

## **Disability**

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# Chapter 6: Disability

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## 6.1 Key messages

### **What are the inequalities? How persistent and how worrying are they?**

We would highlight first the following:

- Learning disability is positively associated with early mortality
- Learning disability is positively associated with mortality due to cardiovascular causes but not with mortality due to cancer
- The suicide rate of those with mental health disorders is high - it has been estimated that around 20% of such suicides are preventable
- There is non-quantitative data suggesting that death from non-natural causes might be an inequality and human rights issue by disability
- Disability is associated with mental health problems although interpretation of this finding is difficult
- There are no data on the meeting of nutritional needs of disabled people in hospitals and other institutions; there is one report from Mencap where this issue is raised in the context of the death of a patient
- There are few clear patterns of difference in relation to lifestyle factors except that those with disability exercise less and are more likely to be overweight or obese
- There are few meaningful data collected nationally; problems arise because of the lack of agreed definitions

### LIFE

Death certificates do not include information about disability. As such, data are largely absent. There is indication from other research of inequality in some areas. The SMR of 277 for all-cause mortality of those with learning disability is striking and some specific-cause SMRs are very high. What these figures do not show is the extent of undue, unexpected or unfair mortality.

Some other data particularly that which relates to process indicators, suggest inequity. The phenomenon of diagnostic overshadowing has been noted, as

have communication issues. In the wake of advocacy, changes have already been made to improve provision for people with disability and learning disability. If these were to result in a reduction in the SMR that might indicate that some of the original inequality was iniquity. Until the data are collected it is not possible to draw any such conclusions. However, process indicators and some academic research suggest that it is worth collecting the mortality data by different types of disability and causes of death. This would enable charting of SMR change over time and with that, improvements or worsening in equity.

Suicide rate data by disability suggest that mental disorder and some physical disorders (such as MS) are associated with increased risk. Again the extent to which this is avoidable is hard to judge but without all the necessary information it seems best to proceed as though the rates could be reduced and then try to do so. This adds further force to the suggestion that mortality data by disability would be worth collecting.

Much of the literature relating to disability and suicide concerns the ethics of assisted suicide. This literature sits uneasily alongside that which proposes measures to reduce suicide rates. Any move to legalise assisted death would need to be judged in part on its implications for equality and rights for the disabled.

Data relating to accidental death associated with disability seem to be absent. The addition of disability to death certificates would close this gap. The information is of interest; if disabled people suffered high rates of accident-related death this might suggest that the environment should be adjusted to reduce this.

Deaths from non-natural causes in institutions have become an issue of concern following the investigation into six deaths of individuals with learning disability, described above. This is clearly an area worth monitoring although again, at present, the lack of disability information on deaths certificates makes this difficult or impossible.

## HEALTH

Around 30% of the population in England, Wales and Scotland have an LLTI (Limiting long-term illness or disability). Having a LLTI is strongly associated with self-report of poor current health. It is also very strongly associated with poor mental health; this finding is hard to interpret, however, as poor mental health can itself be a trigger for LLTI.

Data from England & Wales show no association with LLTI and feeling you are treated with respect by hospital services. There are no data from Scotland. One limitation of this data is that it does not cover those without capacity to say whether they felt treated with respect; as such some, such as those with severe learning difficulty, are excluded.

Support for nutritional needs in hospital is clearly important for those with disability. The majority of the literature on this topic, however, concerns the elderly. This is because the initial concern was that elderly people's needs are neglected. As such, there seem to be no data on the topic aggregated by disability. This is worth rectifying. One of the deaths reported by MenCap in *Death by Indifference* is of Martin Ryan, who was said to have starved to death at Kingston hospital.

People with LLTI in England are neither more nor less likely to smoke than the rest of the population. In Wales, they are slightly less likely to smoke. In Scotland, men with a disability are slightly more likely to smoke.

People with LLTI in England and Scotland are less likely to drink alcohol above the Government recommended limit. In Wales, they are more likely to do so.

People with LLTI in England, Wales and Scotland are less likely to meet Government guidelines for exercise.



In England, Wales and Scotland there is no noticeable association between LLTI and eating fruit and vegetables.

There is however a clear link between LLTI and obesity. In England, having an LLTI is positively associated with not having a healthy weight; 72% with an LLTI do not have a healthy weight, against 61% without an LLTI. In the main, the problem is one of overweight rather than underweight. In Wales, having an LLTI is positively associated with being overweight or obese (65.9% versus 55.4%); this difference is true of both sexes although it is particularly marked in women (63.3% versus 49.8%). In Scotland, an LLTI is positively associated with a non-normal weight (75.9% versus 67.8%). The major problem is being overweight or obese rather than underweight. The inequality is greater for women rather than men although this seems to be because Scottish men *without* an LLTI have a higher proportion of non-normal weight than Scottish women without LLTI.

### **Data quality and quantity**

There are no systematic national data sets on Life and Health outcomes, such as premature death from cancer or heart disease, disaggregated by disability and subsets of disability. Some figures can be disaggregated from, for example, the Welsh Health Survey.

Disability is a broad and disparate category - this makes interpretation of data difficult.

Death certificates include no disability information - there is no national-level picture of inequalities by disability in life indicators.

## 6.2 Disability: Background

The Disability Discrimination Act (1995, amended 2005) often provides the basis in the UK for definitions of disability. This defines a disabled person as one who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. Long-term is taken as at least 12 months. The Act also lists capacities which can be affected by disability: these include mobility, manual dexterity, speech, hearing, seeing and memory. Conditions such as pyromania and hay-fever are excluded; some progressive conditions (e.g. HIV) and fluctuating conditions (e.g. some forms of Multiple Sclerosis) are included as disabilities for the purpose of the act even where the disabling effect on capacity is not yet, or not always, present.

Using the notion of limits on capacity it is possible to distinguish different types of disability, for example, the Disability Rights Commission's (DRCs) disability equality duty<sup>1</sup> suggested:

- Physical disability: for example, a person who has difficulty using their arms or someone who uses a wheelchair.
- Sensory impairment: for example, someone who is partially blind or deaf.
- Mental health condition: such as schizophrenia or depression.
- Learning disability: such as Down's syndrome or Autism.
- Longstanding illness or health condition: such as cancer, diabetes or Multiple sclerosis (MS).

In an earlier document there was an additional category (Molloy, Knight and Woodfield 2003):

- Other forms of disability (for example, disfigurement).

The Department for Work and Pensions (DWP) has also used claiming of disability-related benefits as a marker.<sup>2</sup>

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<sup>1</sup> <http://www.dotheduty.org/>

<sup>2</sup> <http://www.statistics.gov.uk/STATBASE/ssdataset.asp?vlnk=7403>

The Office for National Statistics (ONS) is developing a framework within which disability is more consistently defined. This seems likely to use the definition set out in the Census 2011 which will be a self-definition; people will be asked whether they have, or look after, someone who has, a long-standing illness, disability or infirmity. This approach is used also in the General Household Survey, the Health Survey for England and the Family Resources Survey (Walby, Armstrong and Humphreys 2008). For the long-term purposes of the triennial review, however, the Census 2011 category is likely to be the most useful. However, without the detail that the DWP report above suggests, interpreting the statistics in relation to judging the presence of inequity is difficult.

