS) in Leeds for several reasons. One is that NCIL is a small body and we have a long-standing partnership with CDS. Working co-operatively is our preferred way of working. The CDS has a well-established link with BCODP and has hosted the BCODP's research unit for a number of years now.

We also felt that it was vitally important to work with research partners who share our values. John mentioned that other researchers are keen to study disabled people, but not necessarily starting from our values. We wanted very much to know that people we were working with shared our values and that is why this partnership came about.

Crucially it was also an opportunity to bring people together, having everybody here today is such a thrill. It is so good to see you all. There are old friends, people who I have not seen for years and lots of new friends. One of the great things about this project is that it has given us the opportunity to bring people together to talk about the issues and think about how to move forward.

The outcomes of the project won’t be a big surprise to many of us. The extreme financial fragility of many organisations is very concerning. One of the most worrying things that the study found was that so many organisations have got such short term and uncertain funding it is very hard to for them to plan ahead. On the positive side the research shows the really high value that disabled people and disabled service users place on user-controlled organisations and the services they provide.

(Participants were then invited to ask questions or comment on the presentation).

Question A: Maybe it should be that every Council has a duty to fund a CIL up and down the country rather than looking for insecure funding for three years?

Question B: You mentioned the social model of disability. Within the deaf community we are looking into the cultural model which is very different from the social model and the medical model.

Frances Hasler

We are having a workshop this afternoon on the social model and I would hope that ideas around the cultural model will be discussed there. Certainly some of the people who were the early developers of the social model as an idea were also very much concerned with the concept of developing disability culture.

4. Research Findings and Policy Implications

Colin Barnes: Centre for Disability Studies, University of Leeds

In this presentation I will describe the project and its findings. I think it is important to remember though that this is a first reading of the findings. We will be analysing them in much greater detail in the New Year when we produce the final report/book. Consequently much of what I have to say will be familiar to many of you as we have already produced three short research reports and circulated them to all the organisations that took part in the project. The reports can be downloaded from the CDS website.

The project was initiated by the BCODP Research Committee in 1998 and developed in conjunction with NCIL. The research was co-ordinated by a research advisory committee comprising the then co-directors of NCIL Jane Campbell and Frances Hasler, John Evans, Peter Beresford, Professor of Social Policy at Brunel University, and the research team from CDS; myself, Dr Geof Mercer and the project Research Officer Hannah Morgan. Jane has now left NCIL to take up the Chair of the newly formed Social Care Institute for Excellence. This is a very high profile job and this conference should offer her our warmest congratulations.

The project has three key aims: a/ to provide a critical evaluation of the development, organisation and services provided by CILs and similar user-led initiatives in the UK; b/ to identify the principal forces - economic, political and social - hindering their further development and; c/ to produce and disseminate, in a variety of accessible formats, findings and recommendations to disabled people, their organisations, policy makers in both public and private sectors.

The project has run for two years from January 2000 and comprises four key stages. These are: Stage One, to establish boundaries and criteria; Stage Two, conduct an in-depth analysis of user-led organisations; Stage Three, conduct user interviews and; Stage Four, analysis and dissemination.

Stage One: This included a/ a literature review to provide background information and identify organisations for inclusion in the study; b/ four seminars to explain the aims of the research and determine key issues for analysis and; c/ a survey of all known user-led organisations providing 'independent living' services to disabled people.

Seventy-five organisations were invited to the seminars and 48 sent representatives. Forty-nine of 50 participants were disabled people representing a diversity of experience of user-controlled initiatives. The seminars were held in London, Birmingham, Glasgow and Newcastle in March and April 2000. Seminar topics included the role of the social model, control and accountability processes, finance, employment policies and services. Summaries of each seminar were produced and circulated to all participants for comment.

