

## Parliamentary Briefing

# Disabled Persons (Independent Living) Bill

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## Summary

The Disability Rights Commission strongly supports the Disabled Persons (Independent Living) Bill. The Bill offers the opportunity to liberate millions of people, now and in the future (people with impairments and long-term health conditions and their families/carers) from the current, over-bureaucratised, ineffective system of social care, which limits their contribution to their families, the economy and society.

It does this by providing a new legislative framework for independent living rooted in the principles of freedom, dignity, choice and control and geared towards boosting participation. This builds on commitments to independent living in the Government's Life Chances report and White Paper 'Our health, our care, our say'.

Funding for social care, housing support, employment support and health services would be pooled and accessed via a single assessment – ending the current wasteful and fragmented approach.

Disabled children and adults would gain clear rights to the essential support they need to get on with their lives. For the first time disabled people could determine where they live, who they live with and how they live their lives.

Legislating for independent living is about social justice and human rights. A civilised society should simply not tolerate a situation in which disabled people can be forced to live apart from their families and are entitled to little more than being 'washed and fed'. Legislating for independent living would boost carer's health and participation and enable us to achieve higher employment rates, better health outcomes for all and lower rates of poverty and exclusion among children and older people. Legislation for independent living is what we must deliver to secure our future economic success.

## Introduction

The DRC strongly supports this Bill which we have assisted Lord Ashley of Stoke in preparing. It aims to deliver stronger rights and entitlements to independent living for disabled people based on the principles of freedom, control, choice and dignity. We are extremely grateful to the many organisations and individuals who shared their views and ideas with us and who have helped shape Lord Ashley's proposals.

Independent living means ensuring that disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and to live an ordinary life.

In this briefing, and in the Bill when we talk about disabled people, we are including people with a range of impairments (from a learning disability through to autism or sensory impairments), people with mental health problems and people with conditions like cancer, heart disease and many more who experience barriers to independent living.

## **What are the problems the Bill seeks to address?**

Existing statutory rights and entitlements in relation to social care are not delivering the means for independent living – in some cases they act in complete contradiction – and are subject to tight financial restrictions and draconian means testing. The assumptions which underpin their design and delivery focus on managing "vulnerability", "risk" and "dependency," rather than supporting choice, control, and participation.

Key problems and barriers to independent living:

- The current system is a cat's cradle of costly red tape. To get support, whether in education or to improve their homes, disabled people face more bureaucracy than an average small business. This fragmentation of support leads to stress, unmet needs and duplication of resources on assessment and delivery.
- Disabled people have very few rights to services that would guarantee assistance to enable independent living. What minimum rights there are do not guarantee very much more than being washed and fed. Current legislation does not adequately cover assistance to participate in leisure activities, work, relationships, or to look after children/other family members.
- Age discrimination in the system blights older disabled people's life chances (for example, if you are frail through old age you have lesser entitlements to support).
- There are no positive rights in existing legislation to enable people to choose where they live or who with and no legal protection against disabled people being forced to live in institutional care against their wishes. We know of disabled people who are stuck

in institutions simply because it's assumed to be the cheaper option.

- There is no legal entitlement to advocacy except in extremely limited circumstances.
- There is no right to communication support and equipment.
- The existing 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 care package from scratch.
- The existing system creates significant inconsistencies in local authority provision, resulting in a 'postcode lottery'.
- People with mental health problems have no right to assessment or treatment/support for their mental health needs. A high proportion of mental health service users are (unlawfully) denied an assessment for social care services unless they reach a high initial threshold of serious mental ill health.
- Too many disabled people face barriers to accessing direct payments (a subjective judgement that you are not capable of managing one can exclude you) and there are too many restrictions on how you can use them.
- Enforcement of existing entitlements is incredibly difficult – complaints procedures do not offer speedy redress and people may be left struggling to negotiate an inaccessible legal system with inadequate support.

