
Independent Living Strategy:

A review of progress

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in  Control

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Contents

Preface	Page 4
Executive Summary	Page 5
Introduction	Page 7
Progress against Independent Living Strategy commitments	Page 8
Conclusion	Page 28

Preface

Over the past year, a group of disabled people and allies from a range of organisations have been meeting to discuss concerns about the present state and future of independent living. Our first meeting was chaired by Baroness Jane Campbell, who chaired the Expert Panel advising the Independent Living Strategy during 2007.

The informal, 'Independent Living Strategy Group', includes disabled people who were part of the independent living movement from the 1970s as well as younger activists and others concerned with the future of independent living. The original gathering was prompted by social media discussions about welfare reform and cuts to public service funding, and their actual and potential impacts on people in the context of insufficient UK legal protections for independent living. The group has been

discussing what we and others might practically do in the short, medium and long term to help protect people's access to independent living. To inform our activity and to facilitate wider debate with others we decided to undertake a brief review of evidence about the impact of the 2008 Independent Living Strategy. This has been undertaken by the present author and is published here to stimulate debate and action. Publication has been supported by Disability Rights UK and In Control.

Executive Summary

The 2008 Independent Living Strategy, published in 2008, received all-party support. It set out a general commitment that, by 2013:

- disabled people who need support to go about their daily lives will have greater choice and control over how support is provided.
- disabled people will have greater access to housing, transport, health, employment, education and leisure opportunities and to participation in family and community life.

This short report seeks to measure progress against some of the most important specific aims of the strategy. It found:

- There is no evidence of significant progress in disabled people's experiences of choice and control in their lives since 2008.
- There has been an increase in numbers receiving personal budgets for social care, and when delivered well, they improve outcomes.
- However, there have been significant limitations to effective delivery of personal budgets. Most have taken the form of council-managed services and there is evidence that inadequate funding and restrictions on how personal budgets/direct payments may be used can inhibit choice and control.
- Disabled people who need support in their daily lives are experiencing diminishing opportunities to participate in family and community life.
- Older people are finding it more difficult to access support and are experiencing fewer options and opportunities for independent living.
- People with high levels of support needs are at increasing risk of institutionalisation.
- Mental health needs are increasing, but access to mental health services is becoming more difficult.

Executive Summary (cont...)

- One in four people using social care services say information is fairly or very difficult to find, and there have been significant reductions in advice and advocacy services, particularly those funded by legal aid.
- The employment gap between disabled and non-disabled people remains at 30 per cent - the level it was in 2010.
- There is no evidence that current policies to support disabled people into work are improving employment opportunities: only five per cent of disabled people on the Work Programme have found a job.
- The reported success rate for the Work Choice Programme is much better but only one per cent receive this form of support.
- There has been a 16 per cent decline in the numbers of disabled people receiving support from the Access to Work Programme between 2009/10 and 2012/13.
- Large numbers of disabled people have experienced a reduction in their household income since 2010.
- Disabled people are experiencing a reduction in housing opportunities and an increasing number are living in accommodation which is not suited to their needs.
- There has been a small decrease in the percentage of disabled people experiencing difficulties with transport, but a large increase in transport difficulties experienced by unemployed or economically inactive disabled people.
- There have been significant reductions in expenditure on important programmes intended to increase transport opportunities.

Introduction

The Independent Living Strategy,¹ published in 2008, set out a commitment that, by 2013:

- disabled people who need support to go about their daily lives will have greater choice and control over how support is provided.
- disabled people will have greater access to housing, transport, health, employment, education and leisure opportunities and to participation in family and community life.

Progress was to be measured by a number of sources of data, set out in an annex to the strategy, and - if sufficient progress had not been made against the outcomes by 2013 - the government committed to reviewing the need for legislation to establish an entitlement to independent living.

The current government stated its support for the Independent Living Strategy, but instead of measuring progress on the Independent Living Strategy, it developed another strategy 'Fulfilling Potential'.²

This sets out some similar outcomes but it is not always clear how each will be measured, although the Office for Disability Issues (ODI) states that it will publish an annual report on progress.

This short report takes some of the most important commitments in the Independent Living Strategy and attempts to assess progress made since 2008. Unfortunately, most of the datasets on which the measurements relied have been discontinued and therefore it has not been possible to measure progress on all aspects of the strategy. This is also why much of the data presented here compares developments since 2010/11 rather than since 2008.

¹ Office for Disability Issues, 2008. Independent Living Strategy, Office for Disability Issues. <http://webarchive.nationalarchives.gov.uk/20130703133823/http://odi.dwp.gov.uk/docs/wor/ind/ilr-executive-report.pdf>

² See <http://odi.dwp.gov.uk/fulfilling-potential/index.php>

Progress against Independent Living Strategy commitments

There will be an increase over time in the proportion of disabled people saying they have choice and control over the support needed to go about their daily lives.

At the heart of the experience of independent living is the extent to which people feel that they have a say over their lives and, in particular, have control over how their support needs are met.

Choice and control was one of the Disability Equality Indicators adopted by the ODI and was last reported on using 2011 data. In 2008, 24 per cent of disabled people reported that they did not “frequently” have choice and control in their lives. This percentage fell slightly over the next two years but in 2011 increased to 26 per cent.³

A recent analysis of people’s experiences of autonomy found that disabled people “are significantly less likely to be ‘able to do the things that are important’ to them.” This research also found that limited autonomy was particularly strong amongst disabled people aged 16-44.⁴

The authors comment:

“...the scope of this lack of autonomy – across components of autonomy and across areas of life – is striking. It affects family life, relationships and personal safety as well as the more familiar problem areas of education and employment. Disabled people are at greater risk of experiencing barriers to autonomy related to poverty and location as well as health, and face a significant problem of pressure from others; and among disabled people, those with low socio-economic status are worst affected.”⁵

Amongst people using social care services funded by local authorities there has been a small increase in numbers saying they have choice and control. In 2012-13, 32 per cent reported they have as much control as they want over their daily life (30 per cent reported this in 2010-11) and 44 per cent reported they have adequate control (down one percentage point from 2010-11).

³ Office for Disability Issues: Disability Equality Indicators <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php> Data taken from ONS Opinion Survey.

