



## **Report on the social inclusion and social protection of disabled people in European countries**

**Country:** United Kingdom

**Author(s):** Simon Prideaux, Bill Armer, Jennifer Harris, Laura Hemmingway, Alan Roulstone and Mark Priestley

### **Background:**

The [Academic Network of European Disability experts](#) (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the *Thematic report on the implementation of EU Social Inclusion and Social Protection Strategies in European countries with reference to equality for disabled people*.

The purpose of the report ([Terms of Reference](#)) is to review national implementation of the open method of coordination in Social inclusion and social protection, and in particular the National Strategic Reports of member states from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.

The first version of the report was published in 2008. This is the second version of the report updated with information available up to November 2009.



## Summary of changes since 2008

### Housing and homelessness:

Responsibility for housing is devolved to regional and local governments. Separate questionnaire responses were submitted for England, Scotland and Wales but not for Northern Ireland (see general ANED annex for details). Disabled people may be given priority in housing allocation and receive targeted housing benefit supplements. Allocated housing should also be 'suitable' (but this is not defined in terms of accessibility). The following points may also be argued from research evidence.

There are concerns about the high prevalence of people with impairments (particularly mental health conditions) amongst the homeless population but the characteristics of this population are not well known. Disabled people are less likely to own their own home. Public sector housing played a significant role in providing accessible and adapted housing in the past but there has been a significant decline in available stock since the implementation of 'right to buy' legislation. There has been significant new growth in the supported housing sector, including the role of housing associations. There are concerns that people are often forced to move house rather than aging in place after the onset or development of impairment (local authority tenants may be disadvantaged here by decisions to re-house rather than adapt, while home owners face financial barriers).

The Office for Disability Issues indicator set includes two items on the suitability of such housing for disabled people and their families. Data from the English House Condition Survey<sup>1</sup> suggest marginal year-on-year reductions in the proportion of households living in 'non-decent accommodation', with a marginally worse position for households including a disabled person (although not significantly differently)<sup>2</sup>. ODI also uses data from the Survey of English Housing to indicate the 'suitability of accommodation for disabled people requiring adaptations to their home', which suggest that around 80% of people requiring home adaptations feel that their accommodation meets their needs, with no significant change in recent years<sup>3</sup>. According to the ODI 'Experiences and Expectations' survey, 89% of disabled respondents reported that their accommodation was suitable to their needs, with less satisfaction amongst younger disabled people and particularly people with visual impairments.

### New strategies and actions for the inclusion of disabled people:

The UK government is running a consultation on the right to control<sup>4</sup> support services, from the 11th June to the 30th September 2009. The intention is that from 2010 number of pilot projects will be launched, where disabled people will be able to use funding from a number of different sources to buy the assistance they need for a range of purposes. The initiative is being launched by the Department of Work and Pensions and has a focus on giving disabled people choice and control over support in getting and keeping jobs.

The Health and Social Care Act (2008) legislates for the creation of a Care Quality Commission<sup>5</sup> to oversee regulation of health and adult social care services, as well as oversee the welfare of detained people with mental health conditions. The Act also requires the registration of health and social care workers. An amendment to the Act closed a loophole in the Human Rights Act, extending human rights protection to people in private care homes as well as those provided by public authorities. However people who fund their own health care in private homes are still not covered by the Human Rights Act.

<sup>1</sup> <http://www.communities.gov.uk/documents/statistics/pdf/1346262.pdf>

<sup>2</sup> <http://www.officefordisability.gov.uk/docs/res/annual-report/indicators/g2.pdf>

<sup>3</sup> <http://www.officefordisability.gov.uk/docs/res/annual-report/indicators/g1.pdf>

<sup>4</sup> <http://www.officefordisability.gov.uk/docs/wor/rtc/rtc-consult-standard.pdf>

<sup>5</sup> <http://www.cqc.org.uk/>



From the 12<sup>th</sup> October 2009, it will be an offence for an employer to employ anyone who has been barred from working with children and ‘vulnerable’ adults by the Independent Safeguarding Authority<sup>6</sup>. Registration of workers will start from 2010. The new measures present particular problems for disabled people employing personal assistants because they have been classed as ‘vulnerable people’ rather than employers in relation to personal assistants.

The Disabled Persons’ Parking Places (Scotland) Bill received royal assent on 1.4.09. This measure makes parking places for disabled people enforceable by law.

### **New changes in incomes, benefits and pensions:**

The main development over the past year concerns the replacement of Incapacity Benefit (IB), with the Employment and Support Allowance (ESA)<sup>7</sup>. The Department of Work and Pensions intends that the measure will ‘focus on what people can do, rather than what they can’t.’<sup>8</sup> The aim is to combine a greater expectation that disabled people will work, while granting disabled people a right to control the assistance they receive to do this.

IB claimants are being moved from IB to ESA from October 2009, via medical re-assessments that are more stringent than those for IB. There are four separate assessments, according to circumstances<sup>9</sup>. Three of these concern work capacity and one assesses financial circumstances.

Because of the complexity of change it is difficult to report precise changes in monetary value for these benefits as the circumstances and outcomes for individuals will vary under the new rules.

The number of Disability Living Allowance (DLA) recipients increased from 2,945,570 (Feb 2008) to 3,043,990 (Feb 2009). During the same reference period, the average amount of weekly payment increased from £64.43 to £67. Recipients of Incapacity Benefit / Severe Disablement Allowance (combined data) declined from 2,659,650 to 2,468,620 (approximately 8%). The average weekly payment increased from £53.79 to £56.08.

### **New changes in long-term care and support:**

Current policy continues to emphasise ‘personalisation’ (Leadbetter, 2004) and the pooling of different funding sources for which disabled people are eligible, so that recipients can exercise more choice and control over funds. A pilot study involving 13 local authorities (Glendinning et. al., 2008) concluded that administrative and bureaucratic obstacles presented difficulties with implementation. The Welfare Reform Bill has removed some of these barriers and further pilot projects are planned.

### **Implications of the economic crisis:**

There are no clear indications, as yet, of the social inclusion implications of the crisis. There is some evidence of marginal decline in employment rates, full-time jobs, and permanent contracts (see employment update). General elections are due within eight months and all political parties are committed to public spending restraint (to varying degrees). It is likely that public sector employment and public services will be affected, with likely impact on services and supports for disabled people.

<sup>6</sup> Independent Safeguarding Authority: <http://www.isa.gov.org.uk/>

<sup>7</sup> Employment and Support Allowance: [http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG\\_171894](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171894)

<sup>8</sup> Department for Work and Pensions: <http://campaigns.dwp.gov.uk/esa/key-facts.asp>

<sup>9</sup> Disability Alliance: <http://www.disabilityalliance.org/f32.htm>



## PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

### 1.1 Please describe how and where disabled people are included in your country's published plans for social inclusion and protection?

