



ANED country report on the implementation of policies supporting independent living for disabled people

Country: United Kingdom

Authors: Sarah Woodin, Mark Priestley and Simon Prideaux

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

There has been significant movement towards policy support for independent living in recent years. Historically, this was driven by widespread criticism of the conditions of long-stay institutions and by the emergence of innovative examples (often from within the disabled people's independent living movement). In broad terms there is evidence of progress and a national policy framework with the potential for future implementation of Articles 12 and 19 of the UN Convention - but there are also concerns.

Research and policy evidence point to a long-term shift of people and resources from residential provision in larger institutions towards support for community living and, more recently, towards greater support for choice and control in independent living. However, it is important not to be complacent about the trends, since there have also been concerns about the denial of rights to community living (and there is no absolute right to receive support to live independently in the community). There is still a substantial level of institutional provision but few large-scale residential institutions remain. Expenditure on residential provision appears to be falling but remains a substantial proportion. There is also considerable diversity in the type and level of user-controlled support available in different localities.

The policy framework in the UK provides a range of support to allow the majority of disabled people choices to live in the community, although there are concerns about the denial of choices to some people. Legislation assumes individual capacity to make decisions, with 'protection' for people judged unable to do this administered and safeguarded through a public guardian office. There is national strategy on independent living that emphasises 'choice and control' and there are moves towards legislation on the 'right to control'.

Practical support for disabled people is delivered by a variety of public, voluntary and private sector providers, and by family and friends. Most of this help is funded through a public system of 'community care', which is largely the responsibility of local government and/or health authorities. Most personal assistance and equipment provision is delivered in this way. Recent policy development has been much influenced by the 'personalisation' of social services within a mixed economy of social care. There is evidence of a fairly rapid expansion in direct payments and individual budgets but this is not always supported by appropriate and adequately funded self-assessment and peer support arrangements.



PART 2: LEGAL AND POLICY CONTEXT

The policy framework in the UK provides a range of support to allow the majority of disabled people choices to live in the community rather than in institutions, although there remain concerns about the denial of such choices to some disabled people. The general framework includes rights to receive disability-related financial benefits (mainly through social security systems administered by central government) and practical support (mainly through social care systems administered by local government). The relevant details of these policies are explained in more detail later in this report.

The Disability Discrimination Act (1995, 2005) prohibits discrimination on grounds of disability in the provision of goods, services and infrastructures, while the Disability Equality Duty, from 2006, requires public bodies in Great Britain to promote and monitor disability equality in all areas of their work. The Equality and Human Rights Commission (EHRC) acts as the national enforcement body, in relation to disability and other legal grounds. This rights-based framework means that, in principle, disabled people who choose to live in the community should not be treated 'less favourably' than non-disabled people by those providing access and services.

In terms of national strategy, the Prime Minister's Strategy Unit document *Improving the Life Chances of Disabled People* (PMSU 2005) provided a 20 year vision for the inclusion of disabled people by 2025. The 2008 Independent Living Strategy is then a key reference point (based on a major review in 2006). There is a five year plan, and the main aims include ensuring that all disabled people who need support in daily life achieve 'greater choice and control over how support is provided'. The strategy emphasizes the values of autonomy, choice, freedom, dignity and control. It explicitly addresses disabled people of all ages, throughout the life course. Full details of the Strategy are available at:

<http://www.odi.gov.uk/working/independent-living/strategy.php>

As part of social care reforms, the government document *Putting People First* moved towards the 'personalisation' of support - including commitments towards greater individual choice and control (Department of Health 2007; Leadbeater at al. 2008). This personalisation agenda is seen as posing significant challenges to traditional cultures of public services provision and there are calls for a 'radical rethink of care and support' (HM Government, 2008). It is also acknowledged that this agenda 'cannot be delivered by social care alone and requires partnerships with housing, benefits, transport, health, leisure and others' (Commission for Social Care Inspection 2009: 8).

Some of the key elements (of relevance to this report) include: a greater emphasis on self-assessment of need; person-centred planning and self-directed support; increasing the numbers of people using Direct Payments; and, 'personal budgets for everyone eligible for publicly funded adult social care so that there is a clear, upfront allocation of funding to enable people to make informed choices about how best to meet their needs' (*ibid.*). £520 million has been invested to implement key changes in social care between 2008 and 2011. Further information on the personalisation of social care is available at:

<http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

In England and Wales, the Mental Capacity Act 2005 (which came into force in 2007) assumes that everyone can make decisions for themselves unless proven otherwise. The Act is intended to support people in making decisions for as long as possible, and to 'protect' people who are judged unable to make decisions for themselves (e.g. because they have a significant cognitive or psychological impairment, or become incapacitated in some way). The Act allows a person to choose someone else to act on their behalf in matters of personal finance, health and welfare. It also requires that all decisions are made in the person's 'best interest'.



The protection of people judged not to have mental capacity to make their own decisions is the responsibility of the Office of the Public Guardian (OPG). There is also an Independent Mental Capacity Advocate service that can assist people who do not have a suitable person to nominate. More information about the OPG and the provisions of the Act are available at:

<http://www.publicguardian.gov.uk/>

In Scotland, the Adults with Incapacity (Scotland) Act 2000 deals with capacity for people aged 16 or over. The principles are somewhat similar, in that decisions should benefit the person, take account of their wishes, capitalise on their skills and abilities, and place the minimum restriction on their freedom. Carers can apply for legal power of attorney, access to a person's financial resources, or specific guardianship rights. A 2008 guide to the Scottish Act is available at: <http://www.scotland.gov.uk/Publications/2008/03/25120154/1>. There is some concern about the situation in Northern Ireland, where there is no equivalent legislation on mental capacity.

The UK Government has been finalising arrangements for ratification of the UN Convention in 2009. However, it also recorded reservation on Article 12.4, which requires 'regular review' of any substituted decision making by a competent authority. The reservation acknowledges that there is currently no system for such a review in relation to proxy claims to a person's financial state benefits (it is envisaged that a new system of safeguards will be developed by the Department of Work and Pensions). Otherwise it is assumed that Article 12 is accepted in full.

A new Welfare Reform Bill (under discussion in Parliament at the time of writing) would allow the Secretary of State to make new regulations on a person's 'right to control' over the way in which public support is provided to them (i.e. the right to budgetary control). This provision would apply to people aged 18 and over. The proposals include new rights to extend control over budgets for support received in adult education and employment using direct payments, which currently exist for social care support (this system is explained in more detail later). A consultation on the new proposals was launched in June 2009.

Unsuccessful proposals had also been introduced (privately) before Parliament for a 'Disabled Persons (Independent Living) Bill', which would radically re-shape the system of support. These proposals called, amongst other things, for a national framework of entitlement to social care, a national system of personal budgets, guaranteed assessments of individual advocacy needs, and a basic assumption that all people will be supported in their own homes.

Since the 1990s there have been some significant developments in the policy and legal framework to support independent living, many of which may be regarded as positive and progressive. There has been considerable movement to separate the provision of support from specific types of service or particular physical buildings (e.g. through more flexible purchasing arrangements in a mixed economy of care, and the provision of direct payments to more disabled people). There has been a growing acceptance in the language of government strategy documents that disabled people are entitled to the same rights to an independent life as other citizens, and that 'choice and control' play a major part in this.

Mansell et al. (2007) use England as a case study to illustrate the change process of deinstitutionalisation, highlighting the importance of strategic co-ordination in achieving change across diverse institutions and localities. They point to two significant factors accelerating this change – first, the availability of visionary ideas and alternative models of provision and, second, the availability of evidence about the poor living conditions in residential institutions.

In this context, historical activism within the disabled people's independent living movement (and within critical academic research) contributed significantly to the developing debate.



Innovative local schemes for supporting independent living through accessible housing and direct payments were pioneered with small numbers of users by centres for independent living and user-led organisations of disabled people from the early 1980s (many of which are noted by Campbell and Oliver 1996; Kestenbaum 1996; Priestley 1999; Barnes and Mercer 2006;). A national pilot scheme for direct payments, The Independent Living Fund, was established in 1998 and extended in 1993. This provided further examples of real life outcomes and success stories. Knowledge sharing and lobbying was also enhanced with the establishment of a National Centre for Independent Living. During the past decade there has also been a stronger representation of disabled activists within government strategy consultations (such as the Equality 2025 initiative).



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

Research and policy evidence point to a long-term shift of people and resources from residential provision in larger institutions towards support for community living and, more recently, towards greater support for choice and control in independent living. Whilst de-institutionalisation has been a significant concern in the UK it is relevant to note that the large majority of disabled people live, and have always lived, in private households.

