

**Physical and sensory disability in East Sussex: an epidemiological needs assessment 2008**

<b>Contents</b>	<b>Page</b>
<b>1. Introduction</b>	<b>1</b>
1.1 Definitions of disability	
<b>2. Measuring disability</b>	<b>3</b>
2.1 Severity of disability	
2.2 Type of Disability	
2.3 Conditions leading to disability	
<b>3. Prevalence and incidence</b>	<b>5</b>
3.1 Local population	
3.2 Survey data	
3.2.1 2001 Census	
3.2.2 Health Survey for England	
3.2.3 Disability benefits	
3.2.4 Health Counts	
3.3 Expected trends	
3.4 Epidemiology of specific conditions	
3.4.1 Neurological conditions	
3.4.2 Locomotor conditions	
3.4.3 Sensory disability	
<b>4. Current services</b>	<b>22</b>
4.1 Adult social care	
4.1.1 Registers for sensory disability	
4.2 Primary care	
4.3 Secondary care	
<b>5. Effectiveness and cost-effectiveness of services</b>	<b>33</b>
5.1 Access to services	
5.2 Direct Payments	
5.3 Rehabilitation	
5.4 Housing and equipment	
5.3.1 Housing	
5.3.2 Equipment	
5.3.3 Telecare	
5.3.4 Wheelchair services	
5.6 Employment	
5.6 Communication and information needs	
5.5.1 Communication	
5.5.2 Information needs	
5.7 Transport	
<b>6. Conclusion and recommendations</b>	<b>45</b>
<b>7. References</b>	

# 1. Introduction

Physical and sensory disability can affect people in a variety of ways; they can arise as a result of an accident, illness or congenital disorder. A range of health conditions: neurological, circulatory, respiratory and musculo-skeletal, may cause physical disability and some may lead to sensory impairment. Both types of disability can affect a person suddenly, such as a stroke, or over a period of time, as in multiple sclerosis. It may be a static condition or one that fluctuates. Conditions that lead to physical or sensory disability can arise at any stage of life. Some people are affected by more than one condition, while others experience significant periods of ill-health as a feature of the disability.

The aim of this work is to establish the health and social care needs of the East Sussex population with physical and sensory disability. In doing so it will:

- Estimate the number of people who may need physical and/or sensory impairment services.
- The level and type of service response required to meet those needs; and
- Assess whether available resources are targeted in the right place?

This report examines national prevalence data, national and local epidemiological studies, statutory returns and activity against existing service provision (as a proxy measure for need).

## 1.1 Definitions of disability

The World Health Organisation defines disability in the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This framework describes four terms: pathology, impairment, disability and handicap (see Table 1).

**Table 1: Framework of international classification of impairments, disabilities and handicaps**

Term	Definition
Pathology	Abnormalities or changes in the structure or function of an organ or organ system.
Impairment:	Any loss or abnormality of psychological, physiological, or anatomical structure or function.
Disability:	Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
Handicap:	A disadvantage for a given individual, resulting from an impairment or disability that limits or prevents fulfilment of a role that is normal, depending on age, sex, social or cultural factors' (WHO, 1980).

*Source: World Health Organization. 1980. International classification of impairments, disabilities and handicaps. Geneva.*

Within this framework, which is often called the medical model of disability, a person's functional limitations (impairments) are the cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure.

The International Classification of Functioning, Disability and Health has evolved from the ICIDH and allows for a dynamic rather than static or linear assessment of the interaction between functioning and disability, where: functioning refers to all body functions, activities and participation, while disability refers to impairments, activity limitations and participation restrictions.

The social model of disability shifts the focus from impairment onto disability, using this term to refer to disabling social, environmental and attitudinal barriers rather than lack of ability. The social model of disability makes the distinction between 'impairment' and 'disability' (see Table 2).

**Table 2: Social model definitions of Impairment and Disability**

<b>Term</b>	<b>Definition</b>
Impairment	An injury, illness, or congenital condition that causes or is likely to cause a long term effect on physical appearance and / or limitation of function within the individual that differs from the commonplace.
Disability	The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

*Source: Union of the Physically Impaired Against Segregation. 1976. Fundamental Principles of Disability. London.*

## 2. Measuring disability

Owing to the inherent complexity of the disability concept measuring the level of disability in the population is difficult. Repeated cross-sectional studies can be used to obtain information on trends of limitations and their determinants (diseases) and can be used for planning. There are a range of surveys which have attempted to measure the level of disability in the UK population (Table 3).

**Table 3:** National surveys which have attempted to measure disability

Survey and sample size	Description
Census	Decennial household census it covers all adults aged 16 and over in the UK and achieves around 94-96% coverage, including adults in communal establishments. Questions include self-reported limiting long-term illness and general health, with information on gender, age, ethnicity, and socio economic group.
The OPCS Disability Surveys (1986)	Population screen and follow up, estimating and comparing levels of disability, calibrating severity. Adults and children in general and institutional populations covered.
ONS General Household Survey (continuous 20 000 persons annually)	Personal interviews with adults. Has included at least one question on general health and chronic illness in adults most years since the early 1970s. Special coverage of disability, caring etc in some years.
Health Survey for England	Personal interview and health examination survey carried out for the Department of Health. Questions on chronic illness and disability. Special coverage of disability in 1996 and 2001.
National Health Surveys for Scotland and Wales	Carried out regularly. Scottish survey similar to Health Survey for England, Welsh survey uses postal methodology. Cover general health and disability. Welsh survey uses SF-36 instrument.
Health Education Monitoring Survey	Carried out periodically for the Health Education Authority. Coverage of general health follows the General Household Survey.
Family Resources Survey (25 000 annually)	Carried out for Department for Work and pensions. Covers general health and disability with reference to eligibility for and receipt of benefits. Has attempted to replicate OPCS disability surveys.
Labour Force Survey (60 000 household survey)	For the Office for National Statistics. Main source of statistics on reasons for non-participation in labour force. Covers disability as it affects employment and employability, sometimes using proxy household informant.
Household Conditions Survey	Sponsored periodically by the Office of the Deputy Prime Minister and the Scottish and Welsh Offices. Cover disability as it affects housing needs, sometimes in considerable detail.

*Adapted from: Thomas (2006)*

There are also a wide range of condition-specific epidemiologic studies examining individual diseases, which can result in physical or sensory disability. Different methods for assessing the level of disability within the general population have generally subcategorised disability in three ways: severity; type; or condition.

### 2.1 Severity of disability:

The Health Survey for England 2001 (HSE01) used a disability instrument based on the 1980 WHO ICIDH classification system. Although the ICIDH framework has gone through a number of revisions the HSE continues to use the original framework for comparability. Questions covered limitations in functional activities (seeing, hearing, communication, walking and using stairs) and in activities of daily living: getting in and out of bed or a chair, dressing, washing, eating and toileting. Disabilities were scored according to severity (up to 3 categories) and the highest score for any of the five types of disabilities was then taken as the overall disability score, providing an estimate both of the severity of disability, and also of disability prevalence (a score of 1 or 2 indicating disability, a score of 0 indicating no disability).

### 2.2 Type of disability:

The HSE01 also recorded and coded individual's disability into categories broadly based on the headings of the ICD10. These were grouped into five disability types: Locomotion; Personal Care; Seeing; Hearing; and Communication; mental illness was not included. In addition individuals were asked if they had a longstanding illness or disability and whether any (or all) of these conditions limited their activity.

### 2.3 Conditions leading to disability

There are a large number of conditions that can lead to physical and sensory disability. One review identified over 80 separate conditions that may lead to physical disability.

These included chronic conditions such as respiratory and circulatory diseases, neurological disorders, musculoskeletal disorders and other physical diseases and conditions.

For the purpose of reviewing the epidemiology of specific conditions in this needs assessment conditions have been separated into three distinct categories: neurological; locomotor; and sensory. Chronic conditions such as respiratory and circulatory disease are major causes of disability in the UK. However, the needs of people with many chronic diseases have been covered in detail in the East Sussex Older People's Joint Commissioning Strategy 2007 and will not be revisited in this report, the exception to this is stroke in the under 65s as the needs of this group are often distinct from stroke patients in older age groups.

In terms of service provision it is most useful to consider the severity of an individual's disability. However, it is also useful to examine the epidemiology of individual conditions as individuals with different conditions may have different needs. This report takes both approaches, using both national statistics and academic research to investigate the predicted levels of disability within East Sussex.

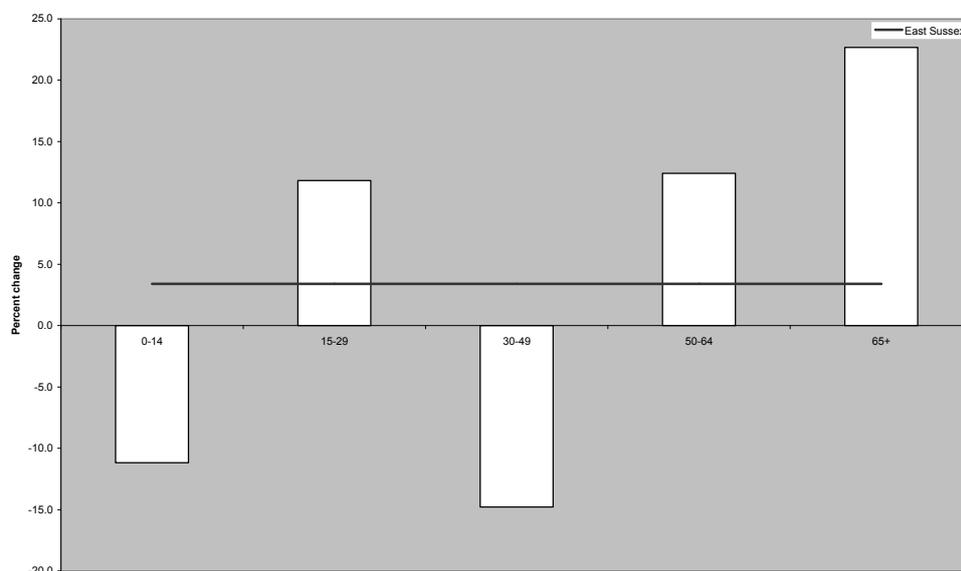
### 3. Prevalence and incidence

Measuring the prevalence of disability is difficult as variations in definition can affect estimates of prevalence as can the objectives of those trying to determine prevalence levels as operational definitions vary from broad, inclusive ones to narrow, specific ones. This report takes a number of approaches to estimating the prevalence of physical disability in the local population.

#### 3.1 Local population

Approximately half a million people live in East Sussex, the population is older than the national profile with one in four residents being over pensionable age. It is predicted that between 2001 and 2016 the population of East Sussex will increase by just below four percent. Within this there will be a: 23% increase in people aged over 65; a 12% increase in those aged 50-64; 15% decrease in those aged 30-49; a 12% increase in those aged 15-29; and an 11% decrease in the number of children aged 0-14 (Figure 1).<sup>†</sup> During the same period there will be no real change in the total number of working-age adults (16-64) with an additional 1100 (0.4% increase) persons.

Figure 1: Projected change in East Sussex population by age band 2001-2016



Source: ONS 2004-based sub-national population projections

#### 3.2 Survey Data

##### 3.2.1 2001 Census

The 2001 Census included a question about disability focused on long term and limiting long term illness:

*Do you have any long-term-illness, health problem or disability which limits your daily activities or the work you can do?*

The question did not discriminate between physical or mental ill health. Nationally, 18% of the population identified as having a limiting long-term illness, in East Sussex this was higher at 20%: ranging from 17% in Wealden to 22% in Eastbourne, Rother and Hastings (Table 4). This is most likely a reflection of the county population being older than England average.

Table 4: Census – long term limiting illness

Area	District	All people	With a	% of
------	----------	------------	--------	------

	count April 2001	limiting long term illness	total
England & Wales	52 041 900	9 484 900	18%
East Sussex	492 300	97 500	20%
Wealden	140 000	23 500	17%
Lewes	92 200	17 400	19%
Eastbourne	89 700	19 400	22%
Hastings	85 000	18 400	22%
Rother	85 400	18 800	22%

Source: [www.neighbourhood.statistics.gov.uk](http://www.neighbourhood.statistics.gov.uk)

The proportion of people with a limiting long-term illness has increased since the 1991 census, when 13.3 per cent of the population of England and Wales were recorded as having a long-term illness. In the same period there has been a 3.4 per cent increase in the number of people aged 65 and over. One in eight people of working age identified as having a long-term illness, health problem or disability which limited their daily activities or the work they could do. However, as the census question is not restricted purely to those with a physical or sensory disability, the results cannot be viewed as a representative reflection of the level of these forms of disability in the county.

### 3.2.2 Health Survey for England 2001

The Health Survey for England 2001 (HSE01) is an annual cross-sectional survey. The survey is based on a random sample of 13 680 addresses and includes all adults aged 16 and over in each household. The estimated response rate is over 67%. The HSE 2001 provides the latest estimates of disability and compares this to the figures for 1995, when disability was first measured.

Prevalence of disability was analysed by age and gender, and by socio-economic correlates of disability (social class, educational attainment, marital status, housing tenure, economic activity and household income) and a multivariate analysis of socio-economic correlates was carried out.

#### Type of disability

The disability questions in the HSE01 covered limitations in functional activities (seeing, hearing communication, walking and using stairs) and activities in daily living (getting in and out of bed or a chair, dressing, washing, eating and toileting). These were grouped into five disability types:

- Locomotion;
- Personal care;
- Seeing;
- Hearing; and
- Communication

Mental illness was not included.

### **Locomotor disability**

Locomotor disability was assessed by asking the participants in the survey whether they required any level of assistance in walking 200 metres, climbing 12 stairs without resting and retrieving things from the floor. Locomotor disability was the most commonly reported type of disability; 12% of men and 14% of women reporting this type of disability with three percent of men and four percent of women reporting serious disability.

For working age adults five percent of men and women reported having moderate locomotor disability, with one percent of men and two percent of women of the same age reporting a serious locomotor disability. This increased in the over 65s with 22% of men and 24 % of men reporting moderate locomotor disability and nine percent of men and 14% of women reporting serious locomotor disability. For respondents over 85 32% of women and 22% of men had serious locomotor disability.

### **Personal care disabilities**

The inability to perform self-care tasks or Activities of Daily Living without help is widely used in social surveys as a measure of physical dependency. Personal care disabilities were the second most common type of disability reported in the survey. Activities of Daily living include getting in and out of bed or a chair, dressing, washing, eating and toileting; overall, six percent of men and seven percent of women reporting this type of disability. One percent of men and women were unable to perform any of the Activities of Daily Living. In working-age adults three percent of man and four percent of women reported a moderate level of personal care disability with one percent of men and 0.5% of women in this age group reporting a serious personal care disability.

### **Seeing; hearing and communication disabilities**

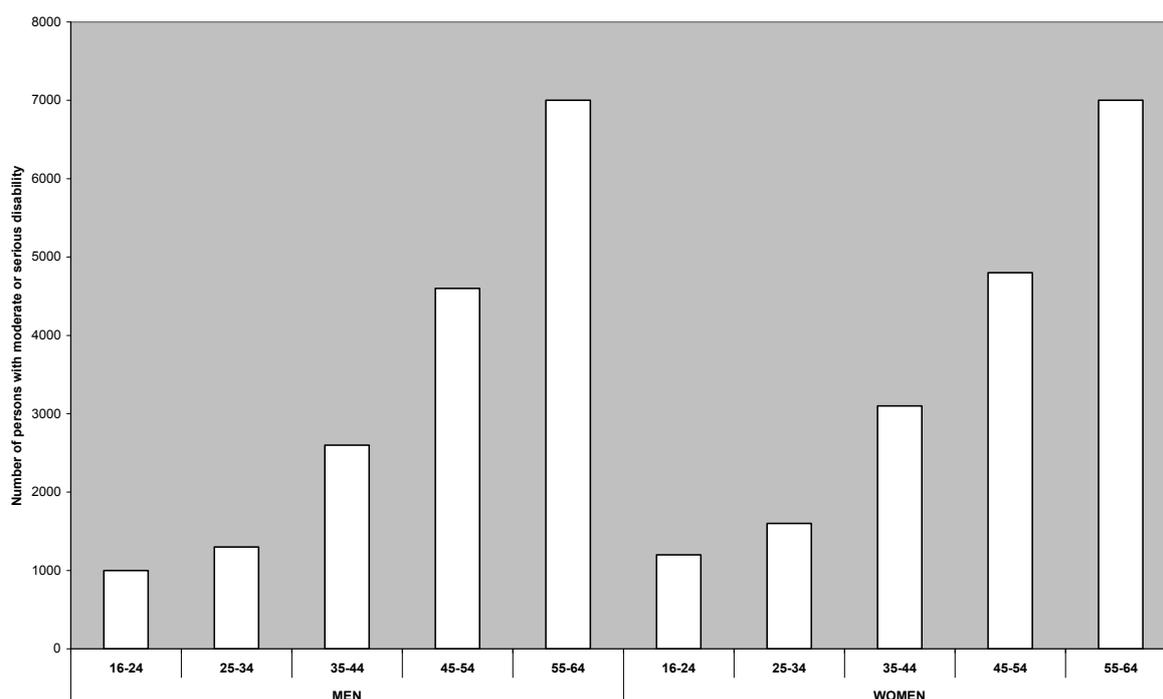
There were three other types of disability measured in the HSE01, hearing, sight and communication. The proportion of individuals reporting these types of disabilities were small, especially for those of working age.

