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A Model for Projecting the Number of People Who Will Require Long-Term Care in the Future

Part I: Data Considerations

by

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A MODEL FOR PROJECTING THE NUMBER OF PEOPLE WHO WILL REQUIRE LONG-TERM CARE IN THE FUTURE

I: Data Considerations

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ABSTRACT

A multiple state model has been developed for projecting the number of people in the United Kingdom with disabilities over the next forty years. The model requires three types of data: prevalence rate data, transition rate data and trends data. This paper reviews, in detail, the sources of information currently available in respect of each of these types of data, and highlights the main areas of uncertainty relating to the data.

KEYWORDS

Long term care; Multiple state model; Healthy life expectancy

1. INTRODUCTION

This paper describes, in three parts, a model which we have developed to project the number of people in the United Kingdom who will be disabled over the next forty years. The projections give an indication of the long-term care needs of the UK population in the future.

The number of elderly people in the UK is growing both in absolute terms and in relation to the number of people of working age. According to the latest projections produced by the Government Actuary's Department (GAD) there will be around 4.3 million people aged 80 or more in forty years' time compared with about 2.3 million now. The number of people aged between 20 and 64 is expected to fall slightly from 34.8 million to 33.8 million (Government Actuary, 1998).

At present the prevalence of disability amongst elderly people is much higher than for the rest of the population. As this situation is likely to continue it is possible that there will be very many more people with some degree of disability in the future. Such people will need some form of long-term care.

The provision of long-term care is expensive (in terms of both time and money). Hence it is very important to be able to estimate the numbers of people who are likely to need long-term care, although it is also necessary to recognise that any such estimate will be subject to much uncertainty. The numbers, while they are fundamental, are only one of several aspects that will affect the provision of long-term care. The other aspects include the connection between the severity and nature of a disability and the cost of caring for someone with the disability; the split between formal and informal provision of care services; and methods of paying for the cost of care provision. This paper (considered in its entirety) focuses on the issue of the number of people who will require care and does not address the other key aspects mentioned above.

The output from the model, for a given set of assumptions, is an estimate of the number of people who are healthy and the number who are disabled. (In this paper we use the terms "healthy", "able" and "not disabled" interchangeably.) The number of disabled people is further split into several categories of disability from relatively mild to very severe. The model covers people aged 20 and over and goes up to the year 2036. The numbers are produced for all combinations of age, year and sex.

The output is very sensitive to the assumptions put into the model, and the necessity of describing these assumptions and the sensitivities accounts for the length of the paper. We describe in some detail the data which we have used as a starting point and the various trends which we have included in the projections. We also present the results of projections produced using a range of assumptions.

This paper follows an earlier one in the UK actuarial literature by Nuttall et al (1994). That paper covered more ground than this one, in particular the financial implications of future demand for long-term care were considered. There are, naturally, some important similarities between the model which we use for the projection of the number of disabled people and the model which Nuttall et al used. There are, though, some key differences as well and we have added considerably to the complexity of the earlier model. Just as important as the new developments in modelling is the existence of new data. The most important new data to be published since Nuttall et al (1994) relates to trends in healthy life expectancy. We discuss this data in detail in section 2.3 and again in Part II, section 4.

The model that we describe in this paper relates to the number of people with disabilities. We do not go into any detail on the associated provision of care services and the cost of these services. Much work has been done in the area of the cost of care. See the review by Darton (1994) for a discussion of the levels of dependency of people in residential care and nursing homes. See Bone (1995) for figures showing how the utilisation of care services (meals on wheels and so on) depends on levels of disability. The costs of providing care services have been compiled by Netten & Dennett (1997) and have been incorporated within the model described by Wittenberg et al (1998).

There are important financial implications of the split between formal and informal care. This topic is discussed by Nuttall et al (1994) who estimate that the bulk of care provision is informal, i.e. it is carried out by family, friends and neighbours of the disabled people rather than by care professionals. Green (1985) has analysed who it is that provides informal care and Glendinning (1992) discusses some of the implications for the carers. The model used by Wittenberg et al (1998) treats informal care as a function of both the level of disability of an elderly person and whether or not the elderly person lives with other people. The provision of informal care in the future will depend on such statistics as the proportion of the elderly population that is married and how far the children of elderly disabled people live from their parents' home.

Part I describes the data that feed into our model. We highlight the data which are particularly important to the projected number of disabled people and the main areas of uncertainty relating to the data.

We need data for three parts of the model:

- Prevalence rate data are needed as a starting point for the model. The data must show what proportion of people at each age have disabilities now.
- Transition rate data are needed so that we can follow the current population forward. Transitions include, for example, a healthy person becoming disabled and a moderately disabled person becoming severely disabled. There is not much published data that can help us to set the transition rates used in the model.
- Trends data are needed to indicate how transition rates change over time. For example, are people becoming more or less likely to become disabled at a particular age? There is some information which can be used indirectly to answer this sort of question.

Part II contains a description of the model and discusses the way in which trends in healthy life expectancy can be used to determine the trends in transition rates which should be incorporated in the model.

In Part III we discuss the results from the projection model for nine sets of assumptions. We also describe the many uncertainties that surround the projection and attempt to indicate to what degree these uncertainties might influence the projections. In addition, we include examples of projections using an entirely different method to the transition rate model considered in the earlier parts. The reason for including this is to demonstrate that the key element determining the output of the projection is not the complexity of the transition rate model but is related to the constraints imposed by the trends data.

2. DATA SOURCES

2.1 *Prevalence rate data*

The starting point for a model that projects the number of people requiring long-term care in the future is a set of data that shows how many people require long-term care now. There is no completely satisfactory set of data for the UK but there have been a number of disability surveys which are useful.

The data from the surveys are generally presented in terms of the proportion of males and females in a range of age bands who are unable to perform one or more specified activities. The surveys differ from each other in many aspects: the number of people surveyed; the date of survey; the activities which are used to categorise disability; the survey method, such as the use of interviews or questionnaires; and whether the target population includes people in households or institutions or both.

As mentioned in the introduction, the inability to perform some task is not the same as the need for long-term care. There is information which does relate directly to the provision of care. Some of the surveys which we discuss in this section contain information on the links between disabilities and care needs (Bone, 1995 and Matthews & Truscott, 1990).

It is essential to recognise that the estimates of the number of people with disabilities in the future that are produced by any projection model will be directly related to the current level of disability rates. This means that the usefulness and accuracy of any projected numbers will inevitably be limited by any problems relating to the initial data. We describe in some detail the data which we use and discuss the limitations associated with them.

Although there have been several disability surveys, we have used one to provide the initial data for the number of people with disabilities. This survey is the OPCS survey of disability in Great Britain (Martin et al, 1988). The reasons for relying on this particular survey are:

- The coverage included both private households and communal establishments;
- The survey was based on interviews rather than responses to a questionnaire;
- The sample was large;
- A wide range of disabilities was covered;

- The survey covers all adults whereas some surveys cover only people over 65 and therefore miss a significant number of disabled people;
- The survey report presents the data in a useful form involving several disability categories and age groups.

This survey was conducted as follows. For private households, a sample of 100,000 addresses was chosen for screening. A short questionnaire was either posted to these addresses or taken along by an interviewer. Questionnaires which indicated that there was a disabled person at the address led to a full interview. 14,308 adults were interviewed. The screening and interviewing took place in 1985.

For the survey of disabled people in communal establishments, 1,408 institutions were contacted. This resulted in a sample of 570 institutions in which interviewing took place. 3,775 adults were interviewed. The screening and interviewing took place in 1986.

The report on the survey allocates disabled people into one of ten categories with category 1 being the least severe and category 10 being the most severe. The category definitions are rather complicated. The process used to assign a category was as follows:

- People were asked questions about 13 different abilities: locomotion; reaching and stretching; dexterity; personal care; continence; seeing; hearing; communication; behaviour; intellectual functioning; consciousness; eating, drinking and digestion; and disfigurement.
- People were graded for each of these functions. Most of the functions were split into about ten grades although the final two functions had only one grade each (in addition to a grade 0 for no disablement).
- A common severity scale was designed. The grades from each of the functions were converted to this scale.
- An overall figure was found by adding the worst score from any of the thirteen categories to 0.4 × the second worst score plus 0.3 × the third worst.
- This overall score was then grouped into ten bands.

It should be noted that only long-term disabilities were counted, not temporary ones.

The following examples were included in the OPCS report. They give an indication of the sorts of disability associated with some of the categories.

- Category 3 — man aged 47 with spinal arthritis. Reaching and stretching: has difficulty putting either hand behind back to put jacket on or tuck shirt in. Locomotion: cannotwalk 200 yards without stopping or severe discomfort; can only walk up or down a flight of 12 stairs if holds on (doesn't need a rest). Personal care: has difficulty getting in and out of bed. Hearing: has difficulty following a conversation against background noise.
- Category 5 — woman aged 75 with phlebitis. Continence: loses control of bladder at least once every 24 hours. Locomotion: cannot walk 50 yards without stopping or severe discomfort; can only walk up and down a flight of 12 stairs if holds on (doesn't need a rest).

