

PUBLIC POLICY AND ORGANISATIONS OF DISABLED PEOPLE

**David Gibbs: Text of seminar presentation,
Centre for Disability Studies, 22 April '05**

This year can be seen as a kind of crossroad for my organisation, Derbyshire Coalition for Inclusive Living (DCIL). We celebrate our 20th anniversary; in January the Prime Minister's Strategy Unit issued a report billed as the government's 20 yr strategy for 'improving the life chances of disabled people'.

The strategy for DCIL was from the grassroots, aimed to develop practical measures that would 'change the way services are provided to disabled people', and to achieve overall goals of 'full participation and equality'. It's ongoing as a Strategic Plan 2001-2010. The strategy from the policy centre aims to improve life chances by concentrating on three areas: independent living, early years support, and support into employment.

The theme for this seminar is to examine the prospects for linking these two strategies. Is it a conflict; is it an opportunity for productive union; is it even a hand-over; or is it 'all of the above'?

The government report is 240-odd pages and has 60 recommendations. I'm not going to attempt a summary, but will just focus on recommendation 4.3:

'Each locality should have a user-led organisation modelled on existing CILs'.

So have we won? Are disabled people going to design all their own services? Before we get too excited, we should look more closely at what that commitment could mean.

First of all, CILs don't have a standard blue-print. A project called 'Creating Independent Futures' was done from the CDS only 4-5 years ago, to see how CILs and similar 'user-led' initiatives in the UK operate, and to assess their prospects. 48 organisations participated, 9 were used for detailed case studies. The study brought out mainly what the organisations had in common:

- they had majority management by disabled people, but the degree of control varied in practice;
- they used a social understanding of disability, but applied it in rather variable ways;
- most had campaign functions as well as service providing or service developing functions, but the nature of campaigning activity varied a lot;
- they all had concerns about stability of funding and the future of user-led services.

Before that study got under way discussion touched on whether it would reveal a potential formula to 'kite-mark' CILs – define at least a minimum set of essential characteristics that could be aimed for in their future development.

The organisations turned out to be too diversified for that to be realistic. The situation may be even more complicated just a few years further on. In '97 the British Council of Disabled People set up its 'National Centre for Independent Living' project, and this became fully independent in '03. NCIL supports the development of local support schemes for personal assistance users, particularly people who've taken the option of Direct Payments. These may or may not be called 'CILs'. Some older CILs think 'NCIL' itself was rather a misnomer, and

that CILs have much wider functions than PA support schemes – although these certainly could be the core of a CIL.

So now we have CILs with broad objectives and CILs that deal with personal assistance as the key to independence. I'll raise another possibility: what's to stop one of the big charities rebranding its institutions and calling them 'Sunnyside CIL'? The name isn't legally protected, anyone could use it. And if they haven't started already, isn't the government's call for more CILs an invitation for them to do just that?

Faced with that prospect I'm going to go a step on from the 'Independent Futures' research and say what I think are the essentials of a CIL. Then after time for discussion we'll look at how those 'essentials' fit in with the government's strategy.

So here are four essential features of a fully developed CIL:

1. Peer Support. A CIL can't happen unless disabled people *come together* and support each other. Their own shared experience will decide what they mean by 'independent living' or a chosen alternative. Their own shared understanding of its obstacles will decide aims and strategy. This process can be encouraged by non-disabled supporters, but it can't be *run* by them.
2. Disabled people's control. This means that all policy decisions *under an organisation's governing document* (its Constitution) are taken by an elected body with a majority of disabled members.
3. A social understanding of disability. The 'social model' of disability is a widely known concept by now, but this

means that sometimes liberties are taken with it. So when stated as a principle, it should have some illustration of the differences it makes in practice.

4. An integrated view of support needs. A social model can't be applied by services that meet needs in isolation. This doesn't mean that a CIL must always run a comprehensive range of services, but it should be a 'one stop shop' for access to whatever support someone needs towards their own goals of independence and inclusion.