The survey was designed by the research team and approved by the research advisory committee in April 2000. The key issues relating to the form and content of the survey were gathered from the literature review and seminars. The questionnaire addressed several topics; namely, organisational structure, wider networks, resources, activities and services, campaigning and aspirations, and included both closed questions (with tick boxes) and open-ended questions for more detailed responses. Eighty-five surveys were distributed, and a total of 69 were returned giving a response rate of 82%. To ensure equal access questionnaires were produced in a variety of formats - large print, Braille, disk and email.

It was clear from the seminars and surveys that organisations providing independent living services experience a range of dilemmas and concerns that limit their future development. Issues concerning general principles, funding, services, employment policies and standardisation were of major concern. These provided the basis for the second and third stages of the research.

Stage Two: Of the 69 organisations that completed the Stage One survey, 9 were selected for inclusion in Stage Two. Notably, all the organisations involved in Stage One agreed to participate in this in-depth review. Selection was based on several criteria including geographic location, year of establishment, membership, user numbers, and services offered.

To ensure the project provided a useful insight into the main issues associated with user-controlled services it was important that the research focused on large well established organisations and those that have emerged in the last decade. The final list included: Cardiff and Vale Coalition of Disabled People, CIL de Gwynedd, Centre for Independent Living in Glasgow (CILiG), Derbyshire Coalition for Inclusive Living (DCIL), Disability Action North East (DANE), Greenwich Association of Disabled People's Centre for Independent Living (GAD), Lothian Centre for Independent Living (LCIL), the Surrey Users Network (SUN), and the West of England Centre for Inclusive Living (WECIL).

Information was collected through semi-structured interviews with various people involved at different levels in the development, organisation and delivery of services. These comprised 32 individual and 10 group interviews. In all 30 women and 26 men took part in Stage Two. These included members of the controlling body, council or executive committee, directors and executive officers, core service managers, clerical and reception staff, voluntary workers and representatives of key funding bodies such as local authority social service departments.

Interviews were based around the key themes identified in Stage One: organizational structure, networks and associations, resources, services, campaigning and ambitions for the future. The 42 interviews lasted between 1 and 2.5 hours. Each conversation was recorded and transcribed in full. The transcriptions were then returned to the interviewees for verification and comment.

Stage Three: This involved further visits to the nine organisations from Stage Two in the early months of 2001. We were interested in user's experiences of services, both past and present. We wanted to know what participants thought about user-controlled services and how they could be improved, and how they compared with those provided by local authorities and other agencies. Additionally, because campaigning was a key concern of the first two stages of the study, we were keen to find out if people shared a similar concern. We also wanted to give participants an opportunity to talk about how they would like services to develop in the future.

In all, 76 individuals and 9 representatives of user organisations were interviewed. This comprised 40 women and 36 men and included people with a variety of impairments such as people with learning difficulties, mental health system users/survivors, and people from various minority ethnic groups. There was a predominance of people with physical impairments and the majority was in the middle age ranges. People from minority ethnic backgrounds were also underrepresented in our sample.

Stage Four: This part of the research involved members of the research team visiting each of the organisations that took part in the Stages Two and Three of the research and presenting the preliminary findings to them. Everyone involved was invited to these discussions and people had the opportunity to discuss, make suggestions and generally comment on the research and how it related to their particular situation. The Conference marks the final element of Stage Four.

The project formally finishes on December the 31st - at least, that is when the funding runs out - but the work will continue into the New Year when we will produce a report from this conference and a book.

In terms of findings and policy implications the research has generated a mountain of information and we have produced a series of reports that summarise our preliminary findings. Rather than simply repeat them here, what we have tried to do is consolidate these findings into a short policy statement which brings together some of the key issues for politicians and policy makers. The aim of this document is to give us something to use in campaigns for better independent living services.

The ‘**Findings and Policy Implications**’ statement reads as follows:

Recent Government initiatives; notably, The Community Care (Direct Payments) Act 1996; The Carers and Disabled Children Act 2000, The Health and Social Care Act 2001, indicate a clear intention to increase the use of direct/indirect payments by disabled people, carers and other health and social service users.

The Government now expects disabled service users to be fully involved in developing the new landscape for Social Care. This is reflected in the much-used phrase “putting users at the heart of social care”.

