

Notes on capacity building for local service provider organisations controlled and run by disabled people often referred to as CILs.

(Briefing Paper submitted for discussion at the SCOPE IL Zone meeting on 21 April 2005, SCOPE Offices London).

These notes are based on long-term involvement with the disabled people's movement and extensive research with disabled people's organisations (see Barnes, Mercer and Morgan 2000: 2001: 2002, Morgan, Barnes and Mercer 2001, Barnes and Mercer 2003, Barnes and Mercer forthcoming) and current research on direct payments (Pearson et al., 2005).

The exact number of organisations controlled and run by disabled people currently operating across the UK is unknown. In 2001/2 there were 85 organisations providing a range of support services for disabled people and their families in the UK that were officially effectively controlled and run by disabled people. It is generally accepted that this figure has subsequently increased.

Organisations controlled and run by disabled people organised around 'independent living' take a variety of forms and date back to the early 1980s. (However, self help organisations run and controlled by people with impairments can be traced back to the nineteenth century).

Although many organisations refer to themselves as CILs and identify with the CIL movement, this abbreviation may refer to either Centre for 'Independent', 'Integrated' or 'Inclusive' Living. This raises important issues about the philosophy and policies adopted by particular organisations. The concept of 'Independent Living' has also been adopted and used (some might say abused) by

organisations controlled and run by professionals and non disabled people.

This raises the question of whether the development of a set of criteria and accredited 'kite mark' for CILs. would be desirable or not. There are obvious advantages and disadvantages of such a development and what evidence there is suggests that opinion within the disabled people's movement is divided on his issue. Opponents argue that such a development might discourage and inhibit grass roots innovation.

There is often a symbiotic, but frequently, uneasy, relationship between CIL type organisations and sponsoring agencies such as local authority social service departments and health authorities, that often inhibits the further development of user controlled initiatives. Whilst these relationships work very well in some areas in others they do not. Some organisations are dependent almost exclusively on local authority resources and support, others are autonomous. There are advantages and disadvantages of both approaches.

To eliminate the disadvantages, policies must be introduced to enable local CIL organisations to be in charge of their own destiny. For local disabled people's organisations to respond quickly and effectively to local needs they must be freed from unnecessary regulation and control by other agencies.

Historically, CIL type organisations have played a crucial role in the advocacy of disabled people's collective and individual rights in various contexts at the local, national and international levels. Such activity is inextricably linked to effective service development and delivery. It is vital therefore that any future strategy employed to further the

development of CIL type agencies in the UK must recognise and encourage its importance and continuity.

Funding is a major problem for all organisations controlled and run by disabled people providing services and support to people with impairments and their families. It is generally short term in nature and in the majority of cases linked to particular projects. This has important negative implications for the premises used, the numbers of staff employed, and the type and long term availability of services offered.

There is an urgent need for the development of an appropriate core funding strategy by Central Government independent of local authority control to secure the further development of existing and new local CIL type initiatives.

Competition for local service contracts from national and local organisations that are not controlled and run by disabled people has intensified considerably over recent years, and seriously threatens the future development of CIL type initiatives.

This is partly explained by the fact that despite national and local government rhetoric to the contrary service contracts are frequently awarded on economic criteria only. This puts organisations controlled and run by disabled people at a considerable disadvantage as their start up and running costs are generally higher than those of agencies controlled and run by non-disabled people. (For example, CIL type organisations tend to pay far more attention to equal opportunities and access issues, all of which have cost implications for the organisation concerned).

To address this problem, national policies must be introduced to regulate the award of local contracts that

take account of such considerations, and ensure contract compliance at the local level in order to level the playing field.

The national network of CIL type organisations has an exemplary record for the employment and training of disabled people for work within the service sector. But the combination of current benefit regulations and the general insecurity associated with employment within local organisations controlled and run by disabled people make the recruitment and retention of skilled staff with impairments extremely difficult.

There is therefore a pressing need for further benefit reform to encourage and enable disabled people to take full advantage of the growing employment opportunities within CIL type services.

Funding must also be made available to disabled people's organisations to work in conjunction with local colleges and universities for the development of appropriate training programmes and courses on 'independent living' and associate support services (what Vic Finkelstein (1998) has referred to as 'Professionals Allied to the Community'). Such courses must be formally accredited nationally in order to ensure that these workers are accorded similar status to other 'social care professionals' and paid accordingly.

These courses should be open to both disabled and non-disabled people. There is an acute shortage of disabled workers with the appropriate aptitude and skills to work in the service sector. Having an impairment does not automatically give someone an affinity with the social model of disability, independent living, or a desire to work in a CIL type organisation, and many CILs have and do employ non disabled staff. (In some respects this has

been unofficially recognised by some organisations who have adopted the phrase Centres for 'integrated', or more recently, 'inclusive' Living in place of the more traditional 'Centre for Independent Living').

References

Barnes, C. Mercer, G and Morgan, H. 2000: *Creating Independent Futures: An Evaluation of Services Led by Disabled People. Stage One Report*, pp.34, Leeds, The Disability Press (Also available on: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>).

Barnes, C. Mercer, G and Morgan, H. 2001: *Creating Independent Futures: An Evaluation of Services Led by Disabled People. Stage Three Report*, pp.36, Leeds, The Disability Press (Also available on: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>).

Barnes, C. Mercer, G and Morgan, H. 2002: *Creating Independent Futures: An Evaluation of Services Led by Disabled People. Conference Report and Findings*, Leeds, The Disability Press (Also available on: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>).

Morgan, H. Barnes C. and Mercer, G, 2001: *Creating Independent Futures: An Evaluation of Services led by Disabled People. Stage Two Report*, Leeds, The Disability Press (Also available on: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>).

Barnes, C. and Mercer, G. 2003: *Research Review on User Involvement for Promoting Change and Enhancing Social 'Care' Services for Disabled People*, Research Report produced for the Social Care Institute for Excellence: London. (Also available on: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

Barnes, C. and Mercer, G. 2006, *Independent Futures: Disability Services in the 21st Century*, Bristol: Policy Press (forthcoming).

Pearson, C. et al., 2005: Personal Assistance Policy in the UK: What's the Problem with Direct Payments? *Disability Studies Quarterly*, Vol: 25 No. (1) pp. 1-11

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