Creating Independent Futures

An Evaluation of Services Led by Disabled People

NCIL BCODP CDS

Stage Two Report

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1/ EXECUTIVE SUMMARY

This report provides a broad overview of preliminary findings from the second stage of the '*Creating Independent Lives*', an evaluation of services led by disabled people' project. This is a two-year study hosted by the British Council of Disabled People's (BCODP) National Centre for Independent Living (NCIL) in London, and conducted by researchers from the Centre for Disability Studies (CDS) at the University of Leeds.

The research shows that whilst user-led services are more than twenty years old, their development is seriously inhibited by several factors: economic, political and social. It is also the case that rather than ease the present situation recent policy developments may make matters worse.

- User-led services clustered around independent living take a variety of forms and date back to the early 1980s. Although disabled people themselves set up several of the organizations studied, others were developed jointly by disabled people and local authority staff. There is a symbiotic but sometimes uneasy relationship between user-led organizations and sponsoring agencies.
- All the organizations studied claim to adhere to a social model approach to disability. However, there are notable differences in interpretation as to what

the social model actually means. This has important implications for the further development of user-led services.

- All the organizations studied have a management structure in which the majority is disabled people. However, there was a notable lack of involvement from particular sections of the disabled community. Some organizations tried to address this problem through enhanced training programmes and establishing links with other agencies.
- All participant organizations strive to be democratic in structure and accountable to disabled people but user involvement is often quite patchy. There was a general recognition of this issue and that more marketing and development work is needed to address this particular problem.
- Funding is a major problem for all the organizations studied: it is invariably short term in nature and in the overwhelming majority of cases limited to particular services. This has important implications in terms of premises, staffing, and what services are provided.
- A limited range of independent living services are being offered by user-led organizations. However, their continuity and further development is under serious threat from current funding strategies.

Competition from non-user-led organizations has intensified considerably over recent years.

- The growing emphasis on formal and bureaucratic procedures by funding agencies has important resource implications for user-led organizations. All the organizations studied engaged in monitoring procedures, the value of which was not always evident.
- All the organizations studied were engaged in campaigning on disability issues but it is important to stress that these activities take a variety of forms. Everyone was also aware that such activity could jeopardise relations with funding agencies but considered them integral to their future development.
- All participants were concerned about the future of user-led services. There was general agreement that there is an urgent need for a comprehensive reappraisal of current policies on resource allocation, at both the national and local levels, if user-led services are to be maintained, let alone continue to develop.
- All the above needs to be located within recent Government proposals that bring together medical and social provision as 'care trusts'. This is mainly because, hitherto, health authorities and medical professionals have shown little or no understanding

of the implications of the social model of disability and independent living, and provided relatively little support for user-led initiatives.

2/ INTRODUCTION

This report provides a preliminary analysis of some of the key issues emerging from the *second stage* of the 'Creating Independent Futures' project. The research initiated by the British Council of Disabled was People's research committee and developed in conjunction with the BCODP National Centre for Independent Living. The project began on 1st January 2000. It is coordinated by a research advisory group comprising: members of the NCIL (Jane Campbell and Frances Hasler) a representative of the BCODP independent living committee, (John Evans), researchers from the Centre for Disability Studies (CDS) (formerly known as the Disability Research Unit) at the University of Leeds (Colin Barnes, Geof Mercer and Hannah Morgan), and an independent research (Peter Beresford of the consultant Centre for Citizenship Participation at Brunel University).

The central aim of the project is to provide a critical evaluation of services led by disabled people.

The research has four distinct but related stages:

1. establishing the boundaries and criteria for research;

- 2. in-depth studies of selected user-led organizations;
- 3. interviews with service users in the sites identified; and
- 4. dissemination.

Stage One comprised an extensive literature review, and focus four seminars group discussions with representatives of user-led groups. The main issues identified were explored in a national survey of all user-led organizations identified by NCIL as providing 'independent living' type services to disabled people and their families. This addressed several general organization, including: wider concerns networks, resources, activities and services, campaigning and ambitions for the future. A preliminary report of key findings from Stage One was produced and circulated to all participant organizations [Barnes, Mercer & Morgan 2000].