Disability has become an increasingly prominent issue in UK policy. Long term strategy is set out in the Prime Minister's Strategy Unit document *Improving the Life Chances of Disabled People* (PMSU 2005), a 20 year vision for the inclusion of disabled people by 2025 (see [www.strategy.gov.uk/work\\_areas/disability](http://www.strategy.gov.uk/work_areas/disability)). According to that document there are around 11 million disabled adults in the UK, or 21% of the population, with the number of adults reporting impairments rising by 22% from 8.7 million in 1975 to 10.7 million (pp. 34-35). Tony Blair, then Prime Minister, stated that:

*This Government is committed to improving the life chances of disabled people. Through the Disability Discrimination Act and the creation of the Disability Rights Commission, new rights are being provided and enforced. We are helping disabled people to get back into work through the New Deal and to have personalised support through Direct Payments (PMSU, 2005: 5).*

Within the Open Method of Co-ordination, the UK National Report on Strategies for Social Inclusion and Social Protection (2006-2008) makes extensive reference to disability and disabled people (there are 71 references in the document). There are both mainstream and specific actions to improve life chances. At the heart of New Labour's strategic approach is the recognition that disabled people are more severely affected in generic inequalities like unemployment, poverty and health.

In relation to 'Increasing Labour Market Participation' (Objective 2) there is a specific section on 'helping ill or disabled people' and in 'Tackling Discrimination' (Objective 4) a separate section on disability discrimination. In terms of discrimination, disabled people are highlighted as a significant group at risk of deprivation (p. 16) alongside people from ethnic minorities. In these respects, disability achieves a higher profile in the document than gender equality.

Disability is highlighted in three of the 'key challenges' areas. For example, eliminating child poverty has been a key concern of government strategy in recent years and a major consultation entitled 'Get Heard' (involving 146 workshops across the UK) revealed specific concerns about support for parents of disabled children. Access to employment highlights people leaving employment because of disability as a key target group. Responses from disabled people in the Get Heard consultation also include concerns to 'enforce equal opportunities policies and to ensure that employers know about the law' (*ibid.*).

The area of 'Tackling discrimination' identifies that disabled people are 'at higher risk of living in low income households' (29%) and that 'more than half of all households where no one has a job include a disabled person' (p. 21). According to one survey, a quarter of households including a disabled person were living on less than 60% median income (p37). Anti-discrimination policies have been viewed by government as a key response to poverty and social exclusion from labour markets. However, disability is not mentioned in the 'key challenges' topic of 'access to quality services', which is surprising (as discussed later). There is no mention of disability in relation to 'fuel poverty', which is a significant issue for those with reduced mobility and additional heating requirements living at home (especially in a time of spiralling fuel costs).

In terms of employment, disabled people are targeted (with other disadvantaged groups) for labour market activation policies under the 'New Deal' programme (see our UK country report on employment). European Social Fund projects investing in employability and skills also include disabled people as a target group, with intention this focus in the 2007-13 programmes.



The National Report proposed specific measures for ‘helping’ disabled people into work, using the characteristic New Labour approach to employment policy of ‘rights and responsibilities’ (p28).

Proposed actions included prevention of transitions out of work onto disability benefits, and a new focus on work ‘capability’ in medical assessments. In terms of accessibility, public transport was recognised as important (p34), with local authorities expected to monitor indicators. Under ‘e-government’, action was identified to ‘improve accessibility for the digitally excluded and ease of use for disabled people’ (p36), including accessibility of all government online services. There is brief mention of equality of access to healthcare (p57) but no specific actions relating to disability.

The key challenges identified in the National Report are reflected in the intervention programmes. In terms of child poverty, there is a mainstreaming approach (e.g. ‘helping’ all parents into work and providing financial support through tax credits). However, this does not include special measures on the additional costs of parenting a disabled child or the additional difficulties such parents may have in working. In this example, ‘mainstreaming’ amounts to visible recognition of special circumstances within the policy but no clear action to address these (i.e. they are addressed by measures outside the mainstream policy). Similarly, concern with educational disadvantage for disabled children (and ethnic minority children) is addressed in the mainstream only by increased ‘monitoring’, with the intention to target future mainstream actions, like the Every Child Matters programme, towards ‘the most vulnerable’. By contrast, action on poverty for older people, through the Pension Credit system, does include increased financial assistance, within the mainstream policy, for people with ‘severe disabilities’ and related housing costs.

The UK government has run a consultation on the right to control<sup>10</sup> support services, from the 11th June to the 30th September 2009. The intention is that from 2010 number of pilot projects will be launched, where disabled people will be able to use funding from a number of different sources to buy the assistance they need for a range of purposes. The initiative is to be launched in 2010 by the Department of Work and Pensions and has a focus on giving disabled people choice and control over support in getting and keeping jobs.

## **1.2 In reality, what major actions has your country taken and what are the positive or negative effects on disabled people? (policy or practical examples)**

Since publication of the 2006-2008 National Report there have been a number of significant developments, including:

- extension of anti-discrimination legislation to include public transport vehicles
- a new duty on public sector organisations to actively promote disability equality
- abolition of the Disability Rights Commission (DRC), and mainstreaming within a new ‘Equality and Human Rights Commission’ (EHRC)
- a new central government ‘Office for Disability Issues’ (ODI)
- a new strategy on independent living
- a new national policy advice network involving disabled people (Equality 2025)
- extension of the direct payments model towards individualised budgets

Implementation of the Disability Discrimination Act (1995 and 2005) suggests some successes, but legal support is hard to access (Roulstone, 2003) and some groups remain less aware of their rights, including people with learning difficulties (Lerpiniere and Stalker 2008). Part III (Provision of Goods, Facilities and Services) is little used but there has been a high success rate in cases of discrimination. By contrast, Part II (Employment) has been much used but with a lower success rate. Monitoring practical implementation is important because legal protection, and successful cases, do not necessarily produce social inclusion in any meaningful sense.

<sup>10</sup> <http://www.officefordisability.gov.uk/docs/wor/rtc/rtc-consult-standard.pdf>



A new Disability Equality Duty came into force in December 2006, which requires public bodies in Great Britain to promote disability equality in all areas of their work and to monitor indicators (this includes schools, colleges, hospitals, local government services etc as well as government departments). This includes mapping disability equality in the organisation, eliminating illegal discrimination, promoting positive attitudes and involving disabled people. Each organisation must publish a Disability Equality Scheme and Action Plan, and assess its impact. National government Ministers will produce reports in their sector every three years for strategic co-ordination (the first reports are due in December 2008). For more details see: [www.dotheduty.org](http://www.dotheduty.org).