- Category 7 — man aged 79 who has had a stroke. Locomotion: has fallen 12 or more times in the last year; cannot walk 50 yards without stopping or severe discomfort; can only walk up and down a flight of 12 stairs if holds on and takes a rest. Dexterity: has difficulty picking up and pouring from a full kettle; has difficulty using a pen or pencil. Continence: loses control of bowels at least twice a month; loses control of bladder occasionally.
- Category 9 — man aged 79 with arthritis of the spine and deafness. Communication: finds it impossible to understand people who know him well. Personal care: cannot get in and out of bed without help. Hearing: cannot follow a TV programme with the volume turned up; has difficulty hearing someone talking in a loud voice in a quiet room; cannot use the telephone. Continence: loses control of bladder at least once every 24 hours. Dexterity: has difficulty serving food from a pan using a spoon or ladle; has difficulty unscrewing the lid of a coffee jar. Locomotion: cannot bend down far enough to touch knees and straighten up again; can only walk up and down a flight of 12 stairs if holds on and takes a rest. Seeing: has difficulty seeing to read ordinary newspaper print.

The categorisation process was developed to handle the data collected from the survey interviews. There have been a few subsequent surveys which have used the same disability scale. However, most surveys do not use the same procedures and definitions and the results from these cannot be compared directly with this large disability survey.

The following pair of tables show the estimated number of disabled adults in Great Britain. These tables are taken from Appendix 5 of Dullaway & Elliott (1998). The numbers are based on the OPCS survey but the original report did not show males and females separately.

Table 1a. OPCS Estimates of the number of disabled females (thousands)

		OPCS Disability Category									
Age	Able	1	2	3	4	5	6	7	8	9	10
20–29	4,102	21	13	14	21	18	18	11	10	8	6
30–39	3,660	36	15	23	27	24	18	15	12	7	4
40–49	2,958	50	28	27	34	30	25	20	15	9	3
50–59	2,604	87	54	57	55	55	36	28	22	19	5
60–69	2,266	138	111	94	86	90	55	49	34	37	11
70–79	1,427	161	151	132	116	122	112	86	66	57	34
80+	364	86	72	80	79	106	96	111	84	100	79

Source: Dullaway & Elliott (1998)

Table 1b. OPCS Estimates of the number of disabled males (thousands)

		OPCS Disability Category									
Age	Able	1	2	3	4	5	6	7	8	9	10
20–29	4,235	24	15	14	16	13	13	9	8	5	7
30–39	3,717	42	16	22	20	18	13	11	10	4	5
40–49	3,015	57	30	25	25	21	18	15	11	6	4
50–59	2,577	100	58	53	41	40	25	21	18	12	6
60–69	1,956	173	116	81	69	58	32	32	30	27	11
70–79	1,020	152	117	86	71	60	46	38	38	29	13
80+	137	55	39	37	38	41	29	34	33	38	18

Source: Dullaway & Elliott (1998)

It is helpful to present the same information as prevalence rates per 1,000 of population at each age (i.e. the proportion of males or females of a particular age who have each level of disability, scaled so that the proportions at each age add to 1,000). The following pair of tables presents the information in this form.

Table 2a. OPCS Disability prevalence rates for females (per 1,000)

		OPCS Disability Category									
Age	Able	1	2	3	4	5	6	7	8	9	10
20–29	967.0	5.0	3.1	3.3	5.0	4.2	4.2	2.6	2.4	1.9	1.4
30–39	952.9	9.4	3.9	6.0	7.0	6.2	4.7	3.9	3.1	1.8	1.0
40–49	924.7	15.6	8.8	8.4	10.6	9.4	7.8	6.3	4.7	2.8	0.9
50–59	861.7	28.8	17.9	18.9	18.2	18.2	11.9	9.3	7.3	6.3	1.7
60–69	762.7	46.4	37.4	31.6	28.9	30.3	18.5	16.5	11.4	12.5	3.7
70–79	579.1	65.3	61.3	53.6	47.1	49.5	45.5	34.9	26.8	23.1	13.8
80+	289.6	68.4	57.3	63.6	62.8	84.3	76.4	88.3	66.8	79.6	62.8

Table 2b. OPCS Disability prevalence rates for males (per 1,000)

		OPCS Disability Category									
Age	Able	1	2	3	4	5	6	7	8	9	10
20–29	971.6	5.5	3.4	3.2	3.7	3.0	3.0	2.1	1.8	1.1	1.6
30–39	958.5	10.8	4.1	5.7	5.2	4.6	3.4	2.8	2.6	1.0	1.3
40–49	934.3	17.7	9.3	7.7	7.7	6.5	5.6	4.6	3.4	1.9	1.2
50–59	873.3	33.9	19.7	18.0	13.9	13.6	8.5	7.1	6.1	4.1	2.0
60–69	756.7	66.9	44.9	31.3	26.7	22.4	12.4	12.4	11.6	10.4	4.3
70–79	610.8	91.0	70.1	51.5	42.5	35.9	27.5	22.8	22.8	17.4	7.8
80+	274.5	110.2	78.2	74.1	76.2	82.2	58.1	68.1	66.1	76.2	36.1

Tables 1 and 2 display the following features:

- The prevalence rates of disability generally increase with age.
- The main exception to this rule is for the most severe categories, 9 and 10, where the prevalence decreases for people in their thirties and, for category 10 only, in their forties.
- The increase in the prevalence rate of category 10 disability is rapid. For females the rate doubles between ages in the forties and the fifties and again between the fifties and the sixties. For higher ages the increase is even more rapid. The increases for males are also large but not quite so rapid except between the two highest age groups.
- The number of disabled females is greatest in the 70–79 age band for categories 1 to 6 and in the 80+ age group for the more severely disabled categories. For males the numbers are greatest at ages 60–69 for category 1, ages 70–79 for categories 3 to 8 and age 80+ for categories 9 and 10.
- Although the prevalence rates and absolute numbers both are highest for people over 60 there is a significant number of disabled adults aged under 60.
- The number of disabled females is higher than the number of disabled males.
- At most ages, the proportion of females who are disabled is also higher than the proportion of males who are disabled. However, males in their sixties and those over eighty are less likely to be healthy than are females at the same ages.
- The average severity of disability amongst disabled females is higher than it is amongst disabled males.
- Since females live longer, on average, there are many more disabled females at high ages than disabled males.

Other aspects emerging from the survey, which are not captured in the preceding tables, include the following:

- The most common disabilities found were related to locomotion, hearing and personal care.
- According to Dullaway & Elliott (1998, page 37) categories 7–10 correspond roughly to the severity of disability needed to trigger long-term care insurance claims.
- According to table 3.3 of Martin et al (1988) there were 5,780,000 disabled adults in private households and 422,000 in communal establishments. At low levels of disability almost everyone is in a private household (1,186,000 in households, 13,000 in institutions in category 1). There is also a very substantial majority amongst people with category 9 disabilities who live in households (285,000 in households compared with 80,000 in establishments). The situation is reversed, but only marginally, for the worst category (102,000 in private households and 108,000 in communal establishments with category 10 disabilities).

Since any projections of the number of people needing long-term care in the future are heavily dependent on the initial data, it is worth considering the key aspects of the OPCS survey data which might cause problems.

All people aged over 80 are put into a single age category. This may be quite a serious problem. Tables 1 and 2 show how rapidly numbers and prevalence rates change with age and it is very likely that rates which apply to people in their early eighties do not apply to people over 90. The number of people who survive to ages well in excess of 80 is expected to grow rapidly over the next few decades, hence it is very important to have some knowledge of the prevalence of disability amongst the most elderly people. The costs of caring for disabled people at these ages may be very high.

The extent of this problem depends on what the prevalence rates are used for. If the only use of the rates were as a starting point for projections, there would be no problem. In projections to, say, 2020 the people who will be aged 90 or more would have been in their 50s and 60s when the OPCS survey was carried out and it is irrelevant that there is some uncertainty about disability amongst the elderly in the mid 1980s. However, in our projections, transition rates are used and we need, for example, some estimate of the probability that a non-disabled 85 year old female will become disabled in the next year. We will choose this probability, along with a great many others, to be compatible with the prevalence rate data. This means that the prevalence rates of disability in the OPCS survey do feed through into the projected prevalence rates in the future.

The information collected in the survey is sufficient to allow prevalence rates to be calculated for narrower age bands. As far as we know, this information has not been published. There is one graph in Martin et al (1988, Figure 3.3) which does show some information broken down into five year age bands. We make some comments on this in Part III.

Other limitations of the OPCS disability survey prevalence rates include:

- The OPCS disability definitions are not directly linked to cost.
- The process of assigning a disability category is complex and hence errors or peculiarities may have crept in.
- Despite the large sample size, if the data are split into the two sexes, seven age groups and eleven disability categories (including “able”) there will be some degree of random errors.
- The survey was carried out in 1985 and 1986 and is therefore out of date. We deal with this point in our models by starting all projections in 1986 rather than starting from the present.