⁴ Burchardt, T, Evans, M. and Holder, H. 2013. Public Policy and Inequalities of Choice and Autonomy, London School of Economics. <http://goo.gl/OXb0Wf>

⁵ Ibid., p.20.

Nineteen per cent reported they have some control but not enough, and four per cent reported they have no control (both measurements down by one per cent since 2010-11).⁶

The available data indicates therefore that there has been no significant progress in disabled people's experiences of choice and control in their lives since 2008.

Support and equipment will be more personalised and fit better into people's lives; there will be an increased take-up of direct payments/individual budgets across all service user groups.

The main mechanism for increasing choice and control has been the implementation of personal budgets and self-directed support in the delivery of

social care, together with the more recent introduction of personal health budgets.

The Care Act 2014 gives people an entitlement to a personal budget, and progress is being made in that:

- the percentage of people aged 18 to 64 who were in receipt of personal budgets and/or direct payments rose from 38.3 per cent in 2011-12 to 51 per cent in 2012-13; and
- the percentage of people aged 65 and over in receipt of personal budgets and/or direct payments rose from 45.2 per cent in 2011-12 to 57.9 per cent in 2012-13.⁷

The National Personal Budgets Survey⁸ reported on the outcomes and experience of people using personal budgets and family carers. The report showed that in important areas of life and support, having a personal budget had a positive impact across groups. It also showed the process and practice conditions that are correlated with better outcomes. These included people's ability to influence support plans, and councils making the processes easy to use.

⁶ Health and Social Care Information Centre, 2011. Personal Social Services Adult Social Care Survey - England, 2010-2011, Final <http://www.hscic.gov.uk/pubs/adultsocialcaresurvey1011> and Health and Social Care Information Centre, 2013. Personal Social Services Adult Social Care Survey, England - 2012-13, Final release. <http://www.hscic.gov.uk/catalogue/PUB13182>

⁷ Health and Social Care Information Centre, 2014. Community Care Statistics Social Services Activity, England 2012-13, Final Release. <http://www.hscic.gov.uk/catalogue/PUB13148/comm-care-stat-act-eng-2012-13-fin-rep.pdf>

⁸ Hatton, C, Waters, J. and Routledge, M. 2013. National Personal Budgets Survey http://www.thinklocalactpersonal.org.uk/_library/POETSummaryFINAL.pdf

However, many councils surveyed are not implementing according to these best practices. Personal budgets (whether taken as a direct payment or control over a budget) are intended to enable disabled people to exert choice and control over the support they need in their daily lives. In support of the National Personal Budgets Survey findings, common anecdotal evidence indicates that some local authorities are implementing personal budgets in ways which do not deliver this choice and control.⁹ This includes: budgets set at levels which do not provide sufficient support (see discussion below); restrictions placed on how personal budgets can be used; a failure to audit personal budgets by outcomes achieved and instead requiring the purchase of specific units of time and type of service; requiring record-keeping and other tasks which disabled people and/or carers find onerous and time-consuming. A small-scale study of people with learning disabilities' experiences of personalisation concluded that the 'choice and control' agenda is not compatible with current aims of reducing expenditure (see discussion below).¹⁰

Most of the increase in personal budgets in recent years is accounted for by council-managed budgets, the increase in numbers using direct payments is smaller and there are also wide variations across local authority areas and service user groups. For example only 4.2 per cent of people using mental health services were reported in the latest NHS Information Centre Survey as using self-directed support. In the council with the highest percentage of direct payments users you are 24 times more likely to get a direct payment than in the poorest performer.¹¹

Improving the Life Chances of Disabled People, the 25-year government strategy launched in 2005, had identified that the fragmentation of support across different funding streams and responsibilities was a major barrier to choice and control.

The Right to Control - included in the Welfare Reform Act of 2007 - was intended to address this. This sought to bring together six different funding streams and give disabled people control over how the resources they were entitled to were used. However, it has been discontinued following the trailblazer phase.

⁹ See, for example, <http://markneary1dotcom1.wordpress.com/2014/05/27/the-personal-budget-review/>

¹⁰ Kendall, S. and Cameron, A. 2013. 'Personalisation of adult social care: self-directed support and the choice and control agenda' British Journal of Learning Disabilities.

¹¹ Hatton, C. and Waters J. Presentation to Ministerial Personalisation Summit September 2103 <http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9649>

People who need support in their daily lives will experience increased opportunities to participate in family and community life; older people with support needs will be accessing the same range of options and opportunities for independent living as younger disabled people.

Expenditure on social care by local authorities fell by £4 billion between 2010/11 and 2012/13, and is predicted to fall by a further £4 billion by 2015 - a total reduction of 33 per cent.¹² The consequences are significant for disabled people who need support to go about their daily lives and to participate in 'family and community life'.

The reduction in social care funding has led to a widespread increase in eligibility thresholds: almost nine out of 10 councils now only support people with 'substantial' or 'critical' needs. It has been calculated that this has led to 69,000 working age disabled adults with moderate needs and 8,000 with substantial needs losing their eligibility for social care.¹³ Amongst older people, the drop is even greater: almost a quarter of a million fewer older people received social

care support in 2012/13 compared to 2009/10, a reduction of 26 per cent, while the number receiving home-delivered meals has more than halved since 2009/10.¹⁴

Even if people are eligible, the level of support may be inadequate. The United Kingdom Homecare Association (which represents home care providers) has expressed concern about the squeeze on the length of time that home care visits take and the amount paid by local authorities. A third of providers in their survey were worried about risks to the dignity of service users and/or the safety of the care that local councils require them to undertake for older and disabled people. Providers also reported that sometimes the level of direct payments is not sufficient to buy the number of hours required.¹⁵

¹² Duffy, S. 2013. A fair society?, Centre for Welfare Reform, <http://www.centreforwelfarereform.org/library/by-date/a-fair-society1.html>; Duffy, S. 2014. Counting the Cuts, Centre for Welfare Reform. <http://www.centreforwelfarereform.org/library/by-date/counting-the-cuts.html>

¹³ Promoting independence, preventing crisis, All Party Parliamentary Local Government Group & All Party Parliamentary Disability Group, April 2013, from modelling published by Fernandez, Snell, Forder & Witten-berg in "Implications of setting eligibility criteria for adult social care at moderate needs level", PSSRU at LSE, DP2851, 2013

¹⁴ Ismail, S, Thorlby, R. and Holder, H. 2014. Focus on: Social care for older people. Nuffield Foundation. <http://www.nuffieldtrust.org.uk/publications/focus-social-care-older-people>

¹⁵ Angel, C. 2012. Care is not a commodity: UKHCA Commissioning Survey 2012, United Kingdom Homecare Association. <http://www.ukhca.co.uk/downloads.aspx?ID=356>

A survey of 619 disabled people of working age,¹⁶ carried out by Scope in 2012, reported that:

- 36 per cent of respondents did not have enough support to eat, wash, dress or get out of the house.
- 47 per cent said the services they receive do not enable them to take part in community life and 34 per cent were unable to work or take part in volunteering or training activities after losing support services.
- 38 per cent of those seeking support said they experienced added stress, strained relationships and overall decline in the wellbeing of friends and family.
- 53 per cent said they felt anxious, isolated, or experienced declining mental health because they had lost care and support services.