Abolition of the Disability Rights Commission (the legal enforcement agency), in October 2007, and transfer of responsibilities to the EHRC is a significant development.

There are positive aspects to mainstreaming disability equality within a generic human rights agency, but there have been concerns that the specific needs of disabled people would not be adequately resourced in this structure. It is too early to be certain about the impact of this change on disabled people. See: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

At the same time, the government established the ODI, with a management board of senior officials from different government departments. The office is located in the Department for Work and Pensions and reports to the Minister for Disabled People (there is also a cross-department Ministerial Group). This approach may balance concerns about the profile for disability, with a single dedicated office 'championing' disability mainstreaming across all government departments (towards common policies goals and collective ownership/commitment for delivery). However, the ODI has little influence over Treasury or departmental budget allocations, which limits its influence in a period of economic downturn. See: [www.officefordisability.gov.uk/](http://www.officefordisability.gov.uk/)

A major review of support for independent living was set up in 2006 and a new strategy published by the ODI in 2008. The report emphasises the need to achieve dignity and full citizenship for disabled people. The proposals focus on (a) increased power, choice and control in how support and equipment for independent living are provided, and (b) 'significant progress in tackling barriers to disabled people's access to health, housing, transport, and employment opportunities'. In terms of support, the strategy is located within a wider 'personalisation' agenda for social care (discussed later in this report). For more details see: <http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp>

'Equality 2025' (established in December 2006) is a national network of 20-25 disabled people, appointed by the Minister for Disabled People to advise the UK government on policy issues arising from its long term strategy. Part of the group's function is to advise how government can 'engage effectively' with disabled people. Its work plan includes: contributing to policy development; independent investigations of policies or services; building the capacity and awareness of disabled people; and encouraging 'shared learning' between government and disabled people. Importantly, the new network does not replace existing mechanisms or claim to be a 'representative' organisation of disabled people, although the members consider themselves voluntarily accountable to disabled people and their organisations. Further details are available at: [www.officefordisability.gov.uk/equality2025](http://www.officefordisability.gov.uk/equality2025)

However there have also been serious concerns from the disabled people's movement, and researchers, about the sustainability of grass-roots organisations of disabled people in the UK. These user-led organisations have played a critical role in advocating progressive policies for many years but are finding it hard to survive in the absence of public funding. Local and national disability information and advice groups have been more effective in supporting legal (formal) rights than civil (substantive) rights. The *Life Chances* report and the independent living strategy proposed Centres for Independent Living in each locality, yet these type of organisations are amongst those at most risk in a competitive market for social care (discussed later).



In June 2008 the Minister for Care Services announced new funding for some disabled people's organisations to improve their sustainability and share good practice, by becoming 'Action and Learning Sites' (£900k to support up to 14 organisations).

The Health and Social Care Act (2008) legislates for the creation of a Care Quality Commission<sup>11</sup> to oversee regulation of health and adult social care services, as well as oversee the welfare of detained people with mental health conditions. The Act also requires the registration of health and social care workers. An amendment to the Act closed a loophole in the Human Rights Act, extending human rights protection to people in private care homes as well as those provided by public authorities. However people who fund their own health care in private homes are still not covered by the Human Rights Act.

From the 12 October 2009, it will be an offence for an employer to employ anyone who has been barred from working with children and 'vulnerable' adults by the Independent Safeguarding Authority<sup>12</sup>. Registration of workers will start from 2010. The new measures present particular problems for disabled people employing personal assistants because they have been classed as 'vulnerable people' rather than employers in relation to personal assistants.

The Disabled Persons' Parking Places (Scotland) Bill received royal assent on 1 March 2009. This measure makes parking places for disabled people enforceable by law.

### **1.3 What is the most recent research about disabled people's equality and social inclusion in your country?**

*NB: research on poverty and incomes, and care and support, is included in later sections.*

Establishment of the ODI has resulted in some improvement in access to relevant research publications, statistics and indicators (such as those previously published by the Disability Rights Commission). A series of brief ODI 'factsheets' have been collated from a range of official statistics on topics such as civic participation, crime, culture and leisure, employment, housing, and transport.

For example, data from the British Crime Survey suggest that disabled people have a greater fear of crime, and less confidence in the criminal justice system, than non-disabled people. The Taking Part survey reveals less participation by disabled people in sport and cultural activities, such as visits to arts events, cinema, museums, etc. Housing surveys (e.g. the Survey for English Housing) suggest that fewer disabled people own their own house, and that more are unsatisfied with the suitability of their accommodation (especially for disabled children and for people living in private rented accommodation). Key facts can be found at: [www.officefordisability.gov.uk/research/Research-keyfacts.asp](http://www.officefordisability.gov.uk/research/Research-keyfacts.asp)

There has been a considerable amount of research and evaluation in the area of employment (addressed in our UK country report on that theme). Berthoud and Blekesaune (2007) compared employment disadvantage for different groups over a 30 year period, and found that 'Disabled people face one of the largest employment penalties of all social groups being compared' (p. 2) and that the gap relative to other groups widened from 1970s to 2003. The data and definitions are complex and there is substantial variation amongst disabled people. However, in contrast to the other most disadvantaged groups (mothers and Muslim women) 'The employment position of disabled people has deteriorated over the last 30 years' (p. 3). For details of a large number of other recent studies on disability and employment, see: [www.officefordisability.gov.uk/research/Research-employment.asp](http://www.officefordisability.gov.uk/research/Research-employment.asp)

<sup>11</sup> <http://www.cqc.org.uk/>

<sup>12</sup> Independent Safeguarding Authority: <http://www.isa.gov.org.uk/>



Research commissioned by the DRC in 2006 highlighted the 'transport gap' between disabled and non-disabled people (Jolly et al. 2006). For example, disabled people attach greater importance to public transport but are less likely to go out or make long journeys (over half of disabled people would like to go out more often). Disabled people find it difficult to travel to basic services, and are twice as likely to turn down a job because of travel difficulties. Lack of access to a car is more than twice as high for disabled people and almost half are totally reliant upon public transport. Relatively few rail stations are accessible. Income differences mean that, on average, disabled people may spend a greater proportion of income on travel costs. However, there is some evidence of improved satisfaction and accessibility. For example, data from the Department for Transport's Annual Sample Survey of Bus Operators suggests that the number of buses with low-floor access has increased dramatically in recent years. Sentinella (2006) found less evidence of progress in air travel.

Beresford, Rabiee and Sloper (2007) questioned the value of mainstream policy indicators in relation to outcomes for disabled children and their parents, and developed a set of participation needs identified by children and families themselves. This, and related research, highlights the potential importance of self-defined indicators in monitoring social inclusion.