If this is to be a realistic goal, then it needs to be resourced and requires a systematic structure for sustainability.

We have largely built the framework for the latter, but because the user created structures of CILs, networks and coalitions have been systematically compromised by a serious lack of public and private investment; the framework is fragile, regionally variable and seriously over stretched.

Investment through funding and capacity building for existing user controlled services, is a cost effective, rational way to ‘place service users at the heart of social ‘care’. This implements Government policy as stated in the White Paper ‘Promoting Independence, the Quality Strategy and Modern Social Services – a commitment to people’.

This policy is greatly welcomed by the disabled population as it maximises individual choice and control, and enables users achieve a truly independent lifestyle. There is substantial evidence suggesting that for this policy to be successful potential users must have access to appropriate user controlled support services sometimes referred to as Centres for Independent/Integrated Living (CILs).

Research by the British Council of Disabled People’s National Centre for Independent Living (NCIL) and the Centre for Disability Studies (CDS) at the University of Leeds, shows that although mainland Britain’s network of user controlled services is more than twenty years old, its future development is seriously inhibited by a range of economic, political and social factors.

Additional findings indicate that:

- User-controlled services organised around independent living take a variety of forms and date back to the early 1980s.

- There is a symbiotic but often uneasy relationship between user-controlled organisations and sponsoring agencies such as local authority social service departments and health authorities that often inhibits the further development of user controlled support.

- For community based user controlled services to respond quickly and effectively to local needs they must be freed from unnecessary bureaucratic regulation and control by other agencies.

- Funding is a major problem for all user-controlled support services. It is generally short term in nature and in the overwhelming majority of cases limited to the development of particular projects.

- This has important negative implications for the type of premises used, the numbers of staff employed and the type and long term availability of the services offered.

- Competition for service contracts from national and local non-user controlled agencies has intensified over recent years and further threatens the future development of local user controlled support.

- There is an urgent need for the development of core funding strategies by Central Government to enable the further long term development of local user controlled support services.

- User controlled organisations have an exemplary record for employing and training disabled people for work as independent living support workers and related skills.

- But the combination of current benefit regulations and the temporary nature of employment within user controlled organisations make the recruitment and retention of skilled staff extremely difficult.

- There is a pressing need for further benefit reform to enable disabled people to take full advantage of the growing employment opportunities within user controlled support services.

- Funding must also be made available to user controlled organisations to work in conjunction with local colleges and universities for the development of appropriate training programmes in independent living support skills for disabled people working in independent living schemes.

- There is general disquiet amongst both users and providers of user controlled services about the lack of information on the availability and benefits of independent living and related services in the public domain.

- Less than half the user participants in the NCIL/DCS research had been referred to user controlled services by representatives of statutory agencies such as local authority social service departments or health authorities

- There is an urgent need for a national marketing campaign to raise public awareness of the benefits and advantages of direct payments and user controlled support services for independent living.

- There is general concern amongst all those involved in the development and delivery of user controlled support services over Government proposals to bring together medical and social provision as 'care trusts'. This is because, hitherto, health authorities and medical professionals have shown little understanding of the benefits of independent living type services for disabled people or their families.

- There is an urgent need for clear and unequivocal guide-lines on the establishment of care trusts to ensure that professional interests and concerns are not prioritised over those of users and/or user controlled organisation. Care Trusts must not mean no trust in disabled people.

- Disabled people must have the right and the responsibility to control their own ‘care’ packages and the support services that enable them to do that’.

(Participants were then invited to ask questions or comment on the presentation).

Question A: What are the distinguishing features of CIL's and user controlled services. How are they different from other services?