Although the disability definitions are not directly linked to care costs, there is some information which shows how much additional expenditure is incurred by disabled people in private households and where the same definitions of disability are used as in the OPCS survey (Matthews & Truscott, 1990). Also, the report on the survey (Martin et al, 1988) does show the proportion of people in each disability category and at each age who were in institutions at the time of the survey. For the people in the more severe categories, it is reasonable to assume most of the institutions were providing care. This, therefore, gives a useful indicator of how care utilisation relates (or, more accurately, related at the survey date) to disability.

There have been other large surveys which cover disability. We have not used the data from these surveys. In the remainder of this section we comment on these surveys and, where possible, compare their findings with those of the OPCS disability survey.

The General Household Survey (GHS) is carried out annually (see, for example, Thomas et al, 1998). The survey has a large sample size (22,001 in 1996, for example). It includes two questions about disability:

1. *Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time or that is likely to affect you over a period of time.*
2. *Does this illness or disability limit your activities in any way?*

The answers to the second of these questions should provide useful information about the level of disability in the population. It is also potentially useful that the survey is carried out every year. We return to this point in section 2.3, when discussing trends.

The survey is confined to households so that there are bound to be differences compared with the OPCS survey which included people in communal establishments. However, there are also very clear differences between the number of people disabled according to the second GHS question given above and the number of people in private households who have any disability according to the OPCS survey. Martin et al (1988) show these differences in their figure 3.4 and table 3.5. Both of these compare the prevalence rates per thousand of population at various ages for GHS survey of 1985 and the OPCS disability survey. The GHS shows substantially more disabled people below the age of 75 and substantially fewer over the age of 75.

The differences below age 75 are explained by Martin et al (1988) as being due to the GHS question allowing any disability to count while the interview based OPCS survey questions related to specific tasks or functions. The suggested reason for the difference amongst people over 75 is that these people may not see themselves as disabled. Any limitations which they have may be thought of as due to old age rather than disability.

As well as the questions contained each year in the General Household Survey, there are supplementary questions which are repeated every few years. One of the areas in which there are a large number of supplementary questions is the health of people over 65. As a result there is much more information available on the abilities of the elderly in the surveys of 1980, 1985, 1991, 1994 and 1996. The availability of this information is very important in showing changes over time. These GHS surveys provide the key data discussed in section 2.3 concerning trends.

People are asked about a variety of tasks such as climbing stairs, dressing, shopping and using a vacuum cleaner. The data are summarised in the form of the proportion of men and women in each of five age groups who have difficulty with each task. The proportions are given separately for each task.

An established way of categorising disabilities is to measure the ability of people to perform certain tasks known as activities of daily living (ADLs). There are a few different definitions in use, but six usual ADLs are bathing, dressing, going to the toilet, transferring (to and from a bed or chair), continence and feeding. The order given here is a typical order in which the activities are failed (see Bone, 1995). Thus, the first task which people become unable to do is bathing and the one failed by fewest people is feeding.

Some research work has been done which enables some comparison between the OPCS disability categories and the ADL based categories which are measured by the GHS. Bone (1995, chapter 3) has defined a disability scale based on ADLs and has reported on the disability prevalence rates shown by the people responding to the GHS surveys.

The GHS surveys have regularly covered only four of the six usual ADLs: feeding, transferring to or from bed, going to the toilet and bathing. The surveys also cover some instrumental activities of daily living (IADLs), specifically shopping, cooking, house cleaning, laundry and travel. The disability scale reflects failure in IADLs and ADLs as shown in the following table.

Table 3. The dependency scale used by Bone (1995) for analysing GHS data

Dependency	Level	Definition
Independent	1	Manages all ADLs and IADLs without help
Least dependent	2	Cannot manage one or more IADL alone but can manage ADLs
	3	Cannot manage one ADL alone and cannot manage one or more IADL
	4	Cannot manage two ADLs alone and cannot manage one or more IADL
	5	Cannot manage three ADLs alone and cannot manage one or more IADL
Most dependent	6	Cannot manage four ADLs alone and cannot manage one or more IADL

Source: Bone (1995)

With these definitions the following levels of dependency were found in the 1985 GHS survey (i.e. the one closest to the date of the OPCS disability survey). These figures refer only to people in households and they are combined values for males and females.

Table 4. Disability prevalence rates (%) according to the 1985 GHS survey

Age	Category				
	2–6	3–6	4–6	5–6	6
65–69	13	3	1	1	0
70–74	18	4	1	0	0
75–79	30	9	3	1	0
80–84	49	15	2	0	0
85+	77	31	9	5	1

Source: 1985 GHS Survey

The prevalence of disability amongst people in private households according to the OPCS survey, using the OPCS disability categories, is given in Table 5.

Table 5. Disability prevalence rates (%) according to the OPCS disability survey
(In private households only)

Age	Category									
	1–10	2–10	3–10	4–10	5–10	6–10	7–10	8–10	9–10	10
60–69	23.6	18.0	13.9	10.8	8.0	5.3	3.8	2.4	1.3	0.3
70–79	39.5	31.8	25.3	20.0	15.5	11.1	7.4	4.6	2.3	0.6
80+	67.4	58.4	51.6	44.5	37.7	29.1	22.2	14.2	8.5	2.5

Source: Martin et al (1988)

A comparison of Table 4 with Table 5 suggests, very roughly, that failing an IADL (Bone's category 2) corresponds with OPCS category 3 in terms of the cumulative prevalence rates. Also, the failure of an ADL (Bone's category 3) appears to correspond, roughly, to OPCS category 7. This is, however, quite misleading. As the examples given earlier indicate, a category 7 disability on the OPCS scale is very severe and would be equivalent to the failure of more than one ADL. The reason why there are so many people in the high OPCS disability categories compared with the high GHS disability categories might be that the OPCS definition of disability covers some elements not measured by ADLs.

Another difference between the two sets of data is that the OPCS survey covered Great Britain whereas the figures analysed by Bone (1995) are for England only.

The fact that the OPCS disability scale is difficult to mesh with an ADL based scale has meant that we have relied solely on the OPCS survey results for providing prevalence rate data. However, we have had to rely on GHS surveys to provide information on trends. This is clearly not an ideal situation.

There have been three surveys subsequent to the OPCS disability survey which have used the disability scale developed for that original report. The first of these has been reported on by Matthews & Truscott (1990). This survey covered disabled adults who had responded to the Family Expenditure Survey (FES) of 1986/87 (this relates to people in private households only). In table 2.2 of their report, Matthews & Truscott show that they found lower prevalence rates of disability than had been found in the OPCS disability survey. The differences are most pronounced for severe disability categories. For example the OPCS survey found 17 adults per 1,000 were in disability category 8, 9 or 10, whereas the FES follow-up survey found just 9 per 1,000. However, rather than regarding this as an indication of any changes in the health of the population, the authors take this as evidence of the impact of different sampling techniques.

Secondly, there was a Retirement Survey in 1988/89 which shows a higher prevalence of disability at the lower end of the scale than was found in the OPCS disability survey. Craig and Greenslade (1998) comment that this difference might be due to lack of screening for the Retirement Survey (see Bone et al, 1994).

Thirdly, Craig & Greenslade (1998) report on a disability survey, following up the family resources survey. The main aims of the survey were related to social security benefits but disability prevalence rates, on the OPCS disability survey scale, were found as a by-product. The results are very different from the original OPCS disability survey. Craig & Greenslade (1998) find substantially more disabled adults in private households than Martin et al (1988) did, except in the highest disability category. They find that the prevalence of disability for people in private households (all categories combined) is higher at all ages in 1996/97 than it had been in 1985. The rates for ages up to 75 are actually closer similar to those found in the General Household Survey in response to the limiting long standing illness question than they are to the OPCS survey. Above age 75 the new survey described by Craig & Greenslade (1998) shows higher prevalence rates than either the OPCS survey or any GHS survey. Craig & Greenslade (1998) discuss several possible causes for the differences in the survey results but they do not come to any firm conclusions. One possibility not discussed is that the prevalence of disability amongst people of each age has actually become worse over the decade since the original survey.

As well as the surveys that measure the prevalence of disability of people living in private households, there have been several reports on the levels of disability shown by people in residential and nursing home care. For example, Netten et al (1997) have looked at a wide cross-section of these homes and found the level of disability of people in various types of home (table 3.7 of Netten et al, 1997). They have also looked at the type of care, such as dressing, injections and feeding, which are provided in the homes (Netten et al, 1997 table 3.9). The characteristics of the residents and patients in residential and nursing homes have also been presented by Darton (1994) in a review of earlier surveys.

Together with data on the number of places available nationally in residential and nursing homes (given by, for example, Department of Health and Social Security, 1996), this information could be used to provide an estimate of the number of people at various levels of disability in communal establishments. If these estimates were further combined with GHS data on disabilities of people in private households, the whole population could be covered. The results should be more up-to-date than the OPCS survey of 1985/86 (Martin et al, 1988).

We have not gone through this exercise because of the requirement to define a common disability scale for the institutional and household data.

