

JRF programme paper:
A Better Life

Demographic issues, projections and trends: Older people with high support needs in the UK

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October 2010

This paper:

- provides an overview of existing knowledge on demographic issues, projections and trends in relation to older people with high support needs in the UK;
- makes conclusions with reference to likely future trends;
- recommends continued investment in data sources to further understanding of health, disability, economic and social well-being in old age.

The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its 'A Better Life' programme, to stimulate and inform thinking on alternative approaches to a better life for older people with high support needs.

ISBN 9781859357590

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This paper was commissioned to inform the work of the JRF's 'A Better Life' programme, a five year programme of work focusing on how to ensure quality of life for the growing number of older people with high support needs in the UK.

The Joseph Rowntree Foundation has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy-makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of JRF or the Better Life programme.

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First published 2010 by the Joseph Rowntree Foundation

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ISBN: 9781859357590

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ESRC Centre for Population Change

The ESRC Centre for Population Change (CPC) is a multi-disciplinary research centre that aims to improve our understanding of the key drivers and implications of population change within the UK. The Centre is a joint initiative between the Universities of Southampton, St Andrews, Edinburgh, Strathclyde, Stirling and Dundee, in partnership with the Office for National Statistics and the General Register Office Scotland. The Centre is funded by the Economic and Social Research Council (ESRC) under a five year grant to December 2013 (Grant Reference RES-625-28-0001).

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Contents

	Page
Executive summary	4
Section 1 Introduction	11
Section 2 Trends in the 'oldest old' population in the four constituent countries of the UK	12
Section 3 Estimating the prevalence of people with high support needs	25
Section 4 Ageing with a learning disability	54
Section 5 Conclusions	56
Notes	57
References	58

Executive summary

This report aims to provide an overview of existing knowledge on demographic issues, projections and trends in relation to older people with high support needs in the UK.

The definition of 'high support needs' used is that defined by the Joseph Rowntree Foundation's Better Life programme:

Older people who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, faith. Equally, some of the very oldest people may never come into this category.
(JRF, A Better Life)

There is no one data source that provides information on this sub-group of the population. The most commonly used approach to estimate the size of the high support population is to use age as a proxy for need.

More 'very old' and 'oldest old' people; more living alone

The population aged 85 and over i.e. the 'oldest old' is the fastest growing age group in the entire UK population. Their numbers have risen by nearly 680,000 in the last 25 years, reaching 1.3 million in 2007. Today the population aged 85 and over represents 2.1% of the total population of the UK.

Those aged 90 and over, i.e. the 'very old', comprise 297,000 women and 99,000 men. There are three women aged 90 and over for every man of the same age; this ratio rises to 6.5:1 amongst centenarians with around 8,360 women in England and Wales aged 100 and over compared to 1,280 men.

One of the most striking changes in the living arrangements of older people living in private households in the second half of the twentieth century has been the rise in the proportion living alone. The rise in solo living has been faster amongst those aged 85 and over than the population aged 65 and over as a whole. In the early 2000s, just under half of men and two-thirds of women aged 85 and over living in private households were living alone. This has implications for the availability of co-residential informal care amongst this age group.

The growing number of people in late old ages reflects significant recent gains in mortality at later ages. In 2007, a man aged 65 in the UK could expect to live on average for another 17.4 years compared to 13.0 in 1981, an increase of 4.4 years. Similarly, a woman of the same age could now expect to live for a further 20 years compared to 16.9 in 1981 and, an improvement of 3.1 years. There are significant differences across the constituent countries of the UK; life expectancy at age 65 is lowest for men and women in Scotland and highest in England.

Although age alone does not determine whether or not people have high support needs, it is a good guide and it is likely that over the next twenty years the numbers requiring such support will rise considerably. The latest Office for National Statistics (ONS) Population Projections suggest that by 2033, the number of people aged 85 and over living in the UK will reach 3.3 million. Of these, 1.9 million will be aged 85–89, 962,000 will be aged 90–94, 384,000 95–99 and 80,000 will be aged 100 or more.

Over the coming decades, the older population will also become more diverse with people from black and minority ethnic backgrounds comprising an increasing share of the population. Changes in both social norms and the legal context mean that it is likely that in future there will be more older people living in civil partnerships and openly gay relationships. Service providers will need to take account of this growing diversity in the provision of culturally sensitive and appropriate services.

Evidence regarding high dependency and disability: surveys

There are a number of approaches to the measurement of the high dependency populations. There is currently no single source of data on disability in the UK and estimates of the prevalence of disability within the UK population vary according to both the definition of disability being applied and data source used. These are summarised in the table below.

	Definition	Data	Prevalence
Disability Discrimination Act (DDA)	A (or multiple) long-term health problem or disability that substantially limits a person's ability to carry out normal day-to-day activities and that has, or is expected to, last at least 12 months (extended by 2005 Act to include person who has been diagnosed with HIV, multiple sclerosis or cancer).	Family Resources Survey	10.6 million, of whom 5 million are over state pension age
Work-Limiting Disability (WLD)	A long-term health problem or disability that affects the amount or type of work a person can do.	Labour Force Survey / Annual Population Survey	15% working age population = 5.4 million
Long-Term Disabled (LTD)	This is the definition of disability used for the DWP's Public Service Agreement on employment. It includes everyone with a Work Limiting Disability (WLD) and/ or a disability covered by the DDA	Labour Force Survey / Annual Population Survey	19% working age population = 6.9 million
Limiting Long-Standing Illness	An illness, disability or infirmity that is longstanding (has	Census General	18.5% of total

(LLSI)	troubled someone over a period of time or is likely to) and limits their activities in any way.	Household Survey	population = 10.9 million
International Classification of Illnesses, Disabilities and Handicaps (ICIDH)	A restriction or lack of ability to perform normal activities which has resulted from the impairment of a structure or function of the body or mind. This definition has now been replaced by the International Classification of Functioning, Disability and Health which includes a set of environmental/ societal factors.		18% of population 16 plus

There is clear evidence that the prevalence of disability, however it is measured, rises with age – with the increase being most pronounced at ages after 74. For example, the prevalence of severe disability as measured by the ability to perform various activities of daily living is less than 5% amongst those aged under 55 compared with around 40% amongst those aged 85 and over.

Data from the Medical Research Council Cognitive Function and Ageing Study suggest that around half a million people in England and Wales have dementia of mild or greater severity, with approximately 163,000 new cases of dementia occurring in England and Wales each year. These may, however, be underestimates; recent data from the EURODEM study that takes into account the prevalence of both diagnosed and undiagnosed dementia puts the figure closer to 820,000 people.

Not all of the oldest old have high support needs. And, although disability rises with age, it is important to remember that simply concentrating on the population aged 85 and over misses out younger people living in the community who also have high support needs.

Data from the English Longitudinal Study of Ageing shows that amongst those aged 60-74, 10% of men and 13% of women reported difficulty in bathing and 6% reported difficulty in getting out of bed unaided. Younger older people (aged 60–74) also report relatively high rates of difficulty in stooping, kneeling or crouching (32% of men and 42% of women) and getting up from a chair after sitting for long periods (24% of men and 29% of women). Although assistance with these sorts of tasks may not count as ‘high support’ it nevertheless highlights increasing difficulties in maintaining independent living in later life.

Numbers receiving disability-related benefits

Data on the receipt of disability-related benefits may also provide a guide to the size of the high dependency population. However, it is important to bear in mind that not all of those people who are eligible to apply for benefits do so. Some may be deterred by the frequently complex forms that have to be completed. If the benefit is

means-tested, some may not wish to reveal their financial situation. Other may believe, rightly or wrongly, that they will only receive a small amount of benefit.

Disability Living Allowance (DLA) is payable to people aged less than 65 who are disabled and who have personal care needs, mobility needs or both. It is paid to those aged 65+ if there is a continuing need for personal care or mobility support. Attendance Allowance (AA) is a similar benefit payable only to those aged 65 and over. It does not have a mobility component. Thus, both these benefits are payable to the over 65s. But, in the case of DLA, payments need to have commenced before age 65. DLA tends, therefore, to be paid to the 'young old', while the take-up of AA is greatest among the 'old old'. Neither benefit is means tested. Therefore, income does not influence take-up. AA is paid at two weekly rates depending on the level of disability. The current higher rate is £70.35 and the lower rate is £47.10. DLA (Care Component) is payable at three weekly rates, £70.35, £47.10 and £18.65. The differences in rates reflect differences in assessed need. Lower rates are payable where mobility and/or personal care needs are moderate.

In November 2009, there were almost 4.6 million claimants of these benefits in the UK. Of these claimants, 2.5 million were aged over 65. Thus, just over one quarter of all those aged 65+ in the UK were receiving such benefits. There was a 48% rise in the number of older AA and DLA claimants in Great Britain between 1997 and 2009. This suggests a rapid increase in disability among older UK citizens. However this finding is not consistent with other measures of disability prevalence in the older UK population. It may reflect previously unmet need or a change in assessment criteria, but information on this issue is sparse.

Of the specific health-related causes for AA eligibility, the most prevalent is arthritis, which accounts for more than 500,000 cases – around one third of all claimants. Heart disease, frailty and mental health are less important, though each accounts for over 100,000 cases. Surprisingly, there are only 35,300 and 33,000 claimants citing malignant disease and Parkinson's disease respectively. Part of the explanation for the prevalence of arthritis in claims is its relatively long duration, compared with other conditions that cause a greater reduction in life expectancy.

In the UK, in November 2009, there were 1.6 million AA claimants. Of these claims, 1.3 million originated in England. Yet, relative to its population aged 65 and over, England's claims are around 3% less than would be expected. In contrast, claims in Scotland are 5% higher, those in Wales 26% higher, while claims for attendance allowance in Northern Ireland were 44% higher relative to its population aged 65 and over. This data suggests huge variations across the different countries in the United Kingdom in the prevalence of disability requiring some form of personal care intervention. As far as we are aware, no study of this variation has been undertaken.

These benefits are intended as a compensation for the additional costs associated with personal care and mobility needs. Their prevalence suggests that a very significant proportion of older people have been assessed as suffering from chronic conditions which merit additional income support.

Numbers receiving care services

Data on service use can provide an important insight in the high dependency population. Continuing care health patients have among the highest level of support needs. They require almost continuous health care. These constitute a small, but important, component of the high support need population. Extrapolating data on continuing care patients in Scotland to the wider UK population suggests that there are around 38,300 continuing care patients in the UK as a whole.

The number of clients receiving overnight or weekend support shows a rapid rise in Scotland between 2006–07 and 2008–09. This may not necessarily indicate changing levels of need across the population, but more a focussing of policy on high dependency home care. This illustrates one of the disadvantages of the use of resource measures as indicators of high-dependency needs: they are susceptible to policy change as well as to underlying levels of need. Nevertheless, during periods when policy is stable, they are a useful adjunct to survey-based measures that frequently cannot identify the most dependent groups within the population.

Older people with learning disabilities

Rising life expectancy amongst people with learning disabilities means that more are surviving into later life. There is some evidence that the onset of chronic physical conditions associated with age occurs earlier amongst this group than the general population. For those with a learning disability other than Down's syndrome, the risk of dementia is about four times higher than for a person without a learning disability. For those with Down's syndrome, the Alzheimer's society suggest that over a third of people aged 50–59 and over half of those aged 60–69 will have dementia.

As the numbers of older people with learning difficulties rise, much more information is needed, both on the numbers and characteristics of older people with learning disability living in the community and on their carers.

Implications: improving data to support better planning and provision

A key question when considering the future number of older people with high support needs is whether the recent increases in life expectancy at older ages have been accompanied by a concurrent postponement of functional limitations and disability. The evidence in the UK is mixed. Estimates of the proportion of years of life remaining at age 65 that will be spent in good or fairly good health or without a limiting long-standing illness have not changed during the period 1981–2001.

The jury is still out regarding whether the extension in life expectancy has been accompanied by improvements in years of good health. Evidence from cross-sectional surveys over time such as the General Household Survey suggests that *within* age groups, health is improving slightly. However, more people are surviving to experience greater levels of severity of disability at older ages. Thus the proportion of life spent in 'not good health' appears to be increasing or, at the very least, stable within the UK.

Planning health and social care services for older people with high support needs requires accurate projections of the future numbers of people with such needs. This in turn requires reliable estimates of the prevalence and incidence of cognitive and functional impairments. There are some estimates for these at the national level, but very little data is available at the sub-national and local level. Moreover, most of these estimates are based on household survey data and thus exclude those living in institutional care.

The data does not allow disaggregation of the population by key characteristics such as ethnicity and sexuality. The ageing of the cohorts that migrated to the UK in the 1950s and 1960s means that over the coming decades black and minority ethnic older people will comprise a growing share of the population aged 75 and over, with particular health needs. Changing social norms and legal context mean more older people will be in civil partnerships and openly gay relationships. This has implications for the design and delivery of appropriate health and social care services to meet their needs as they age, particularly in the residential care sector.

Very little is known about the needs of older people with learning disabilities and their carers. However improvement in life expectancy mean that more people with conditions such as Down's syndrome will be surviving into later life with increased risk of suffering from diseases of old age and dementia. Their carers, many of whom are their parents, will themselves be old and in need to support both for their caring responsibilities and for themselves.

Finally, further research is needed on the relationship between poverty and disability at the national and regional level. Many older people are in receipt of disability-related benefits, which are supposed to offset the additional costs of disability. However, the extent to which these benefits prevent older people from falling into poverty as a result of their increased needs due to disability is unclear.

The 2011 Census will provide more detailed information on disability than in the past, distinguishing between severe and moderate activity limitation. The new UK Household Longitudinal Study, *Understanding Society* (USoc), also offers the possibility of a much more fine-grained analysis of UK society, with a target sample size of 40,000 households and 100,000 individuals, bigger than any comparable longitudinal study. The study design includes a significant sample boost for key ethnic minority groups and aims to collect biomedical measures and samples to enable new research on the social determinants and impacts of health in a household context. This will complement data from the English Longitudinal Study of Ageing (ELSA) and from national birth cohort studies.

The Medical Research Council (MRC) National Survey of Health and Development (NSHD), the oldest of the British birth cohort studies, is unique in having data from birth on the health and social circumstances of a representative sample of men and women born in England, Scotland or Wales in March 1946. The latest wave of data collection, when the sample were aged 60, also offers the opportunity to shed light on the ageing process.

Continued investment in the major data sources in the UK and their analysis is required to further our understanding of the complex interaction of health, disability, economic and social well-being and independent living in old age.

1. Introduction

This report aims to provide an overview of the most up to date information on the size, composition and future trends in the population of older people with high support needs in the UK. The definition of 'high support needs' used is that defined by the Joseph Rowntree Foundation's Better Life programme:

Older people who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, faith. Equally, some of the very oldest people may never come into this category.
(JRF, A Better Life)

There is no one data source that provides information on this sub-group of the population. The report will therefore draw on a range of data to map the profile of the older population using a 'hierarchy of detail' to drill down to those with the highest support needs.

The report is in four main sections. The first section examines recent trends in the number of older people in the UK, paying particular attention to the 'oldest old', i.e. those aged 85 and over, as this age group is often taken as a proxy for those who are most in need of health and social care. Data on the relative differences in life expectancy by gender is presented along with a discussion on how these may be expected to change across time. In any assessment of the likely future numbers of older people, it is important to bear in mind recent historical experience of under-estimating the size of this age group. Thus this section also provides a non-technical overview of the methodology and assumptions behind the recent population projections, before discussing likely future trends for all four UK nations separately. Finally recent evidence on the increasing diversity of the older population is presented, with a particular focus on its changing ethnic composition.

Having set the scene in terms of the numbers and composition of the oldest old, the next section brings together evidence from a range of sources to shed light on the numbers of older people experiencing physical frailty, chronic conditions and mental health problems, including but not limited to dementia. Trends in healthy life expectancy and the effect of disability on longevity are discussed in order to shed light on possible future trends in disability. This is followed by a brief discussion of ageing and people with learning disabilities and the particular challenges this group may face.

Finally, having reviewed the available evidence, the review then highlights the key knowledge gaps and comments on how forthcoming resources such as the 2011 Census and the UK Household Longitudinal Study may contribute towards filling those gaps.

2. Trends in the ‘oldest old’ population in the four constituent countries of the UK

Increasing numbers of ‘oldest old’

The population of the UK is becoming older. Over the last quarter century the number of people aged 65 and over in the UK has grown by 6%, from 7.9 million in 1981 to 9.9 million in 2008. At the same time, the older population itself is ageing. Indeed the fastest growing age group in the entire population has been those aged 85 and over. This age group is often known as the ‘oldest old’ and their numbers have risen by nearly 680,000 in the last 25 years, reaching 1.3 million in 2007 (Dunnell, 2008). Today the population aged 85 and over represents 2.1% of the total population of the UK.

Table 1 Total population and its age structure, UK and constituent countries, 2008

	Total population mid-2008 (thousands)	0–15 (%)	16–60/65* (%)	60/65–84 (%)	85 and over (%)
UK	61,398	18.9	62.2	16.8	2.1
England	51,465	18.9	62.2	16.7	2.2
Wales	2,990	18.7	60.3	18.7	2.4
Scotland	5,169	17.8	62.7	17.5	1.9
Northern Ireland	1,775	21.6	61.9	14.9	1.6

*60 is for women and 65 for men, reflecting the state pension age in 2008.

Source: 2008 mid year estimates ONS, GROS, NISRA

There are significant differences in age structure across the constituent countries of the UK, with those aged 85 and over constituting a larger share of the overall population in Wales (2.4%) compared with Northern Ireland (1.6%).

