Deinstitutionalisation and community living – outcomes and costs: report of a European Study

Country Report

United Kingdom
### Summary of the available data

#### Description of service types

Service descriptions were available for services in all four regions as summarized in the tables below. In most cases these overlapped between the 4 regions of the UK. Information included in these tables for all services, including those providing for older people.

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Size interval</th>
<th>Age Group</th>
<th>Disability group served</th>
<th>Level of support provided</th>
<th>Typical provider</th>
<th>Typical funder</th>
<th>Length admissions</th>
<th>Age of service</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children’s homes/hostels</strong></td>
<td>Less than 6 places</td>
<td>6-18 or 19 years</td>
<td>Mixed but includes those with behavioural and emotional disorders and children in care</td>
<td>24 hour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Residential homes</strong></td>
<td>11 to 30 places</td>
<td>6-18 or 19 years</td>
<td>More than one disability group served (no main group) but not mixed</td>
<td>24 hour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Residential special schools</strong></td>
<td>11 to 30 places</td>
<td>6-18 or 19 years</td>
<td>More than one disability group served (no main group) but not mixed</td>
<td>24 hour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Residential college</strong></td>
<td>31 to 50 places</td>
<td>young adulthood - 16 to 19 or 23</td>
<td>Mixed</td>
<td>Mixed depending on need</td>
<td>Mainly independent (over 50% private or voluntary)</td>
<td>Mainly state or LA (more than 75%)</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td>-</td>
<td>0-18/19 years</td>
<td>MH</td>
<td>24 hour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Village community</strong></td>
<td>11 to 30</td>
<td>Over</td>
<td>Mixed ID with</td>
<td>24 hour</td>
<td>Voluntary/not-for-</td>
<td>Mixed benefits and</td>
<td>Mainly long</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Type of service</td>
<td>Size interval</td>
<td>Age Group</td>
<td>Disability group served</td>
<td>Level of support provided</td>
<td>Typical provider</td>
<td>Typical funder</td>
<td>Length admissions</td>
<td>Age of service</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>---------------</td>
<td>----------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>---------------------------</td>
<td>----------------------------------</td>
<td>-------------------------------------</td>
<td>-------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>NHS campus settings</td>
<td>100 to 150 places</td>
<td>Over 18/25 (i.e. adults only)</td>
<td>PD, SD, MH, Behavioural and other</td>
<td>profit (over 95%)</td>
<td>private</td>
<td>term</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Assessment and treatment units/private hospitals/secure units</td>
<td>11 to 30 places</td>
<td>14 + to adulthood (60/65 years)</td>
<td>Mixed ID with PD, SD, MH, Behavioural and other</td>
<td>24 hour</td>
<td>Mixed</td>
<td>Mixed state/local and private contributions (insurance/private)</td>
<td>Mixed</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Long-stay LD Hospitals</td>
<td>11 to 30 places</td>
<td>Over 18/25 (i.e. adults only)</td>
<td>Mixed ID with PD, SD, MH, Behavioural and other</td>
<td>24 hour</td>
<td>State</td>
<td>Regional authority/LA/County and state</td>
<td>All long term</td>
<td>50 - 100 years</td>
</tr>
<tr>
<td>Psychiatric hospital</td>
<td>.</td>
<td>3 into adulthood (60/65 years)</td>
<td>MH</td>
<td>24 hour</td>
<td>State</td>
<td>State</td>
<td>Mixed</td>
<td>50 - 100 years</td>
</tr>
<tr>
<td>Small Group homes</td>
<td>less than 6 places</td>
<td>Over 18/25 (i.e. adults only)</td>
<td>Mixed</td>
<td>Mixed depending on need</td>
<td>Mainly independent (over 50% private or voluntary)</td>
<td>Mixed benefits and private</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Group homes for older people</td>
<td>less than 6 places</td>
<td>Over 60/65</td>
<td>Mixed ID with PD, SD, MH, Behavioural and other</td>
<td>24 hour</td>
<td>All (over 95%) private</td>
<td>Mixed benefits and private</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Type of service</td>
<td>Size interval</td>
<td>Age Group</td>
<td>Disability group served</td>
<td>Level of support provided</td>
<td>Typical provider</td>
<td>Typical funder</td>
<td>Length admissions</td>
<td>Age of service</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>---------------</td>
<td>---------------------------</td>
<td>-------------------------</td>
<td>----------------------------</td>
<td>-----------------</td>
<td>---------------------</td>
<td>------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Secure/forensic hospitals</td>
<td>151 to 200 places</td>
<td>14 + to adulthood (60/65 years)</td>
<td>MH</td>
<td>24 hour</td>
<td>State</td>
<td>State</td>
<td>Mixed</td>
<td>50 - 100 years</td>
</tr>
<tr>
<td>Residential care homes (no nursing)</td>
<td>6 to 10 places</td>
<td>Over 18/25 (i.e. adults only)</td>
<td>Mixed</td>
<td>24 hour</td>
<td>Mainly independent (over 50% private or voluntary)</td>
<td>Mixed (any)</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Residential care homes</td>
<td>11 to 30 places</td>
<td>over 60/65</td>
<td>Mixed</td>
<td>24 hour</td>
<td>Mainly independent (over 50% private or voluntary)</td>
<td>Mixed benefits and private</td>
<td>Mainly long term</td>
<td></td>
</tr>
<tr>
<td>Residential care home with nursing</td>
<td>11 to 30 places</td>
<td>Over 18/25 (i.e. adults only)</td>
<td>Mixed</td>
<td>24 hour</td>
<td>Mainly independent (over 50% private or voluntary)</td>
<td>Mixed (any)</td>
<td>Mainly long term</td>
<td>0 to 20 years</td>
</tr>
<tr>
<td>Nursing homes (Northern Ireland and Scotland)</td>
<td>31 to 50 places</td>
<td>Over 60/65</td>
<td>Elderly infirm/mentally ill/dementia</td>
<td>24 hour</td>
<td>All (over 95%) private</td>
<td>Mixed benefits and private</td>
<td>Mainly long term</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>.</td>
<td>Over 60/65</td>
<td>Elderly infirm/mentally ill/dementia</td>
<td>24 hour</td>
<td>State</td>
<td>State</td>
<td>Mixed</td>
<td>21 to 50 years</td>
</tr>
</tbody>
</table>
The tables below summarise of data on places and breakdown by size and disability – these include only those service types which provide at least in part for people with disabilities. Some of service types listed above have been amalgamated in order to present the data available. However, because of the nature of the data available it has been necessary to keep separated the data from the different regions at times) The number of places for those who are elderly and infirm or who have dementia (but no other pre-existing disability) are clearly distinguished. Only places for people with disabilities were included in the final analysis of data reported in the main project report.