The Independent Living Fund (ILF) - the main mechanism for enabling disabled people under 64 with high support needs to live in their own homes and to have choice and control - was closed to new applicants in 2010 and is to be abolished in 2015.

Responsibility for funding support to this group of disabled people will be transferred to local authorities.

Disabled people in receipt of ILF grants have voiced their fears that they may be forced into residential care. That this may well not be an unfounded fear is confirmed by the National Association of Financial Assessment Officers (the people who carry out the means-test to determine whether disabled and older people should be charged for their care) who told the government “some councils may determine that residential care would be a less expensive option than a high cost home care package”.¹⁷ The Association of Directors of Adult Social Services and the Local Government Association told the government that “the value of the personal budget calculated through the Resource Allocation System (RAS) will generally be at a lower level than the initial ILF/LA [Independent Living Fund/Local Authority] budget”.¹⁸

The Coalition government accepted that this will be the case when it published an Equality Analysis on closure of the Independent Living Fund.¹⁹

¹⁶ Brawn, E. et al. 2013. The other care crisis: Making social care funding work for disabled adults in England, Scope. http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/The-other-care-crisis_1.pdf?ext=.pdf

¹⁷ National Association of Financial Assessment Officers, 2012. Response to consultation on the future of the ILF. <http://webarchive.nationalarchives.gov.uk/+http://www.dwp.gov.uk/consultations/2012/future-of-ilf-organisations.shtml>

¹⁸ Association of Directors of Adult Social Services and Local Government Association, 2012. Response to consultation on the future of the ILF. <http://webarchive.nationalarchives.gov.uk/+http://www.dwp.gov.uk/consultations/2012/future-of-ilf-organisations.shtml>

¹⁹ Department for Work and Pensions, 2014. Closure of the Independent Living Fund: Equality Analysis. <http://goo.gl/LG9EO7>

There is also evidence that people with learning difficulties may be particularly disadvantaged in terms of their access to 'family and community life'. They account for an increasingly large proportion of social care expenditure²⁰ and will be particularly affected by the squeeze on council funding. Moreover, people with 'severe learning disabilities' make up the largest single group (33 per cent) whose support needs are currently funded by the ILF, and the government has recognised they are likely to experience a reduction in their support package when transferred to local authority funding.²¹

In 2010, a total of 3,376 people with learning difficulties were living in NHS in-patient units. The government committed to move all of them to community-based provision by June 2014 but has now admitted that this will not be achieved. Data collected in September 2013 showed a reduction of only 126²², and between December 2013 and March 2014 there were more people admitted to units than transferred out.²³

More than two-thirds had been given anti-psychotic medication in the period leading up to the census in September 2013 and of these, more than nine out of 10 were given such medication on a regular basis. Nearly six in 10 had been the subject of at least one incident involving self-harm, an accident, physical assault on the service user, hands-on restraint or seclusion during the three months preceding the census.

A survey carried out by Mind and the College of Social Work found that more than three-quarters of mental health social workers and more than 90 per cent of chief executives of local Minds who responded to the survey said that the mental health of people living in the communities where they work had got worse over the past 12 months. More than three-quarters of the mental health social workers surveyed said they were concerned that informal carers and families are now expected to carry too much responsibility for looking after people with mental health service needs.²⁴

²⁰ Brawn, E. et al. 2013. The other care crisis: Making social care funding work for disabled adults in England, Scope. <http://goo.gl/ZSWkKx>

²¹ Department for Work and Pensions, 2014. Closure of the Independent Living Fund: Equality Analysis. <http://goo.gl/O97HS5> p.10.

²² Heath and Social Care Information Centre, 2014. Learning Disabilities Census Report: Further analysis. <http://www.hscic.gov.uk/catalogue/PUB14046/ld-census-further-sep13-rep.pdf>

²³ NHS England, 2014. Assuring Transformation: Meeting the Winterbourne View Concordat commitments: Draft summary information from NHS commissioners first quarterly return <http://www.england.nhs.uk/wp-content/uploads/2014/05/at-data-0314.pdf>

²⁴ The College of Social Work, 2014. Mental Health Crisis in Communities. <http://goo.gl/0m52TL>

Surveys by the Royal College of Psychiatrists and the journal 'Community Care' found:

- More than 1,700 beds catering for people with mental health difficulties were closed between 2011 and 2013.
- Adult psychiatric wards are running occupancy levels of more than 100 per cent, meaning some patients are being sent to private hospitals miles from home or admitted to NHS hospitals without a bed.
- “Critically unwell” patients are being sent home because of the shortage of beds.²⁵

There is therefore evidence that, far from disabled people “who need support in their daily lives [experiencing] increased opportunities to participate in family and community life”, such opportunities are in fact diminishing. Older people are finding it more difficult to access support and therefore their “options and opportunities for independent living” are diminishing. People with high levels of support needs are at increasing risk of institutionalisation and, while mental health needs are increasing, access to mental health services is becoming more and more difficult.

Individuals and their families (including self-funders) will have access to a range of high quality information and advice, advocacy and support brokerage; there will be an increase in information and advice, advocacy, support and brokerage services, including those provided by user-led organisations.

