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## 1 Executive Summary

This is the third Report on the preliminary findings of the *'Creating Independent Futures: an Evaluation of the Services led by Disabled People'* project. It details data collected from users, seventy-six individuals and nine organisations, that took part in the Third Stage of this Project.

The sample included almost equal numbers of disabled men and women, with the majority in the middle age ranges. Most people described themselves as having one or more physical impairments.

All participants had experienced a wide range of services provided by various statutory and voluntary agencies. Although there was considerable variation in people's levels of satisfaction with the services they had received, general concerns were raised about assessment procedures, reliability, flexibility, and helper/helped relations.

There was general disquiet amongst participants about the lack of information on the availability and benefits of user-led services amongst the general public and disabled people. Less than half of the people interviewed had been referred to user-led services by a statutory agency such as a social service department or health authority.

Participants had experienced a variety of services delivered by the case study organisations including information, training, counselling and voluntary work. Over half were in

receipt of direct payments for personal assistance (PA) schemes or PA support programmes of one form or another.

The interviewees were adamant that user-led organisations were far more responsive to their individual needs both in terms of what was on offer and how it was offered. The level of peer support that individuals received was a key consideration.

Participants also identified several areas for increasing the effectiveness of user-led services. These are the need for better marketing, improved environmental access, wider user participation, and greater and more secure resources both financial and human.

There was a general consensus that campaigning on disability issues was a key function of user-led organisations, although opinions differed as to what tactics should be employed.

Whilst the overwhelming majority of those interviewed were firm advocates of user-led initiatives, several concerns about their future development were expressed. These stemmed from the limited resources available, their representativeness, the role of non-disabled staff within user-led services, and relations between user-led and non-user-led services. The dangers of colonisation by non-disabled professionals were a major concern.

## 2 Introduction

This is the final report on the preliminary findings of the *Creating Independent Futures: An Evaluation of Services Led by Disabled People* Project. Copies of the Stage One Report (2000) and Stage Two Report (2001) are available from the Centre for Disability Studies and on the Project website at: [www.leeds.ac.uk/disability-studies/projects/independentfutures.htm](http://www.leeds.ac.uk/disability-studies/projects/independentfutures.htm)

The Stage One Report detailed the background to the Project and the findings of a series of consultative seminars attended by representatives of forty-eight disabled people's organisations that provide services, to identify the salient issues and concerns currently facing the movement. Additionally, it contained information from sixty-nine service providers about the organisational structure, wider networks, resources (both human and financial), activities and services, campaigning and ambitions. Data were collected via a postal survey of all known service providers controlled and run by organisations of disabled people.

The Stage Two Report elaborated on these themes by focusing on nine case study organisations, selected by the Project Steering Committee, to provide a broad overview of the concerns and issues raised by the participant organisations. Semi-structured interviews were conducted with key informants, typically the organisation's director, members of the management committee, staff (both practitioners and administrative), volunteers, members and

representatives of funding agencies. In all but one case this was a member of staff from the local authority.

Key concerns included the difficulty of implementing social-model based independent living services within a context of precarious funding. Also highlighted was the tension between professionalism and a political commitment to a social model approach to user-led services. A symbiotic though problematic relationship between disabled people's organisations and local authorities was identified as a central area of concern, as were issues of control, reflexivity and inclusion. Local authorities provided funding to 83% of user-led organisations although, in many cases, funding was also supplemented by other sources.

Stage Three of the Project is concerned with the experiences and perspectives of those disabled people who use the services provided by the designated case study organisations.

### **3 Stage Three**

Stage Three involved further visits to the nine case study organisations in the early months of 2001. These included Cardiff & Vale Coalition of Disabled People, CIL de Gwynedd, the 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), the Lothian Centre for Integrated Living

(LCIL), the Surrey Users Network (SUN) and the West of England Centre for Integrated Living (WECIL).