### Breakdown of places by size and disability group

<table>
<thead>
<tr>
<th>Type of institution</th>
<th>Places</th>
<th>Under 30 places</th>
<th>Over 30 places</th>
<th>Size unspecified</th>
<th>ID</th>
<th>MH</th>
<th>PSD</th>
<th>Elderly/dementia</th>
<th>Mixed/dual</th>
<th>Other/unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's homes/hostels</td>
<td>620</td>
<td>620</td>
<td></td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>620</td>
</tr>
<tr>
<td>Residential home for children</td>
<td>80</td>
<td>.</td>
<td></td>
<td>.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>80</td>
</tr>
<tr>
<td>Residential special schools</td>
<td>982</td>
<td>.</td>
<td></td>
<td>161</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>821</td>
</tr>
<tr>
<td>NHS provision (includes NHS campuses, NHS secure units etc but not long-stay LD hospitals)</td>
<td>15060</td>
<td>.</td>
<td></td>
<td>2637</td>
<td>8040</td>
<td>792</td>
<td>3591</td>
<td></td>
<td></td>
<td>3591</td>
</tr>
<tr>
<td>Long stay LD hospital</td>
<td>964</td>
<td>139</td>
<td>683</td>
<td>142</td>
<td>964</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Private hospitals and assessment and treatment/secure units</td>
<td>16864</td>
<td></td>
<td></td>
<td>717</td>
<td>1134</td>
<td>6372</td>
<td>7873</td>
<td></td>
<td></td>
<td>8641</td>
</tr>
<tr>
<td>Forensic hospitals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small group homes (England)</td>
<td>11513</td>
<td>11513</td>
<td></td>
<td>0</td>
<td>7935</td>
<td>990</td>
<td>219</td>
<td>579</td>
<td>1808</td>
<td>561</td>
</tr>
<tr>
<td>Residential care homes (England where size data available)</td>
<td>55189</td>
<td>20541</td>
<td>32095</td>
<td>2553</td>
<td>29261</td>
<td>9483</td>
<td>3118</td>
<td>120</td>
<td>9993</td>
<td>3334</td>
</tr>
<tr>
<td>Residential care homes with nursing (England, plus NI dual registered homes)</td>
<td>24136</td>
<td>717</td>
<td>16003</td>
<td>7416</td>
<td>1846</td>
<td>2790</td>
<td>3664</td>
<td>1891</td>
<td>6529</td>
<td>9307</td>
</tr>
<tr>
<td>All other residential homes (grouped together - e.g. for Wales, Scotland – no size data, including older people)</td>
<td>31809</td>
<td></td>
<td></td>
<td></td>
<td>4073</td>
<td>1902</td>
<td>813</td>
<td>4624</td>
<td></td>
<td>25021</td>
</tr>
<tr>
<td>Residential homes for older</td>
<td>210604</td>
<td>3486</td>
<td>207128</td>
<td>10</td>
<td>386</td>
<td>2973</td>
<td>1193</td>
<td>148342</td>
<td>57710</td>
<td>148342</td>
</tr>
<tr>
<td>Type of institution</td>
<td>Places total</td>
<td>Under 30 places</td>
<td>Over 30 places</td>
<td>Size unspecified</td>
<td>ID</td>
<td>MH</td>
<td>PSD</td>
<td>Elderly/ dementia</td>
<td>Mixed/ dual</td>
<td>Other/ unspecified</td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>--------------</td>
<td>-----------------</td>
<td>----------------</td>
<td>------------------</td>
<td>----</td>
<td>----</td>
<td>-----</td>
<td>-------------------</td>
<td>-------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Residential homes with nursing for older people (England)</td>
<td>162387</td>
<td>75</td>
<td>162312</td>
<td>0</td>
<td>91</td>
<td>6591</td>
<td>5268</td>
<td>85729</td>
<td>64708</td>
<td>85729</td>
</tr>
<tr>
<td>Small group homes for older people (England)</td>
<td>756</td>
<td>756</td>
<td>756</td>
<td>0</td>
<td>101</td>
<td>60</td>
<td>1</td>
<td>576</td>
<td>198</td>
<td>396</td>
</tr>
<tr>
<td>TOTAL</td>
<td>530964</td>
<td>37847</td>
<td>418221</td>
<td>10101</td>
<td>48172</td>
<td>33963</td>
<td>21440</td>
<td>253325</td>
<td>140946</td>
<td>285743</td>
</tr>
</tbody>
</table>
### Breakdown of places by gender and age

<table>
<thead>
<tr>
<th>Type of institution</th>
<th>Places total</th>
<th>Male</th>
<th>Female</th>
<th>Gender unspecified</th>
<th>Children</th>
<th>Younger adults</th>
<th>Older adults</th>
<th>Adults over 18</th>
<th>Age unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's homes/hostels</td>
<td>620</td>
<td>440</td>
<td>180</td>
<td>0</td>
<td>620</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>0</td>
</tr>
<tr>
<td>Residential home for children</td>
<td>80</td>
<td>50</td>
<td>30</td>
<td>0</td>
<td>982</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>902</td>
</tr>
<tr>
<td>Residential special schools</td>
<td>982</td>
<td>530</td>
<td>161</td>
<td>291</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>982</td>
</tr>
<tr>
<td>NHS provision (includes NHS campuses, NHS secure units etc but not long-stay LD hospitals)</td>
<td>15060</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>835</td>
<td>10236</td>
<td>3989</td>
<td>.</td>
<td>3591</td>
</tr>
<tr>
<td>Long stay LD hospital</td>
<td>964</td>
<td>114</td>
<td>56</td>
<td>794</td>
<td>8</td>
<td>135</td>
<td>9</td>
<td>.</td>
<td>812</td>
</tr>
<tr>
<td>Private hospitals and assessment and treatment/secure units</td>
<td>16864</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>49</td>
<td>1118</td>
<td>14929</td>
<td>.</td>
<td>7105</td>
</tr>
<tr>
<td>Forensic hospitals</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>Small group homes (England)</td>
<td>11513</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>11513</td>
<td>.</td>
<td>18</td>
<td>597</td>
</tr>
<tr>
<td>Residential care homes (England where size data available)</td>
<td>55189</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>51675</td>
<td>.</td>
<td>300</td>
<td>3094</td>
<td>.</td>
</tr>
<tr>
<td>Residential care homes with nursing (England, plus NI dual registered homes)</td>
<td>24136</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>14869</td>
<td>.</td>
<td>5553</td>
<td>1823</td>
<td>.</td>
</tr>
<tr>
<td>All other residential homes (grouped together - e.g. for Wales, Scotland – no size data, including older people)</td>
<td>31809</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>27185</td>
</tr>
<tr>
<td>Residential homes for older people (England)</td>
<td>210604</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>210604</td>
<td>.</td>
<td>148342</td>
<td>.</td>
</tr>
<tr>
<td>Residential homes with nursing for older people (England)</td>
<td>162387</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>162387</td>
<td>.</td>
<td>85729</td>
<td>.</td>
</tr>
<tr>
<td>Small group homes for older people (England)</td>
<td>756</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>756</td>
<td>.</td>
<td>576</td>
<td>.</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>530964</strong></td>
<td><strong>1134</strong></td>
<td><strong>427</strong></td>
<td><strong>1085</strong></td>
<td><strong>2494</strong></td>
<td><strong>89546</strong></td>
<td><strong>392674</strong></td>
<td><strong>5871</strong></td>
<td><strong>212946</strong></td>
</tr>
</tbody>
</table>
**Staffing data**

Only available for one type of service – children’s homes/hostels.

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Total Number of staff in each type of service</th>
<th>Number care staff/nurses/might include teachers in boarding school</th>
<th>Number managers or other administrative staff (not care staff)</th>
<th>Number educators/day staff</th>
<th>Day and care staff (no distinction made)</th>
<th>Number clinical staff (Drs, therapists, psychologists etc)</th>
<th>Number of other staff (mainly ancillary staff)</th>
<th>Number of other staff (does not include ancillary staff)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s homes/hostels</td>
<td>2125</td>
<td>1360</td>
<td>490</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>280</td>
<td>.</td>
</tr>
</tbody>
</table>
Completeness and accuracy of the data

The four constituent countries of the UK have their own government departments with different degrees of autonomy. Within each country, some social welfare and health care is provided by local government agencies and other health care and social security provided by central government through regional and local organisations that may differ between the four countries. Social care and health care organisation is therefore different in each of the four countries which required consultation of different sources of data in each country. These sources varied in the level of detail available, the nature of the data and to some extent the definitions used. For example, English data is mainly information about places or beds, whilst data from other regions sometimes refers to the number of people supported e.g. by local authorities.

In England access was available to the 2004/2005 data collected by the Commission of Social Care Inspection – the body responsible for registration and inspection of all services providing residential care (as well as those providing domiciliary care, foster care and adoption services). However, for Wales, Northern Ireland and Scotland only summative data was available although for the most part this was data collected by the body responsible for registration and inspection processes.

For England it was also possible to access quite detailed information on long-term care provided by the national health services and although summative in nature it was possible to break this down by age, and to some extent by disability group.

Data on children with disabilities
For the most part the data included in the template refers only to England and uses two main sources: the Annual Reviews in Independent and Non-Maintained Special Schools (available through http://www.scrip.uk.net/) and the Department for Education and Skills/Department of Health, report (2004 and 2005) on Disabled Children in Residential Placements. Most recent data on residential services was for 2002. Data on residential schools referred to 2006. It is also known that there are 291 places in residential schools in Wales but there is no breakdown by disability group available for this figure.

Data on adults with disabilities

Health related statistics
Data on NHS provided services is only available in official form for England and data is taken from Department of Health statistics (Returns Form KH03) published in September 2006. Data is available by Health Authority and summarised across England and data refers to the year 2005-2006. Very little data is available on mental health services in other parts ok the UK apart from in the form of admissions to hospital.
**Social care statistics**

**England**

As noted above, data for England was taken from CSCI data for 2004-2005. The raw data was made available to the project team and complete for all social care homes registered with CSCI at that time. The data is at home level and provides information on the breakdown of places by disability group but does not provide any additional information on the people who live there. There is also no data collected about staffing (although some summary data is available from other sources and presented in the country report below).