Reflecting the changes in the age structure of the population and the increasing numbers of people surviving to later life, since 1991, the Office of National Statistics has begun to publish data on the ‘very old’ defined as those aged 90 and over. Table 2 shows that there are currently just under 420,000 people aged 90 and over in the UK, with the majority of these living in England.

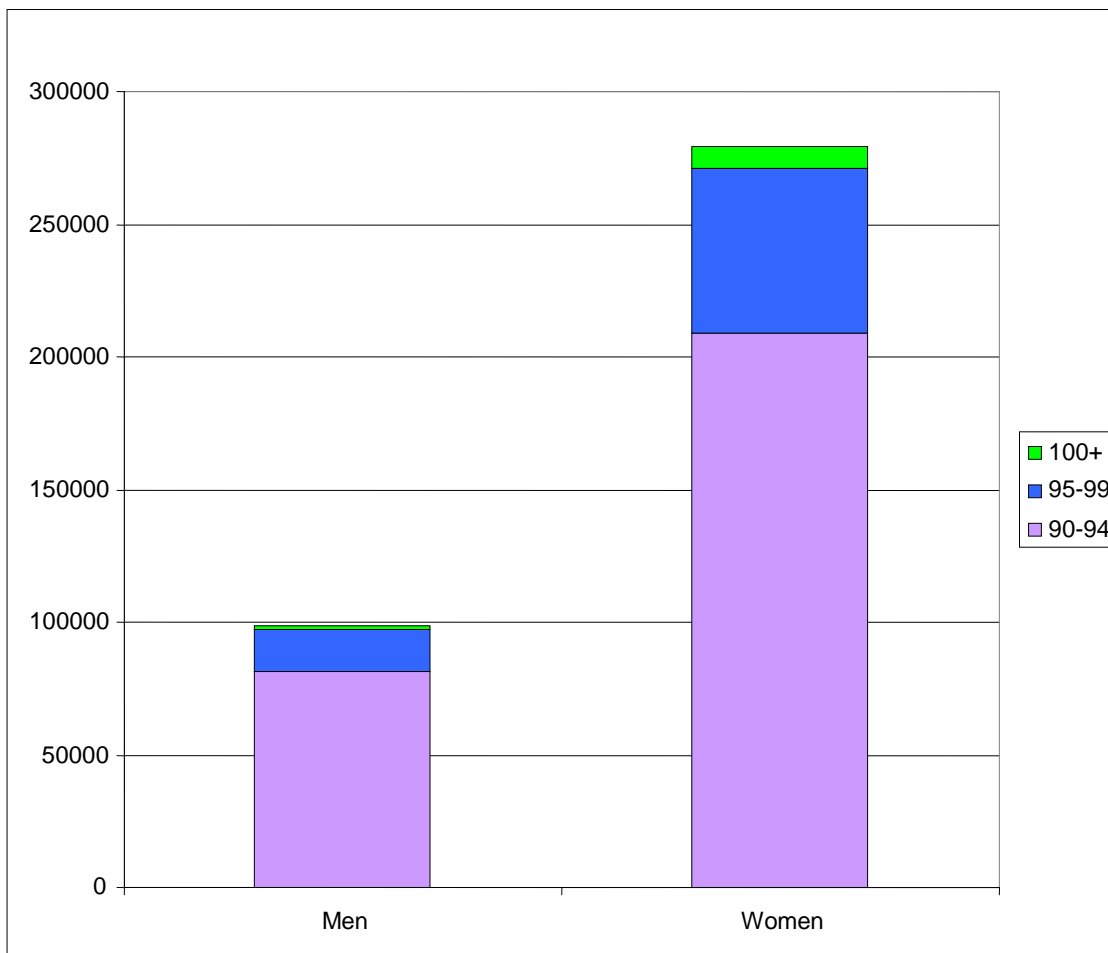
Table 2 Population aged 80 and over (thousands), UK and constituent countries, 2008

	80–84	85–89	90+	Total 80 and over
UK	1,455.0	918.0	417.4	2,790.4
England	1,220.6	778.7	355.9	2,355.2
Wales	79.4	50.4	21.9	151.70
Scotland	119.3	69.3	31.2	219.80
Northern Ireland	35.7	19.5	8.5	63.70

Source: 2008 mid year estimates ONS, GROS, NISRA

Further breakdowns of estimates of the population aged 90 and over are currently only available for England and Wales. As Figure 1 shows, the ‘very old’ are disproportionately female, with 297,000 women aged 90 and over compared to 99,000 men. There are just under three women aged 90 and over for every man of the same age; this ratio rises to 6.5:1 amongst centenarians with around 8,360 women in England and Wales aged 100 and over compared to 1,280 men. Although the number of centenarians is still low, it is rising rapidly. In 2002 there were just over 7,000 people aged over 100. Just six years later, in 2008, this had increased to 9,640 – a rise of nearly 6% per annum.

Figure 1 Number of very old people (aged 90 plus) by age and gender, England and Wales, 2008



Source: ONS Mid-2002 to Mid-2008 Estimates of the very elderly (including centenarians) (experimental) published 13th May 2010.
<http://www.statistics.gov.uk/statbase/Product.asp?vlnk=15003>

Rising life expectancy

The gains in life expectancy at birth during the past hundred years are one of the greatest achievements of the twentieth century. In 1901 a newborn baby boy could expect to live 45.0 years and a newborn baby girl 48.7 years at prevailing mortality rates. By 2001 this had risen to 75.6 years for males and 80.4 years for females (ONS, 2005). Much of this improvement in life expectancy was achieved in the early part of the last century with significant improvements in infant and child mortality as a result of improved sanitation, public health and nutrition. In the last 25 years, however, many of the gains in survivorship have come from improvements in mortality at later ages (Figures 2a and 2b).

Figure 2a Male life expectancy at selected ages, UK, 1981–2007

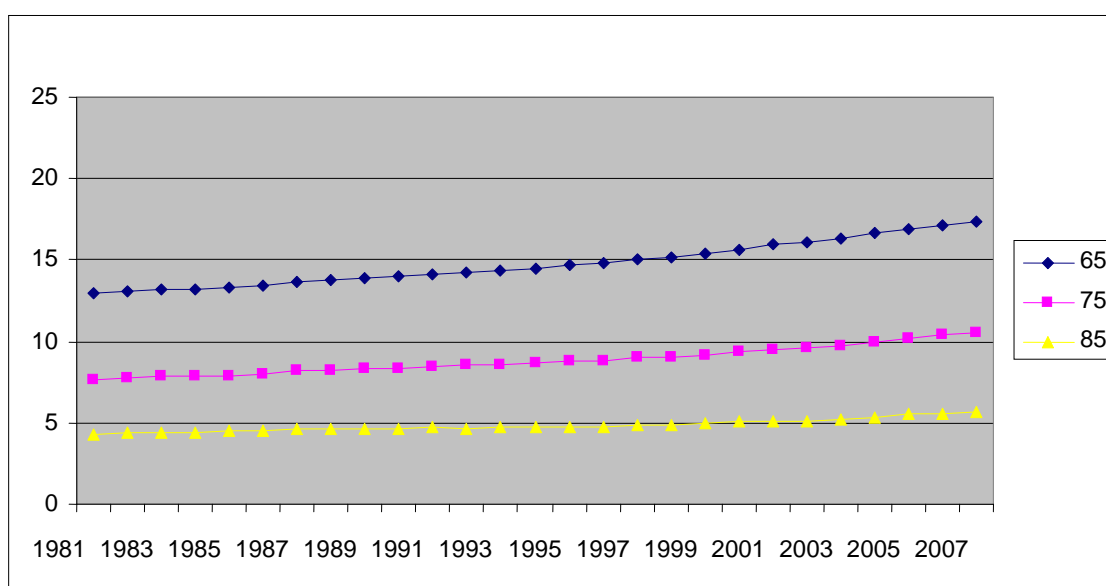
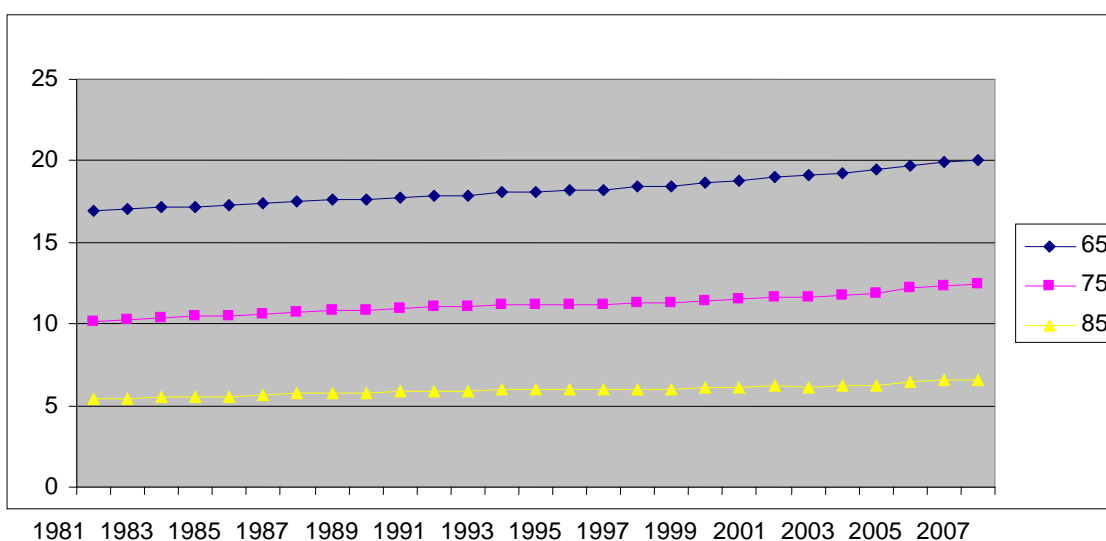


Figure 2b Female life expectancy at selected ages, UK, 1981–2007



Source: *Interim Life Tables, United Kingdom, 1980-82 to 2006-08*

In 2007, a man aged 65 in the UK could expect to live on average for another 17.4 years compared to 13.0 in 1981, an increase of 4.4 years. Similarly, a woman of the same age could now expect to live for a further 20 years compared to 16.9 in 1981, an improvement of 3.1 years. Although life expectancy at older ages remains higher for women than men, the gap has closed somewhat as the rate of improvement over the past 25 years has been markedly higher for men than for women. Over the period 1981–2007, life expectancy at age 65 improved by 34% for men in the UK compared with just 18.5% for women.

Table 3 Changes in life expectancy at age 65 for the UK and constituent countries, 1981–2007

	1981	2007	Improvement years	Improvement %
Men at age 65				
UK	12.96	17.37	4.41	34.0%
England	13.07	17.53	4.46	34.1%
Wales	12.54	17.07	4.53	36.1%
Scotland	12.28	16.17	3.89	31.7%
Northern Ireland	12.46	16.84	4.38	35.2%
Women at age 65				
UK	16.91	20.04	3.13	18.5%
England	17.04	20.20	3.16	18.5%
Wales	16.63	19.82	3.19	19.2%
Scotland	16.04	18.82	2.78	17.3%
Northern Ireland	16.27	19.75	3.48	21.4%

Source: Calculated from Interim Life Tables, United Kingdom and constituent countries, 1980-82 to 2006-08

Table 4 Changes in life expectancy at age 85 for the UK and constituent countries, 1981–2007

	1981	2007	Improvement years	Improvement %
Men at age 85				
UK	4.34	5.66	1.32	30.4%
England	4.35	5.70	1.35	31.0%
Wales	4.26	5.60	1.34	31.5%
Scotland	4.20	5.37	1.17	27.9%
Northern Ireland	4.56	5.22	0.66	14.5%
Women at age 85				
UK	5.38	6.55	1.17	21.7%
England	5.39	6.60	1.21	22.4%
Wales	5.38	6.49	1.11	20.6%
Scotland	5.21	6.21	1	19.2%
Northern Ireland	5.54	6.14	0.6	10.8%

Source: Calculated from Interim Life Tables, United Kingdom and constituent countries, 1980-82 to 2006-08

There are significant differences both in the absolute level of life expectancy and the rate of improvement across the constituent countries of the UK as shown in Tables 3 and 4. Life expectancy at age 65 is lowest for men and women in Scotland and highest in England. The rate of improvement is also lowest in Scotland, but has been highest in Northern Ireland. However, this is not the case at older ages; indeed the

rate of improvement in life expectancy at age 85 in Northern Ireland has been around half that experienced elsewhere in the UK. This differential warrants further investigation. For example, it would be interesting to investigate whether older people aged 85 and over in Northern Ireland are treated differently within the health system to those elsewhere in the UK. It is important to note, however, that the life table estimates in Northern Ireland are based on relatively low numbers; in 2008 there were only 28,000 people aged 85 and over living in the province.

There are also significant differentials in life expectancy at older ages within the countries of the UK. Recent data on sub-national estimates of life expectancy at age 65 shows that a man aged 65 living in Kensington and Chelsea can expect to live on average for a further 23.1 years, whilst a man of the same age in Glasgow City can expect to live just 13.8 years, a difference of over 9 years (Table 5). Even within relatively small areas, there can be substantial differences in life expectancy. A recent WHO report showed that male life expectancy in Calton, a deprived area in inner-city Glasgow, was 54, 28 years less than in Lenzie, a nearby suburb.

Table 5 Local areas with the highest and lowest male life expectancy at age 65 in the UK, 2006–08

Rank	Local area	Country/ English Government Office Region	Life expectancy at age 65 (years)
Highest life expectancy at age 65			
1	Kensington & Chelsea	London	23.1
2	Westminster	London	22.3
3	Crawley	South East	20.6
4	Rutland	East Midlands	19.8
5	Credigion	Wales	19.8
6	Lewes	South East	19.8
7	Tandridge	South East	19.7
8	East Dorset	South West	19.7
9	Christchurch	South West	19.7
10	South Cambridgeshire	East of England	19.6
Lowest life expectancy at age 65			
1	Glasgow City	Scotland	13.8
2	North Lanarkshire	Scotland	15.1
3	West Dunbartonshire	Scotland	15.2
4	Inverclyde	Scotland	15.4
5	Renfrewshire	Scotland	15.5
6	Liverpool	North West	15.5
7	Belfast	Northern Ireland	15.6
8	Halton	North West	15.7
9	Hartlepool	North east	15.7
10	Clackmannanshire	Scotland	15.7

Source: ONS, GROS and NISRA subnational life expectancy estimates, published in ONS (2009)

Similar differentials are evident for woman (Table 6). Nine of the ten areas with the highest life expectancy for women at age 65 are located in London and the South West of England, whilst all of the ten areas with the lowest life expectancy are in Scotland and the North West of England. Although this data reflects differentials in mortality rather than morbidity, it suggests significant geographical differences in the prevalence of poor health in later life, a point we return to in section 3.

Table 6 Local areas with the highest and lowest female life expectancy at age 65 in the UK, 2006–08

Rank	Local area	Country/ English Government Office Region	Life expectancy at age 65 (years)
Highest life expectancy at age 65			
1	Kensington & Chelsea	London	26.3
2	Westminster	London	23.5
3	East Dorset	South West	23.0
4	Hart	South East	22.8
5	West Somerset	South West	22.7
6	Lewes	South East	22.6
7	Brent	London	22.6
8	Hammersmith & Fulham	London	22.5
9	Christchurch	South West	22.4
10	North Dorset	South West	22.3
Lowest life expectancy at age 65			
1	Glasgow City	Scotland	17.4
2	West Dunbartonshire	Scotland	17.8
3	Halton	North West	17.8
4	North Lanarkshire	Scotland	17.8
5	Renfrewshire	Scotland	17.9
6	Falkirk	Scotland	18.0
7	West Lothian	Scotland	18.1
8	Liverpool	North West	18.1
9	Burnley	North West	18.1
10	East Ayrshire	Scotland	18.2

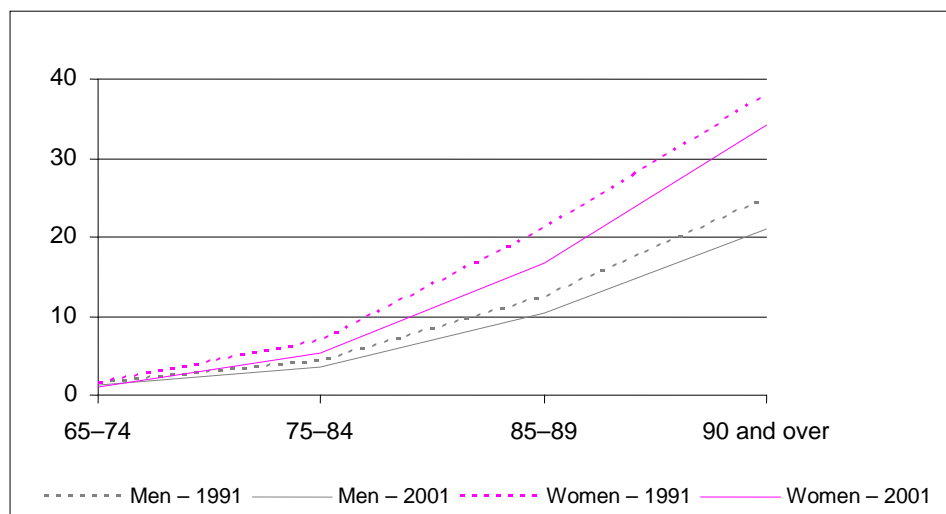
Source: ONS, GROS and NISRA subnational life expectancy estimates, published in ONS (2009)

Living arrangements of the ‘oldest old’

Much of the data on the older population focuses on those aged 65 and over as a group and it is still relatively uncommon to find disaggregated information that allows separate investigation of the ‘oldest old’. This is in part due to small sample sizes in national surveys but also reflects common stereotypes in treating all older people as a homogeneous group. Key exceptions to this are the ONS Social Focus on Older People (ONS, 2005) as well as several recent articles published in *Population Trends* (Tomassini, 2005, 2006; Dini and Goldring, 2008).

