

# Scotland: 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.**

**November 2010**



# **Health and Personal Social Services for People with Disabilities in Scotland**

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## 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. A composite report setting out key learning from across the six jurisdictions is also available ([www.nda.ie](http://www.nda.ie)). 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](http://www.nda.ie).

**Table 1: Population of Jurisdictions**

	Ireland	England	Scotland	Netherlands	Norway	Victoria	N. Zealand
<b>Total Population</b>	4.24m	51.5m	5.14m	17m	4.8m	4.9m	4.4m
<b>Ratio to Ireland</b>	1	12.1	1.2	3.9	1.1	1.2	1.0

## 2. Population

### 2.1 Population with a disability

The 2001/2002 Scottish Household Survey estimated that just under one in five adults in Scotland have a disability and/or a long-term illness with 18 per cent of men and 19 per cent of women reporting that they have a disability and/or a long-term illness.<sup>1 2</sup>

**Table 2. Population with a disability**

Type of Disability	Population
People with physical disabilities	830,000 <sup>3</sup>
People with visual impairments	23,000 <sup>4</sup>
People with partial sight	15,2000 <sup>5</sup>
People with learning disabilities	25, 200 <sup>6</sup>

Table 2 above sets out reported figures on levels of types of disability in Scotland. The Scottish Health Survey suggests that those with a 'high score' on the General Health Questionnaire in relation to mental health problems amounted to some 13% of men aged 16-64, which was constant between 1995 and 2003. For women, however, there was a reduction from 19% to 17% during the same period<sup>7</sup>.

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<sup>1</sup> Social Focus on Disability (2004) Scottish Government  
<http://www.scotland.gov.uk/Publications/2004/08/19818/41699#1> accessed 28 October 2010

<sup>2</sup> This prevalence rate is similar to the findings of Ireland's National Disability Survey when the false negatives are considered.

<sup>3</sup> <http://www.momentumscotland.org/web/News%20Centre/Factsheets/Physical%20Disability>

<sup>4</sup> Scottish Executive National Statistics Publication (2005) Statistics Release. Registered Blind and Partially Sighted Persons Scotland 2005.  
<http://www.scotland.gov.uk/Publications/2005/09/3090610/06119>

<sup>5</sup> *ibid*

<sup>6</sup> Statistics Release:(2008) Adults with Learning Disabilities Implementation of 'The same as you?' Scotland 2008 <http://www.sclid.org.uk/sclid-projects/esay.xhtml>

<sup>7</sup> Scottish Executive (2006c) High level summary of Statistics. According to the Scottish Executive report "Psychosocial health is measured in the Scottish Health Survey by the General Health Questionnaire ( GHQ12). This is a widely used standard measure of mental distress and psychological ill-health. Overall scores ranged between 0 and 12. A score of four or more indicates the presence of a possible psychiatric disorder, whilst a score of zero could, in contrast, be considered to be an indicator of psychological well-being. The proportion of men with high GHQ12 scores (4+) has remained constant over time at 13%, while it declined slightly for women, from 19% in 1995 and 1998 to 17% in 2003. However, there is a marked increase in the numbers with zero scores, for males this increased from 60% in 1995 to 68% in 2003 and for females this increased from 55% in 1995 to 61% in 2003."

### 3. Health and Social Services for People with Disabilities

**Table 3. Organisational Structure of Disability Services in Scotland**

<b>Government Body</b>	<b>Function</b>
<b>Department of Health and Wellbeing (3 ministers)</b>	Responsible for supervising Scotland's health service and provision of health, social and housing services for people with disabilities
<b>*Strategic Board, Director General, Health and Chief Executive of NHS Scotland, Head of Health department</b>	Reports to the Minister on performance of health services. Supervises management of NHS Scotland and 14 NHS boards
<b>Scottish Health Department (10 directorates)</b>	Report to the Director General. Responsible for developing and implementing health and community care policy; 14 NHS boards and 8 special NHS boards which deal with central functions across the 14 NHS areas <sup>8</sup>
<b>Territorial NHS boards (14) Special NHS Boards (8)</b>	Report into the Health department via the directorates. Responsible for delivery of front line health services. Support the NHS boards by providing necessary services
<b>Community Health Partnerships (CHPS) (40)</b>	Report into NHS boards. Manage the primary and community health services. They provide a focus for the integration between primary care, specialist services and social care
<b>Local authorities (32)</b>	Report to Government through the Convention of Scottish Local Authorities (COSLA) <sup>9</sup> . Responsible for providing services including assessment of need for disability benefits and services for people with disabilities in their community. Work with CHPs to provide health and community care services to local population <sup>10</sup>

\*Representatives on Scotland's Strategic board are the equivalent of Ireland's Secretary General.

#### 3.1 Overview of Service Provision System

##### The Department of Health and Wellbeing

The Ministry of Health and Wellbeing funds supports for people with disabilities that are delivered through the Scottish Health Department, NHS

<sup>8</sup> See Appendix for further details

<sup>9</sup> COSLA, the Convention of Scottish Local Authorities, is the representative voice of Scottish local government and also acts as the employers' association on behalf of all Scottish councils. <http://www.cosla.gov.uk/index.asp?leftId=10001DE74-10766726>

<sup>10</sup> [http://www.adviceguide.org.uk/scotland/your\\_rights/civil\\_rights\\_scotland/local\\_government\\_services\\_scotland.htm#Local\\_authority\\_services](http://www.adviceguide.org.uk/scotland/your_rights/civil_rights_scotland/local_government_services_scotland.htm#Local_authority_services)

boards, CHPs and local authorities. The Department of Health and Wellbeing has ultimate responsibility for the operation and monitoring of Scotland's health system and for supervising the provision and evaluation of health and personal social services, including housing for people with disabilities.

### **Director General and Scottish Health Department**

The Director-General of Health/Chief Executive of the NHS Scotland and the Scottish Health Department report into the Department of Health and Wellbeing on the progress of the health services and various bodies such as the NHS boards and the Community Health Partnerships (CHPs).

### **National Health Boards**

In Scotland, regional NHS Boards are responsible for providing and managing the range of health services in their areas including hospitals and primary care. These Boards also provide strategic leadership and performance management for the entire local NHS system in their areas <sup>11</sup>.

The 8 Special NHS Boards support the 14 NHS boards by providing essential services such as ambulance services, 24-hour telephone access. See Appendix 1 for further information about the services provided by these special NHS Boards.

### **Community Health Partnerships**

In 2004 the Scottish government dissolved the NHS Trusts (which still exist in the English system) and their responsibilities and duties reverted to the NHS Boards<sup>12</sup>. The CHPs were created by the NHS to:

- Manage the primary and community health services
- Modernise the NHS and joint services
- Play an important role in partnership, integration and service redesign.

The CHPs provide a focus for the integration between primary care, specialist services and social care. They are part of the Scottish government's initiative to create a single system to ensure that the health needs of each community is at the core of service planning and delivery<sup>13 14</sup>.

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<sup>11</sup> NHS Scotland website <http://www.show.scot.nhs.uk/introduction.aspx>

<sup>12</sup> Public sector, ICT, e-government news & jobs website  
<http://www.publictechnology.net/modules.php?op=modload&name=News&file=article&sid=844>

<sup>13</sup> Community Health Partnerships. <http://www.sehd.scot.nhs.uk/chp/>

<sup>14</sup> Goodwin et al; (2008) Country Case study UK. Primary Care in England and Scotland. Paper presented at Conference on Improving primary care in Europe and the US: Towards patient-centered, proactive and coordinated systems of care, Italy.



This single system ethos is also designed to implement shared aims, common values and clear lines of accountability, in addition to breaking down traditional barriers between primary and acute care.

To achieve this objective the CHPs work with the 32 local authorities in Scotland, in addition to members of the voluntary sector, clinical and care teams, the public, patients and carers<sup>15</sup>. CHPs influence how NHS boards disseminate their resources<sup>16</sup>.

The establishment of managed clinical networks for a wide range of long-term conditions is seen as an effective means of promoting integration and cross-boundary working with social care integration of these services. The CHPs provide a diverse range of community based health services such as: health visiting, district nursing, speech and language therapy, physiotherapy and providing services for people with mental health issues. These services are delivered in homes, health centres, clinics and schools, through a co-ordinated set of partners. Staff providing these services to people in their community may work in consultation with dentists, pharmacists and opticians (on UK-based national contracts), to plan and develop services across the CHP area.

CHPs have separate systems for the governance and financial accountability of services for people with learning disabilities, people with mental health difficulties and people with physical disabilities, and the delivery of these services in each region<sup>17</sup>. Appendix 2 details the model of service delivery by CHPs.

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<sup>15</sup> Goodwin et al; (2008) Country Case study UK. Primary Care in England and Scotland. Paper presented at Conference on Improving primary care in Europe and the US: Towards patient-centered, proactive and coordinated systems of care, Italy.

<sup>16</sup> *ibid*

<sup>17</sup> Breakdown of CHP services provided by key informant

## Local Authorities

Scottish local authorities provide a range of services relevant to people with disabilities, including education, social work, leisure and recreation activities. The Scottish government has recognised the strategic role of local authorities in assisting them in achieving their national goals.