There is no data which would enable us to have a comprehensive picture of progress on this commitment. However, we do know that there has been no increase in the percentage of those using social care services who say they find information either easy or fairly easy to find since 2010; in 2013 - as in 2010 – more than one in four find information either fairly or very difficult to find.²⁶

²⁵ See <http://www.communitycare.co.uk/2013/10/16/patients-at-risk-as-unsafe-mental-health-services-reach-crisis-point-2/#.U6gFjxZ0W3c> and <http://goo.gl/kTyCHG>

²⁶ Health and Social Care Information Centre, 2013. Personal Social Services Adult Social Care Survey, England: 2012-13 Final release. <http://www.hscic.gov.uk/catalogue/PUB13182/per-soc-ser-adu-soc-car-sur-eng-2012-13-fin-report.pdf>. p.59

Funding for learning disability self-advocacy groups fell by 15 per cent between 2009-10 and 2012-13²⁷ and in 2011, People First reported that local People First self-advocacy groups had dropped from 120 to 97 because of council funding cuts.²⁸ There is much anecdotal information about advice and advocacy services closing due to lack of funding: for example, the Dementia Advocacy Network folded at the end of 2013.²⁹ A survey of 54 disabled people's organisations in London found that one in five faced closure in 2012 or 2013, and three out of four had experienced cuts in funding, some of them very significant reductions.³⁰

Concerns have been expressed about the impact of reductions in legal aid provision following the Legal Aid, Sentencing and Punishment of Offenders Act 2012. Submissions to the Justice Select Committee show that Citizens Advice Bureaux have lost £19 million of funding annually with consequent withdrawal of specialist help for approximately 120,000 social welfare law cases in the financial year 2013-14 and a sixth of Law Centres closed in the first year of implementation of the Act. Mind submitted

the results of a survey of its members to the Select Committee, which indicated that only 12 per cent were able to get the advice they needed. A number of submissions highlighted the disproportionate impact on 'vulnerable people' of the reductions in legal aid and consequent cuts in advice, information and legal services.³¹ Figures released by the Ministry for Justice indicate that there has been a reduction in the number of civil cases supported by legal aid between 2009/10 and 2013/14 of two-thirds, accompanied, for example, by a reduction of welfare benefit legal aid providers from 359 in 2011/12 to 11 in 2013/14.³²

²⁷ Roberts, H. et al. 2013. Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. <http://goo.gl/dvwprnv>

²⁸ <http://goo.gl/BnUgBZ>

²⁹ <http://goo.gl/PlfhhM>

³⁰ Inclusion London, 2012. A Matter of Survival: Funding experiences of London's Deaf and disabled people's organisations and implications for disability equality. Inclusion London. <http://www.inclusionlondon.co.uk/a-matter-of-survival>

³¹ See <http://goo.gl/ZaU0lj> for summary of submissions.

³² Ministry for Justice, 2014. Legal Aid Statistics in England and Wales, 2013-14, <http://goo.gl/ixKVuY>

There will be a narrowing of the employment gap between disabled and non-disabled people.

According to the Labour Force Survey, the employment gap between disabled and non-disabled people fell by about 10 per cent between 2002 and 2010. There has been no improvement since then and the employment gap remains at 30 per cent.

The Coalition government's Disability and Health Employment Strategy acknowledges that "The employment rate for working-age people with a long-term health condition is only 58 per cent, compared with 77 per cent for working-age people without a health condition". For disabled people it is lower, at 45 per cent, and for individuals with a mental health condition it is only 37 per cent."³³ For working age adults with learning disabilities known to local authorities, seven per cent are in any form of paid employment; 70 per cent of these were working for less than 16 hours per week.³⁴

Scope's analysis of Labour Force Survey results for 2012/13 found that during that year:

429,000 disabled people fell out of work, and only 207,000 disabled people moved into work. This means that 220,000 more disabled people left work than moved into it.

By contrast, the movement amongst the rest of the population is overwhelmingly in the other direction: 560,000 more non-disabled people found work than became unemployed or inactive.³⁵

Ten per cent of unemployed disabled people have been out of work for five years or more, compared with three per cent of non-disabled people. Scope's analysis also found that the employment gap is likely to widen because disabled people are under-represented amongst the occupations where employment is growing but over-represented amongst those occupations which are declining.

Current policies to support disabled people into employment seem unlikely to make much of an impact on this situation. Only five per cent of disabled people on the Work Programme have found a job.³⁶

³³ Department for Work and Pensions, 2013. The disability and health employment strategy: the discussion so far. <https://www.gov.uk/government/publications/the-disability-and-health-employment-strategy-the-discussion-so-far>

³⁴ Public Health England, 2103. People With Learning Disabilities in England

³⁵ Scope, 2014. A million futures: halving the disability employment gap, Scope. <http://www.scope.org.uk/publications/million-futures>

³⁶ Department for Work and Pensions, 2014. Work Programme statistical summary, March 2014 <http://goo.gl/joxLys>

Although the recent success rate for the specialist Work Choice Programme is much better – 43 per cent found work³⁷ - only one per cent receive this form of support, according to a recent Department for Work and Pensions (DWP) survey of disabled people receiving Job Seekers Allowance (JSA) or Incapacity Benefit/ Employment Support Allowance. (ESA)³⁸ The same survey found that almost seven out of 10 were not receiving any support to find work and “among claimants who were receiving support, over half did not find this useful (60 [per cent]).” There is only one specialist disability employment advisor for every 600 disabled jobseekers in the Job Centre Plus service.³⁹

Half of the claimants accessing support felt under “a lot” of pressure from Jobcentre Plus or their employment advisor to look for work (52 per cent) but the main barriers cited by disabled people seeking employment were lack of jobs (60 per cent),

employer attitudes (42 per cent), lack of qualifications/experience/skills (41 per cent) and transport barriers (37 per cent).⁴⁰

Access to Work funding has now been extended to work experience placements and internships and an additional £2 million was allocated by DWP for this purpose.⁴¹ However, the numbers receiving support from Access to Work fell during 2010/11 and 2011/12 and has only shown a small increase in 2012/13. In 2009/10, 37,280 disabled people received assistance from the programme while in 2012/13 the total was 31,500 - a drop of 16 per cent.⁴²

Since 2008, reforms to Incapacity Benefit mean 650,000 more disabled people are now expected to seek work or risk losing their benefits (see also discussion below on sanctions).⁴³

³⁷ Department for Work and Pensions, 2014. Work Choice: Official Statistics. <http://goo.gl/29EQwL> The rate of ‘success’ for the Work Choice programme may need to be treated with some caution as there have been allegations of fraudulent returns - namely providers claiming that unpaid 6 month work placements meet the 6 months in paid work outcome. See <http://goo.gl/B53oXg>

³⁸ Department for Work and Pensions, 2013. A survey of disabled working age benefit claimants <http://goo.gl/6ziNp1>

³⁹ Trotter, R. 2014. A million futures: halving the disability employment gap, Scope. <http://www.scope.org.uk/publications/million-futures> p.25.