Working age men reported a higher rate of hearing disability (3%) than women (2%). The prevalence of sight and communication disabilities was low, with only 1% of working age men and women reporting any type of sight disability. Only 1% of men and women across all age groups reported having a communication disability, it has been acknowledged that this may be an under-representation as there may be a non-response bias in this group.

### **Age**

The prevalence and severity of disability increases with age for both men and women with the mean age of those reporting at least one disability 62 compared to 44 for those respondents reporting no disability (Figure 2).

**Figure 2:** Number of working age persons with moderate or serious disability by age and gender



### **Disability severity**

The Health Survey used an adaptation of the World Health Organisation (WHO) classification system for impairments, disabilities and handicaps, and questions were adapted from the WHO protocol which was designed to estimate the percentages of the population experiencing different levels of long-term disability, with two levels of severity:

- Low (moderate)
- High (severe)

Responses to questions were scored on a scale of 0-2, where 1 and 2 indicated disability and 0 indicating no disability. For respondents of working age (16-64) the percentage of severe disability was 2.4% for men and 2.1% for women and for moderate disability this was 7.5% for men and 7.3% for women. Across East Sussex this would have been equivalent to 34 200 persons with moderate or severe disability in 2001. Those with moderate disability would have made up the largest proportion, with an estimated 4200 men and 4000 women reporting severe disability.

### **Socioeconomic differences**

There is a strong relationship between disability and social group, with those in lower social groups (IIIM, IV and V) reporting higher rates of disability and more severe forms of disability than those in higher social groups (I, II and IIINM).

### **Ethnicity**

When compared to England as a whole the proportion of working age people (16-64) from black and minority ethnic (BME) groups is lower in East Sussex, with over 93% of working-age residents identifying as 'White British' in the 2001 census (Table 5). This is lowest in Eastbourne (91%) and highest in Wealden and Lewes (94.7%).

**Table 5:** Working age (16-64 years) population by ethnic group (%)

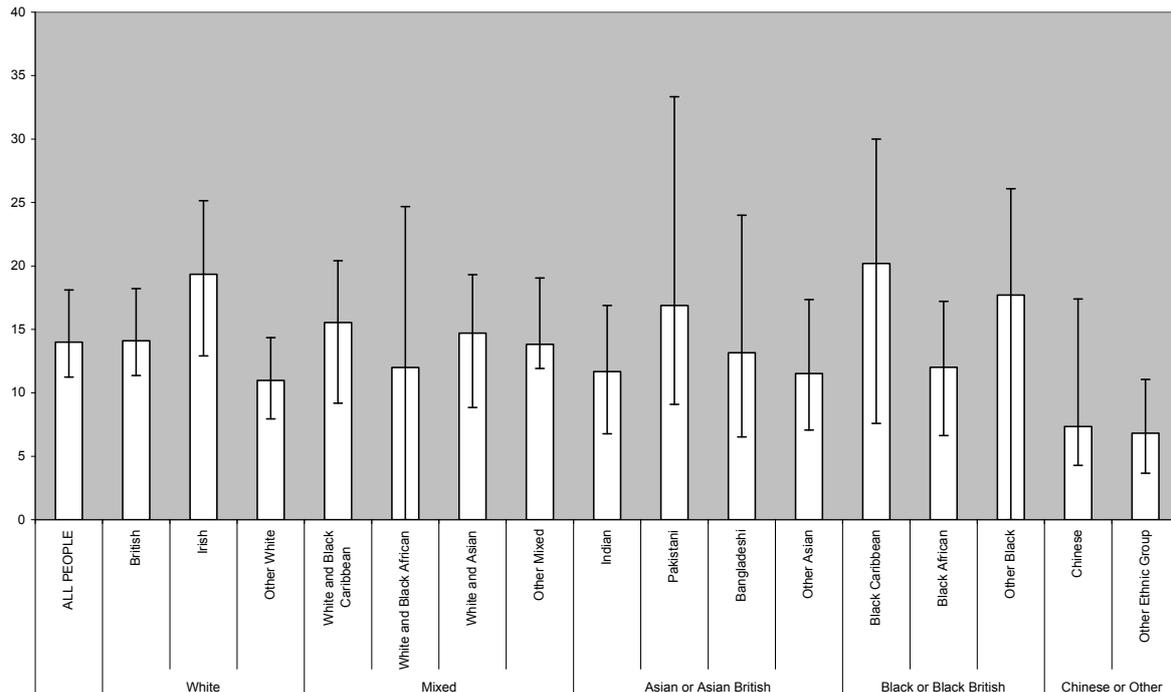
Ethnic Group		England	East Sussex	Wealden	Rother	Lewes	Hastings	Eastbourne
<b>White</b>	British	<b>86.8</b>	<b>93.8</b>	94.7	94.5	94.7	93.4	91.0
	Irish	<b>1.3</b>	<b>0.9</b>	0.7	0.8	0.8	1.1	1.2
	Other White	<b>3.1</b>	<b>2.8</b>	2.8	2.3	2.4	2.4	4.0
	White and Black Caribbean	<b>0.3</b>	<b>0.2</b>	0.1	0.1	0.1	0.3	0.2
<b>Mixed</b>	White and Black African	<b>0.1</b>	<b>0.1</b>	0.0	0.1	0.1	0.1	0.1
	White and Asian	<b>0.3</b>	<b>0.2</b>	0.2	0.2	0.2	0.4	0.3
	Other Mixed	<b>0.2</b>	<b>0.2</b>	0.1	0.2	0.1	0.3	0.2
	Indian	<b>2.2</b>	<b>0.3</b>	0.2	0.3	0.3	0.5	0.5
<b>Asian or Pakistani</b>	Pakistani	<b>1.3</b>	<b>0.1</b>	0.0	0.0	0.0	0.1	0.1
	Bangladeshi	<b>0.5</b>	<b>0.2</b>	0.1	0.1	0.1	0.1	0.3
<b>British Other Asian</b>	Other Asian	<b>0.5</b>	<b>0.2</b>	0.2	0.2	0.2	0.2	0.4
	Black Caribbean	<b>1.2</b>	<b>0.2</b>	0.1	0.1	0.1	0.3	0.2
<b>Black or Black African</b>	Black African	<b>1.0</b>	<b>0.2</b>	0.1	0.2	0.2	0.3	0.3
	Other Black	<b>0.2</b>	<b>0.0</b>	0.0	0.0	0.0	0.1	0.0
<b>Chinese</b>	Chinese	<b>0.5</b>	<b>0.4</b>	0.3	0.2	0.4	0.3	0.6
<b>or Other</b>	Other Ethnic Group	<b>0.5</b>	<b>0.4</b>	0.2	0.8	0.3	0.3	0.7

Source: 2001 Census

The HSE 2004 examined the health of ethnic minorities it found 23% of men and 27% of women reported a longstanding illness that limited their activities in some way, around the same level as found in previous years. Pakistani women and Bangladeshi men were more likely than those in the general population to report a limiting longstanding illness. The levels of both longstanding illness and limiting longstanding illness were significantly higher for Pakistani women in 2004 than they were in 1999.<sup>12</sup>

Locally, the 2001 Census found that the proportion of working-aged adults who identified themselves as having a limiting long-term illness was 14%. This was higher in a number of ethnic groups including: Black Caribbean (20.2%) White Irish (19.3%); Other Black (17.7%); Pakistani (16.9%); White and Black Caribbean (15.5%); and White and Asian (14.7%) (Figure 3). The lowest levels were seen in Chinese (7.3%) and 'Other' (6.8%) ethnic groups which reflect national findings.

**Figure 3:** Proportion of working-age (16-64) with limiting long term illness by ethnic group with maximum and minimum values for districts.



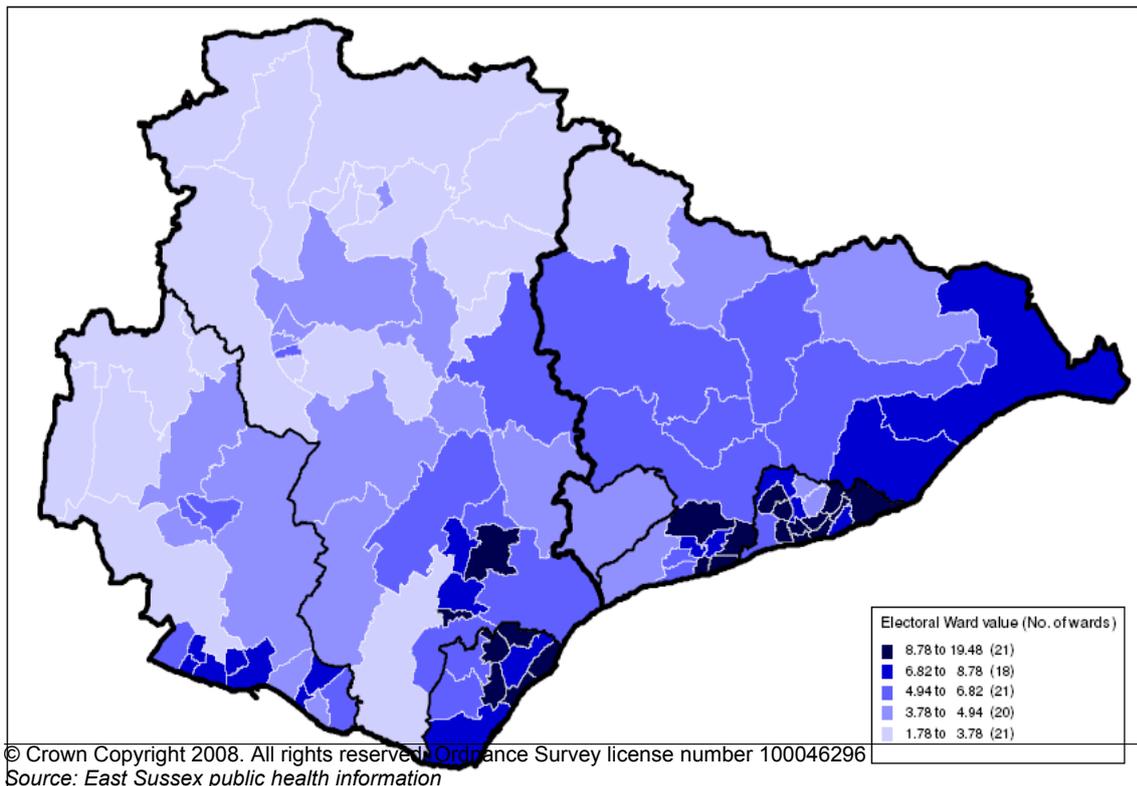
Source: 2001 Census: standard table S107

### 3.2.3 Disability benefits

The Disability Living Allowance (DLA) provides income support for adults and children who require assistance with personal care or have difficulty walking because of physical or mental disabilities. Incapacity Benefit (IB) Allowance provides income support to those people under the state pension age who cannot work because of illness or disability. The numbers of people registered for these allowances gives some limited information about the level of disability in East Sussex.

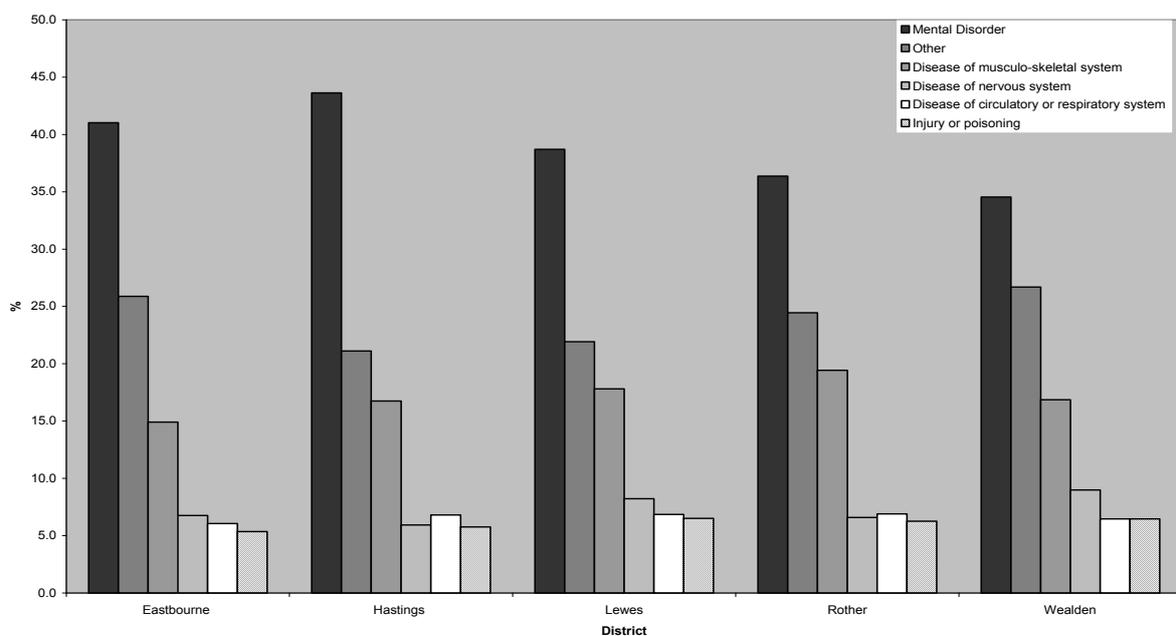
The number of people in East Sussex claiming these allowances of working age is around 19 000 for DLA and 19 500 for IB. It is possible that claimants of DLA will also be receiving IB so it is difficult to determine from these figures the exact number of persons claiming some kind of disability allowance within the county (Table 5). The proportion of people claiming benefits varies across the county (Map 1) with the highest rates seen in and around Boroughs of Eastbourne and Hastings.

**Map 1:** Dependency on health-related benefits – percentage of working-age people claiming incapacity benefit or severe disablement allowance, February 2007.



Across the districts of East Sussex, individuals with mental health problems make up the largest proportion of claimants (Figure 4). People with problems of the musculo-skeletal system, nervous system and circulatory or respiratory system follow this; although there are also a large number of people for whom the reason for claim is not specified (27% of all claimants).

Figure 4: Reason for IB Claim, by district.<sup>4</sup>



Source: [www.neighbourhood.statistics.gov.uk](http://www.neighbourhood.statistics.gov.uk)

### 3.2.4 Health counts 2003

A health related behaviour survey undertaken in the region in 1992 was repeated across the five primary care trust areas existent in 2003. The 2003 questionnaire received a 55% response rate, compared to 57% in 1992. Many of the questions were repeated, to gather comparative data. One question asked about limiting long-term illness and disabilities. The results show that there was no significant change over the 11-year period, with the level of disability recorded at 29%.

### 3.3 Expected trends in physical and sensory disability

At any given time, the underlying prevalence of disability is determined by the combined effect of various factors, such as past and recent incidence, remission rates for diseases and survival rates of people with disability and the general population. These factors may operate in a variety of ways. For example, a higher survival rate of people with long-term disability or disorders that cause disability could increase the prevalence, while a higher rate of recovery from disabling conditions may lead to lower prevalence.

Changes in the prevalence of people aging with disability acquired during childhood or early adulthood could affect future trends in disability among the older population as well as having implications for people & service provision over the lifetime of these people.

According to the HSE 2001, between 1995 and 2001 there was a drop of about one percentage point in the number of people with both severe and moderate disabilities in all age bands except older women. The proportion of women in the 55–64 age-band with moderate disabilities grew by one percentage point. Although the prevalence of most levels of disability decreased over the time period between the HSE 1995 and 2001, the actual numbers increased due to changes in the population structure (Table 6).