One important issue in using data from household surveys for the oldest old is that this data explicitly excludes those living in communal establishments. This is less of a problem for younger age groups but, as Figure 3 shows, the proportion of older men and women living in communal establishments rises sharply at ages over 85. There has, however, been a decline in the propensity to live in communal establishments over time. In 2001, 21% of men and 34% of women aged 90 and over were living in communal establishments compared with 25% and 38% respectively of men and women in 1991. This partly reflects older people’s preferences, but is also a response to the rapidly increasing costs of such establishments.

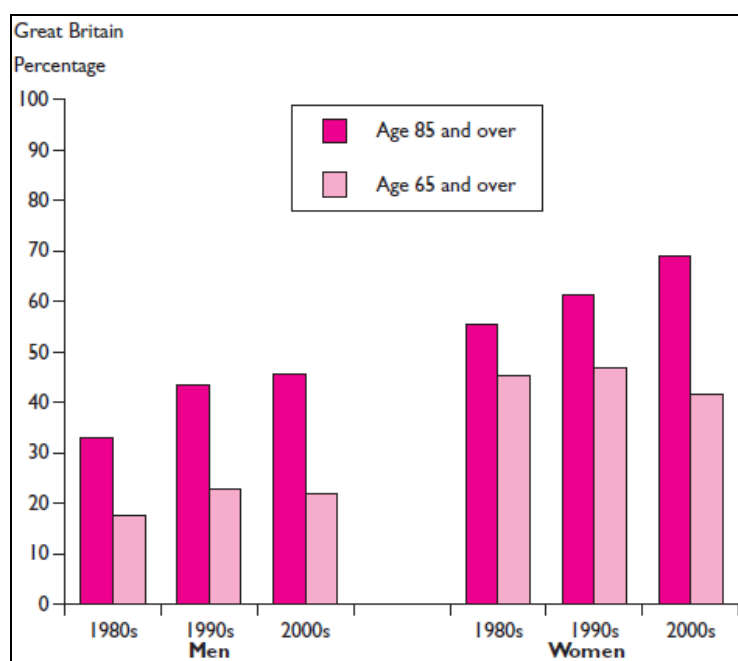
Figure 3 People aged 65 and over in communal establishments by age and sex, 1991 and 2001



Source: ONS (2005) Fig 2.6 using Census 1991 and Census 2001, Office for National Statistics; Census 1991 and Census 2001, General Register Office for Scotland

One of the most striking changes in the living arrangements of older people living in private households in the second half of the twentieth century has been the rise in the proportion living alone. Tomassini (2006), using data from the General Household Survey from the 1980s to 2000s, highlights that the rise in solo living has been faster amongst those aged 85 and over than the population aged 65 and over as a whole. In the early 2000s, just under half of men and two-thirds of women aged 85 and over living in private households were living alone. This has implications for the availability of co-residential informal care amongst this age group.

Figure 4 Proportion of older people living alone, by sex and age



Source: Tomassini (2006), Figure 4

Projecting future numbers of the ‘oldest old’

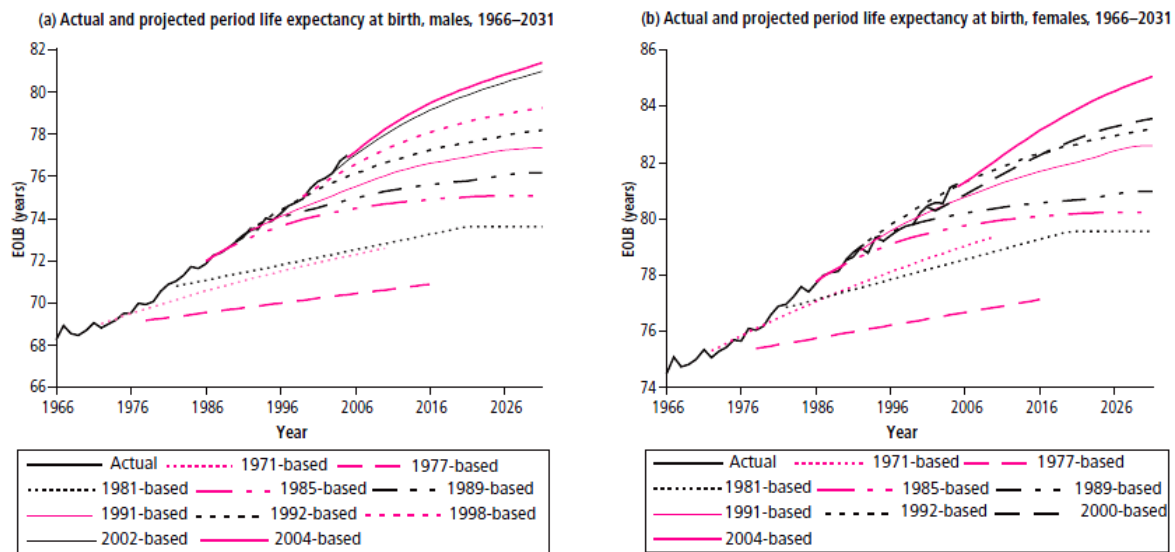
Population projections: how accurate have they been?

In order to plan for services across all age groups, national and local governments need to have reliable projections of the populations in different age groups. National population projections are produced every two years for the UK and constituent countries by ONS in consultation with the statistical offices for these countries. Sub-national population projections are also produced bi-annually, providing estimates of the size of the population by age and sex at Government Office Region, local authority, Primary Care Organisation and strategic health authority level for 25 years into the future. The latest national projections were published by ONS in October 2009 and the latest sub-national in May 2010.

The ONS projections are *not* forecasts but rather trend-based projections, with assumptions about future levels of fertility, mortality and migration based on levels observed over a five year reference period to the base year. Therefore, the projections give an indication of what the future population, by age and sex structure, might be if recent trends continue, and do not attempt to predict the impact that new or future government policies, changing economic circumstances or other factors might have on future demographic behaviour. This means that whilst projections in the short term are reasonably accurate, the longer the time period covered, the higher the degree of uncertainty involved. Those age groups most vulnerable to ‘uncertainty’ are the young (affected by predictions of fertility behaviour) and the old (most affected by mortality assumptions).

Chris Shaw, in an article examining the accuracy of official national population projections over the last 50 years, highlighted the fact that improvements in mortality, particularly at later ages, have been consistently *underestimated* both in the UK and elsewhere (Shaw, 2007). Figures 5a and 5b below, taken from Shaw’s article in Population Trends, show that although each set of projections has adopted more optimistic mortality assumptions than the previous one, they have nevertheless failed to predict the actual improvements in life expectancy observed. Comparison of the predicted number of people aged 85 and over in the population with the actual number 25 years later shows that the numbers have been under-predicted by around 25%.

Figures 5a and 5b Accuracy of mortality assumptions, 1971–2004 based population projections



Source: Shaw (2007) Figure 5

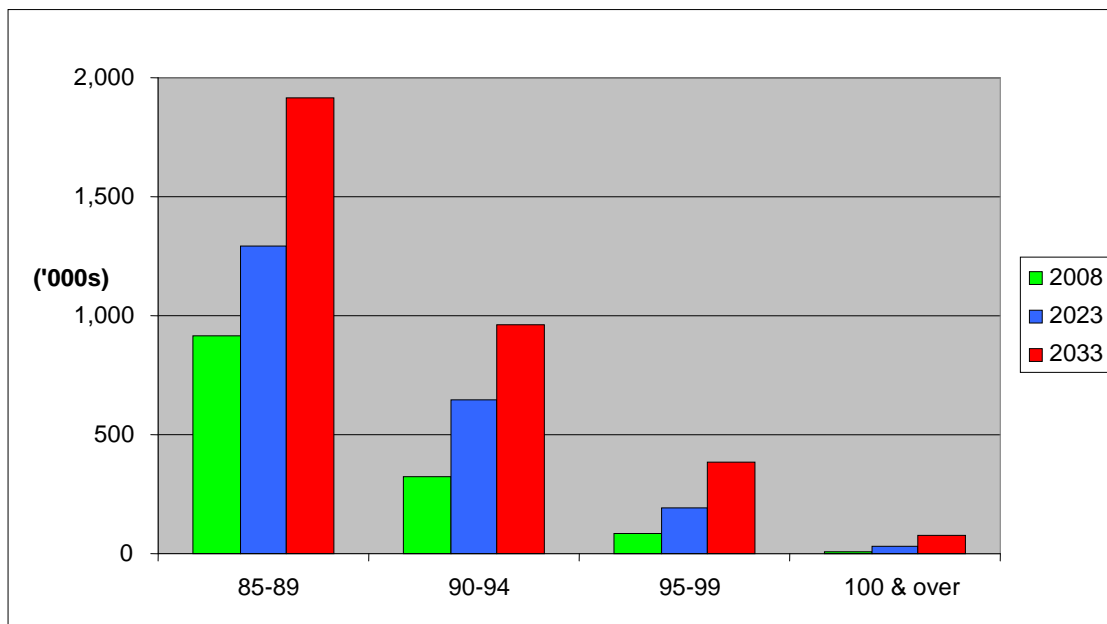
Although these are not forecasts, they are treated as such by many external agencies. Thus, for example, the Care Development Group,¹ which was responsible for estimates of the costs of free personal care, used 1998 population projections of the number of oldest old in Scotland. These were based on data from the 1991 census and substantially underestimated future numbers of older persons in Scotland. This resulted in a significant underestimate of the future costs of free personal care in Scotland. A more accurate estimate might have resulted in a different policy outcome.

Internationally, growing attention is now being given to stochastic projection methods which aim to give users information about the expected accuracy of projections, allowing the calculation of confidence intervals around the point estimate. The ESRC Centre for Population Change is working with ONS in this area on methods to incorporate expert opinion into forecasts, with the aim of providing more informed estimates in the future.

Future numbers of people aged 85 and over in the UK

Bearing in mind the caveats regarding the accuracy of any population projections, this sub-section presents the most recent estimates of the likely future numbers of people aged 85 and over in the UK using the recent 2008-based ONS Population Projections. In 2003 there were 1.3 million people aged 85 and over. By 2033, the number of people aged 85 and over living in the UK is projected to increase to 3.3 million. Of these, 1.9 million will be aged 85–89, 962,000 will be aged 90–94, 384,000 95–99 and 80,000 will be aged 100 or more (Figure 6). These figures assume that annual rates of mortality improvement will converge to a common rate of around 1% per annum and period expectation of life at age 65 in 2033 will be 22.1 years for men and 24.5 years for women, compared to 17.7 years for men and 20.3 years for women today.

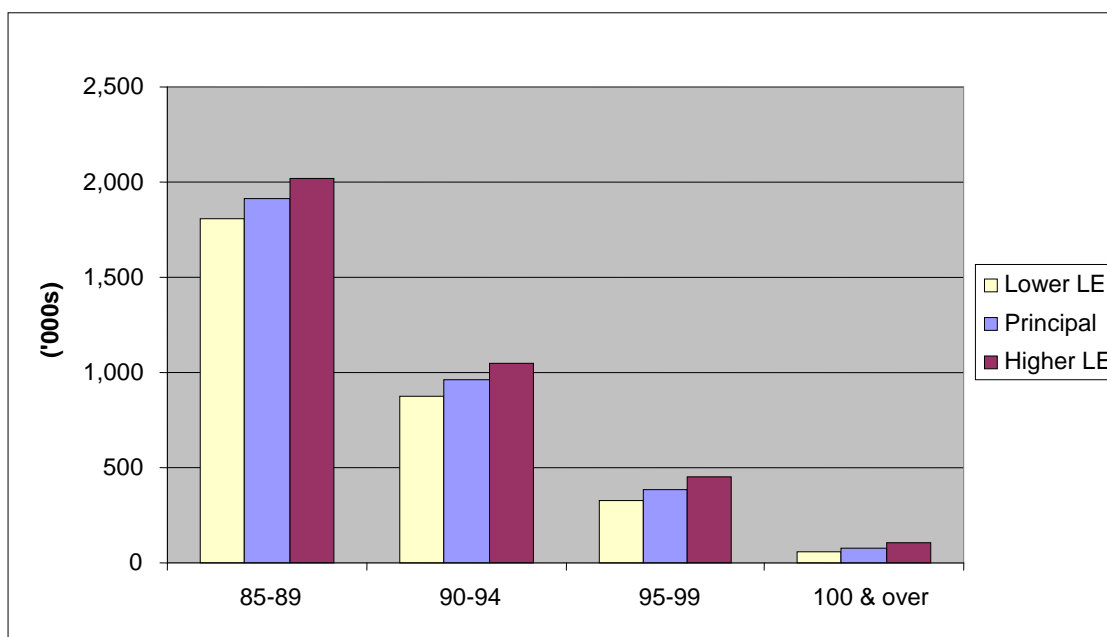
Figure 6 Projected population aged 85 and over, UK, 2008, 2023 and 2033



Source: derived from ONS 2008-based UK Population Projections, principal projection

However, as discussed above, in the past actual improvements in mortality have been greater than those assumed. Therefore Figure 7 compares the projected population of the 'oldest old' in 2033 assuming alternative optimistic (high life expectancy) and pessimistic (low life expectancy) scenarios. If the optimistic scenario is realised, then the population aged 85 and over will be 3.6 million, of whom over half a million will be aged 95 and over.

Figure 7 Population aged 85 and over in 2033, UK principal and variant projections



Source: derived from ONS 2008-based UK Population Projections, principal, high and low life expectancy variant projections

Although age alone does not determine whether or not people have high support needs, it is a good guide and it is likely that over the next twenty years the numbers requiring such support will rise considerably. The majority will reside in England (2.8 million assuming the principal projection) but there will also be sizeable populations of older people with high support needs in the other three UK countries (Table 7).

Table 7 Projected population aged 85 and over (thousands), UK and constituent countries, 2033 (principal projection)

	Age 85–89	Age 90–94	Age 95–99	Age 100+	All 85 and over
UK	1917	962	384	80	3343
England	1617	809	326	68	2820
Wales	104	53	20	4	181
Scotland	149	75	29	6	259
Northern Ireland	47	25	9	2	83

Source: derived from ONS 2008-based National Population Projections

Increasing diversity in later life

The ageing of the ethnic minority population

ONS has only recently started to publish population estimates by ethnic group. According to the most recent estimates for England and Wales, published in February 2010, in 2007 older people from black and minority ethnic (BME) groups comprised just under 8% of the total population aged 60 and over and just under 4% of those aged 90 and over (Table 8).² However, there are significant differentials across regions, with BME older people constituting a much higher proportion of the older population in metropolitan areas. For example, in Inner London BME older people (including white minority groups) make up 38% of all people above statutory pension age (60 for women and 65 for men), with the figure rising to 47% in Haringey and 45% in Hackney. BME older people also comprise a significant proportion of the pensioner population in Leicester (28%), Luton (26%), Birmingham (24%), Manchester (20%), Coventry (19%) and Bradford (13%) (Table EE2 in ONS 2010a).

Table 8 Population aged 60 and over (thousands) by ethnic group, England and Wales, 2007

Age	White British	White other	Mixed	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Other	Total
60–64	2840.8	118.7	10.6	40.8	15.1	4.6	20.2	11.5	8.8	20.9	3092
65–69	2156	101.3	7.9	36.2	15.9	6.6	28.1	9	6.7	14.2	2381.9
70–74	1901.2	86.9	6.2	28	13.6	5	25.3	5.7	5.2	9.7	2086.8
75–79	1622.7	68.3	4.5	17.7	7.7	2.5	16	3	3.2	5.9	1751.5
80–84	1216.5	51.7	2.9	8.9	3.3	0.7	7.8	1.4	1.6	2.9	1297.7
85–89	748.2	25.2	1.5	4.3	1.5	0.4	2.9	0.7	0.7	1.4	786.8
90+	369.9	10.1	0.7	1.5	0.6	0.1	0.9	0.2	0.3	0.6	384.9
Total 60+	10855.3	462.2	34.3	137.4	57.7	19.9	101.2	31.5	26.5	55.6	11781.6
Percentages											
Age	White British	White other	Mixed	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Other	Total
60–64	91.9	3.8	0.3	1.3	0.5	0.1	0.7	0.4	0.3	0.7	100.0
65–69	90.5	4.3	0.3	1.5	0.7	0.3	1.2	0.4	0.3	0.6	100.0
70–74	91.1	4.2	0.3	1.3	0.7	0.2	1.2	0.3	0.2	0.5	100.0
75–79	92.6	3.9	0.3	1.0	0.4	0.1	0.9	0.2	0.2	0.3	100.0
80–84	93.7	4.0	0.2	0.7	0.3	0.1	0.6	0.1	0.1	0.2	100.0
85–89	95.1	3.2	0.2	0.5	0.2	0.1	0.4	0.1	0.1	0.2	100.0
90+	96.1	2.6	0.2	0.4	0.2	0.0	0.2	0.1	0.1	0.2	100.0
Total 60+	92.1	3.9	0.3	1.2	0.5	0.2	0.9	0.3	0.2	0.5	100.0

Source: ONS (2010a)

Over the next two decades the older population is likely to become increasingly diverse as the cohorts of people who have migrated to the UK since the 1960s enter retirement. The Centre for Policy on Ageing, together with Runnymede, have recently published a report examining the likely change in the age structures of the ethnic minority populations in England and Wales up to 2051 (Lievesley, 2010). According to their estimates, by 2051 the total BME population in England and Wales will have grown to 25 million, comprising 36% of the total population. The fastest growing ethnic population will be 'other white', reflecting the recent in-migration from the countries of eastern and central Europe, followed by the Black African, Pakistani and Indian ethnic groups.