⁴⁰ Department for Work and Pensions, 2013. A survey of disabled working age benefit claimants <http://goo.gl/xbFgYC>

⁴¹ Department for Work and Pensions, 2013. Access to work funding extended to help more disabled people into work, Press Release <http://goo.gl/h4C3ji>

⁴² Department for Work and Pensions, 2014. Access to work: Official Statistics <http://goo.gl/wHjtJJ>

⁴³ Analysis by Scope of DWP statistics on outcomes of Work Capability Assessments 2014: <https://www.gov.uk/government/publications/esa-outcomes-of-work-capability-assessments-march-2014>

Alongside this has been an increase in negative attitudes towards people claiming out-of-work sickness/disability benefits. For example, an analysis of newspaper articles between 1995 and 2011 found that over that period there has been a growth in articles with negative content and a fall in articles with more sympathetic content.⁴⁴

An Ipsos Mori poll carried out in 2011 found that 47 per cent of disabled people said that attitudes towards them had got worse in the past year, while focus groups of benefit recipients reported the impact of stigma on their sense of self-worth.⁴⁵

Current data from DWP indicates that the numbers of people determined as eligible for ESA are going up⁴⁶ - whereas forward planning of expenditure on welfare benefits shows ESA expenditure going down.

There will be fewer disabled people, and children of disabled parents, living in poverty.

The proportion of households with a disabled member who are living in poverty fell between 2003/4 and 2011/12 - from 30 per cent to 24 per cent - but they are still more likely to be living in poverty than households without a disabled member (of whom 20 per cent are living in poverty). If Disability Living Allowance (DLA) and Attendance Allowance (which are intended to pay for the additional costs of disability, rather than ordinary day to day expenditure) are discounted, this doubles the number of people in poverty who receive these benefits. "For children, the number rises to 390,000 from 240,000. For working-age adults there is an increase from 730,000 to 1,300,000. The largest proportional increase is for pensioners, where the number in poverty trebles, from 180,000 to 560,000."⁴⁷

There have been a number of attempts to measure disability-related costs, and the most recent survey carried out on behalf of Scope estimated these to be an average of £550 per week.⁴⁸

⁴⁴ Baumberg, B, Bell, K, and Gaffney, D. 2013. 'Disabled people have never had it so bad' New Statesman, March 22nd. <http://goo.gl/kvaqqE>

⁴⁵ Baumberg, B. et al, 2013. Benefits stigma in Britain, Turn to Us. <http://goo.gl/zpgCXG>

⁴⁶ Employment and Support Allowance: Outcomes of Work Capability Assessments <http://goo.gl/avvsoV>

⁴⁷ MacInnes, et al, 2013. Monitoring Poverty and Social Exclusion, New Poverty Institute/Joseph Rowntree Foundation. <http://goo.gl/iv8tcv> p.28

⁴⁸ Wood, C. and Grant, D. 2010. Counting the Cost, Demos. <http://goo.gl/VbhR6z>

The impact of disability-related additional costs combined with lower average incomes can be seen in the facts that disabled people are twice as likely to have unsecured debt totalling more than half their household income and have significantly fewer savings and assets than non-disabled people.⁴⁹

Demos has calculated that the cumulative impact of welfare reform, together with abolition of the ILF, will result in 3.7 million disabled people experiencing some reduction of income, and, over the period to 2017 they would lose £28 billion as a group.⁵⁰

A number of people already assessed as having additional disability-related costs are set to lose their DLA as it is replaced by Personal Independence Payment. 560,000 people currently receiving DLA are to be reassessed for Personal Independent Payment by October 2015 and of these, 160,000 are expected to receive a lower amount of money and 170,000 to receive no additional cost benefit at all.⁵¹ Delays in assessments and decision-making have resulted in a back-log of 760,000 with many people waiting for many months without payment, including those with a terminal diagnosis.⁵²

The introduction of Universal Credit will be accompanied by the removal of benefits resulting in a reduction in the income of some disabled households:

- Replacement of the disability element of child tax credit with a 'disability addition' in Universal Credit, will result in a cut from £57 to £28 a week and affect an estimated 100,000 children with high care needs.
- Abolition of the Severe Disability Premium, provided to adults with severe impairment who have no one living with them to assist them. Some people with the most severe impairments will continue to receive a very reduced sum. This will affect about 230,000 people.
- Abolition of the disability element of working tax credit will remove £54 a week from adults who are in work but have extra costs because of disability. Anyone receiving this will have to take the Work Capability Assessment: if found 'fit for work' they will receive no extra financial support, and if found to have 'limited capability for work' will receive a lower rate of support than that of working tax credits.

⁴⁹ Brawn, E. 2014. Priced Out: Ending the financial penalty of disability by 2020, Scope.<http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Extra-Costs-Report.pdf?ext=.pdf>

⁵⁰ See <http://www.demos.co.uk/files/Table1-headline.pdf> and Wood, C. Destination Unknown - April 2013 <http://www.demos.co.uk/blog/destinationunknownapril2013>

⁵¹ Department for Work and Pensions, 2012. Personal Independence Payment: Reassessments and Impact <http://webarchive.nationalarchives.gov.uk/+http://www.dwp.gov.uk/docs/pip-reassessments-and-impacts.pdf> Table 2.