Colin Barnes

This is not a comparative study. We did not study non-user-controlled organisations but the findings show clearly that the organisations we looked at can be characterised in several ways. First, they all were very clear about the social model of disability and independent living. They all adhered to a social model perspective. Second, they were all controlled and run by disabled people: Over half the organisations studied had constitutions which allowed only disabled people to have voting rights in the way the organisation was organised and run. Third, they all went to great lengths to ensure accountability to their members and users. In some cases users automatically became members. A major concern for everyone involved was increasing participation particularly from those groups who are particularly disadvantaged within the disabled population such as people with learning difficulties, young disabled people and older disabled people. Fourth, they all went out of their way to employ as many disabled people as possible and,, finally, while they all provided services they all saw campaigning as central to their activities.

Question B: I didn't hear much about disabled people from minority racial or ethnic groups in your presentation how did you deal with these issues in the research address.

Colin Barnes

Well as you may recall from the reports the absence of black people and those from minority ethnic background was a major concern for everyone involved in the research. And this is a problem for most of the organisations that took part, but there is a lot of things that prevent involvement which are beyond their control, We did contact several organisations at the start of the study and there was a representative from an Asian organisation for disabled people at the London Seminar. But they did not respond to the questionnaire so we could not include them in either stages two or three of the research.

5. Workshops

Following lunch all participants were divided into several workshops covering the following areas:

i. User Controlled Services

Funding is a major problem for all user-controlled services and Centres for Independent/Integrated/Inclusive Living. Research shows that in the overwhelming majority of cases funding for user controlled initiatives:

- Comes from a variety of sources such as local authority social service departments and the National Lottery/Community Fund:

- Is generally limited to specific projects such as personal assistance support schemes:

- And is short term in character (generally between one and three years).

- All of which has major implications for the continuation and future development of user controlled services.

Questions

a) Should NCIL in conjunction with user controlled organisations develop policy guidelines on funding for user controlled services?

b) Should the BCODP/NCIL be encouraged to campaign for the introduction of state funded core funding for the further development of user controlled services?

Workshop B: The organisation of User Controlled Organisations' and their Relations with Statutory and other Voluntary Agencies

Most user-controlled services have a complex and sometimes difficult relationship with local authorities and other agencies that are often their main source of funding. This can sometimes have an important impact on:

- How the organisation is organised. For example, who sits on the management committee, what services are offered and to whom?

- The amount of paperwork involved. This has important implications for key staff and their actual involvement in service provision.

- Employment policies. User controlled organisations have an excellent record for employing and training disabled staff. This sometimes causes problems when trying to recruit and retain skilled disabled staff and of course service delivery.

Questions

a) Should user led organisations develop a national policy or guidelines for relations with other national/local, statutory and other, agencies?

b) Should user led organisations have a national policy in the employment of disabled/non-disabled staff.

Workshop C: The Social Model of Disability and its impact on Services

All the organisations involved in the Creating Independent Futures project are committed to a social model approach to service delivery. This has implications for:

- Relations with local authorities and other local agencies due to differing interpretations of the social model and what it means for services.
- What services can be provided and to whom because some people see the model as for people with physical impairments only:
- Potential users of user controlled services, some people felt that the social model was too political and might put some potential users off accessing user controlled services

Questions.

a) How and in what ways should the social model of disability influence what and how services should be provided at the local level.

b) Should the BCODP/NCIL develop a national policy statement or guidelines on how the social model of disability should be interpreted by local user controlled organisations hoping to develop local services.

Workshop D: Inclusion, Equality and Access

Although there are several important reasons explaining the current situation, general concern was expressed by many of those interviewed over the relatively low level of involvement by disabled people in the development and use of user controlled services. This was especially evident with reference to:

- The numbers of people from particularly disadvantaged groups within the disabled population such as disabled people from minority ethnic groups:

- The organisation and running of user controlled services. Although many organisations have relatively large memberships active involvement is often quite low.

- Attracting more potential users of user controlled services. There was a general feeling that user controlled services were widely seen as for people with physical and or sensory impairments only..

Questions

a) Given the current limitations under which many local user-controlled organisations operate how might they encourage greater involvement by local disabled people from disadvantaged groups within the disabled population?

b) Should user controlled organisations concentrate on services for impairment specific groups such as a/ people with physical impairments, b/ disabled people generally or c/ others such as ‘carers’, older people, and professionals?