The lack of an agreed definition gives rise to structural problems that can be illustrated with respect to people with learning disabilities. Again, there is no agreed definition of learning disability, even across Government departments. Since LD is a lifelong condition, this means that classifications change as the person ages (as responsibilities for education support and care shift between different government departments); 'official statistics' for people with LD cannot therefore be reproduced with respect to the lifespan and important and well documented transitions (which can be critical) in people's lives; and hence integrated planning by government for this group is dogged by fractured databases. This is in itself an unnecessary and avoidable iniquity. The solution, however, will take wholesale redesign of information systems and official databases right across the public sector at national and local level.<sup>3</sup>

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<sup>3</sup> This point was made by Professor Gordon Grant in personal correspondence.

### 6.3 Disability: Evidence

The Disability Rights Commission [(Disability Rights Commission. ) reports that there are no systematic national data sets on Life and Health outcomes, such as premature death from cancer or heart disease, disaggregated by disability and subsets of disability. Some figures can be disaggregated from, for example, the Welsh Health Survey.

There are other useful data sources, and we report these where available for each indicator below. An important source is a national survey conducted by the Department of Health and a more recent overview which reports this survey primarily but with some additional information (Emerson and Hatton 2008).

The Office for Disability Issues has a set of equality indicators and updates these annually <sup>4</sup>. These do not include Life or Health indicators; but the indicators relating to independent living are of some relevance for matters related to process.

The Disability Rights Commission (DRC) undertook a review of evidence on the nature, extent and causes of inequalities in physical health outcomes and access to, and quality of, primary healthcare services experienced by people with learning disabilities and people with mental health problems; the results are published in a report, *Equal Treatment, Closing the Gap* (Kerr et al. 2005). The report refers to a number of other pieces of evidence, some of which were specially commissioned by the DRC. It is a valuable source of evidence for the two specific disability sub-groups, those with learning disability and those with mental health problems.

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<sup>4</sup> <http://www.officefordisability.gov.uk/research/indicators.php#il>

## 6.3 Life: main indicators

### 6.3.1 Period life expectancy at birth, ages 20, 65 and 80

These data are not collected in the General Register Office for Scotland or the General Register Office Census Longitudinal Study (for England & Wales).

Age and sex standardised standard mortality rates have been performed using figures from three English counties relating to adults with moderate to profound learning disability (Tyrer and McGrother 2009).

Table 1 Age and sex standardised standard mortality rates in three English Counties

	<b>Male</b>	<b>Female</b>	<b>All</b>
	SMR%	SMR%	SMR%
<b>Death: All causes</b>	228	324	277
<i>Base: Death rates of people registered with learning disability in three English counties.</i>			

Source: Tyrer (2009)

This shows the mortality rate to be over two times the average for men and over three times for women. The combined figure is 277. This is an inequality; whether it is an injustice depends on whether the cause is avoidable. This issue is examined further in the discussion section.

### 6.3.2 Cardiovascular disease mortality

These data are not collected in the General Register Office for Scotland or the Registrar General Mortality Statistics (for England & Wales).

Additional data: age and sex standardised standard mortality rates have been performed using figures from three English counties.

Table 2 Age and standardised mortality rates due to cardiovascular disease in three English Counties

<b>CAUSES</b>	<b>Male</b>	<b>Female</b>	<b>All</b>
	SMR%	SMR%	SMR%
<b>Cerebrovascular disease</b>	241	245	240
<b>Ischaemic heart disease</b>	124	174	149
<b>Other circulatory</b>	146	218	178
<i>Base: Death rates of people registered with learning disability in three English counties.</i>			

Source: Tyrer (2009)

As in the previous table, this shows a higher mortality rate for those with learning disability; cerebrovascular disease has an SMR of 240; ischaemic heart disease, 149; and other circulatory disease, 178.

### 6.3.3 Cancer mortality

These data are not collected in the General Register Office for Scotland or the Registrar General Mortality Statistics (for England & Wales). Nor are the available in the list of sources set out in the Equality and Human Rights Commission's own review of equality statistics (Walby, Armstrong and Humphreys 2008) p.18).

Additional data: age and sex standardised standard mortality rates have been performed for men and women with learning disability using figures from three English counties.

Table 3 Age and standardised mortality rates due to cancer in three English Counties

CAUSES	Male	Female	All
CANCER	SMR%	SMR%	SMR%
Breast	0	138	111
Lung, bronchus, trachea	77	0	62
Digestive organs, peritoneum	92	43	80
Other	103	115	112

*Base: Death rates of people registered with learning disability in three English counties.*

Source: Tyrer 2009

The table shows that cancer is not particularly raised for those with learning disability and is, in some cases, lower.

Overall, the three tables adapted from Tyrer and McGrother (2009) are based on small samples from a region of England. The figures are in line with those in a Swedish study cited by the authors. Together, the figures suggest that cancer mortality is not raised in the population with learning disability; it is

slightly raised for ischaemic heart disease and more than doubled for cerebrovascular disease. The Tyrer study found the largest differences in underlying causes were deaths caused from congenital malformations (SMR = 8560), diseases of the nervous system and sense organs (SMR = 1630) and disease of the genitourinary system (SMR = 603).



#### 6.3.4 Suicide rates/risk

These data are not collected in the General Register Office for Scotland or the Registrar General Mortality Statistics (for England & Wales).

Any interpretation of suicide rates and risk by disability requires consideration of the different types of disability. Insofar as mental health conditions such as depression are categorised as a disability we might expect high rates of suicide. Harris et al's evidence review is crucial here although it is dated (Harris and Barraclough 1997). The authors show that 36 out of 44 mental health disorders were associated with higher standardised mortality rates for suicide. The highest rates were found in those with functional mental disorders such as depression rather than substance misuse or organic disorders such as dementia.

How far these suicides were avoidable would be hard to assess although the effectiveness of steps taken to reduce the rates would be pertinent. The *Five Year Report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness* (2001) examined over 6000 suicides of current or recent mental health problems between 2000 and 2004 in the UK. Of these, clinicians estimated that around 20% could have been prevented. The report goes on to make a number of recommendations to reduce this figure. It seems likely, nonetheless, that mental health conditions would remain a risk factor for suicide even in an equitable society.

In relation to other disabilities, such as wheelchair use or Down's syndrome, a finding of high rates of suicide would suggest *prima facie* that needs for flourishing were going unmet. There are few data here. An American literature review looked at the suicide rates of people with MS, spinal cord injury or intellectual disability (Giannini et al. 2009). In the first two groups, the suicide rate is notably higher; in the third group it is slightly lower. None of the data for the review is from UK sources. There is some UK evidence that disorders such as heart disease, cancer, visual impairment and neurological disorders increase the risk of suicide (Waern et al. 2002, Twombly 2006).

### *6.3.5 Accident mortality rate*

These data are not collected in the General Register Office for Scotland or the Registrar General Mortality Statistics (for England & Wales).

### *6.3.6 Deaths from non-natural causes for people resident in health or social care establishments*

These data are not collected in the ONS figures<sup>5</sup>. It will be recalled that in considering this factor in relation to age (section 5.3.6) we were able to give the deaths by external causes in all institutions by sex and age. There is no disaggregation by disability. However, we might infer that those under the age of 65 in non-NHS hospitals (excluding psychiatric hospitals and hospices) and in other communal establishments will include a large proportion of disabled people. However, the numbers in these categories are too small to infer anything. If NHS hospitals are included then the numbers are much larger. However it cannot then be assumed that the figure includes a particularly high proportion of those classified as disabled.

