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# 1. INTRODUCTION

## 1.1 Background to the research

Central to the development of the international Disabled People's Movement has been the gradual but growing demand by disabled people and their organisations for greater involvement in the development and running of services for disabled people (UPIAS, 1976; ENIL, 1989; Ratska, 1992; Bickenbach, 1993; Coleridge, 1993; DPI, 1993; Barnes and Mercer, 1995). Furthermore, changing political climates and the escalating costs of welfare have resulted in greater support for user-led initiatives from both politicians and policy-makers in many countries, including the United Kingdom (Patten, 1990; Albrecht, 1992; Hellender, 1993, Secretaries of State, 1989; NHS Executive, 1995)

A major outcome of these developments has been the formation of organisations controlled and run by disabled people widely known as Centres for Independent/Integrated Living (CIL) which provide services directly to disabled people. Particularly prevalent in America and Canada as well as other parts of the world, (Scotch, 1989; Evans, 1993; Charlton, 1998) CILs have been relatively slow to develop in the UK (Oliver & Zarb, 1989; Morris, 1993; Barnes, Mercer & Morgan, 2000).

Although negotiations began in 1981 Britain's first two CILs began operations in 1984 (Davis and Mullender, 1993; Evans, 1993). Today, the number stands at fourteen. In contrast there are now over 300 CILs in the United States (Charlton, 1998, p132). However, there are many other user-led initiatives providing 'independent living' type services who do not refer to themselves as a CIL (NCIL, 1998; Barnes, Mercer and Morgan, 2000). Exactly why the British CIL movement has been slow to develop and why some organisations do not consider

themselves CILs has yet to be fully explained. This rather confusing situation is made even more complex by the fact that some traditional 'professionally' led service providers have recently adopted the phrase 'independent living' to refer to non user-led services such as Independent Living Centres previously know as Artificial Limb and Appliance Centres (ALACs)

## **1.2 Research aims and objectives**

The project was initiated by the BCODP Research Committee in 1998 and developed in conjunction with the National Centre for Independent Living (NCIL). NCIL was established as a branch of the British Council of Disabled People (BCODP) in 1997 to provide information, advice and to offer a co-ordinated approach to developing new independent living schemes.

The research is co-ordinated by a research advisory committee, comprising the co-directors of NCIL Jane Campbell and Frances Hasler, John Evans, a representative of the BCODP Independent Living Committee, Professor Peter Beresford, a psychiatric system survivor and academic acting as a research consultant and the research team from the Disability Research Unit (DRU) at the University of Leeds, Professor Colin Barnes, Dr Geof Mercer and the project Research Officer Hannah Morgan.

The project has three key aims:

- to provide a critical evaluation of the development, organisation and services provided by CILs and similar user-led initiatives in the UK;
- to identify the principal forces - economic, political and social - hindering their further development;

- 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 will run for two years from January 2000 and comprises four key stages:

- Stage 1 establish boundaries and criteria
- Stage 2 in-depth analysis of user-led organisations
- Stage 3 user interviews
- Stage 4 analysis and dissemination

### **1.3 Research Strategy and Design: Stage One**

To meet the project aims and objectives 3 main research strategies were employed.

1. A literature review was undertaken in order to provide background information and to identify appropriate organisations to include in the study.
2. Four seminars were held to explain the aims of the research and to elicit the support of disabled people and their organisations. Focus group discussions centred on the establishment of criteria to differentiate CIL or similar user-led initiatives from other forms of service provision and to highlight the main themes to be addressed by the subsequent research process.
3. The information gleaned from the literature review and seminars formed the basis of the final section of stage one; a survey of all known user-led organisations providing 'independent living' services to disabled people.

## Literature Review

Relevant information from a variety of secondary sources, including published material, books, journals, disabled people's organisations newsletters, NCIL records and documents as well as internet documents was collected and analysed. This information will provide the basis for a *'History of the CIL Movement in the UK'* and an annotated bibliography of independent living and user-involvement.

## Seminars

All CILs and user led initiatives were contacted and provided with details of the research: rationale, aims and proposed methodologies, as well as an invitation to participate in the seminars and focus groups. Details of the organisations to be contacted were provided by NCIL (Personal Assistance Support Schemes Directory September 1999) and by BCODP (from their membership data). The participating organisations and the research co-ordinating committee provided additional contacts.

A total of 75 organisations of disabled people were invited to participate in the seminars, of which 48 sent representatives. All but one of over 50 participants were disabled people and represented a diversity of experience of user-led initiatives. The seminars were held in London, Birmingham, Glasgow and Newcastle in March and April 2000. The seminars took the form of a brief presentation of the research aims followed by focus group sessions in which participants were asked for their views on a range of issues currently facing user-led initiatives.

Suggested topics by the research advisory committee comprised:

- the role of the social model
- control and accountability processes

- finance and employment policies
- service provision

Summaries of each seminar were produced and circulated to all participants for comment.

## Survey

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 questionnaire were gathered from the literature review and seminars. The questionnaire addressed the following topics:

- organisational structure
- wider networks
- resources
- activities and services
- campaigning
- ambitions.

The questionnaire included both closed questions (with tick boxes) and open-ended questions for more detailed responses.