The earliest origins of public institutionalisation (via ‘indoor relief’ and the workhouse) have been linked with attempts to control claims on public welfare and to distinguish between the ‘deserving’ and ‘undeserving’ poor (Priestley 1997). The development of different impairment categories can be seen more clearly in the nineteenth century with the emergence of specialist institutions and medical wards (e.g. Borsay 2005). Placements in larger health or welfare institutions increased, particularly for people with mental health conditions or learning difficulties, until the 1960s. However, growing public critiques of institutionalisation (including Royal Commissions of enquiry) were evident throughout the post-war period. Change in policy and service provision ensued in the 1970s, particularly for people with learning difficulties. By the mid 1980s there were more evident moves towards supported community living as a policy goal, including the closure of most of the very large long-stay hospitals.

Building on the Chronically Sick and Disabled Persons Act 1970, and the Disabled Persons (Services, Consultation & Representation) Act 1986, the NHS and Community Care Act 1990 sought to rationalise the management of social care and create a mixed economy of provision. Local authority social services were charged with assessing and providing ‘packages of care’ tailored to the needs of individual clients. Market forces were introduced in an attempt to promote choice for consumers about who would provide the support they needed (for a market critique see Priestley 1999). In reality, many needs also went unmet for those without personal financial resources due to budgetary constraints.

The Carer’s (Recognition and Services) Act 1995 placed greater emphasis on the needs of the ‘carer’ in community care policy, in an attempt to improve services as a whole. The Act, however, added some potential for conflict of interests between the rights of disabled people and those of their informal ‘carers’ (while the discourse of caring tended to consolidate negative assumptions about dependency). The Community Care (Direct Payments) Act 1996 can then be seen as a significant development. The legalisation of direct payments, and subsequent extension to disabled people of all ages from all service user groups, has helped to facilitate independent living choices - albeit for a minority of disabled people. The operation of these arrangements is described in more detail later in this report.

There is still a substantial level of institutional provision in the UK today but few large-scale residential institutions remain. It is not easy to compile reliable data on the number of disabled people living in institutions (partly because the definition of ‘institution’ is open to wide interpretation and partly because it is not easy to disaggregate disabled people, especially in the institutional placement of children and older people). Within the UK there are additional difficulties in obtaining comparable data for England, Scotland, Wales and Northern Ireland. In 2005, Mansell et al (2007) identified 14 different types of services with data on size of institution available for only four service types nationally (but for all major services in England), partial data on age and very little data on gender. There was no available data on staffing in adult services. There are, therefore, several instances where we report data for England rather than the UK (other jurisdictions are reported where possible).



Official data for England is collected on registered residential accommodation (local council and independently run residential and nursing homes). The Health and Social Care Information Centre (2008) reports a decline in the number of residents supported through public funds in recent years as a direct consequence of national policies to support people living in their own homes. Conversely, the estimated number of households receiving 'intensive home care' has risen (approximately 100,000 households received more than 10 hours or six visits per week). In 2008, local Councils in England were supporting 236,100 adult residents - 149,100 (62%) of them in independent homes, 65,500 (27%) in independent nursing homes, and 18,600 (9%) in Council-run homes (plus 2,900, or 1%, in adult placement schemes). There has been a large fall in the number of people living in Council-run homes and nine out of ten residents are now placed in independently-run homes. More than three quarters of supported residents (77%) are aged over 65. It is worth noting that some 19% of people in registered accommodation are living in places that are some distance their home area (i.e. they are living in a different local Council area to the one that pays for their support).

In Scotland, there is also evidence of rising investment and intensity of support for people living at home. The Scottish Government (2008) reports that the number of clients receiving 'home care services' (provided or paid for by the local authority) declined slightly from 2007 to 2008 but the average number of hours help that each person received increased markedly (from 5.1 to 9.5 hours per week between 1998 and 2008). The large majority of this support is for people with physical impairments (77%) and 68% were women (although it is important to note that this data includes people with 'frailty' in old age, and 80% of recipients are aged over 65). The proportion of people receiving higher levels of support at home has also increased, and 30% received 10 hours or more per week. There are significant age differences in the amount of support received though, with 21% of those under 65 receiving at least 20 hours but only 5% of those aged over 65.

Allowing for the fact that Mansell et al. (2007) were not able to be precise about the size of residential homes in Scotland, Wales or Northern Ireland (nor for health service institutions like long-stay hospitals) they estimate that there were 129,548 residential placements in the UK, of which: 48,781 were in larger institutions of more than 30 people; 33,530 in smaller settings (and 47,237 in unclassified settings). The vast majority were adult placements. People with learning difficulties or mental health conditions were the largest groups represented. In comparison with other countries, in the same study, the estimated UK rate of institutional care (215 per 100,000 population) was lower than average and ranked 20 out of 24 for the estimated number living in larger institutions (at 110 per 100,000). These estimates present a relatively positive picture of institutionalisation in the UK compared to other European countries (with 12 countries at more than double its large institution placement rate).

It is important not to be complacent about the trends reported, since there have also been concerns about the denial of rights to community living. There is no absolute right to receive support to live independently in the community. Morris (2004) notes that the former Disability Rights Commission adopted the goal of 'a basic enforceable right to independent living for all disabled people' (Disability Rights Commission 2002). It would be possible to challenge a decision by a local authority not to provide social services (e.g. if the decision was not seen as fair and reasonable in a judicial review). The Human Rights Act 1998 does protect against (amongst other things) instances of inhuman and degrading treatment, loss of liberty, respect for private and family life, freedom to marry and have children, and freedom of assembly. Such rights could possibly form the basis of an appeal in cases where support for community living was denied.

A significant loophole was exposed in 2007 when the House of Lords ruled that the Human Rights Act did not apply to people living in private or voluntary sector care homes (see House of Lords / House of Commons 2007).



Whilst people in publicly-funded placements are now protected, those paying privately in such homes are not. According to recent market research, around 146,000 older and/or disabled people were paying private fees to live in care homes (Laing and Buisson 2008).

The Mental Health Act 1983 allows some people to be admitted on a compulsory basis to hospital (28 days) or guardianship (6 months). Two doctors must confirm that there is a mental health condition, which requires detention for treatment, and that there is a health and safety risk if the person is not detained. This decision may be contested. Where people are involved in criminal court proceedings there is a lower burden of proof required for such a detention (involving more 'suspicion' and 'practical' considerations). Initial detentions for assessment may be extended for compulsory treatment.

Deprivation of Liberty Safeguards were introduced in 2007 (implemented April 2009), as an amendment to the Mental Capacity Act, to protect people who are unable to give consent to care arrangements that involve some deprivation of liberty. They apply to provision in hospital or registered care homes (but not to provision authorised under the Mental Health Act above). The intention is to assure that people can access support and care in 'the least restrictive regimes'. Concern over risk of abuse also led to consultation on *Safeguarding Adults* in 2008-9 (Department of Health 2008a). The Safeguarding Adults process is intended to interact with Deprivation of Liberty Safeguards to assure that decisions to deprive liberty are not wrongly implemented and that they can be challenged. See Bonnell (2009) for a brief summary and Pickard (2009) for a brief critique.

Concern has been raised about the placement of disabled children and young people in statutory care systems and full-time residential 'educational' placements (see Morris 1995, 1998; Priestley et al. 2002). In such cases, there is a risk that unjustifiable residential placement of disabled young people may occur where the rationale is justified ostensibly on child protection or educational grounds (when in fact the lack of alternatives arises from disability discrimination or exclusion). In addition, there have also been concerns about the practice of imposing cost ceilings on the provision of support for people to live independently in the community. For example, cases reported by Morris (2004) highlighted certain financial incentives for purchasers to provide residential care rather than support for independent living.

In relation to the Mental Capacity Act, there have been some small-scale investigations of impact on young disabled people in adult transitions (Badger 2009), adults with complex needs in residential settings (Badger and Parnell, 2009), and people with learning difficulties (Williams et al. 2008). Such indicative studies suggest that generalised judgements are still being made about people's overall level of capacity to decide, rather than maximising choice case-by-case, and that there are considerable training needs (e.g. where staff feel that people have more choice than they actually do). There appears to be little consistency in different stakeholders' interpretations of choice and decision making. For example, in Badger and Parnell's report there was no evidence that any of the participants had chosen where to live.