This lack of quantitative data is particularly unfortunate as this topic is widely believed to be important, particularly in relation to learning disability. The underlying concern is that some learning disabled people in health or social care establishments are vulnerable to neglect or abuse. There is qualitative evidence to support this view. In 2006 Mencap published a report documenting the treatment within the NHS of six people with learning disabilities and who had died during treatment or care (Mencap 2007). The Health Service Ombudsman has now responded (Local Government Ombudsman. 2009). She finds that two of the six deaths were either avoidable or probably avoidable; she also lists extensive failure to abide by human rights principles. The numbers behind this data are too small to be generalisable. However, it is worth mentioning as qualitative data because the report had some political impact and is, perhaps, one of the drivers behind non-natural cause being one of the indicators chosen by the Equality and Human Rights Commission.

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<sup>5</sup> [http://www.statistics.gov.uk/downloads/theme\\_health/DR2008/DR\\_08.pdf](http://www.statistics.gov.uk/downloads/theme_health/DR2008/DR_08.pdf)

### 6.3 Health: Main indicators

#### Outcomes

#### 6.3.7 [2.1] Self-report poor current health

- (E,S,W) Percentage who report poor current health status

#### ENGLAND

Table 4 Self-report of poor current health status by LLTI, England

SRH 1			
	Very good to fair	Bad and very bad	N
Has LLTI	76.1	23.9	3675
No LLTI	99.2	0.8	14890
Total	94.6	5.4	18565
X <sup>2</sup> = 3088.43; df = 1; p<.001; Cramers V = .48			
SRH 2			
	Very good and good	Fair to very bad	N
Has LLTI	36.5	63.5	3675
No LLTI	90.0	10.0	14890
Total	79.4	20.62	18565
X <sup>2</sup> = 5156.38; df = 1; p<.001; Cramers V = .53			

Source: Health Survey for England 2008

The table shows that the presence of a life-limiting illness (LLTI) is strongly associated with a self-report of poor health. Two survey instruments are reported in the table. In the first, 23.9% of those with LLTI as against 0.8% without LLTI, self-report bad and very bad health. These figures are statistically significant.

## WALES

Table 5 Self-report of poor current health status, Wales

Recoded SRH - EHRC (top 4 v bottom 1)			
	Excellent to fair	Poor	N
No LLI	99.4	0.7	9032
LLI	81.1	18.9	3873
Total	93.9	6.1	12905
			Cramer's
X2	df	p	V
1565.97	1.00	p<.001	0.35

Source Welsh Health Survey 2008

The table shows that the presence of a long-term life-limiting illness or disability (LLTI) is strongly associated with a self-report of poor health. 18.9% of those with LLTI report poor current health status as against 0.7% of those without.

## SCOTLAND

Table 6 Self-report of poor current health status, Scotland

SRH 1 (EHRC) top 3 v  
bottom 2

	Very good to fair	Bad and very bad	N
Has LLI	76.2	23.9	1971
No LLI	99.3	0.7	6241
Total	93.7	6.3	8212

  

X2	df	p	Cramer's V
1362.744	1.00	p<.001	0.41

Source: Scottish Health Survey

The table shows that the presence of a life-limiting illness (LLTI) is strongly associated with a self-report of poor health. 23.9% of those with LLTI as against 0.8% without LLTI, self-report bad and very bad health.

In all three nations there is a large and statistically significant difference in self-reported health status between those with and those without long-term limiting illness and disability.

The Emerson et al (Emerson and Hatton 2008) survey found 15% of those with learning disability reported their health as not good. The rates were highest in those who were unemployed, socially isolated, older and from a minority ethnic community.

### 6.3.8 [1.1] Longstanding health problem or disability and longstanding illness

As these are generally the defining criteria for disability, we should expect 100% of disabled people to be in this category. The national figures for the proportion of the population that is disabled are as follows.

#### ENGLAND

Table 7 Proportion of people with Life-limiting illness, England

LLI	No LLI	LLI	N
16-24	92.8	7.2	1483
25-34	89.4	10.6	1485
35-44	85.2	14.8	2123
45-54	75.4	24.6	2098
55-64	60.9	39.1	2455
65-74	50.6	49.4	1907
75+	36.2	63.8	1444
All	69.9	30.2	12995
X2	df	p	Cramer's V
2113	6.00	p<.001	0.4

(Source: Health Survey for England 2008)

The table above shows that the proportion of people in England with LLTI is 30%; there is a difference across the age-range; as people age their chance of LLTI increases such that by 75+, the majority of people have one or more LLTI.

## WALES

Table 8 Proportion of people with Life-limiting illness, Wales

LLI	No LLI	LLI	N
16-24	92.8	7.2	1483
25-34	89.4	10.6	1485
35-44	85.2	14.8	2123
45-54	75.4	24.6	2098
55-64	60.9	39.1	2455
65-74	50.6	49.4	1907
75+	36.2	63.8	1444
All	69.9	30.2	12995
X2	df	p	Cramer's V
2113	6.00	p<.001	0.4

Source: Wales Health Survey 2008

The table above shows that the proportion of people in Wales with LLTI is 30%; there is a difference across the age-range; as people age their chance of LLTI increases such that by 75+, the majority of people have one or more LLTI.



## SCOTLAND

Table 9 Proportion of people with Life-limiting illness, Scotland

Limiting longstanding illness			
	Has LLI	No LLI	N
16-24	8.5	91.6	580
25-34	14.8	85.2	768
35-44	20.1	79.9	1108
45-54	23.8	76.2	1167
55-64	35.4	64.6	1157
65-74	43.0	57.0	969
75+	52.2	47.8	714
All	28.8	71.2	6463
X2	df	p	Cramer's V
556.3	6.00	p<.001	0.29

Source: Scottish Health Survey 2008

The table above shows that the proportion of people in Scotland with LLTI is around 30%; there is a difference across the age-range; as people age their chance of LLTI increases such that by 75+, the majority of people have one or more LLTI.

### 6.3.9 [1.2] Poor mental health or wellbeing

Data for assessment of mental health for England and Scotland are taken from the respective health surveys, which use the General Health Questionnaire (GHQ12); the Welsh Health Survey uses the Short Form - 36 (SF36). On the GHQ12, a score of four or more is taken to be a sign of possible psychiatric disorder. The SF-36 includes a section relating to mental health. Higher scores indicate better health; 50 is the population average.

#### ENGLAND

Table 10 GHQ12 Mental health scores by LLTI, England

GHQ			
	0-3	4 or more	N
Has LLI	74.4	25.6	3588
No LLI	92.8	7.2	14771
Total	89.2	10.8	18359
X <sup>2</sup> = 1025.35; df = 1; p<.001; Cramers V = .24			

Source: Health Survey for England 2008

The table above shows that those with an LLTI in England are more likely to report 4 or more symptoms, which is a sign of poor mental health. The difference is large (25.6% against 7.1%). However, mental illness is a possible cause of LLTI and, as such, that makes it difficult to interpret this result.

## WALES

Table 11 SF36 Mental health scores, Wales

Recoded SF 36 score - binary (0-46 v 47 or more)

	Below average mental health	Average or above average mental health	N
No LLI	23.6	76.4	8946
LLI	52.2	47.8	3805
Total	32.2	67.9	12751

  

X2	df	p	Cramer's V
998.12	1.00	p<.001	0.28

Source: Welsh Health Survey 2008

The table above shows that those with an LLTI in Wales have worse mental health. The difference is large, indicating that mental health is worse for those with LLTI.