Eighty-five surveys were distributed, and a total of sixty-nine were returned giving a response rate of eighty-two per cent. Each organisation was contacted beforehand by telephone to discuss the aims of the project and secure compliance. Questionnaires were provided in a variety of formats - large print, braille, disk and email - to ensure equal access.

## 2. SEMINARS AND FOCUS GROUPS

### 2.1 Towards a formal definition of a CIL?

Participants agreed that CILs and user-led initiatives should aspire to meet certain criteria. These included:

- adopt a social model approach to the development and operation of services;
- provide disabled people with meaningful choice and control;
- be flexible and responsive to the needs and wishes of local disabled people;
- be inclusive and offer services based on the common experience of disability;
- A range of core services were identified, but it was agreed CILs should also respond to local needs.

#### A Social Model Approach

There was general agreement that a social model approach should be central to any CIL. This was described as 'fundamental', the 'foundation' or 'defining feature' of user-led initiatives. Some difference was evident however over the definition and implementation of the social model.

It was suggested that the social model should not be a static or prescriptive doctrine but rather a broad concept or ethos that can be adopted and adapted by disabled people and their organisations in response to the needs and wishes of local disabled people.

#### Choice and Control

Disabled People have traditionally had little opportunity to exercise meaningful choice or control over disability services. Participants stressed the importance of disabled

people's 'ownership' of the 'independent living' model of service provision.

Thus the importance of the development of organisational structures and procedures, such as management committees controlled by disabled people and the establishment of formal constitutions and policy documents was emphasised.

### Flexibility and Accountability

Levels of accountability were identified, from current users, local disabled people, the local community as a whole, and the wider Disabled People's Movement. Difficulties were expressed in balancing the needs of users, potential users and the wider disabled people's movement.

Concerns were raised about how to include disabled people who do not readily identify with the social model or independent living.

### Inclusion

It was agreed that a key aspect of the CIL movement is its emphasis on disability rather than impairment specific services. Participants recognised that in their early stages of development CILs often tend to be under used by certain groups of disabled people. These included disabled people from minority ethnic groups, people with the label of learning difficulties, mental health users/survivors and disabled people living in institutions.

Therefore participants agreed that some form of service targeting is sometimes necessary to address this situation. This targeting was seen as a transitional process to promote the development of a more inclusive approach to service delivery.

## Services

There was much discussion about whether an organisation should offer a specific range of services to qualify for CIL status. It was evident that none of the participating organisations offered all the seven basic services originally identified by Derbyshire CIL in 1985 (information, access, housing, technical aids, personal assistance, counselling and transport). However, the merits of services such as employment advice/support and advocacy were highlighted.

There was considerable debate over the CIL role in advocacy and campaigning. Participants were divided as to whether this should be a central function of a CIL, and whether it was practical given the charitable status of many organisations and the constraints explicit or otherwise imposed by some funding agencies.

## **2.2 Emergent Issues**

### The Principle of Independent Living

One of the main concerns of participants was the tension arising from reconciling the principles and ideals of the social model and independent living with the reality of operating within an environment dominated by individual, medical model type ideologies. Frustration was expressed about the constant need for compromise and negotiation to establish even the most basic level of services.

### Funding.

Funding proved to be a contentious and problematic concern for all participants. All CILs and user-led services are dependent on external funding. Organisations face real dilemmas over balancing the demands of funding agencies and the provision of a range of CIL type services.

Some participants felt that funding should be mandatory and from a central source mainly government but concern was expressed over the potential constraints this imposed on organisations. However, in the present context there was a recognised need for a range of funders to strengthen the position of the CIL movement. The significance of thorough planning and an awareness of 'how to play the funding game' was emphasised.

Concerns were expressed that some potential funders might be considered unacceptable. Examples include certain charities and the manufacturers of specific psychiatric drugs; therefore careful negotiation with potential funding agencies is essential to organisational integrity.

### Employment Policies

It was generally felt that the ideal would be for CILs to employ only disabled people. However, a number of difficulties were recognised in relation to this aim. Such a policy may be seen as ghettoising disabled people and contrary to the principle of inclusion.

It was also noted that some jobs may require non-disabled members of staff, such as personal assistance. Some participants felt that the employment of non disabled people was acceptable in the absence of suitably qualified disabled applicants but this raised questions relating to promotion as it was agreed that CILs should be controlled and run by disabled people. Several participants maintained that in situations where vacancies cannot be filled by a disabled person user-led organisations should initiate and develop suitable training programs.

There were differing opinions regarding the employment of volunteers. Some participants felt it was inappropriate to employ volunteers because of the secondary status generally ascribed to non-paid staff. Alternatively volunteering offered disabled people opportunities to

develop skills and gain work experience. Given that many disabled people have problems balancing paid work and benefit entitlements it was generally accepted that CIL type service providers should adopt employment policies which address these issues.

### A CIL Kitemark?

Considerable concern was expressed about the adoption of the language of independent living by traditional professionally led service providers, both statutory agencies and charities.

While some participants felt there was a need for the development of an agreed standard or 'kitemark' based on specified criteria for CIL- type services, others argued that such a development might inhibit and seriously undermine grass roots innovation.