**Table 6:** Change in prevalence and severity of total disability 2000-1 compared to 1995-6, by age and sex (HSE)

HSE Results	Men					Total	Women					Total
	16-24	25-34	35-44	45-54	55-64		16-24	25-34	35-44	45-54	55-64	
Total disability 1995 (%)	5	6	9	16	27		6	7	10	14	22	
Moderate (%)	4	5	8	14	22		5	6	8	12	16	
Severe (%)	1	1	1	2	5		1	1	2	2	6	
Total disability 2000-01 (%)	4	5	8	14	25		5	6	9	14	23	
Moderate (%)	3	4	6	11	18		4	5	7	11	17	
Severe (%)	1	1	2	3	7		1	1	2	3	6	
<b>Estimated numbers in East Sussex</b>												
Total disability 1995* (n)	1200	1600	2700	4100	6200	<b>15600</b>	1400	2000	3200	3700	5900	<b>16200</b>
Total disability 2000-01+ (n)	1000	1300	2600	4600	7000	<b>16500</b>	1200	1600	3100	4800	7000	<b>17700</b>

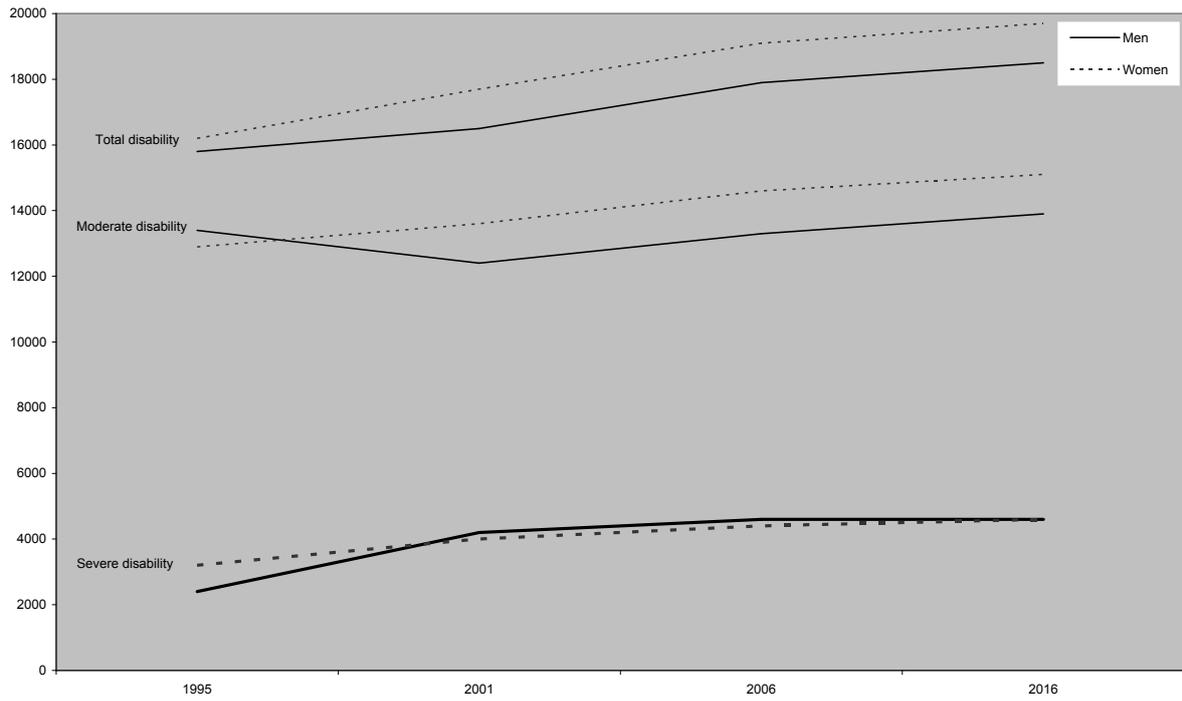
\* Estimate based on 1991 Census population figures

+ Estimate based on 2001 Census population figures

Source: HSE 2001; ONS Census statistics

If it assumed that the prevalence of disability in working age adults had remained stable since the HSE01, it would be expected that in 2006 the total numbers of people in East Sussex with disability would have continued to increase due to the predicted increases in numbers of older working age persons (Figure 5). The largest increase would have been seen in those with moderate disability, whilst the numbers with severe disability remained similar to 2001 levels, with an overall increase of 10% (approximately 400 more women and 400 more men with severe disability). If these projections are extended to 2016 it is estimated that actual numbers will increase slightly in women, but remain stable in men resulting in an extra 200 people of working age with severe disability.

**Figure 5:** Estimated changes in the number of people with disability by severity, 1995-2016.



Source: HSE 1995; HSE2001; Census populations 1991 and 2001; ONS 2004 Mid-year projections

### 3.4 Epidemiology of specific conditions

There are a large number of conditions that can lead to physical and sensory disability, for the purposes of this needs assessment conditions have been separated in to three distinct categories: neurological; locomotor; and sensory (summarised in Table 7). The epidemiology of a number of key conditions for each category has been examined in detail; the conditions described are those which may have significant levels of physical disability associated with them. However, it is beyond the scope of this report to consider in detail all conditions which may lead to physical disability.

**Table 7:** Estimated number of people in East Sussex with conditions leading to physical disability.

Condition	National (rate 100 000 <sup>-1</sup> population)		Estimated number ESCC (500k population)*		
	Incidence	Prevalence	Incidence	Prevalence	
Neurological	ABI including TBI	175	1200	870	6000
	Spinal cord injury	2	50	10	250
	Young onset stroke (<65)	55		275	
	Epilepsy	24-58	430-1000	120-290	2150-5000
	Motor neuron disease	2	7	10	35
	Multiple sclerosis	3-7	100-120	20-40	500-600
	Parkinson's disease	17	200	80	1000
	Huntington's disease		13.5		70
	Muscular dystrophy		50		250
	Cerebral palsy		186		930
	Spina Bifida		2		10
Locomotor	Myalgic encephalomyelitis		300-500		1500-2500
	Rheumatoid arthritis	770	1960	3850	9800
	Osteoarthritis	7620	12 770	38 100	63 850
Sensory	Amputation	9.5		50	
	Deaf or hard of hearing aged 16 to 60		4100		12 300
	Mild to moderate deafness aged 16-60		3900		11 700
	Severe to profound deafness aged 16-60		200		600
	Blind		50		250
	Visually impaired		80		400
Deafblind		40		120	

\*prevalence numbers have been rounded to nearest 10

Source: see footnotes

Most condition-specific studies do not differentiate between different age groups, with the population as a whole the most common denominator for calculating incidence and prevalence rates. Where possible, incidence and prevalence rates for working-age adults are highlighted in this report. However, for most conditions rates given refer to the whole population.

#### 3.4.1 Neurological conditions

Approximately 10 million people across the UK have a neurological condition. These count for 20% of acute hospital admissions and are the third-most common reason for seeing a GP. A 'long-term neurological condition' results from disease of, injury or damage to the body's nervous system which will affect the individual and their family in one way or another for the rest of their life. The National Service Framework (NSF) for long term (neurological) conditions divides neurological conditions into four categories:

1. Sudden onset conditions, for example acquired brain injury or spinal cord injury, followed by a partial recovery;
2. Intermittent and unpredictable conditions, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed;
3. Progressive conditions, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from

- others. For some conditions (e.g. motor neurone disease) deterioration can be rapid. (Note: dementia for all ages is covered in the NSF for Older People);
4. Stable neurological conditions, but with changing needs due to development or ageing, for example post polio syndrome or cerebral palsy in adults.

#### **3.4.1.1 Acquired Brain Injury**

The term 'acquired brain injury' (ABI) is most widely used as an umbrella term to describe disabilities arising from any damage to the brain acquired after birth, regardless of cause. Brain injury acquired at birth or very early in life is sometimes included in the scope of ABI, but more often included within the intellectual disability group.

ABI can result in the deterioration of cognitive, physical, emotional or independent functioning. *Community Care and Health Improvement Programme 2001-05* Causes of ABI include traumatic accidents, neurological diseases, stroke and substance abuse. The Demographics of risk factors in the UK are:

- 70-88% of all people that sustain a head injury are male.
- 10-19% are aged greater than or equal to 65 years.
- 40-50% are children.
- Falls (22-43%) and assaults (30-50%) are the most common cause of a minor head injury, followed by road traffic accidents (25%). Road traffic accidents account for a far greater proportion of moderate to severe head injuries.
- Alcohol may be involved in up to 65% of adult head injuries.

Head injuries requiring hospitalisation occur at the rate of about 300 per 100 000 population annually in the UK, of these approximately 250-280 will be mild, 15-20 moderate and 5-10 severe. Within these numbers there are difference in the rate of head injury between urban and rural areas, and there are peaks at 15-24 years of age and >75 years. Where public transport is not used for journeys to work, the incidence of head injuries requiring hospital admission is high for both urban and rural communities. It is in urban communities where this is combined with higher unemployment rates and other 'lifestyle' indicators that the highest incidence rates are observed.

Most studies of ABI incidence focus on morbidity and mortality, rather than disability. Many such studies are based on hospital data and use rates of hospitalisation (admissions) as indicative of incidence. The operational definitions used in incidence studies often focus on diagnoses and symptoms associated with brain injury, rather than long-term effects, since information on the long-term effects of brain injury is not generally available at the time of occurrence of the injury.

Estimating the numbers of people with residual problems from head injury is difficult. There are relatively few existing estimates of the prevalence of long-term disability attributable to ABI. International prevalence estimates range from 62 to 783 per 100,000 population. The majority of these estimates were based on population surveys and limited to people living in households. It has been suggested that in the UK approximately 150 per 100 000 population have persistent disability resulting from head injury although these are likely to be conservative estimates.

People with ABI often experience a range of physical, social and emotional difficulties due to the complex nature of ABI. Consequently ABI demands intensive health care in the short-term and collaborative input from health, social work and voluntary organisations over the medium to long term.

#### **3.4.1.2 Spinal cord injury**

A spinal cord injury usually begins with a sudden, traumatic blow to the spine that fractures or dislocates vertebrae. The most common causes of spinal cord injury are: motor vehicle accidents; falls; violent assaults, gunshot wounds; sports and recreation

injuries; malignancy, infections, arthritis and inflammation of the spinal cord also cause spinal cord injuries. Spinal cord injuries may be primary or secondary:

- Primary injuries arise from: mechanical disruption; transaction; penetrating injuries; or displaced bony fragments which cause penetrating spinal cord and/or segmental spinal nerve injuries.
- Secondary injuries are mostly caused by arterial disruption or thrombosis, or hypoperfusion due to shock.

In most cases the spinal cord is not completely severed, instead, an injury is more likely to cause fractures and compression of the vertebrae, which then crush and destroy the spinal nerve tracts. The prognosis is variable between almost complete recovery and complete paralysis.

Spinal cord injuries are classified as either complete or incomplete. An incomplete injury means that the ability of the spinal cord to convey messages to or from the brain is not completely lost. People with incomplete injuries retain some motor or sensory function below the injury. A complete injury is indicated by a total lack of sensory and motor function below the level of injury.

Spinal cord injury is less common than ABI with an annual incidence of 2 per 100 000 population. Suggesting that in East Sussex there will be ten patients with spinal cord injury presenting annually.

#### **3.4.1.3 Epilepsy**

Epilepsy is a neurological condition that affects the nervous system. It is also known as a seizure disorder. There are several types of epilepsy, broadly categorised as: idiopathic where the cause is unknown, may be genetic, and may begin in childhood; or symptomatic where the cause is known. This can include head injury, infections or stroke. Diagnosis of epilepsy is not straightforward, and is usually made after at least two seizures not related to an external factor, such drug or alcohol withdrawal.

The overall incidence of epilepsy in developed societies has been found to be around 50 cases per 100 000 persons per year (range 40–70 per 100 000 population per year). The incidence is highest in children under 10 and in the elderly. There is recent evidence that increased incidence may be linked to socioeconomic deprivation.

Typically the prevalence levels quoted for epilepsy are about 5-10 cases per 1000 persons, excluding febrile convulsions, single seizures and inactive cases. The lifetime prevalence of seizures (the risk of having a non-febrile epileptic seizure at some point in an average lifetime) is between two and five percent. In recent community-based studies, it has been shown that for most patients epilepsy is relatively short-lived: over two-thirds enter long-term remission, and once remission has occurred subsequent relapses are uncommon. The course of the condition in its early years is an important predictor of prognosis; the longer epilepsy remains active the poorer the long-term prognosis. Mortality in people with epilepsy has been studied in various populations. In incidence cohort studies, mortality compared to the general population (SMR=1) ranged from 1.6 – 3.

#### **3.4.1.4 Stroke**

Stroke is defined as a neurological impairment of sudden onset that is caused by a disruption of the blood supply to the brain. In a population of 100 000, there will be approximately 200 first-ever and 40 recurrent strokes per year, of these 30% will die in the first month and of the survivors 65% will recover and be capable of living independently whilst 35% will be significantly disabled.

Stroke occurs more commonly in people aged over 65. However, in those aged under 65 there are approximately 20 strokes per 100 000 population per year. In a population the size of East Sussex the estimated number of strokes per year in those aged under-65 would be 80, with approximately 1200 new and recurrent strokes occurring in the population as a whole.

According to the HSE 2004 the national prevalence of stroke for working-aged adults (16-64) in 2003 was 2.14% for men and 1.78% for women. Suggesting that in East Sussex the expected number of working age people who have experienced a stroke would be 3100 men and 2800 women.

#### **3.4.1.5 Multiple sclerosis**

Multiple Sclerosis (MS) is a chronic inflammatory demyelinating disease of the central nervous system leading to progressive impairment of various systems. There are three forms of the disease:

- Relapsing/Remitting MS: symptoms come and go with periods of health or remission followed by sudden symptoms or relapses (80% of patients at onset).
- Secondary progressive MS: follows on from relapsing/remitting MS. There are gradually more or worsening of symptoms with fewer remissions (approximately 50% if those with relapsing/remitting MS develop secondary progressive MS during the first 10 years of their illness).
- Primary progressive MS: from the onset of the illness symptoms gradually develop and worsen over time (10-15% of patients at onset).

MS is most commonly diagnosed in adults between the ages of 20-40 years of age and women are almost twice as likely to be diagnosed as men. MS patients have a normal or near-normal life expectancy and because of the relapsing/remitting nature of the disease an increased demand on medical services as patient's age is to be expected.

Patients with MS may develop a wide range of functional impairments and disabilities that will impact on their quality of life and degree of handicap. The epidemiology of multiple sclerosis has been well studied in relation to the aetiology of the disease. However, there have been few studies on the prevalence of the consequences of the disease. There have been no significant studies on the incidence of specific consequences of the disease, such as how many people in a given population will have a relapse each year. Indeed there is no agreed definition of what constitutes a relapse or on the reliability of its diagnosis. There are few studies investigating the mechanisms linking progressive impairments to limitations in activities and participation.

Between 3-7 people per 100 000 population are newly diagnosed with MS each year and about 100-120 people per 100 000 population have MS. It has been estimated that 15 years after onset 15% of MS patients will need walking aides and 29% will require the use of a wheelchair.

The National Collaborating Centre for Chronic Conditions guideline for diagnosis and management of MS in primary and secondary care recognises that the lack of any firm data on the incidence, prevalence or severity of almost all impairments and activity limitations is a major problem in planning services, and in recommending service organisation.

#### **3.4.1.6 Parkinson's Disease**

Parkinson's disease is the second most common neurodegenerative disease after Alzheimer's disease; it is a movement disorder characterised by degeneration of dopaminergic pathways in the brain. The main features are resting tremor, rigidity and bradykinesia (slowed ability to start and continue movements, and impaired ability to adjust the body's position). Drug-induced Parkinsonism is caused by drugs that block the

dopamine receptors or reduce storage of dopamine. This is mainly the major tranquilisers used to treat psychosis but the condition can also be seen with drugs used to treat nausea. Parkinsonism may also occur following encephalitis or exposure to certain toxins, for example in exposure to manganese dust; carbon disulfide; or severe CO poisoning.

A systematic review of European studies reports wide variation in incidence (5 to 346 per 100 000) and prevalence (65.6 to 12,500 per 100 000), possibly due to genetic and environmental factors, but also due to differences in methodology. Prevalence increases with age and slightly commoner in men, with standardised rates of the order of 1.35. It affects one per cent of the population over 65 years of age, rising to two per cent over 80 years. Onset is insidious with peak age of onset at 55-65 years, although it is estimated that five per cent of patients are diagnosed before the age of 40.

The annual incidence rate in the UK is estimated at 20 per 100 000, with a prevalence rate of 180 per 100 000, about 40% of whom will have severe disability. Suggesting there will be 100 new cases of Parkinson's disease in East Sussex annually, four of whom would be aged 40 or younger.

#### **3.4.1.7 Motor Neuron Disease**

Motor neuron disease (MND) is characterized by progressive degeneration of upper and lower motor neurons with preservation of cognition. There are several forms of MND:

- Amyotrophic lateral sclerosis affects the upper and lower motor neurons. It is usually sporadic although there are known familial cases. It presents as 80% of cases and begins with weakness in the hands or feet and has a prognosis of 3-5 years.
- Progressive muscular atrophy begins in the lower motor neurons and presents as weakness in hands and feet but has a survival of 5–20 years.
- Progressive bulbar palsy presents as 12- 25% of cases by affecting the bulbar nerves as it begins in the throat and can cause death between six months to 3 years from diagnosis.

A further type is Primary Lateral Sclerosis which begins in the upper motor neurons and has a much slower progression and can offer a prognosis of 20 years or near normal life expectancy but with increasing debilitation. All of these diseases are unpredictable and people may develop a combination of types.

MND can affect any adult at any age but most people are diagnosed over the age of 40 years with the highest incidence 50-70 age range. It is more common in men, affecting about three men for every two women. This disease is usually progressive and rapidly fatal, but some patients experience a milder attenuated course. Although thinking and reasoning are not usually affected, around one in five people with MND will experience some level of intellectual difficulty or a change in personality.

The annual incidence of MND is 2 per 100 000. A low median survival time of 1.5 years leads to a prevalence of only 7 per 100 000, with severe disability. The expected number of people diagnosed annually across East Sussex is 10, with a prevalence of only 35 patients across the county.

#### **3.4.1.8 Cerebral palsy, spina bifida, and other muscular dystrophies:**

The incidence rate for cerebral palsy (2 per 1000) and muscular dystrophy (1.3 – 3.3 per 10 000) have remained relatively stable, the prevalence of these conditions (200 and 90 per 100 000 population, respectively) has increased with improved survival.

The incidence of live births with spina bifida, in contrast, is decreasing as it can now be diagnosed antenatally. The prevalence is now less than 2 per 100 000 school leavers.

### **3.4.2 Locomotor conditions**

#### **3.4.2.1 Arthritis**

Arthritic conditions are extremely painful. Musculo-skeletal conditions are associated with significantly decreased quality of life, ranking higher in outcome measures of pain and impact on physical functioning in comparison with other long-term disorders (respiratory, cardiovascular and gastrointestinal). Arthritis places a considerable economic burden on the health care systems of Western countries, musculo-skeletal conditions being the second most common reason for primary care consultation. There are a variety of treatments available for arthritis including medication (for example non-steroidal anti-inflammatory drugs and disease-modifying drugs), physiotherapy and surgery. Another public health consideration is that people presenting to health care services with arthritis are more likely than their age and gender matched peers to be consulting for four or more other complaints.

