

Independent Living Strategy



March 2008
Policy Briefing

On Monday 3rd March, Government published its Independent Living Strategy, the product of an eighteen month review led by the Office for Disability Issues. This briefing provides an essential guide to key points of the strategy, analysis of its likely impact on our lives and suggests how everyone can be part of influencing what happens next.

Our vision:

A just and equal society
whose strength is human
difference

Our mission:

To enable individuals,
networks and
policy makers to do things
differently

Summary

Acknowledging the growing gulf between Government policy and the real experiences of disabled people on the ground, the Independent Living Strategy sets out a five-year cross-government plan for closing the gap. The aims are that by 2013 disabled people have more choice and control over how their needs for support and equipment are met and to make significant progress in tackling barriers to access to health, housing, transport, and employment opportunities.

The Strategy sets out a strong vision for services that support disabled people to live the lives we choose and to participate fully in society. The detail is largely a summary of existing initiatives: moves to self-directed support and the commitment to ensure all publicly funded housing meets the Lifetime Homes criteria by 2011. Also included are welcome pledges to:

- review charging policies against the Disability Equality Duty;
- remove disincentives in the benefits system to disabled people taking up public appointments and
- initiatives to promote better understanding of independent living, boost disabled people's leadership and involvement and develop user-led advocacy and brokerage.

Notable by its absence is the radical reform programme disabled people want. No mention here of reform of eligibility

criteria, protection against involuntary institutionalisation or the lack of portable support packages.

The Government continues to state change can be brought about through the existing framework, conceding only that the need for legislation will be reviewed if sufficient progress (not defined) has not been made by 2013. This goes against advice from the Review's Expert Panel that, without a new legislative framework rooted in independent living principles, guaranteeing a minimum standard of support and providing for individual redress, the strategy risks having but a limited impact and failing to meet the aspirations of disabled people.

Another weakness is that the Strategy does not pitch independent living as a human rights issue. Nor does it explain how it is crucial for gender equality, ending state exploitation of carers or safeguarding the rights of children.

As well as responding to and engaging with the strategy, this paper argues we need to engage with the review of eligibility criteria and forthcoming social care green paper and step up campaigning for the Independent Living Bill. It shows how awareness of the Disability Equality Duty, the Human Rights Act and UN Disability Convention can be used in practical ways to challenge policies and practices which restrict independent living.

Your Guide to the Independent Living Strategy

The Independent Living Review was set up by the Office for Disability Issues in July 2006 to come up with practical proposals to deliver Independent Living, develop the business case for investment and consider the need for changes to the law. The Review Team was advised by an Expert Panel chaired by Baroness Jane Campbell DBE. The Strategy is owned by a group known as the Life Chances Ministers drawn from these Government departments: Work and Pensions; Children, Schools and Families; Communities and Local Government; Innovation, Universities and Skills; Transport.

Promoting independent living

To promote a shared understanding of the principles and practice of independent living, the Strategy says that Government will:-

- develop a programme to build awareness and change attitudes
- develop communication materials for practitioners to effectively explain the case and the ways of promoting it
- communicate this agenda to disabled people with a particular focus on seldom heard groups such as black and minority ethnic (BME) disabled people and young people with autistic spectrum disorder.

Comment: Too many practitioners and even many disabled people still lack clarity about what independent living is and what it is not. This allows bad practice to fester and deprives too many

of opportunities to gain more choice and control. Awareness is a good place to start. Even better would be to enshrine a definition of independent living in law and make it the statutory goal of local authorities, NHS bodies and their partners as in the Independent Living Bill. There are no guiding principles in law which would act as a check on bad practice and give disabled people clarity on the purpose of public service support.

Young disabled people in transition to adulthood

Government will seek to achieve a seamless transition into adulthood for young disabled people, including those with complex health needs, in all aspects of their life by means of:-

- a Transition Support Programme for 14-19 year olds, which will promote joint working, a holistic approach, and include access to an advisor or key worker, advocacy and support (with a view to expanding this up to age 25).
- delivering the cross-government strategy for post-16 learners with learning difficulties/disabilities;
- reducing the proportion of young people aged between 16 and 18 who are not in education, employment or training;
- action to address the housing needs of young disabled people and
- pilots and evaluation of individual budgets for disabled children and young people.

Comment: These are welcome pledges even if certain of them lack a detailed delivery plan. The Independent Living Bill offers disabled youngsters in transition concrete rights to key workers, independent advocacy, support for education, training and employment and the individual budgets which would obliterate current organisational and age barriers to seamless support.