## **2.3 Conclusions**

It was clear from the seminars that organisations providing independent living services experience a range of dilemmas and concerns, which are likely to inhibit and constrain their future development. Issues concerning general principles, funding, services, employment policies and standardisation were of major concern. These will provide the basis for detailed analysis in the second and third stages of this research.

## 3. Survey

### 3.1 Introduction

This section provides a general picture of the user-led initiatives that participated in the survey, their organisation, networks, resources, services and their long-term goals. A more detailed analysis will be included in the final project report.

#### What's in a name?

Participating organisations have adopted an array of names, some explicit, others more exotic. Fifteen refer to themselves as CILs, twenty-four as coalitions, associations or councils of disabled people and thirteen are independent living or direct payments groups. Seven organisations adopted names related to their geographical base and the remaining ten have more unusual names without a direct link to disability or independent living.

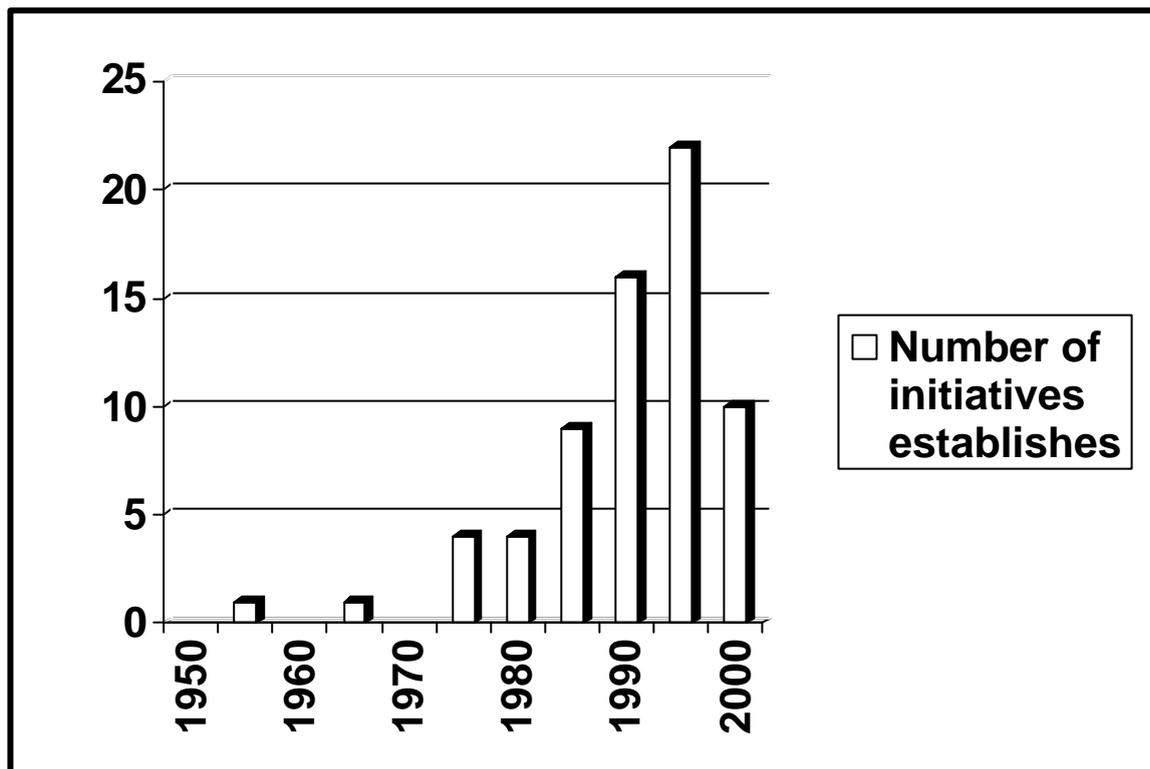
*A full list of participating organisations can be found in Appendix B.*

#### Origin

The establishment of participating organisations ranges from 1952-2000. However, many of the organisations that pre-date 1980 originated as organisations for disabled people but have subsequently evolved into organisations controlled by disabled people. As figure one shows there have been two significant periods when the self-organisation of disabled people has flourished. In the early 1980s 11 formal organisations developed from groups of disabled people leaving residential care and organising around independent living issues, including the UKs first CILs in Derbyshire, Hampshire and Greenwich. Secondly, there has been a proliferation of user-led organisations during the 1990s.

The passage of the 1990 NHS & Community Care Act and the subsequent 1996 Community Care (Direct Payments) Act paved the way for disabled people's organisations to support the growing numbers of disabled people living in the community and choosing to use direct payments.