**Wales**

The Standards Inspectorate for Wales (CSIW) is responsible for registration and inspection of social care services in Wales. Data for Wales is principally drawn from their reports. Separate tables are available for number of places by LA or private and voluntary provision. Statwales provides some data on hospitals and units for persons with intellectual disability, with information on gender available from census data. Numbers of people on intellectual disability register are recorded by county, LA or private provision with little data available by unit. Very little data on mental health services in Wales is readily available. Data for Wales was not available broken down by size but for the purpose of estimations, it was possible to use typical size as a guideline for processing this information.

**Scotland**

The Scottish Commission for the Regulation of Care (SCRC) which regulates a wide range of services for adults, children, provides information on over 320,000 people in Scotland using care services. Of these, about 11.2% are residential care homes. Community care statistics provide summary statistical information of summary data (numbers over time) from different sources on older adults, intellectual disability and physical and sensory disabilities, broken down by local authorities. Inspection Unit data lists all private & voluntary residential homes for ID, PSD, mental health by LA, numbers of homes, numbers of beds, residents, age distribution (for 55+). NHSiS collate information on private nursing homes (mainly for the elderly), but the information is not detailed. Published information on staff and staffing levels is minimal.

The figures entered under private hospitals, nursing homes providing nursing care only, assessment and treatment units etc were for nursing homes in Scotland and are mainly for older people – therefore although some private services aren’t for older people the ones on which we had data were. The Forensic hospitals listed were also for Scotland although data on the number of places was not available. In general there was little information on mental health services in Scotland.

**Northern Ireland**

Sources for Northern Ireland included:

- Department of Health Social Services and Public Safety, Registration and Inspection Unit (NI) 2003-2004
- NI Statistics & Research Agency (NIRAS)
Changes within the organisation of inspection and registration and statistics has meant that recently a new body has taken over the process. At the time of completing the template, no new report was available and this was checked by phone conversations with people within the Northern Ireland Statistics and Research Agency [NISRA] and the Registration and Inspection Department within the Department of Health, Social Services and Public Safety.

Some of the data which was available for Northern Ireland is at institution level and no information was available with regard to size from official sources. However it was possible to estimate size from the typical size of most services as described by McConkey et al (2006) and Mulvany et al (2007)

In Northern Ireland children’s homes cater for those with ID, PSD or behavioural/emotional problems but without the distinction. Very little information is available on mental health services or on hospital services for those with disabilities.

Some data on staffing (numbers) is provided by Health & Personal Social Services Workforce Census (2003).
Commentary: United Kingdom
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1. Overview
The United Kingdom of Great Britain and Northern Ireland was established in 1927 and is made up of 4 nations – England, Wales, Scotland (and island otherwise known as the Kingdom of Great Britain, established in 1707) and Northern Ireland. There are also a number of small Islands which each form parts of the four constituent nations. Each nation has its own capital city (London, Cardiff, Edinburgh and Belfast respectively) and although overall government remains in London, each nation has its own government processes and has devolved powers and responsibilities.

2 Political and social context

2.1 Government organisation and structure
Great Britain is a parliamentary monarchy. The British Monarch is Head of State but executive power is wielded by the prime minister, who is head of government working with a committee of cabinet ministers. Parliament at Westminster in London consists of elected representatives (the House of Commons) and hereditary peers and appointive members (the House of Lords), who pass legislation. In practice, legislation is dominated by the prime minister and cabinet who initiate most bills and are responsible for the administration of the law and affaires of the nation.

The provincial constitutional set up described above means that although health and social services are broadly the same in the four nations, there are certain organisational differences.

The government is elected in a first-past-the-post system, with each constituency represented by the elected member represented in the House of Commons. Wales, Scotland and recently Northern Ireland have their own assemblies, but key powers, particularly in the areas of health and social policy are still retained by Westminster. Beyond the formal structures of state power lie well-established pressure group networks ranging from trades unions to corporate enterprises that may have an influence on power, policies and politics.

Wales
For centuries Wales has shared many political and legal institutions with England. The Welsh National Assembly (NAW) is a unicameral organisation of 60 members elected by proportional representation. It has powers to create only secondary legislation which still requires approval from parliament in London. The organisation of health and social services is the responsibility of the Assembly (Health & Social Services Committee). In addition the Director of the NHS also has responsibilities for social services policy. This means that there is much more alignment between health and social care policy at all levels than in the rest of the UK.
Scotland
The Scotland Act (1988) devolved a range of powers to the re-established Scottish Parliament which was elected in 1999 and has 129 members. Health, social affairs, community care and local governments are so-called devolved matters, in which the Scottish Parliament has the right to pass own laws. The “Scottish Executive” is the government of Scotland, its members are the “Scottish Ministers”.

Northern Ireland
Northern Ireland has been a distinct political entity since it was divided from the southern part (later the Republic) by treaty in 1922. It has experienced varying degrees of autonomy having its own parliament until 1972 when it was suspended as a result of the conflicts which began in 1969. Only very recently has the parliament re-opened.

2.2 Disability relevant policy
There have been three strains of general policy over the past decade, which have had an influence on the lives of people with disabilities.

General disability legislation such as the Disability Discrimination Act (1995) has enforced more equal opportunities and anti-discriminatory policies benefiting all people with disabilities. In particular the Act has been important with regard to improved physical access to all public areas and improved access to appropriate treatment in hospitals.

The Human Rights Act (1998) came into force in October 2000 and the Act gives a way for human right infringement cases to be heard in the UK rather than having to go to the European Court of Human Rights.

There have been a number of general community care policies that have aimed at improving the independence, protection and quality of care for all people receiving community care, including Modernising Social Services (DoH, 1998), The Community Care (Direct Payments) Act (DoH, 1996), the Health and Social Care Act (DoH, 2001), and the Care Standards Act (DoH, 2000). The Community Care (Direct payments) Act was particular important as it opened the doors to increased choice as to how services are provided for individuals. Although uptake of direct payments in some groups has been slow, in particular, those with intellectual disabilities, more and more people are now receiving direct payments and recent introduction of personal budgets as part of self-directed support (see http://www.in-control.org.uk/) have allowed more flexible and creative approaches to be taken by and on behalf of those with more severe disabilities.

Other important government papers and guidance, with particular relevance to those with disabilities, have included: The Valuing People White paper in England (Department of Health 2001); Fulfilling the Promises report in Wales (Learning Disability Advisory Group report to the Welsh National Assembly); Welsh Assembly Government’s Learning Disabilities Strategy on Adults and Older people with learning disabilities (2004) - guidance on service principles and service responses; The same as you? review by the Scottish Executive; and the Independence, Well-being and Choice green paper (Department of Health 2005). All of these papers, reviews and reports focus on the need to improve quality of life for people with
disabilities, with a particular focus on inclusion, independence and choice. The latter of these papers emphasised the importance of personal budgets and direct payments for the achievement of the aims of inclusion, independence and choice.

3. Demographics
The population of the United Kingdom currently stands at 60,587,000 (mid 2006 estimate by Office of National Statistics) and has been rising in recent years courtesy of increasing life expectancy, rising birth rate and increasing immigration. 7.5 million live within London. Over 90% of the population is white (86% White British). Populations estimates for other parts of the UK are as follows: Scotland – 5,116,000 (2006 estimate); Wales – 2,959,000 (2005 estimate); and Northern Ireland - 1,710,000 (2004 estimate).

There has been a major demographic transition over the past one hundred years as the country has moved from being one of high birth and death rates to being low on both counts due to general improvements in social and environmental factors and advances in medical technology. In health and social care terms, one of the most important factors is the increasing numbers of elderly people (accentuated by the decline in the birth rate) which currently stands at about 7.5% of the population over the age of 75 and is expected to rise to over 8% within 10 years (Wall, 1996). On average a person over 75 consumes around nine times the amount of health and social care resources as the average person of working age (DHSS, 1983) as an increase in conditions associated with ageing population, chronic and degenerative disease and illness escalate. These changes also have implications for the availability of carers within society – more people to care for and a smaller proportion of people of working age within the population.

4. Health and Social Care System

4.1 Organisation of health and social care in England
The Department of Health has overall responsibility for health and social care in England. Health care is delivered through the National Health Service (although private health care is also available in the UK) and social care is delivered through social services seated in Local Authorities across England. Social service departments do not usually provide residential services now – rather they are responsible for commissioning service to meet individual needs, usually from independent sector (private and voluntary) organisations.