Since 2002, local government (Councils) have had responsibility for residential and nursing care as well as community based support. The most useful official data for England is reported by Health and Social Care Information Centre (2009). During 2007-8 a total of £22.9 billion was spent on personal social services in England (£17.1 billion on support for adults and £5.8 billion on children and families). The overall amount has increased over time but remained stable for the most recent period reported. Within this total, the largest investment is in support for older people (£8,770 million). For adults aged 18-64, £1,480 was spent on support for people with physical or sensory impairments; £3,455 for people with learning difficulties; £1,120 for people with mental health conditions.



The expenditure data suggests that the amount invested in residential provision in England fell slightly between 2006-7 and 2007-8 when adjusted for inflation. Expenditure on residential service provision accounted for 41% of total gross spending (compared to 43% spent on day care and domiciliary support). So, while more is now invested in support for people living at home the amount invested in residential provision remains substantial.

The figures indicate that £2,650 million was spent on residential provision for adults aged 18-64, compared with £4,740 million on older people and £1,090 million on children (this includes provision not solely associated with disability, for example in children's homes and placements in residential special education). 56% of all residential expenditure was for people aged over 65. Figures for the under 65 adult population are more clearly disaggregated, with £390 million spent on residential provision for people with physical or sensory impairments; £1,860 million for people with learning difficulties; and £400 million for people with mental health conditions.

It is useful to interpret the above data by noting the different proportion of institutional investment for different groups: 24.5% for people with physical or sensory impairments (just over half of that spent on day and home support); 18.5% for people with mental health conditions (about an equal amount as day and home support); but 57% for people with learning difficulties (more than is spent on day and home support). This comparison is shown in the following summary table. Thus significantly more is spent on support for people with learning difficulties and a much larger proportion is spent on residential provision for this group. However, it is important to note that this does not take account of the type of residential provision (which may be in community-based small homes rather than in 'large' institutions). The number of people with learning difficulties supported to live in residential placements has, however, been declining (currently around 34,500 in England).

Table 1: 2007-8 gross expenditure on personal social services support for adults in England (£million, adapted from HSCIC 2009 data)

	Total expenditure	Residential	Day and home
People with physical or sensory impairments	£1,480 (24.5%)	£390 (15%)	£830 (31.7%)
People with learning difficulties	£3,450 (57%)	£1,860 (70%)	£1,390 (53%)
People with mental health conditions	£1,120 (18.5%)	£400 (15%)	£400 (15.3%)

The average cost, per person, (aged 18 and over in England) of residential, nursing and intensive home support was £559 per week. The average cost of home care was estimated at £14.40 per hour in 2007-8. Therefore drawing comparisons between the costs of residential and day/home provision is complex, not least because of the different user groups and needs that may be addressed by different kinds of provision. The following table summarises key elements of published data from the Social Services Performance Assessment Framework Indicators, 2007-2008.

Table 2: 2007-8 unit costs per week of different types of support for adults in England (£million, adapted from HSCIC 2009 data)

	Residential (excluding nursing)	Home care	Direct payments	Day care
People with physical or sensory impairments	£780	£156	£204	£149
People with learning difficulties	£1,059	£352	£191	£291



People with mental health conditions	£602	£78	£69	£85
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There is no evidence of any substantial new investment to move away from support for community living towards residential services. However, it is relevant to note the increasing pressure on service provision arising from demographic ageing and the continuing debate about the role and quality of residential nursing homes in this context.



PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

Social security and income enhancement benefits (as detailed in the ANED UK report on social protection and social inclusion) are funded by central government through both contributory and non-contributory schemes. Practical support for disabled people in the UK is delivered by a wide variety of public, voluntary and private sector providers, and by family and friends. However, most of this kind of help is funded through a public system of 'community care', which is largely the responsibility of local government. Broadly speaking, the same kinds of practical help in the home are available to disabled people and/or to members of their family - if a need for such support has been assessed (see later).

Most personal assistance and equipment/adaptations for daily living are provided through the community care system. This may involve assistance/equipment provided by local authority staff, private or voluntary sector agencies, or purchased through direct payments (where the individual receives control over cash to buy assistance/equipment for themselves). Adults with physical, sensory, learning or cognitive impairments, mental health difficulties, older people and parents/carers may be eligible for such support. According to the Commission for Social Care Inspection (2008, 2009) approximately 1.75 million adults used some form of publicly funded social care support during 2007-8. In the UK, it is not necessary to register as a disabled person to receive these kinds of services.

Certain kinds of practical assistance to live at home and some assistive equipment may be provided by health professionals (such as community nurses, occupational therapists, speech and language therapists or low vision specialists). Wheelchairs and mobility aids also fall into this category. Most health care is provided free at the point of delivery within the structure of the National Health Service. However, direct payments to individuals are also being introduced for health services – in 2009, 68 projects, involving 75 local Primary Care Trusts, were designated as pilot projects for the introduction of personal budgets. In these pilot projects the Health Trust or a third party organisation will hold the budget on individuals' behalf but new legislation (the Health Bill 2009) would permit pilot sites to make direct payments to end users as happens in the social care field.

The mechanism for receiving publicly funded support depends on an assessment, usually carried out by the local authority social services department in England and Wales, social work department in Scotland, or health and social service trust in Northern Ireland. The assessor may be a social worker, disability professional (e.g. occupational therapist) or other person. In some cases there is a 'single assessment', in which both health and social care teams collaborate and share information.

Strong arguments have been made from within the independent living movement for supported self-assessments of need, for example, involving peer support or advocacy to assist those new to the process establish what support they might need (see, e.g. Priestley 1998). More recently there has been increased emphasis on working in partnership with disabled people and on active participation. Self-assessment and person centred planning are advocated as appropriate ways of making services more responsive to individuals seeking assistance (Department of Health 2005). In practice, however, it is by no means clear whether the amount of involvement in individual assessments has been increasing.

To receive support to meet their social care needs, applicants must apply to their local authority to request an assessment of their circumstances. Funding decisions are made under a national procedure called 'Fair Access to Care', which identifies four levels of risk: critical, substantial, moderate and low. In theory, services are provided in response to assessed needs and risks to independence, rather than the availability of particular services (Department of Health 2002) but there is much variation.



For example, Cestari et al. (2006) found considerable variations in the way that mental health service users were treated under FACS in social care and health care assessments.

In practice, due to funding restrictions, most English authorities have raised their eligibility thresholds for assistance to the 'substantial' or 'critical' level of need. An independent review of eligibility criteria for public funding of social care needs (CSCI 2008) queried both the criteria used and the overall amount of funding available, which results in a quality of life divide between those who receive assistance and those who do not. Charles and Manthorpe (2007) point to ambiguities in frontline implementation, training and guidance. Henwood and Hudson (2008) provided a supporting evaluation, focusing on the experience of those assessed as ineligible to receive significant support. They also draw attention to their poor quality of life in relation to choice and control, well-being and dignity etc. and note, for example, that:

'Eligibility for support can be approached in a flexible and personalised way, or in a task-based and mechanistic manner. The difference for people receiving personal care can be profound: a strip-down wash may satisfy requirements for basic hygiene but it fails utterly to meet people's needs for dignity and self-respect'. (p9).

There are a range of formal mechanisms for measuring and assuring quality in community-based support services. However, these are more likely to focus on quality in the provision and process of support rather than quality of outcomes for the recipients of that support.

In 2001, the Government established a new Social Care Institute for Excellence (SCIE) with the objective of improving quality and effectiveness of UK social care services. In relation to adult social care, the focus has been on promoting good practice within the context of *Putting People First* (outlined on p2 of this report). Personalisation of support and individual budgets are viewed as a key concern.

There has also been an increase in the use of standards to define expectations of social care. For example, in Northern Ireland, the Department for Health, Social Services and Public Safety (2006) published *Quality Standards for Health and Social Care*. These are intended as a reference point for users of services as well as a benchmark for quality audits. The standards are monitored through inspections by an independent body (the Health and Personal Social Services Regulation and Improvement Authority). Amongst the key values and standards it is expected that:

'Service users are offered, wherever possible, according to assessed need and available resources, the opportunity to select independently from a range of options based on clear and accurate information, which is presented in a manner that is understood by the service user and carer'. (p7)

Until 2009 there was a range of bodies involved in regulating and assuring the quality of social care (including notably the Commission for Social Care Inspection). However, in England, the Care Quality Commission (CQC) now acts as the independent regulator for both health and social care (i.e. it covers care in hospitals and residential care as well as in community care, and includes people detained under the Mental Health Act described earlier). The CQC seeks to assure common standards of care are enforced, and it does have some focus on outcomes. Past inspection reports (from the previous bodies) can be accessed via the CQC website at:

<http://www.cqc.org.uk/publications.cfm>



Amongst the work now incorporated by the CQC is the publication of social services performance indicators. A set of 50 indicators are reported across 150 local authorities¹. These include, for example, evidence of the 'The number of households receiving intensive home help/care as a percentage of all adults and older people in residential and nursing care and households receiving intensive home help/care'. There are published measures of people placed in permanent residential care, types and costs of care, etc. This also indicates the number of adults and older people supported with direct payments. Recent performance has been viewed as 'generally high' for adults with physical impairments, learning difficulties, mental health conditions, and older people who are helped to live at home (Commission for Social Care Inspection 2008). Performance on direct payments is viewed similarly, with more rigorous indicator definitions (based on 'Social care clients receiving Self Directed Support per 100,000 population').