The two most common forms of the disease: osteoarthritis and rheumatoid arthritis are discussed below.

#### **Rheumatoid arthritis**

Rheumatoid arthritis (RA) is a chronic inflammatory disease of the joints. It is usually a chronic relapsing condition, but its course can vary from a mild disease to a severe destructive form in a few years. Each relapse leads to damage of the joints and the amount of disability that develops is related to the amount of damage done over time. In a minority of cases the disease is constantly progressive leading to severe joint damage and disability developing rapidly.

Approximately one percent of the population have RA. Women are two to three times more likely to develop RA than men: one study finding an incidence of 36 per 100 000 population for women and 14 per 100 000 for men. The disease most commonly develops between the ages of 30 and 60, with approximately 80% of total cases occurring between the ages of 35 and 50.

Estimating disability levels in RA patients is difficult because of the remitting/relapsing nature of the disease. It has been estimated that 11-14% of patients with RA will require a joint replacement within 5 years. An English study found that although 60% of RA patients were still in paid employment after 5 years, the level of work disability was 22%, and was higher in manual workers. The prevalence of severe disability due to RA is 130 per 100 000 population. A total expected prevalence of 1200 persons in East Sussex.

#### **Osteoarthritis**

Osteoarthritis (OA), sometimes called degenerative joint disease, is uncommon in people under 40 and increases with age thereafter. Other risk factors include being overweight and having an injury, operation or repeated strain on a joint.

OA affects 70% of all women and 55% of all men at some time in their lives, and is the most common joint disease in the world. In 2003 the UK rates for men and women were less than 25 per 1000 population up to age 44. After the age of 45 there was a rapid increase in prevalence, with rates increasing six fold to age 64. The rates for women then rose more sharply than for men: among those aged 65-74, the prevalence rate for women was twice that for men (227 per 1000 compared with 113).

The prevalence of severe disability due to osteoarthritis is 300 per 100 000 population, with the same expected prevalence of disability in East Sussex as for rheumatoid arthritis (1200 persons). Table 8 contain estimates for different types

of arthritis compared to long-standing back pain as applied to the East Sussex working-age population.

**Table 8:** Self Reported Symptoms from Living in Britain General Household Survey 2000

Condition	Males				Females			
	16-44		45-64		16-44		45-64	
	%	number	%	number	%	number	%	number
Longstanding arthritis and rheumatism	1.4%	1148	8%	4872	1.4%	1190	11%	7117
Longstanding Back pain	3.5%	2460	7.5%	4568	3%	2250	6%	3882

### 3.4.2.2 Amputation

The amputation of limbs or parts of limbs occur for a number of reasons, the most common reason in Europe is because of occlusive arterial disease, but other reasons include trauma, neuropathy, neuroplasm excision and congenital limb deficiencies.

There are strong gender and age differences in the rates of amputation with men accounting for two thirds of all amputations and one quarter of men and two fifths of women amputees being over 75 years-of-age. Men also present at an earlier average age than women: 65 and 75 respectively. This type of age/sex differentiation is seen across Europe and North America with lower limb amputations accounting for the highest proportion of amputations. Diabetes is a significant factor in lower-limb amputation. People with diabetes constitute 50% of all major lower limb amputees. Diabetes-related lower extremity amputation rates have been found to be 12.5 to 31.6 times those of patients without diabetes.

The National Amputee Statistical Database report annually on the number of patients referred to prosthetic service centres around the UK. In 2005/06 there were a total of 5000 new referrals, this was a reduction on the number from the previous years (5224) and gives a rate of approximately 9.5 per 100 000 population nationally. Suggesting the expected annual number of amputations in East Sussex is approximately 47.

In 2005/06 lower limb amputations accounted for 91% of all amputations with upper limb accounting for 5% and congenital amputations accounting for the remaining 4%. The most common cause for upper limb amputation was trauma; lower limb amputations were most frequently the result of conditions that cause a defective blood supply to the limb, most commonly diabetes (72% of all cases).

Over half of all amputations take place in those aged over 65, with one quarter occurring in those over the age of 75. The median age of men undergoing amputation is younger (66 years) than women (69 years). Those undergoing upper limb amputation have a younger age profile than those undergoing lower limb amputations, with 60% under 55 years of age. This is a reflection of the aetiology of the condition (mainly trauma).

### 3.4.3 Sensory disability

As with physical disability the term 'sensory disability' is a general term used to include people with a wide variety and levels of disability. A sensory disability is blindness, deafness, or a severe vision or hearing impairment or a combination of these.

#### 3.4.3.1 Visual impairment and blindness

Visual impairment can be defined as any chronic visual deficit that impairs everyday function and is not correctable by ordinary glasses or contact lenses. Visual Impairment is a term used to cover those who have some residual vision to those who have no sight at all. Vision impairment is included in the ten most prevalent causes of disability in the UK. In adults, vision impairment is associated with loss of personal independence and difficulty in maintaining employment, often leading to the need for disability pensions, vocational and social services, and nursing home or assistive living placements.

Visual impairment affects all age groups but predominantly older people so the demand for services to prevent and treat people with visual loss and to support them will increase as the population ages. The prevalence and incidence of visual impairment is dependent on a range of factors:

- The incidence of children born with visual impairment or those that develop low vision in the early years of their life;
- Transmission of hereditary conditions;
- The prevalence and incidence of common eye diseases such as age related macular degeneration and glaucoma;
- The prevention and treatment of avoidable causes of blindness;
- Long term conditions that also have an impact on vision such as diabetes and 'diabetic retinopathy'.

The major causes of new blind and partial sight certification in England and Wales for working population aged 16-64 yrs according to certifications received by the ONS in 2006 were: macular degeneration (14%), diabetic retinopathy (10%) and glaucoma (5%).

Estimates of visual impairment in the population aged 16-64 range from 0.8% to 2.0%, mainly due to a difference in the selection criteria in studies. Using these upper and lower estimates as a guide there could be anywhere between 2080 and 5200 people of working age with a registerable visual impairment resident in East Sussex (Based on a working age population of 260 000).

### 3.4.3.2 Hearing Impairment

Deafness is a partial or complete loss of hearing, also known as hearing impairment. The normal hearing range is 0-20 decibels, where zero decibels is the threshold for the perception of sound at a given frequency for people with normal hearing (Table 9).

**Table 9:** Levels of deafness and hearing impairment

Rating	dB HL range	Cannot hear...
mild	20-40	whispers
moderate	41-70	conversational speech
severe	71-95	shouting
profound	>95	sounds that would be painful for a hearing person to listen to

Source: RNID

There are two types of deafness which are not mutually exclusive: conductive and sensorineural hearing loss.

Conductive hearing loss occurs when there is a problem in the transmission of sound waves from the external ear, through the middle ear. The disease processes, which may be congenital or acquired, can occur at any level along this part of the ear and include conditions such as excess ear wax, trauma, otitis externa or media with effusion and otosclerosis.

Sensorineural hearing loss refers to problems occurring in the cochlea (most common site of disease), cochlear nerve, or brain stem resulting in abnormal or absent neurosensory impulses. There are also a number of congenital and acquired conditions resulting in sensorineural hearing loss but by far the most common is presbycusis: age-related hearing loss which may also be associated with tinnitus (noise heard in the ear in the absence of environmental noise).

There are almost 9 million hearing impaired adults in the UK, of whom approximately 8% have severe to profound deafness. There is a clear relationship between age and hearing impairment with an estimated 1% per year of 45-55 year olds and a 1.5% per year in over 55 year olds having some level of hearing impairment, rising to 21.6% of

over 50 year olds and 71.1% of over 70 year olds having some degree of presbycusis (age-related hearing loss). In 0.6% of over 50 year olds and 1.3% of over 70 year olds, this leads to profound hearing loss. Deafness occurs slightly more commonly in males than in females and is thought to be more likely to occur in white ethnic groups.

A high proportion of severely or profoundly deaf people have disabilities as well. Among those under 60 years old, 45% have additional needs: these are more likely to be physical disabilities. Among severely or profoundly deaf people over 60 years old, 77% have some disability. For 45%, this means significant dexterity or sight difficulties, or both.

#### **3.4.3.3 Dual sensory loss**

Deafblind, or dual sensory loss, refers to people with a combination of sight and hearing loss. This includes people who are both deaf and blind from birth, people who are either blind or deaf from birth and who lose the other sense and people who acquire a significant visual and hearing impairment in later life. The majority of deafblind people are over the age of 60 and come into the last group.

The needs of all these groups are very different, especially people born deaf or prelingually deaf, with the consequent difficulties of developing language and speech. The impact of a dual loss is significantly different from a single loss as the individual's ability to compensate is greatly reduced. People with a dual sensory loss typically have difficulty with communication, access to information and mobility.

The Deafblind Services Liaison Group estimate the prevalence rate of deafblindness is 40 per 100 000. Based on this, the estimated number of deafblind people in East Sussex is 200. Although it is estimated that 60% (120) of these will be over the age of 65.

## 4. Current services

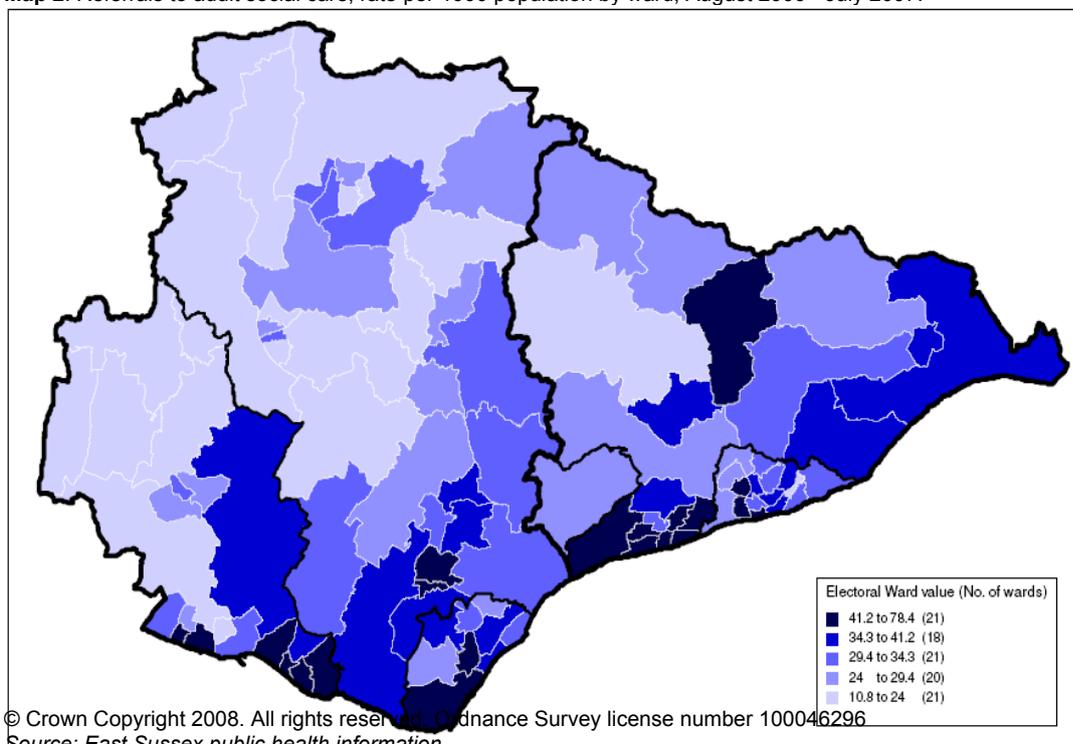
This section summarises the level of service activity dedicated to working age adults with physical and sensory disability from both health and social care.

### 4.1 Social Care

Social care referral data are collected from the 'CareFirst' information system which has records of East Sussex residents with physical disability who have been assessed by adult social care and those people who have received a service. However, it is acknowledged that not everyone with a physical disability will be in contact with social services.

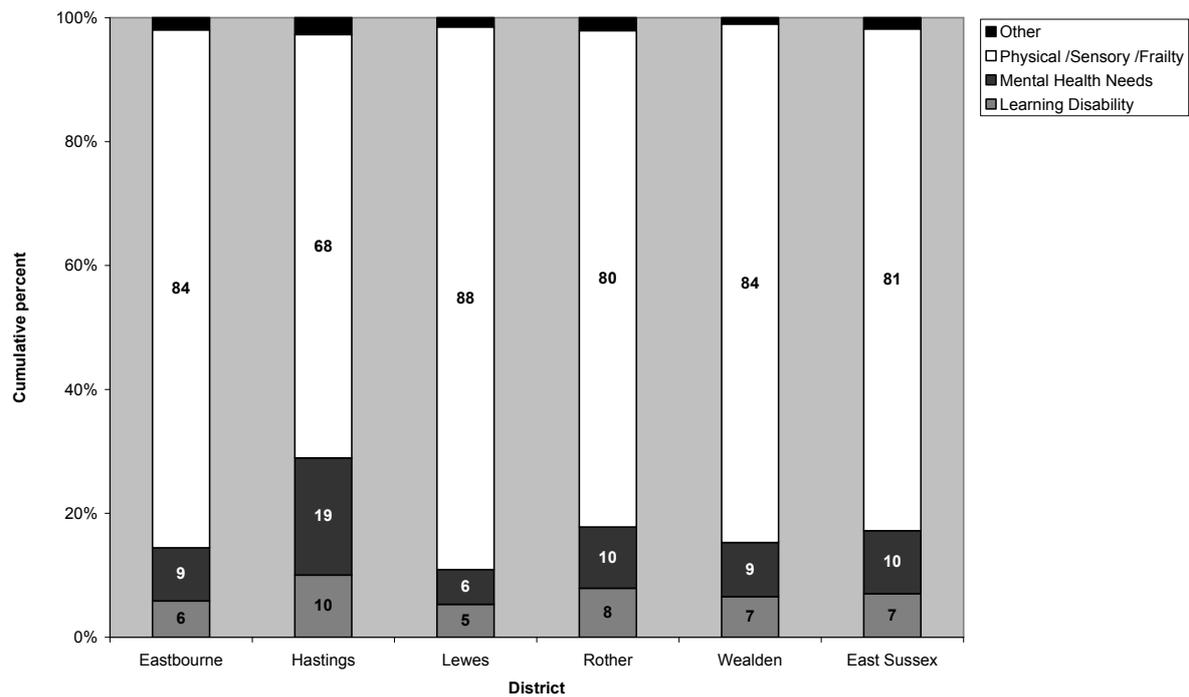
At ward level, the number of referrals to adult social care during the 12 months from August 2006 to July 2007 varied from 10.8 to 78.4 per 1000 population (Map 2). During this time there were a total of 17 034 referrals, of all ages.

**Map 2:** Referrals to adult social care, rate per 1000 population by ward, August 2006 - July 2007.



For the same time period, the number of clients (all ages) in receipt of community equipment services was 11 672. Over 80% of these clients were receiving services as a result of physical or sensory disability, although this proportion was lower in Hastings Borough, where there were a greater proportion of clients receiving services as a result of mental health needs and learning disabilities compared to the other local authorities (Figure 6)

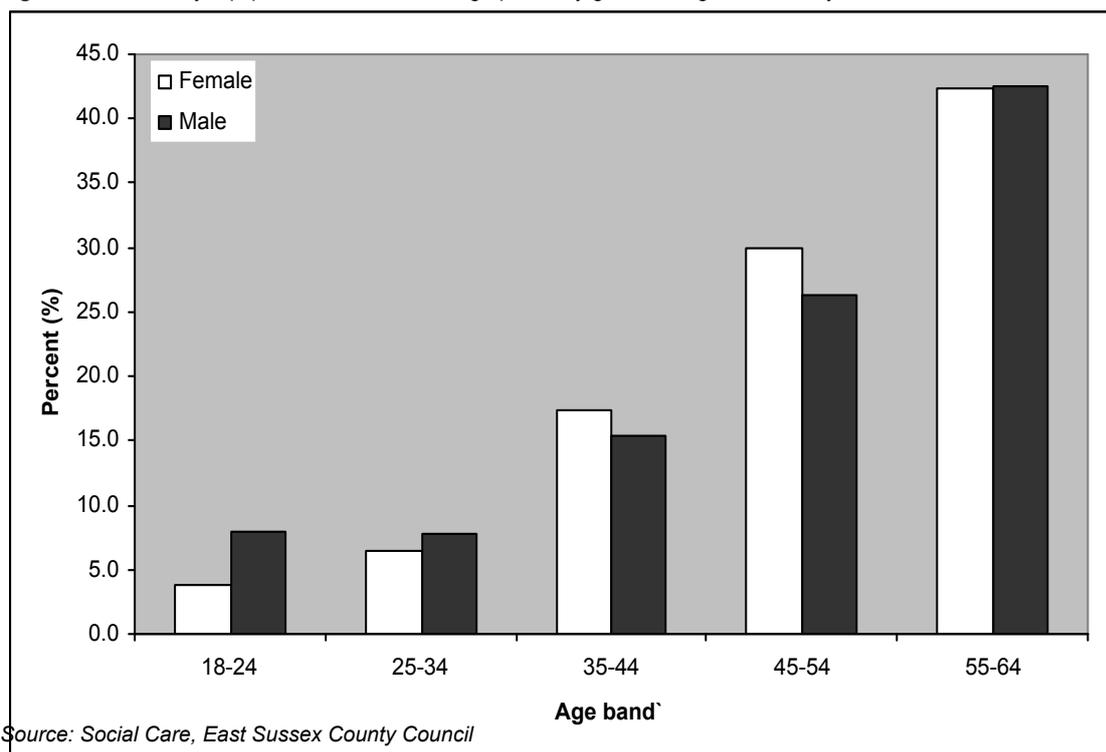
**Figure 6:** Proportion of clients receiving community equipment services by client category and local authority, August 1006 – July 2007.