3/ STAGE TWO

Of the sixty-nine organizations that completed the Stage One survey, the research advisory group selected nine for inclusion in Stage Two. Notably, all the organizations agreed to participate in this in-depth review.

a/ The sample

Selection was based on several criteria including: year size of membership, of establishment and user numbers, geographic location, and the range of services offered. To ensure that the project provides a meaningful insight into the main issues associated with the development of user-led provision, it is important to examine more established organizations as well as those that have emerged over the last ten years. It was considered equally important to include relatively large agencies that employ several staff and provide a variety of services, alongside smaller operations with perhaps only one or two members of staff that offer only a limited number of services. It was also important the sample reflected the work of user-led organizations in different locations and contexts, both rural and urban, across the whole of Great Britain.

The final list of nine organizations selected for inclusion: were Cardiff and Vale Coalition of Disabled People, CIL de Gwynedd, Centre for Endependent Living in Glasgow (CILiG), Derbyshire Coalition for Enclusive Living (DCIL), Disability Action North East (DANE), Greenwich Association of Disabled People's Centre for Endependent Living (GAD), Lothian Centre for Endependent Living (LCIL), the Surrey Users Network (SUN), and the West of England Centre for Enclusive Living (WECIL).

very different 'answers' These represent to developing independent living services. Cardiff and Vale has developed various independent living Coalition alongside campaigning activities since its services inception in 1994. Currently it has four staff. Set up in 1999 with funding from the European Union's social fund and the local authority, CLL de Gwynedd has only one full-time and four part-time members of staff and is currently developing provision across a large, mainly rural, area of Wales. Glasgow's CIL emerged in 1995, initially to develop personal assistance (PA) services for disabled individuals across the city. Its service provision has since expanded and it now employs ten people.

Formally established in 1985 DCIL is one of Britain's oldest and most influential CLLs. It employs 22 staff in three locations across Derbyshire and provides of range of services including; information, peer support and a direct payments scheme. DANE was set up by disabled activists in 1992 and now employees two full time staff members. Its primary function is to provide information on a wide range of activities associated Formed disability rights. 1976 with in as an for disabled people, the organization Greenwich Association of Disabled People became a user-led organization in the early 1980s. It has eight paid staff and provides a range of services in a busy cosmopolitan area of south London.

Lothian CIL was established in 1991 to accommodate the independent living needs of disabled people in Edinburgh and the Lothian region of Scotland. With ten staff it delivers a variety of services including PA support, information and counselling. SUN acts as an intermediary between users of social services and service providers in Surrey and employs five staff. Since 1997 SUN has provided information and support to service users, their families and organizations throughout the county. WECIL is situated in Bristol, and began operating in 1995. Today it employs over 30 people and provides a range of services in Bristol and the former Avon metropolitan area.

b/ Data collection: the interviews

Data collection was by means of semi-structured interviews with various people involved at different levels in the development, organization and delivery of services. These comprised thirty-two individual and ten group interviews. The latter included people who would normally work together and/or are members of service teams or management committees.

Interviews were completed with thirty women and twenty-six These included members of the men. controlling council or executive committee. body, directors executive officers, and core service clerical and reception staff, voluntary managers, workers and representatives of key funding bodies such as local authority social service departments.

The interview schedules were based around the key themes identified in Stage One: organizational and structure. networks associations, resources, services, campaigning and ambitions for the future. discussions were structured The around the organization's responses to the survey questionnaire and focused on emergent issues and concerns such as their interpretation of the social model and its relevance to the organization's structure and development, accountability, finance and employment policies, service monitoring and evaluation, campaigning and future development.