## PART TWO: INCOMES, PENSIONS AND BENEFITS

### 2.1 Research publications (key points)

Data from the Family Resources Survey shows extensive risk of poverty for disabled people in the UK and of child poverty in particular.

**Table 1: Risk of living in low-income households (percentage of individuals)<sup>13</sup>**

Income Thresholds - Below Median Disability and receipt of disability benefits	After Housing Costs			All individuals (millions)
	50%	60%	70%	
No disabled adult, no disabled child	14	20	27	42.8
No disabled adult, 1 or more disabled child	20	30	41	1.5
In receipt of disability benefits	8	19	34	0.4
Not in receipt of disability benefits	24	34	43	1.1
1 or more disabled adult, no disabled child	18	26	36	14.4
In receipt of disability benefits	10	17	27	4.7
Not in receipt of disability benefits	21	31	40	9.7
1 or more disabled adult, 1 or more disabled child		23	34	47
In receipt of disability benefits		8	18	33
Not in receipt of disability benefits		33	45	56

It is difficult to compare incomes when needs and costs vary between people (see, Zaidi and Burchardt 2003) and Tibble (2005) identifies the difficulty in measuring the 'extra costs' of living for disabled people, or knowing whether financial benefits cover these costs. However, a report edited by Preston (2006) illustrates the links between disability and poverty, providing evidence from statistical indicators and interviews with disabled parents. An updated summary in December 2007 suggests that a third of disabled adults of working age are living in poverty (this is double the rate for non-disabled people, and the gap has widened in the last decade). The findings argue that, for disabled adults, the government's anti-poverty strategy of 'work for those who can, security for those who cannot' is failing on both counts. Thus, many disabled people who want to work cannot find work and a disproportionate number who do not work are living in poor households.

Some of the key data and indicators from this work are now incorporated into 'The Poverty Site'. For example, almost 3 in 5 people on out-of-work benefits are sick or disabled, many are younger adults and there is no evidence of significant reduction in their number. Disabled people in work are more likely to be low paid, irrespective of their level of educational qualification. There is particular concern about people with intellectual impairments and mental health conditions, who are considerably over-represented in poor households. See: [www.poverty.org.uk/summary/disability.htm](http://www.poverty.org.uk/summary/disability.htm).

It is not easy to determine the risk of poverty for disabled people across different impairment types. However a recent report from the Parckar, Leonard Cheshire Foundation (2008) on *Disability Poverty in the UK* provides an overview and recommends some useful measures. It is worth noting that the main risk of poverty for disabled adults is being out of work, but that disabled adults in jobless households are actually less likely to be at risk of low income than non-disabled adults.

<sup>13</sup> Source, Family Resources Survey 2006/7, adapted from [http://www.dwp.gov.uk/asd/hbai/hbai2007/excel\\_files/chapters/chapter\\_3\\_excel\\_hbai08.xls#3.6!A1](http://www.dwp.gov.uk/asd/hbai/hbai2007/excel_files/chapters/chapter_3_excel_hbai08.xls#3.6!A1)



Specific concern has also been raised about the link between parental mental health and child poverty, particularly because only 24% of people with long term mental health conditions are employed (see Gould 2006). This research also makes the important point that disability-employment benefit rules need to be sufficiently flexible to accommodate people with fluctuating health conditions. Data from the Labour Force Survey (2007) shows the risk of unemployment (and thereby poverty) also to be significantly higher for people described as having ‘mental illness’ than for people with other conditions (see Parckar 2008).

Stafford et al. (2007) evaluate the impact of the New Deal for Disabled People (NDDP), a national employment activation programme for people claiming disability-related income benefits (discussed in our UK country report on employment). The NDDP is central to the Government’s welfare to work strategy, and involves a ‘voluntary’ programme of advice and practical support to help people from disability benefits into employment. Stafford *et al.* conclude that NDDP is highly beneficial from the Government’s perspective - allowing for reductions in benefit payments, the cost of administering benefits and increases in tax revenue, cost was reduced by more than £2,500 for an average longer-term benefit claimant and by about £750-1,000 for a more recent participant.

Greenberg and Davis (2007) examine the cost-benefit of investing in ‘Job Brokers’ within the programme and conclude that ‘For each pound expended on NDDP, the Government saved between £3.41 and £4.50 for continuing claimants and between £1.71 and £2.26 for new claimants’ (p. 4). However, they also conclude that there is considerable uncertainty about the financial benefits for NDDP participants: especially longer-term claimants. Reviewing this and other data, Stafford et al, 2007 conclude that, for the average longer-term benefit claimant, the net benefit of the programme was £348. Yet, for more recent claimants there was a *negative* benefit of -£155. The net benefit received by longer-term participants was almost entirely attributable to tax credits resulting from employment status, and the gain in earnings was almost entirely offset by loss of incapacity-related benefits, Housing and Council Tax benefits, and indirect taxes.

By comparison with research on social care and employment (including welfare to work), there is a relative lack of recent work on disability, poverty and social protection. For example, more research is required on levels of unmet needs, older disabled people’s social exclusion, the extra living costs for disabled people, the impact of rising food and fuel prices, the work-welfare interface, how disabled people construct notions of social inclusion, and the impact on them of government discourses about disabled welfare recipients (see Barnes and Mercer 2005).

## 2.2 Type and level of benefits (key points and examples)

The system of financial benefits and entitlements available to disabled people in the UK is complex, and further details are provided on the government website <http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport>. Local level data on individual recipients of specific benefits is published quarterly by the Department of Work and Pensions (<http://83.244.183.180/NESS/BEN/iben.htm>) broken down by age, gender, type of impairment and length of claim. The overall figures used here are derived from the DWP Tabulation Tool (<http://83.244.183.180/100pc/tabtool.html>) using most recent figures available.

The number of working-age people in the UK receiving ‘out of work’ benefits fell from around 6 million in 1997 to less than 5 million in 2007, although the number receiving sickness or disability related benefits within this group has remained constant at around 2.7 million (although the number receiving such benefits for more than two years increased from 1.9 million to around 2.2 million in the same period).

The number of Disability Living Allowance (DLA) recipients increased from 2,945,570 (Feb 2008) to 3,043,990 (Feb 2009). During the same reference period, the average amount of weekly payment increased from £64.43 to £67. Recipients of Incapacity Benefit / Severe Disablement Allowance (combined data) declined from 2,659,650 to 2,468,620 (approximately 8%). The average weekly payment increased from £53.79 to £56.08.