In 2007, the Scottish government implemented the National Performance Framework. This Framework has 15 National Outcomes to make Scotland a 'wealthier, fairer, smarter, healthier, safer, stronger and greener country'<sup>18</sup>. The Scottish government recognised that achieving these national outcomes was not possible unless progress was made at a local level via local authorities<sup>19</sup>.

To empower the position of local authorities the Scottish government and the Convention of Scottish Local Authorities (COSLA) agreed a concordat in 2007. Under this concordat:

- The Scottish government sets policy direction and the local authorities carry out service provision
- The Scottish government ended its practice of ring fencing funding to local authorities. Local authorities now have complete independence and flexibility regarding how they allocate funding to local projects that they and their partners have agreed are priorities that fit with the National Outcomes
- Each local authority through their Community Planning Partnerships developed a Single Outcome Agreement (SOA) with the Scottish government<sup>20</sup>

Community Planning Partnerships are partnerships between local authorities and organisations such as Job Centre Plus, Health Boards, education institutions, and businesses/enterprise networks. The objective of the CPPs is to bring different interests together and to involve communities in dealing with issues such as poverty and health inequalities. They provide the link between local authorities and other agencies in aligning national priorities with local priorities. There is no information about the number of CPPs in operation in Scotland but they operate in all 32 local authority areas<sup>21</sup>.

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<sup>18</sup> Scottish government Spending Review (2007)  
<http://www.scotland.gov.uk/Publications/2007/11/13092240/9>

<sup>19</sup> Improvement Services Website <http://www.improvementservice.org.uk/single-outcome-agreements/>

<sup>20</sup> *ibid*

<sup>21</sup> Scottish government website : Community Planning section  
<http://www.scotland.gov.uk/Topics/Government/PublicServiceReform/community-planning>

An SOA is defined as:

"The means by which CPPs agree their strategic priorities for their local area and express those priorities as outcomes to be delivered by the partners, either individually or jointly, while showing how those outcomes should contribute to the Scottish Government's relevant National Outcomes<sup>22</sup>".

Local authorities play a facilitation role in the CPP, but all partners have to sign an SOA.

### 3.2 Governmental Strategy on Disability in Scotland

Scotland's Disability Equality Scheme 2008-2011 sets out the government's legislative and strategic commitment to mainstreaming i.e. embedding disability equality across all of the government departments<sup>23</sup>.

#### Access to services

The Scottish government has published a range of guidance i.e. **Good practice: Equality for disabled people in the NHSiS: access to services (1999)**, the **Partnership for Care White Paper (2003)** to support healthcare providers and local authorities in making their services more accessible to people with disabilities.

The **Better Health and Better Care Action Plan (2007)** reported that many health boards had incorporated best practice guidelines to ensure that their service were more accessible to people with disabilities:

- The appointment of specialist staff, local health promotion strategies and research projects on health issues for people with learning disabilities
- Staff in health boards and local authorities received training in disability awareness to improve the services provided to people with disabilities<sup>24</sup>
- A small number of e-learning initiatives aimed at reaching large numbers of NHS staff in remote areas such as NHS Borders and NHS Highlands

This report also contained proposals for the health system to:

- Enable people with disabilities to book more convenient and longer appointment times

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<sup>22</sup> Improvement Services <http://www.improvementservice.org.uk/single-outcome-agreements/>

<sup>23</sup> Scottish government (2008) Disability Equality Scheme 2008-2011

<sup>24</sup> Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: The Scottish Minister's Duties Health and Well Being.

- Provide written summaries of consultations and interventions in accessible formats in addition to advocacy and communication supports<sup>25</sup>

This report also stated that while some progress had been made, people with disabilities still experienced inequalities in terms of accessing and using Scotland's health care system.

Recent policy work such as the Scottish government's **Equally Well Implementation Plan (2008)**<sup>26</sup> states that providing people with disabilities with access to education and training that will enhance their employment opportunities is one way to counteract what are perceived to be inequities in the Scottish health care system. The Scottish government has created the Employability Learning Network<sup>27</sup> aimed at partners in local employability networks, NHS Boards Community Health Partnerships (CHPs), and local authorities to support education opportunities for people with disabilities.

### **Policy for People with Learning Disabilities**

The Scottish government has placed significant focus on enhancing service provision for people with learning disabilities. In 2000, the Ministry of Community Care undertook an evaluation of a broad range of services for people with learning disabilities that incorporated transportation, education, employment and health<sup>28</sup>. The Ministry of Community Care published the findings in **The Same as You?** From this report 29 recommendations were made to develop a learning disability services through a programme of change over a ten year period<sup>29</sup>. In addition a review of the implementation of the recommendations of **The Same as You (2007)** reported that:

- The number of people with learning disabilities resident in long stay hospitals<sup>30</sup> decreased by over 80% from 1,800 in 2000 to 350 in 2007

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<sup>25</sup> ibid

<sup>26</sup> Scottish Government (2008) Equally Well Implementation Plan  
<http://www.scotland.gov.uk/Publications/2008/12/10094101/5>

<sup>27</sup> Employability Learning Network  
[http://www.employabilityinscotland.com/employabilitylearningnetwork\\_1.aspx](http://www.employabilityinscotland.com/employabilitylearningnetwork_1.aspx)

<sup>28</sup> The term learning disability as used in The Same as You? report is a broad term that includes autistic spectrum disorders but not people with dyslexia, or adults with acquired brain injuries. It is defined as a life long condition that reduced ability to understand new or complex information or to learn new skills, reduced ability to cope independently; a condition which started before adulthood (before the age of 18) with a lasting effect on the individual's development. <http://www.scotland.gov.uk/ldsr/docs/tsay-12.asp>

<sup>29</sup> Scottish Executive (2000b) The same as you? A review of services for people with learning disabilities <http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

<sup>30</sup> The 1913 Mental Deficiency Act led to setting up separate institutions/hospitals for people with learning disabilities in Scotland. The Home at Last? (2004) report notes that these "learning disability hospitals" were built and some accommodated over 1000 people and they "functioned as communities with their own education, work, leisure, health and social care services." Scottish Executive (2004j) Home at last? The Same as you? National Implementation Group Report of the short-life working group on Hospital Closure and Service

- In 2007, approximately 30% of 23,000 people with learning disabilities known to the authorities lived in their own tenancies
- An estimated 32% had a Personal Life Plan<sup>31</sup>

Table 4 below provides a more detailed breakdown of the age group of adults with learning disabilities in 2008.

**Table 4. Adults with learning disabilities known to Local Authorities, 2008<sup>32</sup>**

No. of adults	Total	%of total	Rate per 1,000 population
<b>16 &amp; 17 Not at school</b>	700	2%	5.3
<b>18-20</b>	2,000	8%	9.9
<b>21-34</b>	7,100	28%	7.7
<b>35-49</b>	7,400	30%	6.4
<b>50-64</b>	5,400	22%	5.4
<b>65+</b>	2,400	10%	2.8
<b>Subtotal</b>	25,000	100%	
<b>Unknown age</b>	300		
<b>Total</b>	50,300		5.9

The Scottish Government's Disability Equality Scheme 2008-2011 states its commitment to implement the recommendations from **The Same as You?** across government departments.

In the Disability Equality Scheme the Scottish government stated that it was reviewing the issue of independent living for people with disabilities with a view to informing its policy on this matter. Although no official policy has been named independent living has been a policy issue.

In 2008, the Minister for Communities and Sport<sup>33</sup> announced a new long term policy approach to support people with disabilities to live independently in the community. A working group comprised of government officials, public bodies, and an expert panel from the disability sector was established to consider mechanisms to remove barriers to independent living in housing,

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<sup>31</sup> Scottish government (2007) Statistics Release: Adults with Learning Disabilities Implementation of 'The same as you?' available from <http://www.sclid.org.uk/sclid-projects/esay.xhtml>

<sup>32</sup> ibid

<sup>33</sup> Part of the Department of Health and Wellbeing

transport, education and employment. The Scottish government provided funding of €720,000 (£600,000) for this policy approach<sup>34</sup>.

The Scottish government's national strategy on self directed support (2009), explicitly states that independent living is one of its priorities that will require co-ordinated action across the public sector. Public bodies will be required to report to their Ministers on their progress in implementing processes that support people with disabilities to live independently<sup>35</sup>.

In January 2010, a policy on independent living called **Independent Living - A Shared Vision**, was launched by the Scottish government in partnership with the Convention of Scottish Local Authorities (COSLA) and the Independent Living in Scotland Steering Group (ILiS)<sup>36</sup>.

## 4. Housing, Accommodation and Day Services for people with disabilities

### 4.1 Residential services

Residential or care homes in Scotland are a service which provides accommodation together with nursing, personal care or personal support for adults and children who are vulnerable or in need<sup>37</sup>. People with disabilities are included in this definition. NHS hospitals are not considered to be residential homes. A person with a disability is assessed by their local authority to determine if they need to be in residential care and what their funding options are for paying for this care. There is a trend to reduce this form of housing option in favour of independent living approaches. From 2000-2008, the number of care homes in operation for people with disabilities decreased. During the same time period, the number of care homes for people with learning disabilities decreased from 386 to 312 and the number of residents dropped from 3,321 to 2,415. An increasing number of people with disabilities live by themselves in tenancies or as owner occupiers. Table 5 below details data for service users for 2008<sup>38</sup>.