The forty-two interviews lasted between one hour and two and half-hours in length. Each of the conversations recorded and transcribed in full. The was transcriptions were then returned to the interviewees for verification along with a request to add or detract anything that might substantiate or misrepresent their responses. All original these amendments were recorded and the resulting data then analysed to establish central themes and concerns.

However, because of the volume of the data collected and the deliberate summary character of this report, what follows is a broad overview of the concerns and issues raised by participants: people currently engaged in the complex and difficult process of *creating independent futures* for disabled people and their families.

4/ CASE STUDIES

a/ Origins and Development

Although there is little doubt that disabled people were involved in the development of the organizations studied, in some cases it was not always clear who was the driving force: disabled people's organizations, individual disabled people or disabled local authority staff.

The period in which the organizations emerged played a significant role in their subsequent development. The early CLLs were influenced by the independent living movement in the US. Their development tended to be the result of a process of negotiation. These long periods of gestation reflects the groundbreaking work being undertaken; not only was the social model in its infancy but also there was little practical experience of disabled people running their own services at such a scale anywhere in the UK. The newer CLLs, particularly established in the 1990s, recognise those the inspiration and influence provided by the founders of Many of the CLLs British CIL movement. the undertook 'fact finding' trips and worked closely with more established CIL learning these lessons and adopting best practice. Indeed as they have developed emergent organizations have these undertaken а similar role for fledgling organizations.

With the exception of one organization, all the case studies sought to work in partnership with the local authority in order to gain funding and support for their move into service provision. The nature of this partnership varied, some adopted a more official relationship where local authority representatives were clearly involved in the setting up of the organization, whereas at other locations the process was less formal, for example a number of the organizations evolved wholly campaigning from being а and support organization to taking on the role of service provider.

It was clear at the case study sites that individuals had played an important role in their development. In a number of the organizations it was possible to identify a small number of key activists who were central to pushing forward a social model agenda. Often there was an overlap with local authority staff who were involved in organizations of disabled people and who promoted the user-led services agenda within the statutory agencies. The interviews further illustrated the importance of allies at the senior management and strategic planning level of the local authority in order commitment to to secure а supporting user-led services.

b/ Adopting a social model approach

Discussions during Stage One of the project suggested that disabled people's organizations favoured a broad interpretation of the social model with room for local diversity and priorities. Although there was general agreement amongst the participants that the social model was the basis upon which they and all user-led service providers should operate, there were differences in its interpretation and application at the different case study locations.

Some participants noted that while their organization had a clear commitment to the social model, the exact understanding of the model varied amongst individual staff and members. It was also acknowledged that the social model often meant little to service users who were not active in the disabled people's movement.

A key goal was to translate this broad theoretical model into practical policies, although some did this more explicitly than others. For several of the organizations this was by aspiring to meet the seven needs of disabled people as defined by DCIL in the early 1980s. Others utilised formal planning processes to flesh out their understanding of the social model into more detailed objectives with the social model as their point of reference.

There was considerable discussion in the organizations surveyed about the challenges presented by adopting a social approach within a service-provision context; it tends to be seen as a process rather than an all or nothing affair. Participants were very aware of the difficulties of relying on funders for whom commitment to such an approach is not necessarily paramount.

Though the representatives of the funding agencies interviewed expressed a commitment in principle to the social model many acknowledged that this was often a formal commitment at a policy or political level rather than being embedded within practice. Furthermore, local authority staff recognised that the nature of statutory agency structure and procedure meant that both services and users were compartmentalised into rigid boxes, such as the division between adult, children and elderly services and between 'physical and sensory disabilities', 'learning disabilities', and 'mental health', and that this has obvious implications for the type and scope of services offered.

Thus, seeking to balance a philosophical or ideological commitment to the social model of disability with the day to day realities of service provision produces a tension for user-led organizations. Furthermore, while the broad interpretation of the model favoured gives organizations greater scope to reflect local diversity and priorities, this broadness also allows for confusion and misinterpretation both by user-led organizations and statutory agencies. As the following section of the report makes clear it is these tensions that dominate the agendas of the case study organizations.

c/ Organizational structures and accountability

All the organizations sampled adhered to democratic principles. It was critically important to all of the organizations visited that they were controlled and run by disabled people. Their organizational structures reflected this: accountability was considered a major priority. They all have an executive committee that has overall control of the organization, whether called Board of Directors, Trustees or а Management make-up of the Committee. The management committee varied at each organization (see Table A below), although all required that a majority of the members should be disabled people.