The Project Steering Committee was interested in user's experiences of services, both past and present. We wanted to know what participants think about these services and how they might be improved. It was also thought important to find out if there were any perceived differences between services provided by traditional service providers such as statutory agencies and those that were user-led. The issue of campaigning was a central concern raised in the first two stages of the Project. Consequently, it was important to find out if users shared the priority attached to this activity by the case study organisations. It was also valuable to understand how users viewed the future, in terms of their own experiences of services and of the organisations studied.

### **3.1 The sample**

Interviews were conducted with a range of people who use services provided by the case study organisations. The aim was to talk to people from those groups identified in the earlier stages of the Project that are under-represented within discussions of disability and disability services. This might include people with learning difficulties, mental health system users/survivors and people from minority ethnic groups.

It is important to note that the people interviewed are not a representative sample of service users. As membership

and user lists are confidential, the choice of people to interview was determined by each organisation. This meant that the way in which the organisations identified participants varied. In some, a request for volunteers was placed in the local newsletter. In others a specific mailing was sent out to everyone involved in the organisation. Additionally some of the organisations approached individual users either to supplement the number of volunteers or to try to reflect a broader picture of their user group. The recruitment of interviewees was a joint exercise between the researchers and the organisations.

In all, seventy-six interviews were conducted with individuals from eight organisations. However, the other case study site differs significantly in that it is an information provider to disability and related organisations. Therefore, in consultation with the group's administrator it was decided to target its recipient organisations. These were contacted by telephone or post and asked to complete a postal questionnaire. All groups received follow up telephone calls. This generated seven completed questionnaires. In addition, more detailed telephone interviews were conducted with two of the largest organisations. This gave a total of nine organisations in the survey.

The issue of research fatigue amongst disabled people was highlighted as an issue during this stage of the Project. This occurs where disabled people are constantly being asked for their views in all sorts of surveys, many of which have little or no impact on their lives. There was a particular

problem in recruiting respondents from one organisation that had recently been the subject of an in-depth evaluation of their direct payments scheme. It yielded only four completed interviews against a target of ten. As partial compensation, material from the evaluation of their direct payments scheme will be integrated into this Project's final report. As a general rule, every effort was made in this Project to ensure that participants did not find the research oppressive.

### **3.2 Data collection**

Respondents were asked to select their preferred method of interview, either individually, in pairs or as part of a focus group. Individual participants had the option of face to face, telephone or e-mail interviews. Interpreters and personal assistance (PA) support were provided as requested.

Most people (twenty-six) chose semi-structured interviews (either individually or in pairs), twelve interviews took place over the telephone and via email. Thirty-six people opted for focus groups at six of the studied locations.

All were assured of the confidentiality of their interviews, the transcripts only being available to the research team. The full transcript was returned to each participant for comments and revisions before these data were analysed.

Everyone involved was offered a nominal fee following the interview plus any associated expenses incurred. Several

people chose not to accept the payment and some requested that the money be donated to the host organisation.