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<sup>34</sup> <http://www.scotland.gov.uk/News/Releases/2008/06/24132802>

<sup>35</sup> Scottish government (2009) Self Directed Support a National Strategy for Scotland <http://www.scotland.gov.uk/Resource/Doc/301424/0094007.pdf>

<sup>36</sup> <http://www.scotland.gov.uk/Resource/Doc/935/0093260.pdf>

<sup>37</sup> Scottish government (2008) Statistical Bulletin: Health Series: Care Homes, Scotland

<sup>38</sup> Scottish government (2008) Statistical Bulletin: Health Series: Care Homes, Scotland

**Table 5. No. of people with disabilities using residential homes in 2008**

<b>Client group</b>	<b>LA/NHS</b>	<b>Private</b>	<b>Voluntary</b>	<b>Total</b>
<b>No. of care homes, learning disabilities</b>	13%	22%	65%	300
<b>No. of residents with learning disabilities</b>	11%	37%	51.5%	2,400
<b>No of care homes, physical disabilities</b>	8%	2%	73%	40
<b>No. of residents, physical disabilities</b>	4%	18%	79%	500
<b>No. of care homes, mental health difficulties</b>	6%	19%	75%	80
<b>No. of residents mental health difficulties</b>	4%	30%	66%	900

Scottish government (2008) Statistical Bulletin: Health Series: Care Homes, Scotland

### **Long Care Stay Hospitals**

One of the recommendations from The Same as You? (2000) was to close all long stay hospitals for people with learning disabilities, of which 25 existed in 2000. The NHS QIS Learning Disability Services (2006) report states that out of 19 long stay hospitals, 8 were still in use<sup>39</sup>. These hospitals were still in operation in 2007, and 350 people with learning disabilities were resident in these services<sup>40</sup>.

## **4.2 Medical and allied health services**

A range of specialist services are provided for people with disabilities, though there are efforts to promote the provision of health and allied health services through mainstream settings. In 2005, for instance, a mainstreaming team was established in the Scottish government's Equality Unit to promote and support equality issues, including disability equality, across government departments and in policies and programmes<sup>41</sup>. The Scottish government is

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<sup>39</sup> Scottish Executive (2000b) The same as you? A review of services for people with learning disabilities <http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

<sup>40</sup> NHS Quality Improvement Scotland(2006) National Overview, February 2006 Learning Disability Services

<sup>41</sup> Scottish government (2008) Disability Equality Scheme 2008-2011

focusing on mainstreaming some formerly specialist services via testing of self directed support systems and supported self assessment, and retaining other specialist services for those who are deemed to require them.

### **4.3 Housing**

In Scotland housing for people with disabilities and older people who require subsidised housing is provided by housing associations and local authorities<sup>42</sup>. The Scottish Housing Regulator (under the Department of Health and Wellbeing) was established with the purpose

"to protect the interests of current and future tenants, and other consumers of the housing and homelessness services provided by registered social landlords and local authorities"<sup>43</sup>

Local authorities also provide programmes in order to meet specific housing needs for vulnerable groups to help them continue to live in their own homes.

As noted earlier, an estimated 23,000 adults with learning disabilities were known to local authorities across Scotland in September 2007, 30% of whom are either owner occupiers or living in their own tenancies. This figure represents nearly "a third of all adults with learning disabilities and includes 7% of all 16 - 20 year olds with learning disabilities"<sup>44</sup>.

### **4.4 Assessment of Need**

The local authorities' social services departments are responsible for conducting assessment of needs for people with disabilities and the delivery of these services<sup>45</sup> and social welfare benefits<sup>46</sup>. Like England, regional variations exist in the provision of services offered in Scotland. The Learning Disability Alliance stated that in the Scottish system

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<sup>42</sup> Scottish Government (2009) Housing Statistics for Scotland 2009: Key Trends summary <http://www.scotland.gov.uk/Publications/2009/08/26141508/1>

<sup>43</sup>The Scottish Housing Regulator(2008) [http://www.scottishhousingregulator.gov.uk/stellent/groups/public/documents/webpages/shr\\_homepage.hcsp](http://www.scottishhousingregulator.gov.uk/stellent/groups/public/documents/webpages/shr_homepage.hcsp)

<sup>44</sup> The Statistics Release Adults with Learning Disabilities Implementation of 'Same as You?' Scotland 2007 (2008) is as a result of The Same as You? The aim of this report is to present the fifth set of national figures for services provided by local authorities in Scotland for adults with learning disabilities. Please note the figures for 2007 are provisional and may be subject to change and the final figures published in future publications. Available from <http://www.scotland.gov.uk/Publications/2008/03/20154612/0>

<sup>45</sup> Counsel + Care guide. Assessment and services from your local council in Scotland <http://www.firststopcareadvice.org.uk/downloads/resources/2951.pdf>

<sup>46</sup>[http://www.adviceguide.org.uk/scotland/your\\_money/benefits/benefits\\_for\\_people\\_who\\_are\\_sick\\_or\\_disabled.htm](http://www.adviceguide.org.uk/scotland/your_money/benefits/benefits_for_people_who_are_sick_or_disabled.htm)



"Community care services are not universal. While there is a right to an assessment of need, local authorities have a degree of discretion over how and when they supply services".<sup>47</sup>

### Supported self assessment

The government's **Changing Lives Report**<sup>48</sup> and the Independent Living Movement have argued for a more people centred approach to the assessment process for people with disabilities. One recommendation is that people with disabilities should be supported to carry out self assessment<sup>49</sup>.

In Control Scotland<sup>50</sup> and other organisations, have worked with a number of councils in Scotland to pilot a system of supported self assessment and resource allocation. In 2008, the North Lanarkshire Council Social Work services in partnership with In Control Scotland piloted a self directed support system. A project team was set up in the North Lanarkshire Council that included an independent consultant.

Participants for the scheme were selected on the following basis:

- People who did not have an existing service and who were not having their support needs met
- People who needed to change the way their existing support was being provided
- People across 6 different localities in North Lanarkshire region

Social workers in each of the localities identified and contacted participants who fit the project criteria and who had current community care assessments. The project team met with the participants, their families, and their social workers to discuss the project. Participants also completed a self assessment questionnaire to give the project team an idea of the amount of money they or their family would need to develop their support programme. The answers to the questionnaire were entered into the project's Resource Allocation System (RAS).

Participants received training and support in employing a personal care assistant from the Scottish Personal Assistant Employers Network (SPAEN).

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<sup>47</sup> Learning Disability Alliance Scotland. <http://www.ldascotland.org>

<sup>48</sup> Report of the 21st Century Work Review (2006) Changing Lives  
<http://scotland.gov.uk/Resource/Doc/91931/0021949.pdf>

<sup>49</sup> In the UK, the ADASS (Association of Directors of Adult Social Services) produced a report stating that self-assessment is not legal, and local authorities cannot legally contract out eligibility, resource allocation and support planning decisions. Scottish government (2009) Self Directed Support a National Strategy for Scotland  
<http://www.scotland.gov.uk/Resource/Doc/301424/0094007.pdf>

<sup>50</sup> In Control Scotland <http://www.in-control.org.uk/>

Participants also received assistance from the project team and In Control Scotland in developing their support programmes. The project's progress was reviewed after the first 3 months.

The project was evaluated externally. One of the key findings was that service users had a positive experience of this system and that self directed support is the way forward for the future<sup>51 52</sup>.

The Scottish government (2009) has commented that the piloting of self supported assessment is still in its early stages. A key informant for this background paper stated that the advantage of supported self-assessment is that it allows applicants to clearly identify the assistance they need and that provision may be made for people to receive help with this through peer support.

## **4.5 Care support for people with disabilities**

### **Home care support services**

People with disabilities are assessed by their local authorities regarding home care support services (such as home help, and support for personal care). Home care services are generally associated with older people. In 2009, out of 68,300 service users, 80% were aged 65 years and over<sup>53</sup>. In the past local authorities provided home care services for people with disabilities, but increasingly these services are being procured by local authorities from the private and voluntary sector<sup>54</sup>. Table 6 sets out the number of people with disabilities that use this service.

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<sup>51</sup> Scottish Government (2009) Self Directed Support a National Strategy for Scotland  
<http://www.scotland.gov.uk/Resource/Doc/301424/0094007.pdf>

<sup>52</sup> Ethertington, K., Hatton, C., Water, J. (2009) Way Ahead. Our early experience in North Lanarkshire of demonstrating the impact of the In Control approach. In Control Scotland.

<sup>53</sup> Scottish government (2009) Home care services Scotland.  
<http://www.scotland.gov.uk/Resource/Doc/293019/0090393.pdf>

<sup>54</sup> Scottish government (2009) Home care services Scotland.  
<http://www.scotland.gov.uk/Resource/Doc/293019/0090393.pdf>

**Table 6. People with disabilities using home care services**

Client group	Age Group				Total clients
	0-64	65-74	75-84	85+	
People with learning disabilities	82%	11%	4%	2%	4,400
People with dementia	3%	12%	47%	38%	3,700
People with mental health difficulties	57%	18%	16%	8%	3,200
People with physical disabilities (including fragility associated with ageing)	10%	15%	37%	37%	52,400

Scottish government (2009) Home care services Scotland

The number of people with learning disabilities receiving home care services in their own tenancies has increased from 1,500 in 2000 to 4,438 in 2009<sup>55</sup>. The number of people with physical disabilities receiving home care services had increased rapidly to just over 52,000. The Scottish Government attributed this increase to the availability of free care for older people<sup>56</sup>.