Table A: Minimum percentage of disabled people on the management committee

Cardiff & Vale	100%
DANE	100%
DCIL	51%
Glasgow	75%
GAD-CIL	100%
Gwynedd	90%
LCIL	100%
SUN	100% (service users)
WECIL	100%

(nb. information provided by organizations in stage one survey)

All of the management committees are elected by the membership although a number have the power to coopt 'useful' individuals or non-disabled people if they wish. Most committee members were individuals members of the organization concerned although a minority represented other disabled people's groups or authority. In general local the the management monthly and meet committees' in most of the organizations had sub-committees that focused on specific areas such as finance, personnel, policy and campaigning.

Sometimes concern was expressed about the numeric dominance in the formal organizational structures of 'activists' who had a long history of involvement in disability campaigns rather than service users or newer members. However, it was acknowledged that this is gradually changing. In addition there was an underrepresentation of certain groups within user-led provision, particularly disabled people from minority ethnic groups, people with learning difficulties and psychiatric system survivors. There was a recognition that members require support and training to undertake management role and a number of the their own either provided in-house organizations training or were linked into to training provided by other voluntary organizations.

All the case studies started as, or have become, companies limited by guarantee, although some also hold charitable status. This means that more legalistic

memoranda and articles have superseded many of the constitutions written when the organizations were founded. Consequently, in several cases, principles and philosophy tend to be contained within a more general mission statement. The role of both the constitution and mission statement varied between organizations. In some the constitution (or memorandum of articles) was taken up with procedural detail, which had little day-to-day impact. Others contained more explicit statements of intent.

d/ Participation

Some concern was expressed about the levels of participation within the case study organizations amongst members and disabled people generally. Ιt was widely felt that only a small minority of the membership could be classed as active. This provoked representativeness questions about the of the organizations and the decisions they make. It was recognised that members need active support to participate and that many of the organizations lacked the resources, predominantly financial, to do this. In addition, concerns were raised about the levels of membership in relation to the size of the local disabled population, for example in one location there were around 35,000 disabled people and yet the case study organization had less than 100 members.

It was accepted that there is not a tradition of participation amongst the population generally and

therefore the seemingly low level of disabled people's participation was a reflection of this rather than a level of apathy particular to disabled people. One illustration is that lack of accessible information and information in accessible formats There was an agreed need for extensive development work to mobilise support across the local disabled population.

e/ Resources

i. Premises

Finding and securing suitable accommodation had been a key issue for all the organizations visited. The availability of appropriate offices was a common difficulty; therefore the choice of premises tends to be a compromise of accessibility and affordability. accommodation affordable was often Thus, in unsuitable locations, such as former day centres or on the outskirts of towns with poor public transport links. These decisions have an obvious impact on the nature and scope of services offered.

All organizations believed it was desirable to have a physical distance between themselves and statutory agencies such as hospitals local social services departments and day centres. However, in many cases the high costs of office space precluded a complete separation. A number of the case study sites are housed in former social service buildings and have local authority services in adjacent buildings. The expense of premises was widely cited as a considerable constraint on the development of the organizations. For example, in one location the exorbitant cost of office space was a major factor in the organizations decision not to push for a large-scale centre.

A number of the organizations share premises with other groups in the voluntary sector. This was seen as advantageous as it provided a link into the local network of voluntary groups who provide support and additional information or services. However, there was an issue about which other groups were housed in the same building, for example the close proximity of carer's groups often caused clashed with the goals of user-led organizations.

