RESEARCH REPORT

Background to the Research

Since the appearance of the American Independent Living Movement (ILM) in the 1970s and the international disabled people's movement in subsequent decades, there has been a gradual but growing demand by disabled people and their organizations for greater involvement in the development and running of services for disabled people. Further, 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 throughout the world including Britain.

A major outcome of these developments has been the emergence and development of organizations controlled and run by disabled people widely known as Centres for Independent Living (CILs) which provided services directly to disabled people and their families. Particularly prevalent in America and Canada as well as other parts of the world, CILs have been relatively slow to develop in the UK.

Britain's first two CILs began operations in 1984. Fifteen years later, May 2000, the number has risen to only twelve. However, there are many other user led initiatives providing independent living type services but which do not refer to themselves as a CIL. Exactly why the British CIL movement has been slow to develop and why some organizations do not consider themselves a CIL has yet to be fully explained. The situation is made even more complex by the

fact that some traditional 'professionally' led service providers have recently adopted the phrase independent living.

The research has three key aims:

1. to provide a critical evaluation of the development, organization and services provided by CILs and similar user led initiatives through out the UK;

2. to identify the principal forces - economic, political and social - hindering their further development;

3. to produce and disseminate, in a variety of accessible formats, findings and recommendations to disabled people, their organizations, and policy makers in both the public and private sectors.

The project will run for two years and comprises 4 key stages:

- establish boundaries and criteria;

- in-depth analysis of user led organizations;

- user interviews, and

- analysis and dissemination.

Data collection will include focus groups, large scale surveys, semi-structured interviews with CIL staff, users and other relevant organizations and extensive validation and dissemination procedures.

About this report

This report is based on four seminars held in London, Birmingham, Glasgow and Newcastle in March & April 2000. Invitations based on lists provided by BCODP and NCIL were sent to 75 organizations of disabled people, of which 48 sent representatives.

All but one of the 50 participants were disabled and represented a diversity of experience of user-led initiatives.

The seminars took the form of a brief presentation of the research aims and objectives and were followed by two focus group sessions in which participants were asked for their views on a range of issues currently facing user-led initiatives.

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Suggested topics included:
- the role of the social model;
- control and accountability;
- finance and employment;
- service provision.

Summaries of each seminar were produced and circulated to all participants prior to the production of this report.

Findings

Towards a formal definition of a CIL?

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

These included:

- CILs should adopt a <u>social model</u> approach to the development and operation of services;

- CIL type services should provide disabled people with meaningful <u>choice</u> and <u>control</u>;

- CILs should be <u>flexible</u> and <u>responsive</u> to the needs and wishes of local disabled people;

- CILs must seek to be <u>inclusive</u> and offer services based on the common experience of disability;

NCIL Definition of a CIL

NCIL is the National Centre for Independent Living, it is part of BCODP - the British Council of Disabled People. NCIL provides services to CILs and other initiatives.

A Centre for Independent/ Integrated Living is an organization controlled by disabled people. It is for all disabled people.

It exists to provide services which help disabled people to live independently.

Some of the services that may be provided by CILs include:
- information
- advocacy
- peer support
- housing advice
- personal assistance support
- work training and advice

Not all independent living schemes are called CILs. But all of them provide independent living services for disabled people. In particular they help people use direct payments and employ personal assistants.

Independent living means having choice and control in your life.

- A range of <u>core services</u> were identified, but it was agreed CILs should 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 division was evident however as to how the social model should be defined and implemented.

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

Choice and Control

Disabled People have traditionally operated little 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 organizational 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 often in their early

stages of development CILs tend to be underused 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 a CIL should offer a specific range of services to qualify for CIL status. It was evident that none of the participating organizations offered all the seven basic services originally identified by Derbyshire CIL in 1985 (information, access, housing, technical aids, personal assistance, counselling and transport) Additional services such as employment advice/support and advocacy were also considered important.

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 organizations and the constraints explicit or otherwise imposed by some funding agencies.

Emergent Issues

i. 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 mode type ideologies. Frustration was expressed about the constant need for compromise and negotiation to establish even the most basic level of services.

ii. Funding.

Funding proved to be a contentious and problematic concern for all participants. All CILs and user-led services are dependent on external

funding. Organizations 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 i.e. government but concern was expressed over the potential constraints this imposed on organization. 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 organizational integrity.

iii. 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 CIL-type organizations 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.

iv. 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 may inhibit and seriously undermine grass roots innovation

Conclusion

It was clear from the seminars that organizations providing CIL-type 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.

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