### Local Area Co-ordination of Services (LAC)

**The Same as You? report (2000)** recommended that local authorities and health boards introduce LAC of services for people with learning disabilities and their families. The objective behind the LAC is to use a person centred approach to support people with learning disabilities and their families to enable them to live as part of their community<sup>57</sup>.

By May 2006, 25 local authorities in Scotland had implemented the LAC, and 59 local care co-ordinators were appointed to co-ordinate the services in their respective areas. Each local care co-ordinator supported 50 individuals and their families by building networks with agencies, local community groups etc. and acting as an information point for the families. These co-ordinators were

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<sup>55</sup> ibid

<sup>56</sup> Scottish Executive (2006c) High level summary of Statistics – Equality  
<http://www.scotland.gov.uk/Publications/2006/11/20102424/11>

<sup>57</sup> Stalker, K.O., Malloch, M., Barry, M.A., Watson, J.A. (2008) Local area co-ordination: strengthening support for people with learning disabilities in Scotland. British Journal of Learning Disabilities. Blackwell Publishing Ltd.

generally employed by local authorities. 48% of these local authorities offered life time supports services, from birth to old age<sup>58</sup>.

Local area co-coordinators generally identified individuals with learning disabilities by informal introductions rather than through agency referrals. However some local authorities insisted that service users need to be referred by agencies before they could be allocated a local co-ordinator. The care co-ordinators typically accompanied people to appointments or activities, did follow up work in the office, liaised with other professionals and provided disability awareness training.

A case study of 4 local authorities revealed that local care co-ordinators had succeeded in increasing service users' awareness of service options available to them. Local care co-ordinators also assisted them in how to use them.

The services provided by the local care co-ordinators also increased disability awareness in the respective communities. In one area members of a self advocacy group were paid to deliver disability equality training to front line staff in different organisations<sup>59</sup>.

According to Stalker et al (2008) if the LAC is to provide more equitable nationwide support throughout Scotland:

- The number of LAC posts needs to be increased. Ring fenced government money should be considered to fund these new posts
- Updated guidance on the mission and objectives of LACs and practicalities on operating it in Scotland needs to be produced and disseminated. The creation of a National Development Worker post to promote the development of LAC nationally would assist this<sup>60</sup>

## **4.6 Respite and Carer Supports**

A carer in Scotland is defined as:

" an adult, young person or child who provides a substantial amount of unpaid care on a regular basis for a partner, parent or child, other relative, friend or neighbour who is unable to manage at home without help because of physical or mental ill health, age or disability. A carer may or may not be living with the person they are caring for."

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<sup>58</sup> ibid

<sup>59</sup> Stalker, K.O., Malloch, M., Barry, M.A., Watson, J.A. (2008) Local area co-ordination: strengthening support for people with learning disabilities in Scotland. British Journal of Learning Disabilities. Blackwell Publishing Ltd.

<sup>60</sup> ibid.

Carer supports are available to those who care for people between the ages of 18-64 years of age and 65 years and older with physical and/or learning disabilities, mental health difficulties and dementia. Respite care services are also available for children with physical disabilities, learning disabilities and mental health difficulties. Respite care services may last a few hours or a few weeks<sup>61</sup>. Table 7 shows the number of Overnight Respite Weeks and Daytime Respite Weeks from 2008-2009 for the different service user groups. Service users apply to their local authorities for this service.

**Table 7. Number of respite weeks for 2007/2008 and 2008/2009<sup>62</sup>**

	0-17 years		18-64 years		65 + years	
	2007/2008	2008/2009	2007/2008	2008/2009	2007/2008	2008/2009
<b>Overnight Respite Weeks</b>	7,900	8,000	18,000	18,800	37,000	36,000
<b>Daytime Respite Weeks</b>	16,000	14,800	41,000	39,700	52,900	56,700
<b>Total</b>	23,900	22,000	59,000	58,500	89,900	92,700

Source: Audit Scotland SPI (2009)

In June 2010 the Ministry for Health and Wellbeing announced their Caring Together Strategy for adult and young carers. This strategy sets out a range of measures designed to identify and support carers across Scotland. A budget of €6m, (£5m.) over 5 years has been allocated to the project<sup>63</sup>.

#### **4.7 Care supports in education for children with disabilities**

The Department of Education and Lifelong Learning is responsible for ensuring that the special education needs of children and young people are met. Local authorities are obliged by law to provide education for children of school going age with and without disabilities in their area. 27 out of 32 local authorities have special schools or units<sup>64</sup>.

Special schools are more likely to provide services for children with learning disabilities and in some cases for children with autistic spectrum disorder,

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<sup>61</sup> Scottish government (2010) Respite Care Scotland 2009. Final Figures <http://www.scotland.gov.uk/Resource/Doc/924/0100863.pdf>

<sup>62</sup> *ibid*

<sup>63</sup> Scottish government (2010) Caring Together: The Carers Strategy for Scotland 2010 - 2015. <http://www.scotland.gov.uk/Publications/2010/07/23153304/35>

<sup>64</sup> The Education Acts 2004 & 2009: Consultation on Changes to the Secondary Legislation and Supporting children's Learning Code of Practice [www.scotland.gov.uk/Publications/2009/11/03140104/12](http://www.scotland.gov.uk/Publications/2009/11/03140104/12)

social, emotional and behavioural difficulties, language and speech disorders and physical disabilities<sup>65</sup>.

The Education (Additional Support for Learning) (Scotland) Act 2004 states that all children who require additional support in school receive it and that they have an IEP (Individualised Education Programme). 4.8% of primary pupils and 4.3% of secondary school pupils in Scotland are identified as having additional support needs<sup>66</sup>.

Children and young people i.e. "with multiple and complex disabilities " receive supports from social care services and education and voluntary and non-statutory sectors. Nurses and Allied Health Professionals deliver these type of services in hospital and in the community<sup>67</sup>.

These children's daily care needs including care assistants and social workers are provided through social services provided by the local authorities. Their educational needs are provided through special needs and school nurses, classroom teachers and teaching assistants<sup>68</sup>.

Recent policy on services for children with disabilities has focused on developing joined-up, tighter interagency systems between health, education, social work and the voluntary sector. In the **Getting it Right for Every Child Initiative** there is a commitment to developing an Integrated Assessment Framework and a single support plan for children with disabilities and others with additional support needs<sup>69</sup>. The Care Co-ordination Network UK was established to ensure efficient streamlined care co-ordination between the different agencies involved in the UK and Scotland<sup>70</sup>.

A recent report by the Scottish government stated that many education providers are working towards creating a more inclusive environment with their schools: by providing staff with training in disability equality and assistive technologies; improving physical accessibility of school environments and

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<sup>65</sup> The Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: Education and Lifelong Learning

<sup>66</sup> *ibid*

<sup>67</sup> Law, J., McCann, D., O' May, F., Smart, C., Buchan, J. (2009) Service Provision for Children and Young People with Complex Needs in a Community Setting from The Perspectives of Nursing and Allied Health Professionals. Scottish Government

<sup>68</sup> *ibid*

<sup>69</sup> The Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: Education and Lifelong Learning

<sup>70</sup> *ibid*

accessibility of school curriculum; and consulting with parents, health professionals and other organisations for same<sup>71</sup>.

## 4.8 Day & Employment Services

### Day Care Services

The majority of day care services for people with disabilities in Scotland are run by local authorities. People with learning disabilities use this service more than any other group<sup>72</sup>. In 2007, out of 23,000 people with ID registered with local authorities, 32% avail of day services. Day care services in Scotland provide service users with training in food preparation; shopping; personal care and hygiene; personal and social development; leisure and recreation; education and employment. Education and employment services provide service users with training in literacy skills, basic education, work experience<sup>73</sup>. Table 8 below details the percentage of people with disabilities who are registered with day care services.

**Table 8. Percentage of people with disabilities using registered day care centres**

Client group	LA/NHS	Private	Voluntary	Total
No. of day care centres, learning disabilities	77%	2%	20%	200
No. of users with learning disabilities	86%	1%	12%	7,500
No. of day care centres, physical disabilities	67%	6%	24%	30
No. of users, physical disabilities	72%	4%	24%	1,700

Scottish Government (2007) Statistics Release Day Care Services, Scotland 2007

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<sup>71</sup> *ibid*

<sup>72</sup> Scottish Government (2007) Statistics Release: Adults with Learning Disabilities Implementation of 'The same as you?' available from <http://www.sclid.org.uk/sclid-projects/esay.xhtml>

<sup>73</sup> Scottish Government (2007) Statistics Release Day Care Services, Scotland 2007

**Table 9. Percentage of client receiving this service by service type**

Individual Client group	% of client receiving services on a weekly basis				
	Domestic/ Practical	Social/ Personal Development	Education/ Employment	Leisure/ Recreation	Personal Care
<b>Dementia</b>	18%	91%	12%	92%	62%
<b>Learning Disabilities</b>	29%	90%	34%	94%	52%
<b>Physical Disabilities</b>	20%	91%	15%	91%	55%
<b>Mental Health Difficulties</b>	19%	89%	14%	76%	47%
<b>Drug/ Alcohol Problems</b>	24%	94%	19%	79%	55%
<b>Other Client Groups</b>	25%	96%	22%	75%	35%

Source: Day Care Services Census Return D1-B (2007)

## Employment

### Supported employment

According to a Scottish Executive Report (2005), the provision of supported employment programmes in Scotland has not automatically resulted in a change from existing segregated day services and sheltered workshops. It has been added on as a "continuum of services."<sup>74</sup>

The Scottish government and COSLA undertook a review of supported employment services in 2009 and published its findings in a report entitled **Supported Employment Scoping Exercise** (2009). The report indicated that the term supported employment had different meanings for different service providers. Local authorities had different supported employment models that included sheltered workshops, in addition to social enterprise projects etc.