Source: Social Care, East Sussex County Council

The number of working-age adults (18-64) recorded as receiving community equipment services for 'physical disability' was 2021 representing 18% of all clients. The average number of contacts per working-age client was two, ranging from one to twenty two. There were a greater proportion of female clients (58%) than male clients (42%). Male clients were on average younger than female clients ( $48.7 \pm 95\%CI 0.9$  years' v  $49.9 \pm 0.6$  years). The greatest proportion of clients were aged between 55 and 64, for both males (43%) and females (43%) (Figure 7). In the younger age groups (18-34) there were a greater proportion of male clients, with a greater percentage of female clients aged between 34 and 54.

**Figure 7:** Community equipment services client age profile by gender, August 2006-July 2007



Over 90% of clients in receipt of community equipment services had their ethnicity recorded; the greatest proportion of clients were recorded as 'White British or Irish' (96.8%) and 'White Other' (1.8%). In comparison to the expected population estimates from the Office for National Statistics

**Table 10:** Ethnicity profile of community equipment service clients compared to ONS population estimates by ethnicity, August 2006-July 2007.

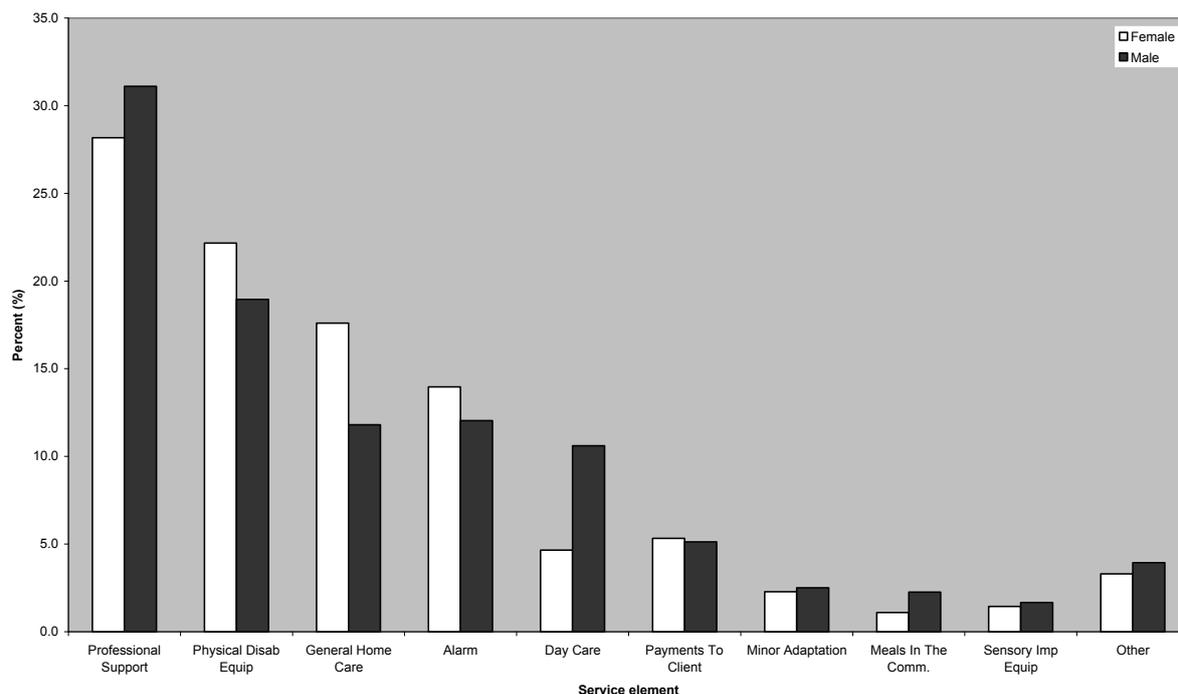
Ethnic group (level 1)*	People receiving equipment	2005 ONS population estimates by ethnicity
White British and Irish	96.8	91.9
White Other	1.8	2.8
All Mixed	0.2	1.1
All Asian and Asian British	0.3	1.3
All Black and Black British	0.1	1.0
All Chinese and Other	0.3	1.0

\*Using ethnicity groupings from the 2001 census

Source: Social Care, East Sussex County Council

Over 90% of client contacts were ascribed to six service elements: 'Professional Support' (29%); 'Physical Disability Equipment' (21%); 'General Home Care' (15%); 'Alarms' (13%); 'Day Care' (7%); and 'Payment to Client' (5%). Figure 8 presents the proportion of clients receiving individual service elements by gender. For both male and female clients 'Professional Support' is the most commonly received service. A greater proportion of male clients were in receipt 'Day Care' and 'Meals in the community' services; whereas, more female clients were in receipt of 'Physical Disability Equipment', 'General Home Care' and 'Alarm' services.

**Figure 8:** Proportion of clients receiving individual service elements by gender, August 2006-July 2007.



Source: Social Care, East Sussex County Council

#### 4.1.2 Registers for sensory disability

Under Section 29 of the National Assistance Act 1948 local authorities are required to compile and maintain classified registers of "persons who are blind, deaf or dumb..." under the categories:

- blind;
- partially sighted;
- deaf with speech;
- deaf without speech;
- hard of hearing; and
- general classes (those whose primary handicap is neither visual nor auditory).

Statistics on registered disabled persons are, in general, collected from local authorities in England on a three year rolling cycle. Information for blind and partially sighted people was last collected in 2006. Information for deaf and hearing impaired people was most recently collected in 2007.

Registration of sensory disability is voluntary and many people choose not to register. However, it is a pre-condition for the receipt of certain financial benefits. It is this factor which gives greater credibility to the registers of the blind and of the deaf than to the registers of the partially sighted or hearing impaired. Registration is not a pre-requisite for social services concessions and this factor, makes it difficult to assign a degree of reliability to these registers.

#### Visual disability registers

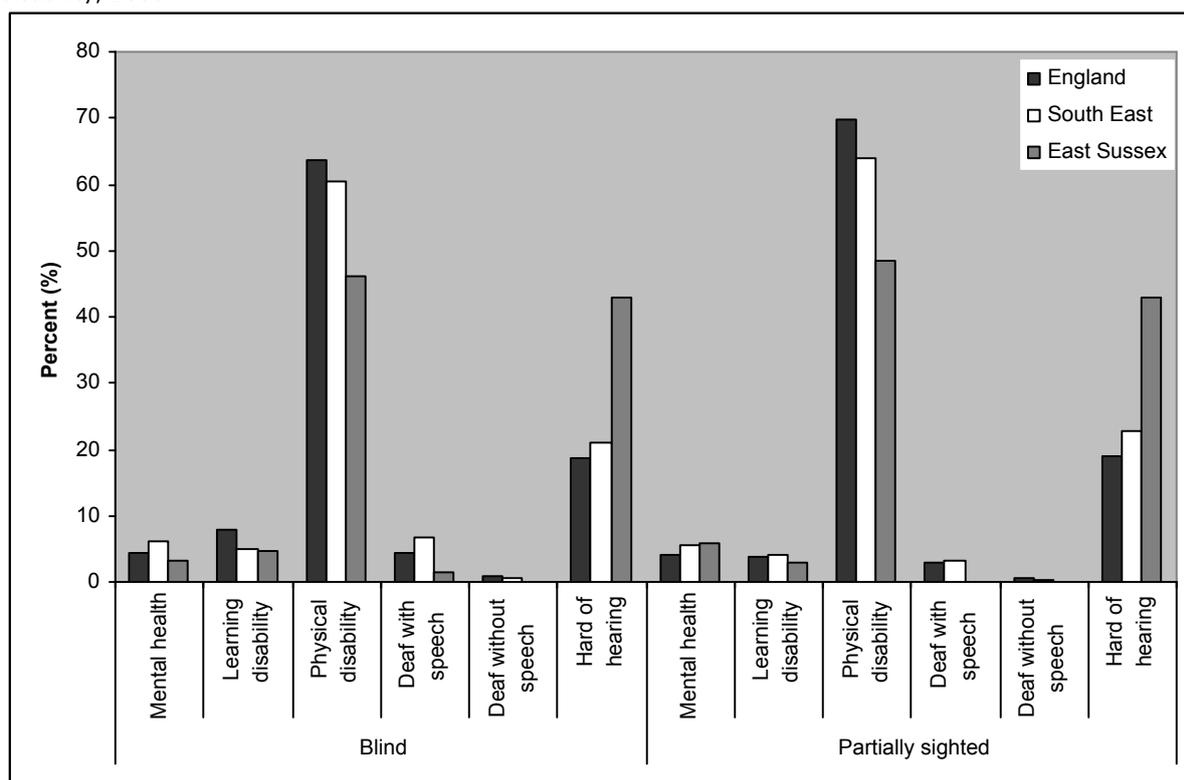
To be registered a person has to be so blind as to be unable to perform any work for which eyesight is essential. It does not mean that the person will have no vision at all. For people to be registered as blind or partially sighted they must first undergo an examination by a consultant ophthalmologist.

Nationally 75% of people registered as blind in 2006 were 65 or older; in East Sussex this proportion was higher at 86% of registrations. Only 11% of persons registered as blind or visually impaired in East Sussex were of working age, approximately 550 of the 4865 registered across the county. This compares to 20% nationally. The Royal National Institute for the Blind (RNIB) has found that approximately only a quarter of the total blind and visually impaired population are registered officially and a large proportion of visually impaired people have little or no contact with social services.

The majority of blind and partially sighted people of working age have disabilities in addition to sight loss, and at least 30% of blind and partially sighted children have severe or profound multiple learning disabilities. These numbers are increasing over time, owing in the main to higher survival rates for premature babies. The proportion of working age adults registered blind who had additional was lower in East Sussex (11%) than regionally (19%) or nationally (24%). This pattern was also reflected in those registered as partially sighted.

Although nationally the most common additional disability in people registered blind or partially sighted was physical disability in East Sussex this was split between physical disability and being hard of hearing, a reflection of the older age-profile of those registered in the county (Figure 9).

**Figure 9:** Proportion of registered blind or partially sighted with an additional disability by category of disability, 2006.



Note: numbers were rounded and those under 6 were suppressed.

Source: The information centre

### Hearing disability registers

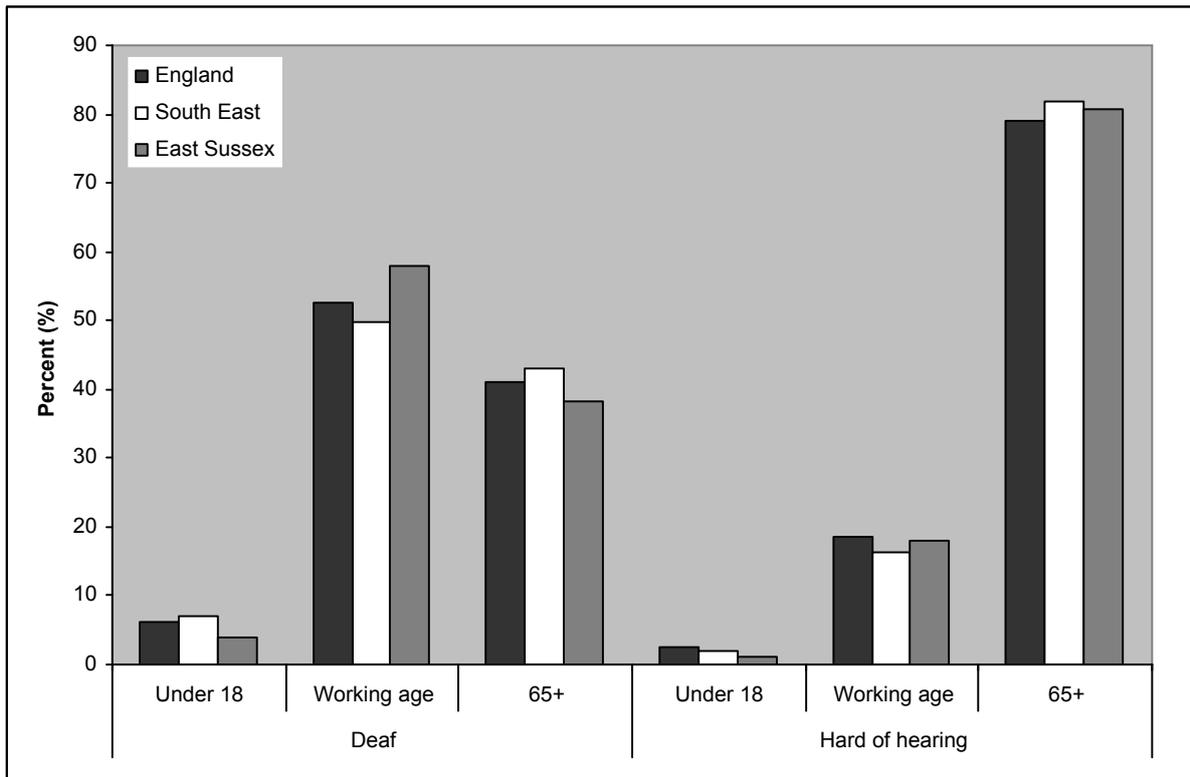
Local authority social services departments' record information on the numbers of people registered as either deaf or hard of hearing by age ranges. Although there is no formal examination procedures for determining whether a person is deaf or hard of hearing cases are classified as follows:

- Deaf: those who (even with a hearing aid) have little useful hearing.
- Hard of hearing: those who (with or without a hearing aid) have some useful hearing and whose normal method of communication by speech, listening and lip reading.

People who are deaf or hard of hearing and also blind and recorded on the 'Register of the Blind' are excluded from the 'Register of the Deaf'.

In 2007 there were 54 500 persons registered as 'deaf' (25%) and 'hard of hearing' (75%) with Councils with Social Services Responsibilities in England. Those registered hard of hearing were more commonly aged over 65, whereas over 50% of those registered 'deaf' were aged between 18 and 64 (Figure 10).

**Figure 10:** Age profile of those registered deaf and hard of hearing, East Sussex 2006.



Note: numbers were rounded and those under 6 were suppressed.  
Source: *The information centre*

Locally there were 2160 people registered as 'deaf' (380) or 'hard of hearing' (1780); the proportion of 'hard of hearing' registrations was greater than the national profile, accounting for 82% of all registrations. There were 540 people registered aged 18-64; 220 'deaf' (57% all 'deaf' registrations) and 320 'hard of hearing' (18% all 'hard of hearing' registrations).

### Deafblind register

Although under section 7 of the Local Authority Social Services Act 1970 local authorities have been asked to take specific action aimed at improving services for deaf blind people, official statistics are not routinely available.

An analysis of ESCC social care records indicated that there were at least 542 people living with dual sensory loss within East Sussex, 47 (9%) of working age.

## User satisfaction

All local authorities in England are carrying out surveys to ask views of Social Service users. The survey for 2003-04 covered physically disabled and sensory impaired users aged 18-64 (excluding those with learning disabilities). The survey asked a range of questions relating to social services users' experience of personal social services.

Nationally 60 500 surveys were completed; the number completed in East Sussex was 600. Table 11 gives a summary of the results and response rates for the survey for East Sussex and England. The proportion of positive response to all questions by East Sussex respondents was equal to or higher than the national level, significantly so for six of the ten questions (Q2, Q3, Q6, Q8, Q9 and Q10).

**Table 11:** Personal Social Services Survey of Physically Disabled and Sensory Impaired Users in England Aged 18-64 satisfaction with 95% confidence intervals and response rate: 2003-04

Question	Test	East Sussex			England		
		%	95% CI	Response rate (%)	%	95% CI	Response rate (%)
Q1	Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you? Percentage of respondents answering 'always'	31	4.1	57	29	0.4	50
Q2	Do you know how to make a complaint about social service? Percentage of respondents answering 'yes and I feel I could if I wanted to'	59	3.3	60	53	0.4	52
Q3	My life would be a lot worse if I didn't have help from social services or direct payments: percentage of respondent answering 'strongly agree' and 'agree'	95	1.8	57	92	0.2	50
Q4	Social service provide all the information I need: percentage of respondent answering 'strongly agree' and 'agree'	66	3.6	56	66	0.4	49
Q5	I can always contact social services if I want to: percentage of respondent answering 'strongly agree' and 'agree'	82	2.8	57	79	0.3	50
Q6	Do your care workers (or personal assistants you employ using direct payments) come at times that suit you? Percentage of respondents answering 'always' or 'usually'	91	3.1	58	85	0.3	50
Q7	Overall, how satisfied are you with the help you receive from social services? Percentage of respondents answering 'extremely satisfied' or 'very satisfied'	48	3.4	59	46	0.4	52
Q8	Has your social worker or care manager told you about direct payments? Percentage of respondents answering 'yes'	47	3.4	59	12	0.4	52
Q9	Do you use direct payments? Percentage of respondents answering 'yes'	33	3.2	59	23	0.4	52
Q10	Overall, how well do you think you have been advised and supported in using direct payments? Percentage of respondents answering 'extremely well' or 'very well'	68	8	19	57	1.1	12

Source: Department of Health

[http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalsocialcare/DH\\_4098131](http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalsocialcare/DH_4098131)

Response rates were higher in East Sussex, with an average of 54% (19-60%) in comparison with 47% (12-52%) nationally.