⁵² <http://www.bbc.co.uk/news/uk-politics-27926419>

There is considerable evidence that disabled people are disproportionately affected by other aspects of welfare reform, resulting in a reduction in their household income:

- Disabled people are more likely to be affected by the “bedroom tax”: the government’s impact assessment estimated that 420,000 disabled people would receive a reduction in their housing benefit.⁵³ Households where health or disability issues make it inappropriate for a couple or a child to share a bedroom, and/or where specific adaptations have been made to the property are not exempt from a reduction in their housing benefit and have to apply for a discretionary housing payment. Such short-term, temporary payments are an inappropriate response to long-term needs and there is inconsistency as to how local authorities are implementing such support.⁵⁴
- One in four households affected by the overall benefit cap are in receipt of ESA and are experiencing a reduction in their household income.⁵⁵
- In 2013 there were 27,595 sanctions imposed on ESA claimants in the Work Related Activity Group. Scope’s analysis of DWP data indicates that, including

disabled JSA claimants, a total of 120,000 disabled people have had their benefits suspended since November 2012.⁵⁶ Payment of benefit is immediately stopped or reduced following a sanction, very few claimants appeal, and there is increasing anecdotal evidence of destitution amongst those affected.

- The abolition of council tax benefit, passing responsibility onto local councils to develop their own rebate scheme, together with a 10 per cent cut in the government grant, will have a disproportionate impact on working age disabled people. Nearly half of all council tax benefit is paid to households where an adult is claiming a disability-related benefit - and this figure is even higher if it includes those with a disabled child in the household.⁵⁷ Councils are required to protect pensioner households and this means the reduction in funding is more like 19 per cent. It is estimated that seven out of 10 councils will pass on the cut to households receiving council tax benefit and that up to a total of 1.38 million disabled households will be worse off as a result of this reform.⁵⁸

⁵³ Department for Work and Pensions, 2012. Housing Benefit: Size criteria for people renting in the social housing sector - Equality impact assessment, updated June 2012, DWP. <http://goo.gl/vOCd8Z> Paragraph 43.

⁵⁴ Wilcox, S. 2014. Housing Benefit Size Criteria: Impacts for social sector tenants and options for reform, Joseph Rowntree Foundation. <http://goo.gl/tr53lu>

⁵⁵ Aldridge, H. and MacInnes, T. 2014. Multiple cuts for the poorest families, Oxfam Research Reports, <http://goo.gl/spw311> p.10.

⁵⁶ Trotter, R. 2014. A million futures: halving the disability employment gap. Scope. <http://goo.gl/ytRW4T> p.24.

⁵⁷ Adam, S. and Browne, J. 2012. Reforming council tax benefit, Institute for Fiscal Studies. <http://www.ifs.org.uk/comms/comm123.pdf>

⁵⁸ <http://www.demos.co.uk/files/Table1-headline.pdf>

- ‘Digital by default’ policies are making it harder for some disabled people to access the support they are entitled to. As the ODI recognises “Sixty per cent of disabled people can access the Internet at home – much less than the 86 per cent of non-disabled people who can. Access varies – it is only 40 per cent among disabled women aged over 64.”⁵⁹

There has been particular concern expressed of the cumulative impact on disabled people of welfare reform, coupled with reductions in funding for social care and the increase in VAT (which has a disproportionate impact on poorer households).⁶⁰ The government’s advisory committee on social security drew attention to the cumulative impact of welfare reform on disabled people, “because they are both more likely to be claiming multiple benefits, and less likely to be able to change their behaviour to mitigate the impact of reforms.”⁶¹

There is mounting evidence of the substantial negative impact of welfare reform on disabled people’s quality of life. Research carried out by Ipsos Mori on behalf of the National Housing Federation found that amongst households affected by the “bedroom tax”

(61 per cent of whom include someone with a disability or long-term illness), nine out of 10 are concerned about meeting their living costs, 32 per cent have cut back on meals and 26 per cent on heating.⁶² The cumulative impact of cuts in benefits and services appears to be also creating additional support needs: a survey by Mind and the College of Social Work found a “worrying picture” of increasing numbers of people becoming “overwhelmed by life circumstances” and trying to access mental health services.⁶³

The Independent Living Strategy included a commitment to carry out “an investigation of the cumulative impact of reforms to the benefits system, employment support programmes and charging policies within adult social care, to establish whether their combined impact promotes disability equality”. This commitment has not been completed. At the same time, there is conclusive evidence that large numbers of disabled people have experienced a reduction in their household income since 2010.

⁵⁹ Office for Disability Issues, 2013. Fulfilling Potential: Building a deeper understanding of disability in the UK today - Summary report. Office for Disability Issues. <http://goo.gl/VtwjBM> p.7

⁶⁰ See for example, Wood, C. and Grant, E. 2011. Tracking the lives of disabled families through the cuts: Destination Unknown Spring 2011. Demos; Duffy, S. 2013. A fair society?, Centre for Welfare Reform, <http://goo.gl/EpEiTb> Duffy, S. 2014. Counting the Cuts, Centre for Welfare Reform. <http://goo.gl/qlzhP5>

⁶¹ Social Security Advisory Committee, 2014. The cumulative impact of welfare reform: a commentary, Social Security Advisory Committee. <http://goo.gl/vgBWef> p.30

⁶² National Housing Federation, 2014. One Year On: The impact of welfare reforms on housing association tenants. <http://goo.gl/bfYr2q>

⁶³ The College of Social Work, 2014. Mental Health Crisis in Communities. <http://goo.gl/bHAZ5S>

Disabled people will experience increased housing opportunities and will be more likely to live in housing which is suited to their needs.

There is a dearth of data which would enable us to properly assess progress on this commitment. However, what evidence there is would tend to indicate that progress is limited, and that housing opportunities for some disabled people have worsened in recent years.

For example, disabled people are over-represented in the social housing sector but have experienced diminishing housing opportunities in this sector owing to the reduction in social housing over the past 20 years or so: in 2001, 33 per cent of households containing a disabled person were social housing tenants and by 2011 this had fallen to 13 per cent.⁶⁴ Mencap's research found that in 2011, an estimated 8,578 people with a learning disability were newly referred to local authorities for housing support while 10,000 people were registered on local authority housing waiting

lists. Almost four in 10 people with learning disabilities known to local authorities live with their families and of these seven out of 10 want to change their housing situation.⁶⁵

We have already noted that disabled people are disproportionately affected by the "bedroom tax". There is anecdotal evidence of disabled people living in especially adapted social housing who are deemed to be 'over-occupying' yet the social housing sector does not offer appropriate alternatives. One example concerns Derby where more than 170 adapted properties were deemed to be over-occupied but there are only nine adapted smaller social housing properties available.⁶⁶ Research carried out for the National Housing Federation by Ipsos Mori found that 70 per cent of people affected by the "bedroom tax" are worried that they will be evicted as a result of rent arrears.⁶⁷