## SCOTLAND

Table 12 GHQ12 Mental health scores, Scotland

GHQ symptoms			
	0-3 symptoms	4 or more	N
Has LLI	73.5	26.5	1690
No LLI	90.6	9.4	4481
Total	85.9	14.1	6171
X2	df	p	Cramer's V
294.944	1.00	p<.001	0.22

Source: Scottish Health Survey 2008

The table above shows that those with an LLTI in Scotland are more likely to report 4 or more symptoms, which is a sign of poor mental health. The difference is large (26.5% against 9.4%) and statistically significant.

*Process*

*6.3.10 [3.1] Low perception of treatment with dignity*

**ENGLAND**

Table 13 Treatment with respect when using health services England & Wales

In general, would you say that you are treated with respect when using health services by LLTI (disability)			
	All the time or most of the time	Some of the time or less	N
Has LLTI	91.5	8.5	2732
No LLTI	91.0	9.0	11244
(			

Source: Citizenship Survey, 2007

The table above shows that having a LLTI was not associated with saying you are treated with respect when using health services; around 90% say they are whether or not they have a LLTI. Excluded from this sample are those without the mental capacity to take part in it. This is a limitation for self-reports of this kind.

### 6.3.10 [3.1] Low perception of treatment with dignity

#### WALES

Table 14 Treatment with respect when using GP services, Wales

Recorded GP surgery - I was treated with dignity and respect			
	Do not disagree	Disagree	N
Has LLI	96.78	3.22	900
No LLI	96.62	3.38	2458
Total	96.66	3.34	3358
X2	df	p	Cramer's V
	0.05	1.00	0.83
Recorded GP surgery - I was treated with dignity and respect			
	Do not disagree	Disagree	N
Registered as disabled or vision impaired	97.87	2.13	470
Not registered as disabled or vision impaired	95.76	4.24	589
Total	96.69	3.31	1059
X2	df	p	Cramer's V
	3.67	1.00	0.06

Source: Living in Wales Survey, 2008

The Welsh survey has more detail on treatment with dignity and respect insofar as it breaks down the health service into categories such as GP service. The table above shows that LLTI makes no difference to the chance of feeling you are treated with dignity and respect by your GP in Wales.

Table 15 Treatment with respect when using hospital services, Wales

Recoded inpatient, outpatient or day case service - I was treated with dignity and respect			
	Do not disagree	Disagree	N
Has LLI	96.5	3.5	1170
No LLI	96.0	4.0	2484
Total	96.2	3.8	3654
X2	df	p	Cramer's V
	0.42	1.00	0.52
Recoded inpatient, outpatient or day case service - I was treated with dignity and respect			
	Do not disagree	Disagree	N
Registered as disabled or vision impaired	96.3	3.7	649
Not registered as disabled or vision impaired	96.4	3.6	699
Total	96.4	3.6	1348
X2	df	p	Cramer's V
	0.01	1.00	0.91

Source: Living in Wales Survey, 2008

The table above shows that LLTI makes no difference to the chance of feeling you are treated with dignity and respect by hospital services in Wales. One limitation of this data is that it does not cover those without capacity to say whether they felt treated with respect; as such some, such as those with severe learning difficulty, are excluded.

### *6.3.10 [3.1] Low perception of treatment with dignity*

#### **SCOTLAND**

The Better Together survey is under development; as such, there are no data yet from it on perception of treatment with dignity in Scotland.



### *6.3.11 [5.1] A&E attendance/accidents A&E accidents and injuries rate by location*

The main source of data for A&E attendance is the Department of Health experimental statistics.<sup>6</sup> These data are not disaggregated by disability status.

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6

### 6.3.12 [3.2] Lack of support for individual nutritional needs during hospital stays

#### ENGLAND

Table 16 Did you get enough help from staff to eat your meals?

**Q30 Did you get enough help from staff to eat your meals?**

	Survey Year						Significant change between 08 and 09	Significant change between 02 and 09
	2002	2005	2006	2007	2008	2009		
Yes, always	58%	62%	58%	60%	63%	63%	↑	
Yes, sometimes	24%	21%	21%	20%	19%	19%	↓	
No	18%	18%	20%	20%	18%	18%		
Number of respondents	19049	19982	19041	20709	21079	20364		

Answered by all who needed help from hospital staff to eat their meals

Source: National patient survey programme 2001/2

Support for nutritional needs in hospital is clearly important for those with disability. The majority of the literature on this topic, however, concerns the elderly. This is because the initial concern was that elderly people's needs are neglected. As such, there seem to be no data on the topic aggregated by disability. This is worth rectifying. One of the deaths reported by MenCap in *Death by Indifference* is of Martin Ryan, who was said to have starved to death at Kingston hospital.

#### WALES and SCOTLAND

No data available.

## Autonomy

### 6.3.13 [4.1] Healthy lifestyle [Smoking, alcohol, exercise, diet (fruit and vegetables), obesity

#### ENGLAND

#### Smoking

Table 17 Cigarette smoking status by LLTI, England

Cigarette smoking status			
	Smokes	Does not smoke	N
Has LLTI	37.8	62.2	2192
No LLTI	38.4	61.6	6263
Total	38.3	61.7	8455
n/s			

Source: Health Survey for England, 2008

Table 18 Cigarette smoking status by LLTI and sex, England

		Smokes cigarettes	Does not smoke	N
Men	Has LLTI	36.8	63.2	1098
	No LLTI	38.6	61.4	3409
	Total	38.2	61.8	4507
Women	Has LLTI	38.8	61.2	1093
	No LLTI	38.2	61.8	2854
	Total	38.4	61.7	3947
n/s				

Source: Health Survey for England, 2008

The tables above show no significant difference in smoking status between those with and without LLTI neither overall nor by sex.

## Alcohol

Table 19 Alcohol intake by LLTI, England

Drinks more than the recommended units of alcohol			
	Drinks up to the recommended amount	Drinks more than the recommended amount	N
Has LLTI	75.0	25.0	3440
No LLTI	60.4	39.7	11367
Total	63.8	36.2	14807
X <sup>2</sup> = 246.26; df = 1; p<.001; Cramers V = .13			

Source: Health Survey for England, 2008

The table above shows that having an LLTI is negatively associated with drinking above the recommended amount in England.

Table 20 Alcohol intake by LLTI and sex, England

Alcohol consumption by LLTI and sex				
		Drinks up to the recommended amount	Drinks more than the recommended amount	N
Men	Has LLTI	70.4	29.7	1501
	No LLTI	55.8	44.2	5710
	Total	58.9	41.2	7211
Women	Has LLTI	78.7	21.4	1939
	No LLTI	64.9	35.1	5657
	Total	68.4	31.6	7596
	X <sup>2</sup>	df	p	Cramer's V
Men	103.497	1	p<.001	0.119802
Women	126.129	1	p<.001	0.128859

Source: Health Survey for England, 2008

The table above shows that the negative association exists across both sexes.

## Exercise

Table 21 Meeting government exercise guidelines by LLTI, England

Whether respondent meets government exercise guidelines			
	Does not meet govt recommendations for exercise	Meets govt recommendations for exercise	N
Has LLI	82.6	17.4	3457
No LLI	61.2	38.8	11503
Total	66.2	33.8	14960

X<sup>2</sup> = 543.17; df = 1; p<.001; Cramers V = .19

Source: Health Survey for England, 2008

The table above shows that meeting exercise guidelines is negatively associated with having an LLTI: 83% of people without an LLTI meet the guidelines, 61% of people with an LLTI.