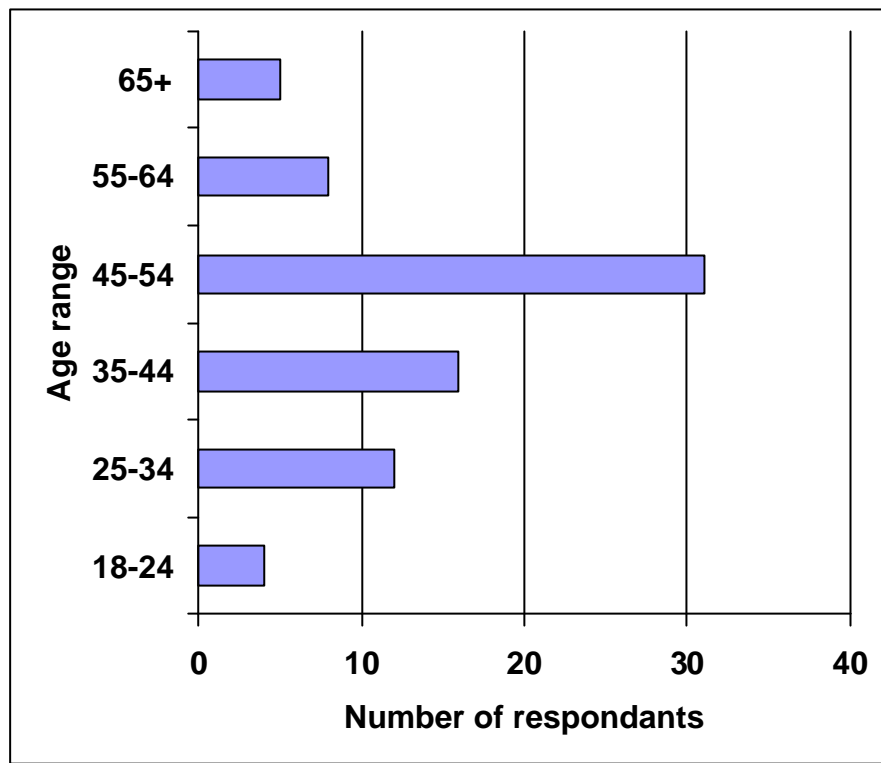
#### **4 User profile**

We asked participants to complete a number of basic biographical questions relating to their gender, age, impairment, living circumstances and ethnicity. The aim was to achieve a basic profile of those interviewed. These questions were voluntary and were processed separately from the main interview transcripts. These questions were considered important as we hoped to include the views of those sections of the disabled community who are usually said to be under represented within the context of disability research. For example people living in residential institutions or from minority ethnic groups.

The main points to note are:

- Gender: the sample comprised forty women (53%) and thirty-six men (47%).
- Age: (See Figure 1 below). Only four people (5.3%) were less than twenty-four years of age. Twelve (15.8%) were between twenty-five and thirty-four. Sixteen (21.1%) were aged thirty-five to forty-four. The largest group of thirty-one people (40.8%) fell into the forty-five to fifty-four age group. Eight people (10.5%) were between fifty-five and sixty-four, and five (6.6%) were over sixty-five years of age.