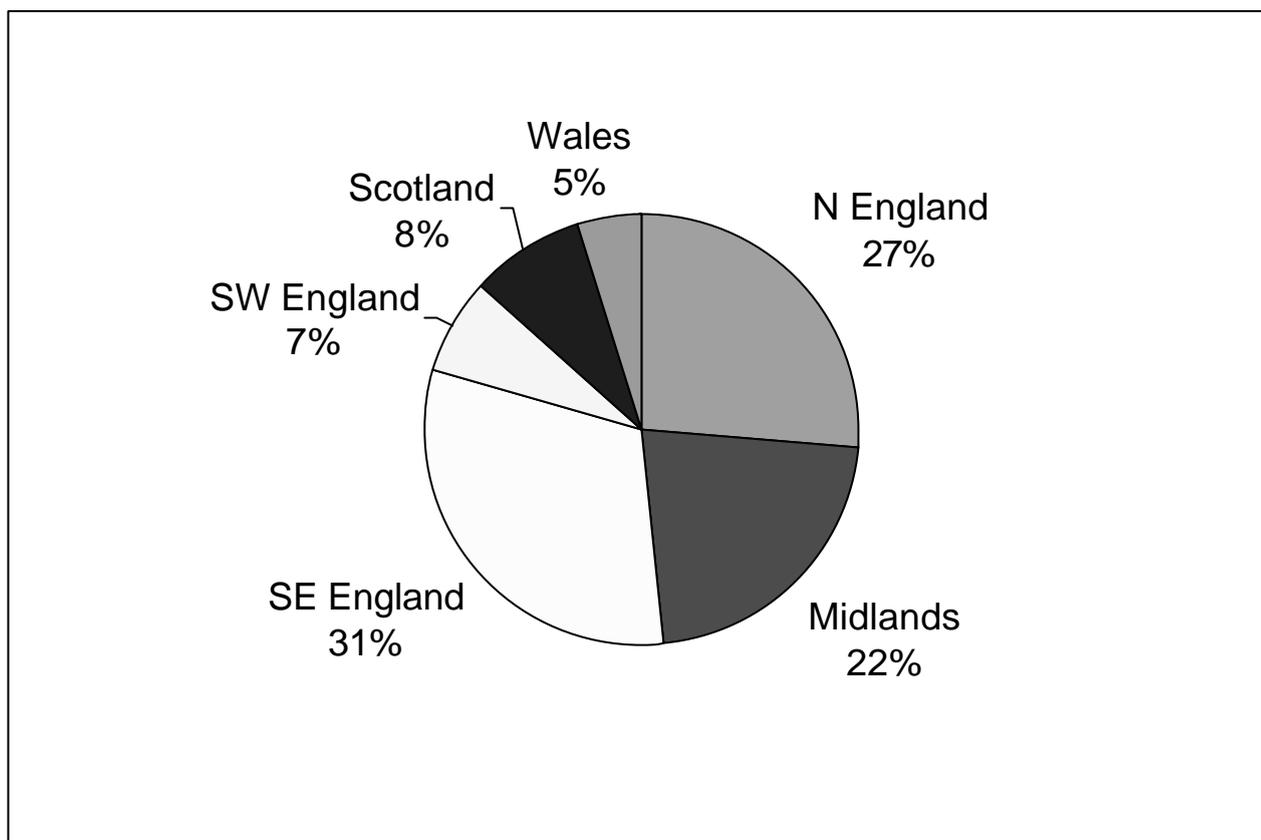
**Figure One: The Establishment of User-led Initiatives**



### Regional distribution

Participating organisations were drawn from a wide geographical area although the south east, midlands and north of England were the areas best represented. It is important to remember that this is not a representative sample of user-led organisations (see section 3.1). In addition of the fourteen organisations that did not respond, ten were from the South East region.

**Figure Two: The Regional Location of Responding Organisations**



### **3.2 Organisational structure**

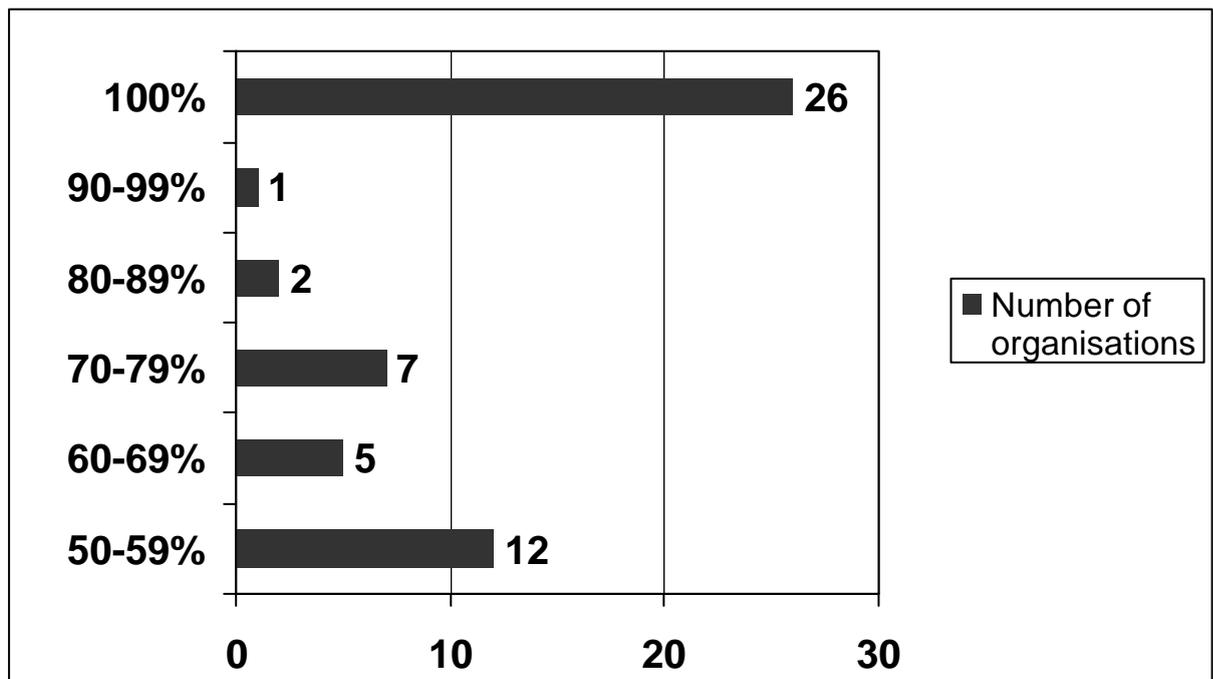
One of the key justifications for services provided by disabled people's organisations is that they tend to be far more accountable to service-users. The majority (96%) of groups have a written constitution and eighty-two per cent a mission or policy statement. Constitutions are usually broad legalistic documents, and are a legal requirement for many organisations, such as those with charitable or company limited status. In comparison, mission and policy statements are far more detailed working documents that contain information about specific aims, principles and practice.