¹http://collections.europarchive.org/tna/20081105165041/http://www.csci.org.uk/professional/councils/performance_assessment/paf_reports_and_data/paf_spreadsheets_2006-07.aspx



4.1: PERSONAL ASSISTANCE SERVICES

As described earlier, since the 1990s, user-controlled personal assistance services have increasingly been provided through the mechanism of 'community care' and 'direct payments'. Essentially, funding to purchase personal assistance is made available in respect of support services and is offered to any eligible older or disabled person aged 16 or over (including those with short as well as long term needs) or to people with parental responsibility for disabled children and to 'carers' aged 16 or over. There should be no local blanket policies that could exclude individuals who need higher levels of support, including older disabled people.

The most important gateway to eligibility is assessment. To gain access to direct payments or individual budgets to pay for user-controlled personal assistance, a disabled person must be assessed by the local council as needing social 'care' (or support) services. In carrying out assessments, councils have to use a framework based on meeting the needs required to achieve and maintain the independence of an individual over time.

Disabled people and their family members have a right to request an assessment under the Chronically Sick and Disabled Persons Act (1970) and Disabled Persons (Services, Consultation and Representation) Act 1986. Local authorities also have a duty to set thresholds for eligibility: to determine the level at which they can afford to meet needs. They do not have to meet needs which are below the threshold ('unmet need') but generally they do have to meet those that are above the threshold. The threshold may be moved according to the level of resources, and people who have been eligible may become ineligible if resources become tighter, as has been the case in the UK in recent years.

Therefore there are no absolute categories for eligibility to services. Age, gender, ethnic group, religion, impairments 'or similar difficulties, personal relationships, location, living and caring arrangements, and similar factors ...may need to be taken into account' but are not directly referred to in the 'Fair Access to Care' framework (Department of Health, 2002: 4).

In 1996, local authorities were given discretionary powers to offer direct payments in lieu of community services they were assessed as needing. However, since 2003, direct payments *must* be offered as an alternative to community care services to people in England and Scotland who are eligible (2004 in Wales and Northern Ireland). Under the terms of 1996 legislation, which still apply, people must be 'willing and able' to manage the payments. Whether this is the case is essentially a judgement made by assessors. To ensure that no individual is forced to accept a self operated service if they do not want one, payments can only be made with the consent of the person involved (Department of Health, 2003). Similarly, Department of Health (2003; 2004; 2006; 2007a) guidance on whether an individual can manage their support effectively theoretically appears to favour the individual.

The Independent Living Fund will also pay for personal assistance services. People who are over 16 and under 65 are eligible and they must already receive social services support (either direct payments or services in kind) worth at least £320 a week (£16,640 a year) or be entitled to a higher rate of Disability Living Allowance if living in England, Wales or Scotland; £200 a week if in Northern Ireland. Applicants and their partners must also have less than £23,000 in savings or capital (see below).

Recently more emphasis has been placed on self assessment, whereby applicants and their families should be able to have more say in the outcomes they want to achieve.



In many areas there are attempts to secure an upfront agreement of the resources to which an individual would be entitled (a Resource Allocation System), following which people can determine how they wish to spend the money. Efforts here have been particularly marked in relation to people with learning difficulties, incorporating person centred planning, where people need assistance and support to decide on a course of action (Duffy, 2004).

An independent review of eligibility criteria for public funding of social care needs (CSCI, 2008) queried both the criteria used and also the overall amount of funding available (also see above). This report noted that while 479,000 people received support in 1997, this had decreased to 358,000 in 2006, at a time when there is rising demand for assistance. Of those who were eligible for assistance, CSCI considered that too little assistance was available to ensure a reasonable quality of life. Concerns centred on assessment criteria, finding that there was a lack of clarity and consistency, a lack of fairness, and an apparent incompatibility between policies concerned with personalisation (involving self assessment, choice and control) and 'Fair Access to Care' procedures (involving standard procedures).

In addition to social care services, there are possibilities for some disabled people to receive user-controlled personal assistance in the context of their employment or higher education. Payment may be made directly from the funding agency to the personal assistant, but the disabled person can decide who to employ and how the assistance will be carried out on a daily basis.

In employment, 'Access to Work' is a support programme available to disabled people via the Department of Work and Pensions. It will fund assistance and/or equipment required in the workplace. It will also pay towards the cost of travelling to work if public transport is not accessible. To receive 100% of this funding, a request must be made within six weeks of starting a new job; otherwise a proportion of the amount is paid. Applicants are eligible if they are in paid employment or self-employed, and if they are unemployed but about to start a job or work trial. Eligibility is assessed by an Access to Work advisor or specialist organisation. Access to Work is no longer available to employees of government departments, whose support should be paid for directly and in full by the department (there has been consultation on proposals to withdraw it from all public sector employment, as there is a public sector Disability Equality Duty).

In higher education, Disabled Students' Allowance (DSA) is intended to allow disabled students to study on an equal basis with others. Allowances may be spent on non-medical assistance (e.g. a personal assistant who acts as note-taker or reader), and/or assistive equipment, additional travel and other costs. Eligible students are those studying on full-time courses lasting a year or more (or equivalent part-time or distance learning courses). To receive DSA, students need to show proof of impairment or health condition from a doctor, or undergo a 'diagnostic assessment' in the case of a specific learning difficulty. This test must be paid for by the student but subsequent payments are additional to other student loans or grants.

More information is available from the following websites



Direct payments –

http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_10016128

Access to Work –

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347

Disabled Students' Allowance –

http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_10034898

During 2007-8, 67,000 adults in England aged 18 and over received a direct payment, an increase of 38% from 2006-7 (National Statistics, 2009). This compares with 1.77 million people who received services during the year. Figures for Scotland (which include people of all ages) record an increase from 207 in 2001 to 2,605 in the year to 31st March 2008. Thus, numbers still remain small when compared to the 37,471 residents living in care homes and 68,759 people receiving home care services at the same date (National Statistics Scotland 2008). In Wales, 88,878 adults received community-based services during the financial year 2007-08 and of these 1,540 received a direct payment as at 31 March (21,258 people were in residential and nursing care accommodation at this time).

In a national survey of all but two English local authorities, Jerome et. al. (2009) review progress on the government strategy 'Putting People First', which required councils to move to a system of personal budgets. They report that on 31 March 2009, almost 93,000 people were receiving personal budgets and predict a rise to more than 200,000 within a year, based on self-reporting by local authorities. This would constitute more than 20% of all those receiving community based services (Local Government Association / Association of Directors of Adult Social Care, 2009). Average expenditure per authority varied from £0.5m to £55m, with almost a third spent on implementation and development investments. While much detail is available, some is missing. For example, some authorities did not include 'one off' payments.

Davey et al.'s (2007) earlier survey report indicated much variation between authorities but showed that, overall, direct payments were more often provided to people with physical or sensory impairments, and least often to people with mental health conditions. Initial uptake of direct payments was highly uneven across the UK (as evidenced by Davey et al.'s 2007 report on a national survey of all authorities in the UK). This identified considerable detail on direct payment numbers, expenditure, intensity and rates of payment, as well as local commissioning practices and support available to users. For example, amongst those authorities surveyed in 2005-6, 15.5% of the budgets of English authorities for people with physical impairment was spent on direct payments, compared to just 1.1% for people with learning difficulties. Average expenditure on payments to people with learning difficulties was also lower than corresponding expenditure for mainstream services provided to the same group. Almost one in three recipients with a physical impairment in England one-third received support for 31 or more hours per week and three quarters received 10 hours or more.

Funding for Access to Work has been rising steadily since its introduction in 1994.