Health care
Within England there are 10 strategic health authorities which are responsible for providing leadership, coordination and support to the NHS within a defined area. They lead on strategic development and manage the performance of Primary Care trusts and NHS trusts and they focus on finding the best ways to deliver and improve health care within their local area.

Both the Department of Health and the Strategic health authorities directly feed the work of Primary Care Trusts which assess local need and commission care. This care is both from Primary Care providers, such as general practitioners, dentist, opticians, pharmacists) and from secondary care providers, i.e. NHS Trusts (providing hospitals
and health care), Mental Health Trusts, Ambulance Trusts, etc. (http://www.nhs.uk/aboutnhs/howthenhsworks/Pages/HowtheNHSworks.aspx).

Social care
The Department of Health website (www.dh.gov.uk/en/Aboutus/HowDHworks/) reports that “at any one time 1.5 million of the most vulnerable people in society are relying on social care workers and support staff for help”. Social care in the UK is defined as services which help people to carry on in their daily lives. There are approximately 25,000 employers, with over one million staff in the field of social care in England and services provide for:

- Elderly people through residential homes, nursing homes, domiciliary/home carers, meal services, day centres, lunch clubs etc.
- People with physical or intellectual disabilities
- People with mental health needs (both in terms of support for those with milder needs in the community and in terms of initiated compulsory admission to psychiatric hospitals for those who are potentially dangerous.

In addition, social care services provide for those with drug and alcohol problems, ex-offenders, and young offenders, families (in particular those with a child with disabilities) and children in care. They also are responsible for children protection.

Social care is managed through social services departments seated within the 150 councils in England. It is the responsibility of councils to assess individual need and arrange care and support to meet those needs. In doing this they work closely with other organisations including the NHS, private and voluntary organisations, education, the probation services, the police etc. Social services in England provide very few residential services for people with disabilities but are generally responsible for commissioning services to meet people’s needs.

Almost all residential care is provided by private and voluntary organisations and even those services provided by the NHS are slowly being reprovided and moving to private and voluntary organisations.

Monitoring of quality
With regard to the NHS, performance is monitored by the Healthcare Commission. The Commission also monitors the quality of independent healthcare providers. Performance of social care providers is regulated and inspected through the Commission for Social Care Inspection. Children’s services (both social and residential) are monitored through OFSTED.

4.2 Financing
The NHS is financed mainly through central government general taxation together with an element of national insurance (NI) contributions, which are paid partly by individuals who are working and partly by their employers. Basic NHS care is free for all patients. Extended care (dentist, prescriptions etc) is provided free for those under 18 and over 60 and those on low incomes. There is also a substantial private healthcare sector although this is only available to those who can afford to pay for it or who have private health insurance.

Social care financing is more complex. Essential people pay for their own social care but many people receive help from the state, either through welfare benefits or from
social service funding. The majority of people have social care services provided directly – i.e. they are assessed as having a particular need, a service is found by their social service department, usually through their care manager to meet that need. For the majority of people this means that a place in a residential home or another setting is paid for by social services along with the person’s benefits which are usually paid directly to the residential home. For a growing number of people, this now means receiving the money to pay for their care directly and then having control over how it is spent in order to meet the assessed need. This is called a “direct payment” (introduced by The Community Care (Direct Payments) Act in 1996. Direct payments cannot be used to purchase a place in residential care, but are usually used to pay personal assistants to support people in their own home. Direct payments are most often used by people with physical disabilities, mental health needs and elderly people but this is becoming more widely used by people with intellectual disabilities too. Direct payments are now by paid to parents of a child under the age of 16 who is eligible for support.

Recently this has been extended to what is called “individual budgets” which have at present been introduced in almost 100 of the 150 local authorities. Individual budgets can be used by people with more severe intellectual disabilities to ensure that they get the package of care they both need and want but are more flexible in that they can be used to purchase residential care if that is what the person wants. Personal budgets are part of a new approach called “self-directed support” (see http://www.in-control.org.uk/) which combines funding with person-centred planning and allows a range of options through which the person can manage their personal budget.

Although the payment of certain benefits (e.g. Disability Living Allowance) is awarded on the basis of severity of disability, the majority of social care funding is means tested. If people have assets of over £16,000 they are expected to pay for their social care in full. If they have assets between £10000 and £16000 then they will pay a contribution towards their services. However over 70 percent of older people living in care homes, for example, get some or all of their costs met by their local council.

There are several types of benefits which people with disabilities would normally be able to access depending on the severity of their disability and living situation.

- Disability Living Allowance (DLA)
- Attendance Allowance
- Incapacity Benefit
- Income support (for those not working)
- Housing benefit (for those living in their own home)
- VAT relief on products and services for disabled people
- Council Tax reduction for disabled people (for those living in their own home)

The Department of Health reports that local authorities spend £10billion a year on social services, and about 70% of this funds community care services for adults (older people, people with physical or intellectual disabilities and the mentally ill). About 27% is spent on services for children.
4.3 Regional variations

4.3.1 Scotland
The Department of Health of the Scottish Office is responsible for health policy and the administration of the NHS in Scotland. The government’s Chief Medical Officer for Scotland heads the Public Health Policy Unit and is the Secretary of State’s chief medical adviser. The Chief Executive (CE) of the NHS in Scotland leads the central management of the service and is accountable to ministers for the efficiency and performance of the service. The CE heads the Management Executive which oversees the work of the 15 area special health boards, plus the State Hospital Board, Scotland, which also provide learning disability services, mainly short-stay assessment and treatment services, respite and rehabilitation services. As in England, the health boards are responsible for the planning and commissioning of health services for their resident populations and the trusts are responsible for the provision of services. The NHS in Scotland employs approximately 132,000 staff, including 63,000 nurses, midwives and health visitors and 8500 doctors. In addition, there are more than 7000 family practitioners, including doctors, dentists, opticians and community pharmacists. The Health Department is responsible for community care (NHS Scotland). Scotland has 32 directly elected local councils that are responsible for delivering social services. (main sources: http://www.show.scot.nhs.uk/organisations/orgindex.htm; http://www.nhshealthquality.org/nhsqis/files/LDS_LRP_MONR06.pdf)

4.3.2 Wales
The Director of the Welsh Office Health Department is accountable to the Secretary of State for the management and performance of the NHS in Wales. The Director, under the Permanent Secretary, is the Secretary of State’s principal policy adviser on the NHS. The Welsh Office Health Department comprises five divisions: Health Financial Management, Health Services and Management, Health Strategy, Primary and Community Health and the Public Health Division. The five Welsh health authorities are directly accountable to the Director of the Health Department. There are 4 regional health offices (North, Mid, Southeast and Southwest) which are self-sufficient for the majority of health care provision. Their role is to ensure implementation of assembly policy and support joint working at local levels between the 22 Local Health Boards (LHBs) and LAs and to monitor local health and social care policies. The 22 LHBs correspond to the 22 LAs whose responsibilities include needs assessment, commissioning of specialist care from the NHS trusts and the management of primary care. Trusts in Wales are constituted in much the same way as their English equivalents, except that each trust provides both acute hospital and community services (including mental health) to the general population. Community Health Councils (CHCs) have been retained in Wales to provide input into the planning process. The Welsh Assembly Government (WAG), since its inception, has sought to tackle the causes of ill-health, particularly through “joined up” policy through partnerships between various parts of the statutory and non-statutory sectors, local communities and individuals (Welsh Assembly Government, 2003). (http://www.wales.nhs.uk/sites3/page.cfm?pid=11600&orgid=452)
4.3.3 Northern Ireland
Close ties with Britain mean that the health and social services are modelled along similar lines, with a NHS established in 1948 and a Department of Health, Social services and Public Safety (DHSSPS). The Department is headed by the Permanent Secretary and comprises a number of core groups. These are the Resources and Social Security Group, Health and Social Policy Group, Health and Social Services Executive, and five professional groups. There are four health and social service boards (HSSBs) that are directly accountable to the Department of Health and Social Services and which are responsible for assessing the needs of the people in their areas and for commissioning services to meet those needs. There are five Health and Social Care Trusts which provide community care and social services within their areas, one for each of the HSSBs plus a separate one for Belfast. As the names of these boards and trusts imply, a major difference between them and the rest of the United Kingdom is that they are responsible for both health and social services. It is widely believed that this makes the coordination between health and social care services less problematic in Northern Ireland than in the rest of the United Kingdom. (http://www.n-i.nhs.uk/).

