England: Health and Personal Social Services for People with Disabilities State Report

A Contemporary Developments in Disability Services Paper

This paper is one of a series of background papers describing how disability services are organised and delivered in selected jurisdictions, to help inform how such services might be organised and delivered in Ireland.

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List of Abbreviations
Community Learning Disability Teams (CLDT)
Councils with Social Services Responsibilities (CSSRs)
Direct Payments (DPs)
Disability Equality Duty (DED)
Equality and Human Rights Commission (EHRC)
Fair Access to Care Services (FACS)
Housing Benefit (HB)
Transitional Housing Benefit (THB)
Individual Budgets (IB)
Joint Strategic Needs Assessments (JSNA)
Learning Disability (LD)
Local authorities (LAs)
National Development Team for Inclusion in England (NDTi)
National Disability Authority (NDA)
National Health Service (NHS)
Office for Disability Issues (ODI)
Patient Advice and Liaison Services (PALS)
Patient and Public Involvement Forums (PPI)
Personal Budgets (PB)
Person centred planning (PCP)
Public Service Agreement (PSA)
Putting People First (PPF)
Supporting People (SP)
UK Home Care Association (UKHCA)
User Led Organisations (ULO)s
1. Introduction

This paper is one of a series of background papers describing how disability services are organised and delivered in selected jurisdictions, to help inform how such services might be organised and delivered in Ireland. The paper describes policy directions and developments that have taken place in England over the last few decades. With the change in government there in mid-2010 some of these directions are currently under review.

A composite report setting out key learning from across the six jurisdictions is also available (hyperlink). This composite report also draws on additional literature from the US and the National Disability Authority’s (NDA) broader programme of work in the area of independent living for people with disabilities.

The jurisdictions were chosen after canvassing expert opinion on where there were opportunities for learning due to innovations in service procurement, design or delivery or evidence of quality. Data was collected for each jurisdiction under a common framework, although information was not always readily available across all elements of the framework for each jurisdiction. The sources of information included published and web sources, as well as interviews with three key informants, with different roles, in each jurisdiction. The draft paper was checked for accuracy and completeness with a national expert in each of the countries studied.

Readers are advised that a key finding from this project is that disability service systems in all of the selected jurisdictions are in transition, and in some areas systems are undergoing rapid development. We welcome any feedback on any of the jurisdictions investigated that can update or enhance these background papers. The jurisdictions investigated include those set out below and can be found at www.nda.ie
2. Population

The population of the selected jurisdictions is shown in Table 1.

<table>
<thead>
<tr>
<th>Total Population 2009</th>
<th>Ireland¹</th>
<th>England²</th>
<th>Scotland³</th>
<th>Netherlands⁴</th>
<th>Norway⁵</th>
<th>Victoria⁶</th>
<th>N. Zealand⁷</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.45m</td>
<td>51.81m</td>
<td>5.19m</td>
<td>16.48m</td>
<td>4.78m</td>
<td>5.42m</td>
<td>4.32m</td>
<td></td>
</tr>
</tbody>
</table>

| Ratio to Ireland      | 1         | 11.6      | 1.2       | 3.7          | 1.1     | 1.2       | 1.0        |

Around 3 million younger adults (18 years to 64 years) have care needs related to a disability. Of these about 550,000 received social care packages through their local council. Around 2.5 million older people (aged over 65 years) - 30% of the

older population - had some difficulties with activities of daily living. Of these, 1.2 million in 2007/2008 used social care that was provided, purchased or supported by a local council including equipment and adaptations to people's homes. The Office for Population Censuses and Surveys (OPCS) found that 32 children per 1,000 have one or more disabilities.

3. **Policy developments underpinning service re-configuration**

Before describing the current system in more detail (Section 4), this section sets out key legislation and policy concepts which underpin the strategic direction in which services have been moving during the last two decades.

3.1. **Legislation and structures**

Key legislation includes:

- The Disability Discrimination Act (DDA) (1995, 2005) which prohibits discrimination on disability grounds in the provision of goods, services and infrastructure

- The Equality and Human rights Commission (EHRC) which acts as the national enforcement body, in relation to disability on other legal grounds

Structures include:

- The **Prime Minister's Strategy Unit** was established in 2002 and is based in the Cabinet Office. The unit reports to the Prime Minister who takes final decisions about the work of the Unit. The main aim of the Unit is to:
  - Improve the Government's capacity to address long term and/or cross-cutting strategic issues including reform of health and social care provision
  - Promote innovation in policy development and the delivery of the Government's objectives on such issues as public sector transformation

- The **Office for Disability Issues (ODI)** was established in 2005. The ODI works with government, disabled people and others to realise the 2025

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11 ibid


13 Taken from: http://www.cabinetoffice.gov.uk/strategy/about.aspx
targets for people with disabilities and to act as their champion within government. The role of the ODI in the disability agenda includes:\textsuperscript{14}

\begin{itemize}
  \item Coordination - seeing the big picture, spotting the gaps and the synergies and keeping things on track.
  \item Creating and encouraging innovation, making interventions, developing solutions, plugging the gaps.
  \item Collaborating, listening, involving, challenging, educating, learning and harnessing expertise.
  \item Communicating, and ensuring others are heard; building relationships, raising awareness, winning hearts and minds
\end{itemize}

\textbf{3.2. Developments in health and social care policy and practice}

Major developments in English services that are particularly pertinent to people with disabilities and people with long-standing care and/or health needs are those that focus on promoting and facilitating independent living. These developments include

\begin{itemize}
  \item Personalisation of services
  \item Individualised funding: direct payments, personal budgets and the piloting of individual budgets
  \item Integration of services and care
  \item The re-configuration of services for people with intellectual (learning) disabilities
\end{itemize}

These developments affect social care services primarily but also health services. Service changes introduced include the integration of services, independent living, the personalisation of care (e.g., direct payments, personal budgets and individual budgets on a pilot basis). There is an extensive literature on these developments in England.

Between 2008 and 2011 £520 million has been invested to help councils reshape their systems and implement key changes in social care services\textsuperscript{15} and councils

\textsuperscript{14} The 2008 Office for Disability Issues Annual report, p.12

are being supported to work more with service users to develop ways of measuring social services ‘success’ at a local level.  

3.2.1. The personalisation of services and Independent Living

While social care was traditionally provided in the form of services determined and delivered by local councils, the government is now promoting the ‘personalisation’ of social care and greater choice.

Personalising services involves promoting self-directed support and overlaps with the concept of independent living or can be seen as part of the promotion of independent living. Personalisation is a broad outcome, while direct payments, personal budgets and individual budgets are means or levers of achieving personalisation. Personalisation offers potential for improvement in terms of the way in which individuals with care needs are supported. It may also involve significant change for a range of agencies and individuals involved in designing and delivering welfare services.

The concept of personalisation is still evolving in terms of policy, implementation and practice and how to turn the rhetoric of personalisation into an effective reality. In England the movement towards personalisation/self-directed support started in the 1990s and continued to develop, underpinned by policy and statutory changes.


18 ibid: “While definitions of the main terms used in discussions of personalisation may seem like an academic debate, they are important as a number of these terms have been used synonymously or incorrectly”, p.5.


21 http://www.in-control.org.uk - The concept of self-directed support was developed by In Control, a national social enterprise that was set up in 2003 by the Department of Health, several local authorities and Mencap. It developed a system of social care called self-directed care that has been adapted as government policy. All 150 local authorities (LA) have converted some of their adult social care services to self-directed support. About 30 health authorities have also introduced self-directed support into their health services.
While developments started with some social and community services, the policy vision and direction of the 2001-2010 government was to extend personalisation of services to all social care services for the whole population and also to other public services including health, education etc.\textsuperscript{22} The 2000-2010 UK Government engaged in creating a shared vision for self-directed services and budgets for social care. Its output of policy papers, strategies, pilots and initiatives and its efforts to win public support for these service developments has been considerable. Consultation has included engaging the public on the need to devolve more responsibility to users, local communities and authorities.

A national strategy from the Prime Minister's Strategy Unit, published in 2005, outlines a 20 year vision for the full societal inclusion of people with disabilities by the year 2025.\textsuperscript{23} The government document, Putting People First\textsuperscript{24}, addresses personalisation of support including greater individual choice and control, self-assessment of need, self-directed support, person-centred planning and increasing the numbers of people using direct payments and personal budgets.\textsuperscript{25} The strategy set targets for personal budgets which are to be available 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.\textsuperscript{26} Personalising services is also an element of a five year cross government strategy set out in 2008 on Independent Living.\textsuperscript{27}

\textsuperscript{22} The Green Paper from the Department of Health, ‘Independence, Well-being and Choice’ (2005), sets out proposals for the direction of social care services for all adults in England: services are to be re-configured to support independence, facilitate self-directed care and give people greater choice and control over the way their needs are met. This paper can be accessed at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitallassets/@dh/@en/documents/digitalasset/dh_4106478.pdf . The Department Health’s strategy “Putting People First” (2007) also highlights the government's commitment towards the personalisation of support.

\textsuperscript{23} Prime Minister’s Strategy Unit (2005) Improving the Life Chances of Disabled People. Available at http://www.odi.gov.uk/working/independent-living/strategy.php

\textsuperscript{24} Department of Health (2007) ‘Putting People First: a shared vision and commitment to the transformation of adult social care’, London: Department of Health


\textsuperscript{26} ibid

\textsuperscript{27} Office for Disability Issues (2008) Independent Living: a cross government strategy about independent living for disabled people. London, Office for Disability Issues. The strategy had input from six government departments: Department for Work and Pensions; Transport; Health; Children, Schools and Families; Communities and Local Government; and, finally, the Department for Innovation, Universities and Skills. It outlines policy commitments to realise equality for disabled people by 2025 including attaining for people with disabilities choice and control over how their support is provided; access to housing, transport, health, employment, education and leisure opportunities and access to full participation in family and community life. The strategy can be
A 2008 Local Authority Circular outlines how a personalised approach to delivering adult social care might be achieved. It stresses the importance of leadership conveying vision and values as well as learning how to work across boundaries with public, private and voluntary entities. A local performance framework has been established to support changes. This framework includes a Local Government National Indicator Set and local area agreements with performance jointly assessed by the new Care Quality Commission and the Comprehensive Area Assessment.

The Department of Health is piloting a number of measures towards increased personalisation and greater efficiency. These include Individual Budget pilots; the work of In Control; the POPP (Partnership for Older Peoples Projects) pilots and the Department for Work and Pensions Link-Age Plus pilots. Other programmes that support personalisation include, for example, a Department of Health Sector Support Programme including a Workforce Strategy.

### 3.2.2. Person-centred planning (PCP)

Person-centred planning (PCP) has been central to the UK Governments strategy for the development and delivery of health and social care services for people with intellectual disabilities although there has been little evidence until recently

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29 http://www.communities.gov.uk/localgovernment/performanceframeworkpartnerships/pffaqs/effic iency strategy/


32 The partnership for Older Peoples Projects (POPP) were carried out in 29 local authorities in England. Each local authority set up one or more local projects to promote the health, well being and independence of older people, and delaying or preventing their need for higher intensity care, including admission to a care home. Some of the interventions were of the low level preventive kind and can be studied in the 2005 Joseph Rowntree Foundation Report, ‘That Little Bit of Help’

33 The LinkAge Plus programme led by the Department of Work and Pensions comprised eight pilots involving central government, local authorities and other organisations and can be studied in the LinkAge Plus National Evaluation: end of project report, DWP Research Report, No. 572, written by Davis, H and Ritters, K (2009)
regarding the impact of introducing PCP or the factors that facilitate or impede the introduction and effectiveness of PCP.34

A longitudinal study on the impact of PCP conducted in England showed that PCP had a positive benefit on the life experiences of people with intellectual disabilities. The benefits identified came without additional service costs once initial training costs were taken into account. However, the benefits associated with PCP did not extend into employment or more inclusive social networks. What is of note is that, in contrast to research on outcomes in supported housing, the study found that greater participant ability was not linked to the outcomes of PCP, with the exception of increased contact with friends. Rather, the findings were that people with mental health, emotional or behavioural problems, or people with more health problems were less likely to receive a plan and less likely to benefit if they did receive a plan. The results indicate inequalities in receiving a person-centred plan. The study also found that committed facilitators are important in ensuring the success of PCP.

3.2.3. Independent Living, choice and control

‘Independent living’ means having the same range of options and the same degree of self-determination that non-disabled people take for granted.35 A key aspect of the notion of independent living includes living in the community like everyone else rather than in an institution. In England, people with disabilities have played an important role in the development of ideas about how to achieve independent living through independent living initiatives and User Led Organisations (ULO). They have contributed to the development of many of the policy initiatives around independent living.36

The term ‘Independent Living’ is used in the UK to describe models or modes of funding and service provision that support people with disabilities to live their lives as full citizens with choice and control over the way in which care is delivered and to live where other people live, that is, in the community. However, ‘personalisation of services’ is also often used in government documents to describe services facilitating ‘choice and control’.


36 ibid

In England policy statements, strategies and guidance material acknowledge that people with disabilities have the potential for independence, choice and control in their lives. Access to services and support for independent living is not restricted, at least in theory, to any particular impairment groups. "Strong and well-established policy commitments to independent living appear, largely, to be matched by continued good practice in terms of implementation at local/practice level".

The policy framework in England provides a range of supports to facilitate people with disabilities to live independently in their communities. These supports include disability-related financial benefits through the social security system and practical support through the social care system administered by local government.

In 2009 a UK five-year "whole-of-government" strategy on Independent Living was published. This was carried out by an Independent Living Review set up in 2006 to develop a strategy as part of the Government's commitment to deliver independent living. The Strategy acknowledges the gap between policy and people's real experiences and outlines measures to close the gap. The personalisation of services is a key element of the "whole-of-government" strategy. Another key element is giving disabled people choice and control over the support they need and the resources available to them in social care as well as across mainstream services (housing, transport, health, employment, education and training); and across all age groups including young disabled people in transition to adulthood and older disabled people. Progress towards the vision and aim of the strategy is to be measured and reported on annually to the Life Chances Ministerial Group. If satisfactory progress is not made on delivering independent living, the then Government promised to review the need for new legislation.

An Explanatory Memorandum to the disabled people's right to control (pilot scheme) (England) regulations 2010 establishes pilot schemes in specific locations within England to enable disabled people over 18 years to exercise greater choice and control over certain services available to them, known as the 'Right to Control'. The pilot schemes commenced in December 2010 for the


39 ibid, p.15


42 ibid
majority of the sites. The regulations set out which services are included in the pilot and the duration of the pilot schemes which will run for up to two years, although in some circumstances the provisions of the regulations will continue to apply after that period. These regulations confer a new legal right for disabled people in Right to Control pilot areas to have choice and control over the publicly funded services they receive. They are being made under enabling powers contained in the Welfare Reform Act 2009. The Office for Disability Issues (ODI) will evaluate these pilots called Trailblazers to inform a decision about wider roll out.

3.2.4. The personalisation of services and User-Led Organisations

Service provider organisations controlled and run by people with disabilities at national, regional and local level in the UK have grown since the 1960s. Legislation in 2001 and 2006 strengthened involvement of users in service design and delivery. These ‘User Led Organisations’ (ULO) support independent living for people with disabilities including the personalisation of services.

Government encourages local authorities (LAs) to work with ULOs and currently is funding relationships between ULOs and LAs in three regions through the Deputy Regional Directors for Social Care and Partnerships.