Workshop E: Campaigning

All the user-controlled organisations studied saw campaigning as central to their role, although the importance and style of such activities varied, all the participants were aware that their campaigning activities had important implications for:

- Relations with funding organisations. Several groups felt that overt campaigning could alienate potential funders:

- Relations with potential users. Some users felt that overt campaigning was demeaning and undermined the image of the organisation.

Questions

a) Should user-controlled organisations providing services for disabled people continue to be involved in political campaigns and is fo what form should they take?

b) Should user- controlled services have a formal written policy on their approach to campaigning on disability issues?

6. Plenary Session

Peter Beresford: Centre for Citizen Participation, Brunel University, London.

I know that everyone involved in the project see the priority as developing ideas and proposals for the future to make things happen. We are going to try and draw out some key points before we have to leave. I would also like people to think about the 'Findings and Policy Implications' read out earlier today. So I am going to report on three of the workshops very quickly. The two on the social model first and then the one on campaigning. It seems that they were very lively discussions. There were different points of view but they were discussed very much in the spirit of solidarity. The key points from the discussions were:

The social model:

- The social model is the foundation upon which independent living services and user controlled organisations were and must be developed.

- A social model perspective is inclusive and includes all disabled people.

- There is still misunderstanding amongst some groups of disabled people about what the social model means. Everyone needs educating and it is a good idea to catch them young.

- Using the term, the 'barriers approach' can be helpful when explaining the social model.

- Organisations of disabled people need to develop ways of explaining the relevance of the social model to all disabled people.

- User-controlled organisations should deliver training based on the social model (Disability Equality Training) to both disabled and non-disabled people.

- The social model needs to be explained and popularised so that employers, social services, and service providers generally are not frightened by the concept unnecessarily.

- The social model should be used as a basis for assessment procedures for accessing services.

Campaigning:

- Given recent developments - the introduction of the 1996 Disability Discrimination Act (DDA), the 1996 Community Care (Direct Payments) Act. the Disability Rights Commission and the 2001 Special Education Needs and Disability Act - there is a widely held belief that disabled people now have civil rights.

- This is very misleading, as there is still a long way to go for disabled people to achieve equality. Disabled people and their organisations must continue to fight for full civil rights.

- Disabled people and their organisations must make full use of the new structures such as the DDA and the Disability Rights Commission.

- Those who work in the DRC must not be allowed to become complacent.

- Disabled people and their organisations must push for further change in order to strengthen these structures. They must be made to work more effectively.

- When campaigning, whether locally, regionally or nationally, disabled people and user-controlled organisations must work together.

- Campaigns for civil rights are more effective if they involve other people and groups.

- Disabled people and their organisations must work to enlist the support of other sections of the population when campaigning, but care must be taken to ensure that these campaigns are led and controlled by disabled people.

- Disabled people’s struggle for full and enforceable civil rights and user controlled independent living services must not become bandwagons for the benefit of others.

Frances Hasler

I am going to summarise three more workshops starting with the one on relationships with statutory authorities.

User controlled organisations' relations with statutory authorities:

- In present circumstances statutory agencies (local authorities and Health authorities) need disabled people’s organisations as much as disabled people’s organisations need them. Statutory authorities need to recognise this and build upon this understanding.

- When working with statutory authorities disabled people’s organisations must ensure that everything they do and are contracted to do must be based on a social model perspective and is about barrier removal.

- It is very important that power stays with disabled people and user controlled organisations.

- To ensure accountability all disabled people’s organisations entering into relations with statutory authorities must have a formal constitution based on the social model of disability. They must also have 100% voting rights reserved for disabled people.

Equal opportunities

- Inclusion is fundamental to the disabled people’s movement and equality is fundamental to inclusion.

- Disabled people’s organisations must attract and cater for disabled people with all kinds of impairments, of all ages and from different cultural backgrounds to ensure a wide pool of expertise and to strengthen the movement.

- All user-controlled organisations must have clear and effective equal opportunities policies.