In 2003/04, 34,800 people received assistance from a budget of £55 million (National Audit Office, 2005). This may be compared with 24,000 disabled people who received assistance in 2006/07 via funding of £62 million (Department for Work and Pensions, 2007).



In 2003/04 the average amount allocated to individuals was £1,600, although in practice this continues to vary widely as funds may be used to pay for a piece of equipment or the wages for a continually present support worker. It is acknowledged that the scheme has been consistently oversubscribed and is poorly advertised as a consequence. In March 2009 an increase of £8 million was announced, with a commitment to increase funding to £138 million by 2013-14; this being part of a strategy to increase the number of disabled people taking up employment.

In 2005-06, £69 million was distributed to full-time, and £4 million to part-time disabled undergraduates. Students in receipt of Disabled Students Allowance are more likely to continue their higher education studies, but take up shows large variation. The National Audit Office (2007) reports that in some institutions less than 10% of students identifying themselves as disabled received DSA, whereas at other institutions 70% of disabled students were in receipt. However, overall, the take-up of Disabled Students' Allowance increased from 4.4% in 2006-07 to 4.6% in 2007-08 by full-time first degree students (Higher Education Statistics Agency, 2009).

A variety of funding streams pay for particular elements of support but it is important to note that all of these are separate from the social security system. Historically, different sources of funding have also been administered separately from one another, a situation that has led to difficulties when trying to combine funding in ways that support independent living.

Most of the funding for personal assistance is paid by local authorities under the provisions for social 'care' (as discussed above). Payments are not treated as income with regard to tax and social security entitlements. Payments made by local authorities should include provision for the employment-related costs for the personal assistants (such as recruitment costs, national insurance contributions, statutory sick, holiday and maternity pay, employer's and public liability insurance, and meet costs for higher wage rates charged on weekends and public holidays).

Direct payments may be subject to means testing under the terms of the Health and Social Services and Social Security Adjudications Act 1983 and where the person has more than £23,000 in savings, they may be asked to pay. Local authorities also have some discretion with regard to these charges. In Scotland, 'care' services are free of charge for older disabled people while they may be paid for in other parts of the UK.

Many tasks carried out by personal assistants encompass work that has been traditionally been the responsibility of administratively separate departments in England, Wales and Scotland: social care and health care (they are not separate in Northern Ireland). Pilot schemes have been established to investigate user control in health services² (further discussion below).

For disabled people in employment, assistance through 'Access to Work' is paid by local centres, with national funding from the Department of Work and Pensions. 100% of costs are reimbursed, except where these amount to between £300 and £10,000 and employees have been working for more than 6 weeks. In this instance, employers are expected to pay 20%. Funding is not means tested.

Disabled Students' Allowance is also not means tested. It is administered by the Student Loan Company in England, the Student Awards Agency for Scotland and Student Finance in Northern Ireland and in Wales.

² Department of Health pilot projects:
http://www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH_090018



It has been acknowledged by both disabled people and the government, that current funding systems are problematic. As well as involving multiple applications and assessments, the complexity of the rules surrounding each system reduces choice in independent living options. Recent attempts to introduce flexibility into funding streams are discussed below.

There are no legal restrictions on the amount and/or type of help a person may receive through direct payments and it is possible for disabled people to receive assistance for 24 hour support at home.

By law, local authorities must provide payments to meet the assessed need and 'equivalent to the reasonable cost of securing the provision of the service concerned' (Health and Social Care Act, 2001, s.57). Therefore there may be variations in payments made according to, for example, the type of assistance needed, the local employment market and so on. CSCI (2008) notes that in some areas local authorities have opted not to pay for certain basic forms of assistance (e.g. shopping or cleaning) as a way of limiting expenditure.

Although needs assessment processes determine eligibility for services and financial assessments the amounts received, it is recognised that service users might meet their needs in a variety of ways and greater flexibility is now encouraged. So while disabled people may be allocated money for a certain item, they may elect to spend it in other ways as long as the need for which it allocated is still met. Local authorities have a duty to secure 'best value' (cost-effectiveness). Some councils have argued in the past that they need not allocate a direct payment where this costs more than a service they might provide themselves, for example because local authorities can make bulk purchases. However this now contradicts the stipulation that all eligible applicants must be offered a direct payment and is therefore open to challenge.

Maximum amounts for Independent Living Funds are £815 per week for people who applied before 1993 and £475 per week for those who applied after this date.

Theoretically there is no upper limit on the amount available through Access to Work. In practice, the larger the amount claimed, the longer the process takes, because larger allowances need to be approved by more senior officers. Funding is for a maximum of three years, after which time allocation is reviewed.

Disabled Students' Allowance is subject to the following maximum claims:

Table 3: 2009/2010 Financial Limits to Disabled Students' Allowances in England (adapted from Directgov, 2009³)

Allowance for:	Full-time students	Part-time students	Postgraduate students
Specialist equipment	£5,161 for entire course	£5,161 for entire course	Maximum of £10,260 to cover all costs.
Non-medical helper	£20,520 a year	£15,390 a year (depends on intensity of course)	
General Allowance	£1,724 a year	£1,293 a year (depends on intensity of course)	

³ http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_070188



There is a basic principle that provision of health and social care should be nationally equivalent. However, health and social care arrangements are locally administered and there is considerable disparity between the experiences of disabled people in different localities. A disabled person is free to move to a different part of the country but must re-apply for a new assessment of their needs with that local authority. The disabled person must give up whatever local direct payments or services they had been receiving and start from the beginning again in negotiating assistance arrangements with the new local authority. This is not necessarily a straightforward matter and usually necessitates negotiations with a number of organisations and is often a cause of stress. There is no guarantee that assistance received in the new location will be the same as that received previously due to local variations in what local authorities will fund and this may act as a powerful disincentive to move. A government consultation, *Shaping the Future of Care Together*⁴ includes proposals for increased portability of assessments, although not services that might result from them.

As mentioned above, a number of recent measures aim to support disabled people in exercising greater choice and control in daily life. These developments concern what funding may be used for, to what purpose, and how choice and control over funds may be exercised in practice. Several terms may be distinguished.

Direct payments refer to money given by local authorities in place of community 'care' services. Disabled people take responsibility for employing their own personal assistants and / or commissioning their own services, as well as dealing with local authority accounting requirements. They may receive help with this if they wish.

"Some people may need help with managing the money. The payment may be made to a third party (nominee) for the recipient ...[direct payments] may also be provided through someone with power of attorney for the individual or a user-controlled trust ...Recipients may choose to ask family or friends, or advocacy or support groups to help them in this way. They might choose to buy in assistance ...with keeping records, management of day-to-day relationships with staff or using a payroll service ...In certain circumstances a trust may take on the employment of staff and the financial management of the payment" (Department of Health, 2003: paragraphs 51-53).

Personal budgets have been introduced more recently. They are similar in that they are based on an assessment of eligibility for services and involve an allocation of money, but recipients do not have to make a straight choice between managing their own support (with help if wanted) or leaving this up to the local authority. In this instance disabled people may take the budget as a direct payment, request that the local authority commissions the services, or request a mix of both. Regardless, disabled people retain the right to decide who provides assistance and how it is done. This process is termed self-directed support. The Department of Health (2007a) states that the ability to 'direct' is more important than the ability to 'manage'.

User-led organisations providing support with Independent Living can trace their more recent history from the 1970s and 1980s.

⁴ http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_102339



Peer support has been found to be a vital component in supporting the take-up of direct payments by applicants (Joseph Rowntree Foundation, 2005; Bott, 2008) although many organisations remain underfunded and face difficulties of capacity (Woodin, 2006). The Department of Health funds several initiatives designed to strengthen user-led organisations.⁵

Individual budgets are different in that they set out to combine a number of funding streams. The idea is that all of the money paying for assistance that disabled people are entitled to may be put into a single pool, which they can then use to secure the assistance, equipment and services they need in a more flexible way. This has not been easy to put into practice. One pilot project, which ran from 2006-2007, involved 13 local authority sites and sought to include, at least some of, six funding streams: Access to Work, Disabled Facilities Grant, the Independent Living fund, Integrated Community Equipment fund, Supporting People fund and Social Care finances. One of the findings of the resulting evaluation report was that local authorities experienced several problems with combining funding streams for reasons of bureaucracy and in some instances, legal barriers, (Glendinning et. al., 2008). Further pilot schemes, aim to put in place a 'right to control'⁶ in the context of gaining employment. Potential funding streams to be included are: Access to Work, Independent Living Funds, Supporting People (housing assistance grants), Disabled Facilities Grant, Workstep (a supported employment programme) and Disabled Students' Allowances. The focus in the most recent initiative is on organisational change. The 'right to control' will be backed up with legislation (the Welfare Reform Bill) and participation will be open to disabled people who do not use, or who are not eligible for, social 'care' services as well as those who do.