**Incapacity Benefit:** Incapacity Benefit (IB) is available to adults who cannot work because of illness or disability (provided they have paid National Insurance contributions, are not receiving Statutory Sick Pay, and were below retirement when they became disabled). It is available to people whose illness or impairment started before the 27 October 2008. IB is paid at three weekly rates: short-term lower rate (£67.75); short-term higher rate (£80.15); long-term (£89.80). Older people, over state retirement age, receive higher short-term payments (£89.80 and £86.20) but are not eligible for long-term IB (although they may get an addition if they were under 45 when they became unable to work). From October 2008, however, the Welfare Reform Act 2007 replaced Incapacity Benefit with a new 'Employment and Support Allowance' and most people (of working age) are now expected to engage in some work-related activity (see also section 2.3).

Claims for IB can be made if unable to work for at least four consecutive days, or for two or more out of seven consecutive days. Young people who have never worked (or recently completing education) and people out of work for more than 28 weeks may be able to claim without National Insurance contributions. When making a claim there is a Personal Capability Assessment (PCA). The PCA is undertaken by an approved Disability Analyst (DA), who may recommend a medical examination if they need to obtain more information. Claimants complete a questionnaire about how the effects of disability/illness on their ability to perform everyday tasks. The individual's doctor may be asked to provide a medical report. The DA decides whether the claim is upheld or not. In February 2008 the average weekly amount received was £52.57 (£47.31 for women and £56.25 for men).

**Table 2: Incapacity Benefit/ Severe Disablement Allowance Caseload (Thousands) : Age of claimant by Gender of claimant. Time Series=MAY09**

	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Total</b>	2,374.21	1,017.01	1,357.20	-
<b>Age of claimant</b>	0.08	0.03	0.05	-
<b>Unknown age</b>				
<b>16-17</b>	2.73	1.15	1.58	-
<b>18-24</b>	118.26	53.85	64.42	-
<b>25-34</b>	282.46	121.08	161.38	-
<b>35-44</b>	509.85	230.35	279.50	-
<b>45-49</b>	331.49	163.20	168.30	-
<b>50-54</b>	363.83	186.98	176.85	-
<b>55-59</b>	440.32	226.75	213.58	-

	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>60-64</b>	294.26	9.80	284.46	-
<b>65 and over</b>	30.92	23.82	7.10	

**Disability Living Allowance:** available to claimants under 65 who require some assistance and support in daily life (in or out of work). It is also available to parents of disabled children. However, it is an additional income benefit and there is no requirement to prove the money is spent on care. DLA includes two components: the 'care' component is paid at three different rates (high £70.35; middle £47.10; low £18.65) and the 'mobility' component at two rates (higher £49.10; lower £18.65). Recipients might therefore receive payment in the range of £18.65 to £119.45 per week. DLA is usually paid without a medical examination and without reference to other sources of income. In February 2008 the average weekly amount received was £64.43 (with no significant gender difference).

**Table 3: Disability Living Allowance - all entitled cases Caseload (Thousands) : Age of claimant by Gender of claimant. Time Series=MAY09**

	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Total</b>	3,096.39	1,542.32	1,554.08	-
<b>Age of claimant</b>	0.12	0.08	0.04	-
<b>Unknown age</b>				
<b>Under 5</b>	43.96	16.99	26.97	-
<b>5 to under 11</b>	130.15	40.27	89.88	-
<b>11 to under 16</b>	143.97	43.35	100.63	-
<b>16 - 17</b>	48.98	16.20	32.77	-
<b>18 - 24</b>	136.25	54.85	81.40	-

	Total		Gender of claimant		
	Caseload (Thousands)	Female	Male	Unknown	
		Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>25 - 29</b>	94.95	43.74	51.21	-	
<b>30 - 34</b>	103.98	50.19	53.79	-	
<b>35 - 39</b>	154.52	78.61	75.91	-	
<b>40 - 44</b>	208.49	109.27	99.22	-	
<b>45 - 49</b>	243.56	130.84	112.72	-	
<b>50 - 54</b>	266.29	146.07	120.22	-	
<b>55 - 59</b>	316.22	173.02	143.20	-	
<b>60 - 64</b>	406.16	216.44	189.72	-	
<b>65 - 69</b>	344.62	179.82	164.80	-	
<b>70 - 74</b>	247.63	129.05	118.58	-	
<b>75 - 79</b>	145.30	78.63	66.67	-	
<b>80 - 84</b>	49.23	27.55	21.68	-	
<b>85 - 89</b>	10.87	6.56	4.31	-	
<b>90 and over</b>	1.12	0.77	0.35		

**Table 4: Disability Living Allowance - all entitled cases Caseload (Thousands) : Care Award Type by Gender of claimant. Time Series=MAY09**

	Total		Gender of claimant		
	Caseload (Thousands)	Female	Male	Unknown	
		Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Total</b>	3,096.39	1,542.32	1,554.08	-	
<b>Care Award Type</b>	753.09	381.35	371.74	-	
<b>Higher Rate</b>					



	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Middle Rate</b>	1,056.12	491.12	565.01	-
<b>Lower Rate</b>	861.27	462.48	398.79	-
<b>Nil Rate</b>	425.91	207.37	218.54	-

**Attendance Allowance:** Claimants over 65 may receive Attendance Allowance (AA) under very similar conditions to DLA. The higher rate is £75.35 and the lower rate £47.10. DLA and AA are not counted as taxable income. In February 2008 the average weekly amount received was £54.71 (with no significant gender difference).

**Table 5: Attendance Allowance - all entitled cases Caseload (Thousands) : Age of claimant by Gender of claimant. Time Series=MAY09**

	Total	Gender of claimant	
		Female	Male
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Total</b>	1,758.70	1,198.60	560.10
<b>Age of claimant</b>	0.06	0.03	0.03
<b>Unknown age</b>			
<b>65 - 69</b>	58.13	32.11	26.02
<b>70 - 74</b>	187.21	109.12	78.09
<b>75 - 79</b>	321.99	201.57	120.42
<b>80 - 84</b>	453.36	304.13	149.24
<b>85 - 89</b>	457.01	329.82	127.19
<b>90 and over</b>	280.94	221.83	59.11

**Income Support disability premium:** Income Support is a general means-tested benefit paid to people who are not available to work and do not have a basic level of income. Disabled people under the age of 60 who receive Income Support may be eligible for an additional 'premium' payment (e.g. if they already receive one of the other disability benefits described above, they have been unable to work for a year, or they are registered blind, etc.).