Health

Government will enhance the understanding of health services contribution to independent living and enable disabled people to have choice and control over their non-acute healthcare needs, and manage their own long-term conditions by:-

- an education and awareness programme for National Health Service (NHS) staff on increasing choice and control, and on the Disability Equality Duty (DED);
- increasing the take-up of self-management programmes and
- publishing good practice guidance on enabling people to have choice and control over their continuing health care needs

Comment: Embedding a commitment to independent living in health services should indeed be a key priority. The big omission is action to break down the barriers between health and social services which leads to unmet needs and reduces choice and control. The Independent Living Bill would obliterate those divisions by requiring pooled budgets and enabling the extension of individual budgets to health. The Strategy contains veiled hints that

Government is considering moves to enable people on continuing health care to retain direct payments.

Transport and mobility

Government will enhance personal mobility and transport choices for disabled people including those whose needs can be met by public transport and improve the service disabled people receive from transport providers by:-

- continuing to promote the training of transport providers in the needs of disabled people;
- a strategy to provide information and confidence training for disabled people in using transport;
- working with local authorities to ensure accessibility planning is reflected in Local Transport Plans and Local Area Agreements and
- action to improve disabled people's participation in the development and implementation of transport policies.

Comment: This is one area where despite recent legislation and investment progress has seemed frustratingly slow, except where . as in London . there are both the structures and political commitment to driving through change at a faster pace. It is not clear what resource and what additional levers will be provided to disabled people at local level so they can influence swifter progress on accessible, integrated transport.

Housing

The strategy pledges action to maximise disabled people's housing opportunities and choices by:

- increasing the provision of housing advice and information;
- updating the Lifetime Homes standard, making it an essential element in the Code for Sustainable Homes and making adherence to it mandatory for all public sector funded housing by 2011;
- setting a clear target for the construction of all new housing to Lifetime Homes standard by 2013, with a commitment to review progress against this target by 2010;
- encouraging the adoption of Accessible Housing Registers;
- investing in rapid response repairs and adaptations services;
- increasing funding for, and improving, the Disabled Facilities Grants (DFG) system and
- continuing to invest in the Supporting People programme

Comment: Recent announcements on increases in funding for DFGs are very welcome. However the pledges fall far short of what is needed to tackle the accessible housing crisis. The Government has flip-flopped on mandating Lifetime Homes in building regulations. The only way to ensure all private housing is built to these standards is to regulate. Delaying until 2013 will limit disabled people's life chances and incur huge costs (in rising demand for adaptations, avoidable hospitalisation and acute social care costs). We have not identified anyone who seriously believes Accessible Housing Registers will be instituted in every local housing authority unless there is a clear statutory requirement.

Disabled Parents

- Government will promote more joined up working locally to provide timely and flexible support to disabled parents, including by encouraging inter-agency protocols to support disabled parents and their children.
- Government departments will produce accessible information for disabled parents.
- There will be work across Government, to ensure those policies which tackle child poverty and unemployment, address the needs and circumstances of families affected by parental disability.

Comment: The focus on disabled parents and the recognition of the importance of inter-agency protocols (mandated in the Independent Living Bill) is welcome. What disabled parents need are clear guarantees of support for independent living. Without this the scandal of young carers, some as young as 5 providing adult support to the detriment of their health, education and social inclusion will continue. Recognition of the links between child poverty and disability is welcome: but it is imperative that we see rapid progress in offering disabled parents seamless support for independent living, employment and child-care.

Employment and economic wellbeing

- There will be a cross-government national strategy on job retention.
- Government will try to increase access to volunteering opportunities for disabled people.
- Government will change benefit reclaim processes and, if required,

regulations to address disincentives and enable participation in public and civic life.

- Government will examine the combined impact of reforms to the benefit system, employment support programmes and charging policies within adult social care, to assess their role in promoting disability equality.
- Department of Health will consult on amending guidance on charging for residential care to remove the current disincentive to paid employment.
- Government will review how Disability Living Allowance (DLA) and Attendance Allowance (AA) can better support independent living.

Comment: Government needs to involve disabled people in setting a job retention strategy and seize the opportunity presented by John Robertson MP's Employment Retention Bill. Early action to remove benefit barriers to taking up paid positions on NHS Boards would be extremely welcome. Disability equality impact assessment of charging policies (suggested by the Independent Living Bill) and recent benefit reforms would be a big leap forward. but must be done openly. Extending the DDA to volunteering and making available an Access to Work type fund for disabled volunteers should be prioritised if we are to make fast enough progress on boosting participation and employability. Removing barriers to work for disabled people in residential homes is essential. Unlike those in receipt of domiciliary care whose earned income is not taken into account for charging purposes,

disabled people in care homes are only allowed to hang on to £20 of anything they earn, the rest being clawed back in charges.