In addition the actual building itself can cause problems, for example one organization has offices in a converted church which some users are unhappy about visiting and another centre is located in an area that people from minority ethnic groups feel uncomfortable in and this impacts on the take up of their services by Black and Asian disabled people.

Several of the organisations operate satellite offices in addition to their main bases, however these offices are usually the first casualties of funding cuts and since we visited it last summer one organization has been forced by financial constraints to close one of its premises.

In contrast several organizations also offered services based, such as that are not centre telephone information services, home visits for advocacy or direct payment support, and the use of a variety of different locations for consultation and other meetings. One organization maintains only a small administrative base and operates a more peripatetic service, which rotates around accessible venues throughout the county.

ii Funding

Funding is a major problem for all the case study organizations. All the organizations taking part in this study relied on short term funding; in most cases from a variety of sources. Funding was not secured for periods longer than three years at any of the organizations, and in one case core funding has less than one year to run with no follow-on funding as yet secured.

All bar one of the organizations have local authority funding (either directly through grants or service level agreements or more indirectly via service income e.g. from direct payment support schemes) as their main source of funding. This had a number of implications including an influence on the nature and scope of the services offered, particularly those activities classed as 'campaigning' (see later section). Furthermore, Local Authority funding tended to be specific department or budget, generally from a disabilities' which limited the range of 'physical services offered to disabled people deemed to be the responsibility of other departments, for example learning difficulties or mental health. Additionally targeting under-represented funding for and traditionally excluded groups was seen to be the remit of Equal Opportunity teams or departments.

Table B Major Sources of Funding over the last three years

li ce yeurs								
	local authority	health authority	central government	lottery grants	European funding	charities	membership fees	service income
Cardiff	\checkmark							
DCIL	✓	\checkmark		\checkmark		\checkmark	\checkmark	\checkmark
DANE				\checkmark				
Glasgow	✓		\checkmark				\checkmark	\checkmark
GAD	\checkmark			\checkmark	\checkmark		\checkmark	✓
Gwynedd	\checkmark		\checkmark		\checkmark			\checkmark
Lothian	\checkmark		\checkmark	\checkmark		\checkmark	\checkmark	✓
SUN	\checkmark			\checkmark				✓
WECIL	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	\checkmark	\checkmark

(nb. information provided by organizations in stage one survey)

The nature of the funding relationship with statutory agencies varied amongst the participants: some had formal relatively secure three year rolling service level agreements while other organizations' funding was not subject to any kind of contract or agreement. There has been a gradual shift from grants to service level agreements or contracts which are more likely to last for three years. Many of the organizations welcomed formal contracts as they provided greater clarity of what was expected from both parties and more scope for longer-term planning. However, concerns were expressed about the larger amount of bureaucracy such agreements required. It was also suggested that entering into formal contracts resulted in a loss of and less scope for creativity and independence reflexivity.

Charging for services is a dilemma for many of the organizations, particularly those with large portfolios of services provided directly to individual disabled people such as advocacy or direct payments support. There was a general consensus against charging individuals for services although there was also an acceptance of its inevitability.

The majority of the organizations visited had developed policies on 'from whom' and 'on what conditions' they would accept funding. Many had clearly defined limits on what were deemed unacceptable sources of funding, for example some

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forms of charitable money. One of the case study organizations has recently employed a professional fund-raising consultant although this has had limited 'success' to date. Overall there was a constant tension between reconciling principles with the reality of achieving necessary funding.

Obviously the nature and amount of the funding received has a huge impact on both day to day operations and on longer term planning. All of the funding received by the case study organizations is time limited and its inadequate and insecure nature is a source of concern. Uncertainty over funding means a lack of security for employees and service users and the constant need to seek out and apply for new funding diverts a lot of time and energy. Organizations were clear that a wider funding base ensured greater self-determination this security and but also represented a more complex set of relationships with a variety of funding organizations.

iii. Staffing

structure, funding aims The and ethos of the organization all played an important part in determining the levels and nature of staffing levels and policies. All the organizations had full time paid employees and a total of 68 full time and 37 part time staff were employed by the study organizations case (nb. information provided by stage one survey). The number of (paid) employees ranges from two full time member of staff to thirty-two full time and five parttime employees at one of the largest CILs. Staff are employed in a wide range of positions with duties ranging from the day to day management and running of the organization through administrative and financial support to practitioners such as advocates or counsellors.