### **Evidence of a failing system:**

- 77% of families with severely disabled children report unmet needs for community equipment and help with eating, going to the toilet and sleeping. (Source: Beresford, B (2003) Community equipment: use and needs of disabled children and their families, University of York.)
- 7 out of 10 disabled people only get support if their needs are 'critical or 'substantial' – and 80 per cent of councils plan to tighten eligibility criteria further this year. This will result in further cuts to support services for many more disabled people. (Source LGA, March 2006)

- 50 per cent of parents with learning disabilities have their children taken away from them.
- The health and social care inspectorates have voiced serious concerns over the quality of care provided for - and the widespread lack of understanding about the rights and needs of – people with learning disabilities in the light of investigations into Cornwall NHS Partnership Trust and care homes in other areas.
- 1.4 million disabled people in England require adaptations to their homes. Nearly a quarter, 329,000, are living in housing unsuitable for their needs. (ODPM 2005) Four in ten disabled people with mobility problems say their housing makes them unnecessarily dependent on other people (John Grooms, 2003).
- Half the people with long-term conditions are not aware of support or treatment options available to them. They do not have a clear plan that lays out what they can do for themselves to allow them to manage their condition better.

## **How the Bill would put things right**

**Part 1** of the Bill sets out the principles which must underpin the delivery of independent living by local authorities, health services and their partners namely:

- enabling freedom, choice, control and participation;
- disabled people's right to self-determination and support in expressing their requirements and managing their lives;
- positive action to address discrimination and disadvantage for older disabled people, disabled people from black and minority ethnic groups;
- the protection of dignity, and respect for family life;
- safeguarding the health and well-being of carers and avoiding undue dependency.

As recommended by the Life Chances report the Bill reforms the definition of disabled people for the purposes of community care law. The old definition from the National Assistance Act 1948 uses offensive terminology. It excludes many older people and people who need support because they are ill. The Independent Living Bill uses an inclusive definition – anyone who has an impairment, illness or health condition or who is recovering from an illness and who faces barriers to independent living.

**Part 2** places a duty on local authorities and NHS bodies to co-operate between themselves and key partners (such as Jobcentre Plus) to promote independent living and improve outcomes for disabled people (similar to the duty proposed in the recent White Paper on health which the Association of Directors of Social Services supports). This is part of a new framework covering the duties and commissioning responsibilities of local authorities and health inspired by the recent LGA paper “A partnership approach for wellbeing”, and informed by the recent White paper. It does go a step further by requiring partners to pool funds wherever necessary to deliver the duties in the Bill. Pooled funds are required here as without them multiple assessments, delay and fragmentation would continue to be the norm and the full benefits of individual budgets would be hard to deliver. Also pooled funds have significant economic benefits eliminating inefficiencies and freeing up resources to deliver better outcomes on the ground.

The Bill acknowledges and supports the major role the voluntary sector plays in delivering independent living on the ground. It requires local authorities and NHS bodies to build capacity and support the long-term sustainability of user-led organisations including Centres for Independent Living, organisations representing disabled people from black and minority ethnic backgrounds, older people’s organisations and impairment-specific groups like local Minds.

All disabled people have the right to a self-directed and comprehensive assessment of their requirements for practical assistance and support under the Bill (including support for parenting) along with any rehabilitation/mental health/ other continuing health care requirements they may have. Some people will be able to assess their own requirements – others will need support and encouragement and input. Whichever is the case they have ONE assessment to go through which is designed to address their personal requirements in a holistic way.

They then have the right to be told what level of resources their local authority and primary care trust/local health board intends to provide (drawing on resources from a wider range of partners) to meet their requirements and are offered the choice of taking the resources in the form of:-

- a cash payment (individual budget);
- a delegated budget (where they nominate an agent/ third party to manage the money on their behalf);
- services arranged by their local authority and PCT/LHB (with input from partners as required) or
- a combination of cash and services.