5. Definition, eligibility and diagnosis/assessment
In the UK, the definition of disability is generally medicalised. Diagnosis with a particular condition, confirmed by medical records, is usually important in order to obtain services. However, there is also a sense in which definition is also functional – the extent of and effect the impairments are assessed (but with a need for confirmation by medical professionals) in order to decide whether people are eligible for particular benefits or services. This slightly more functional approach is especially true of people with physical disabilities and older people.

The terminology used in the UK to label people with intellectual disabilities varies between different organisations and in different situations. For example, in the criminal justice system terminology ranges from ‘mental defective’ in the Sexual Offences Act (1956) to ‘mental impairment’ and ‘severe mental impairment’ in the Mental Health Act (1983). Within the social security system the terms ‘severe mental impairment’ and ‘severe learning disability’ are used. ‘Intellectual Disabilities’ is the term adopted internationally mostly by the academic world. The most commonly used term that is used by the government and in most professional and academic circles is the term ‘learning disability’ and ‘people with learning disabilities’. Some organisations, however, use the term “learning difficulties” which usually has a wider definition in that it includes those with specific educational needs (e.g. dyslexia, ADHD etc).

Intellectual disability in the UK is a medico-legal definition based upon the generally accepted diagnostic criteria used internationally. The diagnosis is made by qualified professionals and is based upon 3 core criteria:
(i) significant impairment of intellectual functioning;
(ii) significant impairment of social/adaptive functioning; and
(iii) age of onset before adulthood.
The White Paper, Valuing People (DoH, 2001) expresses these criteria in less clinical terms as “a significantly reduced ability to understand new or complex information, to learn new skills with a reduced ability to cope independently and which started before adulthood with a lasting effect on development” (Beadle-Brown et al., in European Intellectual Disability Research Network, 2003). This is essentially the same definition as used in Scotland, Wales and Northern Ireland.

However, although a diagnosis is usually necessary in order to be eligible for services, it is not sufficient due to a scarcity of provision. It is at this stage that the functional assessment becomes important and it is at this stage that the postcode lottery becomes an issue for those requiring services. In England it is possible to be eligible for particular services in one local authority but not in another. In May 2002, the Department of Health responded to this by issuing guidance on eligibility criteria for adult social care under the “Fare Access to Care” initiative. All councils had to use this guidance to review and revise their eligibility criteria in order to ensure fair access to care for all those needing social care services. The guidance (which can be downloaded from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653)) states the following:

- Councils should make one decision as to whether someone is eligible for help or not following an assessment of an individual’s “presenting needs”. They should not have different eligibility criteria for different assessments or different services – but the assessment should be comprehensive enough to encompass all the person’s needs. Services should then be matched to eligible needs which may need to be prioritised.
- Reviews and if necessary reassessment should be undertaken to ensure that needs continue to be met.
- The guidance applies to all those with physical, sensory, intellectual disabilities and those with mental health problems.
- The eligibility framework proposed for councils is based on factors that are necessary to maintain an individual’s independence over time and makes no reference to age, gender, ethnic group, disability, religion, personal relationships, location or other similar factors. These factors should be taken into account as needs are assessed and services considered but are not in themselves threats to independence and therefore not to be considered when deciding eligibility for services. There are four bands of seriousness:
  - Critical (e.g. life is or will be threatened in some way; significant health problems, little or not choice or control over vital aspects of immediate environment; serious abuse or neglect; vital involvement in work, education, social support systems, social relationships etc cannot or will be undertaken or sustained, etc.)
  - Substantial (e.g. only partial choice and control; abuse or neglect; inability to carry out personal care or domestic routines; involvement in work, activity etc cannot be sustained; etc)
  - Moderate (e.g. there is or will be an inability to carry out several personal care or domestic routines, involvement in some aspects of work, education or learning cannot or will not be sustained etc.)
  - Low (e.g. when there is an inability to carry out one or two personal care or domestic routines, involvement in one or two aspects of work, education etc cannot be sustained, etc.)
Decisions on eligibility remain with councils, however they are encouraged to consult all the major stakeholders involved in each person’s situation.

All people with severe to profound intellectual disabilities will fall into the critical band and therefore receive services, even if the local authority is only providing services to those judged to be in the critical band. Those with physical disabilities are likely to be in the substantial category. Those in the moderate and low categories are unlikely to receive services from the majority of councils.

6. Prevalence of disability

Statistics on the number of people with disabilities are not very comprehensive. There are few registers of people with disabilities and figures usually relate just to those who are receiving services or numbers financially supported by local authorities or health authorities. Much of the information that is available with regard to health care is in the form of admissions to services, so for example it is known that in England 5190 people with physical or sensory disabilities (1.7 per 10,000 of the population aged 18-64) were admitted to long term residential or nursing care in the six months up to Sept 2001. However, data on how many are being supported at any one time is not easily available.

With regard to people with sensory disabilities in England, there are registers and Department of Health publications indicate that there were 157,000 people who are blind or visually impaired on the register in 2003. In 2004 there were 55,000 who were deaf or with hearing impairments on the respective register.

Concerning those with mental health problems, there is little information on prevalence. It is known that in 2005-2006 there were 47,400 detentions under the mental health act (1983). The Kings Fund is currently working on a project looking at the numbers of people with mental health problems in England [http://www.kingsfund.org.uk/current_projects/review_of_mental_health_funding/index.html](http://www.kingsfund.org.uk/current_projects/review_of_mental_health_funding/index.html).

With regard to those with intellectual disabilities, there is some conflicting information. The Department of Health white paper “Valuing People” (2001) estimated that there were 210,000 people with severe and profound intellectual disabilities in England (with approx 65,000 children, 120,000 adults of working age and 25,000 older people). It was also estimated that there were 1.5 million people with mild to moderate intellectual disabilities. However, in 2004 research work by Lancaster University estimated that there were approximately 985,000 people of which 796,000 were over 20 years old; and in more recent figures published by the Department of Health suggest that there are 55,000-75,000 children with a moderate or severe learning disability in England. As can be seen, different distinctions have been used over the years and so the picture remains unclear – there is no one source of statistical information on intellectual disability in England. However, it is thought that only 20% of people with learning disabilities are known to learning disability services so statistics which use the number of people receiving services, are very much an underestimation.
One of the facts which is relatively clear is that the number of adults with intellectual disabilities is likely to increase and it is predicted that the number aged 15 and over will increase by 11% between 2001 and 2021. Those over 60 are estimated to increase by 36%. (Institute for Health Research, Lancaster University, 2004 – see [www.learningdisabilities.org.uk/information/learning-disability-statistics](http://www.learningdisabilities.org.uk/information/learning-disability-statistics) for a summary).

In Scotland the main learning disability policy guidance, “The same as you?” (Scottish Executive, 2000) estimated that “in Scotland, about 20 people in every 1,000 have mild or moderate learning disabilities and 3 – 4 people in every 1,000 have severe or profound learning disabilities. About 18,000 adults with learning disabilities are currently known to Local Authorities in Scotland”. (page 4, Health Needs Assessment Report – Summary: People with Learning disabilities in Scotland, 2004 [http://www.gla.ac.uk/departments/psychologicalmedicine/UAP%20in%20Learning%20Disabilities/LDSummary.pdf](http://www.gla.ac.uk/departments/psychologicalmedicine/UAP%20in%20Learning%20Disabilities/LDSummary.pdf)) However, as this report points out, there are no detailed studies specific to Scotland on which to base estimates.

In Northern Ireland ([http://www.northernireland.gov.uk/news/news-dfp/news-dfp-july-2007/news-dfp-050707-survey-of-people.htm](http://www.northernireland.gov.uk/news/news-dfp/news-dfp-july-2007/news-dfp-050707-survey-of-people.htm)) the recent survey highlights the extent of some form of disability (including long term illnesses and conditions). 21% of adults (and 6% of children) are thought to have some form of disability affecting activity levels (recent populations estimates of 1.75 million people in Northern Ireland). Of course, the definition used here is very broad (and much broader than the definitions generally used in this study).

The Review of Mental Health and Learning Disability report (2005), entitled Equal Lives, stated that over 16,366 people with a learning disability are known to services. Of these it is estimated that 4,468 people have a severe to profound disability. Almost half of the total number known are children and young people aged up to 19 years ([http://www.rmhldni.gov.uk/index/published-reports/learning-disability-report.htm](http://www.rmhldni.gov.uk/index/published-reports/learning-disability-report.htm)).