Another source of disability prevalence data in the UK is the Census. The 1991 Census (Office of Population Censuses and Surveys, 1993) included a question on limiting long standing illness similar to the one asked in the general household surveys. The Census shows the number of males and females at each age who are in households and the number who are in communal establishments. The number who answered that they did have a limiting long standing health problem is also given. The data on the communal population is further divided into NHS hospitals, non-NHS hospitals, Local Authority homes and so on. This is obviously the largest UK data source available but its usefulness is limited by the fact that only one level of disability was measured.

There is a lack of useful data on transition rates in the UK and because there are some transition rate data in the US it would be advantageous to be able to use it. In order to be confident that the US data might be applicable in the UK it is necessary to make a comparison where there is some overlap (i.e. in respect of prevalence rates). In Table 4 we showed some data for England which was based on the General Household Survey. The table gives the percentage of people in private households who fall into various disability categories based on ADLs. In the US, the National Aging Information Center (1996; NAIC) has analysed data from the National Long-Term Care Survey. The following table is part of table 2-1 from NAIC report. Their table 2-1 is for people in the community, i.e. not in institutions, so it should be comparable to the General Household Survey results.

Table 6. Community residents in the US with ADL limitations lasting 3 months or longer

Age	Number of ADL Limitations		
	0	1–2	3–6
65–74	93.0%	3.8%	3.1%
75–84	83.1%	9.2%	7.7%
85+	59.6%	18.4%	22.0%

Source: NAIC (1996)

Comparison of Tables 4 and 6 shows a higher prevalence of failing at least 1 ADL in the American data set than in the English one. (The numbers in the "3–6" category of Table 4 are lower than the sum of the numbers in the "1–2" and "3–6" categories in Table 6.). The same situation holds for 3 ADLs. Note that in the category definitions given for Table 4 there are 2 ADLs missing: continence and dressing. It is generally the case that dressing is the second of the 6 ADLs to be failed and continence is the fifth. Therefore, comparisons of 1 ADL failure should not be misleading and 3 ADLs failed should correspond roughly to category 4 on the scale defined in Table 3. (The numbers in the "4–6" category in Table 4 are lower than those in the "3–6" category of Table 6.)

This shows that US data are very different from English data. This might be due to: different policies as to who receives care in the community and who goes into an institution to receive care, different surveying methods, different definitions of ADL failure or populations with different levels of disability. Whichever is the case, it provides a warning regarding the use of overseas data.

2.2 *Transition rate data*

In order to project forward the number of people with disabilities we use a transition rate model. This model requires assumptions for the likelihood of various transitions occurring. The sort of transitions we are interested in include:

- A healthy person becoming moderately disabled
- A healthy person becoming severely disabled
- A healthy person dying
- A moderately disabled person becoming severely disabled
- A moderately disabled person recovering from their disability and becoming healthy
- A moderately disabled person dying

In practice, we do not limit ourselves to two categories of disability, moderate and severe, but use all ten of the OPCS categories.

We require estimates of the probabilities of these transitions occurring. The probabilities are likely to depend on age and sex. Many probabilities will also depend on which particular disability category or categories is involved. The probabilities may well change over time and we will need trend data to model this (see section 2.3).

There are a great number of transitions in which we are potentially interested but unfortunately there is very little UK information that we can use to estimate the transition rates. There has been no large scale longitudinal survey which tracks a population at frequent intervals over a number of years and records information on disabilities. We have the choice of using small scale UK longitudinal data sets, larger US longitudinal data sets or not using any longitudinal data at all.

One of the local UK longitudinal surveys is of a population in Melton Mowbray, Leicestershire. A sample of people aged 75 and over were first interviewed in 1981. Of these, 1,124 were living in the community and 79 in institutions. The survivors were interviewed again five years later.

The people were scored on a physical disability scale based on ADLs. The definition of the scale is $1 \times CHAIR + 1 \times BED + 0.5 \times MOBILITY + 0.25 \times TOILET$ where each of CHAIR, BED, MOBILITY and TOILET is scored on a 0-3 integral scale depending on the level of disability. For example, *CHAIR* is 0 for someone who is able to get in and out of a chair independently, 1 for someone who needs an appliance or help to do so, 2 for someone who needs both help and an appliance to do so and 3 for someone who cannot get in and out of a chair (Jagger et al 1986).

The mortality rates over the five year period have been analysed by Jagger & Clarke (1988) to find how they were affected by the level of disability. In total 451 of the survey population had died (about 37%). Table 7 shows results from Jagger & Clarke (1988, table 1). The mortality rate for people without disability has been scaled to 100 and the mortality of disabled people has been compared with this. The rates have been standardised for age and sex.

Table 7. Relative risk of death

Physical Disability	Relative Risk	95% Confidence Interval
None	100	
Mild	135	102 – 179
Moderate	196	143 – 268
Severe	287	222 – 372

Source: Jagger & Clarke (1988)

This shows that mortality rates are very sensitive to the degree of disability. The rates increase along the disability scale, with the severely disabled having a relative mortality risk of 2.87 times that for those with no physical disabilities.

Note that these rates refer to a five year period. For the purposes of our model, we are most interested in probabilities over a period of a single year. This difference could be important. For example, suppose that there was no difference in mortality between people with no physical disability and people with mild disability: i.e. the survival rate of both sets of people were equal for the next year. Suppose also that people with mild disabilities were more likely to become moderately or severely disabled over the next year than people with no disability (this is quite plausible). This means that if the population is looked at again a few years later, many of the people who originally had mild disabilities may have died. This would not be because mild disabilities are life threatening but because mild disabilities, over time, may lead to worse disabilities which are life threatening. Longitudinal data with such large time gaps must, therefore, be used with a degree of caution.

Jagger et al (1993) have also reported on the change in abilities of this elderly population over the same five year period. Table 8 is taken from Jagger et al (1993, table IV). It shows the status five years later of people who were independent, dependent or institutionalised at the date of the first interview. The abbreviations "Indep", "Dep" and "Inst" are used for "Independent", "Dependent" and "Institutionalised". The age referred to is the age at first interview.

Table 8. Transitional probabilities

Sex and age	Initial status	Status after 5 years				Sample size
		Indep	Dep	Inst	Dead	
M: 75–79	Indep	*56%*	8%	3%	34%	158
	Dep	36%	*14%*	6%	44%	66
	Inst	0%	0%	*20%*	80%	5
M: 80+	Indep	*38%*	3%	1%	58%	72
	Dep	9%	*9%*	4%	79%	47
	Inst	0%	0%	*0%*	100%	7
F: 75–79	Indep	*62%*	9%	1%	28%	246
	Dep	31%	*17%*	6%	47%	101
	Inst	0%	0%	*0%*	100%	9
F: 80+	Indep	*44%*	13%	7%	36%	150
	Dep	14%	*18%*	6%	62%	182
	Inst	0%	0%	*21%*	79%	58

Source: Jagger et al (1993)

This table shows:

- Death is the main transition.
- The death rate is higher amongst dependent people than independent people.
- The death rate is much higher for the institutionalised population.
- Improvements are quite frequent amongst dependent people. For males and for females under 80 the majority of dependent people who do not die improved over the five year period.
- Amongst the survivors, people who had been dependent were more likely to end the period in an institution than the people who had been independent.

Another longitudinal study has been carried out in Nottingham. This started with 1,042 people aged 65 and over and living in the community. First interviews were carried out in 1985 and there were follow-up interviews four years later. (See Bone et al (1995) for further information.)

There have been a number of surveys that focus on the progress of an institutionalised population (for example, Donaldson & Jagger, 1983 and Darton & Brown, 1997). These examine the changes in disability from one assessment date to the next. For example, Donaldson & Jagger (1983) find that the only 54% of bedfast patients were alive a year after the first assessment date compared with 87% of those who had been fully ambulant. Similarly, 46% of those who needed spoon feeding survived compared with 81% who could feed unsupervised. These figures have not been standardised for age, sex or duration of stay.

There has been a pilot study to assess the feasibility of using the GHS as the basis for a longitudinal survey of health of the elderly (Goddard, 1998). About 1000 people who had been questioned in the 1994 GHS were asked 2½ years later about their health. Table 9 relates to the limiting long standing illness question. The figures are for people who had a limiting long standing illness in 1994 and who were included in the follow-up survey.

Table 9. Health of people who had a limiting long standing illness 2½ years earlier

	No Long Standing Illness	A Non-Limiting Long Standing Illness	Limiting Long Standing Illness
Males	8%	18%	73%
Females	11%	9%	80%

Source: Goddard (1998)

This shows that improvements are quite common. Over 20% of people with a limiting long standing illness in 1994 had improved over the period.

Transition rates between various levels of disability have been analysed in the US. A report by the Society of Actuaries Long-Term Care Valuation Insurance Methods Task Force (1995) considers data from the National Long-Term Care Surveys of 1982 and 1984. The surveys cover Medicare enrolees in the community and institutions. In table 5 of that report, the number of people who have transferred between each of several disability states is given. Table 10 is based on that data. Transition rates have been found and just divided by two to give approximate annual transition probabilities. The numbers in italics are the probabilities of not changing category. These are calculated as 100% minus the sum of the probabilities of moving out of the category.