Section 11 of the Health and Social Care Act 2001 placed a statutory duty upon National Health Service (NHS) organisations to involve local people in the development of services. The NHS Reform and Health Care Professions Act 2002 introduced the framework of Patient and Public Involvement (PPI) forums, committees comprising patients and public working to influence services, as well as the Patient Advice and Liaison Services (PALS) for all, approximately 600, NHS


44 ibid


dorganisations/DH_083152 accessed 25 January 2011. According to the Department of Health: "The [Improving the ] Life Chances report recognised that local organisations, run and controlled by disabled people, will be a vital part of the implementation of a new approach to supporting independent living. The Government has accepted recommendation 4.3 in the report that: "By 2010, each locality (defined as that area covered by a council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living." The Department of Health provided £750,000 in grants to 12 organisations across England to become a user-led action and learning site in 2008-09.
organisations in England.\textsuperscript{48} A Commission for Patient and Public Involvement in health set up to support and manage the PPI forums was abolished in 2004.\textsuperscript{49}

The Disability Equality Duty (DED) came into force in December 2006 requiring public authorities including government departments to publish a Disability Equality Scheme which people with disabilities must be involved in developing.\textsuperscript{50}

In 2005, the Government published the report ‘Improving the Life Chances of Disabled People’. Outlining a vision for improving disabled people’s lives by 2025, it included the recommendation that disabled people be involved in policy development and delivery. To fulfil this commitment, Equality 2025, The United Kingdom Advisory Network for Disability Equality, was established in December 2006. It is an independent non-departmental public body set up to offer the Westminster Government advice and expertise on disability equality issues. It is sponsored by (but is not part of) the Office for Disability Issues (ODI) and is responsible to the Minister for Disabled People. The group represents the whole of the UK - England, Northern Ireland, Scotland and Wales. A permanent Chair was appointed in December 2008.\textsuperscript{51} The group works across Government to offer Ministers and senior government officials strategic advice at the very early stages of policy development on issues that affect disabled people, as well as providing in-depth examinations of new or existing policy areas.\textsuperscript{52} Equality 2025’s 2010-2011 work plan includes provision of advice on welfare reform, supported employment, improving the attitudes to people with disabilities and promoting access to elected office for people with disabilities.\textsuperscript{53}

User-led organisations are unevenly distributed across the UK, providing a range of support services for people with disabilities and their families. The majority are located in south-east England and the midlands while Scotland, south-west England and Wales have the fewest. A 2003 review of the impact of user

\begin{footnotesize}
\begin{enumerate}
\item 45,000 public bodies across Great Britain are covered by the Disability Equality Duty (DED) which came into force in December 2006. The DED is meant to ensure that all public bodies - such as central or local government, schools, health trusts or emergency services – pay ‘due regard’ to the promotion of equality for disabled people in every area of their work. See http://www.dotheduty.org
\item http://appointments.thesundaytimes.co.uk/job/402452/chair-of-equality-2025 (advertisement for post of chair on Dec 14th 2010)
\end{enumerate}
\end{footnotesize}
involvement and ULOs on the quality of social care services for people with physical disabilities\textsuperscript{54} showed that most ULOs offered a wide range of services including education and employment advice, support for recipients of direct payments and disability equality training while others provided information and advice on other services. However, none offered all the services identified as necessary for independent living for people with physical disabilities: information; counselling; housing; technical aids; personal assistance; transport and access. ULOs were shown to be more responsive to people's needs in terms of what was on offer and how it was delivered, with advocacy and peer support identified as key services.\textsuperscript{55} National level user-led organisations include the Spinal Injuries Association and the National Centre for Independent Living.

3.2.5. Individualised funding: Direct Payments; Personal Budgets and Individual Budgets

Options introduced for how funding of social care support is made available include Direct Payments (DPs), Personal Budgets (PB) and Individual Budgets (IB). The latter have been piloted only. DPs, PB and IB can be defined in the following way in England.\textsuperscript{56}

**Direct Payments**

Direct payments operate by providing cash to individuals to purchase a service. In England DPs are available for social care only. DPs cannot be used to purchase services from public care providers but only from private or voluntary care providers, and they cannot be used to purchase health care. They can be used to contract with private or voluntary sector agencies or to become an employer oneself by hiring staff. They can be seen as a consequence of facilitating 'independent living' including autonomy and choice in the use of services.

Direct Payments developed in England in the following manner: The 1996 Community Care Direct Payments Act allowed government, in lieu of community care/social care services, to make cash payments called direct payments (DPs) directly to people aged 18-65 years based upon a community care assessment process. DPs were subsequently extended to people over 65 years, 16-17 years

\textsuperscript{54} Barnes, C., Mercer, G., Din, I. (2003) Research review on user involvement in promoting change and enhancing the quality of social care services for people with physical disabilities. Leeds: Centre for Disability Studies, University of Leeds.

\textsuperscript{55} ibid

\textsuperscript{56} Definitions of Direct Payments (DPs), Personal Budgets and Individual Budgets (IB) vary from country to country. Even within a territory, definitions have varied with time what they mean in practice evolves through various stages: conceptualisation, piloting, more widespread introduction, modification etc. Terms are also sometimes used by different groups in slightly different ways or with different emphasis depending on interests and needs.
old, carers (including 16-17-years-old carers) and people with parental responsibility for a child with a disability.\textsuperscript{57}

DPs are now mainstream welfare policy and part of social care provision. Their stated purpose is to give choice and flexibility in how services are provided. Resource allocation systems are being developed and refined by councils to calculate the budget a person may get and to facilitate clients using direct payments. "If a person already receives social services, the local council is obliged to offer them the option of direct payments in place of the services they currently receive".\textsuperscript{58} "From April 2003, every local council has had to offer people who need help to stay in their own home the option of money instead of arranging services for them. These direct payments enable people to choose how they organise the help they need".\textsuperscript{59} For persons who choose DPs, local authorities attach a monetary value to these services and add funds for fringe benefits and recruitment and training costs. There is no nationally determined specific maximum budget amount.\textsuperscript{60}

Take-up of DPs has to-date been patchy and low across the UK compared to the eligible population but it has increased.\textsuperscript{61} Evidence from Riddell et al's four-country comparative study on the implementation of direct payments showed significantly higher take-up in the south of England compared with many parts of Scotland, Wales and Northern Ireland.\textsuperscript{62} The variations in take-up by people with disabilities in different localities included local, regional and country-specific factors are attributed to factors such as:

- Local cultures of welfare provision, governance and styles of government
- The influence of disability activism and the different political histories of the disability movement


\textsuperscript{59} ibid, page 351

\textsuperscript{60} ibid

\textsuperscript{61} The Community Care website state that on March 31st 2008, a figure of 55,900 adults were receiving a direct payment compared to 40,600 in 2007, 32,000 in 2006 and 22,100 in 2005. Accessed at www.communitycare.co.uk.

Other barriers to the take up of DPs originating from councils\(^6^3\) included:

- Lack of information for service users
- Low staff awareness of DPs and what they are trying to achieve
- Attitudes on the part of staff about the ability of people to manage DPs
- Inadequate or patchy advocacy or support services for DP users

In summary, individualised funding in the form of Direct Payments (DPs) are now mainstream welfare policy and part of social care provision in England since 1996.

**Personal Budgets**

A personal budget is an amount of funding allocated to a user that allows them to control which services that funding is used to purchase.\(^6^4\) Currently personal budgets are for social care funds and the plan is that everyone accessing adult social care will receive a personal budget.\(^6^5\) A national social enterprise, In Control, independent from government developed the concept of personal budgets for social care supports as a step in the concept of self-directed support which they pioneered. This was later taken up by government.\(^6^6\) In Control has supported local authority staff to implement this way of working.\(^6^7\)

"Putting People First: Self-directed Support" (Oct 2009) requires that every person with an ongoing care and support need who is eligible for council funding should have a personal budget.\(^6^8\) This document states that a personal budget may be

\(^{63}\) [http://www.communitycare.co.uk/Articles/2009/04/08/102669/direct-payments-personal-budgets-and-individual-budgets.htm](http://www.communitycare.co.uk/Articles/2009/04/08/102669/direct-payments-personal-budgets-and-individual-budgets.htm) accessed Jan 2010

\(^{64}\) p.4 The Kings Fund (2009) Funding Adult Social Care.

\(^{65}\) Woodin, S. and Priestley, M. and Prideaux, S. 2009. ANED country report on the implementation of policies supporting independent living for disabled people. Available from: www.disability-europe.net/ [Accessed 18th September 2009] There are important differences between Individual Budgets and Personal Budgets. While some government documents speak of Individual Budgets what have actually been sanctioned are Personal Budgets which are quite different. These differences are not always highlighted or made explicit. Personal budgets are an allocation of funding given to users after an assessment to meet assessed needs.

\(^{66}\) In Control started in 2003. It was set up as a project finding a new way of organising the social care system. It has developed into an independent charity committed to promoting active citizenship, community development and the reform of the welfare state. Accessed at [http://www.in-control.org.uk](http://www.in-control.org.uk)

\(^{67}\) Article accessible at [http://www.communitycare.co.uk/Articles/2009/05/22/111636/Why-people-disagree-about-direct-payments-and-personal.htm](http://www.communitycare.co.uk/Articles/2009/05/22/111636/Why-people-disagree-about-direct-payments-and-personal.htm)

\(^{68}\) [Making progress with putting people first: self-directed support (2009). Accessible at](http://www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_advice/Making_progress_with_PPF_-_self-directed_support_final.pdf) This report builds on the ‘Putting People First’ (PPF) concordat which was published by the Department of Health (DH) in 2007 which set
taken by an eligible person as follows: in the form of a direct (cash) payment, held
directly by the person or where they lack capacity, by a “suitable person” or by way
of an ‘account’ held and managed by the council in line with the person’s wishes
i.e. to pay for community care services which are commissioned by the council, or
as an account placed with a third party (provider) under a council contract and
‘called-off’ by the user in direct negotiation with the provider69

Thus, after a social care assessment, the money available should be clarified with
the individual who should have choice over how the money is spent. Users should
be able to take their personal budget as a direct payment, or, while still choosing
how their care needs are met and by whom, leave councils with the responsibility
to commission the services. Alternatively users should be able to take some
combination of the two and so they provide a potentially good option for people
who do not want to take on the responsibilities of a direct payment.

"Research evidence suggests that in the development of approaches such as
personal budgets and self-directed support, risk-avoidant and defensive practice at
the front line is often geared towards protecting organisations from potential
financial and reputational risk. This focus, rather than the promotion of choice and
control for the individual may compromise how personal budgets are offered and
administered."70 The use of personal budgets and direct payments, requires
change in the way risk is understood, managed and negotiated with the person
using the service. It also implies the need for organisational transformation to
respond to person-centred ways of working in all aspects of adult social care,
including safeguarding.71 "Adult safe-guarding shares the underlying principles of
personalisation - empowerment, autonomy and independence - which implies the
need for it to be fully incorporated into adult social care transformation so that
services focus on the person rather than the process."72

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69 Personal Budgets: Council Commissioned Services Advice Note (January 2010) Accessible at http://www.puttingpeoplefirst.org.uk/_library/Resources/Personalisation/Personalisation_advice/Personal_Budgets_Council_Commissioned_Services_-_Advice_NOTE.pdf


71 ibid

In summary, individualised funding in the form of Personal Budgets are available in England and are to be extended to all who need social care. They are funding allocations given to users to meet their assessed care needs. Users can choose to have a trust fund, use a broker to manage the money for them, ask the local authority to pay for particular services e.g. day care etc or they can get the budget transferred to a special bank account to organise the care they need. Currently personal budgets are for social care supports alone. They can be used to purchase support and/or equipment from public, private or voluntary sector providers. Some or all of the Personal Budget can be taken as a Direct Payment.

**Individual Budgets (IB)**

Individual budgets are similar to personal budgets, but combine local council social care funds with other care and support funding streams to create a single ‘pot’ of resources for purchasing services. The Department of Health undertook pilots to explore integrating additional funding sources for personal budgets and called them Individual Budgets (IB). The piloting of these budgets, using integrated funding streams, was carried out in 13 areas in England in 2008 and evaluated in 2009. Individual budgets differ from personal budgets in covering a multitude of funding streams. The idea in the IB pilots is that there would be integration of at least 5 funding sources: Supporting People, Disabled Facilities Grant, Access to Work, Independent Living Funds and community equipment services. In the pilots there were difficulties with alignment and integration across funding streams. Difficulties included incompatibility in eligibility criteria, parallel and sometimes conflicting monitoring and review arrangements, variation in local arrangements and poor engagement between central and local government agencies.

In summary, Individual Budgets differ from Personal Budgets in covering a multitude of funding streams, besides adult social care. This form of individualised

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77 http://www.communitycare.co.uk/Articles/2009/04/08/102669/direct-payments-personal-budgets-and-individual-budgets.htm accessed 8th January 2010

funding with integrated funding has been piloted only. The government has sanctioned the roll-out of personal budgets but not individual budgets. Thus, while a Local Authority Circular states that a person who needs services will have an individual budget (IB) allocated and that an individual can take part or all of their IB as a direct payment,\(^7^9\) the current state of play is that individual budgets have been piloted and evaluated only and no further decision on their future role in funding services has been taken. However, the roll-out of personal budgets for social care has been sanctioned for all.

3.2.6. Integration of services and care

Integrated care is a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion.\(^8^0\) It is an umbrella term and refers not only to patients' perspectives but equally to managerial, technological and economic implications of service integration.

Integration is not an end in itself but a means to improve services in relation to access, quality, user satisfaction and efficiency. It has the overall aim to improve equitably distributed population health.\(^8^1\) It involves activities that integrate various health services at the point of delivery for patients' benefits or aims to integrate differing health care providers for economic benefits.\(^8^2\) It is an issue that is being addressed by many European, South American and Caribbean countries.\(^8^3\) From the users' perspective, the purpose of integrating services is to ensure that services meet the needs of users in a coordinated manner, and facilitate the legitimate autonomy of service users.

The priority of health and social care integration is increasing in England due to the ageing of the population with its accompanying increase in chronic illnesses and disability.\(^8^4\) The need to integrate social care and health services with other supports and services is increasingly recognised and promoted through partnerships,\(^8^5\) joint commissioning and other mechanisms. For example, the

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\(^8^1\) ibid

\(^8^2\) ibid

\(^8^3\) ibid


\(^8^5\) The NHS works largely in partnership with local authority social services to deliver health and social care services for people with disabilities in England. As a result, delivery systems - including
Department of Health has taken up the concept of “Support-Related Housing” which extends the scope of Housing-Related Support to include care at home. It emphasises the interdependency between housing, health and social care and the need to integrate housing with health and social care. The Department of Health highlights where this concept is already contributing to the transformation of social care and the delivery of efficiency improvements. The Care Service Efficiency Delivery Unit within the Department of Health, in partnership with the National Housing Federation, has developed some case studies to encourage the joint commissioning of housing, health and social support and to stimulate innovations. Appendix 2 outlines how recent government policy and guidance recognises the role of housing in the delivery of cost effective and integrated health and social care support for individuals. Appendix 3 contains an overview of recent achievements and plans as outlined in government documentation on a wide range of services and supports for people with disabilities.

Key points from a series of expert-led seminars in 2009 in England on best policy options for integrating health and social care include:

• Start from service users and from different agencies agreeing what they are to achieve rather than from organisational solutions and structures
• Successful partnerships depends on leadership by senior personnel
• The flexibilities in Section 31 of the Health Act have enabled collaboration and integration of health and social care services where there was leadership and a good understanding of the need for closer integration

Changes to the GP contract in the 1960s and 1990s led to the development of primary health care teams. Some aspects of care were integrated by these teams in an effort to improve the services offered and the quality of life of service users.


87 ibid

88 ibid


The 2008 Department of Health publication NHS Next Stage Review outlines plans for integrated health care to improve the quality of health care.91

Section 31 of the 1999 Health Act facilitated the integration of health and social care by allowing

• Pooled budgets where health and social care authorities transfer resources into a single budget which is managed by one of the authorities on behalf of both

• Integrated provision where one authority takes responsibility for the provision of both health and social care

• Lead commissioning where one authority transfers resources to another which then leads out in commissioning both health and social care.

Partnership has a role to play in service integration just as it has in all aspects of service development including commissioning, joint need assessments and delivering services. The power to create Care Trusts was included in the Health and Social Care Act 2001. Care Trusts are set up on a voluntary92 basis to deliver both health and social care. Care trusts combine NHS and local authority responsibilities in particular areas. They are NHS bodies but include local authority councillors on their boards. The new regulator, the Care Quality Commission, set up by the Health and Social Care Act 2008, covers, for the first time, both health and social care. It may have a role to play in promoting closer integration of health and social care services.

Various pilot initiatives promote service integration. The Individual Budget (IB) Projects in 13 English Local Authorities from November 2005 to December 2007 brought together a number of funding streams. The aim was to provide a more integrated service for a range of service users including people with disabilities and people with chronic conditions. In addition to funding from adult social care, funding streams included: Access to Work; the Independent Living Fund (both the responsibility of the Department for Work and Pensions); Supporting People and the Disabled Facilities Grant (both the responsibility of the Department for Communities and Local Government); and local Integrated Community Equipment Services, funded from pooled social care and NHS resources. These projects are promising and have been evaluated.93 Legislation and accountability barriers were


92 Partners can decide to withdraw from the arrangement

experienced\textsuperscript{94}. Other pilot initiatives include the DHs sixteen, two-year integrated care pilots, launched in July 2009 “to transform the way people experience health and social care”\textsuperscript{95}.

Local area agreements may play a role in promoting both service integration and personalisation of services. These are three-year agreements that have been introduced between local authorities, central government, Local Strategic Partnerships and other key partners at local level to set out local area priorities. Their purpose is to foster integration of services, work across boundaries and promote local involvement including private and voluntary sectors. They promote partnerships, user involvement and the mobilisation of informal family and community networks.