### Control

Sixty-seven of the sixty-nine participating organisations (97%) have a management committee. Thirty-four (52%) of the committees are made up entirely of disabled people, while sixty-five (96%) have at least 50% disabled people. Twenty-seven (42%) of management committees are made up entirely of their service users (both disabled and non-disabled people), with fifty-three (70%) having at least 50% user representation.

Significantly, twenty-two (33%) of respondents had representatives of their funders on the management committee, with six (10.5 %) having over fifty per cent of their members from funding bodies. Additionally, twenty five per cent have local authority representatives and six percent health authority representatives. Seventeen per cent of participating organisations had 'carers' as members of the their committee.

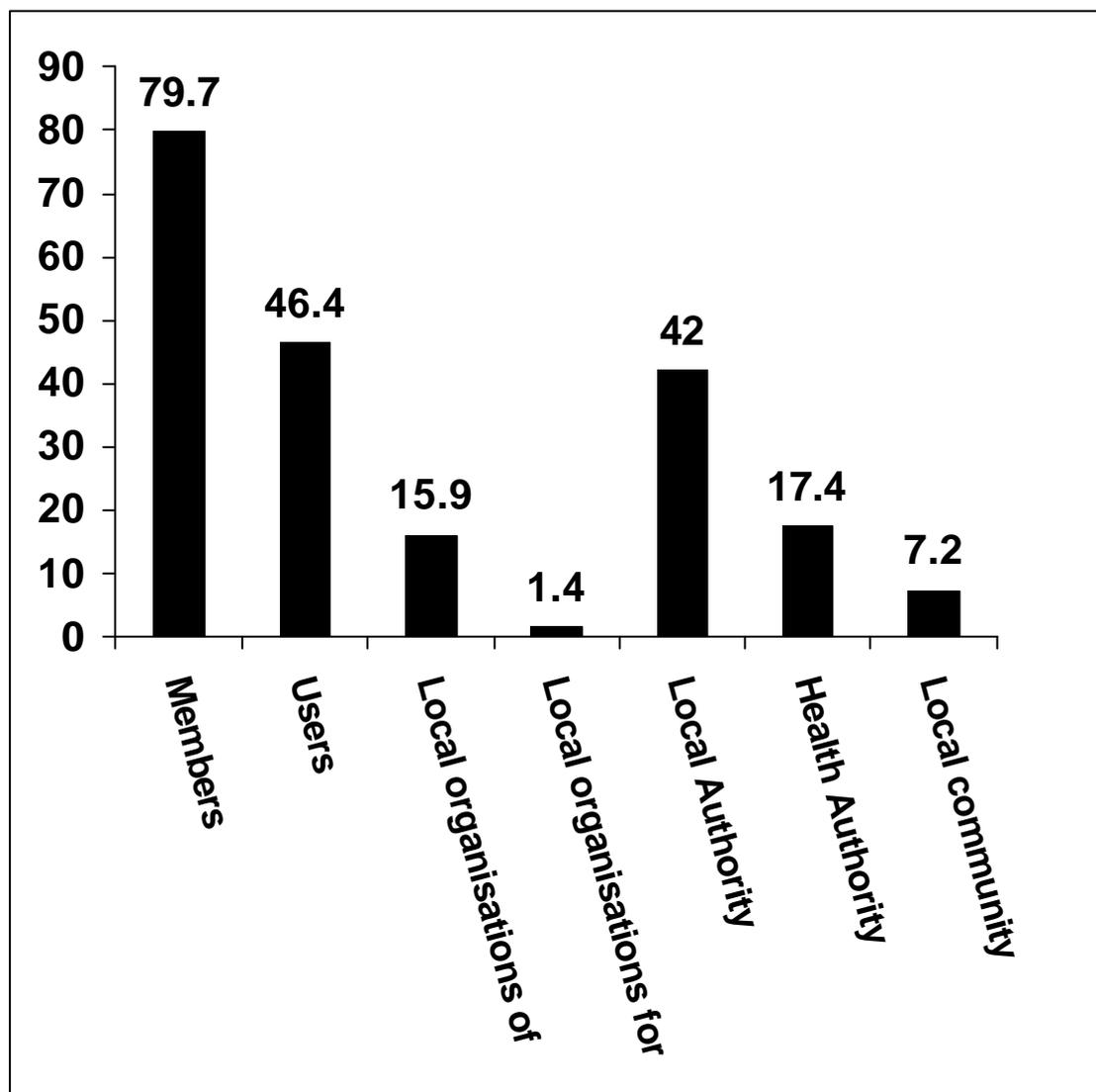
**Figure Three: Disabled People as a minimum percentage of the management committee**