⁶⁴ Department of Communities and Local Government, 2012. English Housing Survey: Households 2011-12. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212496/EHS_HOUSEHOLDS_REPORT_2011-12.pdf p.72

⁶⁵ Mencap, 2012. Housing for people with a learning disability, Mencap

⁶⁶ <http://www.derbytelegraph.co.uk/Bedroom-tax-Derby-s-disabled-devastated-homes/story-21056085-detail/story.html>

⁶⁷ National Housing Federation, 2014. One Year On: The impact of welfare reforms on housing association tenants. <http://nationalhousingfederation.newsweaver.com/files/1/55885/107295/5121661/141c5f6656934a57920e80c6/Impact%20of%20welfare%20reforms%20on%20housing%20association%20tenants.pdf>

The numbers of people accepted as homeless by local authorities reduced considerably between 2003 and 2010 but has increased since then, and this pattern also applies to people accepted as homeless because of old age, physical disability, or mental illness.⁶⁸ Since 2010, “rough sleepers”, the majority of whom have a mental health problem, have increased by 37 per cent while the number of bed spaces to accommodate them has reduced by 12 per cent.⁶⁹

In 2011, 15 per cent of households that included one or more people with a long term limiting illness or disability felt that their current home was not suitable for their needs.⁷⁰ One in five people with learning disabilities are living in accommodation which “needs improvement”.⁷¹

Disabled Facilities Grants (DFG), administered by local authorities with funding provided by government, are the main policy response to the need for adaptations to a home. DFG funding rose each year up from 1997-98 until 2011-12 but has since levelled off.⁷² Research by the Department for Communities and Local Government in 2013 concluded that:

There is a very large demand for adaptations with English house condition survey estimating that some 720 thousand households living in the private sector or renting from housing associations require some adaptations. Around half of these (367 thousand) would be eligible for a grant of at least £1,000 under the current means test. The average amount of grant payable for those eligible would be £5,191 and therefore the amount needed to cover grants for all of those who are theoretically eligible is £1.9 billion at 2005 prices. This is more than 10 times higher than the total amount of disabled facilities grant allocated in England in 2009-10 (£157 million).⁷³

⁶⁸ See Department for Communities and Local Government, Live Tables on Homelessness <https://www.gov.uk/government/statistical-data-sets/live-tables-on-homelessness> - Table 773: Statutory homelessness. Households accepted as owed a main homeless duty by local authorities, by priority need category, England 1998-2013,

⁶⁹ Homeless Link, 2013. Support for single homeless people in England. <http://goo.gl/v5p9re>

⁷⁰ Department of Communities and Local Government, 2012. English Housing Survey: Households 2011-12. <http://goo.gl/CJIMbn> p.70

⁷¹ Mencap, 2012. Housing for people with a learning disability, Mencap

⁷² House of Commons Library, 2013. Disabled Facilities Grants (England) Standard Note SN/SP/3011, House of Commons Library.

⁷³ Department for Communities and Local Government, 2011. Disabled Facilities Grant allocation methodology and means test, DCLG. <http://goo.gl/JVnlwC> para.2.2

Since 2008-9, local authorities have not been required to add to the government allocation they receive for adaptations (previously it was a 60-40 government/local authority split) and in 2010-11 the allocation ceased to be ring-fenced. Although the government announced in 2013 that it would make an additional £40 million available for DFGs in 2015-16, it also announced that all of the DFG funding would be included in the Integration Transformation Fund, a pooled fund intended to enable NHS and local authorities to work together to jointly commission services⁷⁴ (renamed the Better Care Fund).

In terms of new housing, there is concern that recent policy direction has not been sufficiently encouraging of Lifetime Homes Standards, the building standards which require that homes are built to a basic access standard and to be easily adapted should the need arise. A research report for the District Councils' Network and the Society of District Council Treasurers, based on a survey of district councils in England, states that "most new-build homes are still not designed to meet the needs of disabled people, nor to be readily adaptable".⁷⁵ The Good Practice guide on Planning and Access

for Disabled People has been cancelled and archived following the publication of the National Planning Policy Framework; and Design and Access statements have been scrapped for the majority of planning applications. The government's review of planning guidance concluded that the content of the previous Good Practice guide was generally "understood" but organisations such as Habinteg argue that "widespread on-going problems of accessibility would suggest this is very optimistic". Architects specialising in accessible housing were very concerned at the abolition of Design and Access statements with one commenting that the change marked a "worrying reversal for inclusive design, especially for housing".⁷⁶

⁷⁴ House of Commons Library, 2013. Disabled Facilities Grants (England) Standard Note SN/SP/3011, House of Commons Library.

⁷⁵ Astral Advisory, 2013. Disabled Facilities Grants in England. <http://districtcouncils.info/files/2013/07/DFG-Report-Final-pdf.pdf>

⁷⁶ Habinteg Housing Association, 2013. Meeting the Housing Needs of Disabled People, Habinteg. http://www.habinteg.org.uk/mediaFiles/downloads/87088651/Meeting_the_housing_needs_of_disabled_people_final_report.pdf

While there is little data concerning disabled people's housing experiences in the private rented sector, the decision not to introduce a duty for landlords to allow reasonable adjustments to "common parts" (part of the Equality Act 2010) will reduce the likelihood of this housing sector providing suitable housing. The last government's Impact Assessment calculated that reducing the number of disabled people who are "prisoners in their own homes" would have resulted in home care savings of around £15 million for local authorities and cutting the number of people entering residential care could result in savings of up to £25 million.⁷⁷

A small survey by Trailblazers, the young campaigners network of people with muscular dystrophy, indicates the kinds of problems faced by young disabled people: lack of knowledge amongst estate agents and lettings agencies about adapted and accessible housing; difficulties with private landlords when adaptations are required; and a general lack of confidence about being able to move away from the parental home.⁷⁸

Research on older people's housing opportunities concluded that "there is very limited choice for older person households moving home to accommodate their support needs (in terms of tenure, location, size, affordability and type of care/support)". Around five per cent of older people live in specialist housing with support and there is evidence of a reduction in on-site support which has "affected the quality of life for some residents, especially those aged 85+ and/or with high support needs".