The report defined supported employment as:

"a systematic approach that provides flexible support to enable people with physical disabilities, mental health or learning disabilities to secure and maintain paid employment in the open labour market."<sup>75</sup>

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<sup>74</sup> Ridley, J., Hunter, S. & Infusion Co-operative (2005) Go for it! Supporting People with Learning Disabilities and /or Autism Spectrum Disorder in Employment. Scottish Executive Social Research.

<sup>75</sup> Scottish Government & COSLA (2009) Supported Employment Scoping Exercise, Final Report, March 2009



Supported employment services are generally located in the care/community services departments of most local authorities. Some local authorities involve service users in the design of the supported employment services via consultation meetings and working groups<sup>76</sup>.

Funding from these services comes from different sources. Table 10 below details funding for 71 services provided across 17 local authorities who responded to the review. Additional sources of funding for supported employment come from European Structural Funds, European Regional development funds etc.

**Table 10. Funding for supported employment services<sup>77</sup>**

<b>Funding</b>	<b>% of total services</b>
<b>Fully funded by Local Authority</b>	28%
<b>Partially funded by Local Authority</b>	58%
<b>Not funded by Local Authority</b>	15%

From April 2007 - March 2008, 577 out of 1451 service users were referred from job centres to sheltered workshops.

During the same time period, 2,110 people received support to gain supported employment. 48.5% of the 2,110 were people with learning disabilities, 16% were people with mental health difficulties, 10.5% were people with physical disabilities<sup>78</sup>.

Table 11 details the percentage of people with disabilities who obtained paid work through supported employment services, from April 2007 - March 2008.

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<sup>76</sup> ibid

<sup>77</sup> ibid

<sup>78</sup> ibid

**Table 11. % People on supported employment programmes in paid work**

**Total number = 1, 135 people**

<b>Paid job</b>	<b>Learning disabilities</b>	<b>Mental Health difficulties</b>	<b>Physical Disability</b>	<b>Other</b>
<b>Less than 8 hours per week</b>	2.5%	0.53%	0.18%	0.1%
<b>9-16 hours per week</b>	4.4%	1.3%	0.6%	0%
<b>17-24 hours per week</b>	14.2%	6.5%	0.1%	2.2%
<b>More than 24 hours per week</b>	7%	1.8%	3.4%	55.2%
<b>Total</b>	28%	10.1%	4.4%	57.5%

Source: Scottish Government & COSLA (2009) Supported Employment Framework Scoping Report

The private sector is the main employer for people with disabilities in supported employment<sup>79</sup>.

The report on supported employment produced by the Scottish government and COSLA (2009) states that there is a need for :

- A Supported Employment Framework and guidance for local authorities regarding supported employment
- A consistent approach to delivering supported employment programmes across all local authorities
- Connection with the local authorities' Single Outcome Agreements
- High level engagement and support at a local and national level

### **New work initiative**

A key informant for this background paper stated that the Scottish government is in the process of implementing the **Valuing Employment Now Initiative** which was announced in the UK in 2009. The UK government is committed to achieving equality and social inclusion for all people with disabilities by 2025<sup>80</sup>. The **Valuing Employment Now Initiative** is one of the UK

<sup>79</sup> Scottish Government & COSLA (2009) Supported Employment Framework Scoping Report

<sup>80</sup> Prime Minister's Strategy Unit (2005) Improving the Life Chances of Disabled People. <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

government's strategy towards achieving this overall goal. The objective of the initiative is to provide people with moderate to severe learning disabilities with paid employment that exceeds 16 hours or more per week by:

- Changing society's ideas and expectations about the capacity and potential of children and adults with disabilities through government campaigns and building on existing good practice
- Promoting the fact that people with learning disabilities can work and have careers.
- Encouraging employers to see the business case for employing people with disabilities.
- Promoting the concept of self -employment as a viable option for people with learning disabilities
- Better preparation or work at school, college and adult learning for people with learning. Access to better work experience opportunities
- Joined up support systems between statutory, voluntary and private agencies, with integrated funding streams to be implemented that use a person centred approach to map out a clear employment pathway for people with learning disabilities
- Increase the number of job coaches providing high quality services to people with learning disabilities
- Promoting accessible information on disability benefits for people with learning disabilities, their families and social care staff so that their benefits do not become a disincentive to work
- Working with local authorities to remove barriers in public services e.g. transport and the built environment to enable people with learning disabilities to access work.
- Improving data collection and records about the employment situation of people with moderate and severe learning disabilities<sup>81</sup>

## **4.9 Direct Payments**

In 1996, the Community Care (Direct Payments) Act was introduced. From June 2003, local authorities have a duty to offer direct payments of disability benefits in place of providing services to all eligible people with disabilities aged 16 and over and to parents/guardians of children with disabilities aged 15 and under<sup>82</sup>. Direct payments in Scotland are for self directed community

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<sup>81</sup> Department of Health. HM Government (2009) Valuing Employment Now: real jobs for people with learning disabilities

<sup>82</sup> Scottish Executive National Statistics Publication (2006) Statistics Release, Direct Payments Scotland 2006.

care whereby people in receipt of disability benefits are responsible for managing and paying for the care services they are assessed as needing<sup>83</sup>.

Under the Health and Social Services and Social Security Adjudications Act 1983, direct payments can be subject to means testing. If a person has more than €25,600 (£23,000) in savings, they may be asked to pay for their services. Local authorities also have some discretion with regard to these charges<sup>84</sup>.

Since direct payments have been introduced, there has been a "differential use" of them by local authorities in Scotland and initially there was a very low uptake<sup>85</sup>.

There has been an increase in the number of people in Scotland availing of direct payments, from 207 in 2001<sup>86</sup> to 3,017 in 2009<sup>87</sup> an increase of 16% from the 2007/08. 47% of these 3,017 people who received direct payments had a physical disability, 26% were people with learning disabilities. The total value of direct payments has steadily increased from 2001, to €36m.euros (£33 million) in 2009. The estimated average value of a direct payment in 2009 was €10,700 (£9,600)<sup>88</sup>.

### **Issues with direct payments**

There have been a number of ongoing issues regarding the implementation of direct payments in Scotland.

- According to the Scottish government (2009) there are currently waiting lists for people on direct payments because of lack of resources (there is no data on the actual number of people on these waiting lists). The Scottish government has commented on the fact that the demand for the

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<sup>83</sup> Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: The Scottish Minister's Duties Health and Well Being.

<sup>84</sup> Woodin, S; Priestley, M and Prideaux, S (2009) ANED country report on the implementation of policies supporting independent living for disabled people

<sup>85</sup> Witcher et al; 2000; Pearson, C., 2000 and Riddell et al; 2005 in Riddell et al; (2006) The Implementation of Direct Payments in Scotland for People who use Care Services, Centre for Research in Education Inclusion and Diversity.

<sup>86</sup> Scottish Executive National Statistics Publication (2006) Statistics Release, Direct Payments Scotland 2006

<sup>87</sup> Scottish government (2009) Self-directed Support (Direct Payments), Scotland, 2009 <http://www.scotland.gov.uk/Resource/Doc/299811/0093457.pdf>

<sup>88</sup> Scottish government (2009) Self-directed Support (Direct Payments), Scotland, 2009 <http://www.scotland.gov.uk/Resource/Doc/299811/0093457.pdf>

delivery of social work services via delivery payments has exceeded available budgets<sup>89</sup>.

- There is no best practice model for local authorities to set up financial and administrative systems to operate direct payments. Local authorities have indicated their concerns about financial accountability and transparency<sup>90</sup>
- Issues have also been raised by local authorities as to the level of control service users have over how direct payments are used<sup>91</sup>

### **Self-Directed Support (SDS)**

There is no legislation regarding self directed supports in Scotland, but the Scottish government is currently developing a national strategy for self-directed support and advertised for submissions from the public to inform the final strategy<sup>92</sup>. The Scottish government has invested in test sites and projects on the viability of self directed support for people with disabilities, as part of its movement towards personalising health and social care services in Scotland.

The Scottish government defines self directed support as:

"individuals and families can have informed choice about the way support is provided to them. Self-directed support includes a range of options for exercising those choices. Through a co-production approach to agreeing individual outcomes, options are considered for ways in which available resources can be used so people can have greater levels of control over how their support needs are met, and by whom<sup>93</sup>."

In their strategy the Scottish Government states that:

"self directed support should become the mainstream mechanism for the delivery of social care support<sup>94</sup>"

Direct payments and self directed supports differ in the following ways:

The term direct payments describes the official system by which disability benefits are paid directly to people with disabilities and or their families.