(NB The Bill enables cash payments to be extended to health services that support independent living via regulations but does not require this. There are different views about this and pros and cons and a fuller debate needs to take place before such powers are used.)

The enhanced and holistic independent living provisions in the Bill apply equally to disabled children and their families. The Ashley Bill closes the same gaps in the law as Ed Balls' recent Disabled Children's Assessment and Services Bill sought to do and implements the Life Chances recommendation that individual budgets be available to them. This, the Life Chances report noted, would also help deliver a seamless transition between children's and adult services over time.

Disabled people are accorded rights to advocacy or support from a nominated friend alongside communication support and other forms of advice/assistance (key workers/care navigators or brokers as appropriate) in relation to the assessment process. This will enable them to make decisions about how they want their support arranged and delivered. Further advocacy requirements, requirements for communication support, communication aids and equipment must all be considered in relation to a disabled person's independent living support packages.

Where there is a serious dispute between a disabled person and their carer both are entitled to advocacy support and mediation to enable a solution to be developed which respects both parties' human rights and wellbeing.

To eliminate post-code lotteries the Bill says that regulations will set out minimum outcomes that must guide decisions about support packages. These outcomes will focus on delivering the support and any therapies required for enabling a disabled person not just to live with dignity at home but also to participate in work (in the widest sense), education, family life and social/leisure/cultural activities. In this way they support the prevention/early intervention agenda and dignity for all by saying that support is not to be restricted to those people with high support needs, with others hanging on until their life becomes impossible to manage. (NB All regulations under the Bill would be subject to parliamentary approval.)

The Bill also provides rights to portable support. If you move you can retain your individual budget for a transitional period. If you have services there are duties on the new authorities to make equivalent provision and maintain the same level of service for a prescribed transitional period.

On residential care the Bill enshrines an approach based on freedom, choice, control and dignity. It says that disabled people should be empowered to determine where they live and who they live with. No-one would be obliged to live in an institution against their will – it would be unlawful to make arrangements for institutional care against a disabled person's wishes and on grounds of financial expediency (and/or the fact that the proposed placement is due to the absence of accessible and/or supported housing options or alternative independent living services in the community).

Provision is also included for giving those currently in institutions against their will the opportunity to secure alternative living arrangements. (This goes further than the Life Chances Strategy which simply offered a consultation – yet to emerge – on a right to request not to go into an institution).

On the other hand the Bill acknowledges that residential care may sometimes be a positive choice; it maintains the right to choose your preferred establishment and allows an individual budget to be used towards funding a placement.

As well as providing people with mental health problems with rights to assessment, treatment and support for the first time, the Bill also amends the Mental Health Act to ensure – among other things - that independent living options are investigated and applied before the authorities resort to sectioning and compulsory treatment.

On charging policies the Bill sets out a framework which does the following:-

- preserves existing exemptions and draws the line against any further extension of means testing;
- prevents disability benefits from being taken into account in any financial assessment;
- enables regulations to be made by the Secretary of State and the National Assembly for Wales excluding earned income and occupational pensions from financial assessments (earned income is currently discounted in assessments for home care and Independent Living Fund support but not for Disabled Facilities Grants for adults or for residential fees);
- further provides that the national authorities must have due regard to their Disability Equality Duty (under section 49 of the DDA 1995) before making regulations enabling charging. That means there must be a Disability Equality Impact Assessment conducted.

The last point is key: if charging policies act as a barrier to equality and participation, or effectively lead to disabled people being out of pocket for participating, then we would hope that this will create a strong lever for charges to be reshaped or abandoned at a later date.

The framework for complaints set out in the 2003 Health and Social Care Act is amended to ensure a stronger focus on urgent remedies for cases especially those raising issues under the Human Rights Act and to provide clear advocacy rights. The Bill also provides for one of the current inspection or enforcement bodies in each country (e.g. CSCI or the Local Government Ombudsman in relation to England) to be given new strategic enforcement powers. These would be used, where necessary, to require local authorities and NHS to comply with their duties under the Independent Living Act. They would prohibit local authorities and NHS bodies from doing anything which would infringe the Independent Living Bill duties or disabled people's Convention Rights.