**Figure 1: Age distribution of sample**

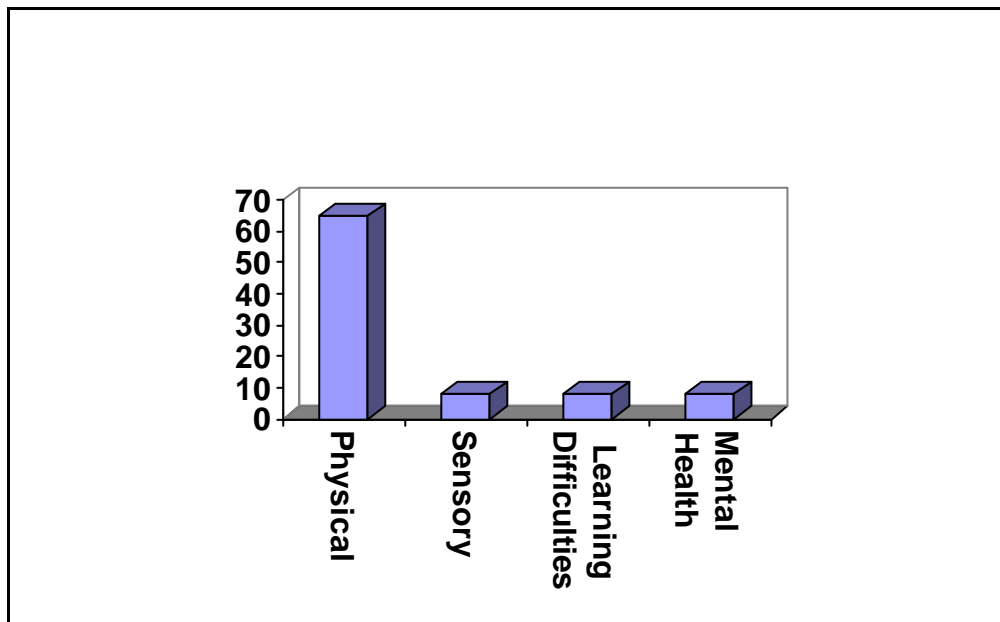


- Living circumstances: thirty-six people (46%) lived with their partner, family or friends and thirty-three (47%) lived alone. Only six (7%) of the people interviewed lived in residential homes/institutions (mainly people with learning difficulties who lived in group homes).
- Impairment: (See Figure 2 below) In order to find how far survey respondents were spread across different impairment groups, participants were asked to confirm whether their impairment(s) fell into any of the following categories: physical, sensory, mental health system users/survivors, and learning difficulties.

Sixty-five of the people interviewed described themselves as having a physical impairment. Eight each self-identified as having learning difficulties, sensory impairments, or experienced emotional distress and/or were users or survivors of the 'mental health' system. Eleven people reported that they had a combination or multiple impairments; e.g. physical and sensory conditions. Hence they are counted more than once in Figure 2.

The fact that only eleven of the seventy-six interviewees did not have a physical impairment (alone or in combination) reinforces the widespread view that user-led services are less successful in attracting disabled people outside this impairment group.

**Figure 2: Participant's Impairment**



Previous research has highlighted the low levels of representation of particular groups of disabled people involved in user-led organisations, both as providers and as users of services. Some of the reasons for this situation were discussed in the Stage Two Report (Morgan, Barnes and Mercer 2001). Therefore, the participants were asked to state their ethnic/national background.

The majority (93.3%) described themselves as White/British (English 48%, Scottish 24%, British 10.7%, Welsh 9.3% and Irish 1.3%). The remaining four respondents described themselves as either African, White European or Jewish. One person chose not to answer this question.

In summary, the sample demonstrated a fairly equal distribution of women and men. The overwhelming majority fitted into the middle age ranges (35-54 years). There was a predominance of people with physical impairments. The users with the label of 'learning difficulties' were concentrated in a few of the case study organisations. And last, there was an almost total absence of disabled people from Afro-Caribbean and Asian groups in the sample.

At this juncture we can only guess at the reasons for the failure to involve black and Asian disabled people in the study. It may be that the organisation studied had very few users from these groups, or although involved, they did not figure in the final list of participants for some reason. User-led services and disability researchers must find ways

to address this (Barnes, Mercer and Morgan 2000; Morgan, Barnes and Mercer 2001).

## **5 Previous experience of services**

All participants have experience of a wide range of services offered by a variety of providers: statutory, private and voluntary. The majority, sixty-eight, have used or were still using local authority social service departments. These included: the allocation of a social worker and/or case manager, home adaptations, home helps, and day centre placements. These services were delivered by several different divisions/departments within local authorities. These ranged from those for 'physical and sensory disabilities', 'mental health', 'learning disabilities' and 'community care'.

Several participants used services provided by health authorities, large charities, local voluntary organisations and private care agencies. Health authorities provided in-patient 'care', occupational therapy and physiotherapy services. Residential home and day centre facilities were offered by the larger established charities such as MENCAP and the Leonard Cheshire Foundation. People used information, peer support and advocacy services provided by local voluntary organisations, and private 'care' agencies delivered 'home help' and 'carer' type services. Some participants were also receiving funding from the Independent Living Fund for personal assistance packages.

There was considerable variation in people's levels of satisfaction with the services they had received.

## **5.1 The assessment process**

Despite a growing rhetoric of 'needs-led' assessment and service provision, many users felt that financial considerations rather than the level of support they required determined their 'care' packages.

Professionals mostly led assessments and participants felt that their own input rarely had any meaningful impact on the outcome. Many thought that traditional service providers were not really interested in their opinions or in providing a more holistic service tailored to the individual. Instead, service users argued that they felt like they were simply one person on a long list of people being supported from limited resources.