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<sup>89</sup> ibid

<sup>90</sup> Scottish Executive National Statistics Publication (2006) Statistics Release, Direct Payments Scotland 2006

<sup>91</sup> ibid

<sup>92</sup> Scottish government (2009) Self-directed Support (Direct Payments), Scotland, 2009 <http://www.scotland.gov.uk/Resource/Doc/299811/0093457.pdf>

<sup>93</sup> ibid

<sup>94</sup> ibid

Self directed supports are the support mechanisms (including needs assessment ) that people with disabilities will be able to avail of to ensure that they will be completely responsible (self directed) about how they use their direct payments and individual budgets.

At present in Scotland, people use direct payments to purchase services through social care.

The long term aims of the self directed support strategy are to enable people with disabilities to purchase many services such as education, housing, transport, employment supports, etc. via a joined up centralised funding stream. The Scottish government in partnership with NHS Scotland and COSLA plans to test an Integrated Resource Framework (IRF) for health and social care with four partnerships (4 health boards and 12 local authorities partners) established as test sites. The objective of the IRF is to enable resources move across different funding systems to meet the needs of service users<sup>95</sup>.

The self directed supports strategy in Scotland is still at a very early stage, however the Scottish government envisions that this system of supports will help them achieve efficiency savings by:

- Centralising and streamlining different funding streams for different services
- Providing service users with a single entry point to access funding for a range of services<sup>96</sup>

### **Individualised Budgets**

The UK Government has been promoting the use of individualised budgets<sup>97</sup>. These budgets require the aggregation of funds that local authorities have established for direct payments, the Independent Living Fund, Attendance Allowance, Access to Work and the Disability Living Allowance<sup>98</sup>.

According to Riddell et al; (2006) streamlining these budgets into one central funding system, would provide savings in terms of administrative expenditure, since each benefit has a separate funding stream. These budgets would also

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<sup>95</sup> Scottish government (2009) Self-directed Support (Direct Payments), Scotland, 2009  
<http://www.scotland.gov.uk/Resource/Doc/299811/0093457.pdf>

<sup>96</sup> *ibid*

<sup>97</sup> Riddell et al; (2006) The Implementation of direct payments in Scotland for people who use care services. Centre for Research in Education, Inclusion and Diversity

<sup>98</sup> *ibid*

give service users greater control over how they use their benefits<sup>99</sup>.

At the moment while Scotland is committed to the delivery of personalised services, the extent to which individualised budgets are incorporated into this system is unclear<sup>100</sup>.

#### 4.10 Supports to Independent Living

Supports for independent living have been incorporated into the Scottish government's disability equality policy since 2000<sup>101</sup>. In 2009, the Scottish government established the ILiS (Independent Living in Scotland) initiative as part of a wider initiative on independent living. ILiS is a Steering Group made up of people with disabilities representing user-led organisations. The project is to be hosted by the EHRC (Equality and Human Rights Commission) until March 2011<sup>102</sup>.

The definition of independent living adopted by the ILiS project is:

“Independent living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”<sup>103</sup>.

A report entitled **Ready for Action** published by ILiS states that in order for people to achieve independent living in Scotland there needs to be :

- A political, social and service structure that supports independent living
- An appropriate environment and transport system
- Adequate personal support and services
- Opportunities to take part in economic, social and public life<sup>104</sup>

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<sup>99</sup> Riddell et al; (2006) The Implementation of direct payments in Scotland for people who use care services. Centre for Research in Education, Inclusion and Diversity

<sup>100</sup> *ibid*

<sup>101</sup> Scottish government (2008) Disability Equality Scheme 2008-2011

<sup>102</sup> Independent Living in Scotland website <http://www.ilis.co.uk/about.aspx>

<sup>103</sup> *ibid*

<sup>104</sup> Reid Howe Associates (2009) Ready for Action. Key issues and disabled people's priorities for independent living. Independent Living in Scotland

92 *ibid*

## **Personal Assistance**

The Scottish government has established funding for personal assistance; housing adaptations; and implemented self directed supports, direct payments and other systems to support independent living for people with disabilities.

SPAEN (Scottish Personal Assistant Employers Network), is a nation wide organisation that provides a range of peer supports such as: personnel management and employment law support; etc, to people with disabilities who are using direct payments and are first time employers of personal care assistants. They have provided training to Scottish local authorities and health boards in setting up self directed support systems<sup>105</sup>. SPAEN is a charity that is funded through various schemes such as the National Lottery.

The Independent Living Fund pays for personal assistance services. To be eligible for this type of funding, people with disabilities must be between 16 – 65 and must be receiving social services support (either direct payments or services in kind) worth at least €360 (£320) a week/ €18,540 (£16,640) a year, or be entitled to a higher rate of Disability Living Allowance. Applicants and their partners must also have less than €25,600 (£23,000) in savings or capital<sup>106</sup>.

To obtain funding for their social care needs, applicants must apply to their local authority to request a needs assessment. Funding decisions are made under the “Fair Access to Care” procedure. This national system identifies four levels of risk: critical, substantial, moderate and low. These services are to be provided according to assessed needs and the impact on a person’s ability to live independently, rather than the availability of particular services.

While a funding agency may be responsible for paying a personal assistant, the person with the disability recruits their personal assistant and chooses how they would like to be assisted<sup>107</sup>.

## **Home adaptations and assistive technology**

People with disabilities can apply for Disabled Facilities grants from their local councils/authorities to make alterations to their homes so that they can continue to live in them. Widening doors and installing ramps, installing stair lifts, showers, making controls easier to use and improving access in the

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<sup>105</sup> SPAEN website <http://www.spaen.co.uk/>

<sup>106</sup> Woodin, S; Priestley, M and Prideaux, S (2009) ANED country report on the implementation of policies supporting independent living for disabled people

<sup>107</sup> *ibid*



house to make it easier to look after children, are examples of housing alterations that can be funded by these grants<sup>108</sup>.

These grants are based on a financial assessment/means testing. Social security benefits are ignored in this assessment. The amount of funding a person can receive is determined by comparing income and capital with assessed needs. The earnings of other people in the house are also taken into account. People with disabilities can receive funding of up to €22,300 (£20,000) in Scotland. Costs over this amount are met by the person with a disability<sup>109</sup>.

In Scotland, after an assessment of need has been conducted, up to 100% of the cost may be granted. For people over 65 years of age, the provision of social services equipment is free<sup>110</sup>.

## **5. Entitlement, Choice and User Involvement**

### **5.1 Entitlement and service procurement**

NHS Scotland is the publicly funded healthcare system for Scotland and primary health care is provided free of charge to those living in Scotland

The Department of Work and Pensions under the UK government is responsible for disability-related income and vocational and employment need. People with disabilities are eligible for social care i.e. disability benefits such as Employment Support Allowance, Disability Living Allowance, Severe Disability Allowance etc., but are not entitled to them. (Details of disability benefits are listed in Appendix 3). Social care is means tested.

In Scotland, health, personal and social services for people with disabilities are provided by a mixture of public bodies such as the Department of Health and Wellbeing, NHS boards, and local authorities<sup>111</sup>, in addition to private organisations and NGOs. NGOs have to put in tenders to be eligible for social care procurement. In January 2010 the Scottish government produced a draft guide for consultation for social care procurement. This guide gives service providers a detailed framework for procurement of social services that

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<sup>108</sup> Woodin, S; Priestley, M and Prideaux, S (2009) ANED country report on the implementation of policies supporting independent living for disabled people

<sup>109</sup> Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: The Scottish Minister's Duties Health and Well Being.

<sup>110</sup> *ibid*

<sup>111</sup> Scottish government's website. About Scotland's Public Bodies.  
<http://www.scotland.gov.uk/Topics/Government/public-bodies/about>

includes preparation, analysis, planning, securing of services and review<sup>112</sup>.

The Scottish government has drafted guidelines regarding procurement of social care services by local authorities, NGOs, and other service providers etc<sup>113</sup>. In practice however local authorities still purchase and provide the majority of health, personal and social care services to people with disabilities<sup>114</sup>. Service users in Scotland have little choice regarding service providers.

However the direct payments system does provide people with disabilities with choice regarding how they manage their disability benefits and the types of services they purchase with their benefits.

The proposed self directed supports are perceived by the Scottish government, disability organisations and by key informants, as offering people with disabilities greater choice regarding how they manage their disability benefits.

## **5.2. Involvement of People with Disabilities**

The Scottish government has worked in consultation with disability organisations and people with disabilities in developing and implementing schemes and initiatives:

- Disability schemes for 2007 and 2008-2011
- Testing and piloting self directed supports and supported self assessment for people with disabilities
- Independent living movement in Scotland
- Supported employments services

## **6. Summary of Key learning Points**

### **Direct payments**

According to a key informant for this background paper, the provision of direct payments is one of the strengths of the Scottish system, as it provides people with disabilities greater empowerment, with the opportunity and independence to manage their disability benefits themselves and pay for their services themselves.

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<sup>112</sup> Scottish Executive, 2010, Guidance on procurement of social care for consultation; <http://www.scotland.gov.uk/Publications/2010/01/13125045/0>

<sup>113</sup> Scottish Executive, 2010, Guidance on procurement of social care for consultation; <http://www.scotland.gov.uk/Publications/2010/01/13125045/0>

<sup>114</sup> Curtice, L. and Fraser, F. (2002) The Domiciliary Care Market in Scotland Quazi-markets revisited, *Health and Social Care in the Community* 8 (4) 260-268

## **Local Area Co-ordination of Services**

The Local Area Co-ordination of Services uses case management and a person centred approach to support people with learning disabilities and their families to enable them to live as part of their community<sup>115</sup>.