- There should be established monitoring procedures showing how organisations are striving to achieve inclusion and effective equal opportunities.

- Disabled people’s organisations need to go out into other community groups and sell the benefits of user controlled services.

Funding

- Core funding must be provided centrally by Government. It must be available to fully accountable user controlled organisations to develop and promote independent living services and promote effective barrier removal.

- Core funding must also be independent of local authority and health authority control so that user controlled organisations are free to provide more effective independent living services and to campaign for barrier removal at the local and national levels

- User controlled organisations must also be free to generate additional income as and where appropriate. But fund raising activities absorb valuable resources in terms of time and effort and therefore must take priority over core activities such as independent living services or barrier removal.

Peter Beresford

Before we open it up I would like to stress two issues. First, what are the next steps that people want to take from this conference? Second, what are the priorities for policy makers to make a difference? I wonder also whether people would like to hear once again that statement that Colin read this morning. Then perhaps we can have some more questions or comments. (Frances then repeated the Findings and Policy Implications from the morning session).

Question A: Can we check the order of the main points? Some of the recommendations are about how things are to be done, whereas others, are about what should be done. We are obviously interested in the how and the what but also the order of what comes first.

Question B: Can you just read the bit about funding of organisations, because I am worried that non-user controlled organisations might try and jump on the bandwagon of core funding. I want to make sure that the priority is to user controlled organisations.

Question C: Is there anything in there about black and ethnic minority communities?

Peter Beresford

I don't recall it being specifically spelt out, certainly in the key recommendations. What we need to do before we can give it our full support is to have something included on this particular issue.

Question D: I wanted to question the use of the word 'care' on the last point.

Frances Hasler

The word care is in inverted commas: it’s difficult to get this across when you’re reading something. We use it because that’s the word politicians use and they need to know what we are talking about. We would change that to support but its their term not ours.

Question E: Can we make sure that the report and the book is written in plain language and accessible formats for people with communication and learning difficulties so that it is available to as many people as possible.

Frances Hasler

What I am hearing is that people like the principle of having a policy statement that we can all sign up to but before we can endorse it we must take it it back to our organisations for discussion. I think we have to have the document produced in accessible formats so you can discuss it with your organisation’s members; then maybe we can think again about how to take the initiative forward. We can come back to you later about how we should develop these ideas and, particularly, about how BCODP can use them.

Before we close we should thank all those who have worked so hard to make today happen. Thank you to all the speakers and workshop leaders and also to all the scribes who worked really hard in the workshops. I would also like to thank Hannah (Morgan) who has done so much to organise this conference and stayed so incredibly calm throughout. But it doesn't just finish here. Independent Living is a movement that has long and well established roots and we are adding to them all the time.

7. Amended Findings and Policy Implications

Recent Government initiatives; notably, The Community Care (Direct Payments) Act 1996; The Carers and Disabled Children Act 2000, The Health and Social Care Act 2001, indicate a clear intention to increase the use of direct/indirect payments by disabled people, carers and other health and social service users.

The Government now expects disabled service users to be fully involved in developing the new landscape for Social Care. This is reflected in the much-used phrase *“putting users at the heart of social care”.*

If this is to be a realistic goal, then it needs to be resourced and requires a systematic structure for sustainability.

We have largely built the framework for the latter, but because the user created structures of CILs, networks and coalitions have been systematically compromised by a serious lack of public and private investment; the framework is fragile, regionally variable and seriously over stretched.

Investment through funding and capacity building for existing user controlled services, is a cost effective, rational way to ‘place service users at the heart of social ‘care’. This implements Government policy as stated in the White Paper ‘Promoting Independence, the Quality Strategy and Modern Social Services – a commitment to people’.

This policy is greatly welcomed by the disabled population as it maximises individual choice and control, and enables users achieve a truly independent lifestyle. There is substantial evidence suggesting that for this policy to be successful potential users must have access to appropriate user controlled support services sometimes referred to as Centres for Independent/Integrated Living (CILs).