3.3. Reconfiguring services for people with intellectual (learning) disability\textsuperscript{96}

Valuing People Now - A New Three Year Strategy for People with Learning Disabilities (2009) set out the then Government’s commitment to implementing the 2001 Valuing People policy more fully for those groups of people with learning disabilities which have benefited least from its policy objectives. The strategy sets out an implementation plan to improve the access for people with learning disabilities to mainstream services. One of the policy objectives in Valuing People Now, is that all people with learning disabilities are supported to become empowered citizens. This include those groups who are generally excluded such as ‘people with more complex needs; people from black and minority ethnic groups and newly arrived communities; people on the autistic spectrum; and offenders in custody and in the community.\textsuperscript{97} In order to fulfill this objective Valuing People Now (2009) detailed key recommended actions at both a national, local and regional capacity.\textsuperscript{98}

Valuing People Now (2007)\textsuperscript{99} highlighted that one of its main priorities is to improve daytime activities available for people with learning disabilities. The policy objective is to support people to live the life they want in their own community and

\textsuperscript{94}Evaluation of the Individual Budgets Pilot Programme can be accessed\textsuperscript{95}Projects can be reviewed at http://www.dhcarenetworks.org.uk/Integration/ICP\textsuperscript{96}In the UK, the term "learning disability" is generally used for what in Ireland is generally called "intellectual disability"\textsuperscript{97}Department of Health (2009, p.38) Valuing People Now - A New Three Year Strategy for People with Learning Disabilities - Making it Happen for Everyone. Available at http://www.valuingpeoplenow.co.uk  (Accessed 3rd September 2009)\textsuperscript{98}ibid, p47-48\textsuperscript{99}Department of Health (2007), Valuing People Now - From Progress to Transformation. Department of Health: London
thus increase their sense of social inclusion, with the crux of the policy being to address the issue of people attending traditional day centres rather than obtaining paid employment or attending an educational setting.

Several cross departmental schemes which include social services, employment and education sectors have been established to assist with this priority:

- To support people in achieving social inclusion, person-centred planning to be used as a tool to design new opportunities and establish required supports. This is a priority for those in receipt of traditional day services. Local Authorities who are developing services to increase social inclusion should ensure that no future school/college leaver attends a segregated day service or centre.

- The "Getting a Life" Programme consists of four government departments (Department of Work and Pensions, Department for Children Schools and Families, Department of Innovation, Universities and Skills and the Department of Health) and aims to assist young people get a job, an education and a social life in the way they want it. This Programme is currently working in 10 different sites throughout England, with a vision that by 2011 there will be more people with learning disabilities in paid employment.100

- A cross departmental working group led by the Department of Work and Pensions (with the Department of Health) has been working in 2010 to develop an action plan to improve the numbers of people with learning disabilities in paid employment.101

- A joint strategy about improving the outcomes for those with a learning disability from the Department for Education and Skills, the Department of Health and the Department for Work and Pensions was published in 2007 called Progression Through Partnership. It highlights how education can improve a persons ability to obtain paid employment.102 The Foundation Learning Tier is an educational tool emphasising employability skills and provides preparation for independent living. The target is to deliver some Foundation Learning for 14 to 19 year olds by 2011.103

- In order to help communities be ready and willing to welcome people with learning disabilities, Valuing People Now (2007, p.34) recommended that local authorities need a strategy for community capacity building in order to address how all people and organisations can develop the skills to involve people with

100 From http://www.gettingalife.org.uk
learning disabilities. The document details five objectives for the following three years and describes how the achievement of these objectives were to be measured. First, more people should be in paid employment with a new Public Service Agreement (PSA) on collecting data on this indicator. Second, the Government should employ more people with learning disabilities with the Government employment data tracking this increase. Third, to assist more people into paid employment there should be a focus on increasing numbers attending post-16 education courses and the Learning and Skills Council should collect data to verify this. Fourth, rather than attending traditional day services, individual budgets and direct payments should support people to spend their day how they choose with nationally collected data measured to ensure that this happens. Finally, the "Getting a Life" project should illustrate "how to bring together funding and the decision making processes around what people do during the day" (p.36) with demonstration sites for this project extended to more parts of the country.

Mansell's 2010 review of services for adults with profound intellectual and multiple disabilities published by the Department of Health outlines what a vision for good services based on contemporary priorities might look like:

- Individualised and person-centred
- Treat the family as expert
- Focus on quality of staff relationships with the person with a disability
- Sustain the package of care
- Cost-effective

There is concern that the significant numbers of ‘out-of-areas placements’ for people with intellectual disability can develop into new institutions. There are around 11,000 people with intellectual disabilities not receiving care in their local area. In Mansell’s evaluation of services, an important obstacle to service development is poor commissioning of specialist services. Other factors include funding cuts, conflicting service trends and an increasing focus on quantity over quality. Many obstacles to service development require reasonable adjustments


106 Information on NHS commissioning processes, including standards and toolkits, can be found at: http://www.library.nhs.uk/commissioning/ViewResource.aspx?resID=291965

107 ibid
to priorities and not large amounts of resources. Mansell's review concluded that while a shortage of resources may influence the speed with which changes can be implemented, it does not mean that the direction of policy and practice should change. While resource constraints may dictate the pace at which objectives are achieved they need not impact on the nature of the objectives themselves.

4. Health and Personal Social Services for people with disabilities in England

4.1. General outline of service organisation

The Department of Health plays a role in both social care and health care. The Department of Health sets the policy direction for the NHS, public health and social care. It develops health and social care policy and monitors the financial and clinical management of both the health and social care system.

Everyone resident in England is entitled to health care, free at the point of entry or first use, that is, every person has free access to GP (General Practice) services which form part of Primary Care. While health care is free at the point of entry, social care is means tested. Local Authorities/Councils with social service responsibilities carry out needs assessments. Social care services are funded and run by local authorities, sometimes in conjunction with local NHS providers and organisations. Authorities sometimes join forces to run social care services.

In England there is a basic principle that provision of health and social care should be nationally equivalent. However, as health and social care are locally administered, there is disparity between the experiences of people with disabilities in different localities.

108 ibid

109 Local Authorities are sometime called Local Councils. There are different types of Local Authorities and a two-tier authority, for example, are comprised of a County Council and a District Council.

110 Established in the late 1940s, the UK ‘Beveridge’ model of welfare provision is based on universal benefits.

Social care is one element of a system of publicly subsidised care and support for people with disabilities. The state makes a contribution to the extra costs associated with disability through disability-related benefits. These are not means tested. Appendix 1 contains some details on disability-related benefits.

Health care is provided through the National Health Service (NHS). The NHS is administered by the Department of Health which funds, directs and supports the NHS. The NHS is a complex environment with hundreds of separate bodies. There is a considerable body of literature on evaluation and learning from the service changes introduced. Appendix 1 contains a summary of the features of the NHS. This includes a comprehensive table of NHS features taken from ‘The Change Foundation’ in Canada.

A more market-oriented welfare system was introduced into the NHS in the early 1990s. The 1990 National Health Service (NHS) and Community Act governing health and social care in the UK was fully implemented in 1993. It sets out how the NHS is to provide for patients based on their assessed needs. It introduced an internal market into the supply of health and social care. It encouraged domiciliary services and highlighted the importance of choice and outcomes for service users and carers. Thus an internal market was created that separated service provision from its commissioning/purchasing. This continues and the responsibility for purchasing services has been moved from corporate managers to primary care.

112 ibid - Attendance Allowance (AA) and Disability Living Allowance (DLA), for example, are alternative social security benefits for those who have impairments that generate a need for care services. AA can be claimed only by people aged over 65 years while DLA must be claimed before reaching 65 years but, when rewarded, it can continue past age 65. In contrast to recent reform proposals which would treat AA recipients less favourably than DLA recipients, a study found no evidence of greater income deprivation among DLA recipients over the age of 65 years. Income deprivation was much higher for both groups than for the over 65’s in general. See Hancock, R., Morciano, M., Pudney, S. (2010) Attendance Allowance and Disability Living Allowance claimants in the older population: Is there a difference in their economic circumstances? Institute for Social and Economic Research: Essex


114 While at some levels the NHS is slow to change, at other levels it is innovative e.g., introducing new clinical products. According to Woolgar (2009) there is, in the NHS, a continuous cycle of reorganisation, restructuring and reform, often resulting in organisational change, increasing layers of bureaucracy and the establishment, adjustment and dismantling of regulatory bodies. See Woolgar, T (2009) Comments on Integrated Health Care in England: Lessons from Ontario. Available at http://www.changefoundation.ca/docs/woolgar_2.pdf


clinicians. Other changes that have been introduced into health and social services since May 2010 include:

- The establishment of a national NHS commissioning board to be responsible for commissioning tertiary care as well as monitoring the commissioning of secondary care by GP consortia.\textsuperscript{118}

- The transformation of current NHS providers of secondary and community care into either semi-autonomous foundation trusts (still owned by the NHS) or into employee-led social enterprises, that is, organisations owned by staff.\textsuperscript{119}

- The introduction of significant cuts in staffing levels in the Department of Health which is to focus on public health with a new Public Health Service based outside the NHS in local government.\textsuperscript{120}

- In terms of social care, the new Government has established a commission on long-term care to report within a year. This has the remit of reviewing the considerable body of work done in recent years including consultation processes and Green and White Papers in the last year proposing a reformation of social care funding with the introduction of voluntary insurance and partnership schemes.\textsuperscript{121}

It is important to note that, as well as health and social care services, people with disabilities\textsuperscript{122} access other key services and supports. These include transport; assistive technology; advocacy; housing; housing adaptations; employment services and rehabilitation services. Such services and supports are crucial in

\begin{itemize}
\item 117 Equity and Excellence: Liberating the NHS (July 2010) The Coalition Government's White Paper on the NHS
\item 118 ibid
\item 119 ibid
\item 120 ibid
\item 121 This work includes the Department of Health (2009) Shaping the future of care together Green Paper London; The Stationery Office Ltd on behalf of the Controller of Her Majesty's Stationery Office - there is more on this in the section on funding social care services
\item 121 ibid
\item 121 ibid
\item 121 The work done to date includes that outlined in the Department of Health (2009) Shaping the future of care together Green Paper London; The Stationery Office Ltd on behalf of the Controller of Her Majesty's Stationery Office and the White Paper published in March 2010
\item 122 In England ‘disabled person’ or ‘disabled people’ is used rather than ‘a person with a disability’ or ‘people with disabilities’.
\end{itemize}
enabling people with disabilities to access education, the labour market and their local community and to participate fully in civic, cultural and social life.

4.2. Accessing personal social services

4.2.1. Social care services

The Department of Health defines social care services as: "the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relations".123

Social care services are required because of needs arising from old age, learning and physical/sensory disabilities, accidents, long-term illness, mental illness, vulnerable home situations etc. They are provided in a person's own home (usually referred to as domiciliary or home care), care homes (residential and nursing homes) and at community venues such as drop-in and day care services.124 The UK Home Care Association (UKHCA) is a representative body for organisations providing personal/nursing care to people in their own homes.125

Distinctions between different types of social care services can be important when determining who pays for the service.126 Personal care covers help with activities of daily living such as dressing, eating, washing or going to the toilet. In a domiciliary care setting, a care package can include both personal care services and practical home help such as domestic cleaning in the home and help with the shopping. In a care home there is a distinction between personal care services and board and lodging.

Some care is provided by the National Health Service (NHS). For example, NHS nursing care is provided free in one's own home and since 2001 the NHS has contributed to the cost of registered nursing care for care home residents by paying a weekly allowance of £103.80 (standard rate) or £142.80 (higher rate). The rate is related to the degree of dependency as assessed. NHS Continuing Healthcare provides a number of ‘continuing care’ services without means testing. These can be supplied in any setting and include fully funded health care and personal care in the patient’s home or a fully funded care home placement including board and accommodation.127 Social care services for people with


125 http://www.ukhca.co.uk/choosingcare.aspx [Accessed August 2009]

126 ibid

127 ibid, p.3
intellectual disabilities, that were previously provided by the NHS, have largely been transferred over to local authorities. These commission social care services for the local community.

4.2.2. Funding social care services

Social care is funded through central government funding allocated to local councils; council tax revenues; individuals' contribution to their council care package and/or to services arranged independently. The voluntary or third sector also provides and subsidises a range of care services. While social care funding is currently based on national and local taxation with national rules for residential care charging, local authorities can decide and set eligibility criteria over what is charged for home care within national guidelines: "The relevant local authority is responsible for interpreting and applying the regulations and guidelines in order to decide what to charge".

In the UK, the 2009 Green Paper, ‘Shaping the Future of Care together’, followed a consultation period. The Paper suggests funding options for social care including partnership and insurance options. It proposed a partnership approach as perhaps the best foundation for a new system. With this approach, everyone would get some help with paying for care and support and people could also choose to protect themselves with insurance against the risk of paying high care and support costs.

What is proposed in the Green Paper is that care and support costs would not include the cost of accommodation. A universal deferred payment mechanism would allow residential care and accommodation costs to be charged upon a person's estate when they die, rather than having to go through the process of selling their home when they need residential care. The Green Paper suggests a move from the current local system to a part-national, part-local system or to a fully national system based on national taxation. This is outlined in figure 1.

**Figure 1: Current and possible future funding options for adult social care**


129 http://www.direct.gov.uk


131 ibid

132 ibid, p. 20. The green paper invited people to participate in a 4-month public consultation between July and November 2009. Prior to the publication of the Green Paper the government ran a six-month engagement process with service users, service providers and the public.

<table>
<thead>
<tr>
<th>Funding Option</th>
<th>Who raises funds for care and support</th>
<th>Who decides who gets state funding and what proportion of an individual’s overall care and support package should be funded</th>
<th>Who decides what the cost of someone’s care and support should be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current system – local system</td>
<td>National and local taxation</td>
<td>Local authorities can set eligibility criteria and have discretion over what is charged for home care (within national guidelines). There are national rules for residential care charging</td>
<td>Local Authorities</td>
</tr>
<tr>
<td>Part-national, part-local</td>
<td>National and local taxation</td>
<td>Eligibility criteria and the proportion of care and support costs met are decided nationally – the proportion of costs met could depend on an individual’s needs and/or means</td>
<td>Local Authorities</td>
</tr>
<tr>
<td>Fully national</td>
<td>National Taxation</td>
<td>Eligibility criteria and the proportion of care and support costs met are decided nationally – the proportion of costs met could depend on an individual’s needs and/or means</td>
<td>Local Authorities</td>
</tr>
</tbody>
</table>

The Green Paper invited further debate, discussion and consultation to feed into a White Paper\(^{134}\) which was published in March 2010. It invited debate on local versus more centralised services asking “consumers” what balance should be sought between local flexibility and national consistency. The 2010 White paper again proposes a service built on social care insurance. In May 2010 the government set up a new Social Care Commission. Its remit is to revisit these issues and to assess the work done to date such as that outlined in the 2009 Green Paper and the 2010 White Paper. The Commission is to report within a year.

### 4.2.3. Individual assessment, eligibility and individual funding for social care

The local council carries out an assessment of need to determine the level and type of disability and dependency of an individual. The council uses the national Fair Access to Care Services (FACS) framework\(^{135}\) to categorise an individual’s level of need as low, moderate, substantial or critical. Each local council has its own budget for adult social care and decides which of these four needs bands it will fund (some councils fund moderate needs, others cover only the critical band).

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\(^{135}\) The Department of Health (2003) National Fair Access to Care Services (FACS) framework
Anyone below their council’s needs eligibility threshold must pay for their own care. In assessing individual need and arranging care and support to meet those needs councils work with other organisations including the NHS, private and voluntary organisations, education, the probation services, the police. Sometimes councils work together to manage social care services. Everyone who applies for social care/support is assessed with a standardised national needs assessment. 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.

Information on assessments and waiting time for receipt of services is outlined in Appendix 4.

A range of standardised needs assessment and resource allocation tools are emerging in practice in the USA and across local authorities in the U.K. "In Control" in England has continued to develop and refine needs assessment and promote self-assessment. Some authorities have online self assessment forms giving people the choice of assessing their own needs or carrying out an assessment on behalf of someone else. See Appendix 4 for waiting times for assessment.

Local authorities with social services responsibilities are asked to carry out Joint Strategic Needs Assessments (JSNA). JSNA is defined as “a systematic method for reviewing the health and wellbeing needs of a population, leading to agreed commissioning priorities that will improve the health and wellbeing


137 ibid

138 The Supports Intensity Scale is one of the tools used in the USA. The Human Services Research Institute (HSRI) has used individual assessment information from this Scale in conjunction with past funding awards to uncover the rationale that states have employed for resource allocation. See, for example, the report Developing Individual Budgets and Reimbursement Levels Using the Supports Intensity Scale Available at http://www.sageresources.org/resources/Individual%20Budgets%20Using%20SIS_FINAL.pdf (Accessed Dec 20th 2009)


140 The Joint Strategic Needs Assessment (JSNA)came from the Social Care Green Paper ‘Independence, wellbeing and choice.’ It was reinforced in the Health White Paper, ‘Our health, Our Care, Our say.’ The Local Government and Public Involvement in Health Act 2007 took effect in England from April 2008. It specifies that local authorities and Primary Care Trusts (PCTs) produce a Joint Strategic Needs Assessment (JSNA) of the health and wellbeing of the local community. The idea was that the JSNA would inform Local Area Agreements and the Sustainable Communities Strategy. The Secretary of State for Health has the power to direct the preparation of further Joint Strategic Needs Assessments. There is a 2008 report on JSNA commissioned by the Dept of Health and the Integrated Care Network, ‘Implementing Joint Strategic Needs Assessment: pitfalls, possibilities and progress’
outcomes and reduce inequalities”. JSNA provides an opportunity for integrated working and planning. Different approaches have been taken to conducting JSNA; one in Cambridgeshire, for example, for people with intellectual disabilities has striven to engage service users through a User Parliament, which enabled users to contribute fully to setting out their needs.