In regard to social care funding, social workers make decisions about capacity as part of eligibility assessments for social care services, and there is evidence that they have been reluctant to offer direct payments in the past (Woodin, 2006a). As stated above, the Community Care (Direct Payments) Act 1996 stipulates that disabled people using direct payments must be 'willing and able' to manage their assistance. This clause has been widely seen as offering justification for the exclusion of whole groups on the basis of their impairment or condition. Reluctance by mental health service staff has been particularly marked (Newbigging & Lowe, 2005; Spandler & Vick, 2005). Holman (2002) notes that the belief that professional staff should provide services has often formed a barrier to access for people with learning difficulties, who have often been excluded from these options (Williams & Holman, 2006). Clark and Spafford (2002) found that care managers experienced initial difficulties extending payments to older people due to time constraints and concerns about how to offer payments, including worries about the 'willing and able' criteria. More recent policy developments, including the compulsion to offer direct payments and increased flexibility in self-assessment and self-directed support have largely been a response to these issues. However, evaluation of the first individual budgets pilot programme shows that social workers retain concerns about risk in relation to individual budgets (Manthorpe et. al., 2008).

The Health and Social Care Act 2008⁷ modifies the provisions of the Mental Capacity Act 2005 (see above). While previously only service users could give consent to receiving a direct payment, the legislation makes it legal for another person (who receives the payment), to give consent on behalf of someone who lacks capacity under the 2005 law. For the payment to be made, the third party recipient must consent, as well as the surrogate (if there is one) and the recipient must be deemed suitable (be seen to be a representative of the person concerned). The law also makes provision for fluctuating mental capacity.

⁵ http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations/DH_079159

⁶ <http://www.officefordisability.gov.uk/docs/wor/rtc/right-to-control-local-agencies.pdf>

⁷ http://opsi.gov.uk/acts/acts2008/ukpga_20080014_en_1



4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Heywood et. al. (2005) have pointed out that the impact of home adaptations can be dramatic. Service users have spoken of their lives being transformed or prolonged by the restoration of independence, dignity and removal of fear of accidents and of strained personal relations.

Equipment is available either through the National Health Service (NHS) or through local authority Social service departments. Wheelchairs and walking aids, hearing and vision aids, artificial limbs and surgical appliances and communication devices, as well as a variety of items concerned with personal health and daily living are supplied by the NHS. Social service departments fund equipment for managing at home. This may include such items as hand rails, furniture raisers, lighting, hoists and small equipment or adaptations to homes. There are a number of Disabled Living Centres throughout the UK, which provide information and a place where equipment can be tried out for suitability.

Eligibility for larger items of equipment is again determined by assessment. For NHS services, referral by a doctor, nurse or therapist is needed. For equipment supplied by social services, assessment is usually carried out by a specialist social worker or occupational therapist. In some instances joint assessments are carried out. Department of Health guidance (2003) states that direct payments apply to equipment as well as other community care services and equipment and adaptations may be sourced by this route as well as directly. Vouchers are given for some items, such as wheelchairs. They have been credited with increasing choice but there are concerns about the level of resources (Morris, 2005). It may be noted that, as for personal assistance, there are variations between localities in both NHS and Social Service provision. This means that eligibility criteria differ between geographical locations.

Heywood et. al. (2005) found that information to service users and potential users was often poor, with providers often trying to avoid discovering needs that could not be met, despite the fact that as a result needs might become more pressing in the future. Black and minority ethnic service users were particularly disadvantaged through this lack of information. More recently, an increasing number of local authorities are using online advice questionnaires⁸ to ask people about the kinds of assistance needed for everyday life, and to suggest certain products. There is a developing emphasis on universal access to information and low-level intervention to support independent living, particularly for older people who develop impairments.

Advice about, and provision of equipment for use in the home is generally available via occupational therapists working for local social service departments. A number of independent charities also offer individual help with equipment or housing adaptations. Access to Work and Disabled Students' Allowances (described in Section 4.1) include provision for equipment at work or in higher education. The process for applying for this is the same as for personal assistance.

Disabled Facilities Grants are available in England, Wales and Northern Ireland. In Scotland, grants are available through local councils. These are for making housing alterations so that people may continue to live in their own homes. Alterations may include such things as: widening doors and installing ramps, installation of stair lifts, showers, making controls easier to use and improving access in the house to make it easier to look after children, and so on.

⁸ See for example: Disabled Living Foundation <http://www.asksara.org.uk/>



Government strategy on 'lifetime homes' is viewed as facilitating long term independent living outcomes (see Department for Communities and Local Government 2008). This includes specific reference to adaptations as well as to the design of accessible homes.

A new demonstration project, the Whole System Demonstrator Programme⁹, which includes trials of 'telecare' and 'telehealth', has been initiated in three local areas in England to investigate the effectiveness of innovative technologies in support for people with complex care needs. Established in 2008, the project runs for two years, aiming to support 2000 people in each locality. Similar work is taking place in Scotland and Wales to establish the usefulness of technology.

Home Adaptations, Equipment and other Public Services:

<http://www.direct.gov.uk/en/DisabledPeople/index.htm>

Disabled Living Centres - Assist UK

http://www.assist-uk.org/assist_uk_centre_details.asp

Disabled Living Foundation:

<http://www.dlf.org.uk/>

Motability:

http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Yourvehicleandlicence/DG_10028000

Equipment from the NHS:

http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/Equipment/DG_4000484

Wheelchair Service:

http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/Equipment/DG_4000495

http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/Equipment/DG_10038381

Employment Service:

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347

Education and University Support Services:

http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_4000917

See section 4.1 for links to: Disabled Students' Allowance, Access to Work

During 2007-8, an estimated 519,000 people received equipment and adaptations via NHS and Social Service departments. Of these, 21,800 (29%) received these at the point of contact, outside a system of formal assessment. Car parking badges, welfare advice and small items of equipment were included in this category. Numbers have remained steady between 2005 and 2008, although they have risen by 6% for 'equipment', and by 14% for the category of 'equipment and adaptations', when 'telecare' is included. In 2008-9, 77% of recipients were aged 65 and over (Health and Social Care Information Centre, 2009a).

⁹ <http://www.wsactionnetwork.org.uk/>



However, Williams et al. (2009) report that 54% of disabled people did not have any aids, adaptations or equipment, although of this group, 26% would have liked them.

There is conflicting evidence concerning the degree to which recipients are satisfied with the equipment they receive.

The Health and Social Care Information Centre (2009a) reports that of those receiving equipment through Social Services departments between 2007-8, (a 55% response rate: 69,900 out of 126,700 service users), 77% were either 'satisfied' or 'extremely satisfied' with their equipment or minor adaptation to the home. Differences according to ethnicity were reported however: 78% of White users compared with only 59% of Asian or Asian British service users.

Service users have expressed concerns about the safety of their equipment and the persistence of attitudinal and physical barriers. In Equality 2025 focus groups, disabled people reported dissatisfaction with the provision of equipment, including not being consulted on the type of equipment provided, lack of opportunity for a trial period and long delivery waiting times. Williams et. al. (2009) also note that of those who received equipment and adaptations, 47% always had a choice of what to get, but 26% reported never having a choice.

Satisfaction with equipment is linked to how it can be used. In a local study, Sapey et al., (2004) found that only half of respondents in residential care agreed that their wheelchair had liberated them, compared with nearly two thirds of wheelchair users living independently.

A pilot project to introduce more choice in the supply of equipment (Transforming Community Equipment Services) recorded a high level of satisfaction (Ipsos-Mori / DH, 2008). Service users were issued with prescriptions to obtain equipment from private accredited retailers instead of designated equipment stores, and were given the option of paying extra to 'top up' their equipment to a preferred, although functionally similar model if they wanted to do so. The report concluded that there was enthusiasm for choice, especially concerning waiting times and customer-oriented service.

Most equipment is provided free through the NHS and Social Services departments (although provision in social care may be subject to local charging as described earlier). An increasing number of local authorities provide information on web sites about small items of equipment that might prove useful to disabled people, and details of suppliers. The intention is to encourage people to buy these of their own accord. A similar service is provided by Disabled Living Centres and the Disabled Living Foundation (see above). Equipment may be bought or hired using direct payments. Where larger items are bought, agreement with the Social Services department has to be reached as to ownership and maintenance costs.