We asked organisations whether they had a requirement of a minimum percentage of disabled people on their management committees. As figure three shows fifty-four (79%) of groups had a minimum representation of disabled people on their management committees. This varied from a simple majority to 100%. Fifty per cent of groups required that their management committees were comprised entirely of disabled people.

### Accountability

**Figure Four: The formal accountability of respondent organisations**



As table four illustrates respondent organisations are accountable, beyond their management committee, to a variety of other organisations and groups.

Eighty per cent are formally answerable to their members, and almost half (46%) to their service users. There is a significant level of formal accountability to statutory and funding agencies such as local and health authorities and the national lottery, often through service agreements or other forms of contract. A small number of organisations (16%) are answerable to local organisations of disabled people. It is unclear to what degree accountability varies with different funding agencies. This is an area to be explored in stages two and three.

### Management

Ninety three per cent of the organisations surveyed have someone nominated with responsibility for their day to day management. The position this person occupies varied between organisations. for example forty-five per cent have a Director or Executive Manager and thirty-eight per cent a Co-ordinator, Administrator or Chairperson.

The majority of 'managers' (78%) are appointed or elected by the management committee. Members elect the manager in fourteen per cent of the organisations and the local authority or other funding body appoints five percent of managers.

Forty-five per cent of managers are appointed for longer than three years, although as many as forty-three per cent are appointed for less than two years.

### **3.3 Wider networks**

Fifty-seven per cent of respondents have formal links with, or are members of, other local organisations. The majority have links with local organisations controlled and run by

disabled people (75%) and with other voluntary organisations (62%). Additionally around a third of groups have links with organisations of people with specific impairments (39%) and local groups for disabled people (31%) Smaller numbers have links with organisations for people with specific impairments (21%) and different impairments (15%) and 'carers' groups (15%). Thirty-nine per cent are formally attached to local authority social services and twenty-one per cent to a health authority.

Seventy-four per cent of organisations are formally attached to national organisations. Eighty-two per cent are attached to national organisations of disabled people, with less than a quarter attached to national organisations for disabled people (23%). Ten per cent of groups were associated with national organisations of and for disabled people with specific impairments.

The groups surveyed work with a variety of organisations at different levels. The majority (93%) work with local groups, generally around the provision of services or with groups representing other minority groups such as minority ethnic organisations. A significant number of groups operate on a national level (65%), working with organisations such as NCIL, BCODP, DIAL (Disability Information Advice Line), Radar and Mencap. Groups from Scotland and Wales were much more likely to work at a regional/national level with groups like Disability Wales or Disability Scotland. A smaller per cent of groups operated at the European (16%) and International (10%) level. There were links with international groups such as the ENIL (European Network on Independent Living) or DPI (Disabled Peoples' International) as well as with local, regional and national groups of disabled people from as far apart as Portugal and Russia.

### **3.4 Resources**

#### Premises

Eighty-nine per cent of organisations have formal premises/offices. Six per cent have no fixed premises at all and four per cent operating out of individuals' homes. Forty-two percent of groups have exclusive use of their offices. The remaining forty-seven per cent share their premises/offices with other groups. These included voluntary organisations (61%), social service departments (15%), health authorities (3%), other disability organisations (3%) and private organisations (3%).

#### Funding

We asked participating organisations to indicate where they had accessed funding from, particularly over the last three years. Only ten of the sixty-nine organisations were sole-funded, with the majority of organisations being jointly financed from a variety of sources. In most cases this means the local authority (83%), lottery grants (55%) and health authorities. Self-generated funding (income from services 35% and membership fees 32%) is also significant.

The majority of organisations received funding for developing and maintaining services, and for administrative, staff and premises costs, including initial start up costs. Core funding is usually provided on a short-term basis. Only four per cent of participating organisations has funding secured for longer than three years. The majority of funding (65%) is guaranteed for two years or less. The short-term nature of the majority of funding means that long-term planning and service development and provision is highly precarious.

## Employment

The nature of the structure and funding of the participating organisations impacted on both the levels of staffing and their formal employment policies. The survey sought to identify the number of staff employed by each organisation and whether staff were employed on a full or part-time basis. We were also interested to know whether participating organisations employed disabled or non-disabled people.

The level of staffing (by both disabled and non-disabled people) varied enormously between organisations. Many organisations had no full-time (and often no part-time) members of staff. One organisation had thirty-seven disabled people working full time and another had twenty-one non-disabled members of staff. A large number of volunteers are employed by the responding organisations. The vast majority of volunteers are disabled people, in fact only twenty-five per cent of organisations employed non-disabled volunteers, whereas seventy-five per cent employed disabled volunteers.