According to the Kings Fund (2009): "There are significant local variations in who is eligible for what kinds of support and a host of complicated local and national rules apply to the funding of different elements of social care services". In theory, services are provided in response to assessed needs and risks to independence, rather than the availability of particular services.

However, in practice, there is much variation. "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 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." Ambiguities have been highlighted in implementation, training and guidance. Those who have been


145 Woodin, S., Priestley, M., Prideaux, S (2009) ANED country report on the implementation of policies supporting independent living for disabled people


147 Woodin, S., Priestley, M., Prideaux, S (2009, p.12) ANED country report on the implementation of policies supporting independent living for disabled people

assessed as ineligible to receive significant support have been studied and their poor quality of life in relation to choice, well being and dignity documented.\textsuperscript{149}

As assessment is underpinned by eligibility criteria, which can change in response to what level of resource is available.\textsuperscript{150} People who have been eligible may become ineligible if resources become tighter: there are no absolute categories for eligibility to services.\textsuperscript{151} Eligibility to direct payments and to individual budgets to pay for personal assistance, for example, are all based on individual assessment and eligibility criteria.

In addition to eligibility, an adult who is eligible to receive social care needs to undergo means testing to determine how much he/she will be expected to contribute to the cost of that care. Means testing rules are summarised in a footnote.\textsuperscript{152}

The social care system is complex with a number of individual funding streams allocated through diverse, uncoordinated mechanisms that use separate assessment processes, regardless of the overlap in recipient populations.\textsuperscript{153}

Attendance Allowance and Disability Living Allowance, for example, provide


\textsuperscript{151} ibid

\textsuperscript{152} The King's Fund (2009) Funding Adults social care in England. Available at www.kingsfund.org.uk (Accessed 14th Jan 2010) - The national rules for residential care for adults is that an individual with assets of more than £22,250 in 2008/2009 receives no financial support. The values of the individual's home is included in the means test from 12 weeks after entry into a care home unless a spouse/partner continues to live there. An assessed income figure is calculated according to national rules that specify what types of income and assets should be included for individuals whose assets are £22,250 or less. All of that assessed income must then be paid towards the costs of residential care, except for a weekly personal expenses allowance of £21.15. Individuals who do not want to sell their home to pay care home fees can apply for a deferred payments agreement whereby the council in effect provides an interest free loan until the agreement is terminated by the user or up to 56 days after the death of the user. Local authorities have discretionary powers to agree this type of arrangements. The rules that determine the charge made for care provided in an individuals own home i.e. domiciliary care are set by the local council but must comply with the Fairer Charging Guidelines of the Department of Health, 2003b. These specify that a user's assessed net income after care charges must not fall below a minimum threshold. There is a big variation in funding systems: a small number of councils provide free services, most use a means-test to determine user charges, and others charge a flat rate. A user with assets above £22,250 is usually asked to pay the full cost of the care plan. Separately from social care, the UK disability-related benefits (Attendance Allowance and Disability Living Allowance) have national eligibility rules and are not means tested. See appendix 1.

\textsuperscript{153} King's Fund (2009) Funding Adult social care in England Available at www.kingsfund.org.uk (Accessed 14th Jan 2010)
national cash benefits linked to need and which are not means tested, while social care is means-tested and subject to local council control. Yet both funding streams exist to support the goals of providing care and support and promoting independence. Users can find it difficult to understand the boundaries between NHS funding and the entire social care system.\textsuperscript{154}

4.2.4. Social care and related services for people with intellectual (learning) disabilities

Services delivered to people with intellectual disability reflect regional variation because there is variation in the nature, amount and quality available between local authorities or health authorities.\textsuperscript{155} A number of reports have outlined issues with quality and variation of services provided to people with intellectual disabilities and these have prompted policy and practice changes and ongoing evaluation of services.\textsuperscript{156}

The Care Quality Commission outlines the current tiered model of services, from lower to more intense supports, available to people with learning disabilities.\textsuperscript{157} Complexity of need increases from Tier 1 at the base of a tiered pyramid of services to Tier 4 at the apex of the model. Conversely, the numbers of people in each tier decrease from base to apex of the tiered model of services. The numbers of people with an intellectual disability within each service tier can be seen in Facts and Figures in the Accommodation and Housing section of this report.

The four tiers of services available are as follows:

**Tier 1 - Care and support involving families, friends and communities:** The majority of people with intellectual (learning) disabilities are not known to services. Family and informal systems are sufficient for most areas of support and care required. When services are accessed, the majority are mainstream public services. Support sought includes, for example, short breaks, part-time support workers or personal assistant or access to college. Support is accessed through social services departments or through community teams (generally,

\textsuperscript{154} ibid


\textsuperscript{157} Care Quality Commission (December, 2009) Strategic Plan 2010-2015 - position statement and action plan for learning disability. London: Care Quality Commission
professionals in joint teams, combining health service clinicians with social workers and care coordinators).  

**Tier 2 - Full-time care and support: Social care for older people; social care for younger people; supported living and shared lives (formerly known as adult placements)** A smaller group of people than in tier 1 live independently of their families. They receive support for most, if not all, of the day and night. The different models include

- **Supported living** - individuals or small groups receive support in their own home, or as a tenant of a home provided by a housing provider. Sometimes a number of tenants with learning disabilities share a group of flats or apartments. The homecare provider as opposed to the housing provider gives support through personal assistants. These arrangements range from intensive support packages to occasional visits.

- **Social care** - in many cases, full time support is provided in traditional residential care homes, generally in small or medium sized groups. There are a number of young and middle aged adults with learning disabilities living in care homes for older people. The care provided can be totally social or have a nursing component.

- **Shared lives (formally known as adult placements)** - a person can live with other people in their own homes, for example, as part of a family unit or with un-related, non-disabled individuals and receive care and support from a home-sharer approved and trained for this role.

**Tier 3 - Specialist healthcare** For a small number of people with learning disabilities, their additional needs and complex behaviour require more specialist services. There are 2 main providers of these services:

- **Local NHS assessment and treatments services** - intended to be relatively short-term placements with access to clinical support and nursing care

- **Independent Hospitals** - these also provide specialist assessment and intervention with the support of nursing and other health professionals. Placements are often longer in the independent sector and some are not in the local area for the person and their family. All people are detained under the Mental Health Act.

**Tier 4 - Regional and secure services** There are an increasing number of secure settings for people with learning disabilities. There are also a number of people with learning disabilities who access generic tier 4 services. There should be

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158 ibid

159 ibid
important liaison and professional relationships between Tier 3 and Tier 4 services to facilitate movement in both directions and to ensure collaborative and positive risk management.\textsuperscript{160} Numbers of people within tiers of services can be seen in table 3.

Delivering specialist services that will meet the needs of particular populations is complex. To illustrate this the following partners were suggested as necessary to implement the Valuing People strategy for people with intellectual disabilities.\textsuperscript{161}

- Ten Government Departments
- The National Directors of Learning Disabilities
- The Office of the National Director for Learning Disabilities
- The Valuing People Team
- Government Offices of the Regions
- Deputy Regional Directors for Social Care and Partnerships
- Strategic Health Authorities
- Directors of Adult Social Services
- Directors of Children Services
- Chief Executives of Primary Care Teams
- Learning Disability Partnership Boards
- National Valuing Families Forum
- Third sector providers
- Independent Providers and
- The Care Quality Commission

To coordinate and integrate service design and delivery across such a large number of bodies is challenging and requires leadership, management and partnership skills and commitment to the partnership approach.

\textsuperscript{160} ibid

Traditionally, the NHS funded social care services for people with intellectual disabilities; "The largest proportion of learning disability funding within the NHS has been dedicated to the funding of social care services. This represents the historic NHS investment in learning disabilities from when the NHS ran large, long-stay hospitals. The funding is now being transferred to local authorities using section 256 (formerly 28A) or section 31 powers to enable local authorities to lead the commissioning of all social services''.

Thus, the goal is that all social care services for people with intellectual disabilities will be transferred from the NHS to the Social Care Sector. To achieve this, budgets and associated commissioning responsibility for social care for adults with learning disabilities are being transferred to local authorities. The Social Care Sector will provide the necessary services, with Local Authorities commissioning the required services from private or voluntary organisations. This includes healthcare and forensic/offender services, which stay with the Primary Care Trusts. By transferring funding from the NHS to the local authority, it is hoped that local authorities as lead commissioners for learning disability services will have direct access to the resources they need to improve services.

There are disability support services in local authorities to assist people with disabilities to access the services they require and other specialists services such as services for continence and diet. In terms of specialist services it is widely recognised that there is a need for services for complex conditions and that early intervention is often important. Furthermore such services should be delivered by staff with the skills and competence appropriate to the level of interventions required. However, many therapists will also agree that, for example, people with learning disabilities and their families need to access specialist help in mainstream health and social care services and should not have all their needs met by learning disability services.

162 ibid
Local Authorities (LA) and/or health trusts have specialist Community Learning Disability Teams (CLDT) usually with a mix of Health and Social Services Staff. CLDT generally sit within Local Authority Adult Social Care. They comprise psychiatrists, psychologists, speech and language specialists, Learning Disability (LD) nurses, social workers/care managers, occupational therapists and physiotherapists, occupational therapists, and physiotherapists, sometimes other managers and specialists like behavioural support.

Long-term partnerships between commissioners and service providers committed to developing local capability to serve people with disability may reverse the trend of ‘out-of-areas placements’ for people with intellectual disability. Planning services for people with intellectual disabilities and challenging behaviour requires advocacy and coordination services, in order that appropriate person-centred plans for current and future service needs can be formulated and translated into action for each person. In England, in order to achieve this, councils\(^\text{166}\) are working to strengthen their commissioning skills combining expertise with competencies in order to develop the services needed.\(^\text{167}\)

### 4.3. Accessing Health Services

People with disabilities access mainstream health services including primary, acute (secondary) and preventative health services as other members of the public do. An individual does not have to register as a person with a disability to receive general health services in England and these services are provided free at the point of entry - primary health care - in the National Health Service (NHS) for the entire population.

While primary health care is provided free of charge to everyone living in the UK, there are some charges for dentistry and optical services and there is a flat rate

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166 Councils in England are a unit of local government. The set-up of UK local government can be confusing due to re-organisations in 1973, the 1980s and 1990s. Up until the 1990s there were two tiers of councils outside major urban areas. County councils looked after services including education, social care and transport. District councils catered for services including housing, building regulations, environmental health and local planning. In the 1990s County Councils were abolished and functions transferred to district councils. Smaller districts were merged together. However, while in Scotland and Wales this was done, in England there was a process of local consultation which led to the single tier model being supported and implemented in some places but rejected in others. There are 34 county councils and 238 district councils in the UK with all purpose authorities in London (32 London boroughs) and other metropolitan areas According to Wikipedia the most complex system of local government in the world is in England, the result of the numerous reforms and reorganisation (http://en.wikipedia.org/wiki/Local_government)

charge per prescription item. There are special circumstances where these fees are waived.\textsuperscript{168}

Primary health care is the term used for health services provided in the local community. This care includes that provided by GPs, pharmacists, dentists and midwives. Primary care providers are usually the first point of contact for a patient and follow a patient throughout their care pathway.\textsuperscript{169} As outlined, the GP service is free for everyone residing in the country.

According to Goodwin et al (2008), "The UK’s focus on a primary care service that is universal, comprehensive and free at the point of delivery is a key factor that has enabled the UK National Health Service (NHS) to be ranked as one of the most progressive and high performing health system in international comparisons though it remains comparatively weak in terms of access and responsiveness to demands".\textsuperscript{170}

In the first four years after the publication of the 2001 Valuing People White Paper on learning (intellectual) disability\textsuperscript{171}, progress on health issues was identified as the weakest area due to clinical governance issues.\textsuperscript{172} Almost all statistics showed geographical variation in health services available to people with intellectual (learning) disabilities.\textsuperscript{173} “Of particular concern is the poor standards of care, and

\begin{footnotesize}
\begin{enumerate}
\item[171] In England the term ‘learning disability’ is used instead of ‘intellectual disability’.
\item[173] ibid
\end{enumerate}
\end{footnotesize}
poor levels of accessibility, to the ‘hard to reach’ population groups..... Tackling health inequalities through primary care has been a recurrent Government policy agenda....a recent ongoing review of the NHS in England has suggested that 100 new primary care practices in the 25 worse-off boroughs ought to be established, a figure underpinning the scale of the problem". 174

In a national survey of people with intellectual (learning) disabilities (2003/2004) information was collected on the types of health services. These are shown in Table 2.

Table 2 Use of health services by people with intellectual disabilities in 2003/2004

<table>
<thead>
<tr>
<th></th>
<th>Mild or moderate</th>
<th>Severe</th>
<th>Profound multiple</th>
<th>Total % people with intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered with GP</td>
<td>99%</td>
<td>100%</td>
<td>99%</td>
<td>99%</td>
</tr>
<tr>
<td>Been to GP in the last year</td>
<td>76%</td>
<td>80%</td>
<td>80%</td>
<td>78%</td>
</tr>
<tr>
<td>Registered with a dentist</td>
<td>77%</td>
<td>85%</td>
<td>83%</td>
<td>82%</td>
</tr>
<tr>
<td>Been to dentist in last year</td>
<td>67%</td>
<td>75%</td>
<td>77%</td>
<td>72%</td>
</tr>
<tr>
<td>Eyes tested in last year</td>
<td>51%</td>
<td>55%</td>
<td>41%</td>
<td>52%</td>
</tr>
<tr>
<td>Hearing tested in last year</td>
<td>17%</td>
<td>25%</td>
<td>23%</td>
<td>21%</td>
</tr>
<tr>
<td>Had cervical smear (of women)</td>
<td>42%</td>
<td>16%</td>
<td>5%</td>
<td>27%</td>
</tr>
<tr>
<td>Had mammogram (of women)</td>
<td>27%</td>
<td>22%</td>
<td>19%</td>
<td>24%</td>
</tr>
</tbody>
</table>

A more recent analysis of primary care data to support the work of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities showed that access to and quality of healthcare for patients with intellectual


disabilities is broadly similar to that of the general patient population for many of the conditions analysed.\textsuperscript{177}

Efforts to improve health services for people with intellectual disabilities have included that

- People with intellectual (learning) disabilities are registered with a GP
- GP’s are trained in communication skills
- People with learning disabilities have annual health checks etc
- New partnerships are forged between specialist learning disability healthcare staff, primary care and acute services
- Local authorities take over social care for people with learning disabilities
- From April 2009 preventative health checks have been offered to everyone between 40 and 74 years with a target that these be fully available across England by 2013.

5.0. Accommodation and Housing Services

5.1. The changing pattern of accommodation provision

The shift from the provision of institutional care to community service provision/community living solutions, as is happening world-wide, started in the UK in the 1970s. It proceeded more quickly in England and Wales than in Scotland or Northern Ireland. The independent living movement in England particularly from the 1980s promoted alternative models of community services to institutional care based on the provision of personal assistance. This movement championed legislative changes so that direct payments for personal assistants for people with physical disabilities mainly could be made in lieu of direct service provision.  

Initially the shift from institutions - large residential settings - for people with intellectual disabilities tended to be to some form of comprehensive placement models. These included cluster housing, group homes, smaller specialist residential facilities and hospital wards. The current trend is to replace a lot of comprehensive placement models - residential care - with more supported living and supported housing models. "Good quality residential care should remain a valid choice, but it should not be the only or predominant choice just because there is little or nothing else available". 