Personalisation, choice and control

The transformation of social care to deliver choice, control and high quality preventive services is to be achieved by:

- the promotion of increased personalisation of support through, for example, individual budgets and direct payments;
- a strategic shift towards investment in early intervention and preventative approaches through initiatives such as the Partnerships for Older People Projects ;
- access to better information, advocacy and support so people are able to navigate health and social care.

Comment: Moves to promote self-directed support and invest in early intervention are welcome. No mention is made of the human rights implications of council decisions to restrict eligibility criteria despite the fact that CSCI reported some 281,000 turned away by social services and left without adequate support. No mention is made of the barriers to mobility and employment or the real suffering created by the lack of portable support packages.

Support, information, advocacy and brokerage

The goal is a universal information, advice and advocacy service for people who need support to exercise real choice and control. To that end:

- ODI will build the case for investment in advocacy support in situations where disabled people are particularly at risk of losing choice and control (when entry to residential care is a possibility; during transition to adulthood; when the children of disabled parents are subject to safeguarding procedures; when disabled people are victims or alleged perpetrators of anti-social behaviour);
- Department of Health (DH) is investing in Action and Learning Sites to deliver the Life Chances commitment that by 2010, each locality will have a user-led organisation modelled on existing Centres for Independent Living;
- Department of Health (DH) will develop a National Advocacy Qualification for independent advocates.

Comment: Recognition of the importance of independent advocacy and support for user-led organisations is very welcome. The failure to commit to rights to independent advocacy is disappointing. Despite recent statutory advances (independent advocacy rights for mental health service users and limited rights for those deemed to lack capacity), there remain a great many situations where disabled people have no explicit right to advocacy, even in cases where they risk loss of liberty or a threat to family life. On CILs, it is not clear how we move from a few action and learning sites and the current (shrinking) network of CILs to a well supported, vibrant national network.

Older people

- ODI, in partnership with other government departments, will develop and publish a cross-government toolkit that provides a one stop information resource on independent living for older people at a national, regional and local level.
- ODI will look at the case for investing in independent living for older disabled people in residential care or at risk of moving into care.

Comment: No strategy here for comprehensively dismantling age discrimination across health, social care and benefits. What is needed is a strong public sector equality duty that covers age equality plus legislative and other reforms to ensure older disabled people have the same rights as younger disabled people. Government should, for example, extend Independent Living Fund eligibility to those who become disabled over the age of 65. Government already knows that if we reduce the rate of institutionalisation of older people by just 1 per cent a year the savings would be £3.8 billion.

Measuring progress

Progress on the Strategy will be measured using the new performance framework, in particular the Equalities Public Services Agreement (PSA) and ODI Life Chances indicators.

- ODI will publish progress on the Independent Living Strategy, as part of its annual report.
- Life Chances departments will review delivery in time for the next Spending Review (2011 - 2014).

- The Government will review the need for legislation if sufficient progress has not been made against the outcomes by 2013.
- An Independent Living Scrutiny Group is proposed to monitor progress annually and report to ODI Board of Management and Ministerial Group. Membership would include members of Equality 2025 and members drawn from the Expert Panel.

Comment: The performance framework and PSAs omit certain key yardsticks . for an example an indicator of success should be an increase in the number of people with moderate or low needs who are in receipt of public support for independent living. It is not made clear what level of progress would be considered acceptable before further action is deemed necessary.

The biggest single flaw in the strategy is the approach to legislation. This flies in the face of expert evidence on the barriers to independent living created and reinforced by the current statutory framework presented to the Review by Luke Clements, Camilla Parker and others. It also goes against the Expert Panel's advice that without a new legislative framework rooted in independent living principles, guaranteeing a minimum standard of support and providing for individual redress, the strategy risks having but a limited impact and failing to meet the aspirations of disabled people. Waving a Strategy at a Care Manager who wants to cut your package is not going to cut it.

Involvement in monitoring is vital. The crucial point is however at some point

Government needs to go beyond listening then rejecting key points to a more genuine form of co-production where listening is followed by real action and changes to policy. Alongside an insider scrutiny group of disabled people, independent external scrutiny will be vital with engagement of disabled people at local as well as national level. RADAR plans to be very involved in this.

