

The Independent Living (Disabled Persons) Bill

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***Independent Living and Direct Payments:
The National Picture Conference***

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Why are we writing an Independent Living Bill?

Lord Ashley approached the DRC last summer to help him write a Bill to deliver stronger rights to independent living for all disabled people. This obviously fits with the DRC's ambition to secure such rights and we leapt at the chance to work with Jack, NCIL and other colleagues to make this happen.

I am assuming knowledge and a level of consensus as to what the current barriers are and how the law contributes to them i.e. a legal framework that

- allows people to be institutionalised against their will;
- subjects many to gross indignities and leads to infringement of basic human rights;
- fails to respect family life and which does little to enable active participation;
- relies massively on informal carers to the detriment of quality of life and choice for both disabled people and their families;
- operates eligibility criteria which leave many without any support whatsoever ;
- is dominated by concerns about risk and short-term financial considerations and
- entrenches blatant age discrimination.

I could go on and on. It ain't social model and it ain't even securing basic protection for human rights. In fact you won't find anything cast in terms of rights- another long-standing criticism. We will

need to get changes to the law if disabled people are to have effective rights to independent living. The major changes we need to culture, policy and practice simply cannot be achieved under the existing framework. With the Government committed to implementing a wide-ranging new strategy to radically improve the life chances of disabled people with independent living at its heart now is the time to strike.

The Life Chances Report said that:

“More coherent and explicit standards should be developed bringing legislation and other rights into a coherent framework.”

Exactly, couldn't have put it better ourselves, but let us not rely on Whitehall to come up with the goods. If it's going to happen there needs to be a huge push. Most of the big changes that have come about in the past have come about because of disabled people's activism, because of creative alliances among disabled people, with parliamentarians of all parties and of none and the odd empathetic mandarin (one of these, strategically placed, is worth their weight in gold). The Community Care (Direct Payments) Act and the DDA are prime examples, I could offer lots more.

Jack aims to introduce the Bill in the House of Lords at the beginning of May and we have two possible dates for second reading (this is the first debate on the principles of the Bill): 19th May or 16th June.

Now I'll say a bit about what we are thinking of putting in the Bill. A lot of it will be very familiar because the Bill is based on all the activism, thinking, research and campaigning that has gone into independent living by a lot of people (some of whom will be here today) over a long period of time.

So now to the Bill.

Purpose and principles

The purpose of the Bill will be set out in Clause 1: i.e. to ensure that disabled persons enjoy the same choice, freedom, dignity and control as persons who are not disabled at home, at work, and as members of the community.

Then we will set out key principles which must inform the exercise of duties under the Bill i.e:

- the primary purpose of social services being to enable participation and equal citizenship for disabled people
- any practical assistance disabled persons require must be based on their own choices and aspirations and should address the practical barriers to participation that they face
- the need to respect and promote the full enjoyment of human rights
- the need to take practical steps to rectify disadvantage relating to age, race, sex, sexual orientation etc.

We're writing in provisions requiring co-operation between local authorities and their partners to deliver better outcomes in relation to independent living.

Who is a disabled person?

The Bill will amend Section 29 (1) of the National Assistance Act 1948, which provides the legal definition of disabled people for the purposes of community care policy. As the Life Chances report notes “ this definition is out of date, offensive and does not provide a useful starting point for enabling disabled people to fulfil their roles as citizens”.

Choosing how and where you live

The Bill will provide a right to effective protection against involuntary institutionalisation combined with a more positive right to choose where and how you live.

Self-assessment

Reform to the assessment regime will be required to ensure that all support packages are based on a starting point of **self-assessment** (or facilitated self-assessment for people lacking capacity) and geared towards facilitating independent living. At the moment assessment is dominated by professionals and is simply geared to fitting people into services rather than empowering them with resources.

Eligibility for support

Access to support services is dependent on local eligibility criteria, which can vary greatly. The Bill will reflect a new approach that safeguards the position of those with high-level support needs while extending support to people with lower support needs.

Minimum guaranteed outcomes

The Bill will include specification of the minimum **outcomes** disabled people have a right to expect when they use independent living assessment and support services. In practical terms, the kind of minimum support envisaged is simply what is required to provide a level playing field in terms of ability to participate in the range of social and economic activities that most people take for granted.

Promoting direct payments and individualised budgets

There is no specific duty on local authorities to proactively inform people about direct payments (what they are, how they work, what support you can get with them). The Bill will address this and identify other ways of promoting take-up, especially among groups such as people with learning disabilities and mental health service users. The DRC strongly supports the concept of individualised

budgets and the Bill will provide the necessary legislative underpinnings. Individualised budgets will cut through bureaucracy and make better use of resources.

Rights to communication support and advocacy

We will enshrine in the Bill:

- Rights to advocacy and supported decision-making (including support for self-advocacy).
- Rights to communication support and equipment for those who need it (with communication needs being routinely recorded in all independent living plans and assessment records).

Portability

The current system does not provide rights to portable support. If you move to a different part of the country you have to start all over again and negotiate a new support package from scratch - with no guarantee about continuity of support, even for a transitional period. The Bill will specify that, at the very least, once a budget/ support package has been agreed, that entitlement follows you wherever they go and need not be renegotiated.

User-led support services

If this is all going to work then it needs to be underpinned by a secure, sustainable future for

user-led IL services locally, regionally and nationally. In line with the Life Chances Report recommendations for a Centre for Independent Living or equivalent in each local area by 2010 the Bill will impose duties upon local authorities to secure the provision of a range of user-led support systems/services to support independent living, including support for self-advocacy. We also need to ensure a more level-playing field in the competition for contracts so that big national organisations can't outdo local 'of' organisations.