The residential care model is legally defined in the Care Standards Act 2000 as an establishment that provides accommodation and personal care which is defined as assistance with bodily functions such as feeding, bathing, toileting when required. Within the residential care model there is an assumption that an older or disabled person needs care and therefore it provides a full package of housing, care and everyday needs for living on the person’s behalf.\textsuperscript{180}

In a 2010 review of progress on providing suitable accommodation for people with learning disabilities, the UK government acknowledged that wide regional variations in quality still existed, that too few people had a real choice over where to live and with whom and that far too many adults with learning disabilities continue to live in residential care, sometimes placed in an emergency and often a long way away from their families.\textsuperscript{181} The target of closing residential campuses - smaller residential sites built on the campus of an institution - by the end of 2010 because of concerns over quality of care has not yet been met.\textsuperscript{182} However, significant progress had been made in some Local Authorities\textsuperscript{183} and this body of evidence is becoming available for others to use. A toolkit for Local Authorities on planning and commissioning housing for people with learning disabilities was published in 2010.\textsuperscript{184}

To date much investment in new housing and support options has been in a narrow range of models. In many local authorities, while it is relatively easy to access group homes with tenancies or residential care, other options are either non-existent or difficult to access.\textsuperscript{185}

According to the National Development Team for Inclusion in England (NDTi)\textsuperscript{186} people with learning disabilities should ideally have access to the following options

- Shared supported housing - see next section

\textsuperscript{180} ibid - p.7
\textsuperscript{181} page, 38, Department of Health (2010) Valuing People Now: The delivery plan for 2010-2011
\textsuperscript{182} ibid - in October 2009 there were circa 900 people living in NHS campuses
\textsuperscript{183} ibid
\textsuperscript{184} http://www.housingoptions.org.uk/general_information/gi_publications_docs/valuing_people_now_publications/VP_Housing_Toolkit.pdf
\textsuperscript{186} The National Development Team for Inclusion (NDTi) is a not-for-profit organisation in England which works to promote inclusive lives for people who are most at risk of exclusion and who may need support to lead a full life.
• Shared Lives formerly known as Adult Family Placement where a person lives in a family home

• Extra Care Schemes with mixed tenures\textsuperscript{187} for people with severe learning disability

• Community Living Networks such as the KeyRing Model\textsuperscript{188}

• Low cost home ownership including Home Ownership for people with long term disabilities (HOLD), Homebuy\textsuperscript{189}, Newbuild Homebuy, and resale of existing schemes, Family Funded shared ownership

• Home ownership on the open market with access to support and advice

• Public sector rented properties

• Private sector rented properties e.g. via Housing Association Leasing Schemes

• Family investment and trust funds to set up a range of housing models with access to advice and support

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\textsuperscript{187} A small number of sheltered / retirement and extra care housing schemes offer a choice of tenure - buy outright, rent, or opt to part buy your property on a 'shared a 'shared ownership' basis with the provider. A 2005 technical brief on Mixed Tenure in Extra Care Housing is available at www.dhcarenetworks.org.uk (Accessed 2nd Nov 2010) from the Department of Health and the Care Services Improvement Partnership. This provides information to help housing and care providers with mixed tenure developments to anticipate and avoid some of the problems and risks inherent in mixed tenure Extra Care Housing. The Health and Social Care Change Agent Team (CAT) was created by the Department of Health to improve hospital and social care associated arrangements. The Housing Learning & Improvement Network, a section of the CAT in the newly formed Care Services Improvement Partnership, is devoted to housing based models of care and support for adults.

\textsuperscript{188} KeyRing, United Kingdom, is a charity providing a model of community supported living for people with intellectual disabilities, who want their own place. KeyRing's support is based on people living in their own homes but sharing skills and talents with each other and with their communities. There is a volunteer in each Network who sees Members regularly and helps the group work together. The volunteer is like a good neighbour who will help out if difficulties arise. Because the volunteer lives in the community, they know what's going on and are able to help Members make links. There are also Community Support Workers and Supported Living Managers who make sure that Members get the support they need. Information on KeyRing is available at http://www.keyring.org/ (Accessed 2nd Nov 2010)

\textsuperscript{189} This shared ownership option offers new homes for sale on a part buy / part rent basis. "You can buy shares worth between 25% and 75% of the property's market value and you pay a subsidised rent on the remaining share. You may need to raise a mortgage to purchase your share. You can buy additional shares at a later date until you own 100%, if you wish to. This is called staircasing and the cost of the additional shares is based on the market value of the property at the time that you purchase the shares. If you increase your share in the property, your rent is recalculated and reduced proportionately" from http://www.homebuy.co.uk/new_build_homebuy.aspx (Accessed 2nd Nov 2010)
• Residential care

5.2. Facts and figures on accommodation for people with intellectual disabilities

Approximately half of the population of adults with learning disabilities in England live with their families, most of the remainder (33%) live in residential care. Only 15% of adults with learning disabilities have a secure long-term tenancy or their own home. This is in comparison with 70% of the general adult population who own their own home and nearly 30% who rent.¹⁹¹

The Health and Social Care Act 2008 focuses registration and inspection on the needs of individual service users and the ability of service providers to respond adequately to those needs. Local Authorities have largely withdrawn from direct residential provision so that most of these services are now provided by private providers or voluntary bodies.¹⁹²

There is guidance from the Care Quality Commission to its inspectors to help them determine whether a home should be registered as a care home or not.¹⁹³ If the following criteria are met, the housing is unlikely to be registerable as a care home:

- The separate providers of accommodation and care do not need to co-ordinate their work and are not accountable to each other
- People who use the service have real choice e.g., they can change their care provider without jeopardising their accommodation rights
- People using the service have exclusive occupation and can deny entry to others, even carers
- The tenancy can be assigned to someone else
- Occupants can remain even if they no longer need a care service
- There are separate contracts for the care and the accommodation

In 2006 there were more than 129,000 residential placements in the whole UK, of which: more than 48,000 were in large institutions of greater than 30 people; more than 33,000 in smaller settings and more than 47,000 in unclassified settings.¹⁹⁴

¹⁹⁰ ibid
¹⁹¹ ibid
¹⁹² http://www.care-plan-management-system.co.uk/care-service-types/residential-care/
¹⁹³ Care Quality Commission Document ref. 014/08  Available at www.cqc.org.uk/
¹⁹⁴ ibid
There is more accurate information available on the size of residential homes and health service institutions such as long stay hospitals for England than there is for Scotland, Wales or Northern Ireland.\footnote{195}

There are 6,255 homes registered for people with learning disabilities in England and 562 (9\%) of those homes were registered in the last 12 months.\footnote{196} In 2009 the Care Quality Commission outlined the current tiered model of services for people with learning disabilities in England and the numbers of people in each tier. This is shown in Table 3.\footnote{197}

\begin{table}
\centering
\caption{Numbers of people with intellectual disabilities within tiers of service and number and types of tier 3 services available\footnote{198}}
\begin{tabular}{|l|l|}
\hline
\textbf{Tier 1} & Family, friends and community & Unknown - estimated 575,000 \\
\hline
\textbf{Tier 1} & Part-time support & Unknown - estimated 125,000 \\
\hline
\textbf{Tier 2} & Supported living & 40,000 \\
\hline
\textbf{Tier 2} & Shared lives & 1,300 \\
\hline
\textbf{Tier 2} & Residential Home & 46,928 \\
\hline
\end{tabular}
\end{table}


\footnote{197 Care Quality Commission (December, 2009) Strategic Plan 2010-2015 - position statement and action plan for learning disability. London: Care Quality Commission}

\footnote{198 ibid -The figures in Table 3 are compiled from tables in Appendix 2}
| Tier 2 Residential Home with nursing | 4,863 |
| Tier 2 Local Authority | 3,381 |
| Tier 2 NHS | 3,223 |
| Tier 3 Number of people receiving Specialist healthcare | 4,000 |
| Tier 3 Number of people under section for the mental health act | 1,223 |

### Number of the Tier Three Services Available

| Tier 3 Number of independent healthcare services available | 55 |
| Tier 3 places in independent sector services available | 1,038 |
| Tier 3 Number of Assessment and treatment Services | 120 |

#### 5.3. Developing adequate housing

A lack of suitable housing-related support can lead to an escalation in care needs and can trigger events that result in admission to hospital or reduce the individual’s or carer’s confidence that they can live safely in the community. This increases the pressure for residential solutions whereas suitable support to live at home could help individuals have greater choice and control over their life, and yield efficiency savings since support to live at home often costs less than institutional care.  

Integrated housing, health and social support can increase independence, choice and control and can also be cost effective. The UK government recognises the interdependence of housing with health and social support and highlights this in its policy and guidance (See Appendix 2).


200 ibid

201 ibid
Responsibilities (CSSRs) have to develop their understanding of the support needs of populations in order to appreciate the potential role for housing in meeting those needs and to reflect this in commissioning.\textsuperscript{202}

The Public Service Agreement (PSA) 16 in England is about increasing the proportion of socially excluded adults in settled accommodation and employment, education or training.\textsuperscript{203} Guidance has been published by the National Housing Federation, with support from the Cabinet Office, and Communities and Local Government (CLG), outlining the role housing associations and support providers can play in attaining the PSA 16 target.\textsuperscript{204} A cross-government plan, led by the Department of Health and Department for Communities and Local Government, to help people with learning disabilities get more choice and control in where they live, was launched in March 2010. The delivery plan is supported by the Socially Excluded Adults Public Service Agreement target (PSA 16 target).\textsuperscript{205}

The 2008 Independent Living Strategy\textsuperscript{206} details actions to maximise housing choices and opportunities for people with disabilities as well as ensuring that they live in housing suited to their needs. These include:

- Increasing the provision of information and advice on housing issues
- All housing to be constructed to the Lifetimes Homes standard for 2013 and progress in this area is to be reviewed - ensure that all new public sector funded housing is adhering to the Lifetime Homes standard\textsuperscript{207} - this standard was intended to become mandatory by 2011

\textsuperscript{202} ibid


\textsuperscript{207} A new British Lifetime Homes standard clearly defines the standards that must be met and guidelines to be adhered to by designers (in relation to accessible housing). Communities and
• A commitment was made to encourage the implementation of Accessible Housing Registers and dissemination of good practice models. The Accessible Housing Register is a "database of properties designed or adapted for use by people with access needs". Some local authorities and housing associations currently maintain an Accessible Housing Register, which help to ensure the best use is made of "purpose built or adapted stock".

• It was planned to continue investment in rapid response repairs as well as adaptations services. It is hoped to use predictive risk modelling in the future to identify those at risk of health and care crises. Funding was to be improved and increased for the Disabled Facilities Grants (DFG) system. The DFG system enables approximately 37,000 elderly and disabled people to continue living in their own homes.

• All local authorities are required to produce a housing strategy, which will include the housing needs of people with learning disabilities in their areas. Government Offices are to ensure each local authority has an appropriate housing strategy.

• Where appropriate, “transition plans and yearly reviews" were to address future accommodation choices.

Efforts to address housing needs in local development plans include, for example, a briefing document for the local planning authorities drawn up by the Adult and Community Services in Devon County Council. This document requested that the authorities would take into account six standards, two of which are:

**Lifetime Home Standards** - All new housing of any tenure, and conversions (particularly ground floor) should fully meet Lifetime Home Standards.

**Wheelchair Design Standards** - 10% of all new housing of any tenure should meet full wheelchair design standards

Local Government (CLG) will revise the Lifetime Homes standard following this new development (Office for Disability Issues, Independent Living publication)


209 ibid p.44

210 Valuing People Now, 2009:82

Housing adaptations and equipment can sometimes save money on a significant scale when they are an alternative to residential care, while other adaptations and equipment for people with disabilities can yield better outcomes while producing savings to health and social care budgets. These were the findings from a survey of the international literature on outcomes and costs in relation to adaptations and equipment for the Office for Disability Issues in England. Adaptations saved money in a number of ways. They reduced the cost of residential care e.g. adaptations and equipment that enable someone to move out of a residential placement can produce direct savings, often within the first year. Adaptations also reduced the need for home care in some instances, noting for example that, an hour’s home care per day cost £5,000 a year. Significant savings in home care costs are mainly found in relation to younger and middle aged people with disabilities. Adaptations that reduce or remove the need for daily visits paid for themselves within a few months to three years and continued to produce annual savings.

5.4. Supported Living and its evaluation
Supported living emerged as a concept and model of service delivery in England in the 1990s as an alternative to institutional care. It was introduced by the National Development Team (NDT), now called the National Development Team for Inclusion (NDTi). This organisation was started in the 1970s as part of the government’s decision to close institutions for people with intellectual disability. From 2011 to 2014, NDTi Housing and Social Inclusion Projects will continue their work by exploring how some of the barriers to shifting resources from residential care to real supported living that still exist might be challenged and overcome.

The main principles of supported living are “that people with disabilities own or rent their home and have control over the support they get, who they live with (if


213 ibid

214 ibid


anyone) and how they live their lives. Supported living assumes that all people with learning disabilities, regardless of the level or type of disability, are able to make choices about how to live their lives even if the person does not make choices in conventional ways. Supported living is not a prescriptive service model. It can look different for different people. For one person it may be a few hours support a week to live alone in a rented flat, for another it may be round the clock support to live in their own home, and for others it may be a shared house with friends and support to meet individual needs. The key to whether it is supported living or not, is how much choice and control the person has over their home and life, rather than what the service looks like.

Supported living has no legal definition but a set of principles that are defined in the Reach Standards in Supported Living: “I choose who I live with; where I live; how I am supported; who supports me; my friends and relationships; how to be healthy and safe and how to take part in my community”. Principles also include that: I have my own home; I get good support; I have the same rights and responsibilities as other citizens and I get help to make changes in my life.

The Supporting People (SP) Funding Programme/Grant in the UK was introduced in 2003 to provide supported living - short-term or long-term housing related support services through the local authorities to enable vulnerable people to live more independently and avoid residential care. It separates the costs of support from those of housing and brings together a number of funding streams for support. Short-term supports were provided free and could last for up to 2 years with the aim of moving the individual on to independent living or increasing their ability to live independently. Following this, longer term services were means tested. The funding streams for support included the support element of Housing Benefit (HB) which was widely used in unregistered services for people with learning disabilities. Leading up to the delivery of the SP Programme in 2003, there was a transitional


218 ibid -p.8

219 Paradigm, REACH: Standards in Supported Living, 2003

220 The Government has invested over £8.7bn since the programme began in 2003; and announced a further £4.9bn funding up to 31 March 2011. It is the biggest single source of Government revenue funding for the Third Sector - over £1 billion per year. From April 2009, for the first time, Supporting People has been allocated to councils as a non-ring-fenced named grant, paid separately to, but with the same financial flexibility as, Area Based Grants. This removal of the ring fence provides councils with the opportunity to come up with new and innovative ways to support vulnerable people in a range of different situations. See http://www.communities.gov.uk/housing/supportandadaptations/supportingpeople. Accessed 25th March 2010.

phase to claim and separate out the support element of HB, called Transitional Housing Benefit (THB). ²²²

"This transitional phase led to a significant development of new supported living schemes for people with learning disabilities through the change of registration of existing residential care homes. A common scenario at this time was a residential provider changing from being registered as a care home provider to being registered as a domiciliary care provider (where personal care was being provided) and in some cases where no personal care was provided, removing registration completely. To satisfy requirements for this change of registration and provision of tenancies, the provider separated out the delivery of housing and support by either creating a housing arm of their organisation or by leasing the property to a housing provider. Tenancies were then issued to individuals and they were able to claim HB for housing and THB for support."²²³

Some of the main advantages of supported living over residential care²²⁴ include

- Having one’s own home or tenancy and security of tenure
- As a tenant or homeowner the person has a right to choose who they live with if anyone
- As a tenant/homeowner the person has the right to full welfare benefits including housing benefit, income support and disability living allowance
- Service users can access Direct Payments, Personal Budget, Supporting People Grant, Independent Living Fund for Support

Research by the Joseph Rowntree Foundation²²⁵ found that supported living schemes had a positive impact for people with learning disabilities. People could access a full range of welfare benefits and had more choice and control over day to day activities.


²²³ ibid, p.11


However, many new supported living services were not very different from registered care homes in terms of how much choice, rights, control and independence people had. This was particularly the case when the principles of supported living appeared to be overlooked\textsuperscript{226} e.g. staff offices within peoples’ homes, staff routinely holding and using front door keys and staff hours of work based on a set pattern of shifts which limited the flexibility of support. Choice was often limited even if tenants were happy and proud of such elements of choice as, for example, being able to watch TV when they wanted to. Choice over where to live, who to live with and who to receive support from, were still often made by managers and service commissioners, with little or no input from service users. Services were often restricted to those with mild learning disabilities and low support needs, to keep down costs.\textsuperscript{227}

Thus, many services are not being provided within the principles of supported living because people are not making decisions about fundamental aspects of their lives. Many shared supported housing schemes have support as a condition of the tenancy. The level of support is fixed at a certain amount of hours and does not meet the principles of supported living, but is called supported living. Historically, this approach to supported housing was used as a temporary housing model rather than to offer a permanent home. According to NDTi, calling such services ‘supported living’ has caused misunderstanding about what supported living is and what it can achieve for people.\textsuperscript{228}

Some advantages and disadvantages found in two support options provided by the Supporting People Programme are outlined in Figure 2.