Linked to this was the frustration expressed by many of the interviewees about the limitations of the actual support they received. This included the type of services they were entitled to, what these services actually covered and the number of hours or days of support allowed.

There was frequent mention of the restrictions on what home helps are supposed to do. Many of those interviewed referred to the difficulties that this posed, particularly in relation to lifting and handling as well as specific domestic tasks such as washing up and putting things away. However,

others reported that some helpers carried out tasks that they were not supposed to do, but this was put down to the character of individual personal assistants.

## **5.2 Reliability and flexibility**

Reliability or lack of it was a common complaint amongst participants with experience of traditional service providers. Again home help services, including agency staff and those working as volunteers, came in for particular criticism. Several people talked about the frustration of not knowing when or sometimes even whether their 'carer' would turn up. If service providers were short-staffed individuals were liable to be kept waiting for long periods of time.

The lack of flexibility amongst professionally controlled service providers was also a frequent source of irritation. The timing of 'care' was usually determined by service agencies. This was a particular problem for people whose health condition can vary from day to day as the level of support needed varied accordingly. Examples include people with multiple sclerosis or people experiencing severe emotional distress. Participants suggested that there was little flexibility within conventional forms of provision to accommodate such support needs.

## **5.3 Helper/helped relations**

Another frequently raised issue was the participant's relationship with helpers. Because of the relatively high

levels of staff turnover within organisations providing support for disabled people, good helper/helped relations are often difficult to establish and maintain. Having a different home help or 'carer' come into their home on a regular basis was a major cause for concern. Indeed, the indignity of having different people unfamiliar with their particular needs undertaking intimate and potentially embarrassing personal tasks such as toileting, for example, was especially upsetting for some participants.

The quality of 'care' received often depended on the integrity of individual workers. Some people considered themselves 'very lucky' to have a 'good' social worker or home help. However, it was very evident that participants resented the fact that the quality of support available was such a lottery.

Respondents also felt that their opinions and priorities were not taken seriously by conventional service agencies, and that they were expected to be grateful for any services they received. Moreover, several people commented on their lack of control over the services provided by professionally-led statutory and voluntary service agencies.

Another issue for disabled people was that they felt they had to be constantly on their guard to ensure that they received an appropriate level of support. This was deemed an unnecessary and unacceptable drain on personal resources.

#### **5.4 Complaining**

The organisation and bureaucracy of conventional services means that complaining is often very difficult. The people in this study felt that complaints were rarely dealt with satisfactorily. Where people had complained little was resolved. Participants felt that making a complaint often led to them being labelled as a 'trouble maker', or their complaint was too quickly dismissed as unreasonable.

## **6 User-led services used**

The Project Steering Committee were keen to know how participants had found out about the organisation, which services they were using, what they thought about these services, and whether they felt any improvements could be made.

### **6.1 How users accessed user-led services**

As Figure 3 illustrates, thirty-three people had been referred to user-led organisations by a statutory service provider such as social services or the local health authority. These referrals were predominately made by social workers, and where this was the case, they proved higher in those organisations with close links with the local authority or who provided direct payments support services. This was especially evident for the more recently established user-led organisations. There was a clear correlation between referral by a social worker and use of direct payment related services.

Where there were lower levels of referrals from social services this appears to be the result of a lack of awareness rather than an unwillingness to support user-led organisations.

**Figure 3: Means of accessing services**

<i>Type of access</i>	<i>Number of users (total = 76)</i>
Referral by professionals	33
Word of mouth	19
Contact by the organisation	15
Referral by other impairment/disability organisation	4
Self referral	3
Unknown	2

However, there was no evidence of an automatic referral at the point of diagnosis to disabled people's organisations whether by medical or other health 'care' professionals. A number of users who had acquired an impairment when adults talked about the failure of health service professionals to provide information about disability and user-led organisations. This left them feeling isolated and unsure of their future.

Fifteen of the seventy-six individuals interviewed had been contacted directly by the case study organisation either by

telephone, through an outreach/development worker or received a publicity leaflet.