Table 10. US transition rates (% per year)

	Age	Initial status	Status after 2 years				
			0 ADL	1 ADL	2 ADL	3+ ADL	DEAD
Males	65–74	0 ADL	*94.23*	0.45	0.27	0.48	4.57
		1 ADL	17.60	*59.60*	5.20	3.60	14.00
		2 ADL	9.80	9.80	*56.86*	5.88	17.65
		3+ ADL	5.97	1.49	4.48	*66.42*	21.64
	75–84	0 ADL	*89.50*	1.21	0.47	0.92	7.89
		1 ADL	10.98	*54.55*	4.92	5.30	24.24
		2 ADL	5.88	3.92	*56.86*	9.80	23.53
		3+ ADL	3.17	1.59	3.17	*66.67*	25.40
	85+	0 ADL	*81.38*	2.28	1.46	1.79	13.09
		1 ADL	7.14	*59.52*	2.38	10.32	20.63
		2 ADL	0.00	6.25	*54.17*	10.42	29.17
		3+ ADL	2.63	0.00	13.16	*57.89*	26.32
Females	65–74	0 ADL	*96.62*	0.67	0.19	0.30	2.21
		1 ADL	19.06	*62.81*	4.69	4.69	8.75
		2 ADL	10.94	8.59	*57.03*	13.28	10.16
		3+ ADL	4.49	3.21	3.85	*69.87*	18.59
	75–84	0 ADL	*90.78*	2.21	0.64	0.91	5.46
		1 ADL	16.20	*61.97*	3.05	7.98	10.80
		2 ADL	8.67	5.33	*58.67*	12.00	15.33
		3+ ADL	4.79	2.66	5.85	*70.74*	15.96
	85+	0 ADL	*81.44*	4.77	1.58	2.37	9.84
		1 ADL	10.49	*62.94*	3.50	7.69	15.38
		2 ADL	5.00	6.67	*57.50*	9.17	21.67
		3+ ADL	4.12	2.94	2.94	*64.71*	25.29

Source: Society of Actuaries Long-Term Care Valuation Insurance Methods Task Force (1995)

The dependence of death on disability shows the following features:

- The mortality rate increases with the level of disability.
- At the higher ages there does not appear to be much difference in the mortality rate between people failing 2 ADLs and people failing 3 or more ADLs.
- The ratio of mortality rates for those failing 3 or more ADLs to those failing no ADLs falls with age.
- The differences between the mortality rates of those failing 3 or more ADLs and those failing no ADLs are 17.1%, 17.5% and 13.2% for males (starting with the lowest age group) and 16.4%, 10.5% and 15.5% for females. Very roughly, this is consistent with a constant addition of 0.15 to the mortality rate each year, independent of age and sex.
- For females the difference in mortality rate between those failing 1 ADL and those failing none appears to be independent of age: it is 6.5%, 5.3% and 5.5% for the three age groups.

The factor of three difference shown in Table 7 for the mortality of severely disabled people aged over 75 compared with people showing no physical disability is compatible with the US data for males and females age 75 to 84. The extreme mortality found by Donaldson & Jagger (1983) for people who were bedfast or who needed spoon feeding is much higher than for any of the categories in Table 10.

The following features relating to deterioration in ability are shown in Table 10:

- Deterioration is less frequent than death.
- People who fail no ADLs are less likely to fall into the 2 ADL category than those who already fail 1 ADL. This applies to all ages and both sexes.
- People who fail no ADLs are less likely to fall into the 3+ ADL category than those who already fail 1 ADL, and they in turn are less likely to fall into the 3+ ADL category than those who already fail 2 ADLs. This applies to all ages and both sexes.
- Deterioration from no ADL failure increases with age.
- For males, deterioration from 1 ADL failure to 2 ADL failure decreases with age while the deterioration from 1 ADL failure to 3+ ADL failure increases with age.

The following features relating to improvements in ability are shown in Table 10:

- Improvements from 1 ADL are more frequent than deaths for males aged 65 to 74 and females aged 65 to 84.
- Improvements rates to 0 ADLs are higher for people who had failed 1 ADL than people who had failed 2 ADLs and, generally, are higher for those failing 2 ADLs than for those failing 3+ ADLs.
- Most improvement probabilities decrease with age but there are some exceptions to this.
- Some improvements are very great, i.e. those from failing 3+ ADLs to failing none.

The existence of a significant number of improvements is consistent with UK population data.

As well as using the information on transitions which we have described in this section, it is possible to use prevalence rate data to determine transition rates. Under a given set of assumptions it is possible to derive transition rates from prevalence rate data. This is, in fact, the approach we have adopted. The approach is described in detail in Part II. Some of the "shape" of the transition rate model is determined by the data in this section. An example of this is the requirement that the probability of a moderately disabled person becoming severely disabled should be higher than the probability of a non-disabled person becoming severely disabled in the next year. This "rule" is inferred from the US data, but in our model we include a parameter which describes just how great the difference is. The value for this parameter is determined by looking at UK prevalence rate data.

2.3 *Trends data*

We can use prevalence rate data as a starting point for our projections of the number of people requiring long-term care and we can use the transition rate model to move this population forward. However, there are likely to be changes in the transition rates over time.

We have looked for evidence of what changes have happened in the recent past to determine what trends should be included in our model.

The trends assumptions we adopt are important because the number of people who are projected to require long term care according to our model is very sensitive to them.

The main type of trend information concerns healthy life expectancy (HLE). Just as life expectancy gives a measure of the time someone may expect to live, healthy life expectancy gives a measure of the time someone expects to live and to be healthy. Like life expectancy, it can be determined by a snapshot of the population rather than actually involving any forecasting. We will be considering this type of HLE. We will also consider disabled life expectancy (DLE) which is a measure of the time someone expects to live whilst in a state of disability.

HLE depends on age and sex. It also depends on the definition of "healthy". If the definition is very narrow, so that many conditions count as unhealthy, HLE will be relatively short. On the other hand, if a wide definition is used, many people will be classed as healthy and HLE will be relatively long, and will tend towards the total life expectancy if very few people are counted as unhealthy.

The data which we discuss relate only to people aged 65 and over. We concentrate on these ages because they are the most important in terms of the number of people needing care.

It is important to note that, because of the way HLE is calculated, the time spent unhealthy depends both on how many people ever become unhealthy and on how long they live once they are unhealthy. This matters most for definitions in which anyone counted as unhealthy is in a severe state. It is quite plausible that improvements in medicine and care act both to prevent people ever reaching this severe state and also to prolong the life of anyone who does reach the state. These two effects work in opposite directions in terms of DLE — the former decreases it and the latter increases it.

Before we discuss the data on trends in HLE we will describe how we can use information on HLE trends. HLE is not an input for our projection model but it may be derived from the populations produced by the model. For a given set of input assumptions, including trends in, say, the probability that someone becomes severely disabled, we can examine how HLE changes over time. By adjusting the input trends, we can find a set which is compatible with the externally available HLE trend data.

The HLE data we use are taken from the booklet *Health Expectancy and Its Uses* (Bone et al, 1995) and the discussion paper *Healthy Life Expectancy in England and Wales: Recent Evidence* (Bebbington & Darton, 1996). The main set of data considered in both of these publications is derived from the General Household Survey. Both publications only consider data for England and Wales. (Some of the data are for 1976 and these are from the Elderly at Home Survey which only covered England.) The two publications are not independent, being based on the same raw data; however, the more recent publication also considers data from a more up-to-date survey.

We will principally be looking at two definitions of "healthy", but will also make some comments on other definitions. We use the phrases "free from any disability" and "disability free" to refer to people who do not have any limiting long-standing illness. We use the phrases "free from severe disability" and "severe-disability free" to refer to people who are unable to perform ADLs.

Although the HLE estimates are derived from GHS data, Bone et al (1995) and Bebbington & Darton (1996) have adjusted the data to allow for the fact that part of the population is not resident in households. Hence the numbers that we show in most of the tables in this section are intended to represent the disabilities of the whole population, including those in institutions. The ways the adjustments are made by Bone et al (1995) and by Bebbington & Darton (1996) are different from each other. We will describe both methods of adjustment later in this section.

The numbers in Table 11 are from table 2 of Bebbington & Darton (1996). They relate to disability free life expectancy. Similar numbers are given in table 6.1 of Bone et al (1995) for 1976 to 1992. The Bebbington & Darton (1996) and Bone et al (1995) values for disability free life expectancy differ by up to 0.3 years.