**Table 6: Income Support claimants with a disability premium by age and gender: 1997 and 2005**

		All claimants	Males			Females		
			Under 18	18 to 24	25 to 59	Under 18	18 to 24	25 to 59
1998	February	42,620	160	1,820	23,000	160	1,760	15,720
1999	February	45,380	160	2,080	24,020	100	1,920	17,100
2000	February	46,460	160	2,380	23,720	160	2,000	18,040
2001	February	49,800	100	2,300	26,200	140	1,820	19,240
2002	February	52,640	140	2,440	27,460	140	1,820	20,640
2003	February	54,900	140	2,180	28,880	100	1,560	22,040
2004	February	57,480	160	2,060	29,840	140	1,580	23,700
2005	February	59,300	120	2,180	30,580	*	1,480	24,900
2006	February	59,640	100	2,140	30,500	*	1,680	25,180
2007	February	59,600	120	2,060	29,740	*	1,460	26,140
2008	February	58,100	*	2,060	28,760	0	1,440	25,800
2009	February	58,500	*	2,120	28,800	*	1,540	25,980

**Industrial Injuries Disablement Benefit:**

Industrial Injuries Disablement Benefit can be paid to people aged 16-65 who became disabled through work-related accident or illness (but not self-employed people). The degree/percentage of disability is assessed by a doctor and there are nine rates of pay from £28.72 per week (20%) to £143.60 (100%), with lower rates for people aged under 18.

**Table 7: Industrial Injuries Disablement Benefit and Reduced Earnings Allowance in payment**

			<i>Thousands</i>			
Total <sup>1</sup>			Industrial Injuries Disablement Benefit only	Reduced Earnings Allowance only	IIDB with Reduced Earnings Allowance	Not Known <sup>2</sup>
1998	March	343.0	194.3	81.0	67.8	.
2007	March	334.240	204.480	69.360	60.400	10

**War Disablement Pension:** People who become disabled as a consequence of armed service may be eligible for a War Disablement Pension. The medical assessment is similar with a pension paid at more than 20%. There is also an Armed Forces Compensation Scheme, which can provide an additional lump sum payment.

**Constant Attendance Allowance:** Some disabled people who receive Industrial Injuries Disablement Benefit are eligible for the Constant Attendance Allowance (if they are certified as '100% disabled' in a medical examination and require care every day). The same benefit may be payable to people receiving an 80% War Disablement Pension and needing care for that reason. There are four rates (exceptional £115.00; intermediate £86.25; normal maximum £57.50; part-time £28.75).

**Severe Disablement Allowance:** New claims for Severe Disablement Allowance (for disabled people unable to work for six months) were stopped in 2001 but some previous claimants still receive this. The maximum rate is £57.45 per week.

There are, in addition, a number of financial concessions available to disabled people. For example, households may receive a reduction in Council Tax (a local tax based on the value of the house) where additional space is required because of disability, such as an additional bathroom, ground floor bedroom or accessible parking space. Tenants on low incomes who receive Housing Benefit from the local authority may also claim an additional disability premium. Disabled people may be eligible for National Insurance credits because of incapacity.

On top of these benefits, there are some financial concessions on transport. For example, in most local areas, disabled people are able to travel free or at half price on public transport (a national scheme in Scotland) and there is a national Disabled Person's Railcard, which allows tickets to be purchased at half price. Most specialist equipment and services are exempt from VAT and registered blind people receive a 50% discount on the TV licence. Some private providers of services (such as cinemas) may offer reduced entry prices.

The national minimum wage was last updated in October 2009 and is payable to everyone working legally who is not self-employed. There are currently three rates of minimum pay (£3.57 for those under 18; £4.83 aged 18-21; £5.80 aged 22 and over). Assuming a 35 hour working week at the higher rate, a full-time worker might therefore expect to earn a minimum of £203.00 gross per week. It is not easy to make direct comparisons with levels of income for disabled people out of work and receiving benefits (including combinations of mainstream and disability-related benefits for low income households). There are few scenarios in which an individual disabled person out of work would receive income benefits equivalent to the full-time minimum wage. Some disability benefits are retained in employment but significant concerns have been expressed about the 'benefits trap' that leaves some disabled people and families with a higher residual income out of work than in. A kind of 'Disability Income Guarantee' (originally part of the Minimum Income Guarantee, until 2003) is achieved via the Income Support disability premium.

The overall number of claimants for all combinations of benefits<sup>14</sup> (by gender) is shown in the following table:

	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Total</b>	18,655.36	10,681.69	7,973.68	-
<b>Benefit combination</b>	8,300.36	5,044.25	3,256.10	-
<b>SP only</b>				
<b>SP and PC/IS</b>	1,108.71	725.22	383.49	-
<b>JSA only</b>	1,414.51	364.82	1,049.69	-

<sup>14</sup> **Benefit being claimed:** Attendance Allowance (AA), Bereavement Benefit (BB), Carer's Allowance (CA), Disability Living Allowance (DLA), Incapacity Benefit/Severe Disablement Allowance (IB), Income Support (IS), Jobseeker's Allowance (JSA), Pension Credit (PC), State Pension (SP) and Widow's Benefit (WB)





	<b>Total</b>	<b>Gender of claimant</b>		
		<b>Female</b>	<b>Male</b>	<b>Unknown</b>
	<b>Caseload (Thousands)</b>	<b>Caseload (Thousands)</b>	<b>Caseload (Thousands)</b>	<b>Caseload (Thousands)</b>
<b>IB only</b>	531.94	222.48	309.47	-
<b>SP and AA</b>	881.73	552.12	329.61	-
<b>IS/PC only</b>	860.59	689.94	170.65	-
<b>IS/PC, SP and AA</b>	733.11	560.53	172.58	-
<b>DLA only</b>	696.48	296.95	399.53	-
<b>IS/PC and IB</b>	492.70	191.80	300.90	-
<b>IB and DLA</b>	523.54	217.88	305.67	-
<b>SP and DLA</b>	526.66	324.04	202.63	-
<b>IS/PC, IB and DLA</b>	528.91	220.67	308.24	-
<b>IS/PC, SP and DLA</b>	355.13	220.73	134.40	-
<b>CA only</b>	293.36	229.20	64.16	-
<b>IS/PC, DLA and SDA</b>	168.36	81.80	86.55	-
<b>IS/PC and CA</b>	161.34	104.93	56.42	-
<b>CA and SP</b>	156.69	112.91	43.78	-
<b>WB only</b>	50.11	50.11	-	-
<b>DLA, SDA</b>	50.67	38.20	12.47	-
<b>IS/PC, CA and SP</b>	80.49	40.44	40.05	-
<b>SDA only</b>	6.89	4.79	2.11	-
<b>SDA and IS/PC</b>	11.09	5.86	5.23	-
<b>ESA</b>	240.77	94.87	145.90	-
<b>ESA and DLA</b>	41.64	19.19	22.45	-



	Total	Gender of claimant		
		Female	Male	Unknown
	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)	Caseload (Thousands)
<b>Other Combination</b>	439.59	267.97	171.63	-

### 2.3 Policy and practice (summary)

While there has been considerable and increasing attention to the legal rights and social inclusion of disabled people in recent years, there has been rather less attention to their financial circumstances and disproportionate poverty. The modernisation of policies has focused on streamlining a complex benefits system towards a primary focus on employment activation programmes (which generate cost benefits for government but not necessarily for recipients). The benefits system is complex and appears to provide basic levels of income security against absolute poverty, but in relative terms poverty remains a very substantial problem. In general, there is no major incentive to choose disability benefits over employment but there is evidence of a ‘benefits trap’ for some disabled people and families. This problem is exacerbated by extra costs of living, low pay, and disabling barriers to employment, transport and family life. There is considerable pressure in the current work-welfare regime for disabled adults to engage in work or employment training and this pressure will increase with new reforms in 2010.