\textsuperscript{226} ibid - Services and support were based on legal tenancies and tenants were supposed to have keys to their properties, control over who entered their homes, and support staff were not to have offices on the premises. Different authorities chose a variety of ways of operationalising their definition but each had one thing in common: to ensure that the cost of individual support packages was limited using 4 common means of limiting costs

\textsuperscript{227} ibid

Figure 2  Advantages and disadvantages of different methods of providing housing support (Joseph Rowntree Foundation)\textsuperscript{229}

<table>
<thead>
<tr>
<th>Shared tenancies with accommodation based support</th>
<th>Individual tenancies with floating support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key Advantages:</strong></td>
<td><strong>Key advantages</strong></td>
</tr>
<tr>
<td>• System suited to the employment of full-time</td>
<td>• Separation between landlord and support provider</td>
</tr>
<tr>
<td>staff giving greater consistency of support</td>
<td>• Fully personalised support</td>
</tr>
<tr>
<td>• Maximum flexibility of support as staff are at</td>
<td>• More privacy/time alone</td>
</tr>
<tr>
<td>hand</td>
<td></td>
</tr>
<tr>
<td>• 24-hour staff cover sometimes possible</td>
<td><strong>Key Disadvantages</strong></td>
</tr>
<tr>
<td>• Possibility of minimising costs per hour of</td>
<td>• More chance of service user being lonely</td>
</tr>
<tr>
<td>support</td>
<td>• Difficult to change support hours at short notice</td>
</tr>
<tr>
<td>• Less chance of being lonely</td>
<td>• Potentially higher costs per hour for those with complex needs who require ongoing or intense staff support</td>
</tr>
<tr>
<td>• Housing and support often provided by the</td>
<td>• Less consistency of support</td>
</tr>
<tr>
<td>organisation which can therefore provide a</td>
<td>• Limited number of support hours available each day</td>
</tr>
<tr>
<td>more seamless service</td>
<td></td>
</tr>
<tr>
<td><strong>Key Disadvantages:</strong></td>
<td></td>
</tr>
<tr>
<td>• Danger of less individualised support</td>
<td></td>
</tr>
<tr>
<td>• Less privacy/time alone</td>
<td></td>
</tr>
</tbody>
</table>

6. Day and Employment Services

In England the day services available for adults with disabilities can be broadly categorised as follows:

- Day Care Programmes (not work-related): High-support services focused on health needs
- Facility-based day activation programmes (not work-related): Training in independent living skills; social/recreational activities; health-related and therapeutic supports; some programmes promote community participation and the utilisation of mainstream services
- Rehabilitative Training (some training in work-related skills): programmes to equip participants with basic skills including personal, social and work related skills
- Sheltered Work: (1) therapeutic and non-paid; (2) commercial where service-users may/may not receive remuneration for products/services provided; (3) ‘like work’ where service users assist in service provider organisations e.g., in catering, gardens, shops, maintenance work, often with discretionary payment
- Sheltered Employment: employment in enterprise specifically established for the employment of people with disabilities
- Supported Employment\(^{230}\): This is paid employment in the open labour market with the provision of supports such as that of a job coach.
- Open Employment: employment in open market, for all or part of the week

In England there is a general thrust to close all sheltered workshops for people with learning disabilities by the year 2025.\(^{231}\) To replace sheltered workshops,

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\(^{230}\) Supported employment provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision. “Supported Employment is a systematic approach that provides flexible support to enable people with disabilities or other disadvantaged groups to secure and maintain paid employment in the open labour market. This definition is concurrent with the European Union of Supported Employment definition.” Many countries have some model, albeit limited, of supported employment services for people who have limited access to the labour market. Supported employment was developed in North America in the 1970's to assist people with significant intellectual disabilities to access ordinary employment. Over time, supported employment has been found to work for different groups of people that have difficulty entering the labour market. Supported employment is evolving from a model of “training and placing” people in work to one of “place and train” (Scottish government/COSLA, 2009 Accessed at http://www.cosla.gov.uk, 21st Feb 2010).

\(^{231}\) REMPLOY Ltd is a publicly subsidised company which, in 2004-2005, comprised 83 sheltered factories throughout the UK and supported 9,400 individuals at a cost of £116 million. In 2001 the numbers of persons in REMPLOY factories was 6,684. Activities carried out in the factories include furniture making, packaging, library and print services etc. In addition to these supported factories a second, and developing strand entitled ‘REMPLOY Interwork’ provides community-based employment options where host companies receive wage subsidies based on productivity assessments. In 2001, 5,383 persons were supported by REMPLOY Interwork. The proportion of people with intellectual disabilities is higher in REMPLOY Interwork than REMPLOY factories. In
there are pilot programmes running that, for example, integrate people with learning disabilities into local sectors of employment.\textsuperscript{232} Valuing People Now (2009) sets out an implementation strategy for a significant transformation of ‘traditional day services’ to promote meaningful, purposeful activity in non-facility based programmes.\textsuperscript{233}

A ‘family’ of national New Deal Programmes of job activation for distinct client groups was introduced in the UK in 1998 with the programme for people with disabilities commencing in 2001.\textsuperscript{234}

A network of job brokers/personal advisers, paid on the basis of outcomes, provide advice and support to find and prepare for work. Outcomes include registering participants, job entries and sustained employment. This policy is an active, supply-side welfare policy based on the belief that flexible, integrated, personalised or caseworker services backed by investment in information and communication technology can increase employment rates.\textsuperscript{235} The Personal Adviser model is now a feature of the mandatory work-focused interviews conducted in Jobcentre Plus Offices. Kelleher et al (2002) found that, in general, customers and staff like the personal adviser model. However, the service principally focuses on work

\begin{footnotesize}
2006, a five year funding envelop of £111 million per annum was agreed to enable REMPLOY support more individuals with disabilities into work. The strategy was triggered by three factors: (1) Government policy favouring inclusive employment options (2) a National Audit Office report which noted low levels of progression from REMPLOY factories into open employment and which recommended greater focus on the more cost-effective Interwork programme (3) the rising cost and recurrent financial losses of REMPLOY. Following an evaluation of REMPLOY in 2006 (PriceWaterhouseCooper, 2006). Government supported a programme of closure or merger, without compulsory redundancies, of REMPLOY factories. The closures have generated considerable debate with service providers typically supporting the closure of the factories, while unions are typically opposed. REMPLOY is seeking to place 20,000 persons with disabilities in mainstream employment by 2011. To date, a total of 29 factories have been either merged or closed without any compulsory redundancies which, according to REMPLOY’s Annual Report, has ‘significantly reduced the losses in our factory-based businesses’ (REMPLOY, p4)\textsuperscript{231}

232 Key informant Anne Williams


234 In 1998 programmes were introduced for lone parents (voluntary), young people,18 to 24 years (mandatory) and people 25 years and over (mandatory) in 1998. In 2000 programmes for people 50 + years, musicians and for partners of recipients of jobseeker's allowance, income support, incapacity benefit, severe disablement allowance and carers allowance. In 2001 the New Deal for Disabled People began.

235 Stafford, B., Kellard, K. (2007) Reforming the public sector: personalised activation services in the UK in Making it personal, Individualising activation services in the EU, Eds Rik van Berkel and Ben Valkenburg Policy Press Bristol
\end{footnotesize}
outcomes for unemployed people so those claiming other benefits, especially people with complex needs, receive a limited service.\textsuperscript{236}

Tables 4 and 5 give a snapshot of day service provision in England compared to two other jurisdictions in 2004-2005.

Table 4: Statutory and Independent Day Service Registrations by Programmes of Care per 1000 head of adult population (adults >20 years) in 2004-2005\textsuperscript{237}

<table>
<thead>
<tr>
<th></th>
<th>England**</th>
<th>Scotland*</th>
<th>N. Ireland*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
<td>0.7</td>
<td>0.1</td>
<td>1.3</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>1.3</td>
<td>1.7</td>
<td>4.3</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>0.5</td>
<td>0.3</td>
<td>0.8</td>
</tr>
<tr>
<td>Elderly</td>
<td>2.6</td>
<td>2.0</td>
<td>2.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5.0</td>
<td>4.1</td>
<td>8.6</td>
</tr>
</tbody>
</table>

\* Statutory \*\* Statutory & Independent

Table 5: Range, activity, costs and staffing of day services (taken from Audit of Day services by PriceWaterhouseCoopers LLP (2007) for the Department Health, Social Services and Public Safety in Northern Ireland)\textsuperscript{238}

<table>
<thead>
<tr>
<th></th>
<th>England**</th>
<th>Scotland*</th>
<th>N. Ireland*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statutory/Independent ***</td>
<td>73%/ 27%****</td>
<td>73%/ 27%</td>
<td>86%/ 14%</td>
</tr>
<tr>
<td>Total persons registered</td>
<td>190,163</td>
<td>15,830</td>
<td>10,677</td>
</tr>
<tr>
<td>Total persons registered per 1000 head population &gt; 20 yrs</td>
<td>5.0</td>
<td>4.1</td>
<td>8.6</td>
</tr>
<tr>
<td>Total expenditure</td>
<td>£1.27 billion</td>
<td>N/A</td>
<td>£61 million</td>
</tr>
<tr>
<td>Spend per head pop &gt; 20 years</td>
<td>£33.64</td>
<td>n/a</td>
<td>£49.05</td>
</tr>
</tbody>
</table>


\textsuperscript{237} Taken from Government and Public Sector, Department of Health, Social Services and Public Safety Northern Ireland (September 2007) Audit of Day services Final Report by PriceWaterhouseCoopers LLP Accessible at http://www.dhsspsni.gov.uk/day-services-report.pdf

\textsuperscript{238} ibid
<table>
<thead>
<tr>
<th>Proportion of Staff:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Managerial</td>
<td>11%</td>
<td>17%</td>
<td>13%</td>
</tr>
<tr>
<td>Day Care Worker/ Assistant</td>
<td>66%</td>
<td>62%</td>
<td>63%</td>
</tr>
<tr>
<td>Other</td>
<td>21%</td>
<td>20%</td>
<td>23%</td>
</tr>
</tbody>
</table>

* Statutory  ** Statutory & Independent  ***Based on Spend  ****Based on number of Clients

Source: NI - Korner Returns & Reference Costs, England - CIPFA Data, Scotland - ISD

Innovative practice in supported employment include social firms including social farms. Social firms are social enterprises designed to create jobs for people with disabilities or other people disadvantaged in finding employment. They are a modern development of the sheltered employment models. A high profile example of social enterprises includes Cafédirect\(^{239}\). This is a social enterprise combining the strengths of business and charity and delivering sustainable poverty relief while at the same time taking market share from the largest multinational companies.\(^{240}\) These new forms of social enterprise models are promising. They take on board ideas around social and financial inclusion - employing both people with and without disabilities in real jobs. They are also built on the broader social enterprise movement: that it is possible to use self-financing business structures and methods to achieve social benefits. Because they are quite new, there is little research carried out on them although the evidence available is positive.

Sheltered employment or therapeutic work may be successfully transformed into a social firm over a timescale of probably at least 5 years. Social firms represent less than 1% of social enterprise. The UK had 119 social firms in 2005 employing 1550 people of whom 55% had a disability. The number of these enterprises has continued to grow in the UK.\(^{241}\) A study suggests that 35% of all new entrepreneurs are social entrepreneurs.\(^{242}\) The Department of Health in England

239 Cafédirect is the UK’s leading Fairtrade hot drinks company taking it from a niche market and placing it into the mainstream. Today a quarter of a million coffee, tea and cocoa producers benefit from Cafédirect’s trading model. Cafédirect is the leading Fairtrade hot drinks brand in both retail and out of home, as well as the 6th largest coffee brand, the 4th largest Roast & Ground brand, and one of the fastest growing tea brands in the UK. Penny Newman is the CEO. From http://www.prowess.org.uk (Accessed 2nd Nov 2010)

240 See Social Firms: Key Issues Study Number 4 by RIPFA (Research in Practice For Adults Department, a national research utilisation organisation for adult social care and part of the Dartington Trust) Available at www.cspda.org/articles/downloads/ripfa_keyissues_04.pdf (Accessed 17th May 2010)

241 Social Firms: Key Issues Study Number 4 by RIPFA (Research in Practice For Adults Department, a national research utilisation organisation for adult social care and part of the Dartington Trust) Available at http://www.cspda.org/articles/downloads/ripfa_keyissues_04.pdf (Accessed 17th May 2010)

242 Harding R (2008) Social Entrepreneurship in the UK, Delta Economics cited in Social Firms - see previous footnote
has established a £100 million Social Enterprise Investment Fund financing business structures and methods to achieve social benefits.243

Social farming244 describes farming practices aimed at promoting well-being for people with disabilities and other disadvantaged groups through skills development and re-integration into the wider community. While in some countries such as Norway and the Netherlands there are hundreds of social farms, in England there are around 45 farms.245

7. Regulating health and personal social services

7.1. The regulation of statutory and outsourced i.e., non-statutory services

Regulation of health care in England comprises two main elements: regulation of the quality and safety of care offered by health care providers, currently undertaken by the Care Quality Commission (CQC), and regulation of the market in health care services, currently the responsibility of Monitor (in relation to foundation trusts) and the Department of Health.246

7.1.1. England's Care Quality Commission:

On 1 April 2009, an independent body - the Care Quality Commission (CQC) - was established under the Health and Social Care Act 2008, as an integrated regulator of health and adult social care in England.247 As of April 2009, all regulated services including hospitals, ambulances and a variety of other types of health services are required to register with CQC. This body replaced a number of pre-existing health and social care regulators such as the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection. It is responsible for inspecting, monitoring and regulating adult mental health and social care in England. The general remit of the CQC has been to:

__________________________

243 A 2005 EU study suggested that there were 8000 social firms in the EU employing 80000 workers, 30000 with disabilities. Italy had the greatest number of firms, followed by Germany with 500 social firms employing 16500 people of whom 50% had disabilities. The size of the German and Italian social firm movements is enabled by Government support. Social Firms UK argue for a waiver of PAYE and NI for any company that employs more than 25% people with disabilities. (Taken from Social Firms as cited in previous footnote)

244 Social farming is sometimes knows as care farming or green care.


247 See the Care Quality Commission (CQC) Website at www.cqc.org.uk
• improve the safety and quality of health and social care in England and
• encourage person centred and cost effective care provision for service users.

CQC has a wide range of enforcement powers including authority to issue warning letters, suspensions and fines. Early impact assessments make reference to regular surveys and annual enforcement reports.

7.1.2. Monitor

Monitor is an independent regulator of NHS foundation trusts. It was established in January 2004. Independent of central government and directly accountable to Parliament, Monitor was set up to authorise and regulate NHS foundation trusts, with three main strands of work:

• Determining whether NHS trusts are ready to become NHS foundation trusts

• Ensuring that NHS foundation trusts comply with the conditions they signed up to – that they are well-led and financially robust; and

• Supporting NHS foundation trust development

The current government’s intention is to free providers so that they can focus on improving outcomes, be more responsive to patients, and innovate. In order to do this all NHS trusts are to become or, at least, be part of foundation trusts. Monitor is to continue to apply its current standards to those organisations applying to become Foundation Trusts.

From April 2013, Monitor will take on the responsibility of regulating all providers of NHS care, irrespective of their status. The legislative framework for foundation trusts is to be maintained and their broad statutory framework will allow that any surplus, and any proceeds from the sale of assets, are reinvested in the organisation or used to repay debt, so that patients reap the benefits. Foundation trusts are already effectively social enterprises and will continue to provide services to the NHS, with staff enjoying greater flexibility and freedom to deliver better services for patients.

248 http://www.monitor-nhsft.gov.uk/home/about-monitor/what-we-do

7.1.3. Proposals to change how regulation is carried out

Proposals by the coalition government formed in May 2010 are outlined in the NHS White Paper: Regulation (October 2010). The proposals are designed to take the development of a mixed economy further, and to extend the role of the independent regulators and reduce that of the Department of Health.250

Key proposals relating to regulation are:

- Monitor will become the economic regulator for all health and social care in England.251
- Monitor will have a new licensing role. It will license all providers of NHS services and will have the power to impose special licence conditions to promote competition or to maintain continuity of services.
- The CQC will retain responsibility for the regulation of quality.
- Monitor will set the tariff for NHS-funded services and will work together with the NHS Commissioning Board – the new organisation set up to carry out some national commissioning functions – in developing tariffs and prices.
- The Co-operation and Competition Panel will be absorbed into Monitor, but eventually the NHS will come within the remit of the Office of Fair Trading and general UK as well as EU competition law.
- All NHS providers should become foundation trusts by 2013, and the NHS trust legislative model will be repealed in due course. The coalition government has proposed greater freedom for foundation trusts, for example, in respect of their governance arrangements, their ability to raise capital and their ability to raise income from private patients.
- Monitor will have responsibility for continuity of essential trust services, for example in the event of financial failure.252


251 “As the NHS moves away from a system of top-down performance management, the rationale for economic regulation is to protect the public interest in the provision of services, particularly where communities are highly dependent on one, or very few, providers. Furthermore, as the NHS seeks to offer patients choice of ‘any willing provider’ for most services, the benefit of this new approach is the ability to address potentially anticompetitive behaviour, through regulation where appropriate, rather than through costly legal proceedings.” See http://www.psnc.org.uk/data/files/Liberating_the_NHS/lpc_briefing__regulating_healthcare_providers.pdf (Accessed 19th Jan 2011)

252 ibid
Monitor’s principal duty will be to protect the interests of patients and the public in relation to health and adult social care services, by promoting competition where appropriate, and through regulation where necessary. Monitor will be required to exercise its functions in a manner consistent with the Secretary of State’s duty to promote a comprehensive health service in England and have regard to the following objectives:  

- maintaining the safety of patients and individuals accessing services;
- securing ongoing improvements in quality of care;
- providing equitable access to essential health and adult social care services;
- supporting commissioners in maintaining continuity of essential services;
- securing ongoing improvements in the efficiency of services;
- promoting appropriate investment and innovation; and making best use of limited NHS and adult social care resources

Its statutory remit will be limited to the provision of health and adult social care services.