Table 11a. Life expectancy (years) free of any disability

	Age	1976	1981	1985	1988	1991	1992	1994
Males	65 – 74	7.1	7.9	7.9	7.6	8.0	7.9	8.5
	75+	3.6	4.2	4.4	4.2	4.5	4.3	4.7
Females	65 – 74	8.7	8.6	9.3	8.8	10.1	9.5	9.8
	75+	4.3	4.2	4.7	4.3	5.0	5.0	5.4

Table 11b. Ratio of disability free life expectancy to total life expectancy (%)

	Age	1976	1981	1985	1988	1991	1992	1994
Males	65 – 74	57	60	59	56	56	55	57
	75+	49	54	55	52	51	48	52
Females	65 – 74	52	50	54	50	56	52	53
	75+	43	41	45	40	44	43	46

Source: Bebbington & Darton (1996)

These tables suggest that for both males and females the disability free life expectancy has been increasing and the ratio of disability free life expectancy to total life expectancy has been roughly constant. The 1976 data are from a different source. If this year were excluded, it would be possible to argue that the ratio has been falling slightly for males.

The existence of some large changes between adjoining survey dates is a cause for concern. For example, the increase in healthy life expectancy for the female 65-74 age group between 1988 and 1991 is 1.3 years. This is greater than the change over the period from 1976 to 1994. This suggests that it is not safe to rely on interpretations that hinge on only one survey. If, for some reason, the 1994 survey-based life expectancies for males were anomalous (and the 1976 Survey were discounted as being different from the later ones), then the data would be consistent with a constant disability free life expectancy for males.

As we noted in section 2.1, the number of people with some form of disability according to the GHS is different from the number of people in private households with some disability according to the OPCS disability survey (Martin et al, 1988). This was interpreted by Martin et al (1988) to be due in part to perceptions of what is and is not a disability. If perceptions have been changing over time, any trends appearing in the GHS data may be caused by these changes rather than by any change in the level of disability in the population.

As indicated, there is some uncertainty surrounding the interpretation of the trends in healthy life expectancy based on a catch-all definition of disability. The situation is, however, far more confusing as regards severely disabled life expectancy. Bone et al (1995) examine HLE from the Elderly at Home Survey of 1976 and the GHS surveys of 1980, 1985 and 1991. Three definitions of severe disability are considered.

The trends apparent for the three definitions differ in the following ways:

- The time spent severely disabled appears to have been falling if failure of an ADL is used to identify severe disability.
- The time spent severely disabled appears to have been rising if inability to manage stairs and steps is used to identify severe disability.
- The time spent severely disabled shows an erratic pattern if inability to get out doors is used to identify severe disability.

In addition to the complicated picture emerging from the GHS data, there are further complications introduced if another regional survey is considered. A pair of surveys in Melton Mowbray in 1981 and 1988 shows that there has been an increase in the time spent severely disabled where an ADL based definition of disability is used.

Bebbington & Darton (1996) are able to include the 1994 GHS data in their analysis. However, they do not cover the 1976 or 1991 surveys. The questions asked in these years were different from those asked in the other years (see Appendix A of Bone et al, 1995, for a list of questions). Bebbington & Darton (1996) argue that the difference in the questions makes comparisons between the years unreliable.

The only difference between the Bone et al (1995) calculations for HLE and those used by Bebbington & Darton (1996) appears to be the way that the number of people in institutions was calculated. However, there are considerable differences between the resulting life expectancies in the two years covered in both publications, i.e. 1980 and 1985. In one case (females in 1985, where the ADL definition of disability is used) the difference appears to be due to the use of the wrong data by Bebbington & Darton (1996). It is disappointing that the numbers in the other cases are quite sensitive to the adjustment method used to calculate the number of people in institutions.

We include the key tables from both Bone et al (1995) and Bebbington & Darton (1996) in this section, but we note first how the data were interpreted by those authors. Bone et al (1995) make the following observations (the references are to sections in the Bone et al booklet):

- There is international evidence that the number of years spent severely disabled is staying constant. The data referred to are from USA, France and Japan. This is referred to as a "compression" of morbidity — a decreasing proportion of time is being spent disabled according to the severe definitions. (Section 5.2.)
- The trend shown by the GHS data using the ADL based definition of disability shows a compression of morbidity. (Section 5.2.)
- The compression shown by the data based on the ADL based definition is in contrast to the pattern shown by data based on the other definitions. (Section 6.3.)
- The ADL definition of disability is more stringent than the mobility out of doors definition (i.e. fewer people fail the ADL criterion). Perhaps the improving trend in the time spent severely disabled according to the ADL based definition is a consequence of the health care system targeting the high end of disability. (Section 6.3.)

Bebbington & Darton (1996) repeat several of the comments made by Bone et al (1995). Their interpretation, given in the synopsis of their paper, is: "If these trends continue ... the demand for services for severe disablement may not necessarily increase."

Table 12 is in six parts. All relate to the inability to perform any one of four ADLs. The first three parts (12a, 12b and 12c) are taken from table 6.1 of Bone et al (1995) and the other three parts (12d, 12e and 12f) are taken from table 5A of Bebbington & Darton (1996). The three parts for each of the two sources just show the same data in different ways — the life expectancy free of severe disability, the ratio of this quantity to the total life expectancy and the severely disabled life expectancy. We have not merged the sets of tables (e.g. by combining 12a with 12d and so on) because the figures shown in each paper in the two years that are common (i.e. 1980 and 1985) are quite different from one another.

Table 12a. Life expectancy (years) free of severe disability

	Age	1976	1980	1985	1991
Males	65 – 69	11.0	11.8	12.3	13.6
	70 – 74	8.0	8.9	9.5	10.4
	75 – 79	5.6	6.5	6.9	7.8
	80 – 84	3.9	4.4	5.0	5.6
	85+	2.4	3.0	3.5	3.8
Females	65 – 69	13.0	15.0	15.5	16.9
	70 – 74	9.4	11.4	11.8	13.3
	75 – 79	6.5	8.3	8.6	10.0
	80 – 84	4.1	5.7	5.9	7.3
	85+	2.6	3.6	3.9	4.9

Source: Bone et al (1995)

Table 12b. Ratio of severe-disability free life expectancy to total life expectancy (%)

		1976	1980	1985	1991
Males	65 – 69	88	91	92	95
	70 – 74	83	89	90	93
	75 – 79	76	85	86	91
	80 – 84	69	77	83	87
	85+	58	69	77	80
Females	65 – 69	79	89	89	93
	70 – 74	73	86	86	92
	75 – 79	67	83	82	90
	80 – 84	58	77	75	87
	85+	51	67	70	81

Source: Bone et al (1995)

Table 12c. Severely-disabled life expectancy (years)

		1976	1980	1985	1991
Males	65 – 69	1.5	1.1	1.1	0.7
	70 – 74	1.7	1.1	1.0	0.8
	75 – 79	1.8	1.1	1.1	0.8
	80 – 84	1.7	1.3	1.0	0.9
	85+	1.7	1.3	1.0	1.0
Females	65 – 69	3.5	1.9	1.9	1.2
	70 – 74	3.5	1.9	2.0	1.2
	75 – 79	3.3	1.8	2.0	1.2
	80 – 84	3.0	1.7	1.9	1.1
	85+	2.5	1.7	1.7	1.2

Source: Bone et al (1995)

Table 12d. Life expectancy (years) free of severe disability

	Age	1980	1985	1994
Males	65 – 69	11.6	12.1	13.5
	70 – 74	8.6	9.1	10.3
	75 – 79	6.2	6.5	7.6
	80 – 84	4.1	4.6	5.4
	85+	2.7	3.1	3.8
Females	65 – 69	14.4	14.2	15.6
	70 – 74	10.8	10.5	12.0
	75 – 79	7.7	7.2	8.8
	80 – 84	5.0	4.3	6.1
	85+	2.7	2.2	3.8

Source: Bebbington & Darton (1996)

Table 12e. Ratio of severe-disability free life expectancy to total life expectancy (%)

	Age	1980	1985	1994
Males	65 – 69	90	90	91
	70 – 74	87	88	89
	75 – 79	82	83	85
	80 – 84	72	78	79
	85+	61	69	72
Females	65 – 69	85	82	84
	70 – 74	81	77	80
	75 – 79	76	68	75
	80 – 84	67	55	67
	85+	52	40	58

Source: Bebbington & Darton (1996)

Table 12f. Severely disabled life expectancy (years)

	Age	1980	1985	1994
Males	65 – 69	1.3	1.3	1.4
	70 – 74	1.3	1.2	1.3
	75 – 79	1.4	1.4	1.3
	80 – 84	1.6	1.3	1.5
	85+	1.7	1.4	1.5
Females	65 – 69	2.5	3.1	3.0
	70 – 74	2.5	3.2	2.9
	75 – 79	2.4	3.3	2.9
	80 – 84	2.4	3.5	2.9
	85+	2.6	3.4	2.9

Source: Bebbington & Darton (1996)

Note that Bebbington & Darton (1996) appear to use incorrect values for the GHS data on disabilities for females in 1985. The values they use are higher than those used by Bone et al (1995). If we ignore the figures in Tables 12d, 12e and 12f for females in 1985, the tables suggest the following:

- The severe-disability free life expectancy has been rising for males and females. There are no exceptions to this in Table 12a and none in Table 12d other than those relating to females in 1985.
- The ratio of severe-disability free life expectancy to total life expectancy has been increasing for males at all ages. There are no exceptions in Table 12b for males and in Table 12e the ratios for males all either rise or stay level. For females, Table 12b shows an increase between 1976 and 1980 and between 1985 and 1991, but not between 1980 and 1985. Since the 1976 and 1991 values may be misleading, as mentioned above, because different questions were asked, the evidence regarding trends in the ratio is not clear. It is difficult to use Table 12e for identifying trends in the ratio for females if the 1985 values are not used. The 1980 and 1994 figures show no significant changes except at age 85+.
- The time spent with severe disability has been decreasing according to Table 12c. There was a decrease between 1976 and 1980, no change between 1980 and 1985 and a further decrease between 1985 and 1991. However, Table 12f shows no clear change for the severely disabled life expectancy of males from 1980 to 1985 or from 1985 to 1994. For females, ignoring 1985 again, the time spent severely disabled appears to have increased significantly between 1980 and 1994.