## 4.2 Primary care

Although the majority of ongoing care of people with physical disability occurs within the primary care setting there is little routine data available to estimate the numbers of patients attending primary care consultations.

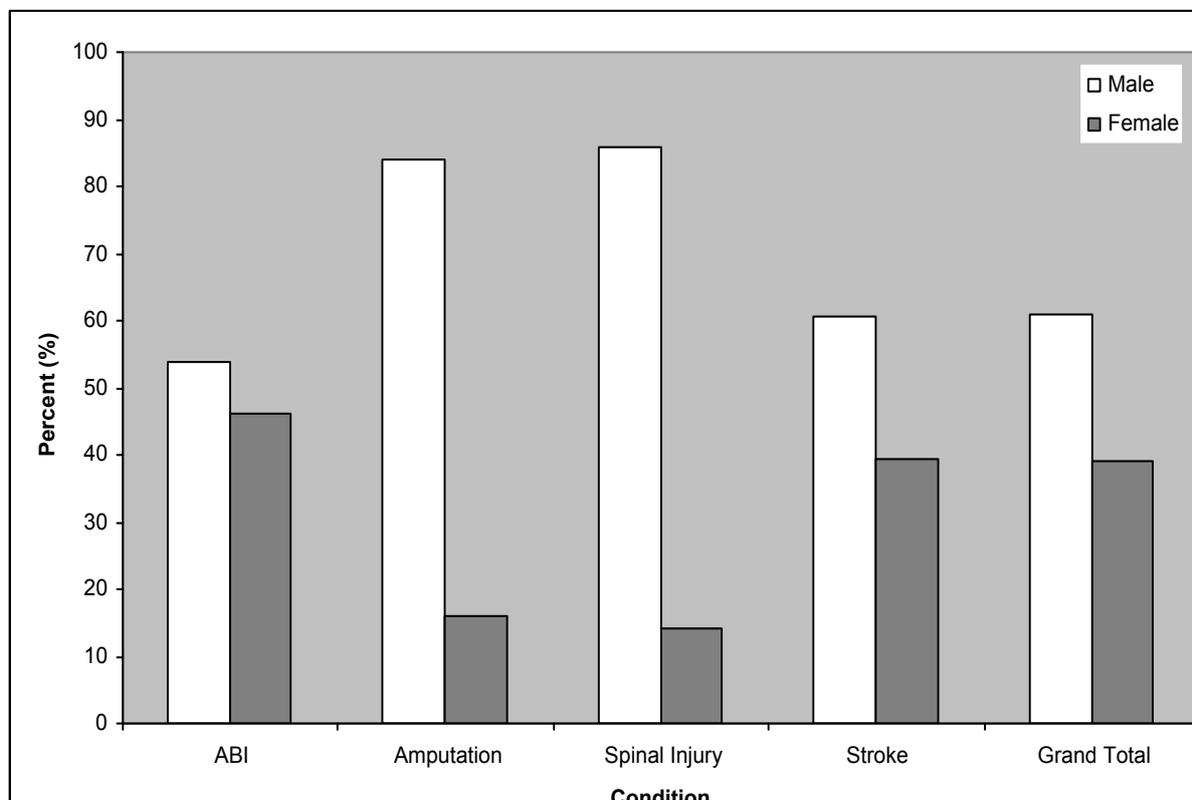
The Quality and Outcomes Framework (QOF) is the major source of data on primary care activity; it records the number of people registered with GPs who have a diagnosis of particular chronic diseases and process and outcome indicators related to their care. In terms of physical disability there are only two neurological conditions, stroke and epilepsy, included. The data available through the QOF is fully anonymised and as such it is not possible to distinguish between specific age groups or between the sexes. As a result the data provided through the QOF is of limited use in evaluating the level of primary care provided to those with physical disability, and there is none available for those with sensory disability.

### 4.3 Secondary care

Many of the conditions that lead to physical and sensory disability do not have an acute onset which requires hospitalisation. Although people with physical or sensory disability may be admitted as a result of complications of their underlying disability it is rare that the underlying condition is recorded. This limits the usefulness of hospital activity to conditions where there is acute onset such as stroke, spinal injury, and acquired brain injury (ABI) and to major events such as amputations.

During the April 2004 to March 2007 there were 651 first-time episodes for people aged 18-64 for the conditions of stroke, spinal injury, ABI and amputation across East Sussex. Stroke accounted for 59% of all episodes, followed by ABI (31%), Amputation (9%) and spinal injury (1%). For all conditions there were more male than female patients, with men accounting for 61% of all episodes (Figure 11).

**Figure 11:** Proportion of working-age adults admitted for ABI, amputation, spinal injury or stroke, 2004/5 – 2006/7, by gender 2004/05 – 2006/07



Source: Hospital Episode Statistics

The average age was 48.9 years and was similar for men (48.7) and women (49.1). There was no significant difference in the age of men and women for the different conditions. However, those patients admitted for stroke were significantly older than those admitted for other conditions (Table 12).

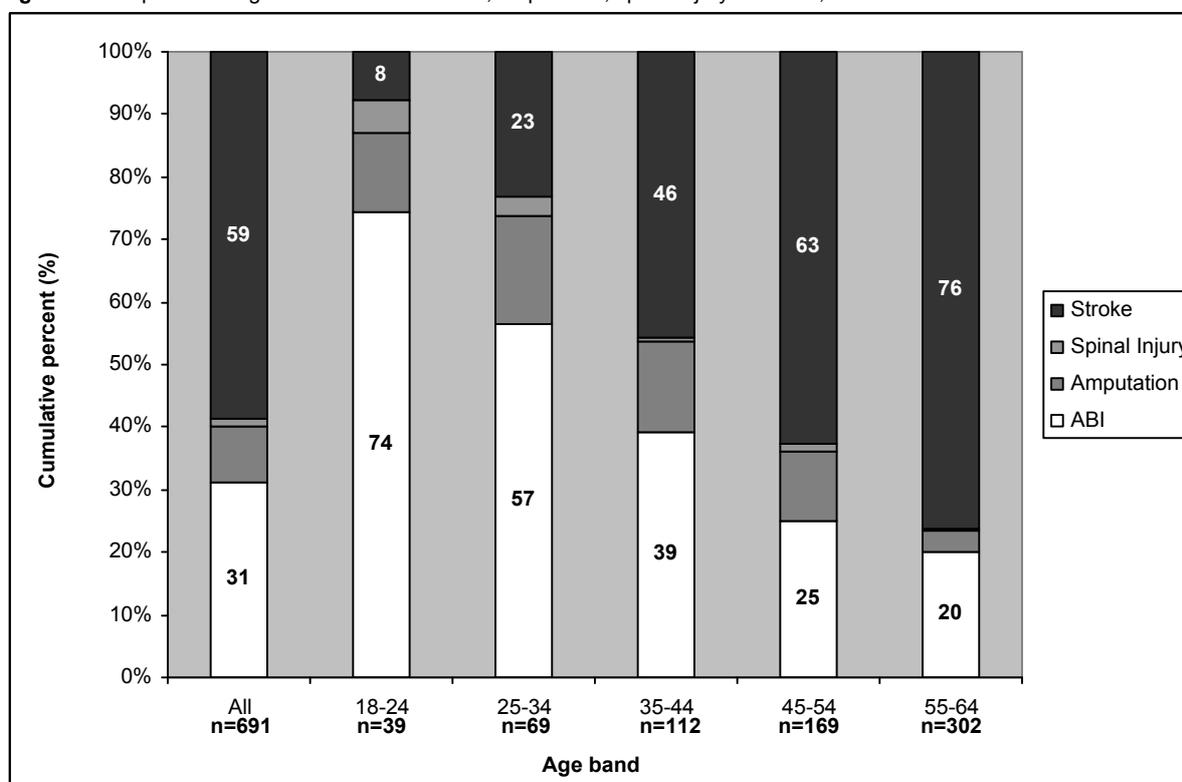
**Table 12:** Average age (with 95% confidence interval) working-age adults admitted for ABI, amputation, spinal injury or stroke, by gender 2004/5 – 2006/7

Group	Male		Female		All	
	Av. age	95% CI	Av. age	95% CI	Av. age	95% CI
ABI	42.4	(39.7-45.1)	43.4	(40.8-46.0)	42.8	(41.0-44.7)
Amputation	42.9	(39.7-46.2)	41.0	(33.9-48.1)	42.6	(39.7-45.5)
Spinal Injury	37.7	(25.3-50.1)	31.0		36.9	(26.0-47.7)
Stroke	53.3	(52.1-54.5)	53.3	(52.0-54.6)	53.3	(52.4-54.2)
All conditions	48.7	(47.5-50.0)	49.1	(47.8-50.5)	48.9	(48.0-49.8)

Source: Hospital Episode Statistics

This difference is illustrated in Figure 12 where it can be seen that there is a direct relationship between age and the proportion of patients admitted for stroke with only eight percent of 18-24 year-olds admitted for stroke increasing to 76% of 55-64 year-olds. This pattern is reversed for ABI with 74% of 18-24 year-olds admitted as a result of ABI and only 20% of 55-64 year-olds (Figure 12).

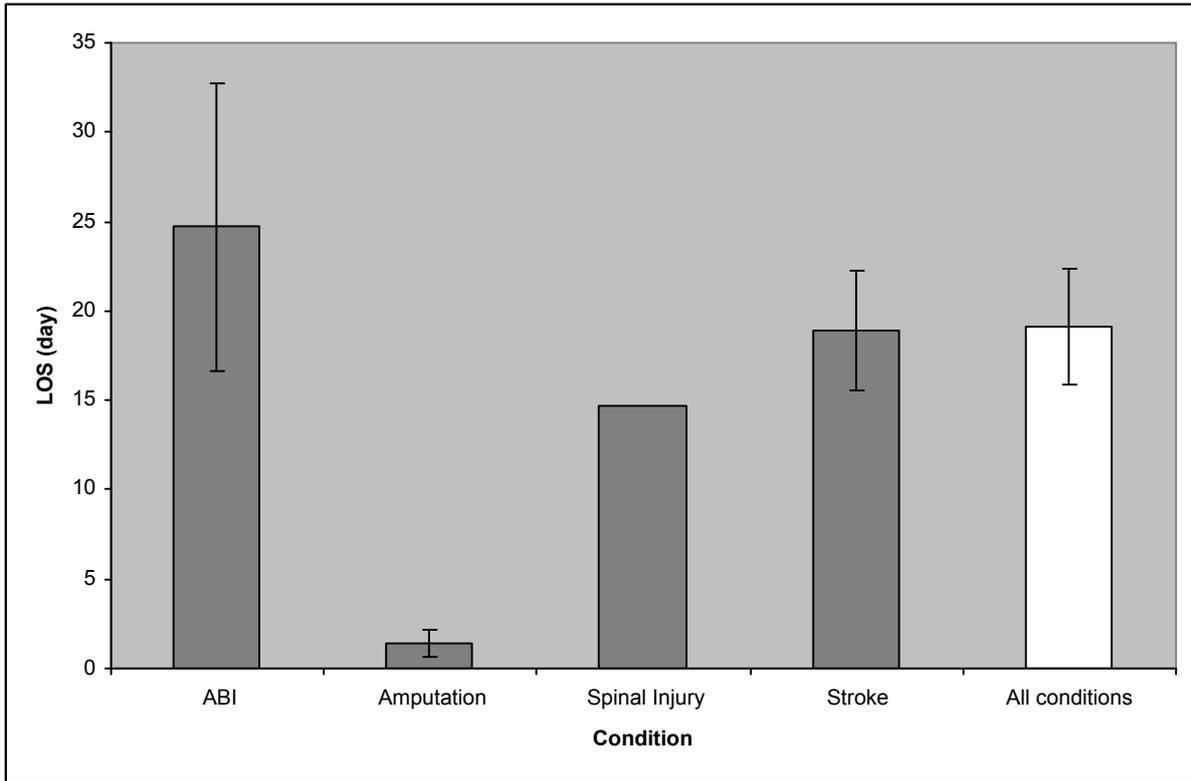
**Figure 12:** Proportion of age band admitted for ABI, amputation, spinal injury or stroke, 2004/5 – 2006/7



Source: Hospital Episode Statistics

Average length of stay (LOS) was longer for ABI (25 days) than for stroke (19) and spinal injury (15 days) (Figure 13). Average LOS was only one day for amputation, in the 18-64 age group all amputations were at a low level (individual or multiple toes) not at a high level (limbs).

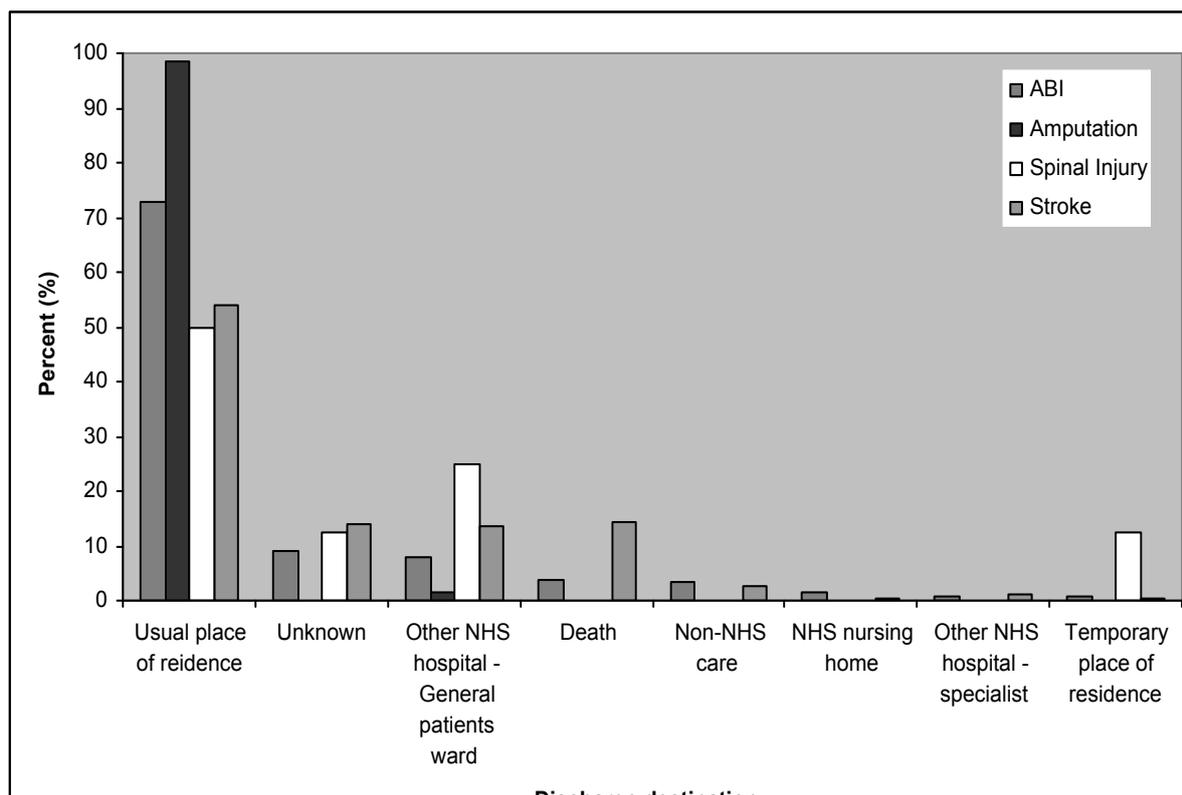
**Figure 13:** Average length of stay for working-age adults admitted for ABI, amputation, spinal injury or stroke, 2004/5 – 2006/7



Source: Hospital Episode Statistics

Over 60% of all 18-64 admissions were discharged to their 'usual place of residence' (Figure 14). This was highest for those undergoing amputation (98%) and ABI (73%) with only 50% of spinal injury patients and 54% of stroke patients returning to their 'usual place of residence'. Fourteen percent of stroke patients died before they were discharged compared to only four percent of ABI patients.

**Figure 14:** Discharge destination of working-age adults admitted for ABI, amputation, spinal injury or stroke, 2004/5 – 2006/7



Source: Hospital Episode Statistics

### Healthcare Resource Group

Healthcare Resource Group (HRG) is a group of health-related activities that have been judged to consume a similar level of resources. For instance, there may be a number of different knee-related procedures that all require similar levels of clinical care and take a similar duration. They may all be assigned to one HRG. The HRG system forms part of Payment by Results

Table 13 summarises the number of units, the total cost and cost per unit for HRGs relating to physical disability for East Sussex residents during 2005/06 and 2006/07. The leading HRG for total cost was stroke accounting for 59% of the total cost across the two years. However, in terms of cost per unit the leading HRGs were: Spinal Cord Injury (£6300); Stroke (£3800); and Motor Neuron Disease (£3600).

**Table 13:** Physical disability HRG unit, cost and unit cost 2006/07, all ages.

HRG description	2005/06			2006/07		
	Units	Cost (£)	Cost per unit (£)	Units	Cost (£)	Cost per unit (£)
Stroke	301	1 178 300	3900	360	1 323 300	3700
Epilepsy	316	336 900	1100	382	363 100	1000
Multiple Sclerosis	101	141 400	1400	84	263 600	3100
Spinal Cord Injury	18	140 800	7800	18	87 400	4900
ABI	40	117 800	2900	48	106 700	2200
Parkinsons Disease	40	76 900	1900	44	59 300	1300
Motor Neuron Disease	4	21 300	5300	6	14 900	2500
Osteoarthritis	6	6100	1000	2	2000	1000

Source: Hospital Episode Statistics

HRGs report on costs attributable to all-ages and therefore it is not possible to distinguish costs attributable only to the working-age population with physical disability.