"The regulatory framework of health care in England is still developing – the government’s proposals leave a number of areas unclear. In particular, the boundaries between the respective roles of the regulators and between them and the NHS Commissioning Board and the Secretary of State will need clarification.

7.2. The inspection of services

The primary foci of CQC’s Enforcement Policy as published 30 March, 2009 are: (1) registration; (2) the pursuit of non-registered providers and (3) ensuring that poorly performing providers receive the level of inspection and intervention necessary to maintain the safety and quality of their services - including prosecution for particular offences. The CQC has stated that its intention is that organisations responsible for health and adult social care services are accountable for the quality and value of the services they provide. The role of regulation is to reinforce that accountability. CQC will, therefore, be more active where the risks of harm are greater; where people are less able to assert their rights; where

253 http://www.psnc.org.uk/data/files/Liberating_the_NHS/lpc_briefing__regulating_healthcare_providers.pdf
254 ibid
255 ibid
commissioning is weaker; where information on quality is poor; or where monopoly
providers are failing to improve.”

From 1st October 2010, every health and adult social care service in England is
legally responsible to ensure it meets new essential standards of quality and
safety. The change in focus is from processes and systems to the care that is
received by clients/service users. There are standards on the provision of

- Adequate information to clients/service users and adequate involvement of
  them in planning how to address their health and care needs

- Personalised care, treatment and support

- Safeguarding and safety (safeguarding people who use services from
  abuse; cleanliness and infection control; management of medicines; safety
  and suitability of premises; safety, availability and suitability of equipment;
  suitability of staffing)

- Quality and management

- Suitability of management

The essential standards to be expected can be accessed by clients online.

7.3. Services for children and young people:

Compliance inspections are conducted by the CQC alongside Her Majesty’s Chief
Inspector of Education, Children’s Services and Skills - as per assignment of
functions in the Health and Social Care Act, 2008.

Almost all residential and boarding education and care (incl. ‘residential special
schools’) became subject to National Minimum Standards following the
implementation of the Care Standards Act (2000). Other service standards
referenced in National Contracts include professional standards such as the Royal
College of Psychiatrist's Service Standards for Therapeutic Communities for
Children and Young People. There are currently moves underway to examine the
possibility of producing a generic set of Service Standards to cover the key needs
of all young people who live in residences. Further information may be found at
www.children.webmag.com

256 Care Quality Commission Enforcement Policy (2009, p.27) London: Care Quality Commission
Accessible at http://www.cqc.org.uk/_db/_documents/CQC_Enforcement_Policy_Final2.pdf
(Accessed Jan 2010)

257 The essential standards of quality and safety a person can expect can be viewed on the Care
Quality Commission's website:
http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm (Accessed on
the 20th January 2011)
7.4. Other developments of note

The Social Care Institute for Excellence is a voluntary organisation funded by the Department of Health which publishes online resources and systematic research reviews to identify and spread knowledge about good practice in the social care field.\(^{258}\) It should be noted that a number of academic papers, whilst acknowledging evidence of interdependence and willingness to pursue integration of services for multi-need users, criticise the complexity of the English system and call for further work on systems integration.

8. Conclusion: Key Learning Points

The UK has well-established policy commitments to independent living which are generally matched by good practice at local/practice level. A shared vision of independent, self-directed services and budgets for social care is supported. Policy provides that commissioners of services ensure that a transition takes place away from the purchase of services that do not deliver on quality of life (outcome measurement) or that are too large to provide individualised support or which move people too far away from their communities and homes.\(^{259}\)

Research on UK disability services shows links between participant ability, staff support, service design, management practices and the outcomes achieved. Resources, costs and staff ratio were found to have little impact on the quality of

\(^{258}\) Its website is www.scie.org.uk

outcomes for people with intellectual disability. However, staff training may be the missing link between resource input and quality of outcome and, in particular, training staff to provide active support. It may therefore be effective that, to deal with challenging behaviour, commissioners would fund higher levels of skill through training rather than adding more staff at greater cost.

In terms of providing services such as occupational therapy, for example, services need to be timely and provided at the level and intensity required, wherever they are accessed.

Research on self-directed services and person-centred planning shows that unmet need is more likely to continue for those with complex or more severe disabilities. This is being addressed by paying attention to more appropriate commissioning of specialist services and by developing the required expertise. Attention is also being focused on comprehensive baseline measurement of need to enable measurement of progress towards meeting need, including measures of the amount of service provided, the range of options and the quality of services as assessed by the service users.

There are initiatives to increase user involvement in service development and the government is currently providing financial support to promote further user involvement in service development in three regions. Equality 2025 a network of people with disabilities advises the Government on how to achieve disability equality.

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While there is commitment to the aspirations of inclusion, independent living and choice as outlined in the 2001 Valuing People White Paper\textsuperscript{265}, variations in service provision continue to exist. Obstacles to service development highlighted in a review of services for adults with profound intellectual and multiple disabilities\textsuperscript{266} included poor commissioning of specialist services, conflicting service trends and an increasing focus on quantity over quality.\textsuperscript{267}

Conflicting trends in service provision and policy include, for example, an emphasis on inclusion approaches based on individual need, user outcomes and quality of life and also a promotion of market forces which tend to operate to maximise quantity over quality. Another conflicting trend identified is that between facilitating people to live independently while ensuring greater safety and quality through regulation and standardisation.

Individualised funding (direct payments and personal budgets) has enabled some people with disabilities to live independently and increased their choice. The Supporting People Programme has enabled the development of a number of supported living services for people with intellectual disabilities.\textsuperscript{268} Evaluations highlight that those delivering services need to understand the legal and ideological differences between supported living and group homes that have 24-hour staff input. There is also a need to enforce the rule that staff should not have offices in people's homes and that tenants should be able to control access to their own homes.\textsuperscript{269}

Supported living schemes are been developed for people with learning disabilities. The main principles of supported living are that people own or rent their home and have control over the support they get, who they live with (if anyone) and how they live their lives. The costs of support are generally separated from housing costs. The key to whether a service is a supported living one or not, is how much choice and control the person has over their home and life, rather than what the service


\textsuperscript{267} ibid - Improving commissioning services included developing effective transition arrangements as people move into adulthood; recruiting and training personal assistants; using assistive technology in services; supporting families to access help and advice in securing and running self-directed services from user-led organisations, self-help groups or other families.

\textsuperscript{268} See background paper on England for details: these papers are or will be accessible on the NDA website: http://www.nda.ie/

Research has shown that many new supported living services were not very different from registered care homes. This was particularly the case when the principles of supported living were overlooked.

To date much investment in new housing and support options has been in a narrow range of models. A wider range of options have been recommended such as shared supported housing, adult family placements and extra care schemes. Integrated housing, health and social support increases choice and control and can be cost effective. This is being highlighted in government's policy and guidance. Housing can play a role in meeting the support needs of population and this can be reflected in commissioning.

Housing adaptations and equipment can save money on a significant scale when they are an alternative to residential care. Other equipment and adaptations for people with disabilities can yield better outcomes while producing savings to health and social care budgets.

Outcome measurement models have been under development since 2008. The models collect data for service performance and measure outcome indicators. Keeping a focus on outcome measurement rather than output based measurement promotes service development in the direction of desired outcomes for people with disabilities.

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273 ibid


275 ibid

Appendices

Appendix 1 Disability related benefits and financial support

Disability benefits through the social welfare and tax systems include:277

- A disability and living allowance
- An employment and support allowance
- An incapacity benefit
- An attendance allowance

277 http://www.direct.gov.uk/en/index.htm Directgov website Disability section
• Several tax and V.A.T relief schemes

The application procedure for each allowance varies, for example claiming the disability and living allowance can be done through a local jobcentre or social security office or by phoning the Benefit Enquiry Line²⁷⁸ whereas the employment and support allowance is through the Department for Work and Pensions. A medical examination is sometimes required to deem eligibility for payments/schemes.²⁷⁹

The two main UK disability related benefits are the Attendance Allowance and Disability Living Allowance. These benefits have national eligibility rules and are not means tested. Attendance Allowance is the main disability benefit for older people.²⁸⁰ It is available to anyone who has a care need that develops at or after the age of 65 years. Attendance Allowance operates in parallel with the social care system for those aged 65 years and over. In 2007/2008 total expenditure on Disability Living Allowance in the UK was £9.86 billion and on Attendance Allowance £4.44 billion.²⁸¹

The 2009 Green Paper, Shaping the Future of Care Together, proposed to draw funding streams together: "integrate some elements of disability benefits, for example, Attendance Allowance, to create a new offer for individuals with care and support needs."²⁸² "The social care and disability benefits systems have developed in isolation from each other and these two largest portions of government care and support expenditure are being allocated on different bases".²⁸³

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²⁷⁸ The Benefit Enquiry Line is a confidential free-phone service for disabled people and carers. When contacted a claim pack can be forwarded. The claim pack can be sent in an alternative format if required - for example, Braille. The Benefit Enquiry Line can also arrange for someone to help fill out a claim form if required (Directgov website Disability section).

²⁷⁹ http://www.direct.gov.uk/en/index.htm Directgov website Disability section

²⁸⁰ Attendance Allowance is a tax-free benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled. To get attendance allowance a person's disability must 1) be severe enough to require help with everyday living activities such as washing, eating, getting to the toilet etc or 2) require supervision to avoid putting themselves or others in danger. There is a lower and higher rate of attendance allowance depending on how the disability affects the person. The attendance allowance can be given even if there is no one giving the care required. A person with a physical or mental disability or both can get a disability living allowance which has a mobility component and a care component. A person may be entitled to one or both components (http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport).

²⁸¹ Department for Work and Pensions 2008


²⁸³ ibid, p.102
The existence of the Independent Living Fund (ILF) provides money to disabled people needing financial assistance for domestic and personal care support. If a person is eligible to apply they are assessed by their local authority Social Worker. This visit will assess what level of care a person needs and establish the cost of funding that care. The ILF will calculate how much it can fund towards the cost. If offered assistance, a person can choose whether or not to accept it and if accepted payment is made every four weeks in arrears directly into their account. In terms of funding the ILF there are two funds set up and financed by UK central government. These are: the Independent Living (Extension) Fund, which is closed to new applications, and administers the payments to clients of the original ILF (prior to April 1993) and the Independent Living (1993) Fund, which is open to applications from severely disabled people who meet the eligibility criteria and are also permanent residents of the United Kingdom.284

Appendix 2 Inter-dependence of housing, health and social care

In government policy and guidance there is recognition of the inter-dependence of housing with health and social support. This is demonstrated in figure 3 below.285

Figure 3: The interdependence of housing with health and social support in government policy and guidance

<table>
<thead>
<tr>
<th>Documents</th>
<th>What is Emphasised</th>
<th>Implication for Housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Quality Care For All (2008)*</td>
<td>Access, choice and personalisation and care closer to home.</td>
<td>Housing as a place to receive personalised care and support.</td>
</tr>
</tbody>
</table>


286 Lord Darzi (2008) High Quality Care for All: Next stage review Final Report
Putting People First (2007)\textsuperscript{287} Control and choice over care and support including where it is received. Housing as a place to receive personalised care and support.

Independent Living Strategy (2008)\textsuperscript{288} Actions needed to overcome barriers to independence inc. housing, transport, employment etc. Well designed/ located housing with support to stay independent needed

Department of Health Business Plan 2008/09\textsuperscript{289} Includes Valuing People. It is continuing a programme of learning disability campus closures. Alternative community based accommodation is needed.

Department of Health Business Plan 2008/09\textsuperscript{289} Includes the National Dementia Strategy. It envisages earlier interventions and replacing residential care where possible. Suitable housing and support needed to replace residential care.

Lifetime Homes, Lifetime neighbourhoods\textsuperscript{290} Identifies the key role housing has in terms of prevention, personalisation, coordination and integration. Well designed/ located housing with support to stay independent needed

Joint Strategic Needs Assessment (JSNA) The local government and public involvement in health act 2007 requites PCTs and local authorities to prepare a JSNA for their area. Housing and supporting people are included as key partners in the JSNA.

Set of 198 National Indicators National indicators measure “Adults in settled accommodations” e.g. NI145 for Learning Disabled Adults, NI149 for Mental Health Adults. Housing and support is crucial to performance against these measures.

### Appendix 3 Disability Strategy: achievements and plans

The achievements and plans outlined in Figure 4 and 5 below draw on government documentation (Office for Disability Issues).\textsuperscript{291}


\textsuperscript{289} Department of Health – Social Care, Local Government and Care Partnerships Directorate Business Plan for 2008/2009

\textsuperscript{290} 2008 Lifetime Homes, Lifetime Neighbourhoods – National Strategy for housing in an ageing society

\textsuperscript{291} These themes and achievements are taken from page 4 of the Roadmap Report published by the Office for Disability Issues in England in December 2009. The Roadmap report sets out how government departments are working towards disability equality by 2025. It is accessible at http://www.officefordisability.gov.uk/docs/res/annual-report/roadmap-full.pdf . The themes identified by disabled people can be found in a 2007 report ‘Equality for disabled people: how will we know that we are making progress?’
**Figure 4:** Achievements in England on the themes identified by people with disabilities as ones that will make the biggest contribution to equality

<table>
<thead>
<tr>
<th>Themes</th>
<th>Achievements 2005 -2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communications</td>
<td>Directgov (<a href="http://www.direct.gov.uk">www.direct.gov.uk</a>) delivered over 250 pages of information directly to disabled people.</td>
</tr>
<tr>
<td>Employment</td>
<td>Employment rate of disabled people increased from 44.5% in 2005 to 48.4% in 2008. The gap compared to the overall employment rate has narrowed from 35.6% in 2005 to 31.2% in 2008.</td>
</tr>
<tr>
<td>Housing</td>
<td>£33 million investment to provide rapid repairs and adaptations services between 2009 and 2011.</td>
</tr>
<tr>
<td>Justice system</td>
<td>Joint working between the Ministry of Justice and the Department of Health to develop a National Offender Health Delivery Plan to help improve access to mental health services including learning disability services for offenders.</td>
</tr>
<tr>
<td>Living standards</td>
<td>The child and pensioner poverty strategies ensure that government and other bodies attach the highest priority to tackling poverty among those at particular risk, including families with disabled members.</td>
</tr>
<tr>
<td>Participation</td>
<td>The Disability Equality Duty, which came into force in December 2006, introduced a new duty for public authorities to involve disabled people in creating Disability Equality Schemes.</td>
</tr>
<tr>
<td>Post-19 education and training participation</td>
<td>Increase in percentage of learners with a learning difficulty or disability participating in Further Education from 10.5% of all learners in 2005/06 to 11.6% in 2006/07, and 11.9% in 2007/08.</td>
</tr>
<tr>
<td>Transport</td>
<td>£370 million fund to improve access to stations from 2006–2015. ‘GOJO’ Campaign to encourage disabled people to use public transport.</td>
</tr>
</tbody>
</table>
Figure 5: Plans - next steps for Office for Disability Issues

| **£370 million to support short breaks for families with disabled children, and continued investment in education and play** |
| **Further develop the Images of Disability campaign to improve the attitudes, standards and practice of government communicators and other groups towards disabled people** |
| **Equality Bill streamlines and strengthens discrimination legislation making Britain a stronger, fairer place. The Hate Crime Action Plan is implemented.** |
| **Transfer of incapacity benefit customers to Employment Support Allowance From 2010, with increased work-related support.** |
| **Renewed drive to tackle health inequalities, paying particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.** |
| **Modernise the Disabled Facilities Grant programme, which provides help towards the cost of providing adaptations to accommodation to enable disabled and older people to continue to live independently in their own homes.** |
| **Government believes that change can be achieved without new legislation, but we will review the situation if sufficient progress has not been made by 2013.** |
| **Implementation of the recommendations in Lord Bradley’s report to divert offenders with mental health problems or learning disabilities away from prison into other more appropriate services.** |
| **Hosting a successful Olympic and Paralympic Games in 2012, which is accessible to all, and will promote inclusion, positive attitudes towards and the active participation of disabled people.** |
| **Increase proportion of disabled adults in education and training.** |
| **Disabled people to make up 14% of new appointments made by the Office of the Commissioner for Public Appointments (OCPA) by 2011.** |
| **Child Poverty Bill to ensure that eradicating child poverty is a priority for every future government and a shared mission for our society.** |
| **Greater involvement of service users in the transformation of social care and personal budgets.** |
| **Implementing the Blue Badge reform programme, ensuring that it stays fit for purpose and improves the lives of disabled people who use it.** |

Appendix 4 Assessments and waiting time Information

The Information Centre for Health and Social Care report of 2009 (Community Care Statistics 2007-08: Referrals, Assessments and Packages of Care for Adults England) includes some figures on waiting times\textsuperscript{293}. This information refers to people in England receiving social/community care, including services such as residential care, day care, meals, home care and direct payments. The client groups include physical and sensory disability/frailty; learning disability; mental health; substance misuse and vulnerable people.