Generally participating organisations had a greater proportion of disabled members of staff, particularly where there was a policy on employment. Fifty-five per cent of responding organisations have a formal employment policy.

### **3.5 Activities and services**

#### Service Provision

Most of the organisations surveyed offered a range of services, although none offered all seven of the basic needs. Some organisations provided a comprehensive range of services whilst others acted as a signpost to services provided elsewhere.

In the majority of organisations (90%) it is the management committee that decides which services are developed and provided. Service users have a role in deciding service provision in fifty-five per cent of organisations. Funding bodies including local (20%) and health authorities (10%) also play a significant role in determining which services are provided, as in thirty-three per cent of organisations service provision is a condition of funding.

**Table One: Services currently offered by user-led organisations**

Service	Currently offered	Hope to offer
Information	<b>82%</b>	<b>65%</b>
Peer support by disabled people	<b>67%</b>	<b>13%</b>
Disability/distress awareness/equality training	<b>58%</b>	<b>9%</b>
Personal assistance	<b>54%</b>	<b>8%</b>
Employment advice/training	<b>38%</b>	<b>12%</b>
Housing advice	<b>36%</b>	<b>15%</b>
Environmental access	<b>32%</b>	<b>13%</b>
Education advice/support	<b>30%</b>	<b>12%</b>
Transport	<b>22%</b>	<b>6%</b>
Counselling	<b>16%</b>	<b>20%</b>
Health/impairment related	<b>15%</b>	<b>9%</b>
Technical aids & assistance	<b>13%</b>	<b>6%</b>

### Monitoring

Forty-five of the participating organisations monitor the number of people who use their services. However, only

thirty-six organisations provided details of their user numbers. A variety of reasons were given, including not having up to date information or being unwilling to provide quantitative data on service usage preferring a more qualitative assessment of their service provision.

### User Groups

It was clear from the focus group discussions that organisations controlled by disabled people sought to be inclusive in their membership and user groups. The identification of the social model as central to the ethos and practice of user-led provision meant organisations aimed to make their services accessible and relevant to all disabled people, regardless of the nature of their impairment.

**Table Two: Under-representation of particular groups within user-led service provision**

disabled people from minority ethnic groups	<b>64%</b>
gay & lesbian disabled people	<b>54%</b>
younger disabled people (16-25)	<b>51%</b>
disabled young people under 16	<b>41%</b>
people with learning difficulties	<b>37%</b>
mental health users/survivors	<b>31%</b>
older disabled people (60 years +)	<b>23%</b>
people with sensory impairments	<b>22%</b>
people with specific impairments/conditions	<b>15%</b>
people with physical impairments	<b>10%</b>
disabled women	<b>10%</b>
disabled people generally	<b>9%</b>
'carers'	<b>9%</b>
families with a disabled member	<b>7%</b>
professionals working with disabled people	<b>3%</b>

However, there was recognition that structural and cultural barriers have perpetuated an under-representation of certain groups of disabled people within user-led services.

As table six shows many groups identified disabled people from minority ethnic groups, lesbian and gay disabled people and younger disabled people under 25 as significantly under-represented. In addition people with the label of learning difficulties and mental health system users/survivors were also considered to be under-represented.

### **3.6 Campaigning**

A central feature of the disabled people's movement has been campaigning around a variety of issues. Seventy per cent of the organisations sampled actively campaign on disability rights. Issues included service cuts, the campaign against charging, and access issues.

Almost a quarter of groups (23%) organise on impairment specific issues addressing the particular problems encountered by people with different impairments, such as people with the label of learning difficulties or people with head injuries. Sixteen per cent of organisation support campaigning on other related issues such as gender, race/ethnicity and sexuality, the majority of these campaigns focused on inclusion. Only nine per cent campaigned on 'carers' issues, and this tended to be related to personal assistance rather than more traditional 'carers' issues.

Table Three shows the amount at which this campaigning activity takes place. Most organisations campaign at the local level, although a significant level of activity occurs at the regional and national level. This was most common in Wales and Scotland. A small number of organisations participate at both a European and international level.

**Table Three: Campaigning activity**

	Local	Regional	National	European	International
Disability Rights issues	<b>73%</b>	<b>42%</b>	<b>53%</b>	<b>9%</b>	<b>6%</b>
impairment specific issues	<b>28%</b>	<b>10%</b>	<b>9%</b>	<b>1%</b>	<b>n/a</b>
carers issues	<b>10%</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>
other e.g. gender, sexuality, ethnicity	<b>13%</b>	<b>7%</b>	<b>7%</b>	<b>1%</b>	<b>1%</b>

### **3.7 Ambitions**

The final section of the questionnaire offered participating organisations the opportunity to identify their future aspirations and in particular to address the ways in which they would like to improve their services.

Aspirations were wide-ranging, a number of user-led groups expressed their desire to become CILs; this was viewed as a process that required an expansion in services and more permanent formal organisation. It was clearly linked to the second main area of concern, the security of funding. The short-term and precarious nature of funding was identified as a major problem that hindered the development of services. Within the general expansion of services particular emphasis was placed on the implementation of direct payments and the provision of

direct payment services including supporting personal assistant employment. The inclusion of many more disabled people within CILs and similar organisations was highlighted as an important medium term aim, in particular to those groups who have not traditionally aligned themselves with the Disabled People's Movement. There were also calls for a renewed focus on disabled people living in institutions or residential care.