The same report predicts that by 2051, there will be 3.8 million BME people aged 65 and over compared with 675,000 today. This increasing diversity will have implications for local authorities and national agencies involved in the provision of services to older people.

Growing numbers of older gay people

Sexuality is another important dimension of diversity in later life. The most reliable estimates of the size of the lesbian and gay population in Britain come from the National Survey of Sexual Attitudes and Lifestyles (NATSAL) carried out in 1990, 2000 and 2010. In 2000, 6.3% of men and 5.7% of women aged 16-44 interviewed had ever had sex with a same sex partner, and 2.6% of both men and women reported having a same sex partner in the last 5 years (Erens *et al.*, 2001). This is equivalent to around 1.5 million people. Unfortunately the 2000 survey focussed only on people aged 16–44 and no nationally representative data exists on the number of older lesbians or gay men. The age range of the 2010 survey is being extended and the study will interview 15,000 men and women aged between 16 and 74. The results of the study, which will be published in 2013, will provide the first estimates of sexuality in later life in Britain.

Some evidence is available from ONS data on civil partnerships. The Civil Partnership Act 2004 came into force on 5 December 2005 in the UK. In the remaining days of December 2005 there were 3,906 civil partnerships registered, of which 27% were between people aged 60 and over and 10% between people 70 and over, reflecting the number of older lesbian and gay couples who wished to formalise their relationship. In 2006, there were 32,212 civil partnerships registered, of which 19,296 were between men and 12,916 between women. Of these, just over 13% of civil partnerships were between people aged 60 and over, and 5% were between people 70 and over. Since then the annual number of civil partnerships has been falling. In 2008, same-sex couples formed 7,169 civil partnerships (3,824 male and 3,345 female).

Changes in both social norms and the legal context mean that it is likely that in future there will be more older people living in civil partnerships and openly gay relationships. The seminal report by Hubbard and Rossington (1995), *As we grow older*, drew attention to the fact that the needs and wishes of older gay people were not being met, particularly with regard to care for high support needs. The report highlighted that nursing homes rarely make provision for the sexual expression of their residents, but even less so for their homosexual residents. Although the legal context has moved on since then, many of the issues remain, with the assumptions and prejudices of some people still being the cause of difficulties and challenges (Age UK, 2010).

3. Estimating the prevalence of people with high support needs

So far this report has focussed almost exclusively on chronological age as providing an indicator of the likely size of the population with high support needs. This section reviews the available evidence on the prevalence and trends in chronic illness, impairment and disability from national data sources. The need for accurate and reliable measurement of disability has received greater prominence following the *Disability Discrimination Act 2005* and the publication of the strategy to improve the life chances of disabled people (Prime Minister's Strategy Unit, 2005). Inadequacies in the level of detail and consistency of disability data collected in household surveys were identified in the recent *Review of Equality Data* (ONS, 2007) and there is currently a cross-departmental project to improve statistics in this area (White, 2009).

Defining disability

The Department for Work and Pensions *Review of Disability Estimates and Definitions* (2004) identified five working definitions of disability:

- **Disability Discrimination Act (DDA):** A (or multiple) long-term health problem or disability that substantially limits a person's ability to carry out normal day-to-day activities and that has, or is expected to, last at least 12 months (extended by 2005 Act to include person who has been diagnosed with HIV, multiple sclerosis or cancer).
- **Work-Limiting Disability (WLD):** A long-term health problem or disability that affects the amount or type of work a person can do.
- **Long-Term Disabled (LTD):** This is the definition of disability used for the Department for Work and Pension's Public Service Agreement on employment. It includes everyone with a Work Limiting Disability (WLD) and/ or a disability covered by the DDA.
- **Limiting Long-Standing Illness (LLSI):** An illness, disability or infirmity that is longstanding (has troubled someone over a period of time or is likely to) and limits their activities in any way.
- **International Classification of Illnesses, Disabilities and Handicaps (ICIDH):** A restriction or lack of ability to perform normal activities which has resulted from the impairment of a structure or function of the body or mind. This definition has now been replaced by the International Classification of Functioning, Disability and Health which includes a set of environmental/societal factors.

There are a number of approaches to the measurement of high dependency populations. They hinge on the issue of who is doing the assessment and how it is being carried out. Some of the approaches include:

- Self-assessment of health/disability status (usually as part of a survey).
- Assessment by third party of health/disability status. The third party acts as a gatekeeper to service provision and the data is drawn from the resulting administrative records.

- Assessment of resource need, after admission to care programme. Data will again come from administrative sources, but the assessment will not be conditional on a decision on whether services will or will not be provided.

These often produce quite different outcomes. For reasons of time and expense, general household surveys rarely include a great deal of detail on health and disability. It is known that responses to the surveys may be biased if respondents seek to use their health status to justify other aspects of their behaviour. This is known as 'justification bias' and might occur, for example, if someone seeks to justify labour market inactivity by claiming to be disabled. Objective and subjective assessments of health status do not necessarily coincide. We begin by considering self-assessment.

Self-assessed health/disability

Self-assessed health and disability data is generally collected in large-scale surveys. This has the advantage of large samples and consistency in the questions that are used. Providing there are no systematic differences in response, this data can be used to analyse health and disability across e.g. age, gender, ethnicity, region etc. If the surveys are repeated, for example annually, in the same form, then trends in these variables can be assessed.

Disability

Historically, there have been several national surveys of the disabled population in 1969, 1985 and 1996 (Martin, Meltzer and Elliott, 1988; Grundy *et al*, 1999). However, there is currently no single source of data on disability in the UK and estimates of the prevalence of disability within the UK population vary according to both the definition of disability being applied and data source used.

Data on disability as defined by the **Disability Discrimination Act (2005)** is currently collected in the Family Resources Survey (FRS) and this data is used by the Office of Disability Issues (ODI) to produce their estimates of disability prevalence. The latest ODI estimates using the FRS for 2007/8 show that there are over ten million disabled people in Britain, of whom five million are over state pension age.

Data on **Work Limiting Disability** is available from the Labour Force Survey (LFS) and the Annual Population Survey (APS). Recent estimates using the LFS suggest that the prevalence of work limiting disability is around 15%, i.e. 5.4 million people. The same data are used to estimate the number of people who are **Long-Term Disabled (LTD)**. In Spring 2003 there were around 6.9 million people of working age with a long-term disability (Tibble, 2004).

Information on **Long-Standing Illness** and activity limitation has been collected in the General Household Survey since 1972, and these questions are now included in the new General Lifestyle Survey (GLF). Table 9 shows that overall the proportion of older men and women reporting LLSI disability has fallen slightly over the past decade. However, the trend has not been clear cut, with fluctuations year on year.

Given that the age profile of those aged 75 and over has been rising, this downward trend is encouraging.

Table 9 Percentage of older men and women reporting suffering from a long-standing illness that limits their activity 1998-2008

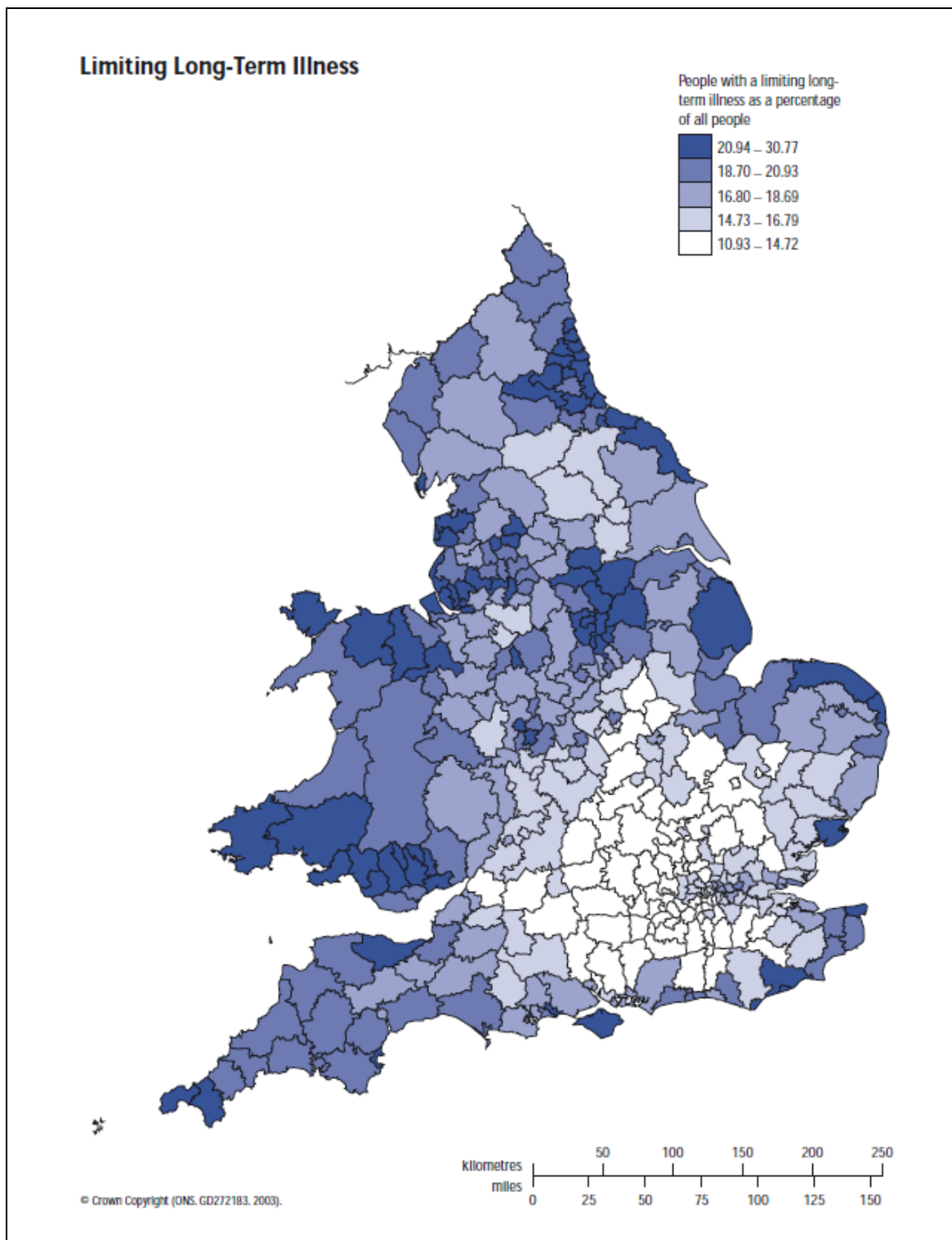
	1998	2000	2001	2002	2003	2004	2005	2006	2007	2008
Males										
65-74	36	38	36	43	37	33	36	37	37	33
75 and over	48	44	47	52	41	43	44	47	47	45
Females										
65-74	39	35	37	39	37	33	39	39	36	34
75 and over	51	48	45	53	46	48	48	51	48	48

Source: ONS General LiFestyle Survey 2008. Table 7.2

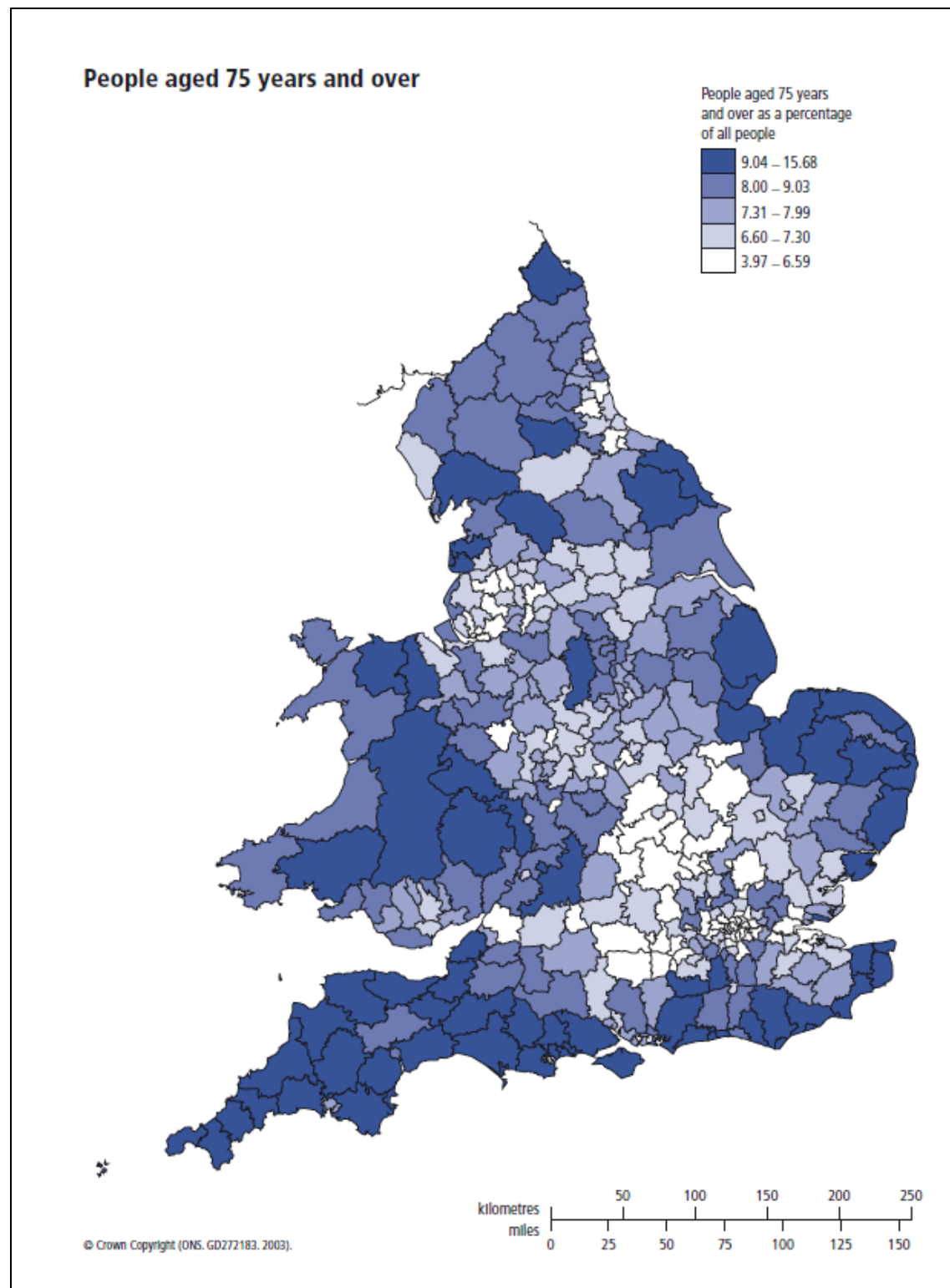
The new Integrated Household Survey (IHS), which will incorporate the GLF, will include further differentiation of activity limitation to distinguish between 'strongly limited' and 'limited' activity. With a larger sample size of 345,000 individuals, it is envisaged that the IHS will provide reliable estimates of ill-health, disability and activity limitation at local authority level between censuses by pooling over three years. The first round of the IHS is planned for Spring 2010.

At present the only source of data that provides estimates of the prevalence of disability at the sub-national level is the Census, which in 1991 and 2001 included a question designed to capture disability as defined by limiting long-term illness. In 2001, 18.5% of the population of the UK reported having a limiting long-standing illness, equivalent to 10.9 million people – a very similar figure to the prevalence of disability found using the FRS. The likelihood of reporting a LLSI varied across the country, in part reflecting the age structure of different local authorities. Maps 1 and 2 show the prevalence of limiting long term illness across England and Wales and the share of the population who are aged 75 and over. Not surprisingly, the prevalence of LLTI is higher in the areas where the proportion of the population aged 75 and over is also high.