Table 22 Meeting government exercise guidelines by LLTI and sex, England

Whether does at least 30 mins moderate exercise for 5 days a week				
		Does not meet govt recommendations for exercise	Meets govt recommendations for exercise	N
Men	Has LLI	79.4	20.7	1511
	No LLI	59.0	44.0	5792
	Total	60.8	39.2	7303
Women	Has LLI	85.1	14.9	1947
	No LLI	66.6	33.4	5711
	Total	71.3	28.7	7658
	X <sup>2</sup>	df	p	Cramer's V
Men	275.191	1	p<.001	.190
Women	243.62	1	p<.001	.178

Source: Health Survey for England, 2008

The table above shows that meeting exercise guidelines is negatively associated with having an LLTI and that this difference is true for both sexes.

## Consumption of Fruit and Vegetables

Table 23 Portions of fruit and veg eaten the previous day by LLTI, England

Portions of fruit and veg eaten the previous day			
	Less than 5	5 or more	N
Has LLI	78.7	21.3	3439
No LLI	78.5	21.5	13038
Total	78.5	21.4	16477
n/s			

Source: Health Survey for England, 2008

Table 24 Portions of fruit and vegetables eaten the previous day by LLTI and sex, England

Portions of fruit and veg eaten previous dat				
	Less than 5	5 or more	N	
Men	Has LLI	79.5	20.5	1516
	No LLI	80.5	19.5	6604
	Total	80.3	19.7	8120
Women	Has LLI	78.2	21.8	1922
	No LLI	76.6	23.4	6433
	Total	76.9	23.1	8355

Source: Health Survey for England, 2008

The two tables above show no statistical link between having a LLTI and portions of fruit and vegetables eaten the previous day.

## Body Mass

Table 25 Body mass index and healthy weight by LLTI, England

BMI healthy weight versus unhealthy weight			
	Healthy weight	Not healthy weight	N
Has LLI	28.2	71.7	2756
No LLI	39.2	60.8	10077
Total	36.8	63.2	12833
X <sup>2</sup> = 111.90; df = 1; p<.001; Cramers V = .09			
BMI overweight and obese versus not overweight or obese			
	Underweight and normal weight	Overweight and obese	N
Has LLI	29.6	70.4	2756
No LLI	41.1	58.9	10077
Total	38.6	61.4	12833
X <sup>2</sup> = 120.70; df = 1; p<.001; Cramers V = .10			

Source: Health Survey for England, 2008

The table above shows that having an LLTI is positively associated with not having a healthy weight; 72% with an LLTI do not have a healthy weight, against 61% without an LLTI. In the main, the problem is one of overweight rather than underweight.

## WALES

### *Smoking*

Table 26 Cigarette smoking status by LLTI, Wales

Recorded smoking status				
	Smokes	Does not smoke	N	
No LLTI	23.4	76.6	9036	
LLTI	20.8	79.2	3861	
Total	22.6	77.4	12897	
X2	df	p	Cramer's V	
10.64	1.00	p<.05	0.03	

Recorded smoking status				
	Smokes	Does not smoke	N	
Men	Has LLTI	24.2	75.8	4216
	No LLTI	21.7	78.4	1723
	Total	23.5	76.5	5939
Women	Has LLTI	22.7	77.3	4820
	No LLTI	20.1	80.0	2138
	Total	21.9	78.1	6958
X2	df	p	Cramer's V	
Men	4.575	1	p<.05	0.03
Women	5.817	1	p<.05	0.03

Source: Welsh Health Survey 2008

The table above shows that in Wales there is a slightly lower occurrence of smoking for those with an LLTI against those without (20.8% versus 23.0%); the difference is found across both sexes.



## Alcohol

Table 27 Alcohol intake by LLTI, Wales

(D) Maximum daily alcohol consumption: above guidelines - binary				
	Above guidelines	Up to guidelines	N	
No LLTI	51.4	48.6	8850	
LLTI	69.6	30.4	3758	
Total	56.9	43.2	12608	
X2	df	p	Cramer's V	
356.76	1.00	p<.001	0.17	

(D) Maximum daily alcohol consumption: above guidelines - binary				
		Up to guidelines	Above guidelines	N
Men	Has LLTI	45.0	55.0	4132
	No LLTI	60.2	39.8	1692
	Total	49.4	50.6	5824
Women	Has LLTI	57.1	42.9	4718
	No LLTI	77.4	22.75	2066
	Total	63.3	36.8	6784
X2	df	p	Cramer's V	
Men	111.811	1	p<.001	0.14
Women	253.937	1	p<.001	0.19

Source: Welsh Health Survey 2008

The table above shows that in Wales a higher proportion of those with LLTI than those without drink above the recommended guidelines (68.6% versus 51.4%). This is true for both sexes. Note that the reverse pattern is found in England.

## Exercise

Table 28 Exercise above 30 minutes, 5 times weekly, by LLTI Wales

(D) At least 30 mins mod/vigorous exercise on 5+ days				
	No	Yes	N	
No LLTI	65.3	34.7	8989	
LLTI	85.8	14.2	3843	
Total	71.4	28.6	12832	
X2	df	p	Cramer's V	
556	1.00	p<.001	0.21	

(D) At least 30 mins mod/vigorous exercise on 5+ days				
	No	Yes	N	
Men	Has LLTI	56.7	43.3	4188
	No LLTI	80.7	19.3	1705
	Total	63.6	36.4	5893
Women	Has LLTI	72.7	27.3	4801
	No LLTI	89.9	10.2	2138
	Total	78.0	22.0	6939
X2	df	p	Cramer's V	
Men	302.057	1	p<.001	.23
Women	252.593	1	p<.001	.19

Source: Welsh Health Survey 2008

The table above shows that those with LLTI are less likely to exercise sufficiently than those without one (85.8% versus 65.3%); this difference occurs across both sexes.

## Consumption of Fruit and Vegetables

Table 29 Eating five or more portions of fruit and vegetables, by LLTI, Wales

(D) Eaten 5+ fruit or veg the previous day - binary			
	No	Yes	N
No LLI	63.1	36.9	8892
LLI	63.7	36.4	3785
Total	63.2	36.8	12677
X2	df	p	Cramer's V
0.35		1 n/s	

(D) Eaten 5+ fruit or veg the previous day - binary				
		No	Yes	N
Men	Has LLI	65.2	34.8	4143
	No LLI	63.9	36.1	1684
	Total	64.8	35.2	5827
Women	Has LLI	61.2	38.8	4749
	No LLI	63.5	36.6	2101
	Total	61.9	38.1	6850
X2	df	p	Cramer's V	
Men	0.886		1 n/s	0.01
Women	3.138		1 n/s	0.02

Source: Welsh Health Survey 2008

The table above shows that having an LLTI has no effect on your likelihood of eating sufficient fruit and vegetables.