Even if this full package is taken on, the ways it can be organised show a lot of variation. In a small survey of options, done for the management group of the forming CIL here in Leeds, we came across several alternative ways that something with the essentials of a CIL has been produced:

- one that starts with a core service and adds on others;
- one where several existing services are brought together under a new management structure;
- one where a range of services and projects are managed in a loose association;
- one where a range of closely linked projects are set up from the start.

There are some other points about what a CIL isn't, and some of these may be a surprise at first.

- A CIL can't be called simply a 'service provider', because providing a service ourselves is only one of the options available for meeting the various objectives set by disabled people.
- It isn't strictly a 'user' organisation, because that implies use of a particular prescribed set of existing services, and we will often want to develop alternative kinds of support altogether.

- We don't even speak about 'involving users', because our organisation's history may have been more about disabled people involving workers than about 'a service involving users'. In fact it may be hard to say who our 'users' are, given that one person might be user, volunteer, worker, or elected Board member at different times, or even several of these at the same time.

That's my angle on my organisation; others might not be concerned with such fine distinctions. Different views of what a CIL should be reflect division between individualist and collectivist approaches to human affairs in general.

In one view, dependable personal assistance under your own control is the key to independent living, and that in turn is the key to full citizenship. In another view, addressing the barriers in individual lives will only take you so far. To achieve full participation it's also necessary to remove barriers that are built into the way society is organised. And these individual and collective approaches can be extended further, to a *historical* level, where you address the deep seated imbalances of power that create barriers all through society. At that level disabled people could link their struggle with those of other excluded, marginalised or disadvantaged groups – a development that Vic Finkelstein foresaw in one of these seminars four years ago.

Now we'll use the basic requirements for a CIL to look critically at the Strategy Unit's proposals. I said they have three areas of action: independent living, early years support; support into employment. The recommendation about a CIL-type support service in every area is in the first, on independent living – a 30 page chapter of the report.

We'll go through our perceptions of a CIL in turn, and ask how well they're reflected in the proposals.

Peer Support

This is a test to start with. Government in the last 25 years has been highly centralised and hierarchical, and tends to prescribe detail further and further down the line. Peer support, on the other hand – disabled people supporting one another – is the defining 'grassroots' activity: they almost mean the same thing. Can we really expect centralised government to encourage peer support, when it's something that can never be in its control?

The phrase appears 5 times in the whole report, twice in the Independent Living section. It's given in a list of what CILs provide, as 'advocacy and peer support', then in a list of the *minimum* services that public bodies should support new organisations to provide. The whole of this second list is:

- information & advice
- advocacy and peer support
- assistance with self-assessment
- support in using individual budgets (another recommendation of the report)
- support to recruit and employ personal assistants
- disability equality training
- consumer audits of local services

So the report does contain an encouraging recognition of the importance of peer support.

Disabled people's control

The minister's first announcement of the report was at an event held at National CIL. NCIL was also asked to help find organisations to pilot the operation of individualised budgets. This suggests a real commitment to organisations of disabled people, where only a few years ago signs were that the traditional big charities had regained the Government's ear at the expense of direct representation through the British Council of Disabled People.

But NCIL's 'independent living' model of support is all about personal barriers, and mostly steers clear of social barriers and deeper cultural barriers. It's possible this reflects the way most disabled people in the country see what's needed, but it has limitations. It may be that local organisations' involvement in community projects and campaigns will find little support in the new strategy. Certainly one big CIL recently had to drop a number of projects because of funding problems, and had NCIL in to advise on change to what is now more or less the 'government approved list' of services.

If disabled people want the wider input, we may have to go outside our own organisations into new partnerships of local and regional bodies, and into projects that have to be funded independently.

Social understanding of disability

The phrase 'social model' isn't used in the body of the strategy unit paper at all. Oddly, this may be a positive sign. The social model has tended to appear in explanatory appendices of recent policy papers, in a way that often seems largely cosmetic. The whole *language* of the new paper, on the other hand, is a big advance on anything we've seen from government before. Most of it

sounds, quite easily and naturally, like practical measures for applying a social understanding of disability without shouting about it.