Map 1

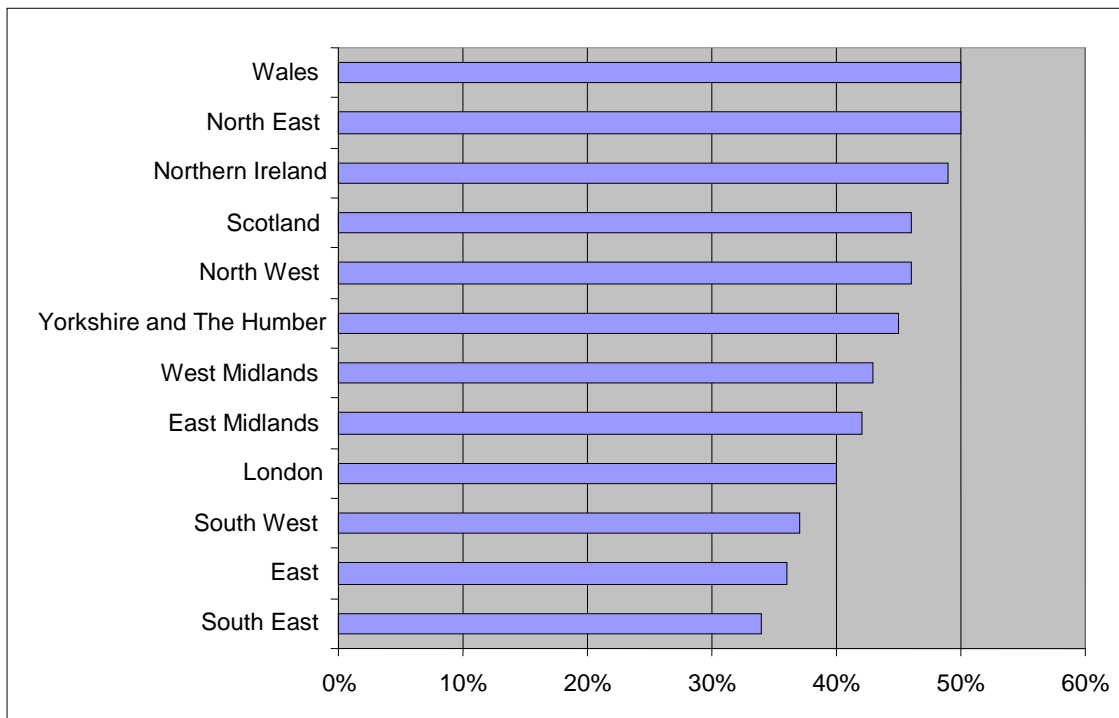


Map 2



Looking at older people, the proportion of adults aged 65 to 74 who have a limiting long-standing illness is higher in Wales, the North of England, Northern Ireland and Scotland than elsewhere (Figure 8). It is planned that the 2011 Census will also include a question on disability, with a three category response on the extent of activity limitation, allowing for finer grained estimates of the severity of the disability.

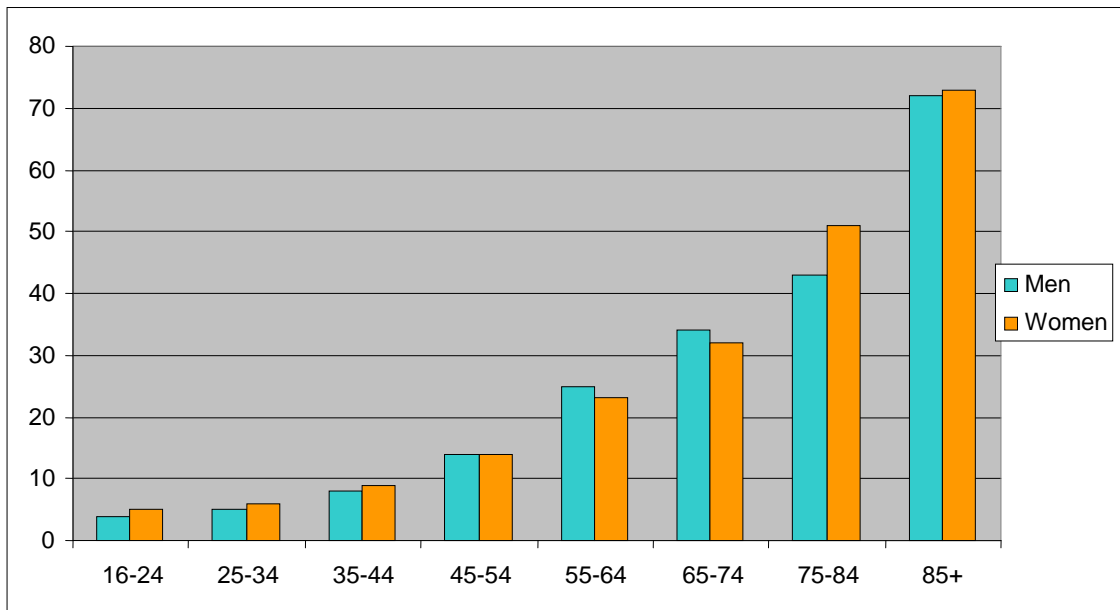
Figure 8 Percentage of adults aged 65–74 reporting a limiting long term illness, 2001



Source: 2001 Census, ONS, GROS and NISRA

Finally, the Health Survey for England measured disability in accordance with the **International Classification of Illness, Disabilities and Handicaps (ICIDH)** in its 2001 Disability Module. The disability questions covered limitations in five functional activities (seeing, hearing, communication, walking and using stairs). Of men and women aged 16 and over, 18% reported having at least one of the five types of disability, almost the same level as reporting a LLTI in the Census. The prevalence of disability increased steadily with age (Figure 9).

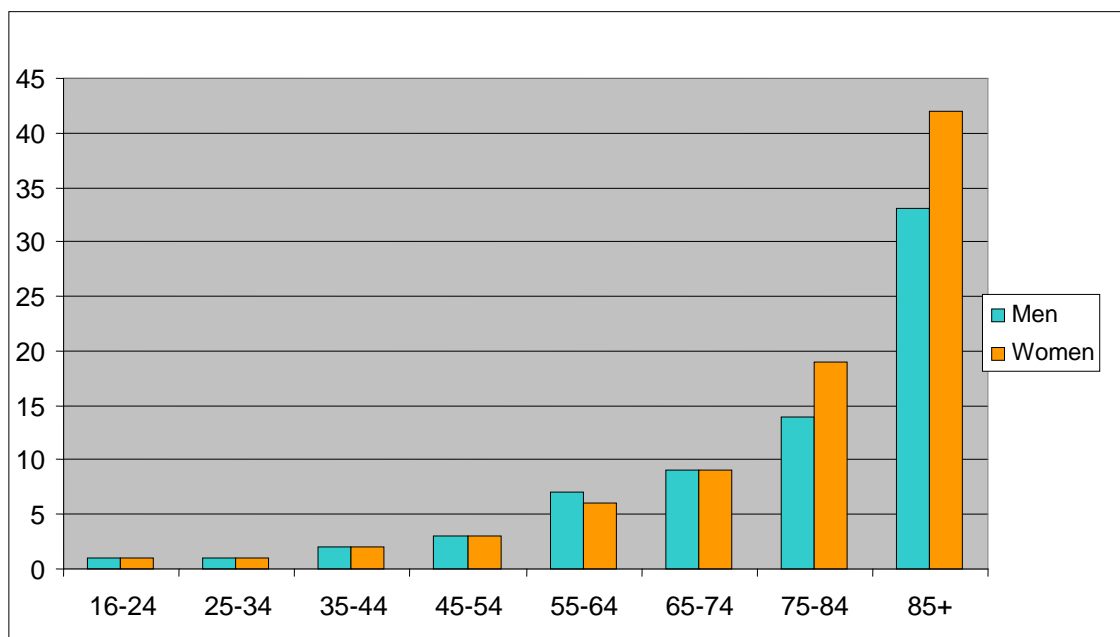
Figure 9 Prevalence of disability by age and sex, Health Survey for England 2001



Source: Table 1, Health, Survey for England 2001, Disability Module

Data on the degree of difficulty in carrying out the five functional activities was used to produce a disability score, allowing estimation of the severity of disability. The prevalence of ‘serious’ disability was less than 5% amongst those aged under 55 and under 10% for 55–74, rising steeply after age 75, indicating that age remains a good proxy for high support needs.

Figure 10 Prevalence of ‘serious’ disability by age and sex, Health Survey for England 2001



Source: Table 1, Health, Survey for England 2001, Disability Module

Dementia: Evidence from the Medical Research Council Cognitive Function and Ageing Study (CFAS) and EURODEM

In addition to the large scale household surveys, there are a range of ad hoc surveys that provide important insights into the prevalence of disability amongst older people. One of the most important is the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS) (see <http://www.cfas.ac.uk/>). This study collected data on a sample of over 13,000 people aged 65 and over in five sites in Cambridgeshire, Gwynedd, Newcastle, Nottingham and Oxford at baseline and two years later. Throughout the study a subgroup of the participants has been seen every year and further interviews of other selected participants took place in 1997, 1999 and 2001. In 2002/3 all survivors were approached by the study and 3,145 were re-interviewed. Data was collected on disability through questions on the ability to perform various activities of daily living (put on shoes or socks, have a bath or all over wash, transfer to and from bed), as well as self-reported morbidity from 11 diseases, including diagnosed stroke, coronary heart disease and arthritis.

In addition, the study collected information on cognitive impairment using diagnostic scales. Tables 10 and 11 below show the estimated prevalence and incidence of dementia from the study. These estimates suggest that around half a million people in England and Wales would be expected to be suffering from dementia of mild or greater severity, with approximately 163,000 new cases of dementia occurring in England and Wales each year (95% CI 96,000 to 272,000) (Matthews *et al.*, 2005). The large confidence intervals around the estimate of the incidence of dementia reflects the fact that for accurate estimates one requires diagnoses that successfully distinguish disease from normality (i.e. recognise disease at an early stage). Then one requires the resources to make such diagnoses consistently across the whole population.

Table 10 Prevalence of dementia by age and sex (%), CFAS

Age group	Men (%)	Women (%)
65–69	1.4	1.5
70–74	3.1	2.2
75–79	5.6	7.1
80–84	10.2	14.1
85+	19.6	27.5

Source: MRC CFAS

Table 11 Incidence rate of dementia per 1,000 person years with 95% confidence intervals, CFAS

Age group	Men	Women	Men & Women
65–69	6.9 (3.3-14.5)	6.3 (2.9-15.6)	6.7 (3.8-12.4)
70–74	14.5 (7.4-34.1)	6.1 (2.8-12.6)	10.3 (6.2-19.9)
75–79	14.2 (6.7-25.1)	14.8 (8.5-25.1)	14.5 (9.6-20.7)
80–84	17.0 (6.7-34.1)	31.2 (21.2-34.1)	26.5 (18.3-37.7)

Source: MRC CFAS

Alternative estimates of the number of cases of dementia have recently been published by the Alzheimer's Research Trust (Luengo-Ferandez, Leal and Gray,

2010) using data from the **European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) study**. As part of this study, data on the prevalence of both diagnosed and undiagnosed moderate to severe dementia from a range of surveys conducted in several European countries were pooled to calculate prevalence rates by age for both men and women (Table 12). Not surprisingly, as the EURODEM data includes undiagnosed dementia, the prevalence rates within age groups in Table 12 are generally higher than those from the MRC CFAS study, particularly at ages under 75. The larger sample size of the EURODEM data also allows calculation of separate rates for those aged 85 and over, illustrating the significant increase in prevalence between those aged 85-89 and over age 90.

Table 12 Prevalence rates of diagnosed and undiagnosed dementia (%) in the UK

Age group	Men	Women
30–59	0.16	0.09
60–64	1.58	0.47
65–69	2.17	1.10
70–74	4.61	3.86
75–79	5.04	6.67
80–84	12.12	13.50
85–89	18.45	22.76
90–94	32.1	32.25
95–99	31.58	36.00

Source: Luengo-Ferandez, Leal and Gray, 2010 using EURODEM data

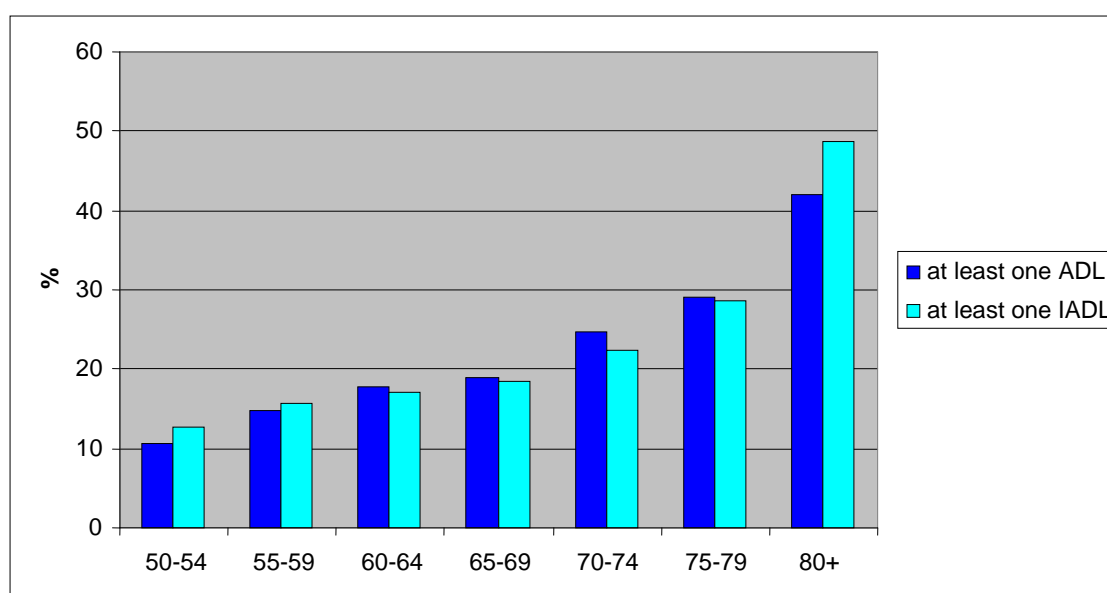
The EURODEM data suggests that around 820,000 people suffer from dementia in the UK today. Work by the Health Economics Research Centre at Oxford estimates that the associated costs amount to around £23 billion i.e. £21,647 per dementia sufferer (Luengo-Ferandez *et al.*, 2010). A recent study has calculated the median survival time following a diagnosis of dementia in a general practice population to be 6.7 years at age 60-69 and 1.9 years at age 90 and over. A diagnosis of dementia was associated with higher relative mortality, especially in the first year after diagnosis. The incidence of dementia was higher in women and in younger age groups in deprived areas (Rait *et al*, 2010).

The Dementia strategies for England, Scotland and Northern Ireland all state the need to increase the diagnoses of dementia. The process of setting targets may facilitate the improvement of data on dementia diagnosis, which in turn may impact upon estimates of incidence and prevalence.

Physical functions: Evidence from the English Longitudinal Study of Ageing

The English Longitudinal Study of Ageing (ELSA)³ collects information on a sample of around 12,000 individuals aged 50 and over. There have currently been four rounds of data collection, with the first in 2002–3 and the most recent in 2008 (see <http://www.ifs.org.uk/elsa/index.php>). The survey collects a range of information on health including respondents' ability to carry out everyday tasks. These self-reports of physical functioning are divided into three types: activities of daily living (ADLs),⁴ instrumental activities of daily living (IADLs)⁵ and motor skills or strength.⁶

Figure 11 Proportion of older people reporting difficulty with activities of daily living, ELSA 2002



Source: ELSA Wave 1

The prevalence of reported difficulty with both ADLs and IADLs increases with age. Amongst those aged 80 and over 44% of women and 38% of men report difficulty with at least one ADL and 53% of women and 42% of men report difficulties with at least one IADL.

Table 13 Proportion of older men and women reporting difficulty with specific ADLs, ELSA 2002

	50–59	60–74	75+	All
Men				
Dressing including putting on shoes and socks	10.5	15.3	21.1	14.4
Walking across a room	1.8	3.0	5.6	3.0
Bathing or showering	6.1	10.1	20.7	10.4
Eating such as cutting up your food	1.3	1.6	2.9	1.7
Getting in and out of bed	5.1	6.1	9.2	6.3
Using the toilet, including getting up or down	2.1	3.3	6.1	3.3
Women				
Dressing including putting on shoes and socks	7.8	11.3	20.9	12.4

Walking across a room	1.8	3.0	8.1	3.8
Bathing or showering	6.2	13.0	28.4	14.4
Eating such as cutting up your food	1.4	2.1	2.8	2.0
Getting in and out of bed	6.1	6.3	9.7	7.1
Using the toilet, including getting up or down	2.7	3.5	6.3	3.9

Source: ELSA Wave 1

Over a fifth of men aged 75 and over and nearly one in three women of the same age reported difficulty in bathing or showering. However, this also means that four-fifths of men and over two-thirds of women are able to perform these self-care tasks themselves. Table 13 illustrates, however, that simply concentrating on the population aged 85 and over will miss out some younger people living in the community who also have high support needs. Amongst those aged 60-74, 10% of men and 13% of women reported difficulty in bathing and 6% of both men and women reporting difficulty in getting out of bed unaided.

Table 14 Proportion of older men and women reporting difficulty with specific mobility and upper limb tasks, ELSA 2002

	50–59	60–74	75+	All
Men				
Walking 100 yards	7.5	12.4	20.7	11.9
Getting up from a chair after sitting for long periods	15.5	23.8	33.3	22.2
Climbing one flight of stairs without resting	7.1	13.0	22.7	12.4
Stooping, kneeling or crouching	23.1	32.3	47.3	31.4
Lifting or carrying weights over 10 pounds, like a heavy bag of groceries	10.7	17.8	28.6	16.9
Picking up a 5p coin from a table	3.2	4.5	7.4	4.5
Women				
Walking 100 yards	6.7	11.7	25.9	13.4
Getting up from a chair after sitting for long periods	21.0	29.7	41.6	29.5
Climbing one flight of stairs without resting	8.2	16.7	32.8	17.7
Stooping, kneeling or crouching	25.6	41.7	58.2	40.0
Lifting or carrying weights over 10 pounds, like a heavy bag of groceries	22.0	32.5	55.3	34.4
Picking up a 5p coin from a table	2.7	5.5	11.3	5.9

Source: ELSA Wave 1

People aged 60–74 also report relatively high rates of difficulty in stooping, kneeling or crouching and getting up from a chair after sitting for long periods (Table 14). Although assistance with these sorts of tasks may not count as ‘high support’, this nevertheless highlights increasing difficulties in maintaining living independently in later life. Some of these difficulties can be overcome through the use of aids. Table 15 shows the percentage reporting using selected aids amongst those who have difficulty with one or more ADL, IADL or mobility function.