Four of the organizations had a formal policy to employ only disabled people, while other groups employ nondisabled people in certain positions, for example nonfrontline or administrative positions, or operated an equal opportunities policy that privileges the 'personal experience of disability'. Three organizations employ a non-disabled director or manager.

A number of the concerns raised during Stage One of the project were elaborated upon when discussing the practicalities of promoting and supporting the employment of disabled people within user-controlled with interviewees. organizations Directors and Managers in particular highlighted the conflict they face in balancing operating in competitive а marketplace with obtaining the resources necessary to support disabled employees. It was suggested that there was an over-reliance on agencies like PACT to gain funding to pay personal assistants or purchase specialised equipment.

Some of the organizations also experience difficulties finding adequate and trained staff to cover when

members of staff were absent or sick. Considerable difficulties were experienced in finding disabled people willing to undertake short and temporary contacts as this can cause problems for benefits and related payments and this meant organizations with a 'disabled staff only' policy had to readdress this issue in order to find cover.

	Full-time	Full-time	Part-time	Part-time
	disabled	non-	disabled	non-
	staff	disabled	staff	disabled
		staff		staff
Cardiff	4	-	-	-
& Vale				
DANE	2	-	-	-
DCIL	2	5	9	8
Glasgow	7	1	-	2
GAD	4	-	4	-
Gwynedd	1	-	2	2
LCIL	3	3	2	2
SUN	2	2	1	-
WECIL	29	3	5	-

Table C Paid Staffing Levels

(nb. information provided by organizations in stage one survey)

There was also a tension between promoting good employment practice with the difficulties of precarious and generally short-term funding. Despite this, many staff were on 'permanent' contracts subject to sufficient funding being retained. In addition many of the case study organization provided induction processes for new members of staff (both paid an voluntary) and were committed to providing training and career development although this was severely constrained by limited funding.

All the organizations were dependent on volunteers for their trustees or members of their management Furthermore, in a number committee. of the organizations volunteers played a central role in the day to day functioning. Again voluntary workers require support in order to undertake meaningful roles within the organization. All the groups were keen to point out that they were valued highly and sought to ensure that volunteers were given roles that benefited the individual volunteer as well both as the organization. Many of the organizations formalise the role of their volunteers by way of volunteer contracts, induction and training programs.

f/ Services

In some cases the range of services offered was extensive, while other organizations were more limited in the services they provided. The variety and scale of services was clearly linked to the size of the organization and level of funding it enjoys. In general the first services to be offered tend to be information and peer support as they can often be run on a very limited budget and with the support of volunteers. As already mentioned the limited and short-term nature of funding has implications for service development. It appears that success can breed success, as larger contracts offer organizations more breathing space in which to work up bids and grant applications whereas smaller organizations with very short-term money are unable to focus their limited resources in the planning and development of services. Additionally, if an organization has a variety of sources of funding it is better placed to take risks as it is less dependent on one contract or service for its survival.

At both a national and local level there are now a multitude of both disability specific and more generic voluntary agencies and private companies providing services to disabled people, and despite government rhetoric about user-led services, a number of the organizations involved in this project are suffering increased competition for funding and specific service contracts from non-user-led service providers, examples include Leonard Cheshire and SCOPE. Indeed one of the case study organizations recently lost the contract for the direct payments support scheme to a less local (and with less certain claims to be a user-led) organization.

Others identified competition with organizations not committed to user-involvement, supporting disabled members of staff, and a social model basis for service provision as increasing source of concern given the government priority for 'best value'. Location has a significant impact. For example in London there are a number of organizations in relatively close proximity offering direct payment related services whereas in more rural areas the case study organizations were often the only organization bidding for the contract.