## Body Mass

Table 30 Body mass index and healthy weight by LLTI, Wales

Recorded BMI (EHRC)				
	Underweight and normal weight	Overweight and obese	N	
No LLI	44.6	55.4	8387	
LLI	34.0	65.9	3680	
Total	41.4	58.6	12067	
X2	df	p	Cramer's V	
115.85	1.00	p<.001	0.1	

Recorded BMI (EHRC)					
		Underweight and normal weight	Overweight and obese	N	
Men	Has LLI	38.4	61.6	4004	
	No LLI	30.9	69.1	1671	
	Total	36.2	63.8	5675	
Women	Has LLI	50.2	49.8	4383	
	No LLI	36.7	63.3	2009	
	Total	46.0	54.1	6392	
	X2	df	p	Cramer's V	
Men	28.312	1	p<.001	0.07	
Women	101.224	1	p<.001	0.13	

Source: Welsh Health Survey 2008

The table above shows that in Wales having an LLTI is positively associated with being overweight or obese (65.9% versus 55.4%); this difference is true of both sexes although it is particularly marked in women (63.3% versus 49.8%).

## SCOTLAND

### Smoking

Table 31 Cigarette smoking status by LLTI, Scotland

Whether the respondent smokes			
	Smokes	Does not smoke	N
Has LLTI	26.5	73.5	1852
No LLTI	23.5	76.5	4418
Total	24.4	75.7	6270
X <sup>2</sup>	df	p	Cramer's V
6.32	1.00	p<.05	0.03

Whether the respondent smokes				
		Smokes	Does not smoke	N
Men	Has LLTI	29.2	70.8	774
	No LLTI	23.1	76.9	1982
	Total	24.8	75.2	2756
Women	Has LLTI	24.5	75.5	1078
	No LLTI	23.8	76.2	2436
	Total	24.0	76.0	3514
	X <sup>2</sup>	df	p	Cramer's V
Men	11.068	1	p<.005	0.05
Women	0.213	1	n/s	0.01

Source: Scottish Health Survey, 2008

The table above shows that there is little statistically significant difference in smoking status overall for those with and without LLTI. There is a slight difference in smoking status for men, with having an LLTI being associated with smoking (29.2% with LLTI smoke versus 23.1% without).

## Alcohol

Table 32 Alcohol intake by LLTI, Scotland

Whether respondent drinks more than recommended amount				
	Respondent drinks up to recommended amount		Respondent drinks more than recommended amount	
Has LLI		52.1	47.9	913
No LLI		38.1	61.9	3062
Total		41.3	58.7	3975
X2	df		p	Cramer's V
57.037	1.00		p<.001	0.12

Whether respondent drinks more than recommended amount				
	Respondent drinks up to recommended amount		Respondent drinks more than recommended amount	
Men	Has LLI	53.4	46.2	444
	No LLI	38.2	61.2	1498
	Total	41.7	58.4	1942
Women	Has LLI	51.0	49.4	469
	No LLI	38.0	62.0	1564
	Total	41.2	58.9	2033
	X2	df	p	Cramer's V
Men	32.532	1	p<.001	0.13
Women	24.878	1	p<.001	0.11

Source: Scottish Health Survey, 2008

The table above show that in Scotland having an LLTI is negatively associated with drinking more than the recommended amount (47.9% versus 61.9%), and that this is true for both men and women.

## Exercise

Table 33 Meeting government exercise guidelines by LLTI, Scotland

Whether respondent meets govt exercise guidelines			
	Does not meet govt guidelines	Meets govt guidelines	N
Has LLI	82.3	17.7	1861
No LLI	58.3	41.7	4591
Total	65.2	34.8	6452
X2	df	p	Cramer's V
335.08	1.00	p<.001	0.23

Whether respondent meets govt exercise guidelines				
	Does not meet govt guidelines	Meets govt guidelines	N	
Men	Has LLI	81.2	18.8	777
	No LLI	52.0	48.0	2060
	Total	60.0	40.0	2837
Women	Has LLI	83.0	17.0	1084
	No LLI	63.5	36.6	2531
	Total	69.3	31.6	3615
X2	df	p	Cramer's V	
Men	200.695	1	p<.001	.266
Women	136.715	1	p<.001	.194

Source: Scottish Health Survey, 2008

The table above shows that in Scotland having an LLTI is negatively associated with sufficient exercise. This is true for both sexes and is statistically significant.

## Consumption of Fruit and Vegetables

Table 34 Portions of fruit and vegetables eaten the previous day by LLTI, Scotland

Whether respondent ate 5 more more portions of fruit & veg in previous day			
	Less than 5 portions	5 portions or more	N
Has LLTI	79.9	20.1	1966
No LLTI	78.6	21.4	6011
Total	79.0	21.1	7977
X <sup>2</sup>	df	p	Cramer's V

Whether respondent ate 5 more more portions of fruit & veg in previous day					
		Less than 5 portions	5 portions or more	N	
Men	Has LLTI	82.3	17.7	830	
	No LLTI	80.3	19.7	2774	
	Total	80.8	19.2	3604	
Women	Has LLTI	78.2	21.8	1136	
	No LLTI	77.2	22.8	3237	
	Total	77.5	22.6	4373	
X <sup>2</sup>	df	p	Cramer's V		
Men	1.599	1	n/s	0.02	
Women	0.451	1	n/s	0.01	

Source: Scottish Health Survey, 2008

The table above shows that in Scotland there is no association between having an LLTI and whether or not a person eats five or more portions of fruit and vegetables.



## Body Mass

Table 35 Body mass index and healthy weight by LLTI, Scotland

Recorded BMI normal v not normal weight				
	Normal weight	Non-normal weight	N	
Has LLI	24.1	75.9	1501	
No LLI	32.2	67.8	3972	
Total	30.0	70.0	5473	
X2	df	p	Cramer's V	
33.7	1.00	p<.001	0.78	
Recorded BMI (EHRC) not overweight v overweight				
	Underweight and normal	Overweight and obese	N	
Has LLI	25.5	74.5	1501	
No LLI	33.6	66.4	3972	
Total	31.4	68.6	5473	
X2	df	p	Cramer's V	
32.94	1.00	p<.001	0.78	

Recorded BMI (EHRC) not overweight v overweight				
		Underweight and normal	Overweight and obese	N
Men	Has LLI	24.1	75.9	630
	No LLI	27.9	72.2	1824
	Total	26.9	73.1	2454
Women	Has LLI	26.5	73.5	871
	No LLI	38.5	61.6	2148
	Total	35.0	65.0	3019
	X2	df	p	Cramer's V
Men	3.303	1	n/s	0.04
Women	38.784	1	p<.001	0.11

Source: Scottish Health Survey, 2008

The table above shows that in Scotland having an LLTI is positively associated with a non-normal weight (75.9% versus 67.8%). The major problem is being overweight or obese rather than underweight. The inequality is greater for women rather than men although this seems to be because Scottish men *without* an LLTI have a higher proportion of non-normal weight than Scottish women without LLTI.

## 6.4 Cross-over themes

There is a complicated interplay of disability with other strands of inequality. For example, disabled people are more likely to be unemployed or in low-income work. But it is not clear whether the unemployment is a product of disability or that (later-onset) disability is a product of unemployment and deprivation. This reinforces the need to have more nuanced statistics, perhaps using the categories suggested by Rolland (1994) and discussed in the section below.

The phenomenon of multiple disadvantage is perhaps clearest in relation to disability. For example, we know that for people with learning disabilities their health and wellbeing is mediated by other personal factors (severity of LD, additional disabilities, mental health, gender, age), social and cultural factors (family support, ethnicity) and economic factors (income, area deprivation). Those who are most disadvantaged, and who have been persistently disadvantaged, are those characterised by such multiple markers. It is this same group that is most likely to be excluded from health and social care research (often on the grounds of mental capacity), and so this serves to weaken the evidence base about strategies for supporting them.