## 5. Effectiveness and cost-effectiveness of services

It is recognised that young disabled people often require support that is more flexible, or a different type, than social services can offer. Activities such as facilitating access to employment, training for work or new skills, leisure and sports and support with parenting are all key areas which are prioritised by younger disabled people. The Social Policy Research Unit developed a framework for understanding social care outcomes which identify key aspects of quality of life that enable people with long-term conditions to live their lives as independently as possible (Figure 15).

Figure 15: Social Policy Research Unit

<b>Autonomy Outcomes</b>	<b>Personal Comfort Outcomes</b>
<ul style="list-style-type: none"> <li>• Access to all areas of the home</li> <li>• Access to locality and wider environment</li> <li>• Communicative access</li> <li>• Financial Security</li> </ul>	<ul style="list-style-type: none"> <li>• Personal hygiene</li> <li>• Safety/security</li> <li>• Desired level of cleanliness of home</li> <li>• Emotional well-being</li> <li>• Physical health</li> </ul>
<b>Economic Participation Outcomes</b>	<b>Social Participation Outcomes</b>
<ul style="list-style-type: none"> <li>• Access to paid employment as desired</li> <li>• Access to training</li> <li>• Access to further/higher education/employment</li> <li>• Access to appropriate training for new skills (e.g. lip reading)</li> </ul>	<ul style="list-style-type: none"> <li>• Access to mainstream leisure activities</li> <li>• Access to support in parenting role</li> <li>• Access to support for personal secure relationships</li> <li>• Access to advocacy/peer support</li> <li>• Citizenship</li> </ul>

Taken from: Harris et al. 2005.

The term 'Independent Living' refers to all disabled people having the same choice, control and freedom as any other citizen: at home; at work; and as members of the community. This requires that any practical assistance people need should be based on their individual choices and aspirations. It is not just about having choice and empowerment in personal care: independence; choice; control; access to information; accessible housing; accessible transport; and access to employment are recognised as the 'Principles of Independent Living'.

Nationally, the three main strategic drivers for services for improving services for people with physical or sensory disabilities are:

- 'Independence Matters' a report on the performance of social service departments in providing services for people with a physical or sensory disability by the Social Services Inspectorate;
- 'Improving the life Chances of Disabled People' described as a radical strategy for transforming the life chances of disabled people;
- The National Service Framework for long-term (neurological) conditions which identifies clear 'quality expectations' around these services.

Improved disability services have the potential to significantly increase the quality of life and psychological and physiological health and wellbeing of people with disabilities.

### 5.1 Service eligibility assessment

The aim of health and social care is to ensure that "... those who are disabled should get the support they need to lead a fulfilling life with dignity". The World Health Organisation's Impairment, Disability and Handicap model defines disability as 'any restriction or lack (resulting from an impairment) of ability to perform an activity within the range considered normal for a human being'. Using this definition, disability can be assessed at the level of the body (impairment), person (activity) or society (participation).

Appropriate assessment is fundamental to effective service delivery of health and social care provision. Its purpose is to identify and evaluate an individual's needs and how they constrain or support their capacity to live a full and independent life. The role of needs assessment is to identify those with specific needs. It requires detailed information about the person and environment and is influenced by the organisation and structure of service organisations and support programmes.

The identification of activity limitation may focus on certain types of activities, for example, basic activities of daily living (ADL), and the identification of participation restriction may be restricted to certain realms of participation, such as paid employment. Screening devices are central to identifying disability. Screening questions identify the existence of 'disability', and the dimension on which they are focused - usually impairment or activity limitation.

The ADL scale and Instrumental Activities of Daily Living (IADL) scale are measures of functional ability that have been widely used to define disability and to assess need for services. However, if 'physical disability' is defined primarily on the basis of activity limitation some problems are encountered; simple activities (e.g. gripping an object) can be readily identified as physical or otherwise. However, complex activities (e.g. driving) are more difficult to label because we use many different parts of ourselves, many different abilities, in combination. Therefore, it may be more appropriate to take an approach based largely on factors operating at the body level. A physical disability may then be identified as a disability associated with a physical impairment.

The 2003 Department of Health guidance on eligibility guidelines for adult social care in the UK provided local authorities with social care responsibilities a framework for determining eligibility for adult social care. It stated that local authorities should operate just one set of eligibility criteria for all people who seek support from adult social services, and that these criteria should be based on a national framework that is built on needs and associated risks to independence (Table 14). Factors such as age, gender, race, living arrangements and location should play no part in deciding an adult's eligibility to care services. Thus, individuals with similar needs will receive similar decisions on their eligibility for social care.

**Table 14:** National framework for evaluation of need for social care

Need level	Risk
Critical:	risk of major harm/danger to a person or major risks to independence.
Substantial:	risk of significant impairment to health and well-being or significant risk to independence.
Moderate:	risk of some impairment to health and well being or some risk to independence.
Low:	promoting a person's quality of life although there is a low risk to their in dependence.

*Source: Department of Health. 2003. Fair Access to Care Services: guidance on eligibility criteria for adult social care.*

These are considered against the needs of the individual in three key areas: physical, learning disability and mental health; personal care, domestic routines and home environment; and family and social responsibilities. Additionally, the needs of their carers are also considered. It was recommended that, where appropriate, assessment should take account of health and other problems such as housing,

It is important for assessment to be rounded and person-centred, and for the evaluation of assessment information to lead to appropriate eligibility decisions and services that promote independence. Work with younger disabled people, which is undertaken in a purely functional manner, reflecting a narrow concern with activities of daily living, is likely to meet with severe criticism. Issues of language and terminology are crucial in conveying and reflecting these differences.

## 5.2 Direct Payments

*"all disabled people having the same choice, control and freedoms as any other citizen – at home, at work and as members of the community. This does not necessarily mean people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations."*

Choice and control includes people having direct control over how the support individuals need is delivered in order to address all aspects of someone's life and needs, low level preventative support provided at levels of need which prevent higher levels of need and/or dependency.

Direct Payments are available to all those who are eligible for a service from Social Care and payments are made in lieu of services, giving service users choice and control over how, when and from where they obtain their support. The aim of direct payments is to promote independence, autonomy and choice. Direct payments have moved to the heart of the government's drive for increased user choice. They have been shown to fundamentally change the traditional relationship between the service user and the service. Direct payments have been described as the 'prime example' of extending choice in public services and people who receive direct payments speak highly of them.

Local authorities were first given discretionary powers to make payments to disabled people in 1996 via Direct Payments. In 2003, the power to provide Direct Payments was replaced by a requirement for all local authorities to offer them to those assessed as needing community care services who wished to have them and were capable of managing their own support, with or without assistance.

Direct payments provided to people with a physical disability tended to be of high intensity. Three quarters of recipients with a physical disability in England received funding equivalent to over 10 hours of support per week, with nearly one-third receiving 31 hours per week.

Although those with physical disabilities represent a large proportion of the numbers of people taking up direct payments, there are still recognised barriers to overcome. The research evidence strongly suggests that the successful implementation of Direct Payments is dependent upon the processes and procedures associated with accessing them. A national survey of users and providers found the key barriers to uptake to be:

- Lack of clear information for people who might use direct payments;
- Low staff awareness of direct payments and what they are intended to achieve;
- Restrictive attitudes about the capabilities of people who might use direct payments and a reluctance to devolve power away from professionals to the people who use the service.
- Inadequate or patchy advocacy and support services for people applying for and using direct payments
- Inconsistencies between the intention of the legislation and local practice
- Unnecessary, over-bureaucratic paperwork
- Problems in recruiting, employing, retaining and developing personal assistants and assuring quality.

In order to overcome these barriers the Commission for Social Care Inspection has made a number of recommendations for local authorities that move away from viewing direct payment systems as 'schemes' to viewing them as mainstream services. Specific areas of action were identified:

- Increasing awareness and encouraging uptake of direct payments.

- Ensure proper employment support and advice services are developed, and where people prefer take control of some functions, such as recruitment.
- Consider the related issues of workforce requirements, pay, pensions, holidays, employment status (directly or self employed), development and training of personal assistants.
- Increase the capacity of the local voluntary sector, drawing upon funds from a range of sources to provide advocacy and independent support services.
- Publish clear entitlements so that people understand the options and know what to expect from the council.
- Apply the Better Regulation Task Force principles of proportionality, assessment of risk, and information requirements, which are focused on the needs of the person using the direct payments, in their systems of monitoring and accountability for the use of the money.

### 5.3 Rehabilitation

There have been a number of reviews assessing the literature around effectiveness and rehabilitation, including cost-effectiveness; clinical effectiveness and effectiveness in terms of improving quality of life for disabled people. ,,,

Rehabilitation is the process of educating a person with a disability to enable them to cope with the activities of daily living as independently as possible. It is a package of measures designed to lessen the impact (physical, psychological and social) of disabling conditions. The international classification of impairments, disabilities and handicaps model created by the WHO is designed to move the concept of rehabilitation away from a medical model towards a more social model and is based around the concepts of Impairment, Activity and Participation. The model emphasises the relation between disease and disability and sets the rehabilitation agenda clearly in a social context while still recognising that disease has an important influence on patients' levels of physical activity, social participation and on the process of rehabilitation.

It is widely recognised that there are five basic categories that people with disabilities fall into:

- 1) People who will make a spontaneous full improvement over a short period of time e.g. mild stroke;
- 2) People who will improve steadily and may or may not return to pre-morbid function e.g. moderate stroke or traumatic brain injury (TBI);
- 3) People who will not improve greatly and who can expect a residual level of disability, but in whom some progress is possible e.g. severe stroke or TBI;
- 4) People who will deteriorate slowly over time e.g. multiple sclerosis or Parkinson's disease; and
- 5) People who will deteriorate steadily and rapidly e.g. motor neuron disease.

There is growing evidence that rehabilitation is effective in improving individual quality of life across all five categories. Although there is a tendency to move away from categorising patients by pathology as rehabilitation is now more commonly based on individual need, the literature is still largely divided into discrete conditions.

The specialised service's definition set recognises that fundamental to understanding rehabilitation is the awareness that different patients need different things. Moreover, the same patient needs different things at different stages in recovery:

- Acute care:  
Following severe insult or injury, the patient often requires acute care in hospital for up to a few weeks. Rehabilitation should start as soon as possible and, in the acute stage, should focus on nursing care and therapy that reduces the

consequences of immobility, confusion, bulbar dysfunction (swallowing and breathing difficulties) and learned behaviour.

- **Post-acute in-patient rehabilitation:**  
Specialist rehabilitation comes into its own in the post-acute stage as the patient starts to recover and needs to make the transition between hospital and community. It focuses on regaining the skills of independent living to allow the patient to manage at home.
- **Community rehabilitation:**  
Once back at home, patients need continued input to maximise their ability to function in their environment. Depending on the goals for that patient, this may require visits back to the hospital to use special facilities there (day or outpatient services) or may be more appropriately undertaken in the patients own familiar surroundings by an outreach team or domiciliary therapy.
- **Continued support for disabled individuals and their families:**  
In the long term most patients will not require continuous rehabilitation, but may need drop in clinics or access to services or information by self-referral. Integration of health, social services, education and employment authorities is important to optimise function and minimise handicap.

The majority of patients with mild to moderate injuries will travel satisfactorily down the path from injury to independence with the help of their local (high volume) district services. A small minority, however, will have particularly severe or complex problems and require the services of a complex specialized rehabilitation service to progress. As such, it is not a question of providing services 'either in the hospital or the community'. Each area requires a network of inter-linked complementary services, with flexible funding arrangements to ensure that each patient has access to the most appropriate service for their needs at each stage in their recovery.

## **5.4 Housing & equipment**

### **5.4.1 Housing**

In 2006 the Disability Rights Commission reported that more than a million disabled people and people with long-term health conditions were living in unsuitable housing. A further 9000 young adults were inappropriately housed., Independent Living means having the same choices and opportunities as all other citizens, but this is not possible if the circumstances of home present constant barriers and discomfort, or excessive dependence on other people, whether family members or professional carers. In many cases these problems could be solved by a greater investment in adaptations and equipment.

For a seriously disabled wheelchair user, the cost of residential care is £700-£800 a week - £400 000 in 10 years. The provision of adaptation and equipment that enables someone to move out of a residential placement produces direct savings, normally within the first year. Home modifications can also help to prevent or defer entry into residential care for older people. In this case, one year's delay will save £26 000 per person, less the cost of the adaptation (average £6000).

An hour's home care per day costs £5000 a year. Adaptations that remove or reduce the need for daily visits pay for themselves in a time-span ranging from a few months to three years and then produce annual savings. In the cases reviewed, annual savings varied from £1 200 to £29 000 a year. Significant savings in home care cost are mainly found in relation to younger disabled people.

As a snapshot of services in East Sussex, July 2007, found that there were 2964 people in permanent residential or permanent nursing care. Approximately one quarter of

people in permanent accommodation (24%) were aged 18-64; 92% of these were in permanent residential accommodation. The proportion of individuals in permanent nursing care was higher in Hastings and Eastbourne (Table 14). If the needs of some or all of these individuals could be met within their own home substantial savings could be made.

**Table 14:** Number and percent of 16-64 year-olds in permanent residential and permanent nursing care in East Sussex, by district, 2007.

District	Permanent Residential		Permanent Nursing		Total
	Number	%	Number	%	
Eastbourne	126	89.4	15	10.6	141
Hastings & St. Leonards	164	87.2	24	12.8	188
Lewes	80	93.0	6	7.0	86
Rother	168	96.6	6	3.4	174
Wealden	114	92.7	9	7.3	123
East Sussex	652	91.6	60	8.4	712

One of the difficulties for meeting the housing needs of people with physical disabilities is the limited information flow between the various housing agencies and people with disabilities. For example, research has revealed that commonly housing providers in both the statutory and voluntary sectors have not quantified the extent of inaccessible housing in their communities.

Research carried out by the University of Glasgow into the housing aspirations of young disabled people revealed that they have similar aspirations to their non-disabled peers. Most parents also expected their adult offspring to leave home at some stage, seeing this as a normal part of adult life. However, whilst young people wanted to move out of the family home, it was difficult for them to find out about the range of choices available. The report suggested that parents' and young adults' lack of information about local housing options, and where to find help and advice, were the main barriers they faced.

Not all people with a physical disability or sensory impairment will require support but a suitably adapted property is essential if someone is to remain in his or her own home rather than go into residential accommodation.

#### **5.4.2 Equipment**

Equipment services provide the gateway to the independence, dignity and self-esteem of some 4 million older or disabled people and for 1.7 million informal carers. The availability of appropriate aids, adaptations and equipment is essential to maximise individuals' independence and improve their quality of life.

Advances in assistive technology mean that many more people with complex physical needs and sensory impairments are able to both retain and regain maximum independence and control in their own lives. The Department of Health has noted that the provision of appropriate equipment benefits the individual and also has a positive impact on:

- Reducing admissions to A&E departments;
- Minimising in-patient episodes;
- Reducing delayed discharge; and
- Supporting whole-systems approaches.

The Department of Health recommend that specialist assessment, provision of equipment and training should be delivered as part of a total package of care, to ensure that service users are provided with the most appropriate equipment and are enabled to use it to optimal advantage.

Working-age adults comprise a small proportion of clients receiving services from East Sussex Adult Social Care (18%). Although this reflects the older population structure of the county and the increasing prevalence of disability with age the actual numbers accessing equipment services (2021) is much smaller than the estimated 9000 working-age adults with severe disability (based on 2006 population projections).

### 5.4.3 Telecare

The Audit Commission define telecare as 'any service that brings health and social care directly to a user, generally in their own homes, supported by communication and information technology. Data is collected through sensors, fed into a home hub and sent electronically to a monitoring centre'. The government believes that telecare can help older people to remain in their homes for longer; it gives reassurance to carers and contributes to the shortfall in the workforce. The Department of Health preventative Technology Grant is providing local authorities with £80m over two years to promote and invest in new technology.

Technology cannot deliver care, but can enable the redeployment of care time and manage risk by providing security and alerts. Telecare equipment and services provide the opportunity to react to hazardous events and to alert and prevent deterioration in an individual's ability to care for them self (Table 14). A number of pilots have shown that providing early packages of telecare can delay elderly people moving into residential care.

Of the 22 people receiving Telecare across East Sussex in July 2007 six (27%) were aged between 18 and 64 years. This was evenly split between men and women.

**Table 14:** Audit Commission 2004 classification of telecare services

Service area	Service
<b>Information</b>	Advice, self help groups and web based information systems which could also include internet services such as shopping.
<b>Electronic assistive technology</b>	intelligent heating systems, automatic beds, doors and electronic prompts such as to take medication and video telephones.
<b>Safety and security monitoring</b>	Sensors that transmit signals to a central hub to monitor floods, gas leaks, unlocked doors, fire, carbon monoxide and other safety indicators. In an emergency an alarm rings in the home and is transmitted to a call centre where staff will alert previously agreed contacts.
<b>Personal monitoring</b>	At a basic level this would include falls detectors or a wander monitor that will trigger an alert. More intelligent systems can detect 'abnormal' activity such as overnight absence from a bed. Changes in normal patterns trigger an alert.
<b>Vital signs monitoring</b>	these systems can record information about weight, temperature, blood pressure and other physiological signs. The data is assessed by clinicians and can be set to alert them to changes. Monitoring also builds up a health record.