The strengths and benefits of this system have been seen regarding increases in:

- Service users' awareness of service options available to them. Local care co-ordinators assisted them in how to use these services
- Disability awareness in communities<sup>116</sup>

## **SPAEN and peer support**

In the opinion of a key informant for this paper, the peer support and other work carried out by SPAEN has been essential to the development of Independent Living in Scotland. It has been a beneficial training resource for local authorities and other organisations regarding the delivery of direct payments.

## **Individualised budgets and self directed support systems**

User led individualised budgets, and self directed support were identified by key informants in Scotland as important strengths in the system, empowering service users and improving choice and control in the system.

## **Gaps in service provision**

A Scottish Executive report (2008) stated that research revealed that there were certain gaps and shortages regarding the provision of care services for particular groups, including people with early onset of dementia.<sup>117</sup>

## **Unmet Needs**

A Scottish government report stated that statistics were kept about unmet need in terms of care services. It found that 'needs were often discussed in terms of the services deemed necessary to meet them rather than in a wider 'needs-led' context'. It also reported that people with disabilities had a low level of involvement in community care assessments and that needs assessment was subject to geographic variation, with local authorities, and sometimes local teams within authorities, interpreting central guidance

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<sup>115</sup> Stalker, K.O., Malloch, M., Barry, M.A., Watson, J.A. (2008) Local area co-ordination: strengthening support for people with learning disabilities in Scotland. British Journal of Learning Disabilities. Blackwell Publishing Ltd.

<sup>116</sup> *ibid*

<sup>117</sup> Scottish Executive (2004g) A Map of independent Advocacy Across Scotland

differently<sup>118</sup>.

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<sup>118</sup> Scottish Government (2008) Reporting on Progress towards Equality of Opportunity between Disabled Persons and other persons made by Public Authorities in Scotland: The Scottish Minister's Duties Health and Well Being.

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## Appendix 1 Services provided by 8 special NHS Boards

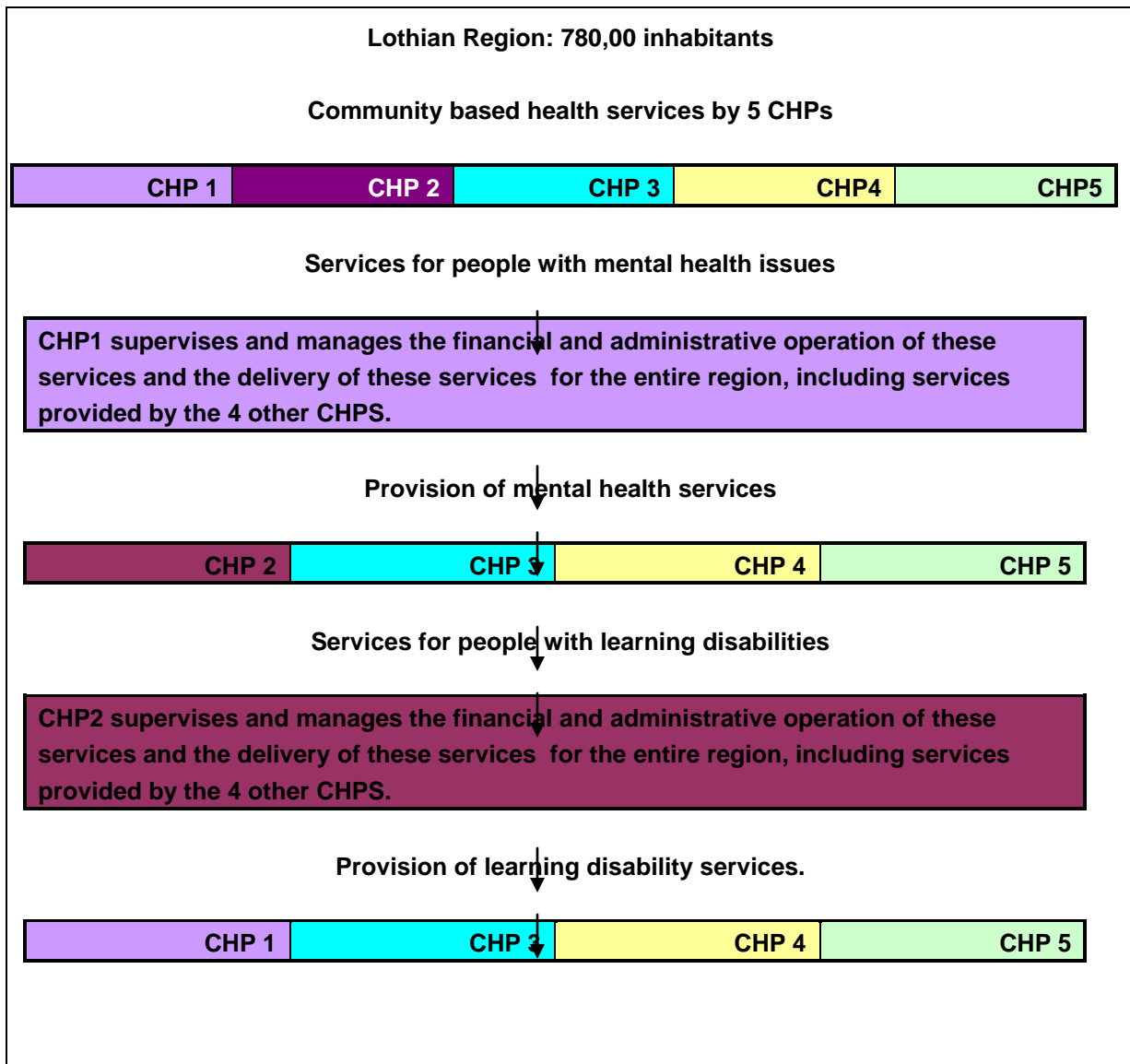
There are 8 Special NHS Boards that provide health services throughout Scotland. They are as follows:

- The Scottish Ambulance Service serves all of Scotland and is a Special NHS Board funded directly by the Scottish Government Health Directorate. It provides an Accident and Emergency service that responds to 999 calls, in addition to a Non-Emergency service that performs an essential role in getting patients to and from health services
- NHS 24 provides people with 24-hour telephone access to medical advice from clinical professionals
- The State Hospital at Carstairs is the only high security hospital in Scotland that provides care for high security patients
- NHS Health Scotland is a national organisation that promotes healthy lifestyles, provides information to the public on improving their health, in addition to focusing on reducing inequalities in the health care system
- NHS Quality Improvement Scotland focuses on improving the quality of health care in Scotland. This organisation also works with NHS professionals and the public to produce, implement and monitor national standards of care
- <http://www.nhsnss.org/home/index.php> The NHS National Services Scotland (formerly known as the Common Services Agency) provides a range of important specialist services such as: provision of health statistics; blood transfusion services; national surveillance of communicable diseases; national screening programmes; managing payments for primary care practitioners etc
- NHS Education for Scotland is the training organisation for NHSScotland. It enables the staff of NHSScotland to continue to develop their skills and to deliver the highest standards in patient care
- National Waiting Times Centre Board (The Golden Jubilee National Hospital) provides a dedicated elective facility in specialist services for patients throughout Scotland to reducing waiting times<sup>119</sup>

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<sup>119</sup> NHS Scotland website <http://www.show.scot.nhs.uk/introduction.aspx>

## Appendix 2      CHP Model of Service Delivery



## Appendix 3 Benefits for People with Disabilities

### Employment and Support Allowance

Prior to 2008 people with limited capacity to work due to an disability received the Incapacity Benefit. Post October, 2008 this allowance has now been changed to the Employment and Support Allowance (ESA)<sup>120</sup>. It is for people who can't work because of sickness or disability, and who are not getting Statutory Sick Pay.

There are two types of ESA:

- contributory ESA, which the recipient can get if he/she has paid enough national insurance contributions
- income-related ESA which is paid if he/she has income and capital are low enough

### Eligibility

The recipient may be able to get both contributory ESA and income-related ESA, depending on their circumstances. For both types of ESA, the recipient will usually have to have various tests to confirm that they have limited capability for work. ESA is paid by the Department for Work and Pensions (DWP).

People cannot get ESA if they or their partner are getting Income Support, income-based Jobseeker's Allowance or Pension Credit.

In order to qualify for contributory ESA, the recipient will usually have to have paid enough national insurance contributions. However, if the recipient becomes unfit for work before they are 20 (25 if they have been in full-time education) they do not need to meet the contribution conditions or have paid national insurance.

1. To get income-related ESA, a person's income will be compared with the amount that the government thinks is enough for them to live on. A person is ineligible for income-related ESA if they have savings of more than €17,800 (£16,000).

Proof of incapacity needs to be shown via medical certificates to the Department for Work and Pensions (DWP).

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The rate of ESA a person receives is dependent on whether they are eligible for contributory ESA or income-related ESA and an assessment of their work capacity.

The assessment phase rate is paid for the first 13 weeks of a recipient's claim while a decision is made on their capability for work through the Work Capability Assessment. See Table below.