Disabled Facilities Grants are based on a financial assessment (means test). Payments are for up to £25,000 in Northern Ireland, £30,000 in England, £36,000 in Wales, and 20,000 in Scotland, and costs over this amount are paid by the householder. Social security benefits are generally ignored for the purposes of the financial assessment. The amounts payable by householders are worked out by comparing income and capital with assessed needs, and the earnings of other householders are taken into account.

There are several options open to wheelchair users. They may be assessed and receive a free wheelchair, which will also be maintained free of charge. Alternatively, they may receive a voucher which they can use towards the cost of a wheelchair that they choose. In this case, the wheelchair is also maintained free of charge. The final option is to buy one independently (or apply to an independent charity for help).



The financial arrangements for equipment for Access to Work and Disabled Students' Allowances are the same as for personal assistance (described above).

While NHS equipment has so far provided free of charge, social services' equipment charges vary in different parts of the UK. In England, social services should pay for 'community care' equipment and minor housing adaptations up to £1,000. In Wales and Northern Ireland councils may charge and in Scotland, following assessment, up to 100% of the cost may be granted, and must be granted for people over 65.

See Section 4.1 on Personal Assistance for limits to Access to Work funding and Disabled Students' Allowances.

If equipment has been provided free of charge, it often belongs to the department that supplied it and should be returned when people move to a different administrative area. In the short term, the two authorities should make arrangements for the same equipment to be available in the new area for a period of time. However, after this period, disabled people must re-apply for equipment in the new area. This provides a considerable disincentive to moving.

Where homes have been adapted and equipment such as stair lifts installed, people have to negotiate with the authorities about taking equipment with them. Wheelchairs acquired through the NHS Wheelchair Service may be taken anywhere but maintenance agreements must be re-negotiated with the new health authority.

Relocation grants may be offered by some local authorities for moving, but not by all. Again, local councils set their own eligibility criteria and maximum amounts.

The same arrangements apply for equipment as for personal assistance where it has been funded by local authorities (see Section 4.1 on direct payments and individual budgets, etc.).

Financial budgets for items of equipment under Access to Work are controlled by regional centres, contacted through Jobcentre Plus. The equipment technically remains the property of the Employment Service when disabled employees leave their jobs, but sometimes may be left as the property of the employer.

Items of equipment bought through Disabled Students' Allowances become the property of the student, unless they leave their course early, when they may be asked to pay back some money. Although they may have some choice over the equipment they find most useful, students do not control the budget, which is in many instances managed by educational institutions, from national government funding.

Arrangements for assessment are the same as for personal assistance (see Section 4).



PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

The following examples are illustrative of good practice in the UK.

'Equality 2025' (established in December 2006) is a strategic 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 network does not claim to be a 'representative' organisation of disabled people, although most of the members consider themselves to be voluntarily accountable to disabled people and their organisations¹⁰.

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 (see, Barnes & Mercer 2006).

As an example, The National Centre for Independent Living received funding from the Department of Health to work with the 13 pilot projects for 'individual budgets'. 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 their 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 (NCIL provided extensive information about the new choices on its website, by phone and email).

In December 2008 NCIL published a review on *Peer Support & Personalisation*¹¹, which set out the nature of good practice, drawing on examples from seven peer local support groups. They begin with the following example (p19):

"Derbyshire Coalition for Inclusive Living (DCIL)

DCIL trains disabled people to give peer support to other disabled people who want to make changes to their lives, for example to go out socially. Many people are isolated in their own homes. Peer supporters help people to live the lives they want to live including going to college or trying to find employment. At the first meeting the peer supporter makes a plan of action with the person seeking support. There are monthly meetings where disabled people discuss various issues of concern and interest. They also support each other to campaign for changes.

DCIL also provides peer support in other areas including direct payments and independent living.

Personal empowerment training is available and is effective in building confidence and facilitating people to talk through their issues, often for the first time. For example a woman using mental health services found that her emotional well being was substantially improved by the training course.

¹⁰ Further details are available at: www.officefordisability.gov.uk/equality2025

¹¹ http://www.ncil.org.uk/uploads/pdf/872661770_Peer%20support%20Final%201.doc



Peer support has identified a particular gap in the support available to disabled women in abusive relationships. DCIL are now working with Women’s Aid to increase the support available.”

The DCIL example is particularly useful because it has a long history that has been extensively documented and discussed as a model of peer-based support for self assessment and user-controlled independent living (Davis & Mullender 1993; Priestley 1998, 1999; Barnes & Mercer 2006). DCIL is now seeking accreditation for the skills training it provides to disabled people as peer supporters.

However, NCIL note that DCIL is unusual in its ability to maintain sufficient funding for these activities, and points to the high sustainability risk facing most genuine local peer-support schemes. All of the projects reviewed showed that peer-support carries additional costs. Most employed one or more people but all appeared to rely mainly on disabled people working as volunteers (paid only expenses). As the NCIL report observes:

‘Peer support services are often working with inadequate resources, and sometimes have no additional funding at all... the funding available for peer support in these contexts also remains ad hoc and inadequate and there is little evidence of a strategic approach.’
(p26)

The report concludes that the government could usefully work together with disabled people and peer support organisations to develop national strategy on ‘the role of peer support in the transformation of social care and personalisation’.



PART 6: REFERENCES

Badger, J. (2009). *Making Choice a Reality: The Impact of the Mental Capacity Act on Young People in Transition to Adulthood*, London: Social Care Institute for Excellence/Scope

Badger, J. And Parnell, R. (2009). *A Long Road to Travel: The Impact of the Mental Capacity Act on Adults with Complex Needs in Residential Settings*, Department of Health/Scope, <http://www.scie.org.uk/publications/mca/files/longroadtotravel.pdf>

Barnes, C. and Mercer, G. (2006). *Independent Futures: creating user-led disability services in a disabling society*, Bristol: Policy Press.

Bonell, S. (2009). 'The Deprivation of Liberty Safeguards: a summary', *Advances in Mental Health and Learning Disabilities*, 3(1): 15-17

Borsay, A. (2005). *Disability and Social Policy in Britain Since 1750: a history of exclusion*. Basingstoke: Palgrave.

Bott, S. (2008). *Peer Support and Personalisation: review prepared for the Department of Health*. London: NCIL

Campbell, J. and Oliver, M. (1996) *Disability Politics: understanding our past, changing our future*, London: Routledge.

Cestari, L., Munroe, M. and Evans, S. (2006). 'Fair Access to Care Services (FACS): implementation in the mental health context of the UK', *Health & Social Care in the Community*, 14(6):474-481.

Charles, N. and Manthorpe, J. (2007). 'FACS or Fiction? The impact of the policy Fair Access to Care Services on social care assessments of older visually impaired people', *Practice*, 19(2):143-157

Clark, H., & Spafford, J. (2002). 'Adapting to the Culture of User Control?' *Social Work Education*, 21(2), 247-257

Commission for Social Care Inspection (2008). 'Social Services Performance Assessment Framework Indicators Adults 2007-08', *National Statistics*, http://www.cqc.org.uk/db/documents/PAF_2008_LO_02.pdf

Commission for Social Care Inspection (2009) *The State of Social Care in England 2007-08*, London: CSCI

CSCI (2008). *Cutting the cake fairly: CSCI review of eligibility criteria for social care* http://www.cqc.org.uk/db/documents/FACS_2008_03.pdf

Davey, V., Fernández, J., Knapp, M., Vick, N., Jolly, D., Swift, P., Tobin, R., Kendall, J., Ferrie, J., Pearson, C., Mercer, G., and Priestley, M. (2007). *Direct Payments: a national survey of direct payments policy and practice*, London: PSSRU, London School of Economics and Political Science

Davis, K. and Mullender, A. (1993). *Ten Turbulent Years: a review of the work of the Derbyshire Coalition of Disabled People*, Nottingham: Centre for Social Action, School of Social Studies, University of Nottingham



Department for Communities and Local Government (2008). *Lifetime Homes, Lifetime Neighbourhoods: a national strategy for housing in an ageing society*, <http://www.communities.gov.uk/publications/housing/lifetimehomesneighbourhoods>

Department for Work and Pensions (2007). *Improving Specialist Disability Employment Services*, Sheffield: Department for Work and Pensions

Department for Health, Social Services and Public Safety (2006). *Quality Standards for Health and Social Care*, London: Department of Health
http://www.dhsspsni.gov.uk/qpi_quality_standards_for_health_social_care.pdf