The main development over the past year concerns the replacement of Incapacity Benefit (IB), with the Employment and Support Allowance (ESA)<sup>15</sup>. The Department of Work and Pensions intends that the measure will ‘focus on what people can do, rather than what they can’t.’<sup>16</sup> The aim is to combine a greater expectation that disabled people will work, while granting disabled people a right to control the assistance they receive to do this.

IB claimants are being moved from IB to ESA from October 2009, via medical re-assessments that are more stringent than those for IB. There are four separate assessments, according to circumstances<sup>17</sup>. Three of these concern work capacity and one assesses financial circumstances. Because of the complexity of change it is difficult to report precise changes in monetary value for these benefits as the circumstances and outcomes for individuals will vary under the new rules.

<sup>15</sup> Employment and Support Allowance:

[http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG\\_171894](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171894)

<sup>16</sup> Department for Work and Pensions: <http://campaigns.dwp.gov.uk/esa/key-facts.asp>

<sup>17</sup> Disability Alliance: <http://www.disabilityalliance.org/f32.htm>



## SECTION THREE: CARE AND SUPPORT

### 3.1 Recent research publications (key points)

Hurstfield et al. (2007) found extensive gaps in knowledge about the costs and benefits of support for independent living and no systematic means of comparison with traditional service provision. However, preliminary conclusions do support the view that independent living (e.g. supported through direct payments) is less expensive than traditional institutional care and support. In addition, 'considerable cost savings could accrue to the Exchequer, in increased tax revenues and reduced benefits payments, from investing in independent living support' (p. 96). These findings were supported by case study research in five localities - for example, it was cheaper to support disabled children in local schools than residential special schools, or to support parents with learning difficulties to look after their children rather than to taking them into care.

Similarly, Heywood and Turner (2006) conclude that investing in housing adaptations and equipment led to 'better outcomes and lower costs', because of savings on expensive residential care or intensive home support. They cite numerous examples of substantial cost savings from their evidence review. For example, the cost of adapting to accommodate a 'seriously disabled wheelchair user' at home could be saved within one year compared to residential care (saving £26,000 from care budgets, minus an average of £6,000 for adaptations). An hour a week of help at home can cost £5,000 per year, so investing in adaptations and equipment could therefore save £millions on a national scale. However, they note that the potential cost savings appear much lower for older disabled people. See also Mansell et al (2007).

There have been concerns about equity in the provision of support for independent living in different regions of the UK, and between different groups. Priestley et al. (2006/7) and Davey et al. (2007) found enormous variation in the implementation of direct payments policies in different parts of the UK. Overall, direct payments were most often provided to people with physical or sensory impairments, and least often to people with mental health conditions. Local leadership, professional practices and discretion play a very significant part in determining who benefits in practice.

Pilot projects for 'individualised budgets' (discussed later) have been completed and evaluated. Challis et al. (2007) reviewed early evidence and found that there were 'winners and losers' in the new system – and that mental health service users were again being left behind. However, there has been optimism about the potential for increased choice and control by disabled people. The full evaluation report and other publications are available at: <http://php.york.ac.uk/inst/spru/research/summs/ibsen.php>

There remains a significant information gap about the availability of local health and social care services (Picker Institute 2007) in some areas, although good practice shows that co-ordinated disability information advice services and Centres for Independent Living can play an important role in informing disabled people about the options available to them.

There is a need for continuing research on personalised support and individual budgets (including the limitations of these mechanisms in delivering social inclusion). There is also a need to explore the management of direct payments as 'work' in which disabled people become producers of welfare and employers of staff (Woodin 2006).

### 3.2 Types of care and support (key points and examples)

Care and support services for disabled people in the UK are delivered by a wide variety of public, voluntary and private sector providers, and by family and friends. However, the majority are funded through a public system of 'community care'.



The mechanism for receiving support depends on a health and social care assessment, usually carried out by the local authority social services department (social work department in Scotland, or health and social service trust in Northern Ireland).

The assessor may be a social worker, disability specialist (such as an occupational therapist), or other individual. This provides the gateway to funding for help at home, specialist equipment, care provided in day centres, specialist childcare, residential institutions, etc. In some cases there is a 'single assessment' for all services in which health and social care teams collaborate and share information. It is not necessary to 'register' as a disabled person to receive these kinds of services (although local authorities do keep disability registers).

In assessing a need for social care, purchasing authorities use an eligibility framework based on maintaining independence over time. Age, gender, ethnicity, religion, disability/impairment and other personal factors can be taken into account. Need is assessed in four bands: 'Critical' (e.g. where life is threatened, there is serious abuse, or vital work, educational or social functions cannot be sustained); 'Substantial' (e.g. where the 'majority' of personal, domestic, work, educational or social functions cannot be carried out without support); 'Moderate' (e.g. where 'several' of these functions cannot be undertaken); 'Low' (e.g. where 'one or two' of these functions cannot be sustained). See, DoH (2002: 4-5)

Once eligibility and need for social care has been established then help and support may be provided in a variety of ways – either by public services, by purchasing services from voluntary or private sector organisations, or by providing the disabled person with cash payments to purchase their own support directly. Since the early 1990s, publicly funded social care and support has operated in a 'mixed economy'. Although public funds are allocated to meet assessed needs, the support required may be purchased from providers in any sector. The role of 'purchaser' and 'provider' of care is thus separated.

Within this framework, there has been a substantial move towards the 'personalisation' of care and support (see Leadbeater et al. 2008), in which individual disabled people are increasingly encouraged to participate in the design and co-ordination of the support they require. The official policy discourse has shifted considerably towards the concept of disabled people 'employing' professionals to help them (suggesting a move from passive consumer to active producer of welfare). The primary mechanism used to drive this agenda has been the implementation of 'direct payments' (and, more recently, 'individual budgets'). This mechanism was first pioneered by disabled people's organisations within the independent living movement from the 1980s (Barnes and Mercer 2006), and later piloted through the Independent Living Fund, which can provide up to £455 per week of support costs for people receiving substantial packages of social care (see [www.ilf.org.uk](http://www.ilf.org.uk)).