## 6.5 Health and life: Strand: Discussion

As an equality strand, disability presents unique problems in assessing inequity in the indicators of health and life. The Census 2011 definition of disability incorporates the indicator relating to reporting long-lasting health problems, disability or illness. Thus, by definition, 100% of disabled people will be in this inequality indicator. For similar reasons, we would expect a high proportion to self-report poor current health.

How, then, do we decide whether an inequality is iniquitous? There are at least two models of disability and the answer to this question depends to some extent on the one chosen.

- The social model describes disability as socially created: wheelchair use is a disability because society is organised for pedestrians; deafness is a disability because it is organised for oral language users. On this account, all inequalities that are a function of a disability that could be overcome were society arranged differently are iniquitous. Thus, for example, a lower rate of exercise and a higher rate of obesity for disabled people are iniquitous because the social environment disadvantages them in these regards.
- The medical model is one in which disability is intrinsic to the individual, it is a product of a malfunctioning part rather than a social injustice. On this account, the exercise/obesity problem is due to the disability and the way it inhibits exercise. This is natural rather than unjust. Society might develop systems to help the disabled; however, this is a matter of charity rather than justice. Society is not to blame for the existence of the disability in the first place.

How are we to choose between these approaches? In the first place there are good philosophical grounds to reject the medical model. At its heart is a false belief that illness and disability are facts about someone; no value judgement is involved in deciding that, for example, cancer is an illness and Down syndrome a disability. In fact, however, these statements are not simply empirical facts but rather they are judgements based on the facts

(Kennedy 1983). That someone has a low IQ might be a fact about them; that this is a disability is a judgement involving values. That someone has a tumour might be a fact; that it is an illness is a judgement involving values. We do not declare high IQ to be a disability; and some tumours are dismissed as benign. Low IQ is deemed a disability and some tumours deemed illnesses because they are associated with things we don't like, that we disvalue. In the case of low IQ it is the difficulty in coping with a complex world, perhaps; with some tumours, it is the association with limited function, pain and death.

Thus the medical model is grounded in a false account of the nature of illness and disability. This might lead us to favour the social account but more is needed. Someone might accept this rejection of the medical model but nonetheless say that someone having the conditions we disvalue as disability is still the product of nature, society is not to blame. At this point, Nussbaum's account of the Capability approach becomes relevant (Nussbaum 2006, Nussbaum 1999).

In our chapter on methodology above, we set out some of the details of Nussbaum's approach. We noted that Nussbaum gives a set of ten capacities that she takes to be essential for a human being to live a good life or to flourish. These capacities give rise to the demands of justice, often in the form of human rights. For example, the capacity to live a reasonable life-span gives rise to the rights not to be killed and where possible to resources to enable life; the capacity to bodily health gives rise to the rights to nourishment, shelter and health care. We saw also that these ten capacities are closely allied to the ten domains set out by the Equality and Human Rights Commission in its *Equality Measurement Framework*.

For Nussbaum, though, disability creates a puzzle. It might be said that some disability, for example, a learning disability such as Down syndrome, is associated with inability to meet these capacities; for example, it is associated with short life-span, constrained abilities to take part in civic life, and problems with health. If this is so, should we say either that people with Down

syndrome have a different set of capacities so that they can be said to flourish in their way, which is different to those without the disability? Or should we say that people with Down syndrome are unable to live a truly flourishing human life?

Nussbaum believes that the first option is unacceptable. The problem is that it declares to be natural and inevitable that which is often social and, in particular, based on cost. For example, were we to believe Down syndrome to be inevitably and naturally associated with a shorter lifespan we might make decisions that reinforce it, such as not providing life-prolonging surgery on the basis that people with Down syndrome will not benefit from it sufficiently. This is the argument that has been used in denying children with Down syndrome access to cardiac surgery (Savulescu 2001). By declaring that people with Down syndrome have the capacity to a full lifespan we make a priority the research and care necessary to achieve it; and we potentially declare it a violation of rights to deny life-prolonging treatment that is available to others.

Thus Nussbaum favours giving all people the same rights based on the same set of capacities. There will, of course, be some who do not and will never have these capacities; someone in persistent vegetative state, for example. But Nussbaum wants us to err on the side of trying to achieve capacities for all. People with a learning disability, for example, might need more help in achieving civic involvement, including voting, for example; the capabilities approach says we should provide that help. This idea is reflected in the England & Wales *Mental Capacity Act 2005* which requires practitioners to do all that is possible to help someone make their own decisions rather than simply to take over decision making for them.

It follows that the capabilities approach sits comfortably with the social model of disability rather than the medical model. For example, if a blind person could live independently were resources allocated to the necessary aids then that person has a claim on society for those aids; whether she has a right to those aids will depend on other factors, particularly resources.

In interpreting the inequalities related to disability, therefore, we should err on the side of viewing them as of concern, as issues of justice. The shorter lifespan of many people with disability should not be dismissed simply as natural and acceptable but should be viewed as a spur to action, something which requires action. In practice, this is often what happens, as we've seen with the improvements in treatment for people with Down syndrome or with cerebral palsy that have resulted in longer lifespan. However, also in practice, we've seen discrimination justified on the basis of differences in capacity being too lightly accepted as inevitable.

In practical terms, a model suggested by Rolland might be useful in collecting more nuanced data (Rolland 1994). He talks about four related parameters: onset (which may be sudden or gradual, expected or not expected), course (which may be progressive, constant or relapsing/episodic), outcome (concerning the likelihood of a shortened lifespan or death, and finally there is incapacity (cognitive, sensory, mobility, energy and stigma). These perspectives may be useful where there is a premium on the linking of experience (health status, community integration, family coping etc) across or between groups of disabled people.

### **What are the inequalities? How persistent and how worrying are they?**

#### Life indicators

Death certificates do not include information about disability. As such, data are largely absent. There is indication from other research of inequality in some areas. The SMR of 277% for all-cause mortality of those with learning disability is striking and some specific-cause SMRs are very high. What these figures do not show is the extent of undue, unexpected or unfair mortality, presumably the issue of interest to the Equality and Human Rights Commission.

Some other data particularly that which relates to process indicators, suggest inequity. The phenomenon of diagnostic overshadowing has been noted, as

have communication issues. In the wake of advocacy, changes have already been made to improve provision for people with disability and learning disability. If these were to result in a reduction in the SMR that might indicate that some of the original inequality was iniquity. Until the data are collected it is not possible to draw any such conclusions. However, process indicators and some academic research suggest that it is worth collecting the mortality data by different types of disability and causes of death. This would enable charting of SMR change over time and with that, improvements or worsening in equity.

Suicide rate data by disability suggest that mental disorder and some physical disorders (such as MS) are associated with increased risk. Again the extent to which this is avoidable is hard to judge but without all the necessary information it seems best to proceed as though the rates could be reduced and then try to do so. This adds further force to the suggestion that mortality data by disability would be worth collecting.

Much of the literature relating to disability and suicide concerns the ethics of assisted suicide. This literature sits uneasily alongside that which proposes measures to reduce suicide rates. Any move to legalise assisted death would need to be judged in part on its implications for equality and rights for the disabled.