Research on older people's housing opportunities concluded that "there is very limited choice for older person households moving home to accommodate their support needs (in terms of tenure, location, size, affordability and type of care/support)".⁷⁹ Around five per cent of older people live in specialist housing with support and there is evidence of a reduction in on-site support which has "affected the quality of life for some residents, especially those aged 85+ and/or with high support needs".⁸⁰

⁷⁷ HM Government, 2010. Equality Act 2010 Impact Assessment, <http://goo.gl/6af4EP>

⁷⁸ Trailblazers, 2013. Locked Out: The Trailblazers' report into accessible housing, Muscular Dystrophy Society. <http://goo.gl/nglrzj>

⁷⁹ Pannell, J, Aldridge, H. and Kenway, P. 2012. Market Assessment of Housing Options for Older People, New Policy Institute. <http://goo.gl/oTx5wc>

⁸⁰ Pannell, J. and Blood, I. 2012. Supported Housing for Older People in the UK: an evidence review, Joseph Rowntree Foundation. <http://goo.gl/PzV80T>

Disabled people will have improved access to information and travel training, so they can make informed choices about using public transport and about alternatives when public transport is not suitable for them; disabled people will experience transport providers as being helpful and facilitating their access; it will be easier for disabled people to use public transport.

When the ODI commissioned research in 2010 on disabled people's experiences of choice and control in their lives, transport was one of the most frequent issues mentioned:

Access to appropriate forms of transport was a key factor in explaining the amount of choice and control participants felt they had. Lack of transport was often mentioned as a barrier affecting all areas of participant's lives, particularly for those reliant on public transport. Lack of regular, accessible and direct public transport resulted in participants not being able to go shopping, attend courses, or take part in leisure activities. Participants who experienced these barriers tended to feel they had less choice and control over the areas of life discussed. In comparison, those who had access to transport as and when they needed it, usually because they owned a car, were more likely to report having choice and control in many aspects of their lives.⁸¹

There has been some progress in terms of improving disabled people's access to transport. For example, the percentage of disabled people experiencing difficulties in using transport dropped from 25 per cent in 2008 to 22 per cent in 2011; and the percentage of accessible buses increased from 76 per cent in 2008-9 to 88 per cent in 2011-12.⁸² However, bus and coach providers are not required to be compliant with accessibility regulations until 2020 and many bus routes advertised as being operated with accessible buses sometimes run step access only buses.⁸³

⁸¹ Ipsos Mori, 2010. The Life Opportunities of Disabled People, Office for Disability Issues. <http://odi.dwp.gov.uk/docs/res/los/los-qr-cc.pdf> p.14.

⁸² Office for Disability Issues, Disability Equality Indicators - data taken from the ONS Opinion Survey. <http://goo.gl/mQ6ysf>

⁸³ House of Commons Select Committee on Transport, 2013. Access to transport for disabled people, <http://goo.gl/j2uBcs>

There is also evidence that access to transport may have worsened for some groups: the Life Opportunities Survey of 2009-11 reported that 17 per cent of unemployed disabled people experienced transport barriers⁸⁴ whereas research carried out by the Department of Work and Pensions in 2013 found that 42 per cent of disabled people claiming JSA and 36 per cent of those on ESA/WRAG cite difficulties with transport as a barrier to employment.⁸⁵ Cost of transport may well be an increasingly significant barrier for people claiming benefits, particularly because of the reducing value of benefits and increase in sanctions (discussed above).

Young disabled people gave evidence to an All Party Parliamentary Group in 2012 about the barriers they experience to transport, including: attitudes of service providers; difficulties with the Assisted Passenger Reservation Service; inaccessibility of much of the London Underground; poor or no access to some railway stations; barriers at all stages of using air travel.⁸⁶

The Department for Transport has cut funding for the Access for All rail programme from £43 million to £25 million annually between 2015 and 2019, a reduction of 42 per cent⁸⁷ and is also likely to drop two more rail access schemes. Although rail industry staff are required to have disability awareness training, the government exercised an exemption to the EU requirement for bus and coach operators to provide disability awareness training to staff.⁸⁹

For those who have the greatest difficulties using public transport, the Taxicard scheme provides subsidised journeys by taxi. However, since 2011 Transport for London has reduced funding to London boroughs, resulting in a cut in the number of journeys individuals can make, an increase in the fares they pay and a reduction in the length of journeys they can make.⁹⁰

Further funding cuts in 2013 meant, for example, that disabled people in Harrow can only have 20 return journeys per year⁹¹ while in Newham - which funds the highest number of subsidised journeys - the previous total of return journeys is being cut by 72 per cent over 2013 and 2014, from 261 to 72.⁹²

⁸⁴ Life Opportunities Survey Wave 1 2009/2011, Appendix Table 20.2, cited in Office for Disability Issues, 2013. Fulfilling Potential: Building a deeper understanding of disability in the UK today, <http://goo.gl/kCLnhY> Slide 65

⁸⁵ Department for Work and Pensions, 2013. A survey of working age benefit claimants, DWP. <http://goo.gl/WUg718>

⁸⁶ All Party Parliamentary Group on Young Disabled People, 2012. Removing barriers, promoting independence. <http://goo.gl/wQL6BT>

⁸⁷ Independent 13th April 2014. <http://goo.gl/zQFwXV>

⁸⁸ <http://goo.gl/h0KPHm>

⁸⁹ House of Commons Select Committee on Transport, 2013. Access to transport for disabled people, <http://goo.gl/EU2IC6>

⁹⁰ <http://www.transportforall.org.uk/news/taxicard-cuts-start-today>

⁹¹ <http://www.harrowtimes.co.uk/news/10594316.print/>

⁹² <http://goo.gl/21jS8O>

Conclusion

When the Independent Living Strategy was published in 2008, it had all-party support and was widely welcomed by disabled people. Indeed, one disability organisation said that public policy “doesn’t get much better than this”. It is of great concern, therefore, that there is a lack of significant progress on important commitments and that, instead, disabled people are experiencing diminishing opportunities for independent living. In these really difficult times, it is hoped that the evidence presented here can be used to alert government (national and local) that action is needed if we are not to see continuing serious reversals for independent living after decades of sometimes slow but positive improvement.

Independent Living Strategy: A review of progress

Jenny Morris

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