Direct payments are cash payments made by local authorities to disabled people (or to the parents of disabled children, or to carers) who have been assessed as eligible and in need of social care. The purpose is to give choice and control in how support is provided. Payments may be used to purchase any support or adaptation that has been assessed as a need (most are used to employ personal assistants to help with personal care, domestic tasks and social activities). They cannot be used to purchase long-term residential care or public services. There should be no local policy to exclude people from particular groups of with particular levels of need. Direct payments must be offered as an option to anyone who has been assessed as needing social care (although there is strong evidence that this does not happen routinely). For a user guide, see, Department of Health (2007).

It is important to emphasise that direct payments are not an income benefit, and are not treated as income for tax purposes (i.e. they must be spent on purchasing the social care that has been agreed in the assessment). Direct payments are not means-tested but local authorities may apply charges as if the individual concerned was receiving an equivalent service.



There is a responsibility to 'secure best value' and the payment may not cover the full cost of the support the individual would choose.

The government published a significant new agreement in December 2007, called Putting People First: A shared vision and commitment to the transformation of Adult Social Care. Local authorities have received guidance on the development of a new personalisation agenda, with new funding to radically reform the provision of social care in the next three years. See:

<http://www.dhcarenetworks.org.uk/personalisation/index.cfm>

Within the 'personalisation agenda', the direct payments concept is now being extended towards 'individual budgets'. In the pilot projects for this new model, disabled people were able to bring together funds from a variety of different sources into a single budget, from which they could choose how care, support and equipment would be purchased. This included money from local social care services; 'Supporting People' funding; the Independent Living Fund; Disabled Facilities Grant; Integrated Community Equipment Services; and Access to Work schemes.

It is important to note that the overall number of disabled people receiving direct payments remains very low (although there are rapid increases). The majority receive more traditional services and there has been concern about an apparent rise in the number of people with learning difficulties or mental health conditions admitted to residential institutions and nursing homes (e.g. 20-40% increase since 1997). A considerable number of young adults are living in residential institutions not intended for their needs. However, there is significant change.

More information about the range of services, entitlements and benefits can be found at: <http://www.direct.gov.uk/en/DisabledPeople>

The EU Disability High Level Group document *Quality of social services of general interest*, emphasises that 'Access to social services by people with disabilities means that those services are affordable, available and accessible'<sup>18</sup>. This raises some concerns in the UK context over the implementation of 'fair' charging policies in recent years by Local Authorities responsible for social care provision (although the majority of services and supports are received free of charge). For example, although there may be no charge for assessment, information and advice, discretionary charges may be applied for the provision of supported accommodation, supported living at home, day services, etc.<sup>19</sup> Any level of means-tested local charging may be allowed, provided that the person retains an income 25% above the Income Support level (in England, 16.5% in Scotland). The implication is that very substantial local charges could be levied on personal income for services and personal assistance to live independently. Concerns about inconsistent and increasing charges have been expressed by disabled people's organisations and carers' organisations in the UK (survey evidence is presented in a recent report by Holmes and McMullen, 2008).

A more detailed analysis of the system for direct payments and support for independent living is provided in our 2009 ANED country report on that topic.

Current policy continues to emphasise 'personalisation' (Leadbetter, 2004) and the pooling of different funding sources for which disabled people are eligible, so that recipients can exercise more choice and control over funds. A pilot study involving 13 local authorities (Glendinning et. al., 2008) concluded that administrative and bureaucratic obstacles presented difficulties with implementation. The Welfare Reform Bill has removed some of these barriers and further pilot projects are planned.

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<sup>18</sup> See [http://ec.europa.eu/employment\\_social/index/final\\_mainstreaming\\_en.pdf](http://ec.europa.eu/employment_social/index/final_mainstreaming_en.pdf) (page 3)

<sup>19</sup> See <http://www.dh.gov.uk/en/SocialCare/Chargingandassessment/ChargingforSocialCare/index.htm>



## **PART FOUR: SUMMARY INFORMATION**

### **4.1 Conclusions and recommendations (summary)**

Disability has achieved a high visibility and status in UK strategies for social inclusion and social protection, with significant policy commitments on promoting equality, reforming welfare, and transforming social care. There is a complex and extensive system of financial benefits and services, within a mixed economy of care. The 'rights and responsibilities' approach places increasing emphasis on work and employment for disabled adults, while the 'personalisation' agenda emphasises greater flexibility, choice and control. Research evidence is improving but more reliable indicators of equality are required. There is evidence that investment in independent living is more cost effective than traditional institutions and services, and that recipients do benefit from improved life choices. However, there is also evidence of substantial relative poverty and the uneven implementation of support for independent living. There is emerging concern about the relative disadvantage of mental health service users and, by implication, the poverty of disabled (particularly Muslim) women. Further research is needed to monitor equality of outcomes, best practice in personalised social care, and the relative exclusion of specific groups.

There are no clear indications, as yet, of the social inclusion implications of the economic crisis. There is some evidence of marginal decline in employment rates, full-time jobs, and permanent contracts (see employment update). A general election is due before June 2010 and all political parties are committed to public spending restraint (to varying degrees). It is likely that public sector employment and public services will be affected, with likely impact on services and supports for disabled people.

### **4.2 One example of best practice (brief details)**

The UK model of personalisation and individual budgets has its origins in the claims and experiences of disabled activists within the independent living movement. Best practice in supporting choice and flexibility has been achieved where local organisations, controlled by disabled people, have been actively engaged as partners in co-ordinating and providing advocacy and support services. The National Centre for Independent Living received funding from the Department of health to work with the 13 pilot projects for 'individual budgets' (now funded to work on the development of user-led organisations). This was used to publicise the scheme and to build local networks of disabled people to provide peer support (helping people with self-assessment and planning how to maximise the outcomes from the budgets). In this way, the involvement of disabled people operated at three levels: individual users were involved in decision making about their social care; local organisations of disabled people were involved in peer support; a national organisation of disabled people was involved in capacity building. For example, in one city (Coventry), an outcomes approach was adopted and disabled people were actively involved in the evaluation.

The evaluation for the Coventry project is available here:

[http://www.integratedcarenetwork.gov.uk/library/Resources/Personalisation/Personalisation\\_advise/Coventry\\_Individual\\_Budgets\\_Our\\_Stories.pdf](http://www.integratedcarenetwork.gov.uk/library/Resources/Personalisation/Personalisation_advise/Coventry_Individual_Budgets_Our_Stories.pdf)

The Individual Budgets Evaluation Network published its national report in 2008.

<http://php.york.ac.uk/inst/spru/research/summs/ibsen.php>



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