Overall within the UK, it is estimated that approximately 2% of the population has an intellectual disability. But similar figures are not available for those with mental health problems or those with physical disabilities.

### 7. Residential Services for people with a disability

#### 7.1 Overview

The pattern of service provision in the UK has changed dramatically since 1970 as provision moved from mainly institutional provision to largely community care and independent living solutions. The shift occurred more quickly in England and Wales than in Scotland and Northern Ireland.

The majority of provision is in small group homes in the community, although there still exist some larger services (mainly private and voluntary sector). Supported living and the use of personal assistants is becoming more and more common in the UK and most people with physical disabilities are now supported to live in their own home. More and more older people are also supported to stay at home for longer, so that it is only the most severely disabled or ill or those with no family to advocate for them, who end up in residential care. People with less severe mental health problems are
also generally provided for within their own homes, although again those with more severe problems and those who are considered dangerous to themselves or others are still hospitalised in general.

With regard to people with intellectual disabilities the Foundation for People with Learning Disabilities (www.learningdisabilities.org.uk/information/learning-disability-statistics) suggest that approximately 60% of adults with a learning disability live with their families. According to Department of health publications (Valuing People – what do the numbers tell us, 2005), 39,500 people in England with intellectual disabilities live in care homes and hospitals, which is about one third of those known to learning disability services. Approximately 11,000 of these are thought to live “out-of-area” – i.e. away from their home area. In addition 34,000 people with learning disabilities are reported to be receiving help from support workers paid for by the Supporting People programme (designed to help people live in their own homes) and are living in hostels or shared housing owned or rented by themselves or housing agencies, not by the organisations providing the support.

With regard to direct payments, the state of Social Care report (CSCI, 2006, http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf) notes than in England there has been a substantial increase in the number of people receiving direct payments, with expenditure on direct payments almost doubling between 2004 and 2006. At 31 March 2005, the report notes that there were 22,000 people in England using a direct payment, which was a 57% increase from the year before. By 31 March 2006 this had risen to 32,000. The majority of people using direct payments are younger adults with physical and sensory disabilities. There has been a three-fold increase in direct payments to young people and their carers and although there was an increase in the number of older people receiving direct payments, the number of older people receiving direct payments remains very small. Despite the overall increase in number of people receiving direct payments, the total expenditure on direct payments amounted to only £1 in every £100 spent, implying that the majority of funds is still spent on residential care and perhaps that only those with lower levels of need are receiving direct payments. The postcode lottery within England also comes into effect here, with more than half of all local authorities in England providing 10 or less direct payments at the end of March 2005.

In Scotland current statistics for 2007 identify 2291 people receiving a direct payment - over ½ of these are people with physical disability and about ¼ people with and intellectual disability (http://www.scotland.gov.uk/Publications/2007/09/24155213/0). There were 570 people in Wales using direct payments in 2004.

The sections below will review the types of residential services available for children and adults with disabilities, along with information about the size and frequency of such places where available. Services across the four regions are very similar, however, were differences arise, these will be highlighted.

7.2 Services for children with a disability

With regard to children’s services, the State of Social Care report outlines that council expenditure in England has increased overall in recent years with the biggest increase in the areas of adoption and family support services and the smallest increase in
residential care. Between 2003-2004 and 2004-2005, there was a slight decrease in the number of children in residential children’s homes and hostels from 6800 to 6,700, down from 6,800 in 2003-04. Over the same period, the proportion of looked after children cared for in residential settings, including secure units, homes, hostels and residential schools, remained at 13%.

Between March 2005 and March 2006, the number of children’s homes in England has risen by 40 to 2,025 homes, providing 11,649 places, representing an increase of 289 places. However the majority of these homes (53%) were for children with emotional or behavioural problems, with 29% of homes registered for children with intellectual disabilities and 12% for children with physical disabilities. In general children with disabilities are supported to live with their families were possible and carers are now eligible for much more support than previously through a carers assessment. Young people can now receive direct payments, which can be paid to family carers. Residential care is in general only used for children with disabilities who have been abandoned by their parents or who have been taken into care for their own protection. Where possible children are placed with foster families but some children do spend large portions of their childhood in a children’s care home. These homes are usually quite small in nature – usually about 6 places – and tend to serve children between 10 and 15 although they do take younger children.

In addition, those with complex needs such as autism, challenging behaviour or very profound intellectual or physical disabilities sometimes access residential schools of varying intensity. However, only approximately 1000 children attend 52 week schools in England and Wales – the majority of children attend schools where they go home for the holidays and in some cases for the weekends too. 9176 children attend some form of boarding school, approximately 6000 of these are in maintained and non-maintained schools (i.e. supported by local authorities in some way), the remainder in schools run by the independent sector. Of the 6000 children attending residential schools, over 2000 of these have emotional and behavioural disorders and approx 1700 have a physical disability. 985 have an intellectual disability and 522 have autism (Department for Education and Skills/Department of Health, 2004).

In addition, in England, there are 835 children in NHS provided accommodation – these are almost entirely children with physical and sensory disabilities, with only 26 places for children with intellectual disabilities and 17 for children with mental health problems (www.performance.doh.gov.uk/hospitalactivity/).

### 7.3 Services for adults with a disability

As highlighted above, the majority of adults who receive support from local authorities, do so in residential care, although there has been a decrease in recent years, with the total figures of people supported in England standing at 267,240 in 2004-2005. In terms of the balance of expenditure across groups, local authorities spent 58% of their budgets on older people, 9% on people with physical or sensory disabilities, 24% on people with intellectual disabilities and 7% on people with mental health problems (http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf). However, in terms of the proportion of people supported in residential care the proportions are similar to the expenditure, with 77% of the people supported being
United Kingdom

over 65, 13% people with intellectual disabilities, 5% people with mental health problems and 4% people with physical or sensory disabilities.

At the end of March 2006, there were 18,718 registered residential care homes for adults in England, providing 441,335 places. Although the number of registered places has risen by 449, there are now 315 fewer homes than at the end of March 2005. This change represents both the decline in the number of residential services registered with CSCI but the gradual increase in the size of homes (http://www.csci.org.uk/pdf/state_of_social_care_05-06_1.pdf). The most recent figures (March 2006) put the average size of home registered for people over the age of 65 at 34 places, with the average size of residential care home for younger adults ranging from nine places for homes for people with learning disabilities to 45 places for homes for people who are terminally ill. The majority of services are run by the independent sector. Statistics on Wales, Scotland and Northern Ireland are outlined in section 7.4 below.

In general across the UK, the same types of services exist for younger and older adults – as the template data summarised at the beginning of this report illustrates, there are small group homes, residential care homes and nursing homes for people of all ages. However, in general small group homes are more widely available for younger people. Where they are available for older people they tend to be for people with intellectual disabilities. Residential colleges also tend to be for younger adults with intellectual disabilities and usually those aged between 16 and 25, although a few colleges have places for slightly older adults. These colleges vary in design, with some being organised within one large college building and others more in a campus setting where each of the small homes in which people live are dispersed in the area around the college building and are registered separately as care homes but with the educational element integral to the package.

The same is true for village communities. These services usually take the form of a number of smaller homes within the same setting, with day activities (education (school and college), leisure and other day activities such as craft workshops, gardening workshops) also provided on site. In general each of the houses in the community are registered separately. In some of the village communities, there is one bigger house and then several satellite homes. Many of these communities in the UK are based on a particular religious basis but do take people from all backgrounds. They vary in size but are usually between 11 to 30 places on one site (Emerson et al, 1999). In general village communities are provided only for people with intellectual disabilities. In some of these communities (e.g. L’arche) staffing is provided through a number of core permanent staff plus volunteers from overseas who live in the homes with the users of the service but usually only for between 6 months and 2 years.

Therefore in general, statistics don’t separate out village communities, residential colleges, small group homes, residential care homes or nursing homes – homes are registered with CSCI in England (and CSSIW in Wales) under just two categories – care home or care home with nursing. These two categories are used for homes registered for younger adults as well as for homes for older adults. A small number of homes in England are dual registered for younger and older people (providing just over 2000 places).
By far the greatest number of places in residential care is for those who are over 65 (mostly people without a pre-existing disability). At the end of March 2006 in England, there are 11,085 residential care homes registered with CSCI providing 57,587 places for people with learning disabilities, 97,580 places for people with physical and sensory disabilities and 39,210 places for those with mental health problems. In contrast, there were 12,215 care homes registered for older people, providing 169,919 places for those over 65.