Final verdict?

While the Strategy may not represent a watershed in the long fight for independent living, it could yet become an important milestone. Its impact will be diminished by the lack of legislative underpinning, but insiders are convinced it holds the seeds of real progress . if we engage actively with it and hold Government to account. Another positive is the focus on BME disabled people, usually routinely sidelined in Government policy.

Have your say - Along with your views on the strategy generally, there are specific questions concerning implementation and monitoring that **government wants your input on by 20th June** such as how to best involve disabled people at national level in monitoring progress. The full Strategy can be accessed at: www.officefordisability.gov.uk. The Review team are at independent-living-review@dwp.gsi.gov.uk

Campaigning for the Independent Living Bill

Baroness Jane Campbell has said we should regard the Strategy as complementary to the Independent Living Bill. Campaigning continues and we must step up our efforts. The Bill itself has been passed for a second time by the House of Lords and is now on its way to the Commons. Once again it will join the back of a long Private Members Bill queue. How long it languishes there is up to us.

Following a successful mass lobby in October, organised by the Our Lives, Our Choices coalition (which RADAR helped found with NCIL and others), where 250 people came from around the country to lobby MPs direct, further action is planned for June. Meanwhile it is vital that everyone:-

- Lobbies their MP . ask them to sign Early Day Motion 348 entitled Independent Living and the Our Lives, Our Choices Campaign ask them to write to Anne McGuire, Minister for Disabled People and Ivan Lewis, Care Services Minister. Please give us feedback on what your MP says.
- Signs a new e-petition just created on the Prime Minister's website . <http://petitions.pm.gov.uk/ashleybill> - and gets friends and family to do likewise.
- Joins Our Lives, Our Choices as individuals and groups (no charge) go to www.ncil.org.uk and the RADAR Change Network so you get the latest info.

You might also consider sharing your experiences with us . good and bad. Case studies are vital for bringing the issues to life and have great sway with parliamentarians and media. Or indeed you could start your own local campaign.

Independent Living Bill – reminder of the key points

- “ Freedom, choice, control, dignity, equality would become guiding principles for health and social care support, enshrined in law.
- “ Minimum guaranteed entitlements to support which enables participation (as opposed to current feed and clean only culture)
- “ Self-directed support with individual budgets (social care, housing, health, access to work and other funding streams are pooled)
- “ Portability . if you move, you can take your support package with you.
- “ Protection against involuntary institutionalisation . and choice of where and who you live with.
- “ Lifetime homes; Disability Housing Registers . real housing choice.

Independent living: it's our human right

Both the **European Convention on Human Rights** (enshrined in UK law by the Human Rights Act) and the recent UN Disability Convention provide considerable support to independent living as a human right.

Under the European Convention there are positive obligations on the state to: ensure disabled people and carers are not subject to serious physical risk (article 2) or inhuman or degrading treatment (article 3) and to promote respect for family and private life . including the right to personal development and to establish and maintain social relations, the right to participate in the life of the community and to have access to essential economic and social activities and to an appropriate range of recreational and cultural activities (article 8).

Inappropriate institutionalisation of disabled people (i.e. against someone's will and on cost grounds) would be a breach of ECHR Article 8 and Article 14 (non discrimination).

The **UN Disability Convention**, signed but not yet ratified by the UK, then fleshes out these existing human rights standards for disabled people and its provisions will become the benchmark of acceptable standards of state behaviour. It could act to radicalise judges' interpretation of how far Government should go to make independent living a reality. Article 19 of the Convention gives us the right to choose where and who we live with and not to be forced into any particular living arrangement plus the right to access to range of support services to enable inclusion in community life.

An equally potent tool is the **Disability Equality Duty** which has started to be used . sometimes in combination with human rights arguments . to great effect to prevent policies and practices which limit independent living. For example, Hammersmith and Fulham had to abandon plans to freeze direct payment rates. This followed a stiff letter from Leigh, Day and Co acting on behalf of disabled residents asking where the Disability Equality Impact Assessment was and flagging up the negative impact on people's ability to participate in their communities and enjoy family life.

Harrow Council have recently been forced to halt plans to restrict access to support to those with critical needs only, following a judicial review brought against them by the Public Law Project. The High Court held that the policy was unlawful because the council could not show that they had had due regard to the impact of the decision on disabled people's equality.

Quick guide to related initiatives

Health and Social Care Bill – Creates new Care Quality Commission, extends direct payments to people lacking capacity. Shortly up for debate in the Lords, following its passage through the Commons. A chance to press for care homes to be covered by Human Rights Act and to run the arguments for fundamental reform. RADAR has proposed key amendments including a right to portable support.