Under **Part 3** of the Bill disabled people in residential care must have an independent living agreement which sets out how the provider will meet their requirements for choice, freedom, control and dignity. They must also be involved in the running of the care home. Given that the question of coverage of private and voluntary sector care homes and agencies under the Human Rights Act remains to be resolved the Bill will bring those care establishments within the definition of a public authority under the Act.

Finally accessible and affordable housing is key to independent living for disabled people and to achieving strong sustainability dividends from the Bill. Therefore **Part 4** of the Bill includes:-

- a duty on local housing authorities to set up a disability housing service to ensure disabled people can choose properties for rent which match their access and other disability-related needs;
- stronger duties on local housing authorities to allocate disabled people suitable housing in the community and to plan for the current and future housing needs of all disabled people in their area;
- provisions to make Lifetime Homes Standards mandatory by incorporating them into the Building Regulations. Reasonable access and adaptation for the widest possible range of people will be a requirement for the sustainable development of all new houses under the planning system.

## **Who needs the Ashley Bill?**

People like these....

Melis Berk a 9 year old with physical impairments and a learning disability who only gets 11 hours a week of support. His care workers are unreliable and don't turn up on time. His mum, Sengul can't make any plans or take a holiday and is depressed.

Isabella Devani who has MS and a new baby, Laurence. She is finding it tough to care for her baby son properly because her care package is insufficient for her needs as a person with MS and a disabled parent.

Ian Jacobs who had a stroke in 2003 – cuts in his care package have left him isolated, lonely and despondent about the future. He has no help to get out of the house, go to the shops or cook for himself. Ian says the experience has left him feeling as if he's been "written off".

Doug Paulley who lives in a care home and has had to turn down jobs because his entire salary (bar £20 a week) would be swallowed up in paying for the £900 plus a week fees.

Paul Casey, 28 who has spinal muscular atrophy and who has been forced to live apart from his partner and two children after being denied a Disabled Facilities Grant (DFG).

Couples like Maria and Dennis Cramp who face enforced separation – Dennis, 80, recently rescued his 88 year old wife from a care home accusing social services of kidnapping her and placing her there against her will. While social services insist that Mrs Cramp, who has dementia, needs institutional care, Mr Cramp is adamant that only he can provide her with the intensive and personalised care and mental stimulation that she needs.

## **What difference would this Bill make?**

Together the reforms set out in the Independent Living Bill would dramatically enhance the life chances of millions of disabled people and their families. They will reduce waste and inefficiency, promote the wellbeing and opportunities of carers as well as creating a truly sustainable approach to independent living.

Those currently receiving social care and other support (1.74 million disabled people are currently receiving social care support of whom 1.25 million are over 65) would enjoy enhanced choice, dignity and control. The many disabled people who receive little to no support at present would finally get the help they need. For example, the Wanless Review team estimated that if we were delivering a more ambitious level of service today 450,000 more older people would be receiving social care services at any given time and to a greater intensity.

The Bill would also potentially benefit people with relatively low levels of need who do not qualify for any support under current arrangements, but whose opportunities for participation and quality of life suffer as a result. We know from local authority returns to the Department of Health and National Assembly of Wales that there are currently around 1 million disabled people referred for assessment who do not get assessed or have support packages put in place.

The Bill would also go a long way to raising morale and job satisfaction among practitioners. A Community Care survey of 2,200 social work professionals carried out at the end of last year revealed that more than half spend at least 60%, and over a fifth spend at least 80%, of their working week on paperwork. An overwhelming 95% agreed that social work has become more bureaucratic and less client-focused over the past five years. Community Care report that "The key motivation for many practitioners is to care and act as advocates for people, so this increasing shift away from direct contact with clients is having a drastic effect on morale, job satisfaction, recruitment and retention."