In addition to social care services, there are several types of NHS provided and funded services:

1. Learning disability hospitals, in their old form, have all but disappeared now in England and Wales, and are reducing in Scotland and Northern Ireland. These were old style hospitals and which have impoverished environments and generally poor standards of care. However, there also are some newer NHS provided hospitals which replaced these in the early days and although smaller they suffer from many of the limitations of the larger settings. Within England there are targets to close these newer settings by 2010. Many for these newer NHS settings take the form of residential campuses in which there are currently approximately 1600 people.

2. NHS campuses are newly built residential campuses that have been developed to provide support and services on a centralised campus site, typically supporting people with more severe disabilities. Usually up to 100 persons are housed in living units for 8-10 people. Currently at least 1600 people who have a learning disability live in NHS campuses. Many campuses are in the South East, but most regions in England have people living in campuses.

<table>
<thead>
<tr>
<th>Strategic Health Authority</th>
<th>Campus-Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>South West</td>
<td>317</td>
</tr>
<tr>
<td>South Central</td>
<td>123</td>
</tr>
<tr>
<td>South East Coastal</td>
<td>101</td>
</tr>
<tr>
<td>London</td>
<td>250</td>
</tr>
<tr>
<td>Eastern</td>
<td>254</td>
</tr>
<tr>
<td>East Midlands</td>
<td>260</td>
</tr>
<tr>
<td>West Midlands</td>
<td>195</td>
</tr>
<tr>
<td>Yorkshire and Humber</td>
<td>37</td>
</tr>
<tr>
<td>North East</td>
<td>66</td>
</tr>
<tr>
<td>North West</td>
<td>6</td>
</tr>
<tr>
<td>Totals</td>
<td>1609</td>
</tr>
</tbody>
</table>

3. NHS Psychiatric hospitals and wards. Little collated information is available about the size or characteristics of psychiatric hospitals. However, in general these are quite big. In addition to psychiatric hospitals, there are mental health services in the community provided by the NHS, although these are relatively rare. There are also NHS provided assessment and treatment units which although intended for short-term care, often provided longer term accommodation and support for those with challenging behaviour.

4. Private hospitals and assessment and treatment units. Although these services are intended for those with mental health needs, substantial numbers of people
with intellectual disabilities and challenging behaviour are treated in these settings. These services tend to be bigger than community based services.

5. Secure units/forensic hospitals/special prisons. People who are considered dangerous or who are offenders are usually placed in these types of locked settings, which are provided both by the state and by independent sector providers. They vary from smaller locked units in the community to larger units and prisons. In Scotland there remains one larger forensic hospital providing for over 150 people.

7.4 Regional variation in arrangements/service types

7.4.1 Wales
As for England, information is more readily available on intellectual disabilities than other groups. There are just over 12,000 people an intellectual disability in Wales, but the numbers of those who are described as resident in hospital is now only 170, and 65% of these stayed in hospital in excess of 2 years. (http://new.wales.gov.uk/topics/statistics/headlines/health-2007/hdw200701316/?lang=en). As in England, the types of residential accommodation have varied over time and across localities. The moves to community-based housing for people with more severe and complex disabilities (initially in units of 20-24 persons) has given way to services in smaller scale, more domestic units, and, in a parallel development, to those in other kinds of settings such as village communities (operated by charitable organisations), residential campus-style accommodation (operated by NHS), dispersed housing schemes (24 hour support in domestic-style housing) and supported living schemes. The latter only forms about 2% of overall provision, smaller homes with 2-6 people are usually newer homes (and new builds) and this form of provision is the largest single type (Welsh Assembly Government, 2003).

CSSIW regulates care homes, domiciliary services, adult placements and nurses agencies in Wales. They predict that in the next 15 years the numbers of people aged 65 and over will be 28% of the population of Wales, and those over 85 will total 82,000. Some psychiatric hospitals in Wales deal with both mental health problems and learning disabilities and statistical returns include data on both areas. Of people with long-term illness, 1 in 4 report mental health problems. Levels are higher in women than men and there are regional variations. The highest hospital admission rates are for over 75s. In 2000/2001 2, 185 of those over 75 in hospital were described as “resident” patients.

7.4.2 Scotland

Again, as for England and Wales information on learning disabilities is the most prevalent. Statistics on mental health are usually included in general statistics about Britain (http://www.mentalhealth.org.uk/information/mental-health-overview/statistics/).

However, it is known that Scotland has 830,000 people with a physical disability, of which 96,000 are wheelchair users registered with the NHS.
With regard to intellectual disabilities, there are approximately 120,000 people with intellectual disabilities in Scotland, 25% of whom were under 15 years of age and 25% of whom were described as having complex needs (NHSQIS, 2006).

As reported earlier, over 18,000 adults with learning disabilities are known to local authorities in Scotland although this includes those who attended day services. 23% of adults known to local authorities were thought to be living independently. About 60% of those known to services were men (10,002) and this was true for younger age groups but not for those over 65, where the gender split was almost 50:50 (n=1777).

As noted above, progress with hospital closures and development of community services was slower in Scotland than in England or Wales. By 1999 only one long-stay hospital had implemented a closure plan (Whoriskey, 2003). The Same as You? review (2000) highlighted that 37% of expenditure goes on hospitals for people with intellectual disabilities (compared to 15% in England). As might be expected, the contrast is that only 58% of health spending goes through local authority community care services, compared to for example 74% in Wales.

Since 2004, the NHS Quality Improvement Scotland (NHSQIS) and The Scottish Commission for the Regulation of Care have worked together in monitoring services provided by private sector organisations and contracted by the NHS. The NHSQIS review found that by the end of 2005, 11 of the 19 long-stay hospitals for people with LD in Scotland were closed down and their services re-provided in the community leaving 165 long-stay residents and 106 people on longer term assessment and treatment places in the remaining 8 NHS hospitals that were planned to close by the end of 2007 (although there remain some long-stay residents, predominantly those with forensic needs, people with autistic spectrum disorders, those with severe challenging behaviour or complex physical needs, in NHS assessment units). The remaining hospitals have been described as “in need of refurbishment”, although most of the people remaining in hospital have single-bedded rooms. (Stalker & Hunter, 1999; Hunter & Stalker, 2003; NHSQIS (Scotland), 2006).

In Scotland, care homes are identified as being primarily intended for one client/user group, but it is possible that residents in any one home could come from other client groups. Private nursing homes are registered under the terms of the Private Nursing Home Registration (Scotland), 1938 or the Mental Health Act 1960/1984. Information on nursing homes is supplied on a census date once a year to ISD (Scotland) (Scottish Executive, 2004).
7.4.3 Northern Ireland

Community Statistics for Northern Ireland for 2006-2007, provide detailed information on the numbers of people in receipt of packages of care, the nature of those packages and the number of residential services for different groups (http://www.dhsspsni.gov.uk/community_statistics_06-07.pdf). The table below summarises the information provided in the report.

<table>
<thead>
<tr>
<th></th>
<th>Total known to services</th>
<th>Number receiving home help or meals</th>
<th>Number benefiting from care management</th>
<th>Number supported at home</th>
<th>Number supported in nursing homes/residential homes</th>
<th>Number of residential and nursing homes and places.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older people</td>
<td>40,852</td>
<td>19599 home help 6058 meals</td>
<td>15194</td>
<td>5610</td>
<td>6444 in nursing homes (almost all private) 3141 in residential homes (mixed statutory and private with a small number of places in voluntary providers) 189 homes for elderly people with 3945 places</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems</td>
<td>14990</td>
<td>403 home help 189 meals</td>
<td>1273</td>
<td>477</td>
<td>337 in nursing care (all private providers) 459 in residential care (mixed private and voluntary) 47 residential homes solely for MH, providing 602 places</td>
<td></td>
</tr>
<tr>
<td>People with physical or sensory disabilities</td>
<td>2110/327 4 blind/partially sighted 443/452/5775 deaf with/without speech/hard of hearing 7651, general physical disabilities</td>
<td>1889 home help 263 meals</td>
<td>1543</td>
<td>1132</td>
<td>323 in nursing care (almost all private) 88 in residential care (mixed pattern of provision but 50% private). 4 residential homes solely for people with PSD, with 64 places</td>
<td></td>
</tr>
<tr>
<td>People with intellectual disabilities</td>
<td>9459</td>
<td>755 home help 74 meals</td>
<td>2555</td>
<td>1071</td>
<td>835 in residential care (mixed pattern of provision) 649 in nursing 75 homes solely for ID, with 1005 places</td>
<td></td>
</tr>
</tbody>
</table>
### United Kingdom

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total homes (almost all private)</td>
<td>51,306</td>
</tr>
<tr>
<td>23,913 home help (18,769 of these people were not disabled – mainly older people, 1267 of these were under 65) 6670 meals (5128 not material disability, 88 were under 65)</td>
<td>20723</td>
</tr>
<tr>
<td>4526 in residential care 7768 in nursing care</td>
<td>8429</td>
</tr>
<tr>
<td>329 residential homes homes, 5558 places 252 nursing homes, 9571 places</td>
<td></td>
</tr>
</tbody>
</table>
In terms of people with an intellectual disability there is additional information through research. An estimated 440-470 live in long-stay hospitals (of which there are 4), 1,900 in residential care and nursing homes and 14,000 in community setting (McConkey, 2003). In NI the proportion of people with ID living with their families is 61.9% (as compared to 44.1% in the Republic) and the number living in residential care is correspondingly significantly lower in NI compared to their counterparts in the Republic (McConkey, 2007).