Review of Eligibility Criteria . led by the Commission for Social Care Inspection. A review ordered by Care Minister Ivan Lewis after CSCI's damning ~~£~~ State of Social Care in England report which found that some 281,000 older people, with a mixture of high support and less intensive needs, receive no support of any kind with a further 450,000 getting some assistance, but not enough to maintain a decent standard of wellbeing. CSCI has pledged to involve service users closely and is to report to Government in September.

Green paper on social care – Department of Health. The Government announced in the Pre-Budget Report 2007 that it will publish a Green Paper on reform of the care and support system. The Green Paper will consider issues around the long-term funding of care, with an emphasis on supporting independence, choice and control. Currently debate on this focuses strongly on older people and much is to be gained by working together looking at services for people of any age requiring independent living support.

Lifetime Homes, Lifetime Neighbourhoods . Department for Communities and Local Government recently published this national strategy for housing for an ageing population. Pledges regulatory action in future if private sector drags heels implementing Lifetime Homes.

Putting people first – a concordat or statement of aims and commitments on adult social care reform by Ministers, ADASS (Association of Directors of Social Services), CSCI, NHS Confederation. States an intention to roll out self-directed support.

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Glossary of Terms

Lifetime Homes (LTH)

The Lifetime Homes Standards (developed by the Joseph Rowntree Foundation and Habinteg Housing Association) specify 16 design features for both the interior and exterior of a home which together will create a home that is accessible for as many people as possible and which can meet the changing needs of any occupiers over their life course.

Disability Equality Duty (DED)

The DED is a positive duty on all public sector bodies to pay due regard to the promotion of equality for disabled people in every area of their work (required under the Disability Discrimination Act 2005).

Portable Support

Portable support would give disabled people portable care packages when they move between different local authorities. The new authority would have a duty to give services or direct payments to that individual enabling an equivalent type and quantity of support for a transitional period.

Local Area Agreements (LAAs)

LAAs set out the priorities for a local area agreed between central government and a local area (the local authority and Local Strategic Partnership) and other key partners at the local level. LAAs simplify some central funding, help join up public services more effectively and allow greater flexibility for local solutions to local circumstances

Accessible Housing Registers (AHR)

A record of existing or planned accessible residential properties in a local authority area which would meet the particular requirements of disabled persons. Alongside the AHR there should be a record of disabled persons who require such properties; a service of enabling and supporting disabled persons to bid for properties so recorded and a mechanism for ensuring such persons are accorded priority status for such properties within the allocations process.

Disabled Facilities Grant (DFG)

A local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical.

Attendance Allowance (AA)

A tax-free benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled.

Access to Work (AtW)

This is a Government scheme which provides practical financial support to tackle barriers faced by disabled employees. This includes communication support (e.g. BSL interpretation), special equipment (e.g. screen reader) and help towards additional travel costs.

Direct Payments

Direct payments give individuals greater choice and control of their care provision. Individuals are given means tested cash payments rather than the community care services they have been assessed as needing, so they can decide what services they want to pay for. As a result of direct payments recipients will become employers, and will have to commission services.

Individual Budgets

Individual budgets give people a clear, up-front idea about how much money there is for their support. Individuals get an overall budget for not just social care (as with direct payments) but also Disabled Facilities Grant, the Independent Living Fund, Supporting People fund, Access to Work and Community Equipment Services. Users can choose to take this budget as cash payments, services or a mixture of both.

Improving the Life Chances of Disabled People Report

This report was published by the Prime Minister's Strategy Unit in 2005:

<http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf>

Centre for Independent Living (CIL)

The National Centre for Independent Living (NCIL) is an umbrella organisation made up of individual CILs . local centres run and controlled by disabled people. Many give support and information around direct payments and individual budgets, providing accessible information for disabled people and for employers with information on employing people on direct payments of individual budgets.

Public Service Agreements (PSA)

Every government department has to produce a PSA detailing the Department's aims and objectives for the forthcoming three years. The agreement also describes how targets will be achieved and how performance against these targets will be measured. The last PSAs were published in 2007.

Standing Commission on Carers

In September 2007 the Prime Minister announced a Standing Commission on Carers. It aims to ensure the voice of carers is central to the development of Government policy, and will look at the affect on carers of issues including demographic change and changes to people's choice of where they want to receive care. It will also oversee the carers's strategy due to be published this year.