At the older, more established organisations the nature of referrals was more mixed. A few users had been involved from the outset helping develop user friendly services because they were unavailable elsewhere. Examples included; information services, peer support and training schemes. One individual had been involved with the oldest organisation since its inception over twenty years ago. However, almost half of the people interviewed had been using user-led services for less than two years. Needless to say the length of involvement in newer organisations spanned much shorter periods of time.

Larger established organisations generally had more users who had heard about their services from other disabled people, family and friends. Several people commented that they had only heard about the organisation by 'chance' or 'luck'. Surprisingly, only four of the participants had become aware of the services offered by user-led organisations through their involvement with other impairment/disability groups.

Indeed, there was general disquiet amongst *all* participants about the lack of information on the benefits of user-led services, and of the organisations offering them - both amongst the general public and disabled people.

Participants had experience of a range of services provided by the case study organisations. However, none of the

sample had used advocacy services although these are provided by several of the case study organisations (see Figure 4 below).

## 6.2 Services used

Over half (thirty-nine) of those interviewed received direct payments via the case study organisations. Thirty-eight (50%) used direct payment/personal assistant (PA) employer support services. Not everyone used both services in those organisations where they were each offered (Morgan, Barnes and Mercer 2001).

**Figure 4: Services used**

<i>Services</i>	<i>Number of users</i>
Direct Payments	39
Direct Payments/PA employers support services	38
Information	37
Training	31
Counselling	12
Volunteers	11

Long-term users tended to use direct payments but not necessarily the support service, other than as trainers, or to offer peer support. Some people accessed direct payments from other agencies but attended PA employers support groups run by the case study organisation.

Others used support services in order to prepare the way for employing PAs. Almost everyone interviewed felt that this was a particularly important service as the majority of disabled people have no experience as employers and therefore were often reluctant to access direct payments to employ PAs.

### **6.3 Information**

Thirty-seven of the respondents (49%) had accessed information services. This included information provided face-to-face, over the telephone and via the internet. The type of information supplied ranged from welfare rights to accessible holidays.

However, it is very likely that the overwhelming majority of those interviewed actually had access to information from their organisation. For instance, most of the groups studied produced some form of newsletter or periodical for circulation to members.

### **6.4 Training**

Training was offered at the majority of case study organisations and had been used by twenty-nine (38%) of the interview participants. Examples of the sort of training received included training as Disability Equality Trainers, computer skills, art and drama, practical independent living skills as well as training towards competency in fields such as counselling and advocacy. Those who were involved in the

running of the organisation, either as members or as volunteers also received relevant training.

## **6.5 Counselling**

Twelve people were involved in counselling programmes; either as trainee counsellors or as users of the counselling services. These services were considered especially important by participants who argued that there was an urgent need for the expansion and marketing of these services particularly for people who have recently acquired an impairment and become disabled.

## **6.6 Voluntary work**

The role of volunteers was central at all the case study organisations. Thirty-four of the people interviewed were both users and members. Twelve were also volunteers. At all of the organisations the involvement of users in the management board and the planning and delivering services was actively encouraged. Examples included, covering reception, working on the information service, and clerical and administrative duties. These activities were thought to enhance both self-esteem and self-confidence, while some participants considered that their involvement helped them prepare for paid employment.

## **7 Perceptions of user-led services**

Comments from the participants cannot be regarded as a comprehensive evaluation of the services provided by the case study organisations. Nonetheless, this section highlights a number of common themes.

## **7.1 Choice and Control**

In comparing professional/provider-led and user-led services two key themes emerged: choice and control. All participants were quite adamant that user-led organisations were far more responsive to their needs both in terms of what was on offer and how it was offered. They felt that they had a greater choice of services and, equally important, more control over how they were delivered. This is almost certainly due to the fact that the majority of interviewees were involved in some way with direct payments programmes.