Table 15 Amongst those reporting difficulty with one or more ADL, IADL or mobility function, percentage reporting selected aids, ELSA 2002

	50–59	60–74	75+	All
Men				
No aid used	80.7	72.1	46.1	68.6
A cane or walking stick	17.5	25.8	47.3	29.0
A Zimmer frame or walker	0.6	1.4	4.9	2.1
A manual wheel chair	2.6	3.1	3.7	3.1
An electric wheel chair	0.6	0.6	1.3	0.8
A buggy or scooter	0.6	1.8	2.9	1.7
Special eating utensils	0.6	0.6	0.4	0.6
A personal alarm	1.4	1.5	7.0	2.9
Women				
No aid used	87.4	77.2	46.3	70.2
A cane or walking stick	10.4	19.7	45.5	25.3
A Zimmer frame or walker	0.6	1.9	11.0	4.4
A manual wheel chair	2.7	4.1	8.1	5.0
An electric wheel chair	0.5	0.9	0.6	0.7
A buggy or scooter	1.2	1.5	1.8	1.5
Special eating utensils	0.6	0.6	0.5	0.6
A personal alarm	0.8	3.0	14.8	6.1

Source: ELSA Wave 1

Interestingly only around a third of all men and women aged 50 and over who have difficulties with activities of daily living and/or mobility report using any aid, with the most common being a Zimmer frame or walker. However, use of aids rises with age, with over half of those aged 75 and over using some aids.

Gatekeeper administrative data

In the UK, health/disability status determines eligibility for disability-related benefits. To ensure fairness, it is important that these assessments are consistent. Since a third-party is involved, such assessments could be expected to be objective. But it is important to recognise the gatekeeper's perspective. When the gatekeeper has no financial interest in the outcome, assessments are less likely to be influenced by financial considerations.

Not all who are eligible for disability-related benefits apply. Some may be deterred by the frequently complex forms that have to be completed. If the benefit is means-tested, some may not wish to reveal their financial situation. Others may believe, rightly or wrongly, that they will only receive a small amount of benefit. Hancock *et al.* (2005) argue that take-up is greater among those with greater entitlement. Department for Work and Pensions (DWP) disability-related benefits include assessment by a medical practitioner paid for by DWP. The principal DWP benefits for disabled people are Disability Living Allowance and Attendance Allowance.

Disability Living Allowance (DLA) is payable to people aged less than 65 who are disabled and who have personal care needs, mobility needs or both. It is paid to those aged 65+ if there is a continuing need for personal care or mobility support. Attendance Allowance (AA) is a similar benefit payable only to those aged 65 and over. It does not have a mobility component. Thus, both these benefits are payable to the over 65s. But, in the case of DLA, payments need to have commenced before

age 65. DLA tends therefore to be paid to the 'younger old', while the take-up of AA is greatest among those aged 75 and over.

To qualify for DLA or AA, the need for help must have existed for three months (the qualifying period) and be expected to last for at least a further six months (the prospective test). People who are not expected to live longer than six months because of an illness do not have to satisfy either the qualifying period or the prospective test (DWP guidelines).

The care component is paid at one of three rates and the mobility component at one of two rates, depending on the severity of the need. In November 2009, 3.3 million people living in the UK were in receipt of DLA, of whom 872,000 were aged 65 and over. The vast majority of people aged 65 and over are in receipt of a benefit for the higher level of mobility and higher/middle care (Table 16). The majority are resident in England (Table 17).

Table 16 Total number of claimants for Disability Living Allowance by level of benefit and age, Great Britain, November 2009

Disability Living Allowance (entitlement)	aged 65–69	aged 70–74	aged 75–79	aged 80–84	aged 85–89	aged 90+	Total all ages (including below age 65)
Any entitlement	348,800	252,410	149,360	53,720	11,620	1,310	3,142,500
Higher care and higher mobility	68,250	52,130	36,100	14,910	3,160	340	535,630
Higher care and lower mobility	7,320	5,090	3,020	910	~	~	190,120
Higher care only	1,870	3,260	2,810	900	10	~	44,110
Middle care and higher mobility	70,370	54,780	34,770	14,010	3,020	350	468,050
Middle care and lower mobility	18,580	10,690	5,190	1,260	~	~	495,350
Middle care only	4,560	5,200	3,270	960	~	~	115,650
Lower care and higher mobility	73,280	44,340	18,550	2,960	20	~	418,070
Lower care and lower mobility	11,590	5,800	2,380	490	~	~	206,380
Lower care only	27,330	14,690	5,010	550	~	~	250,910
Higher mobility only	61,940	54,320	37,250	16,530	5,410	620	359,730
Lower mobility only	3,700	2,120	1,010	240	~	~	58,490

Source: DWP Nomis Database, accessed 21st May 2010

Table 17 Total number of claimants for Disability Living Allowance by age by country, November 2009

Disability Living Allowance (entitlement)	aged 65–69	aged 70–74	aged 75–79	aged 80–84	aged 85–89	aged 90+	Total all ages (including below age 65)
England							
Men	131,940	95,190	53,710	18,420	3,650	310	1,289,760
Women	145,680	104,280	63,040	24,130	5,590	730	1,268,360
Scotland							
Men	18,220	13,040	7,420	2,330	400	30	166,120
Women	20,530	15,360	9,650	3,170	610	80	175,580
Wales							
Men	15,720	12,260	7,570	2,730	620	70	120,920
Women	16,720	12,280	7,970	2,940	740	90	121,760

Source: DWP Nomis Database, accessed 21st May 2010

Table 18 shows the number of claimants for AA in Great Britain in November 1997 and November 2009. All claimants are aged 65+. There were 1.6 million claimants in total. Together there were almost 2.4 million claimants aged over 65 for either AA or DLA. This suggests that, at the end of 2009, 25.2% of those aged 65+ in the UK were either receiving AA or DLA and therefore had been assessed as being in need of help with either personal care or mobility or both.

Table 18 illustrates the very substantial increase in AA claims between 1997 and 2009. In Great Britain, there was a 37% increase in AA claims over this 12 year period. The increase has varied widely by condition. For example, AA claims associated with stroke and with epilepsy fell by over 10% during the period. But claims for renal disorders, deafness, and of muscle/joint/bone disease each increased by more than 160%. In absolute numbers, the greatest contribution to the increase in the number of claimants came from arthritis, which accounted for 159,000 of the additional AA claims. More than 500,000 individuals with arthritis receive either AA or DLA. Heart disease, frailty and mental health are less important, though each accounts for over 100,000 cases. Surprisingly, there are only 35,300 and 33,000 claimants citing malignant disease and Parkinson's disease respectively.

For AA, peak claims in terms of absolute numbers are in the 80–84 age group, although AA claimants comprise a higher proportion of those aged 85 and over.

Table 18 Total number of claimants for Attendance Allowance by condition and age: Great Britain, November 2009

Condition	Nov-09				Nov-97			
	Age 65-74	Age 75-84	Age 85+	Total	Age 65-74	Age 75-84	Age 85+	Total
Any disabling condition	238,600	709,000	626,100	1,573,800	231,200	567,400	418,500	1,217,100
Arthritis	71,000	233,400	206,100	510,500	63,100	171,000	117,700	351,800
Muscle/joint/bone disease	12,600	43,000	37,200	92,900	7,500	17,500	10,300	35,300
Blindness	4,300	21,800	30,000	56,000	6,500	23,900	24,200	54,600
Stroke related	18,200	50,500	32,300	101,000	27,600	56,600	29,200	113,400
Mental health causes	20,600	71,100	57,400	149,100	20,600	62,300	51,900	134,800
Epilepsy	1,100	2,300	1,000	4,300	1,400	2,500	900	4,800
Deafness	1,100	3,200	2,700	7,000	0	1,400	1,200	2,600
Malignant disease	10,700	16,900	7,800	35,300	4,600	8,100	3,800	16,500
Chest disease	18,800	36,900	16,300	72,000	16,300	28,400	10,100	54,800
Back ailments	8,400	19,000	11,600	39,000	5,900	10,800	4,600	21,300
Heart disease	15,900	63,100	55,900	134,900	19,200	50,800	31,800	101,800
Parkinson's disease	7,900	18,400	6,700	33,000	6,500	13,100	5,300	24,900
Diabetes mellitus	7,700	17,500	8,600	33,700	5,800	9,800	3,900	19,500
Renal disorders	2,100	3,600	2,600	8,300	1,000	1,500	600	3,100
Frailty	6,100	50,200	112,700	169,000	10,800	57,300	98,400	166,500
Multiple sclerosis	700	900	800	2,400	1,700	1,900	600	4,200
Learning difficulty	700	1,000	500	2,300	1,800	2,000	400	4,200
Other disabling condition	31,000	56,100	36,000	123,100	30,400	48,300	23,400	102,100

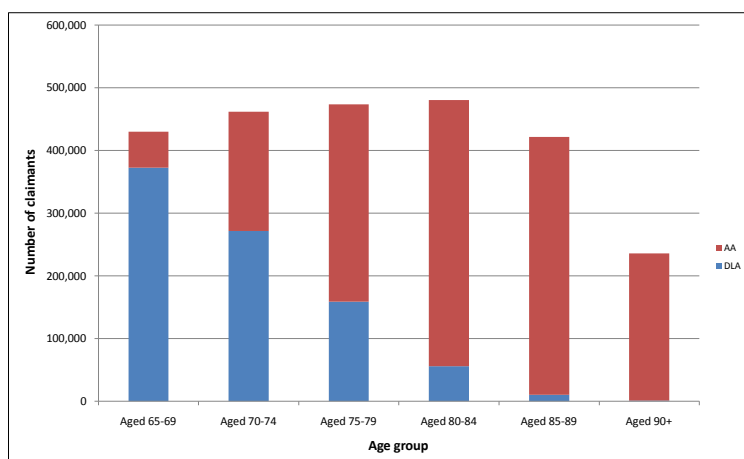
Source: DWP Nomis Database, accessed 18th July 2010

Figure 12 illustrates how DLA claimants aged over 65 are typically the 'young old', while AA claimants are generally more common among the 'old old'. DLA is concentrated among the 'young old', because the claim must be agreed before the age of 65. The peak age for claims of either benefit falls in the 80 to 84 age group. The growth in DLA claims among those aged 65+ has been even more rapid than that in AA claims. Between 1997 and 2009, DLA claims among those aged 65+ increased by 103%, from 403,000 to 820,000. This is one of the clearest exemplars of the impact of the ageing disabled population. Those that are disabled at a relatively young age and whose condition is not life threatening eventually become older disabled people.

Table 19 shows the distribution of AA claimants by age and country. The bulk of claims, more than 2.6 million, were made in England. Yet, relative to its population

aged 65+, England's claims are around 3% lower than the UK norm. In contrast, Scotland's are 5% higher, those in Wales are 26% higher, while the number of claimants for AA in Northern Ireland is 44% higher than the average for the UK as a whole. This suggests substantially higher rates of disability in Wales and Northern Ireland compared to Scotland and England. As far as we know, there has been no substantive research into these disparities.

Figure 12 AA and DLA claimants by age group, November 2009



Source: Nomis Database

Table 19 AA Claimants by country and age, November 2009

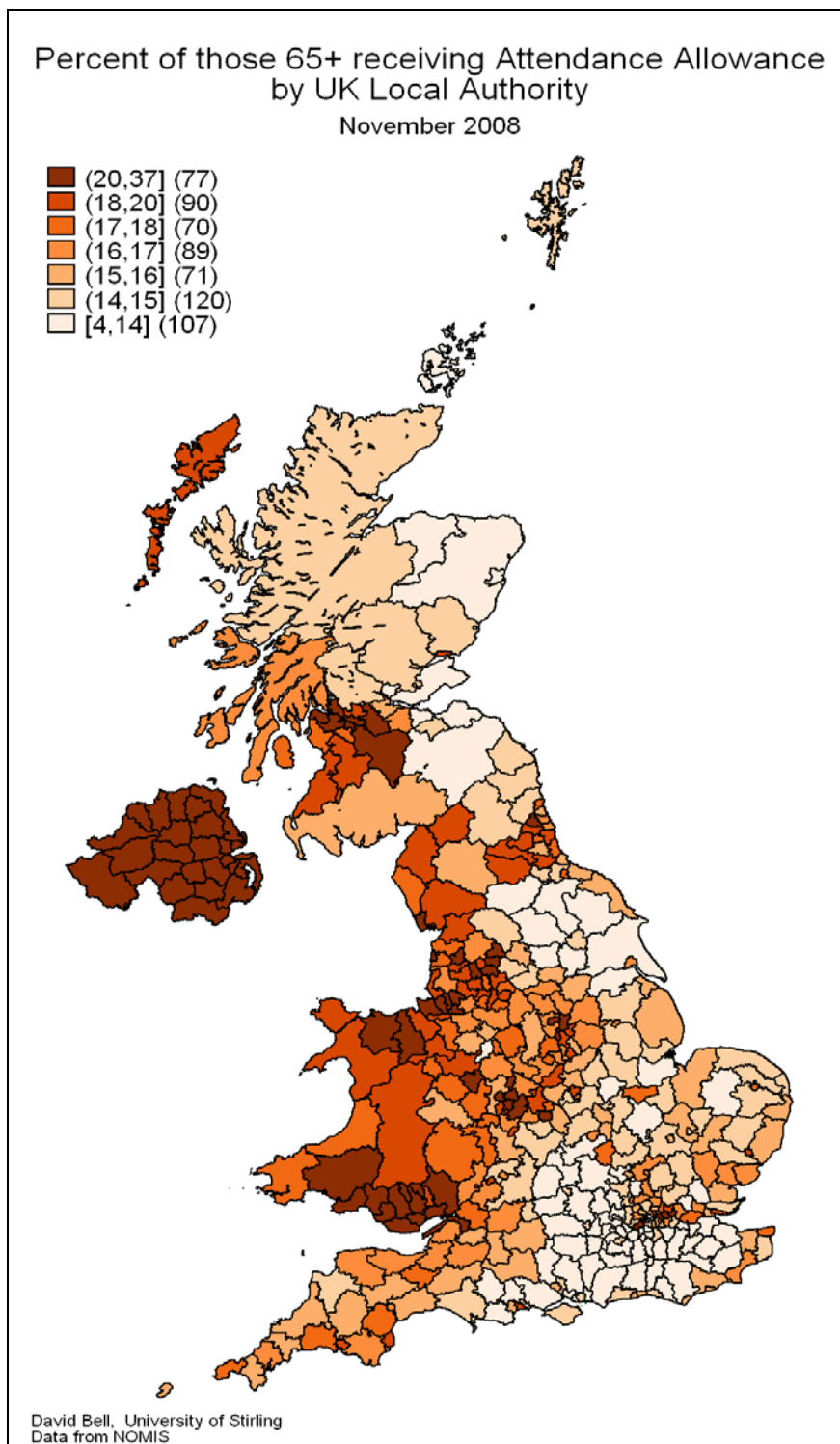
	Total	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85-89	Aged 90+
England	1,315,000	44,800	149,100	248,500	337,900	336,500	198,000
Wales	111,500	4,100	13,400	21,100	30,100	28,700	14,200
Scotland	147,300	6,700	20,500	32,300	39,100	32,300	16,400
Northern Ireland	58851	1867	7092	12754	17283	13527	6328
United Kingdom	1,632,651	57,467	190,092	314,654	424,383	411,027	234,928

Source: Nomis Database

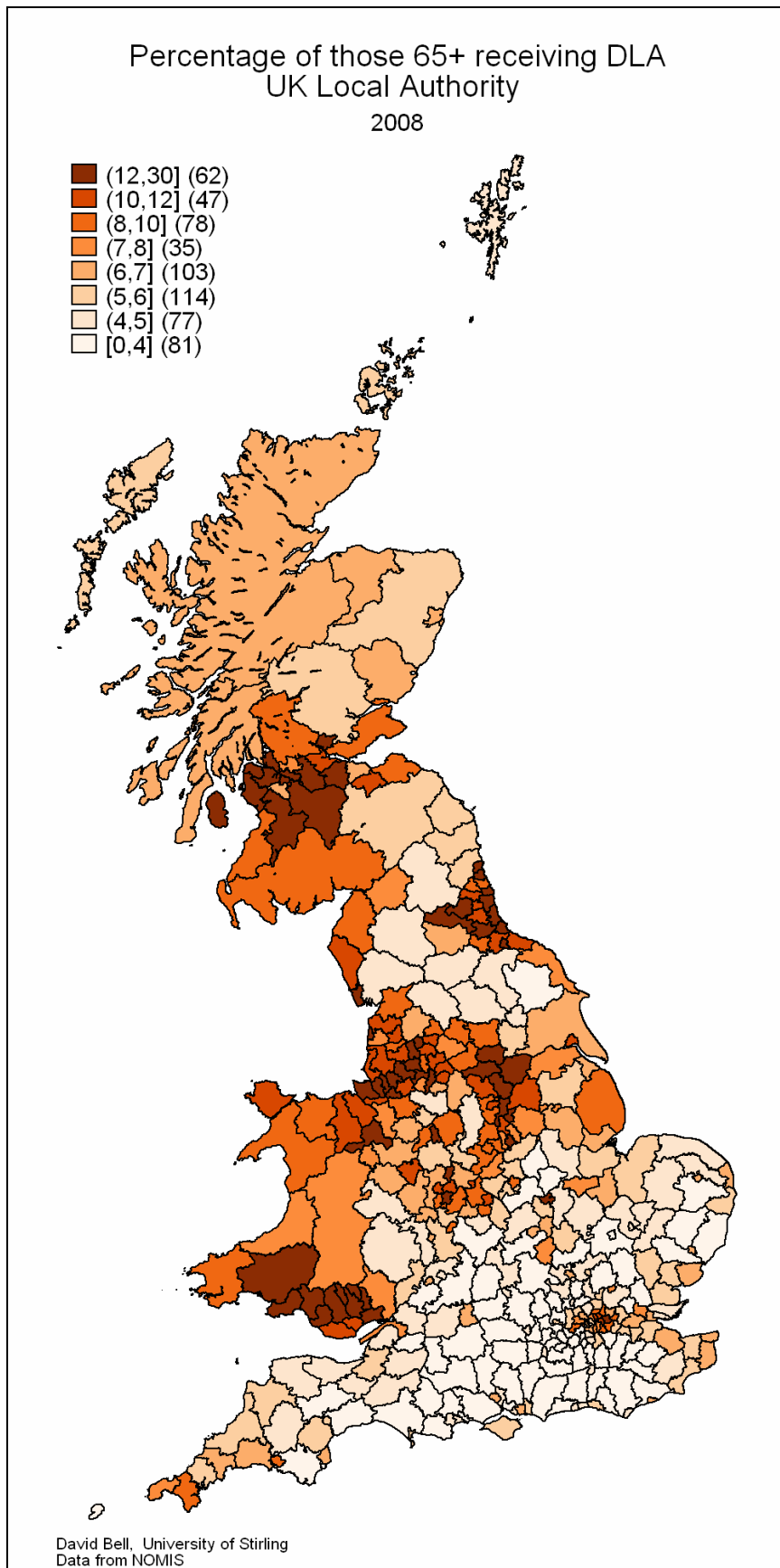
At a local authority level, the distribution of these benefits across the UK is fairly stable. Map 3 shows the proportion of those aged 65+ receiving Attendance Allowance by UK local authority in 2008. Thus, for example, in the Western Isles, the Glasgow area, all of Northern Ireland, North and South Wales and Merseyside and some parts of Central London, between 20% and 37% of those aged 65+ receive Attendance Allowance.