The trend in severe disabilities is crucial because these disabilities give rise to large costs. It is therefore worth considering whether the numbers might be misleading. Four aspects, in particular, will be addressed in Section 2.4 to 2.7 below.

(i) Data give the proportions of people who are severely disabled. Might there be problems in converting these to healthy life expectancies?
(ii) Might small number fluctuations be to blame?
(iii) Might possible distortions due to changes in the levels of disabilities of people in institutions be large enough to influence the numbers?
(iv) Do other analyses based on GHS data find the same trends?

2.4 *Obtaining healthy life expectancy information from the GHS data*

By looking at the data before they were converted to healthy life expectancies, it is apparent that the conversion process does not introduce the trends visible in Table 12. Table 13 shows the percentages of people who were severely disabled based on the GHS data. The numbers in Table 13 combine those in table 6.4 of Bone et al (1995) with those of table 4A of Bebbington & Darton (1996).

Table 13. Proportion severely disabled (%)

	Age	1976	1980	1985	1991	1994
Males	65 – 69	4	4	4	2	4
	70 – 74	8	6	4	3	5
	75 – 79	18	8	11	5	6
	80 – 84	25	18	15	9	13
	85+	43	31	23	20	18
Females	65 – 69	6	4	3	3	6
	70 – 74	15	8	6	3	7
	75 – 79	22	10	9	6	9
	80 – 84	36	13	19	7	15
	85+	54	36	33	21	25

Source: General Household Surveys

It is clear that the decreasing trends in the prevalence of severe disabilities shown in Tables 12a to 12c are present in the underlying GHS data. The proportion of people severely disabled decrease from 1976 to 1991. Also, the "anomalous" nature of the 1991 data (due to different questions having been asked) is also apparent.

Note that some of the difference between 1991 and 1994 may have been due to the introduction of the Community Care Act of 1990. This included the objective of trying to reduce the number of people receiving institutional care. The effect of implementing this could have been to increase the numbers of severely disabled people in households, which is what the 1994 GHS suggests, without there being an increase in the number of severely disabled people in total.

2.5 *Sample sizes*

The sample sizes vary between survey dates, but not greatly. In 1991 the samples at each of the age categories were 544, 412, 334, 202, and 66 for males and 686, 520, 477, 144 and 160 for females. These are quite small. They mean that in 1991 there were roughly 10 disabled males in each age group.

This means that the uncertainties are quite large. The sampling should lead to a Poisson process, with variance equal to the mean. Hence if p is the observed underlying rate of disability and N the sample size, this is consistent with an approximate 95 per cent confidence interval for the actual rate being $p-2\times\sqrt{p/N}$ to $p+2\times\sqrt{p/N}$. So, for example, the observed halving between 1985 and 1991 of the percentage of 65-year-old males who are severely disabled is not statistically significant.

This suggests that individually most changes shown in Table 12 are not significant. However, when all changes are alike, the significance is high. This means, for example, that the evidence in Table 12a and Table 12d regarding the time spent free from severe disabilities is statistically reliable.

2.6 *Adjusting for institutional care*

The six parts of Table 12 relate to the whole population. They are based on data from the GHS, which only covers people in households. People in institutions are allowed for by Bone et al (1995) as follows:

- The number of people in institutions is known for census years, and interpolated between them.
- The disabilities of people in institutions are assumed to follow the same pattern as in the OPCS survey (Martin et al, 1988).
- For both sexes and each age group the number of severely disabled people in institutions is found by combining these two pieces of information.
- These people are then added to the severely disabled people identified in households.

The only difference in the way which Bebbington & Darton (1996) allows for the institutional population appears to be in calculating the number of people in institutions. The distribution of disabilities follows the same pattern as in the OPCS disability survey (Martin et al, 1988). The census data were used where no better source exists, but for many types of institution there are other publications which show directly or indirectly the number of people who are being accommodated. Such publications are available in non-census years. Bebbington & Darton's (1996) estimates of the number of people in institutions ought to be superior to the values used by Bone et al (1995).

Darton (1994) has found some evidence that the average level of dependency of people in care establishments increased in the 1980s. However, Bone (1995) interprets the review by Darton (1994) as showing "no clear evidence of changes in the 1980s". Bone (1995) also points out that if the least disabled people who had been in institutions move out into the community (or, equivalently, people with this level of disability no longer enter institutions) this would increase the average levels of disability of people in institutions and of people outside institutions.

If the proportion of institutionalised people who are severely disabled has changed since the OPCS survey, the estimates of the total number of severely disabled people will be incorrect. If the disabilities of people in institutions were now more severe than they were in 1985 (e.g. because of government support for care in the community) then to assume no change has occurred would lead to an underestimate of the number of severely disabled people in the whole population. It is possible to calculate the maximum possible distortion which could be caused by a change in the disabilities of people in institutions. The maximum distortion would occur if everyone in an institution at a particular survey date were actually severely disabled. We have calculated the possible distortion to the 1991 figures (this is the simplest date to consider because it was a Census year). The steps in the calculation of the possible distortion are:

- Use the 1985 OPCS disability survey (Martin et al, 1988) to determine what fraction of people in institutions, by age and sex, were severely disabled at that time. This requires a decision as to which OPCS disability category equates with the required severity of disability.
- Use the 1991 Census to show how many people were in institutions in 1991.
- Use the OPCS proportions to split the 1991 institutional population into mildly and severely disabled.
- Use the 1991 Census for the household population and the GHS severe-disability prevalence rates to estimate the number of severely disabled people there were outside institutions in 1991.
- Find the total number of severely disabled people at each age in 1991 under the two assumptions: a) the 1991 institutional population having the same levels of disability as in 1986 and b) the 1991 institutional population all being severely disabled.
- Use these last two sets of figures to find the maximum possible effect of assuming there was no change in the disability levels of people in institutions.

This maximum possible distortion to the number of severely disabled people in 1991 works out at around 25%. This would in turn lead to an increase in disabled life expectancies of around the same amount. Applying this 25% to the 1991 values in Table 12c would make the severely-disabled life expectancies for males similar to the 1980 and 1985 figures (but note that this 25% change is based on an extreme scenario of a huge change in the disability levels institutional population between 1985 and 1991). They would not change the values for females by enough to remove the reduction in severely-disabled life expectancy.

2.7 *Other analyses of GHS data*

In another analysis of GHS surveys, Bone (1995) finds little evidence of any trends in dependency in the 1980s. She suggests that there is some decline in the proportion disabled over age 70 but thinks that might be due to more people being institutionalised. The numbers in Table 14 are from table 3.2 of Bone (1995) (the figures do not separate males and females). Note that this table from Bone (1995) also provided the data in Table 4 in section 2.1. The disability categories covered in Table 14 are 3 to 6 on the scale used by Bone (1995) and defined in Table 3.

Table 14. Percentage failing ADLs

Age	1980	1985	1991
65 – 69	2	3	2
70 – 74	5	4	3
75 – 79	8	9	7
80 – 84	14	15	8
85+	31	31	21

Source: Bone et al (1995)

These are consistent with the proportion having severe disabilities decreasing over time, although this is not clear below age 80.

In summary, the trends in HLE shown by data from the General Household Survey are:

- Life expectancy free from any disability has been slowly increasing (Table 11a).
- The proportion of life spent free from any disability has been roughly constant (Table 11b).
- Severe-disability free life expectancy has been increasing according to an ADL based definition of severe disability (Table 12a and 12d).
- The proportion of life spent free from severe disability has been increasing (Table 12b and 12e).
- The severely-disabled life expectancy may have been falling (Table 12c and 12f), but this is far from clear.

It is important to recognise that all this trend information relates to disabilities recorded in the General Household Surveys. We mentioned in section 2.1 that there are difficulties in aligning the GHS disability categories with those used in the OPCS disability surveys. In discussing Table 5, we suggested that there are several types of disability captured by the OPCS definitions which are not measured by the GHS questions. It is quite possible that some of these disabilities, such as those related to behaviour and intellectual functioning, do not follow the same trends as the physical disabilities measured in the GHS. If this were the case, the HLE trend data would not be so useful.