## **7.2 Peer support**

However, it is more than simply the type of services available that makes the case study organisations different. Because all the organisations studied were user-led and actively encouraged user involvement, all the participants considered them to be far more aware of the problems faced by disabled people and, consequently, more responsive to individual need.

The peer support that individual service users received from other disabled people was a key consideration. Having the opportunity to meet other disabled people either

formally (e.g. PA Employers support groups) or informally (e.g. general meetings, social occasions, drop-in) was regarded as of immense benefit by the overwhelming majority. Peer support helps to address the isolation many disabled people experienced particularly in the period after the onset of impairment and/or becoming disabled.

However, whilst many people were relieved at finding an organisation of disabled people providing services and support, they identified a number of areas that they felt could be improved.

### **7.3 Marketing**

Many participants were concerned about the lack of information generally available about user-led services. Most people suggested that there must be an improvement in the ways that user-led organisations are marketed and promoted.

### **7.4 Access**

Linked to this was the difficulty of covering a large geographical area, particularly given the poor provision of accessible transport nationally. Several of the case study organisations covered large areas, much of it rural. Hence some people experienced difficulties in accessing services. A few organisations have tried to address this problem by developing telephone and computer based options as well as operating from several locations. However, as the Stage

Two Report argued, such activities are severely restricted by limited funds.

The lack of accessibility of some of the buildings used by organisations was a further issue. Comments related to the geographical location, inaccessible public transport, the type of building and in some instances, physical access once inside. However, people were also aware that those responsible for the development of user-led services often had relatively little control over these matters.

## **7.5 Wider involvement**

All the participants were aware that user-led services tend to be used by particular groups of disabled people and that others are conspicuous by their absence, such as people from minority ethnic groups. However, the interviewees did not feel that the organisations were slanted deliberately towards particular impairments or sections of the disabled community to the exclusion of others.

Several people mentioned the positive action being taken by some organisations to address this problem, whilst generally acknowledging the difficulties: economic, political and social, under which many user-led organisations are currently working. There was a widespread view that much more community development work needed to be done to resolve this problem.

## **7.6 Effectiveness**

Several individuals were critical of the efficiency of the case study organisations. These criticisms were mainly related to administrative issues and the difficulties of employing a large proportion of disabled people. Staff turnover in some organisations was thought relatively high and difficulties relating sick leave coverage was highlighted.

Some people linked these problems to the innovatory nature of the services offered, although there were concerns that these problems might be exploited by those arguing the case against user-led provision.

## **7.7 Insecurity**

Most of the people we talked to were very aware of the precarious nature of their organisation's funding. This was particularly true of services that were funded by short-term monies such as lottery grants for example. Some participants felt that user-led services were under funded when compared to those led by professionals. Everyone was very aware of the problems that this created in terms of continuity of services and staff retention.

## **8 Campaigning**

It was clear during earlier stages of this Project that the disabled people's movement views campaigning as a key activity. Though its nature and scope varied, all the case study organisations were involved in campaigning in one way or another (Morgan, Barnes and Mercer 2001).

All participants were aware of their respective organisation's campaigning activities. However, there were differing views on the preferred campaigning role of user-led service providers. Some wanted their organisation to be more proactive in disability campaigning, others were happy with their organisation's current level of involvement, and some people believed that organisations should concentrate on service provision and not get involved in politics of any kind.

Several people had been actively involved in campaigning and were positive about that involvement. A significant number had also participated in campaigns organised by other disability organisations. For this group, campaigning was integral to the further development of user-led activities.

Nonetheless, views on the tactics employed varied considerably. The vast majority of interviewees were very supportive of their organisation's involvement in conventional lobbying and holding regular discussions with local councils, social services management committees and similar bodies. A smaller group favoured more direct political action on disability issues and had taken part in public demonstrations.

A minority was vehemently opposed to direct action. Some felt that it was demeaning and that it would antagonise public opinion and erode their support. Indeed, some argued that user-led service providers should take no part in political campaigns of any kind. They maintained that such organisations were already over-stretched and that

campaigning undermined their ability to provide effective disability services.