*Source: Audit Commission (2004), Older People: Implementing Telecare, London: Audit Commission*

A systematic review of patient satisfaction with telecare found that although the studies included suggest that teleconsultation is acceptable to patients in a variety of circumstances, methodological deficiencies (low sample sizes, context, and study designs) of the published research limit the generalisability of the findings. Additionally, the existing evidence base for the impact and cost effectiveness of telecare is limited.

However, one cost model suggested that the cost benefits of telecare would be split across the health and social care system as follows: local authority housing 4%; NHS 43%; Residential care 53%. Ideally, information from telecare should be derived from both health and social services and should be considered as part of a reconfiguration of services taking account of the whole patient pathway or *Supporting People* plan.

### 5.4.4 Wheelchair services

England does not have a single common model for the delivery of wheelchair services, but a variety of different service configurations across the country. There are 151 wheelchair services in England, a ratio of 1:300 000 of the population.

In 2002, the Department of Health, the Modernisation Agency and the Accounts Commission set up a collaboration with around one-third of wheelchair services in England and one of the two Welsh centres to look at:

- reducing delays
- Maximising efficiency
- Ensuring user and carer needs were addressed, that the outcome of contact with services was an enabling experience, and promoting independence.

The minimum national standards and best practice framework provides guidance, based on the needs of users and legal requirements, outlines the framework for NHS wheelchair services in England (Table 15).

**Table 15:** Framework standards for wheelchair services in England

Area	Standard
<b>Referrals</b>	<ul style="list-style-type: none"> <li>• All Referrals are to be acknowledged within 5 working days.</li> </ul>
<b>Requests</b>	<ul style="list-style-type: none"> <li>• Every new request for a wheelchair must be supported by an initial assessment statement, from an appropriate NHS/Social Services/voluntary organisation/professional, setting out the clinical and lifestyle mobility needs of the applicant.</li> <li>• The Wheelchair Service must, in the light of the assessment statement, form an initial view of the priority to be given to the request and notify the applicant of this priority within five working days.</li> </ul>
<b>Assessments</b>	<ul style="list-style-type: none"> <li>• Following the initial “paper” assessment and prioritisation the clinical and lifestyle needs of the applicant are to be fully assessed. The full assessment must provide compatibility with other transport modes of the applicant e.g. private car, wheelchair accessible vehicle, etc.</li> <li>• Except for “only occasional” or “casual” Users, all assessments are to include, at minimum, guidance from a Physiotherapist or from an Occupational Therapist. No Assessment should be delayed on account of budgetary or supply constraints.</li> <li>• The applicant and, where appropriate, his/her carers/enablers, must be fully consulted and meaningfully involved throughout the assessment process. Assessors must arrive at optimum recommended solutions to needs and must not be influenced by resource constraints. Inability to provide must not be presumed for whatever reason and must not compromise or diminish the optimum assessment of what the clinical and lifestyle needs of the applicant require.</li> <li>• Effective and economical deployment of limited resources, giving the greatest good for the greatest number, require prescription of the least expensive solution which will meet the applicant’s assessed clinical and lifestyle needs.</li> <li>• For full-time, active users, all routine non-specialist assessments are to be carried out within 7 days. For casual or occasional users a period of up to 6 weeks is acceptable.</li> <li>• All complex multi-disciplinary assessments are to be carried out within 6 weeks for fulltime users and 13 weeks for other users.</li> </ul>
<b>Eligibility criteria</b>	<ul style="list-style-type: none"> <li>• The only acceptable eligibility criteria are clinical and lifestyle needs and the ability to use the wheelchair safely. Exclusion on the grounds of age or prognosis alone is unacceptable and discriminatory.</li> </ul>
<b>Changing needs/ circumstances/prognosis</b>	<ul style="list-style-type: none"> <li>• A growing child or a person with conditions which are known or expected to deteriorate must be kept under regular review. Frequency of the review will be consistent with the prognosis.</li> <li>• All Users must have available to them continuing contacts/reviews based on original assessment objectives.</li> <li>• An existing User or someone acting on his/her behalf must, independently, be entitled to request a new assessment at any time if his/her needs or circumstances have changed or are changing.</li> <li>• In some progressive conditions, where future loss of walking ability is certain, the assessment must take place and wheelchair supply be achieved before total inability to walk occurs.</li> </ul>
<b>Supply</b>	<ul style="list-style-type: none"> <li>• Services are required to supply from a range of wheelchairs sufficient to meet the assessed needs of all Users. The time from prescription to provision is to be determined by the priority of each applicant. Supply within ten working days should be standard for long-term full-time Users who are unable to walk.</li> </ul>

<b>Maintenance</b>	<ul style="list-style-type: none"> <li>• All equipment is to be regularly maintained on a pre-planned basis against NHS control standards. Emergency requests for repairs must be met within 5 working days of the request. Where a wheelchair develops a fault which makes it unusable, and it is on supply to a full-time user with no suitable additional or alternative mobility provision, repair must be effected within a maximum of 24 hours.</li> </ul>
<b>Information</b>	<ul style="list-style-type: none"> <li>• Each Wheelchair Service must publicise widely, in accessible formats, information about the services and facilities it provides, including eligibility criteria, and the NHS complaints procedure.</li> <li>• Users and Carers must receive clear and appropriate information about the wheelchair supplied, full tuition and a point of contact if problems arise.</li> </ul>
<b>Vouchers</b>	<ul style="list-style-type: none"> <li>• All Wheelchair Services participating in the Voucher Scheme must offer vouchers towards EPIOCs (subject to criteria satisfaction) as well as towards manual chairs.</li> </ul>

Source: <http://www.limbless-association.org/pdfs/Wheelchairstandards.pdf>

High quality wheelchair services are a vital key to the independence of people with severe mobility impairments. Although the vast majority of wheelchair users are over 60 it is important that services for working age adults meet the standards outlined in the framework and meet the needs of this client group as well.

### 5.5 Employment

The World Health Organisation recognises the importance of employment as a part of social health, and therefore, quality of life. Nearly one in five people of working age (6.9 million) have a disability. Although there has been a gradual increase in the number of working age people reporting a disability in the UK, regional variation in rates of disability and in numbers in employment remain, and disabled people continue to experience high rates of unemployment.

Disabled individuals are significantly more likely than non-disabled people to be unemployed and economically inactive, the median annual growth in earnings was 1.4% lower for disabled men and 0.6% lower for disabled women compared to their non-disabled counterparts. Disabled people were also three times more likely to exit work than non-disabled individuals, the difference being most significant between those whom the study defines as 'more-severely disabled' people, and non-disabled people.

Disabled people are also more likely to face barriers such as discrimination at work and elsewhere and social exclusion. There are several economic studies which have found unexplained differences in earnings and employment rates between disabled and non-disabled people, which could not be attributed to personal or job characteristics and that could be due to discrimination, which is generally hard to measure.

Guidelines of vocational assessment and rehabilitation after acquired brain injury (ABI) which recommend that staff from local NHS brain injury services, Jobcentre Plus, local councils and independent vocational, occupational and educational providers:

- Undertake a joint review of services and develop local protocols, drawing on these inter-agency guidelines and framework, both to assist staff in working together to facilitate appropriate and timely access to current services and also to identify gaps in local service provision.
- Establish ongoing service links to discuss the vocational needs of individuals.
- Adopt a joint approach both to increasing awareness of vocational needs and to the development of specialist skills training for all providers of vocational assessment and rehabilitation services.

Although targeted at those with ABI, this guideline could assist agencies to develop services for all working-age people with disability.

Projects such as 'Access to Work' provide support to disabled employees and employers it ensures that employers and employees receive advice and practical support in areas

such as assessing an individual's needs, identifying appropriate support and procuring equipment.

## **5.6 Communication and information needs**

### **5.6.1 Communication**

Communication difficulties and assistive technology for assisting with these difficulties is of particular importance to those with sensory disability, but also needs to be considered for those with severe physical disability.

#### **Visually impaired**

As sight is a prime way of gathering information, not only for reading and writing but also for social interaction and practical activities, a visual impairment can, without appropriate support, be a serious disadvantage. However, the majority of people with vision impairment have some sight, although what they see and how they see it will vary from person to person. People with a visual impairment often require written information to be available in alternative formats.

Some people can access written information if it is appropriately formatted - for example in large print. Written information can also be provided in tactile forms such as Braille or in auditory forms, such as audiotape. Voice recognition software, adapted computer hardware and reading aides are all important in increasing opportunities for visually impaired people.

#### **Hearing impairment**

As hearing is such an important way for most people to gather information, and speech is how nearly everyone communicates, deaf people can easily be disadvantaged in a working, learning or social environment. People with a hearing impairment often have some hearing: the level of hearing will vary from person to person. Some people use hearing aids to amplify sound. However, for some people, particularly those who have very little residual hearing, hearing aids are not beneficial.

There is an important distinction to be made between people who are prelingually deaf, that is became deaf before learning to speak and those who became deaf later in life. Prelingually deaf people usually find it harder than others to acquire spoken and written language as this is generally learnt through hearing the spoken word.

Many Deaf and hard of hearing people can lip-read to some extent. Some use it as their main way of receiving speech from others. Makaton, and British Sign Language (BSL) which also includes the deaf-blind finger-spelling alphabet are the most commonly used in the UK. (RNID) Sign language is to communicate by many, but not all, deaf people. Trained sign language interpreters or communication support workers may be required where sign language is an individual's preferred method of communication.

#### **Physical disability**

For some people, a physical disability will have no effect on their ability to communicate. For others, the ability to communicate via speech may be affected to varying degrees. Some people with physical disability use communication methods that supplement (augment) or are a replacement (alternative) for speech. Collectively these are known as augmentative and alternative communication systems.

There are a wide variety of communication methods that people use, depending on their individual needs. These include the use of signs, gestures and facial expressions and body movements or other communication aids such as

communication boards, displays or electronic communication devices. Most people will use a combination of communication methods.

The availability of communication devices can improve physically and sensory disabled people's opportunities in employment, training and education.

### **5.6.2 Information**

The availability of accurate and easily accessible information is a key requirement for service users, carers and health professionals alike. Quality requirement one of the NSF for long term (neurological) conditions states: "*People with long-term neurological conditions ... are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves*".

Working-age people with disabilities have a wide range of information needs, which are often categorised as either medical or psychosocial. Psychosocial information needs are derived from the need to manage the impacts of the condition on the emotional, social, educational, employment and future aspects of a person's life. Meeting the information needs of this group requires a holistic and individualistic approach to identifying and responding to information needs.

Information needs to be up-to-date and impartial. Both specific information regarding disability and broader information on how to access services are required. Information serves to increase knowledge of options with regards to medication, support, housing and transport, amongst others. The way in which information is presented needs to take into consideration the various communication difficulties that may arise as a result of physical or sensory disability.

The provision of information to patients is a key feature of health service policy, and lies alongside a commitment to promote working partnerships between health professionals and patients. Information needs extend beyond relevant medical facts to include information which enables an individual to deal with the psychosocial impacts of having a chronic medical condition. Service users need information to make appropriate choices and decisions about their health and well-being. Voluntary groups play an important role in the provision and dissemination of information and they need to be supported by the statutory organisations.

#### **Internet usage by disabled people in the UK**

There is evidence to show that providing computer technology and training to people with physical disabilities reduces social isolation, increases choice and improves their employment prospects.

Direct information concerning Internet usage by disabled people in the UK is scarce. Disabled people are not included as a separate group in the regular surveys on Internet usage that have been carried out by the Office of National Statistics. However, as these surveys show a very strong relationship between gross household income and home Internet access and given the evidence for the lower income of households containing a disabled adult it seems very likely from these figures that disabled people will have less Internet access than non-disabled people.

A few direct comparisons of Internet usage by disabled and non-disabled people do exist. These have consistently found computer ownership and internet use to be considerably lower for disabled people compared to the total population. However, these differences might be due to the older ages of those with a disability. Surveys of Internet use and home access have shown strong decreases

with age. As such, the differences between the disabled and total population could possibly be due to the age difference.

## **5.7 Transport**

Disabled people attach greater importance to public transport than non-disabled people. Almost half of disabled people are completely dependent on public transport. Results from a Transport and Ageing survey identified a range of transport issues specific to those with physical or sensory disability:

- Over half of disabled people would like to go out more often;
- Disabled people find it difficult to travel to basic services, such as their GP or Post Office;
- Disabled people are twice as likely to turn down a job because of travel difficulties;
- The biggest reason for disabled people using public transport is lack of access to a car; the second is not wanting to ask for lifts;
- Lack of access to a car is more than twice as high for disabled people;
- Non disabled people are almost twice as likely to have full driving licence and six times more likely to have a company car;
- Disabled people are less satisfied with public transport and more likely to see it as unreliable;
- Reported difficulties in using buses have improved since 1999, including difficulties getting on and off buses;
- Transport operators think of largely in terms of wheelchair accessibility and sensory impairments are often overlooked;
- Specific barriers are easily identified but need to be viewed within the wider context of whole journeys and the 'travel chain';
- Disabled people are up to three times less likely to be aware of travel information services, and are less likely to use travel information web-sites;
- Disabled people are more than twice as likely to be unsatisfied with travel information available during bus and train journeys;
- Poor connections inhibit travel for disabled people;
- Underlying income differences between disabled and non-disabled people mean that on average disabled people may spend a greater proportion of their income on travel costs.

Improvements in public transport would significantly contribute to improved quality of life and higher usage by disabled people. Sixty-four percent of disabled people survey said that improved public transport would significantly improve their quality of life, with 71% claiming that they would use public transport more often if it was improved.

## 6. Conclusion and recommendations

Physical disability can arise from a wide range of conditions, which affect people in varying ways. Estimating the prevalence of physical disability in a population based on disease/condition prevalence is difficult as individuals are affected in different ways and on different timescales.

There is an overall lack of consistent and useful information available about the number of disabled residents and their characteristics. Estimates of numbers of disabled people often come from population surveys. Most data on disability relies on self-reporting, and for certain impairments under-reporting may occur. This is highlighted by the broad range of methodologies used to estimate the prevalence of physical and sensory disability within populations and the large variation in these estimations.

In 2001 7.5% of men and 8% of women of working age reported having a moderate disability and 2.5% of men and 2% of women of the same age reported serious disability. From these figures, it is estimated that the numbers of people with disability in East Sussex will rise from 37 000 in 2006 to 38 200 in 2026. Of those, the number of people with severe disability across the county is estimated to increase to 9200 in 2016 from 9000 in 2006. In comparison, during 2007 there were 2010 working-age clients in contact with social services for professional support, community equipment, general home care and other reasons.

Although estimated numbers for East Sussex are much higher than the number in contact with services, many people with moderate disability will not require ongoing contact with services. However, those with moderate disability, and their carers, do require clear information regarding possible eligibility for services, opportunities for training and opportunities to engage in paid employment.

Estimations of the numbers of individuals in East Sussex with severe disability suggest that numbers are increasing slowly due to the aging population. It is in this group where unmet need is likely to be highest. There is an ever increasing evidence base regarding the epidemiology of specific conditions that may result in physical or sensory disability. These may be used to estimate the prevalence of these conditions in East Sussex. However, they are limited in their ability to predict service requirements as very few focus on the progression of disability or on its effects on individual's quality of life.

Where conditions contribute significantly to the burden of disability in working-age adults a more detailed assessment, including service providers and user's views may elicit a more detailed picture of the need for services. A detailed assessment of Traumatic Brain Injury services found that there was a large amount of unmet need in areas such as counselling, neuropsychology; and for continuous multidisciplinary needs assessment enabling to gain sustainable employment. It is likely that detailed assessment of services for other conditions would find similar gaps. However, with no data on disease/condition available from Adult Social Care data systems it is difficult to quantify conditions where gaps may be identified.

Within the NHS patients increasingly play a part in assessing the quality of care. There is a duty on Primary Care Trusts to make arrangements to involve and consult patients and the public in service planning and operation and in the development of proposals for changes. People with long-term conditions and their carers are experts in how their condition affects them and their lives.

Fair Access to Care Services states that strategies should be developed to improve the range, accessibility (especially for those in remote and rural areas) and effectiveness of service options. For optimal care working-age individuals with physical or sensory

disability require help from a wide range of professionals, spanning health, social care and other sectors. Therefore, a partnership approach to developing services is required.

### **Recommendations**

1. The principles of independent living: independence; choice; control; access to information; accessible housing; accessible transport; and access to employment should underpin services for physically and sensory disabled working age-adults.
2. In order to better understand the potential needs of clients and potential gaps more complete information on those receiving services from adult social care is required. Information such as diagnosis/condition and level of disability would enable a more complete assessment of those accessing services and those who do not access services.
3. More work is required to identify and utilise appropriate primary care information, to improve understanding of the level of care occurring in this setting.
4. It is clear from the comparison of expected and known numbers of people accessing care services that there are many with physical or sensory disability who do not obtain formal care through this route. The information needs of those not requiring ongoing contact with services needs to be considered as part of the wider strategy, including information on: resources; services available and eligibility; signposting to other support services; benefits; and opportunities for education, training and employment.
5. Access issues for people in rural and remote areas of the county need to be investigated further.
6. The views and opinions of users and their carers should be sought to ensure that services are sensitive to, and respect, the culture and faith, and communication and sensory attributes, of service users.

Claire Turner  
StR Public Health  
East Sussex Downs & Weald PCT  
September 2008

## References