Research by the British Council of Disabled People's National Centre for Independent Living (NCIL) and the Centre for Disability Studies (CDS) at the University of Leeds, shows that although mainland Britain's network of user controlled services is more than twenty years old, its future development is seriously inhibited by a range of economic, political and social factors.

Additional findings indicate that:

- User-controlled services organised around independent living take a variety of forms and date back to the early 1980s.

- There is a symbiotic but often uneasy relationship between user-controlled organisations and sponsoring agencies such as local authority social service departments and health authorities that often inhibits the further development of user controlled support.

- For community based user controlled services to respond quickly and effectively to local needs they must be freed from unnecessary bureaucratic regulation and control by other agencies.

- Funding is a major problem for all user-controlled support services. It is generally short term in nature and in the overwhelming majority of cases limited to the development of particular projects.

- This has important negative implications for the type of premises used, the numbers of staff employed and the type and long term availability of the services offered.

- Competition for service contracts from national and local non-user controlled agencies has intensified over recent years and further threatens the future development of local user controlled support.

- There is an urgent need for the development of core funding strategies by Central Government to enable the further long term development of local user controlled support services.

- User controlled organisations have an exemplary record for employing and training disabled people for work as independent living support workers and related skills.

- But the combination of current benefit regulations and the temporary nature of employment within user controlled organisations make the recruitment and retention of skilled staff extremely difficult.

- There is a pressing need for further benefit reform to enable disabled people to take full advantage of the growing employment opportunities within user controlled support services.

- Funding must also be made available to user controlled organisations to work in conjunction with local colleges and universities for the development of appropriate training programmes in independent living support skills for disabled people working in independent living schemes.

- There is general disquiet amongst both users and providers of user controlled services about the lack of information on the availability and benefits of independent living and related services in the public domain.

- Less than half the user participants in the NCIL/DCS research had been referred to user controlled services by representatives of statutory agencies such as local authority social service departments or health authorities

- There is an urgent need for a national marketing campaign to raise public awareness of the benefits and advantages of direct payments and user controlled support services for independent living.

- Due to various factors particular sections of the disabled population are unable to take full advantage of independent living services provided by user controlled organisations. Examples include disabled people with learning difficulties, mental health system user and survivors, disabled people from minority ethnic communities and groups and disabled people from the older and younger age groups.

- There is an urgent need for targetted funding to be made available to user controlled organisations to develop resources to reach all sections of the disabled population.

- There is general concern amongst all those involved in the development and delivery of user controlled support services over Government proposals to bring together medical and social provision as 'care trusts'. This is because, hitherto, health authorities and medical professionals have shown little understanding of the benefits of independent living type services for disabled people or their families.

- There is an urgent need for clear and unequivocal guide-lines on the establishment of care trusts to ensure that professional interests and concerns are not prioritised over those of users and/or user controlled organisation. Care Trusts must not mean no trust in disabled people.

- Disabled people must have the right and the responsibility to control their own ‘care’ packages and the support services that enable them to do that.

Conference Participants

Melissa	Agnew	Hartford CIL
Maria	Aitkin	Sheffield University
Sandra	Aitkinson	Lothian CIL
Liz	Ash	University of Lincoln
Mark	Baggley	Choice & Rights Disability Coalition
Colin	Barnes	Centre for Disability Studies
Patricia	Barnes	Disabled People's Alliance Northamptonshire
Patrick	Barwise	Liverpool City Council
Karen	Beauchamp-Pryor	BCODP
Peter	Beresford	Open Services Project
Sarajini	Bhadhuri	Disability Doncaster
Rebecca	Bond	Independent Living Association (West Sussex)
Selina	Bonnie	Dublin CIL
Sue	Bott	Shropshire Disability Forum
Normand	Boucher	Centre for Disability Studies
Erika	Bowker	Calderdale Coalition of People with Disabilities
Keiran	Bright	REGARD
Angie	Carmichael	Sparring Partners
Nicky	Chapman	Leeds CIL
Julie	Charles	Equalities
Lesley M	Child	Disability Equality in Education
Laurence	Clark	Liverpool Health Authority
Tom	Clark	Council of Disabled People Warwickshire
Steph	Cooper	Independent Living Association (West Sussex)
David	Corbett	Bury People First
Claire	Craven	UCE Centre for Mental Health Policy
Jane	Cummings	Lothian CIL
Nick	Danagher	BCODP Independent Living Committee
Jaspal	Dhani	Disability Action in Barnet
Daniel	Docherty	Manchester People First
Kevin	Donnellon	Liverpool Forum
Heather	Doughy	DCIL
Angela	Duffy	MFODP (Liverpool)
Duncan	Edge	Choice & Rights Disability Coalition
Fisher	Edie	BCODP