Everyone would gain from adoption of the Lifetime Homes Standard.

Everyone, including those not currently affected by disability, could live secure in the knowledge that developing an impairment or long-term health condition in the future would not mean that they are forced to move out of their house because it could not be adapted to meet their needs. This will boost both quality of life and independence.

Realising independent living for disabled people is central to many other major public policy objectives: improving outcomes for children, improving employment rates, sustainable development, achieving gender equality, delivering improved health outcomes and tackling social exclusion in later life.

## **Why is legislation required? Can change be delivered without it?**

Legislation enshrining rights to independent living has long been recommended both by the DRC and organisations such as the National Centre for Independent Living, the British Council of Disabled People and RADAR. The Bill follows in the long tradition of private member's legislation extending the entitlements of disabled people in relation to social care – of which the Chronically Sick and Disabled Persons Act 1970 pioneered by Alf Morris (now Lord Morris of Manchester) is the earliest and most notable example.

Current policy and practice on meeting older and disabled people's support needs does not adequately reflect either the spirit or the legal requirements of the European Convention on Human Rights (ECHR). For the most part legal cases that have highlighted Human Rights failings in existing community care arrangements (e.g. East Sussex and Enfield) have not resulted in any corrective measures in either legislation or statutory guidance.

As Help the Aged have highlighted in relation to older people - although their findings apply equally to disabled people - the very system by which support is currently organised and delivered can actually put people's human rights at risk. For example, eligibility for support is often so tightly rationed that people are left in deteriorating circumstances until such time that their situation is deemed critical enough to warrant support. (See Tessa Harding, *Rights at Risk: Older people and human rights*, Help the Aged, 2005).

Similarly few services go beyond very basic 'life and limb' support to address the range of social, psychological or emotional needs, which may be essential for sustaining the level of dignity and integrity required by the ECHR. Most importantly perhaps, people's rights to respect for private and family life under the ECHR are completely over-ridden when they are required to leave their homes and families against their will because it is deemed more cost effective to place them in residential care rather than provide adequate support at home.

To secure the real and lasting shift in the direction of health and social care envisaged the Government's recent *Our Health, Our Care, Our Say* White Paper (key elements of which will require legislation anyway) and the Life Chances strategy goal of equal citizenship for all disabled people we need a legislative framework for social and health care and holistic disability support that is rooted in independent living.

Community care law fails to provide that and must be overhauled.

None of the changes outlined above can be accomplished uniformly across the country within the current hotchpotch of overlapping and sometimes conflicting statutory provisions. And if increased investment is required into what we currently define as social care – which it undoubtedly is – then we need to know what exactly are we asking for Government and our fellow citizens to invest in?

## **Will there be additional regulatory burden?**

No. We are not proposing more regulation, but different, more streamlined and better regulation which is more clearly targeted at improving outcomes for disabled people in a tangible way. The Bill will cut down on much of the bureaucracy and duplication inherent in the current system. This will free up energies and resources for front-line support and empowerment.

## **How much would the Bill cost to implement?**

Lord Ashley has asked us to prepare a full cost-benefit analysis of the Bill. The initial findings should be available in the autumn in time to influence the Comprehensive Spending Review 2007. Our costings will also be compared with the figures produced by the recent review carried out by Derek Wanless, which estimated it would require extra investment of £3 billion in 2007 to bring social care outcomes up to the optimum, cost effective levels (equivalent to just 3 per cent of current overall NHS and social care spending)

Our cost-benefit analysis will also provide details of some of the medium to longer term savings stemming from the Bill. Enhancing and extending entitlements to independent living support will result in savings to the health service. For example the Audit Commission estimates that £130 million per year is spent as a result of falls by people with visual impairments that could be avoided by supplying suitable aids or adaptations. Evidence from Northern Ireland shows that adopting the Lifetime Home Standard for all housing also reduces accidents and falls in the home.