Waiting time between first contact and first contact with client
The report states "for all client groups over three quarters of clients had contact with social services within 2 days of first contact. 14 percent and 12 per cent of clients with learning disabilities and mental health problems waited more than 2 weeks between first contact to first contact with client respectively" (p.22).

Waiting time between first contact and completed assessment
For this length of time the report states "of those with primary client type 'learning disability' about 29 per cent of new clients received a completed assessment within two days of first contact, 44 per cent received a completed assessment within 2 weeks and a further 12 per cent received a completed assessment between 2 and 4 weeks. In comparison, 38 per cent of new clients with primary client type 'Mental Health' received a completed assessment within 2 days of first contact, 61 per cent received a completed assessment within 2 weeks and a further 16 per cent received a complete assessment within between 2 and 4 weeks" (p.24).

Waiting time between assessment and receipt of all services
For this group the report states "of those new clients aged 65 and over with primary client type 'mental health', 69 per cent had received all services within 2 weeks of their completed assessment, 82 per cent received all services within 4 weeks and 88 per cent received all services within 6 weeks. In comparison, of those with primary client type 'physical and sensory disability/frailty', approximately 82 per cent of clients had received all services within 2 weeks of their completed assessment, 92 per cent received all services within 4 weeks and 95 per cent received all services within 6 weeks" (p.2
Appendix 5 National Health Service (NHS)

The NHS is financed primarily through general taxation and requires little patient cost-sharing (mainly for outpatient prescription drugs, dental care and optometry care). About ten per cent of residents has supplementary private insurance covering choice of specialists and faster access to elective surgery.

The NHS includes hospital and physician services and prescription drugs. Eighty percent of the NHS budget is controlled by 152 primary care trusts (PCTs) which contract with physicians and hospitals to provide care to a geographically defined population. PCTs are responsible for assessing local needs; developing a local health system strategy e.g., appropriate providers, level of competition and cooperation between providers, capital spending etc; commissioning services from providers of preventive, primary, secondary and specialist care; monitoring service delivery; integrating health and social services; and, in most cases, directly providing services e.g. district nursing, community services. PCTS are

In 2002, 28 strategic health authorities (SHAs) were established to manage the local NHS on behalf of the Department of Health. In 2006, boundaries were changed resulting in ten SHAs – essentially regional organizations of the Department of Health – responsible for populations ranging from 2.6 million to 7.5 million. The SHAs have a system management role with a mandate to develop plans for improved health services, monitor performance of the Primary Care Trusts and NHS Trusts, and ensure national priorities are integrated into local health service plans.

Hospitals are organised as trusts responsible to the Secretary of State for Health with varying degrees of autonomy. Specialists are mainly salaried hospital employees, although many supplement their income treating private patients. Since 2003, the NHS has begun purchasing a small but increasing share of routine elective surgery and diagnostics from private providers. Primary care providers are mainly private, operate under an annual national contract, and are paid directly by PCTs through a combination of salary, capitation, and fee-for-service. The 2004 GP contract introduce a comprehensive pay-for-performance initiative, providing substantial financial incentives tied to achievement of clinical and other performance targets. Since 2003, a new payment framework has been introduced gradually, basing contracts with acute, mental health, ambulance, and community service providers on activity and, since 2009, a proportion of their income is conditional on quality and innovation”.

294 Information on NHS commissioning processes, including standards and toolkits, can be found at: http://www.library.nhs.uk/commissioning/ViewResource.aspx?resID=291965

The NHS in England has favoured the development of a purchaser-provider model of care with a growing role of the private and voluntary sector in delivering services. The Primary Care Trusts (PCTs) in England are responsible for the health and wellbeing of people in its local area. By introducing a purchaser-provider model of commissioning care services (and sometimes direct provision) from a budget received directly from the Department of Health enables PCTs to contract for all primary care services and consequently hold them to accountable for their performance. The PCT manages nationally-agreed contracts to primary care providers such as GPs, pharmacists, dentist and optometrists. Goodwin et al (2008) go on to explain that "the PCT can also employ other local contractual mechanisms to substitute for, enhance or provide additional services. Though primarily concerned with primary medical care, PCTs are encouraged to jointly-commission with local authority departments where combinations of social and medical care are sought. PCTs are themselves held to account for their performance by 10 Strategic Health Authorities and a regulator, the Health Care Commission" (Goodwin et al, 2008, p.10).

In England various types of Trusts provide publicly funded services for the NHS. It is of note that while Wales has a similar structure to that in England, Scotland and Northern Ireland have distinct structures with no trusts in these jurisdictions.

296 A purchaser-provider separation or split is designed to use contractual arrangements to introduce competitive elements into a publicly-managed health system. The purchasing of services i.e. politicians allocating resources is separated from the provision of services by private or public bodies who respond to the purchaser’s orders. Contracts specify the terms of purchasing and providing. Separating the purchase and provision of health and social care has meant that health and social care purchasers must assess the needs of their local population. Consequently Local Authorities are responsible for providing services on a needs-led basis. Previously patients were assess and then ‘fitted’ into services that already existed (Hodge, 1992:p306).

297 In 2002 the government created 28 Strategic Health Authorities (SHA) to manage the NHS and lead on strategic development. In 2006 the number of SHA were reduced to 10. The SHA are responsible for 1) developing plans for improving health services in their local area 2) making sure local health services are of a high quality and are performing well 3) increasing the capacity of local health services - so they can provide more services and 4) making sure national priorities - for example, programmes for improving cancer services - are integrated into local health service plans. http://www.nhs.uk/NHSEngland/aboutnhs/Pages/Authoritiesandtrusts.aspx (Accessed 17/09/2009) (NHS website, About the NHS Structure).

298 Since 1999, devolution of political autonomy across the four home nations of the UK (England, Scotland, Wales and Northern Ireland) has led to explicit variations in the nature of health reform and primary care delivery (Goodwin, 2008).

299 Commissioning Trusts such as NHS Primary Care Trusts (PCTs) provide primary care services and commission secondary care services. NHS Care Trusts provide/ commission health and social care services, authority. Commissioned Trusts provide secondary care health services.
## Figure 6: KEY COMPONENTS of the NHS (Taken from the Change Foundation in Ontario, Canada)

<table>
<thead>
<tr>
<th>Population Base</th>
<th>Strategic Health Authorities (SHAs)</th>
<th>Primary Care Trusts (PCTs)</th>
<th>Primary Care, General Practice</th>
<th>Secondary, Tertiary, Specialist Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10 SHAs responsible for 2.6 to 7.5 million populations</td>
<td>152 PCTs responsible for local populations ranging from 90,000 to 1,253,000 (average 330,000)</td>
<td>Wide variability of GP practice ranging from solo GP practices (less than 10%) to large multidisciplinary practices</td>
<td>NHS Trusts: 158 (94 Acute, 43 Mental Health, 12 Ambulance, 9 Care)</td>
</tr>
<tr>
<td></td>
<td>PCT boundaries largely coincide with Local Authority boundaries if effort to facilitate cooperation between health &amp; social sector</td>
<td>90% of patient contact with the NHS does not go beyond their GP</td>
<td>NHS Foundation Trusts (FTs): 109 (77 Acute, 31 mental health, 1 Care)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mandate</td>
<td>Providers include: GPs, community / practice nurses, dentists, therapists, opticians, pharmacists</td>
<td>Must provide health care according to NHS principles of free care based on need</td>
<td></td>
</tr>
<tr>
<td></td>
<td>System managers: develop health services plans; monitor performance of PCTs, NHS Trusts; ensure national priorities are integrated into local health service plans</td>
<td>GPs play a gatekeeper role - patients need referral to access secondary, specialist care</td>
<td>Providers primarily through NHS Trusts and NHS FTs: acute / specialist, secondary / tertiary health care (e.g., community, specialized hospitals; hospital, community mental health services; etc.) [but also providers in the private/non-profit sector]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Commissioners of health care: assess local needs; develop local health system strategy; commission preventive, primary, secondary, specialist care; monitor service delivery; integrate health &amp; social services; provide services</td>
<td>Nurses have significant managerial and clinical responsibilities, including ability to prescribe medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Statutory framework: NHS Act, 1977; NHS &amp; Community Care Act,</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Account-ability</th>
<th>Strategic Health Authorities (SHAs)</th>
<th>Primary Care Trusts (PCTs)</th>
<th>Primary Care, General Practice</th>
<th>Secondary, Tertiary, Specialist Care</th>
</tr>
</thead>
</table>
|                | Statutory framework: NHS Act, 1977; NHS & Community Care Act, 1990; Health Authorities Act, 1995; Health & Social Care Act, 2001 | Expected to work with Local Authorities & social care organizations to establish policies, care networks | Primary care practice increasingly more standardized due to:  
- NICE302 Clinical Practice Guidelines  
- Dept. of Health National Service Frameworks (NSF)  
- Practitioners with Special Interests clinical practice frameworks (PwSI) | Most NHS Trusts are attempting to qualify as self governing FTs; statutory framework for NHS FTs created under the Health and Social Care Act, 2003 |
|                | Statutory accountability to Department of Health / Secretary of State for Health | Organizational accountability to SHAs | GPs/medical profession is regulated by General Medical Council (licenses) | NHS Trusts: Accountable to SHAs |
|                | SHAs closely monitor PCTs & NHS Trusts given their accountability role on financial and quality targets – earned | Statutory accountability to Department of Health / Secretary of State for Health; CEOs are “accountable officers” and can be summoned before the Public Accounts Committee of the House of Commons | Other influential bodies are the Royal Colleges, respective provider Councils (e.g., Nursing and Midwifery Council, General Optical Council, Royal Pharmaceutical Society, etc.). | NHS FTs: Independent public benefit corporations accountable to a council of governors with elected members – including local residents, patients, staff - & appointed governors – PCT, SHA, local organizational representation |
|                | Statutory duty to consult local |  | GPs do not have an automatic right to establish a practice – practices must be registered by the PCT which has a statutory | NHS FTs are authorized by Monitor to provide mandatory goods & services they are required to provide, which differ depending on local |

302 National Institute for Health and Clinical Excellence (NICE)
<table>
<thead>
<tr>
<th>Strategic Health Authorities (SHAs)</th>
<th>Primary Care Trusts (PCTs)</th>
<th>Primary Care, General Practice</th>
<th>Secondary, Tertiary, Specialist Care</th>
</tr>
</thead>
</table>
| autonomy appears to be operating principle | communities about changes to services:  
   a) Local Involvement Networks – 150, mostly co-terminus with PCTs  
   b) Health Scutiny Committees – committees of Local Authorities with a mandate to monitor health care provision | responsibility to maximize reasonable access to GP services for all residents.  
   GP practices are accountable to PCTs for their PBC plans (i.e., must be in line with local health plans and targets) | service needs, other providers; they are free to develop new services or change way services are provided |
| Funding | Allocated 85% of total NHS budget; based on population size, estimated health needs, CoL adjustments  
   Funding to cover comprehensive range of NHS services (e.g., preventive, primary, secondary, tertiary, specialist care, health promotion, etc.)  
   Statutory requirement to achieve financial balance, but have significant discretion over allocation of funds  
   Contracts with providers specify | General Medical Services (GMS) contract (GP contract) – nationally negotiated & latest contract implemented in 2004; included new investments in primary care (33% over 3 yrs), introduced financial incentives for performance targets, provided more flexibility / autonomy in service delivery | NHS Trusts and NHS FTs: funded by PCTs; nearly all hospital doctors & nurses employed by NHS  
   NHS FTs: can retain surpluses or borrow money for new investments; can commit to capital investments to improve services / increase capacity |
| Department of Health – essentially regional offices of the Department  
   Government has recognized the vulnerability of the commissioning function of PCTs and has established the “World Class Commissioning” programme to develop the decision- | | | Private sector involvement primarily in non- |
<table>
<thead>
<tr>
<th>Strategic Health Authorities (SHAs)</th>
<th>Primary Care Trusts (PCTs)</th>
<th>Primary Care, General Practice</th>
<th>Secondary, Tertiary, Specialist Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>making capacity at the local PCT level</td>
<td>range of services, volumes, quality, timeliness of services; payment according to tariff system with limited capacity for incentives and penalties</td>
<td>(PMS) contract with their PCT. Other contracting routes include:</td>
<td>emergency surgery, diagnostics</td>
</tr>
<tr>
<td></td>
<td>New financing models expected in 2010/11 to enable greater commissioner leverage to incentivize quality and improve outcome by overlaying the tariff payments with bonus payments</td>
<td>- Alternative Provider Medical Services – contracts with individuals, organizations that meet provider conditions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most PCTs provide direct services – are expected to ‘externalize’ their provider services by end of 2009 due to conflict of interest concerns.</td>
<td>- PCT Medical Services: for employing practitioners directly</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Practice Based Commissioning (PBC) - GP practices expected to hold a PBC budget from PCT; practices given a ‘virtual’ budget to ‘buy’ health services for their population; based on premise that GPs will commission better quality of care, will less likely make unnecessary referrals to hospitals if they are responsible for their own budget; allowed to keep 70% of savings for capital investments to support expansion of primary care services. (Recent evaluations conclude PBC has been slow to develop.) Limited private sector involvement in primary care</td>
<td></td>
</tr>
<tr>
<td>Performance Management</td>
<td>Strategic Health Authorities (SHAs)</td>
<td>Primary Care Trusts (PCTs)</td>
<td>Primary Care, General Practice</td>
</tr>
<tr>
<td>------------------------</td>
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<tr>
<td></td>
<td>National performance framework with indicators, targets, standards – some targets are monitored</td>
<td>Rigorously regulated to ensure they comply with core clinical standards and meet financial targets: - responsible for ensuring implementation of NICE clinical practice guidelines - assessed annually by Healthcare Commission re quality standards, targets and Audit Commission re financial management Confusion re performance management system for PCTs: dual performance accountability to 2 regulators; Dept. of Health requesting more comprehensive performance criteria; subject to Local Authority Health Scrutiny</td>
<td>Primary practice providers’ performance is monitored by PCT as per contracting, accountability agreements PCTs are taking a much more proactive approach to performance management of GPs; as more data becomes available providing analysis of performance, PCTs can issue an external peer review of a GP practice; if unacceptable levels of performance are confirmed, the GP is suspended, pending referral to the General Medical Council</td>
</tr>
</tbody>
</table>

303 The Healthcare Commission becomes the Care Quality Commission in April 2009, incorporating the Commission for Social Care Inspection and the Mental Health Act Commission.
<table>
<thead>
<tr>
<th>Strategic Health Authorities (SHAs)</th>
<th>Primary Care Trusts (PCTs)</th>
<th>Primary Care, General Practice</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Committees.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient, Public Perspective</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public still views the government – or SHAs, as regional offices of the Department of Health - as carrying ultimate responsibility for health care</td>
<td>Statutory duty to consult local communities about changes to services, as noted above</td>
<td>Patients may choose to register with any GP (overwhelming majority select providers within their PCT)</td>
<td>Patients can choose where to have specialist treatment from a growing list of hospitals, clinics that meet standards set by the NHS (e.g., NHS Trusts, NHS FTs, independent sector)</td>
</tr>
<tr>
<td></td>
<td>Increasingly putting more effort into communicating with their local communities about their role, responsibilities</td>
<td>Increasing focus on Payment by Results (PbR) - 2002 policy to provide patient choice for elective services and create a form of voucher system (i.e., a GP referral for an elective service gives the patient a voucher that they cash in with their chosen provider who then receives payment in accordance with tariff). Patient experience of continuity of care between primary &amp; secondary care, &amp; health &amp; social care is challenged by historical administrative, budgetary, territorial separation between health &amp; social care sectors, &amp; historical competition between primary &amp; secondary care; there are limited local success stories of well integrated public policies &amp; easy patient navigation</td>
<td>Healthcare Commission reports to the public on health system performance – annual ratings for individual organizations (e.g., PCTs, hospitals, etc.) Information on provider performance is posted on the NHS website as a resource for patients to make informed choices for secondary, specialist care. In reality, patient choice has remained limited, primarily due to supply. FTs provide for greater local ownership, involvement - residents, patients, staff eligible to stand for, vote in elections for Governors; however, effectiveness &amp; genuine representativeness of this public involvement has yet to be evaluated.</td>
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<td>Effectiveness and genuine representativeness of public involvement in PCT planning has yet to be evaluated</td>
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