Jim	Elder-Woodward	CILiG/SPAEN
Kate	Eldon	Bristol People First
John	Evans	BCODP Independent Living C'ttee
Beth	Ford	Disability Action North East
Carl	Ford	Shropshire Consortium
Jean	Glaves	DCIL
Lorraine	Gradwell	Breakthrough UK
Barry	Green	Bury People First
Wendy	Gross	Disabled People's Alliance Northamptonshire
Irene	Hart	
Frances	Hasler	NCIL
Linda	Haynes	Disability Doncaster
Liz	Henderson	Direct Payments Scotland
Mike	Higgins	New Perspectives (Sheffield)
Brian	Hodges	Disabled Peoples Forum (Sheffield)
Lorraine	Hughes	Trafford MBC Disability Project Group
Stephen	Hughes	Manchester People First
Patrick	Joyce	Lothian CIL
Edward	Kane	Manchester People First
Ian	Loynes	Southampton CIL
Caroline	MacDonald	Disability Gateshead
Steve	Marsh	Liverpool Health Authority
Philomena	McCrory	Belfast CIL
Siobhian	McCurrach	SUN
Bob	McSorland	East Dunbartonshire Association for Mental Health
Geof	Mercer	Centre for Disability Studies
Maria	Mietz	Bury People First
Colin	Mitchell	DCIL
John	Mitchell	Sheffield
Colette	Morgan	Cardiff & Vale Coalition of Disabled People
Hannah	Morgan	Centre for Disability Studies
Mary	Morgan	SUN
Susan	Morrel	Leeds CIL
Dave W	Morris	HAFAD
Marc	Moss	Kingston CIL
Paula	Moulton	Hartford CIL
Mike	Nash	Disability Action in Barnet
Andy	Needle	Manchester People First

Merle	Ochota	Hartford CIL
Alex	O'Neil	Joseph Rowntree Foundation
Martin	Pagel	MCC
Christine	Parkinson	Leicestershire CIL
Avantika	Patel	Leicestershire CIL
Zoe	Pelham	Manchester People First
Patricia	Phillips	Manchester People First
Fred	Postles	DCIL
Marie	Proudman	Disability Solutions
Susan	Quick	Calder Valley Disabled Women's Network
Brenda	Regan	Bury People First
Andy	Rickell	BCODP
Craig	Rodgie	East Dunbartonshire Association for Mental Health
Joseph	Rooney	Manchester People First
Lynn	Rothwell	Bury People First
Joan	Rutherford	Manchester City Council
Rachel	Scragg	Merseyside CALL
Tricia	Smith	SUN
Sharon	Stalker	Martin Yates Independent Living Services
Keith	Stephens	NW Region DP Group
Neville	Strowger	Manchester City Council
Mariam	Tarawelli	GMCDP
Pam	Thomas	BCODP External Affairs C'ttee
Gareth	Timms	Lothian CIL
Anne	Tober	Trafford MBC Disability Project Group
Dave	Tombs	SUN
Thelma	Tomlinson	GMCDP
Sarah	Topley	
Liza	Ware	Barnados
Chandra	Wilby	Bristol People First
Marion	Wood	GMCDP
Sarah	Woodin	Centre for Disability Studies