Data relating to accidental death associated with disability seem to be absent. The addition of disability to death certificates would close this gap. The information is of interest; if disabled people suffered high rates of accident-related death this might suggest that the environment should be adjusted to reduce this.

Deaths from non-natural causes in institutions have become an issue of concern following the investigation into six deaths of individuals with learning disability, described above. This is clearly an area worth monitoring although again, at present, the lack of disability information on deaths certificates makes this difficult or impossible.

## HEALTH

Around 30% of the population in England, Wales and Scotland have an LLTI. Having a LLTI is strongly associated with self-report of poor current health. It is also very strongly associated with poor mental health; this finding is hard to interpret, however, as poor mental health can itself be a trigger for LLTI.

Data from England & Wales show no association with LLTI and feeling you are treated with respect by hospital services. There are no data from Scotland. One limitation of this data is that it does not cover those without capacity to say whether they felt treated with respect; as such some, such as those with severe learning difficulty, are excluded.

Support for nutritional needs in hospital is clearly important for those with disability. The majority of the literature on this topic, however, concerns the elderly. This is because the initial concern was that elderly people's needs are neglected. As such, there seem to be no data on the topic aggregated by disability. This is worth rectifying. One of the deaths reported by MenCap in *Death by Indifference* is of Martin Ryan, who was said to have starved to death at Kingston hospital.

People with LLTI in England are neither more nor less likely to smoke than the rest of the population. In Wales, they are slightly less likely to smoke. In Scotland, men with a disability are slightly more likely to smoke.

People with LLTI in England and Scotland are less likely to drink alcohol above the Government recommended limit. In Wales, they are more likely to do so.

People with LLTI in England, Wales and Scotland are less likely to meet Government guidelines for exercise.

In England, Wales and Scotland there is no noticeable association between LLTI and eating fruit and vegetables.



There is however a clear link between LLTI and obesity. In England, having an LLTI is positively associated with not having a healthy weight; 72% with an LLTI do not have a healthy weight, against 61% without an LLTI. In the main, the problem is one of overweight rather than underweight. In Wales, having an LLTI is positively associated with being overweight or obese (65.9% versus 55.4%); this difference is true of both sexes although it is particularly marked in women (63.3% versus 49.8%). In Scotland, an LLTI is positively associated with a non-normal weight (75.9% versus 67.8%). The major problem is being overweight or obese rather than underweight. The inequality is greater for women rather than men although this seems to be because Scottish men *without* an LLTI have a higher proportion of non-normal weight than Scottish women without LLTI.

### **How might change be measured?**

There is a danger that the presence of capacity and articulacy difficulties for some disabled people result in issues to do with NHS process being missed by indicators that stress satisfaction with services. Those whose needs are not understood might not be able to express themselves through satisfaction surveys. Other indicators are required. One marker might be registration with a GP, although the numbers not registered seem to be small (Disability Rights Commission 2006). Another indicator could be access to communication aids, such as loop, signing and alternative communication (AAC) systems; and training of staff in competent communication. At the moment, such data are hard to come by and generally collected locally, or are the product of specific research such as (Ubido, Huntington and Warburton 2002).

Though only likely to apply to a small minority of people, the mapping of Serious Case Reviews that have involved children and adults with disabilities is likely to raise some questions about inequity. These data could perhaps be coupled to data about non-accidental injury.

In regard to suicides, there is a case for collecting data about secondary diagnoses, lifestyle factors, social and financial factors. The data show that

mental health and recent use of mental health and primary care services are key and significant markers in suicide; data also suggest markers include the existence of a variety of secondary physical illnesses/conditions such as HIV/AIDS, Huntington's disease, certain malignant neoplasms and MS (National Institute for Mental Health in England. 2005). As shown by the data presented here, the information currently collected on suicide tends to be broad and of limited use in painting the picture of inequality related to suicide.

### **Data quality and quantity**

There are no systematic national data sets on Life and Health outcomes, such as premature death from cancer or heart disease, disaggregated by disability and subsets of disability. Some figures can be disaggregated from, for example, the Welsh Health Survey.

Disability is a broad and disparate category - this makes interpretation of data difficult.

Death certificates include no disability information - there is no national-level picture of inequalities by disability in life indicators.

## References

Disability Rights Commission. *Tackling Health Inequalities*. [online]. Last accessed 06/24 2010 at:  
[http://drc.uat.rroom.net/DisabilityDebate/recommendations/tackling\\_health\\_in\\_equalities.aspx](http://drc.uat.rroom.net/DisabilityDebate/recommendations/tackling_health_in_equalities.aspx).

Disability Rights Commission (2006). *Equal Treatment: Closing the gap*. [online.] :ast accessed 06/25 2010 at  
<http://www.library.nhs.uk/mentalhealth/ViewResource.aspx?resID=187303>.

EMERSON, E. and HATTON, C. (2008). *People with learning disabilities in England*. Lancaster, Centre for Disability Research, Lancaster University.

GIANNINI, M., et al. (2009). Understanding suicide and disability through three major disabling conditions: Intellectual disability, spinal cord injury, and multiple sclerosis. *Disability and health journal*, **3** (2), 74-78.

HARRIS, E. and BARRACLOUGH, B. (1997). Suicide as an outcome for mental disorders. A meta-analysis. *The British journal of psychiatry*, **170** (3), 205-228.

KENNEDY, I. (1983). *The Unmasking of Medicine*. London, Paladin.

KERR, M., et al. (2005). Equal treatment: Closing the gap. *Final report from the Welsh centre for learning disabilities*, .

Local Government Ombudsman. (2009). *Six lives: The provision of public services to people with learning disabilities*. London, The Stationary Office.

Mencap (2007). *Death by indifference*. London, Mencap.

MOLLOY, D., KNIGHT, T. and WOODFIELD, K. (2003). Diversity in disability. *Department Cabinet Office*, .

National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (2001) *Five Year Report* London.

National Institute for Mental Health in England. (2005). *National suicide prevention strategy for England: Annual report on progress*. London, Department of Health.

NUSSBAUM, M. (2006). *Frontiers of Justice: Disability, nationality, species membership*. USA, Belknap.

NUSSBAUM, M. (1999). Women and equality: The capabilities approach. *International labour review*, **138** (3), 227-245.

ROLLAND, J. (1994). *Families, illness, and disability: An integrative treatment model*. USA, Basic Books.

SAVULESCU, J. (2001). Resources, Down's syndrome, and cardiac surgery. *British Medical Journal*, **322** (7291), 875.

TWOMBLY, R. (2006). Decades after cancer, suicide risk remains high. *JNCI/ Journal of the National Cancer Institute*, **98** (19), 1356.

TYRER, F. and MCGROTHER, C. (2009). Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of intellectual disability research*, **53** (11), 898-904.

UBIDO, J., HUNTINGTON, J. and WARBURTON, D. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health and social care in the community*, **10** (4), 247-253.

WAERN, M., et al. (2002). Burden of illness and suicide in elderly people: Case-control study. *British Medical Journal*, **324** (7350), 1355.

WALBY, S., ARMSTRONG, J. and HUMPHREYS, L. (2008). *Review of equality statistics*. [online]. EHRC. EHRC Research Report Series. last accessed 23 June 2010 at:  
[http://www.equalityhumanrights.com/uploaded\\_files/research/1\\_review\\_of\\_equality\\_statistics\\_241008.pdf](http://www.equalityhumanrights.com/uploaded_files/research/1_review_of_equality_statistics_241008.pdf).