In Northern Ireland the pattern of care followed the British model of creating state-managed, long-stay “specialist” hospitals for people with “mental handicap” as the main alternative to family care. Many of these hospitals were opened from the 1950s onwards, in 1962 there were over 1800 persons resident in Northern Ireland (Scally & Mackay, quoted in McConkey, 2007). By the 1980s de-institutionalisation became an accepted policy and in recent years large numbers have been resettled but a sizable number (many under 65) remain. In Northern Ireland, 61% of people on the database were in “special settings”, 20% in ordinary housing and 19% in hospital settings (McConkey, 2007).

In NI the main model of special provision is based on registered nursing homes or registered care homes. The private and voluntary sector provide 65% of available places in residential accommodation (In 2007 private accounted for 60%, not-for-profit, 20%, statutory 12% and Housing Associations 8%). These homes have an average of 19 residents and are located mostly in community settings. There are also a number of “village communities” set in rural areas and managed by a voluntary agency. In NI increasing numbers of people reside in supported living arrangements in which they hold the tenancy to a house or apartment which they might share with one or two others. Some of these units are clustered in one area to facilitate staffing arrangements. State-managed hospital accommodation generally consists of dormitory-style wards accommodating up to 20 people with nurses and nursing assistants as the principal carers (Mooney et al., 2004; Mulvaney et al., 2007). There are variations in provision of services between NI and the Republic which can only be explained on the history of services, the philosophy and preferences of providers and the availability of funding arrangements rather than on any determination based on the needs of the recipient (McConkey et al., 2006).

8. Other relevant information on services for people with disabilities
There is substantial research originating in the UK on the quality of services, especially for people with intellectual disabilities, comparing different services models and documenting the quality of people’s lives living in services. In general smaller homes in the community have generally better outcomes than larger group homes which have generally better outcomes than institutions (Emerson and Hatton 1994). Newer paradigms such as supported living have also been found to have positive outcomes for people although there are also some risks which have to be managed (Emerson, Robertson et al. 1999). However, previous research has shown that outcome in terms of the quality of people’s day to day lives is variable within settings and therefore more recent research has focused on what is important in
ensuring a good outcome for those living in services. This work has concluding that once resident ability has been taken into account, the most important factor is staff care practices – i.e. how staff interact and support people minute by minute (Hatton, Emerson et al. 1996; Felce, Lowe et al. 2000; Felce, Jones et al. 2003; Mansell, Beadle-Brown et al. 2003).

Other important factor in provision within the UK, has been a recent emphasis on person-centred approaches, in particular person-centred planning and person-centred action such as active support (Department of Health 2001; Robertson et al, 2005; Mansell, Beadle-Brown et al. 2005). Whilst this work originated with a focus on intellectual disability, the general approaches are felt to be applicable to people with physical and sensory disabilities and mental health problems. However, in contrast to people with intellectual disabilities, there is much less research or guidance available on good practice for services providing support for people with PSD or mental health problems.

9. Staffing

Data for staffing of residential care in the UK is limited and provides little information about conditions at unit level. There is limited published information on overall numbers of staff, with some indications of the percentages of trained versus untrained staff, but this is not broken down at unit level. There are also figures for the total numbers of different professional groups, but no indication of the numbers of each grouping at individual locations. Council-run accommodation retains some records particularly whose homes that provide for children (Local Authority Workforce Intelligence Group, Social Care Workforce Study, 2006, No. 36; Adult, Children and Young People Local Authority Social Care, 2006), but otherwise only global figures of numbers of staff employed are available.

In terms of staff training, the majority of social care staff are untrained when they first start to work in services. In 2000 it was identified that 75% of staff in social care services have no formal education (Topss England, 2000). In the past 15 years, National Vocational Qualifications in Care have been introduced and services are now expected to support all staff to go through these qualifications. However, these qualifications are rather general in nature and there remain a large number of staff who are unqualified. Even within the NHS based services, whilst there will, by necessity, be more nurses in senior and team leader positions, there are still large numbers of unqualified staff employed. The Sector Skills Council: Skills for Care and Development set the agenda and issue guidance for training and support of staff in care positions (http://www.topssengland.net/view.asp?id=36).

Recruitment of staff is a problematic issue in many social care services in many parts of the UK, especially where unemployment rates are low – social care jobs are not paid particularly well, there are few opportunities for advancement and opportunities for personal development are also often limited by budgetary considerations. Attracting people of high calibre, with good qualifications can be difficult. Many services especially those in London and the South East of England, employ staff other parts of the world. This can lead to difficulties with communication and also cultural adaptation.
10. Costs

The UK is fortunate in having relatively good literature on cost issues related to community and social care costs going back over 25 years, particularly with regard to mental health re-provision and the hospital closure programme dating back to the 1980s (more detailed information on costs and outcomes within England in particular is provided in the main report). As illustrated above information on expenditure in social care in particular is readily available in reports and statistically summaries such as the “State of Social Care” reports. In addition there is a long tradition of research in this area, including the mapping and evaluation of care management arrangements for people with mental health problems in England (Venables et al., 2006); costs, quality and outcomes (Hallam et al., 2002; Netten et al., 2005, 2006); the financing of care for older people (Wittenberg et al., 2006); mental health economics and policy (Moscone, 2005); and valuing social service outcomes (Burge et al., 2006).

11. Issues

11.1 Regional variation
Variations between the 4 constituent countries of the UK has already been illustrated above. However, as also issued there can be variation in the nature, amount and quality of services available between local authorities or health authorities within each of the countries – this is often referred to as the “postcode lottery”, implying that what services are available to you can depend on where you live.

11.2 Issues related to ethnicity
Within mental health services in particular, there are substantial numbers of people from black and minority ethnic (BME) backgrounds. Department of Health publications put the ratio of BME users of mental health services at 1 in 5, which is substantially more than one would expect from the general population. The department of health has published guidelines on working with people from BME backgrounds in order to combat inequalities in service provision. (http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Mentalhealth/BMEmentalhealth/index.htm).

There are also similar issues for people with intellectual disabilities – work by Mencap, for example, has highlighted that people from BME backgrounds with an intellectual disability experience double discrimination due to language and cultural differences (http://www.mencap.org.uk/html/ethnicity/reaching_out_report.asp). Research by Emerson et al (1997) illustrated that prevalence of severe intellectual disabilities was three times higher in Asian families than non-Asian families (See http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=34865).

12. Acknowledgements

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Thank you to Agnes Kozma for proofreading and help with formatting this country.
13. Information sources on disability used to compile the template and commentary.

Department of Health (2006) Hospital Activity Statistics - Residential Care Beds


Annual Reviews in Independent and Non-Maintained Special Schools
http://www.scrip.uk.net/


The Learning Disability Implementation Advisory group (Wales)
http://www.ldiag.org.uk/information/archive/archive.html

14. References


Curtis, L., A. Netten (eds) The Unit Costs of Health and Social Care 2005. PSSRU, University of Kent, Canterbury


Local Authority Workforce Intelligence Group. Social Care Workforce Study, 2006, No. 36 Adult, Children and Young People Local Authority Social Care, 2006 (http://www.lga.gov.uk/Documents/Briefing/Our_Work/Projects/workforcesurvey.pdf)


Welsh Assembly Government (2001) Fulfilling the Promises