A valuation of the In Control pilots (a partnership involving Mencap, Valuing People, CSIP and local authorities) has found that self-directed support (provided for in the Bill) can save money. The 18-month evaluation of the pilots highlighted a case where a person with learning

disabilities who previously had funding of £114,000 for an "unsatisfactory" placement moved to self-directed support with an allocation of £60,000.

Currently a significant amount of funding is tied up in block contracts with hospitals and care homes run by the independent sector. Annual charges for 'learning disability hospitals' range from £180,000 to £230,000 for each patient. One company, Care Tech which runs care homes for people with learning difficulties, increased turnover 26 per cent to £13.3 million in the six months to March with pre-tax profits of £1.2m. Its chairman has likened the business to receiving an 'annuity' from local government (quoted on <http://www.growthcompany.co.uk>). Clearly there is scope for making scarce resources go much further and work more effectively than they do now.

Part 4 of the Bill (which reforms housing and planning law) will deliver over £100 million a year in savings – which could and should be ploughed back into housing adaptations and other independent living support. These are just some examples of how the Bill will save money.

## **What makes you think the Bill would work?**

The Bill fits the direction Government has set out for health and social care and for achieving equal citizenship for disabled people. It also fits the aspirations of disabled people and those with long-term health conditions and it fits with the strong desire and commitment at local level to work across organisational boundaries to deliver on independent living.

Many local authorities are already attempting to reconfigure social care services along independent living lines. But to quote from In Control: "In the long-run local authorities cannot make a full shift to a rights-based approach alone, it is vital that central government supports this shift with the necessary legislative change".

## **Conclusion**

With strong civil rights on the statute book, we now need to underpin them with stronger entitlements to practical support. For many disabled people the entire equal citizenship agenda depends on this.

The DRC believes that this Bill offers the opportunity to liberate millions of people, now and in the future (people with impairments and long-term health conditions and their families/carers) from the current, over-

bureaucratised, ineffective system of social care, which limits their contribution to their families, the economy and society.

The need for such legislation is urgent and its benefits would extend across the whole of society.

## **Here are six reasons why MPs and Peers of all parties should support the Bill**

**1. It's about fairness and justice.** It's unacceptable to leave so many disabled people trapped in poverty, inaccessible and unsuitable housing, to deprive people of basic choice and dignity or to allow disabled couples to be split up or have their children taken away. It's unacceptable to deny so many disabled people the opportunity to learn, work and contribute to their local community.

**2. The current system is completely unsustainable.** Local authorities are struggling even now to deliver the basics and just won't be able to deal with rising demand from an ageing population. Today the system relies hugely on carers but the availability of unpaid support by carers may well not keep pace with increases in support requirements and people's expectations of social care in the future.

Further the whole system is riddled with waste, bureaucracy and inefficiencies. Implementing the Bill would save money in key areas – with reduced hospital admissions and benefit bills - but it would also give us something that is worth investing in for the future.

**3. Implementing the Bill would deliver the legislative and other beneficial changes the Government pledged in the Life Chances strategy and the White Paper 'Our health, our care, our say' and enable the roll-out of individual budgets.**

**4. It will help reach key public policy targets.** If we don't reform social care we may not reach the targets for:

- Ending child poverty.
- Getting 1 million disabled people, more carers and more single parents into work.
- Delivering better health outcomes.
- Ending exclusion in later life.

**5. Community care law and practice is out of step with the requirements of the Human Rights Act.** Putting that right will avoid costly and embarrassing legal challenges.

**6. It would be hugely popular.** The Independent Living Bill has strong backing from many disability organisations and organisations representing people with long-term health conditions, Carers UK and organisations representing older people.

We look forward to working with all stakeholders and with Parliamentarians of all parties and of none to secure the provisions of Lord Ashley's Bill.