Where you have a strong disability group working locally to support independent living you get better results in terms of choice, control and better outcomes for disabled people. We will consider and consult on possible models for delivering support and advice services that would be accessible to the full range of service users, including older disabled people and disabled people from BME communities. One option, for example, might be a local federation model utilising both CILs and other local organisations (e.g. Age Concern, Mind etc) working to a common service protocol based on IL principles to ensure consistency of approach.

Charging

Charges continue to adversely affect thousands of disabled people. They amount to a tax on disability. The Bill will, at the very least, need to take disability benefits out of the charging equation. We will also consider the feasibility of removing charging

altogether, looking at recent experiences of local authorities which have abolished charging and undertaking a cost benefit analysis.

Restoring rights and the Gloucestershire Judgement

Under the Gloucestershire judgement councils can justify failure to provide a disabled person with a service they are assessed as needing on the grounds that they cannot afford this. The Bill will attempt to address this long-standing problem by defining minimum outcomes (i.e. a level of support which is, as far as possible, sacrosanct) and by requiring a much tougher level of justification of how resources have been allocated and evidence of planned action to address unmet requirements. We are undertaking research to pinpoint the additional level of investment the Bill would entail and that will be set against anticipated savings over the long term in relation to reductions in hospital admissions, increased labour market participation or savings from housing adaptations. The DRC is clear that when we're talking about meeting basic human rights standards we've simply got to pay up.

Reform of housing and planning legislation

In addition we think that the Bill will also need to make improvements to rights under housing legislation and strengthen access requirements under the planning/building regulations systems. Major savings would be made if all new homes met

the Lifetime homes standards and if housing authorities made better use of their accessible housing stock. We're looking too at further changes to the law on housing allocations and Disabled Facilities Grant rules to provide a really robust package that underpins the right to a home of one's own.

Disabled parents

Throughout the Bill we will be emphasising the principle that disabled parents must be supported and enabled. But we believe there will be a need to go further than this. In 2006 people can still have their children removed from them (or live with that fear lurking at the back of the mind which is bad enough in itself) without justification and even though there may be practical support which would avoid it. We know this is happening. It's a major human rights issue and we've got to provide effective safeguards.

Disabled children, young people and their families

Under the Bill disabled children, young people and their families will have access to individualised budgets – providing choice and control across multiple transitions. Disabled youngsters will get a stronger voice in determining their own requirements and we'll look at anything else which would strengthen freedom, choice and control.

Rights to mental health services

We're going to enter 'reform of the Mental Health Act' territory too. We have too. There is no enforceable right for people with mental health problems to assessment, resources and provision, you are lucky if you get anywhere near a social support package and the safeguards against compulsory treatment are wholly inadequate.

Measures to address race discrimination

If independent living is to start meaning something for BME disabled people then we need support for and investment in their organisations, we need to ensure key professionals receive race equality and cultural awareness training and lots more. We are getting direct input to the Bill from BME disability groups.

Measures to address age discrimination

Older people face blatant age discrimination. If you become a disabled person before you're 65 you can apply for the mobility component of Disability Living Allowance to help meet your extra costs. But if you start having mobility problems when you are 66 then it's tough, you are not entitled to the mobility component. Indeed the very name of older disabled people's extra costs benefit 'Attendance Allowance' infers that basically you just need tending to rather than actually being empowered to live a full life. People can't access money from the Independent

Living Fund either once they are 66 – another blatant and unjustifiable age bar that the Bill will remove.

Carers and families

The Bill may refer to support for families and unpaid supporters of disabled people so that they can be enabled to be a positive resource for supporting disabled people's independence. We feel that the independent living agenda will necessarily improve the life chances and health of informal carers and supporters by ensuring disabled people are not forced into unwanted dependency. Of course we are all interdependent and many informal carers are in fact themselves disabled people supporting another disabled member of their family. It is important to recognise that appropriate support for carers is often an essential part of making Independent Living possible.

Enforcement

Disabled people need to be able to enforce their rights without going to the expense of a judicial review. Obviously we need to improve local authority complaints systems and advocacy rights will also help here. But we are also thinking we need to entrust an existing body (the existing care commissions perhaps or an ombudsman – equipped with stronger input from disabled people) with a duty to investigate and resolve complaints. Resolution might involve the power to order

remedial action. Any creative thoughts in this area would be extremely welcome.

What good will this Bill do?

We do not expect this Bill to be passed in to law – not the first time around anyway. We would aim to get the Bill passed by the House of Lords in the first instance and if that happens we think a lot of MPs could be interested in introducing it to the House of Commons. We will keep going though until we get the rights in the Bill onto the statute book. What we aim to create is a broad alliance for independent living rights that puts unstoppable pressure on the Government to get moving and that leads in the next couple of years to the kind of legislation we need.

I'll end with an 'ask'. It's for input, insight and support. We're talking to lots of stakeholders – from the disability movement and further afield, cancer patients groups, the EOC, Carers UK, Help the Aged, social care movers and shakers. It's all going to hinge on effective alliances. We're forging a better understanding of what cancer patients for example want from independent living, what people with other long-term health conditions who don't self-identify as disabled people expect from the Bill. It's enriching the overall package.

We need as many people to engage with the Bill as possible and feed in, (ideas, views latest research findings, case studies – good and bad) then we'll

need you to support lobbying and campaign activities. There's a fuller briefing and Easy Read briefing on the DRC website (url: <http://www.drc.org.uk/newsroom/parliamentary.asp>) and its available in ALL formats from Rebecca in the IL Bill Team (tel: 020 7543 7049; text 7002; fax 7001 independentlivingbill@drc-gb.org).

DRC and partners may be the midwives of this Bill to be parented by Jack but the DNA comes from legions of disabled people and pioneers of independent living and you can donate yours today.