The spatial pattern of Disability Living Allowance payments to those aged 65+ is very similar and is shown in Map 4. Although the average proportion of the older population receiving DLA is lower than the proportion receiving AA, the DLA group have been growing much more rapidly in recent years, implying that there are an increasing proportion of the 'young old' that are assessed as requiring personal care or mobility needs.

Map 3 Distribution of Attendance Allowance by Local Authority, UK, 2008



Map 4 Distribution of Disability Living Allowance amongst those aged 65+ by Local Authority, UK, 2008



Other administrative information

The final category of estimates of those with high support needs constitute those where assessment has occurred and service provision is agreed. Agreement may result from statutory obligation, or after the application of relevant guidelines. Their application tends to be limited by the many different ways in which disability and health status are categorised in such studies, many of which reflect the particular ways in which services are provided. These may include specific assessments of health or disability status, of the impairments to function caused by the disability, or of the level of resources needed to alleviate symptoms or reduce the functional impact of disability. We consider examples of each of these.

Continuing care: Evidence from Scotland

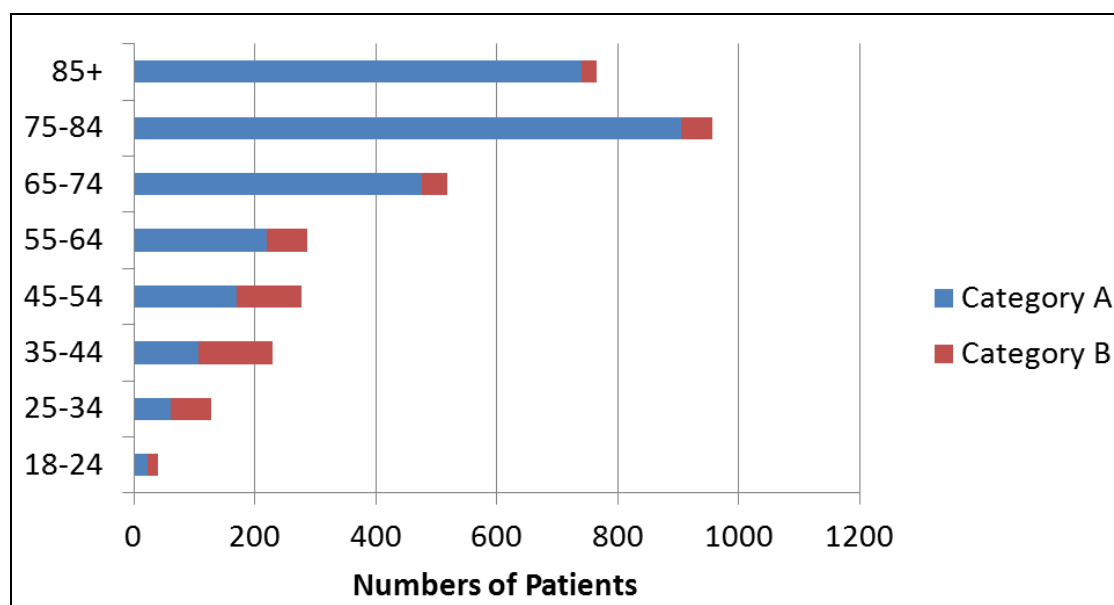
Continuing care health patients have among the highest level of support needs. They require almost continuous health care. These constitute a small, but important, component of the high support need population. Continuing care has proved controversial, particularly in England, where a legal judgement that a patient requires continuing care implies very significant costs for the NHS.

The Scottish Government has recently introduced a regular census of continuing care patients. In September 2009, 2644 patients were described as Category A – NHS continuing care health patients – and 486 as category B, i.e. patients who do not specifically meet the criteria for NHS continuing health care but who have been in hospital for over one year and for whom no estimated date of discharge has been set.

The majority (77%) of Category A patients are aged 65 years and over. Among Category B patients, only 22% were 65 years and over at the census. Figure 13 shows their age distribution. It is constructed by averaging the three censuses that have been carried out thus far – in September 2008, March 2009 and September 2009. It is clear that continuing care is more prevalent among older age groups. Around 61% are aged 75 or above.

This information can be used to estimate the UK continuing care population. As a first approximation, we can apply the same age specific rates of continuing care as in Scotland to the UK as a whole. This method suggests that there would be around 38,300 continuing care patients in the UK as a whole. This is a crude estimate that does not take account of differences in disability across the UK. Data from, for example, AA and DLA take-up suggests that disability rates in Scotland are slightly higher than in England, but significantly lower than either Wales or Northern Ireland. Nevertheless, the estimate does provide a useful indication of the numbers requiring continuing care across the UK. The average cost of a week's stay in Scottish long-term/acute hospitals in 2008-09 was £1933.⁷

Figure 13 Continuing care patients in Scotland by age



Source: Information Services Division, Scottish Government

Examining the classification of high dependency based on resource usage, the Scottish Government has developed assessment ‘tools’ to classify older clients in hospital, care homes and receiving care at home. These have been linked with the policy of ‘free personal care’ in Scotland, but their introduction addresses a wider set of concerns about equity and resource use for such clients. Clearly the relative treatment of clients and the associated resource provision across health boards and local authorities cannot be compared unless that is a common way of describing client needs.

The assessment tools are described as ‘SHRUGS’, ‘SCRUGS’ and ‘IoRN’. These cover long-stay care hospitals for older people, care homes and care at home and stand, respectively, for Scottish Health Resource Utilisation Groups, Scottish Care Resource Utilisation Groups and Indicator of Relative Need.

The SHRUGs resource grouping is listed below.

SHRUGs Group	Description
A	Low dependency; no behavioural difficulties
B	Low dependency; with behavioural difficulties
C	Moderate dependency; no needs for special care or clinically complex treatments
D	Moderate dependency; with needs for special care and/or clinically complex treatments or High dependency; no needs for special care or clinically complex treatments
E	High dependency; with needs for special care and/or clinically complex treatments

This system has been used to classify high dependency older hospital patients since 2004. Outcomes of the earliest and latest overall assessments are shown in Table 20 below.

Table 20 Classification of high dependency hospital patients in Scotland 2004 and 2009

	Mar-04	Jul-09
No of patients	2415	1255
Percentage		
A	9	8
B	1	1
C	28	25
D	32	30
E	29	35

Source: Information Services Division, Scottish Government

There was a slight increase in the number of very high dependency patients between 2004 and 2009. This partly reflects the reduction in the number of long stay beds for older people: the numbers staying in long-stay beds has almost halved over this period – the result of a deliberate policy to shift care towards more community settings. It is likely that those remaining in long-stay facilities will be those for whom movement into the community is difficult and these are likely, on average, to have higher dependency needs. In the most recent census (July 2009), over 80% of patients classified under SHRUGS were aged over 75.

For care homes, the SCRUGs resource grouping is shown below:

SCRUGs Group	Description
A	Low dependency; Neither Behaviour nor Special Care Needs
B	Low dependency; Either Behaviour or Special Care Needs
C	Low to moderate dependency; Neither Behaviour nor Special Care Needs
D	Low to moderate dependency; Either Behaviour or Special Care Needs
E	Moderate dependency; Neither Behaviour nor Special Care Needs
F	Moderate dependency; Either Behaviour or Special Care Needs
	OR
	High dependency; Neither Behaviour nor Special Care Needs

- G Moderate dependency; Both Behaviour and Special Care Needs
OR High dependency; Either Behaviour or Special Care Needs
- H High dependency; Both Behaviour and Special Care Needs

The average proportion of care home residents in each SCRUGs group between 2005 and 2009 is shown in Table 21 below.

Table 21 Care home residents in each SCRUGs group

SCRUGS Group	Percent
A	29
B	9
C	12
D	7
E	15
F	17
G	10
H	1

Source: Information Services Division, Scottish Government

During this period, the number of care home clients in Scotland was fairly static at around 30,000. The data is not yet sufficiently robust to indicate a trend toward an increasing proportion of high-dependency residents. This is what one would expect given the increased policy emphasis on providing care for even quite complex cases in individual's homes. Nevertheless, such data will provide a useful mechanism for identifying such trends in the future.

Finally, we consider the IoRN classification for clients receiving care at home. The nine categories are listed below:

IoRN Groups	Description
A	Low ADL, Low personal care/food/drink preparation
B	Low ADL, Medium personal care/food/drink preparation
C	Medium ADL, No/low mental well being
D	Low ADL, High personal care/food/drink preparation
E	Medium ADL, Medium mental well being
F	High ADL, Low bowel management, No/low mental well being
G	Medium ADL, High mental well being
H	High ADL, Low bowel management, High mental well

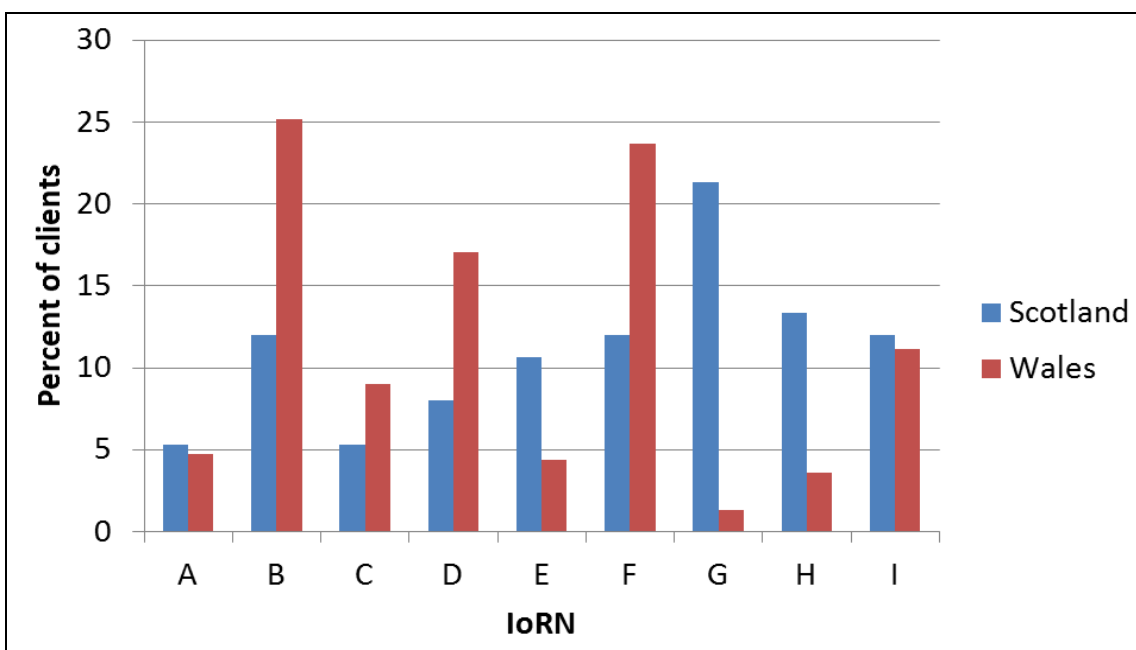
being

I High ADL, High bowel management

The use of IoRN has been limited thus far, perhaps because it has not gained widespread acceptance among the professional bodies likely to make use of it. Nevertheless, some data is available both for Scotland and for Wales. The Welsh Assembly Government experimented with the use of IoRN in a survey of four local authorities that it carried out when considering the introduction of free personal care. See Bell and Dawson (2008) for a description.

Figure 14 shows distribution of clients across IoRN groups for both Scotland and Wales. The Scottish data is based on information from a set of four test sites. It is clear that the Scottish and Welsh approaches to the same classification system yielded quite different results. In particular, there is a large difference in the proportion of Scots and Welsh care clients classified as 'Medium ADL, high mental well-being'. While this may reflect real differences in care needs between Scotland and Wales, it also suggests the importance of establishing a clear set of guidelines to accompany any system for classifying high dependency patients.

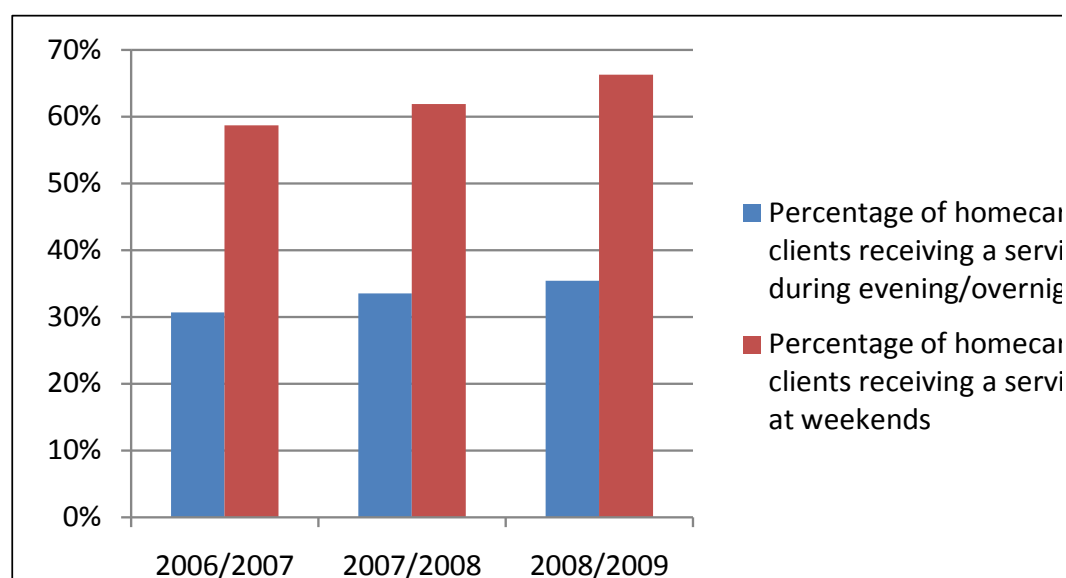
Figure 14 Proportion of clients by IoRN Group



Source: Information Services Division, Scottish Government

Another approach to resource use as a measure of high dependency is to classify the number of weekly hours of care required or the times at which care is provided. A good example is the number of clients receiving overnight or weekend support. Clearly, such care is high cost, and will indicate a relatively high level of dependency.

Figure 15 Growth in high-dependency homecare in Scotland



Source: Scottish Government

This data indicates a very rapid rise both in overnight and weekend provision for older home care clients in Scotland between 2006–07 and 2008–09. This does not necessarily indicate changing levels of need across the population, but more a focussing of policy on high dependency home care. This illustrates one of the disadvantages of the use of resource measures as indicators of high-dependency needs: they are susceptible to policy change as well as to underlying levels of need. Nevertheless, during periods when policy is stable, they are a useful adjunct to survey-based measures that frequently cannot identify the most dependent groups within the population.

Trends in healthy life expectancy

A key question when considering the number of older people with high support needs is whether the recent increases in life expectancy at older ages discussed in section 2 have been accompanied by a concurrent postponement of functional limitations and disability. Recent research suggests that in some countries people are living longer without severe disability (Christensen *et al.*, 2009). Data from the 1982–2004 National Long-Term Care Survey (NLTC) in the United States found that the prevalence of chronic disability amongst people aged 65 and over declined by 2.2% per annum over the period 1999 to 2004 (Manton, 2008). Similar declines in disability prevalence have been found in other U.S. national health surveys (Freedman *et al.*, 2002) and in Spain (Zunzunegui *et al.*, 2006). However, there are some concerns whether these improvements in disability will continue because of recent increases in obesity prevalence. The evidence in the UK is not as conclusive as in the US.