There was also some apprehension that involvement in campaigning might create difficulties in the relationships with local authorities and other funders, and, as a consequence, put the future development of user-led services in jeopardy. This was thought a risk not worth taking.

## **9 Future concerns**

Stages One and Two of this Project demonstrated that those involved in the development and running of user-led services had several major concerns regarding the future of user-led initiatives. These were also reflected in the discussions with those who actually used those services. Indeed, all the participants expressed anxieties about the limited resources available to disability services generally and user-led services in particular.

This generated disquiet about the future of user-led services. The overwhelming majority of those interviewed said that it was vitally important that disabled people should be involved, at every level, in the development of services for disabled people. There was a general consensus that disabled people 'know best' about what disabled people want because it is rooted in personal experience.

People also felt that those involved in the development of services should represent a range of impairments and that

no one group should be over represented. When asked, no one expressed a preference for impairment-specific organisations.

It was felt to be an empowering experience to have disabled people at all levels of the organisation. It presented a direct contrast with other agencies that were dominated by non-disabled professionals.

However whilst participants were strident advocates of user-led services they were very aware of their limitations and the need for continued development. This raised a number of points relating to the role of non-disabled people in user-led services, and links with statutory and other professionally-led providers.

There was a division of opinion whether the experience of disability alone was insufficient to equip disabled people and their organisations with the knowledge and skills necessary to develop and run the increasingly complex array of services needed.

Some people felt that it was very important for user-led services to be run and controlled exclusively by disabled people. For this group everyone involved should have personally experienced disability. Others maintained that non-disabled people should only be involved where they provide expertise and support that otherwise would not be available. This was also identified as a reason for training more disabled people to participate in user-led organisations.

Conversely, several people felt that it was very important that user-led organisations should not become 'disability ghettos' and thus reproduce the type of segregation so evident elsewhere in society. This argument centred on the claim that if the aim of user-led services is to promote integrated or inclusive living then it is important that disabled people's organisations are inclusive of everyone and not just of disabled people.

Participants also presented contrasting views on the relationship between user-led services and other forms of provision. Some people argued strongly that CILs and other user-led initiatives should be independent of other agencies and service providers. They were fearful of the tendency for non-disabled professionals to take over or 'colonise' disabled people's initiatives, and also that their presence would deter other disabled people from becoming involved.

However, others acknowledged that the majority of user-led services are dependent to varying degrees on the support of statutory agencies such as local authority social service departments or health authorities. This could take the form of core funding, service level agreements or grants. Indeed it was felt that local authority funding was the lesser of two evils, the main alternative being charitable status.

Several participants argued positively for close links with statutory agencies. Their reasoning was that user-led services had much to gain from sharing information, support

and so on. Participants were nevertheless very aware of the tensions that can arise when user-led initiatives become too close to local authorities. This viewpoint was especially prevalent amongst those involved in organisations that had suffered from, or were threatened with, funding cuts.

In spite of these differences, all the participants were convinced that CILs and other user-led initiatives should be provided with the appropriate resources to initiate and develop services for disabled people and their families. Where people had experience of other forms of user involvement initiated and led by service professionals, these were dismissed as tokenistic rather than meaningful attempts to develop the type of services required by disabled people.

## **10 Future activities**

The draft findings from the whole Project, covering Stages One to Three, will be discussed with users and staff in the nine case study organisations in the final stage of the research.

The Project will culminate with a conference for disabled people from user-led organisations in December, 2001 (the full details are yet to be confirmed but can be obtained from Hannah Morgan).

The final Report will then be compiled and produced along with policy recommendations in early 2002.

## References

Barnes, Mercer & Morgan (2000) *Creating Independent Futures: An Evaluation of Services Led by Disabled People Stage One Report*, Leeds, The Disability Press

Barnes, Morgan & Mercer (2001) *Creating Independent Futures: An Evaluation of Services Led by Disabled People Stage Two Report*, Leeds, The Disability Press