#### Initial Assessment Period for ESA

Assessment period	Claimant's Age	Marital Status	Weekly Allowance Amount
<b>Initial period (weeks 1-13)</b>	Under 25	Single	Up to £50.95
<b>Initial Assessment Phase</b>	25 and older	Single	Up to £64.30

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

Generally people do not get any money for the first three days of their claim.

If the Work Capability Assessment shows that the recipient's illness or disability does limit their ability to work then they receive the allowance. However, the Assessment also looks at how people's work capacity can be developed. Some recipients whose capacity for work is assessed as higher will be in a Work Related Activity Group, while others will be placed in a Support Group.

#### Rates after Work Capability Assessment

Type of group	Marital Status	Weekly Amount
<b>Work Related Activity Group</b>	Single	Up to £89.80
<b>Support Group</b>	Single	£95.15

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

Further information about criteria for the ESA is available at [http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG\\_171896](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171896)

## **Severe Disablement Allowance**

This allowance was abolished in 2001. New claimants receive the Employment and Support Allowance. People in receipt of this allowance are incapable of work because of illness or disability for at least 28 weeks in a row and are between 16 and 64 years old.

### **Rates**

Depending on someone's age when they became unable to work they get an age-related additional weekly amount, the current maximum weekly rate is £57.45 (if the recipient has been getting Severe Disablement Allowance before April 2001).

- under 40 years old, the recipient is eligible for an extra £15.65 (higher rate)
- 40-49, the recipient is eligible for an extra £9.10 (middle rate)
- 50-59, the recipient is eligible for an extra £5.35 (lower rate)

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

## **Disability Living Allowance**

A person can get Disability Living Allowance (DLA) if they:

- Claim before they are 65
- Have had care needs or mobility needs for at least three months
- Are likely to have these needs for at least another six months

If a recipient is already getting DLA when they reach 65, they can continue to get it as long as they still have care or mobility needs. The recipient will not be able to get DLA if they are living permanently in a hospital or in a care home and their local council is helping them with their fees.

### **Care needs**

The care component of Disability Living Allowance (DLA) is paid at three different rates. The recipient gets the lower rate if they need help with cooking a main meal or care for a significant part of the day. The recipient gets the middle rate if they need frequent care throughout the day or night, or continual supervision throughout the day or night. The recipient can also get the middle rate if they need someone with them while they are on dialysis. The recipient gets the higher rate if they need frequent care or supervision throughout the day and night, or if they are terminally ill.

### **Care component -Weekly rates from 6 April 2009**

Higher rate    £70.35

Middle rate   £47.10

Lower rate     £18.65

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

### **Mobility needs**

The mobility component of DLA is paid at two different rates.

The recipient gets the lower rate if they cannot walk outdoors on an unfamiliar route without guidance or supervision from another person for most of the time. This could be because of either a physical or mental disability.

The recipient gets the higher rate mobility component if they are unable or virtually unable to walk because of pain, the effect on their health or the limitations on their walking. The recipient can only get the higher rate if they are blind and/or deaf and if they use a guide dog, they will still qualify for the DLA mobility component if they can show that they would need help from another person if they didn't have the dog, or if they were using a new route unfamiliar to the dog.

The recipient does not actually have to be receiving help with their mobility needs to get the mobility component of DLA, as long as they can show that they need it.

### **Mobility component              Weekly rate from 6 April 2009**

Higher rate    £49.10

Lower rate     £18.65

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

Disability Living Allowance (DLA) can be paid for children under 16, but there are extra conditions about their care and mobility needs.

To get the care component of DLA, a child must meet the same conditions as an adult, but they must also show that they need a lot more care or supervision than other children of the same age. For example, a child aged under 16 cannot get the DLA care component just because they are unable to cook a main meal for themselves.

A person can make a claim for the care component of DLA as soon as a child is born, but the claimant won't be paid any benefit until the child is three months old.

Children under 16 can't get the mobility component of DLA until they are three, for the higher rate, or five, for the lower rate. To get the lower rate, they must also need more help or supervision than other children of the same age. This extra condition no longer applies, once the child reaches the age of 16.

### **Attendance Allowance**

A person can get Attendance Allowance (AA) if they are disabled, they have care needs and they are 65 or over. The person must not be living permanently in hospital or accommodation funded by a local authority, for example, a local authority care home.

To get Attendance Allowance (AA) a person has to have had care needs for at least six months (unless you are terminally ill).

A recipient is defined as having care needs if they need help with their 'bodily functions', for example, washing, getting dressed and going to the toilet. This help can include attention, which allows them to take part in social activities. The recipient also has care needs if they need supervision to stop them from being a danger to themselves or others. If they are terminally ill, they are automatically treated as having care needs.

A recipient does not actually have to be receiving help for their care needs. As long as they have the needs, it does not matter whether they are getting or planning to get care. Attendance Allowance (AA) is paid at two rates, a higher rate and a lower rate. A recipient gets the lower rate of AA if they need frequent care throughout the day or night. The recipient gets the higher rate if they need frequent care throughout the day and night or if they are terminally ill.

### **Attendance Allowance      Weekly rate**

Higher rate	£70.35
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Lower rate                      £47.10 <sup>121</sup>

\*Conversion rate for 22/03/2010 is £1=€1.11387

<http://www.xe.com/ucc/convert.cgi?Amount=20%2C000&From=GBP&To=EUR&image.x=29&image.y=13>

### **Disablement Benefit**

There are different claim forms for Disablement Benefit, depending on whether the disability was caused by an accident or whether a person is claiming because they have a particular industrial disease. People should ask at the local benefit office for the right form. For more details:

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

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<sup>121</sup>[http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG\\_10012442](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/AttendanceAllowance/DG_10012442)

## **Appendix 4: How health and personal services are overseen and monitored in Scotland**

### **1) How are outsourced (i.e., non-statutory) services monitored (how is their performance to contract assessed)?**

All care services in Scotland - whether they are provided by local authorities, the private or voluntary sector - are regulated against the Regulation of Care (Scotland) Act 2001 ('the Act'), its associated regulations and the National Care Standards, by the Scottish Commission for the Regulation of Care ('the Care Commission').

The Care Commission's regulatory responsibilities include registering services defined in the Act, inspecting these services, taking enforcement action where good quality care is not provided, and dealing with complaints.

Information about what the Care Commission does and how it does it can be found in their website, at [www.carecommission.com](http://www.carecommission.com).

Further information on how local authorities monitor contracts with care service providers can be obtained from the policy manager team leader of the Convention of Scottish Local Authorities (COSLA) Health and Social Care Team for information on contract monitoring.

### **2) How are state services monitored?**

As above at 1.

### **3) Are services licensed?**

All care services must register with the Care Commission.

Each pays an initial registration fee followed by a yearly continuation fee as long as they run.

The maximum fees that the Care Commission can charge are set by Scottish Ministers.

These fees cover the direct cost of regulating services except where the Scottish Government subsidises fees in order to support policy, for example: the policy on affordable childcare.

The process of registering and paying a yearly fee is regarded as a licence to operate.

It is an offence to operate a care service as defined in the Act without being registered with the Care Commission.

#### **4) What regulations apply?**

There are a number of regulations associated with the Act.

For example:

The Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002 as amended set out requirements on care services and include provisions relating to:

- fitness requirements for providers, managers and employees,
- staffing and
- welfare of users.

Further information about all the regulations can be found on the Scottish Government website for the Care Standards and Sponsorship Branch, at: <http://www.scotland.gov.uk/Topics/Health/care/17652> .

#### **5) Are services inspected?**

The Care Commission inspects to a *minimum* frequency set out in regulations.

For example: care homes are inspected a minimum of two times a year.

The Care Commission sets the policy on inspection within that minimum frequency. Services may therefore be inspected in excess of the minimum.

The relevant regulations, The Regulation of Care (Scotland) Act 2001 (Minimum Frequency of Inspection ) Order 2007 and 2009, can be found at: <http://www.scotland.gov.uk/Topics/Health/care/17652>.

The Care Commission has the power to go into registered services at any time in response to concerns about quality or complaints raised by people using care services, their family or carers, or anyone else.

The Care Commission introduced a grading system in April 2008.

Services are graded across 4 quality themes (depending on what type of service they provide) as follows:

- care and support
- environment
- staffing
- management and leadership.

Inspection reports and grading for services are published on the Care Commission website so that they are available to the public.

Further information about inspections, the Commission's policy on inspection frequency and the grading scheme can be obtained from the Care Commission.

#### **6) What standards exist to support such inspections?**

The Act requires Scottish Ministers to prepare and publish National Care Standards which must be taken into account by the Care Commission in all its regulatory functions.

The National Care Standards are user and outcome focussed and set out what people using care services can expect from the provider and what to do if they are not getting good quality care that meets their needs.

The Scottish Government is currently running an awareness campaign to promote the National Care Standards and their use, both for users and carers.

More information about the Standards can be found at [http://www.infoscotland.com/nationalcarestandards/CCC\\_FirstPage.jsp](http://www.infoscotland.com/nationalcarestandards/CCC_FirstPage.jsp).

You can also view any of the Standards which are of interest at this link.

#### **7) Other developments of note**

Scottish Ministers have announced that managers of 'care at home' services will be included in the scope of registration within the SSSC.

Registration of managers of care at home services and housing services will commence in 2010, following a period of consultation.