The Office for National Statistics (ONS) has published two alternative estimates of health expectancy for Great Britain from 1981 onwards: healthy life expectancy (HLE), defined as expected years of life in good or fairly good health; and disability-free life expectancy (DFLE), defined as expected years of life free from a limiting

chronic illness or disability. These are calculated by combining data on life expectancy with either the prevalence of self-perceived fairly good or good health status (HLE) or limiting long-standing illness (DFLE), based on data from the General Household Survey and adjusted to include people living in communal establishments using a technique known as the Sullivan method (Jagger, 1999). As Table 22 illustrates, the proportion of years of life remaining at age 65 that will be spent in good or fairly good health or without a limiting long-standing illness has either not changed over the period 1981–2001 or actually fallen, with the exception of female DFLE.

Table 22 Life expectancy and healthy life expectancy at age 65, Great Britain, 1981–2001

	Men			Women		
(a) using good / fairly good health						
	LE	HLE	% of years in good health	LE	HLE	% of years in good health
1981	12.97	9.94	76.6%	16.92	11.8	69.7%
1991	14.15	10.84	76.6%	17.91	12.97	72.4%
2001	15.94	11.62	72.9%	19.03	13.17	69.2%
(b) using limiting long standing illness						
	LE	DFLE	% of years with no disability	LE	DFLE	% of years with no disability
1981	12.97	7.57	58.4%	16.92	8.50	50.2%
1991	14.15	7.90	55.8%	17.91	9.28	51.8%
2001	15.94	8.81	55.3%	19.03	10.07	52.9%

Source: Derived from ONS (2004)

Estimates of life expectancy (LE), HLE and DFLE for the constituent countries of the UK are only available from 2000–02 onwards, with the latest data being for the period 2005–07. These are shown in Figures 16a and 16b and Table 23 below. At age 65, women in England enjoy the highest HLE of the four countries. For men, the highest HLE at 65 is shared between England and Northern Ireland. Interestingly, however, Scottish residents are estimated to spend the highest proportion of their remaining lives in good or fairly good health on average compared with residents of the other UK countries.

Figure 16a Life expectancy and healthy life expectancy at age 65, men, 2005–2007

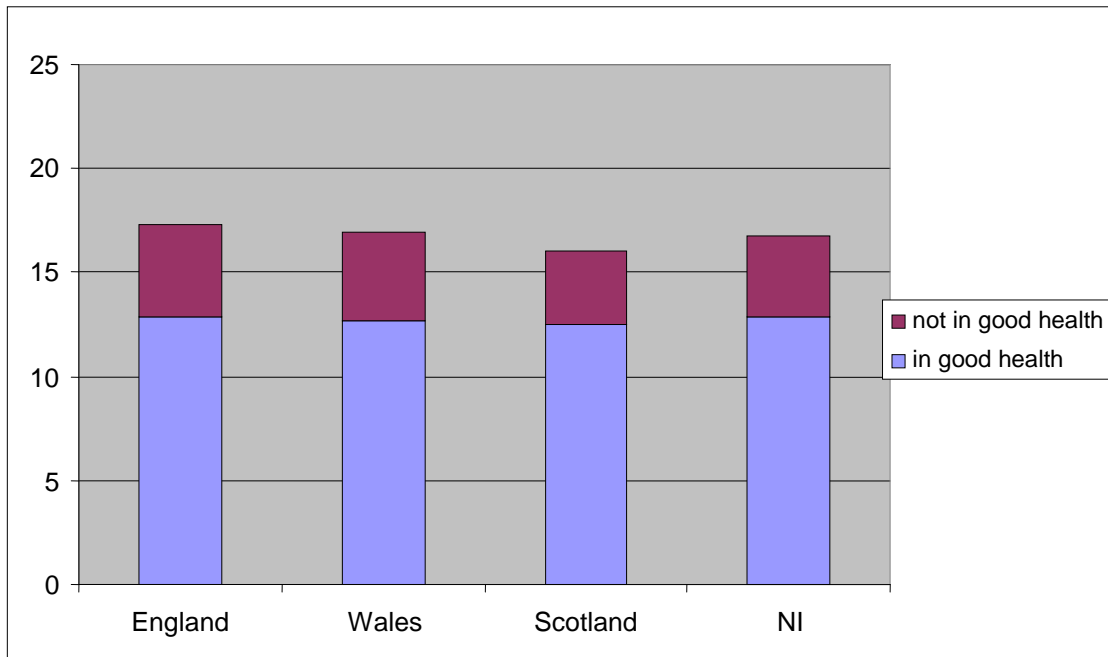


Figure 16b Life expectancy and healthy life expectancy at age 65, women, 2005–2007

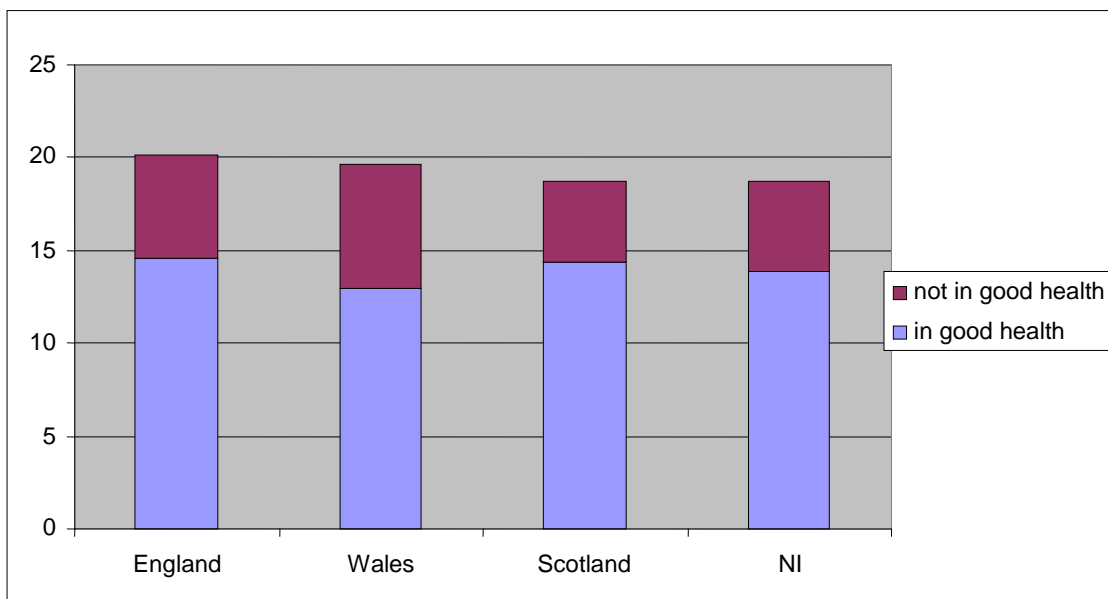


Table 23 Life expectancy and healthy life expectancy at age 65, constituent countries of the UK, 2005-2007

	Men			Women		
(a) using good / fairly good health						
	LE	HLE	% of years in good health	LE	HLE	% of years in good health
England	17.3	12.9	74.6%	20.1	14.6	72.6%
Wales	16.9	12.7	75.1%	19.6	13.0	66.3%
Scotland	16.0	12.5	78.1%	18.7	14.4	77.0%
Northern Ireland	16.8	12.9	76.8%	18.7	13.9	74.3%
(b) using limiting long standing illness						
	LE	DFLE	% of years with no disability	LE	DFLE	% of years with no disability
England	17.3	10.2	59.0%	20.1	10.7	53.2%
Wales	16.9	8.7	51.5%	19.6	9.9	50.5%
Scotland	16.0	9.4	58.8%	18.7	10.6	56.7%
Northern Ireland	16.8	8.9	53.0%	18.7	9.1	48.7%

Source: Derived from ONS (2009)

Of the four UK counties, England has the highest DFLE at age 65 for both men and women. As with HLE, Scottish residents are estimated to spend the lowest proportion of their life with a limiting chronic illness or disability compared with residents of the rest of the UK. This arises, in part, because of their lower life expectancy. However, DFLE in Scotland is higher than that for Wales or Northern Ireland; women in Northern Ireland can expect to spend more than half of the remaining years of life at age 65 with a chronic condition.

Projecting future numbers of disabled older people: the relationship between disability and longevity

Many projections of the future numbers of disabled older people take current prevalence rates by age and gender and apply these to the projected number of people in these age and gender groups in the future. For example, simply applying the prevalence rates on dementia in Table 9 to the latest ONS population projections suggests that in 2033 there will be 1.4 million older people suffering from dementia. However, this approach fails to take into account changes in medical treatments and better, or poorer, health behaviours.

Historical experience suggests that the assumption of constant age and sex specific prevalence rates of disability may not be justifiable. However, it is far from clear what impact improvements in overall population health and reduced mortality may have on disability. Much depends on whether the onset of chronic ill-health is postponed to a time closer to death i.e. the compression of morbidity (Fries, 1980) or whether improvements in mortality simply mean those in poor health are kept alive longer, i.e. the expansion of morbidity (Kramer, 1980). Research in the Netherlands suggests that continued reductions in mortality at older ages will result in more years with a

disability and thus potentially higher health care costs (Bonneux *et al.*, 1998), a finding supported by the trends in DFLE in Table 23.

Professor Carol Jagger and colleagues at the Leicester Nuffield Research Unit have developed a simulation model to explore how changing patterns of diseases will affect the burden of disability and DFLE to 2030 (Jagger *et al.*, 2006; Jagger *et al.*, 2009). Their findings suggest that life expectancy will continue to rise, but that most of the extra years will be spent with a disability. Scenarios with improving population health result in higher numbers of older people overall, with reductions in the prevalence of diseases such as stroke, coronary heart disease and arthritis barely offsetting the effects of population ageing on disability. They conclude that:

If the emphasis of public health interventions and medical treatments continues to be on extending life at older ages, with little or no consideration for alleviating or postponing the disabling consequences of disease, there will be around 50,000 more older people with disability at a level that needs care by 2025, *in addition to the rises resulting from the ageing of the population* [our emphasis].
(Jagger *et al.*, 2006)

4. Ageing with a learning disability

The main focus of this report has been to provide a review of the evidence regarding future numbers of older people with high support needs. As such, the review has focussed on estimates of the oldest old (85+) and on the prevalence of disability, dementia and long term illness. However, it is important to also highlight the growing number of older people who have been disabled from a young age. Improvements in life expectancy mean that many people with learning and other disabilities are surviving into old age. This is illustrated most vividly by people with Down's syndrome. At the beginning of the twentieth century, average life expectancy for those with Down's syndrome was less than ten years; today it is around 50 (Holland, 2000).

Learning disability is defined as a disability that affects a person's ability to learn, understand or communicate. The degree of learning disability varies considerably, ranging from mild disability where only minimal support is required, through to having a severe or profound multiple learning disability (PMLD) which can require support 24 hours a day.

There is no centrally held data on the number of people with learning disabilities. The Government White Paper, *Valuing People* (2001) estimated that there were around 1.2 million adults with mild/moderate learning disabilities in England and 145,000 adults with PMLD, of whom 20,000 were older adults (Butcher, 2009). The vast majority of people with learning difficulties live at home and only a minority are in receipt of services. The latest data from the Department of Health indicates that in 2008–09, 34,550 adults with learning disabilities were supported by social service departments in residential care and 141,000 people with a learning disability were in receipt of day care services from local authorities, of whom 13,000 were aged 65 and over (The Information Centre for Health and Social Care, 2010).

Emerson and Hatton (2008) have produced estimates for the future need for adult social care services for people with learning disabilities in England. Their research suggests an annual growth rate of around 1% in the need for social care services for this group as a whole. They highlight three key drivers for change: decreasing mortality among people with learning disabilities, especially in older age ranges (exerting an upward pressure); the impact of changes in fertility in the population (exerting a downward pressure); and the ageing of the 'baby boomers', amongst whom, they argue, there appears to be increased incidence of learning disabilities (exerting an upward pressure).

There is a growing body of evidence that the ageing process may begin earlier and be more accelerated in those with learning disabilities than in the general population (Holland, 2000; Butcher, 2009). A study of people aged 65 and over with learning difficulties in Hull found three-quarters had continence problems identified as age-related and a third had eyesight conditions that were age-related (Bland *et al.*, 2003). It is estimated for older people with a learning disability other than Down's syndrome, the risk of dementia is about four times higher than for a person without a learning disability. And for those with Down's syndrome, the Alzheimer's society suggest that

the age of people who have dementia rises from 2% amongst those aged 30–39, to 9% at ages 40–49, 36% at ages 50–59 and to 54.5% at ages 60–69.

The fact that people with a learning disability are living longer means that their carers, who are often their parents, are also growing older and may have their own needs. A study for Joseph Rowntree Foundation in 1998 (Walker and Walker) highlighted that older family carers for adults with learning difficulties differ from other groups of carers in that they are more likely to be sole carers, have smaller support networks, have usually negative experiences of the paid service sector and are especially reluctant to seek help. As the numbers of older people with learning difficulties rise, much more information is needed, both on the numbers and characteristics of older people with learning disability living in the community and on their carers.

5. Conclusions

Current population projections suggest that the number of people aged 85 and over will more than double between 2008 and 2033 to reach 3.3 million, and to account for 5% of the total population. Within this 'oldest old' population, the number of centenarians will reach almost 80,000 by mid-2033. This is an eight-fold increase from the 2008 figure, representing an annual average rate of increase of nearly 10% a year.

The jury is still out regarding whether the extension in life expectancy has been accompanied by improvements in years of good health. Evidence from cross-sectional surveys over time such as the General Household Survey suggests that *within* age groups, health is improving slightly. However, more people are surviving to experience greater levels of severity of disability at older ages. Thus the proportion of life spent in 'not good health' appears to be increasing or, at the very least, stable within the UK.

Planning health and social care services for older people with high support needs requires accurate projections of the future numbers of people with such needs. This in turn requires reliable estimates of the prevalence and incidence of cognitive and functional impairments. There are some estimates for these at the national level, but very little data is available at the sub-national and local level. Moreover, most of these estimates are based on household survey data and thus necessarily exclude those living in institutional care. The data also does not allow disaggregation of the population by key characteristics such as ethnicity. The ageing of the cohorts that migrated to the UK in the 1950s and 1960s means that over the coming decades BME older people will comprise a growing share of the population aged 75 and over, with particular health needs.

The 2011 Census will provide more detailed information on disability than in the past, distinguishing between severe and moderate activity limitation. The new UK Household Longitudinal Study, *Understanding Society* (USoc), also offers the possibility of a much more fine-grained analysis of UK society, with a target sample size of 40,000 households and 100,000 individuals, bigger than any comparable longitudinal study. The study design includes a significant sample boost for key ethnic minority groups and aims to collect biomedical measures and samples to enable new research on the social determinants and impacts of health in a household context. This will complement data from ELSA and from the national birth cohort studies. The MRC National Survey of Health and Development (NSHD) the oldest of the British birth cohort studies, is unique in having data from birth on the health and social circumstances of a representative sample of men and women born in England, Scotland or Wales in March 1946. The latest wave of data collection, when the sample were aged 60, also offers the opportunity to shed light on the ageing process.

Continued investment in the major data sources in the UK and their analysis is required to further our understanding of the complex interaction of health, disability, economic and social well-being and independent living in old age.

Notes

1. See report from Care Development Group (2001) *Fair Care for Older People*. Downloaded at <http://www.scotland.gov.uk/Publications/2001/09/10069/File-1>
2. The data is only available for England and Wales. It should be noted however that in 2007 almost all (96%) of UK residents that were born outside Europe were resident in England and Wales, with just 4% resident in Scotland and Northern Ireland.
3. Note that even though it is part funded by the Department for Work and Pensions, a department with a UK wide remit, there is currently no equivalent to ELSA in Scotland, Wales or Northern Ireland. Similar longitudinal studies to ELSA do however exist for the rest of Western Europe and North America. The original sample for ELSA was drawn from respondents from the Health Survey for England.
4. Activities of daily living (ADLs) in the English Longitudinal Study of Ageing include: dressing, including putting on shoes and socks; walking across a room; bathing or showering; eating, such as cutting up food; getting in or out of bed; and using the toilet, including getting up or down.
5. Instrumental activities of daily living (IADLs) in the English Longitudinal Study of Ageing include: preparing a hot meal; shopping for groceries; making telephone calls; taking medications; doing work around the house or garden; and managing money, such as paying bills or keeping track of expenses.
6. Respondents in the English Longitudinal Study of Ageing are asked about ten items referring to movements involving the upper and/or lower limbs, most of which require a degree of muscle strength but a few of which are more to do with dexterity and flexibility. The ten items are: walking 100 yards; getting up from a chair after sitting for long periods; climbing several flights of stairs without resting; climbing one flight of stairs without resting; stooping, kneeling or crouching; pulling or pushing large objects like a living-room chair; lifting or carrying weights over ten pounds, like a heavy bag of groceries; reaching or extending arms above shoulder level; sitting for about two hours; and picking up a small coin from a table.
7. Scottish Government, Information Services Division, Costs Book 2008-09. Downloaded from: http://www.isdscotland.org/isd/costs-book-detailed-tables.jsp?pContentID=3647&p_applic=CCC&p_service=Content.show Hospital.

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