## 4. Future Concerns

The survey confirmed many of the concerns and priorities identified in the seminar discussions. The difficulty of implementing social model based independent living services within a context of precious funding was highlighted, as was the tension between professionalism and a political commitment to the social model.

The surveys reflect the tension acknowledged in the seminars of reconciling the principles and ideals of the social model with the reality of operating within an environment that limited the campaigning role of organisations.

The second and third phases of the **Creating independent Futures** project will build on the themes identified in the seminars and survey responses. This will take the form of detailed in-depth analysis of nine organisations led by disabled people. This element of the research will involve:

- visits and empirical evaluations of the environments in which these organisations currently operate.
- scrutiny of relevant documents, including constitution, funding arrangements and business plans, facilities and service procedures.
- semi-structured interviews with key informants and staff. This will include members of the executive or management committee, employees, members and, where appropriate, a representative of an associate body such as a local authority or local voluntary organisation.

This will then link into the third phase which will involve a detailed analysis of this information. This will inform the construction of semi-structured interview schedule for the user-survey. Its aim is to enable users of services

provided by disabled people's organisations to articulate their experiences of these organisations, the services they provide and to contribute to their development. Approximately ninety users will be interviewed (ten from each of the nine organisations visited in phase two).

As suggested by the seminar and survey participants, key areas of concern for the second and third phases of the study centre around issues of control, reflexivity and inclusion, as well as the tensions arising from reconciling the principles and ideals of the social model and independent living with the realities of operating within a context that demands professionalism and is dominated by an agenda that does not generally privilege the experience of disabled people.

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## **APPENDIX A**

### Membership of the Research Co-ordinating Committee

Jane Campbell	Co-Director NCIL
Frances Hasler	Co-Director NCIL
Peter Beresford	Centre for Citizen Participation, Brunel University Open Services Project Shaping Our Lives
John Evans	European Network on Independent Living Hampshire CIL

### **Research Team Disability Research Unit, University of Leeds**

Colin Barnes

Geof Mercer

Hannah Morgan

## **APPENDIX B**

### **Survey Participants**

(those asterisked did not respond)

Asian People with Disabilities \*

Ayrshire Independent Living Group

Barking and Dagenham CIL Consortium

Barnet Independent Living Advisory Group

Barrow and District Disability Association

Bedfordshire & Luton Disability Resource Centre

Birmingham Independent Living Project

Brent Independent Living Scheme

Brighton & Hove Federation of Disabled People \*

Cardiff and Vale Coalition of Disabled People

Castle Morpeth Disability Association

Choice & Rights disability Coalition (Kingston Upon Hull)

Choice in Hackney

CIL de Gwynedd

Cleveland Disability Forum

Coventry CIL

Darlington Association of Disabled People \*

DASH (Hillingdon) \*

Derbyshire CIL

Design Options for A Versatile Environment (DOVE)

Direct Payments Peer Support Group - Cambridge

Disability Action North East

Disability Doncaster

Disability in Camden

Disability North \*

Disability Wales

Dumfries and Galloway Coalition of Disabled People

Durham Co-operative Development Association

East Suffolk Coalition of Disabled People

East Yorkshire Council of Disabled People

Essex Coalition of Disabled People

Fairdeal Independent Living Project

Gateshead Coalition on Disability

GLAD

Glasgow CIL  
Greater Manchester Coalition of Disabled People  
Greenwich CIL  
Hammersmith & Fulham Action for Disability \*  
Hampshire CIL  
Harrow Association of Disabled People  
Herefordshire CIL  
Independent Choices \*  
Independent Living Agency  
Kingston upon Thames Association of Disabled People  
Leeds CIL  
Leeds People First  
Leicester CIL  
Lewisham (ILSUG PA Agency)  
Living Independently in Gloucestershire  
Lothian CIL  
Merseyside Independent Living Group  
Milton Keynes Coalition of Disabled People  
Newham Independent Living Scheme \*  
Norfolk Coalition of Disabled People  
North Tyneside Coalition of Disabled People  
Nottinghamshire Coalition of Disabled People  
Oxfordshire Council of Disabled People  
Personal Assistance Employer Support Group  
Redbridge Independent Living Project  
RHC Trust (Swindon)  
Richmond Independent Living Project  
Sandwell DLC (Ideal for All)  
Scottish Personal Assistant Employers Network  
SHAD Hounslow \*  
SHAD Wandsworth \*  
Sheffield CIL Group  
Shropshire Disability Consortium  
Skills for People (Newcastle)  
South Devon Coalition of Disabled People  
South Tyneside Council of the Disabled  
Southampton CIL  
Stewartry Coalition of Disabled People

Surrey Users Network  
Sutton Alliance of Disabled People \*  
The Support Service for Independent Living  
Tower Hamlets Coalition of Disabled People \*  
UK Coalition of People Living with HIV & AIDS  
Waltham Forest Association of People with Disabilities  
Warwickshire Coalition of Disabled People  
West of England CIL (WECIL)  
Worcestershire Lifestyles  
Ynys Mon CIL  
York Coalition of Disabled People