Department of Health. (2002). *Fair Access To Care Services: guidance on eligibility criteria for adult social care*. London: Department of Health.
http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Localauthoritiesocialserviceletters/DH_4004734

Department of Health (2003). *Direct Payments Guidance: community care, services for carers and children's services (direct payments)*, London: Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4096246

Department of Health (2004). *An Easy Guide to Direct Payments: giving you the choice and control*, London: Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005704

Department of Health (2005). *Independence, Well-being and Choice: our vision for the future of social care for adults in England*. London: HMSO
http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_4116631

Department of Health (2006). *Our Health, Our Care, Our Say: a new direction for community services (A brief guide)*. London: Department of Health

Department of Health (2007). *Putting People First: a shared vision and commitment to the transformation of adult social care*, London: Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

Department of Health (2007a). *A Guide to Receiving Direct Payments From Your Local Council: a route to independent living*. London: Department of Health

Department of Health (2008a). *Safeguarding adults: a consultation on the review of the 'No Secrets' guidance*, http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_089098

Disability Rights Commission (2002). *Policy Statement on Social Care and Independent Living*, http://83.137.212.42/sitearchive/DRC/library/policy/health_and_independent_living/drc_policy_statement_on_social.html

Duffy, S. (2004). 'In Control' *Journal of Integrated Care*, 12(6): 7-13



Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report*, Social Policy Research Unit: University of York, York.

Health and Social Care Information Centre (2008). *Community Care Statistics 2008: Supported Residents, England*,
<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2008-supported-residents-adults-england>

Health and Social Care Information Centre (2009). *Personal Social Services Expenditure and Unit Costs England, 2007-08*,
http://www.ic.nhs.uk/cmsincludes/_process_document.asp?sPublicationID=1232719765590&sDocID=4876

Health and Social Care Information Centre (2009a). *Referrals, Assessments and Packages of Care for Adults, England*
<http://www.ic.nhs.uk/webfiles/publications/Social%20Care/RAP%20Full%20Report/2007-08/RAP%20Report.pdf>

HM Government (2008). *The Case for Change – why England needs a new care and support system*, London: Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084725

Henwood, M. and Hudson, B. (2008). *Lost to the System? The Impact of Fair Access to Care*, London: Commission for Social Care Inspection

Heywood, F., Gangoli, G., Langan, J., Marsh, A., Moyers, S., Smith R., Sutton, E., Hodges, M. and Hamilton, J. (2005). *Reviewing the Disabled Facilities Grant Programme* London: Office of Deputy Prime Minister Higher Education Statistics Agency (2009). *2007/08 Performance Indicators (PIs)*
<http://www.hesa.ac.uk/>

Holman, A. (2002). 'Direct Payments: commentary and review'. *Tizzard Learning Disability Review*, 7(4), 17-20.

House of Lords / House of Commons (2007). *The Human Rights of Older People in Healthcare Eighteenth report of session 2006-07 Volume 1*, London: Stationery Office

Ipsos MORI (2007). *Public Bodies' Response to the Disability Equality Duty: an audit of compliance with the requirement to publish a Disability Equality Scheme*,
http://www.odi.gov.uk/docs/res/compliance_report/ded_report_2007combined.pdf

Jerome, J., Doherty, L., Hills, K. & Williams, C. (2009). *Putting People First: Measuring Progress* London: ADSS / LGA

Joseph Rowntree Foundation. (2005). *Response to the Department of Health Green Paper 'Independence, Well-Being and Choice: our vision for the future of social care for adults in England*.
<http://www.jrf.org.uk>

Kestenbaum, A. (1996). *Independent Living: A Review*, York: Joseph Rowntree Foundation

Laing and Buisson (2008). *Care of Elderly People UK Market Survey 2008*, London: Laing and Buisson



Leadbeater, C., Bartlett, J. and Gallagher, N. (2008). *Making it Personal*, London: DEMOS.

Local Government Association / Association of Directors of Adult Social Care, (2009) *Putting People First: Measuring Progress*

<http://www.adass.org.uk/images/stories/PPF%20Measuring%20Progress%207%20May%20NA.pdf>

Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: main report*, Canterbury: Tizard Centre: University of Kent

Manthorpe, J., Stevens, M., Rapaport, J., Harris, J., Jacobs, S., Challis, D., Netten, A., Knapp, M., Wilberforce, M., & Glendinning, C. (2008). 'Safeguarding and System Change: early perceptions of the implications for adult protection of the English individual budgets pilots - a qualitative study'. *British Journal of Social Work, Advance Access*.

Morris, J. (1995). *Gone Missing? A research and policy review of disabled children living away from their Families*. The Who Cares? Trust: London

Morris, J. (1998). *Still Missing. Volume 2. Disabled children and the Children Act*. The Who Cares? Trust: London

Morris, J. (2004). 'Independent living and community care: a disempowering framework', *Disability & Society*, 19(5):427-442

Morris, J. (2005) *Citizenship and disabled people: A scoping paper prepared for the Disability Rights Commission* Manchester: Disability Rights Commission

National Audit Office (2005). *Gaining and retaining a job: the Department for Work and Pensions' support for disabled people* Report by the Comptroller and Auditor General, HC 455 Session 2005-6, 13 October 2005.

National Audit Office (2007). *Staying the Course: the retention of students in higher education*, London: The Stationery Office
National Statistics (2009). *NHS Information Centre Community Care Statistics 2007-08: Referrals, Assessments and Packages of Care for Adults, England*, <http://www.ic.nhs.uk/webfiles/publications/Social%20Care/RAP%20Full%20Report/2007-08/RAP%20Report.pdf>

National Statistics Scotland (2008). *Health and Community Care Publications*, <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Publications>

Newbigging, K., & Lowe, J. (2005). *Direct Payments and Mental Health: new directions*. Brighton: Pavilion Publishing.

Pickard, M. (2009) Deprivation of Liberty Safeguards in people with learning disabilities — a philosophical perspective, *Advances in Mental Health and Learning Disabilities*, 3(1): 18-22

PMSU (2005). *Improving the Life Chances of Disabled People*, London: HMSO
Priestley, M. (1997). 'The Origins of a Legislative Disability Category in England: a speculative history'. *Disability Studies Quarterly*, 17(2), 87-94.



Priestley, M. (1998). 'Discourse and Resistance in Care Assessment: integrated living and community care', *British Journal of Social Work*, 28(5): 659-673

Priestley, M. (1999). *Disability Politics and Community Care*, London: Jessica Kingsley

Priestley, M., Rabiee, P., Harris, J. (2002). 'Young Disabled People and the 'New Arrangements' for Leaving Care in England and Wales' *Children and Youth Services Review*, 25(11): 863-890.

Sapey, B., Stewart, J. and Donaldson, G. (2004). *The Social Implications of Increases in Wheelchair Use*, Lancaster: Lancaster University

Scotland Government (2008). *2008 Home Care Services in Scotland*, <http://www.scotland.gov.uk/Publications/2008/11/25082031/1>

Spandler, H., and Vick, N. (2005). 'Enabling Access to Direct Payments: an exploration of care co-ordinators decision-making practices'. *Journal of Mental Health*, 14(2), 145-155.

Stone, D. (1984). *The Disabled State*, Philadelphia, PA: Temple University Press.

Williams, B., Copestake, P., Eversley, J. and Stafford, B. (2009). *Experiences and Expectations of Disabled People: A research report for the Office for Disability Issues*, London: ODI, <http://www.odi.gov.uk/docs/res/eedp/eedp-full-report.pdf>

Williams, V., Jepson, M., Tarleton, B., Marriott, A. and Ponting, L. (2008). "*Listen to what I want*": the potential impact of the Mental Capacity Act (2005) on major life decisions by people with learning disabilities, Norah Fry Research Centre: http://www.scie.org.uk/publications/mca/files/norahfry_report.pdf

Williams, V., & Holman, A. (2006). 'Direct Payments and Autonomy: issues for people with learning difficulties'. In J. Leece & J. Bornat (Eds.), *Developments in Direct Payments*. Bristol: The Policy Press.

Woodin, S. (2006). Mapping User-Led Organisations: User-Led Services and Centres for Independent / Integrated / Inclusive Living: a literature review for the Department of Health <http://www.disability-archive.leeds.ac.uk/>

Woodin, S. (2006a). *Social Relations and Disabled People: The Impact of Direct Payments*, Unpublished PhD Thesis: University of Leeds.