For many of the organizations, resources were a major factor in preventing them developing and implementing strategies to target under-represented groups. For example in one location the take-up of direct payments is particularly low amongst disabled people from minority ethnic groups. While the organization would like to target these groups they have already achieved the maximum number of direct payment users they are able to support with current levels of funding.

This problem was echoed in many of the other centres, where there was a feeling that any sort of publicity work aimed at under represented groups would stimulate a demand they would be unable to meet given current levels of funding. It was pointed out that funding for targeting minority ethnic groups was rarely forthcoming from the local authority social service department that provided the bulk of the funding as 'equalities' issues were the domain (and financial responsibility) of the equal opportunities department.

Furthermore, many organizations felt unwilling to target specific sections of the disabled community, preferring to provide non-impairment specific services open to all disabled people. Additionally, there were more specific factors that influenced the provision of services to certain groups of disabled people in particular locations. For example one organization is constitutionally restricted to service provision for disabled people aged between 18-65 years with physical impairments.

g/ Monitoring and evaluation procedures

In general, the move towards service level agreements and a more formalised relationship with statutory agencies has resulted in a large increase in the level of monitoring user-led organizations are expected to undertake. This raises a number of issues; firstly, the cost implications of monitoring were highlighted. Monitoring is and is further resource intensive complicated by funding bodies requiring different information in a variety of formats. This is particularly an issue for organizations whose catchment area covers more than one local or health authority. In one organization monitoring data was required by two health and two local authorities using four different criteria. It took considerable effort to gain agreement for a single monitoring system.

Secondly, statutory agencies tend to focus on quantative data rather than on the more qualitative information preferred by user-led service providers. Thirdly, many of the organizations felt a tension between a commitment to a social model approach to

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service provision and having to undertake impairment specific monitoring.

h/ Campaigning

All of the organizations visited see campaigning as with interlinked service provision, although 'campaigning' was interpreted in different ways. A proactive campaigning style was evident at many of the case study locations: this was seen as an integral aspect of the organizations work and inseparable from its role as representative organization of disabled people and as a service provider. It involved activity in national campaigns such as those against charging and for anti-discrimination legislation, as well as more local Other organizations operated a more 'behind issues. approach to campaigning using the scenes' their position on council committees or other local bodies behind the scenes. Even those organizations with a 'twin' campaigning arm were involved in this type of campaigning. One organization is currently developing a proposal for a policy officer to be funded by the local authority to undertake all the consultation and representation work the organization is asked to do.

A wide range of campaigning methods was employed, from the production of newsletters and other publicity and information material to more direct action. There was often an overlap of membership with more radical groups such as the Direct Action Network. Several of the organizations sought to develop alliances with other groups, such as local minority ethnic group organizations and more broad community groups.

All of the organizations were conscious of the potential impact of their campaigning activity, however limited, on their relationship with funding agencies and particularly the local authority. Although none of them have reached the stage where funding has been threatened by council hostility to their activities all the organizations viewed this as a real possibility in the future, a position echoed by the local authority representatives interviewed.

i/ Hopes and fears for the future

The specific nature of the case study organizations plans for the short and medium term varied although there were certain common themes. All the organizations were committed to maintaining current levels of funding and service provision, furthermore they were keen to develop and expand upon these services. Building upon current membership numbers and encouraging a more active membership was also highlighted as a key aim.

Concerns for the future followed similar lines at all the organizations. The increasingly precarious and conditional nature of funding was а maior preoccupation, as was the huge increase in the amount of bureaucracy required. The organizations sampled also identified the increased competition from nonuser led organizations as a threat to user-led services. Concern was also expressed over recent Government plans for community based support: particularly, with regard to the proposed greater involvement of health authorities in 'community care' type services.

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Further copies of this report and all project literature are available on the internet at: http://www.leeds.ac.uk/disability-studies/projects/ independentfutures.htm