Integrated approach to support needs

As I said in relation to 'control', a 'whole system' approach may be in danger if the focus is going to be on personal independence rather than the 'full participation and equality' that disabled people made their goal in '81.

In the report, however, 'promoting independent living' means more than control over help you receive in your home.

- The independent living section includes recommendations about housing: the ills of disabled facilities grants are already under review and there's added commitment to implement findings; 'lifetime homes' standards of design will be integrated with mainstream supports, for example with low cost home ownership.
- Other recommendations are on transport: transport needs will be a part of assessments for IL support; there will be responsibilities to look at all stages of a journey where barriers may arise.
- And a separate section of the report deals with support into employment, building on encouraging results we've begun to see from some schemes, like 'Pathways to Work'.

Remarks so far have taken a quite optimistic view, but now some balance needs to be introduced.

The first follow-up we're to expect is a new green paper about 'Adult Social Care'. In the 20 years of our past

strategy we've never talked in terms of 'care' – social, community, or any other sort – but new kinds of care and new lots of caring professionals are what's been on offer. None of the essentials of a CIL can be equated with 'care' or can usefully combine with care – they provide a complete alternative that simply rejects a 'care model'.

Nothing in the report itself reinforces my paranoid remark about 'Sunnyside CILs' run by traditional charities. However, what's happening in practice is that contracts to administer local authority direct payment support schemes are going, overwhelmingly, to big national charities that have had make-overs for that express purpose. They've exploited the work of our organisations to do so, and used us to give credibility to bids that exclude us. Often they show themselves willing to run volume contracts under which people go back to being 'warehoused', cut off from peer support, or to exert a degree of monitoring control over use of direct payments that's nearer to house arrest than independence. There's nothing in the report to stop that trend, or to empower our organisations to challenge it, and yet it makes nonsense of strategy for improving 'life chances'.

The life chances strategy has to be seen in its wider policy context.

Government aims to increase the role of the 'voluntary & community sector' in service provision. The increasingly controlling nature of government may reach into community self-organisation so far that it confronts the basic founding charters of our organisations. These are rooted in very ancient Trust Laws that empower people to set out their terms of association. The objectives set often will address community issues long before central government even notices they exist. We have many examples of community initiatives that have begun to show impacts on policy making 10 or 15 years or even a

generation, later. They include the social understanding of disability itself, and ideas based on it about housing, technical aids, personal assistance, transport, general community access, that have been entering legislation in recent years. If government tries to replace that innovating process altogether with new service provider roles, it risks stalling one of the creative engines of society.

In the still longer term, the end of the 20 year strategy will be nearing a time when current projections suggest more people will be drawing pensions than earning. That makes disabled people a major resource. Government research suggests there could be a 'missing million' - people who would take work if disabling barriers were removed. If that's true, then the pressure is on to get a grip of what's needed to really get that queue moving. With incentive like that, we may see changes that seem only remote possibilities from where we are now.

I'll end with a few suggestions of changes we'd have to see if disabled people's strategies and the 'life chances' strategy are to come together during the next 20 years.

- First, the *government's* 20 year strategy is going to need *our* ongoing strategies to make it workable.
- Conversion from 'needs' based to outcomes based service provision. This means transforming *assessment* - that foundation of professional intervention - to a process where people define where they want to get to and *useful technicians* contribute appropriate support.
- Conversion from 'maintenance' to focused support at any transition stage of someone's life course where barriers are met.
- Conversion from professions that assess and prescribe, modelled on medicine, to 'professions allied to the

community' as proposed by Vic Finkelstein. The core skills and knowledge base of these would stress normalising communities to let in the whole diversity of their members, rather than 'normalising' individuals to fit into disabling communities. It would mean training in quite different mixes of skills from existing 'care' professions. Some CILs have begun to pilot ways this might work.