As well as calculating life expectancies according to the ADL based definition of disability, Bone et al (1995; tables 6.8 and 6.9) and Bebbington & Darton (1996; tables 5B and 5C) consider two other definitions. The severely-disabled life expectancies for the two definitions are shown in Tables 15a, 15b, 15c and 15d. This table should be compared with Table 12c and 12f. The two definitions of ability relate to the climbing of stairs and steps without help and getting out of doors without help.

Table 15a. Severely-disabled life expectancy (years)
(managing stairs and steps)

	Age	1976	1980	1985	1991
Males	65 – 69	0.6	0.8	0.8	1.0
	70 – 74	0.6	0.8	0.8	0.9
	75 – 79	0.6	0.8	0.9	1.0
	80 – 84	0.5	1.0	0.9	1.0
	85+	0.5	1.3	1.1	1.2
Females	65 – 69	1.5	1.8	2.2	2.1
	70 – 74	1.5	1.8	2.2	2.1
	75 – 79	1.5	1.8	2.2	2.1
	80 – 84	1.3	1.7	2.0	2.0
	85+	1.1	1.5	1.6	1.8

Source: Bone et al (1995)

Table 15b. Severely-disabled life expectancy (years)
(managing stairs and steps)

	Age	1980	1985	1994
Males	65 – 69	0.9	1.0	1.1
	70 – 74	1.0	0.9	0.9
	75 – 79	1.0	1.0	0.9
	80 – 84	1.2	1.1	0.9
	85+	1.4	1.3	0.9
Females	65 – 69	2.2	2.5	2.9
	70 – 74	2.2	2.5	2.8
	75 – 79	2.2	2.5	2.7
	80 – 84	2.2	2.4	2.6
	85 +	2.1	2.2	2.6

Source: Bebbington & Darton (1996)

Table 15c. Severely-disabled life expectancy (years)
(getting out of doors)

	Age	1976	1980	1985	1991
Males	65 – 69	1.1	1.1	1.2	1.1
	70 – 74	1.2	1.1	1.2	1.1
	75 – 79	1.1	1.1	1.2	1.2
	80 – 84	1.3	1.0	1.1	1.5
	85+	1.5	1.0	1.0	1.7
Females	65 – 69	2.9	3.4	3.6	2.9
	70 – 74	2.9	3.3	3.5	2.9
	75 – 79	2.8	3.3	3.5	2.9
	80 – 84	2.8	3.2	3.4	2.8
	85+	2.4	2.8	3.0	2.7

Source: Bone et al (1995)

Table 15d. Severely-disabled life expectancy (years)
(getting out of doors)

	Age	1980	1985	1994
Males	65 – 69	1.3	1.4	1.9
	70 – 74	1.4	1.3	1.7
	75 – 79	1.4	1.4	1.7
	80 – 84	1.6	1.3	1.8
	85+	1.9	1.3	1.7
Females	65 – 69	3.6	4.0	4.7
	70 – 74	3.5	4.0	4.5
	75 – 79	3.5	4.0	4.4
	80 – 84	3.5	4.0	4.2
	85 +	3.2	3.7	4.1

Source: Bebbington & Darton (1996)

These four tables indicate that the time being spent severely disabled may have been increasing. This is the opposite of what Table 12c shows.

The definition of disability used for Table 12 ought to have more in common with the OPCS disability scale than either of the two definitions used in Table 15. This is because it is based on a range of abilities rather than just one.

The disabled life expectancies in Table 15 are based on data for England and Wales only. We would expect that there would be little difference for the British population as a whole. There are, however, some surprisingly large differences in the disability prevalence rates for England and Wales and for the whole of Britain. Bone et al (1995) and Bebbington & Darton (1996) both show the prevalence rates from which they derive healthy life expectancies. These prevalence rates differ from those which are given in the GHS reports. As an example of how large the differences can be, the following numbers show the percentages of elderly people who were unable to get out of doors without help in 1994. The numbers are for five age groups (65 to 69, 70 to 74, 75 to 79, 80 to 84 and 85 and above). For England and Wales the percentages were 7, 7, 9, 20 and 24 for males and 11, 13, 19, 26 and 50 for females in each age group (Bebbington & Darton, 1996 table 4C). For Britain the percentages were 4, 6, 8, 18 and 18 for males and 9, 10, 16, 23 and 44 for females (Bennett et al, 1996). Note that people in Scotland make up only around 10% of the population of Britain. The health of the Scottish people in 1994 must have been drastically different from that of the English and Welsh people to account for such differences.

Neither Bone et al (1995) nor Bebbington & Darton (1996) were able to include the 1996 GHS data in their analyses. The 1996 data are in the form of percentages of respondents unable to perform various tasks. They are not in the form of healthy life expectancies and do not cover the institutionalised population. The failure rates in 1996 can be compared with the rates in earlier surveys — i.e. those in 1980, 1985, 1991 and 1994 when there were extra questions about the health of elderly people. For some ages and tasks, the 1996 population is more able than in any of the previous survey years while for some other ages and tasks the population is less able than in any of the previous years.

- In terms of mobility out of doors, 1996 was the worst year for males aged 65 to 69 and 70 to 74 and females aged 70 to 74. It was the best year for males aged 80 to 84 and 85 and over. (For the other ages the proportion not mobile out of doors was neither highest nor lowest in 1996.)
- In terms of ability to manage steps, 1996 was the worst year for males aged 70 to 74 and 75 to 79 and for females aged 65 to 69 and 85 and over. It was the best year for males aged 80 to 85.
- In terms of ability to bathe (which is the most commonly failed ADL), 1996 was the worst year for males aged 65 to 69 and females aged 80 to 84.

The fact that 1996 figures were sometimes worse than in earlier years and sometimes better indicates that they do not make it any easier to identify trends in the data.

Another source of information on trends is the annual GHS question on limiting long standing illness. The question was first asked in 1974. For the whole population there was a small increase in the prevalence of limiting long standing illness from 1974 to around 1984 but the data show no clear pattern since then. For elderly people there is no evidence of a trend in the data.

2.8 *Other analyses of healthy life expectancy data*

The signs of a decrease in severely-disabled life expectancy which are indicated by the ADL-based GHS HLE data also appear to be the opposite to the trend shown by some other HLE data. Surveys of the health of the elderly in Melton Mowbray in 1981 and 1988 show a clear increase in the time spent severely disabled. The definition of disability is close to that used in the analysis of the GHS data. In the Melton Mowbray surveys, all people in institutions were counted as disabled. Table 16 is taken from part of table 10.10 of Bone et al (1995). The numbers in it should be compared with Table 12c and 12f. Note that the ages involved differ for the two tables.

Table 16. Severely-disabled life expectancy (years)

	Age	1981	1988
Males	75	1.31	1.57
	80	1.20	1.67
	85	1.14	1.51
	90	0.96	1.38
Females	75	3.05	3.23
	80	2.97	3.29
	85	2.85	3.35
	90	3.02	2.62

Source: Bone et al (1995)

Although the definition of severe disability is similar to that used in analysing the GHS data, there may be some important differences. For females, the severely-disabled life expectancies shown in Table 16 are higher than those in Table 12c for the 1980s. For males, the 1981 Melton Mowbray figures are similar to the 1980 GHS figures given by Bone et al (1995).

The life expectancies have also been calculated from the Melton Mowbray data using more severe definitions of disability. For some of these definitions the severely-disabled life expectancy has fallen (visual impairment), while for others it has risen (mental impairment) and for some the changes have been mixed (urinary incontinence, mobility impairment).

There are two major overseas data sources referred to by Bonita (1997) in a short article in the Lancet. Bonita makes the following comments on what these sources indicate:

- "Findings suggest that the life expectancy with severe disability has not increased and that active life expectancy has at least kept pace with the gains in life expectancy." The source referred to by Bonita is Robine et al (1997).
- "A recent study indicates that in the USA, the rate of chronic disability and institutionalisation among older people has fallen substantially over the past decade." She refers to the study by Manton et al (1997a).

The comments by Bone et al (1995) on international evidence that we have mentioned earlier in this section were based on earlier work by the same groups — i.e. those of Robine and Manton.

In another examination of the US data, Manton et al (1997b) consider possible causes of the reductions in the level of disability of elderly people. Amongst the possibilities is that improvements in nutrition in the first half of the century (e.g. having enough vitamins) meant that people grew up healthier and that this has followed through to lower levels of disability in old age. Another possibility is that the introduction of the Medicare system (in 1965, for people aged 65 and over) has had a significant impact on the health of the elderly.

3. *Conclusions*

We have reviewed the various data sources and decided to proceed as follows:

- use, as an initial data set, the OPCS survey of disability in Great Britain which is summarised in Martin et al, 1988.
- incorporate within the model the trends in healthy life expectancy exhibited within the General Household Surveys over the last 20 years.

As regards the latter, there are some trends in severely-disabled life expectancy which show that more time is being spent severely disabled and other trends which show that less time is being spent severely disabled. According to Bone et al (1995, chapter 5) the overall picture appears to be that:

- People spend an increasing amount of time with some form of disability.
- People spend a constant amount of time with severe disability.
- This applies to the UK and to other countries.

Clearly, trends in the amount of time which people spend, on average, with a severe disability have important implications with regard to the demand for, and cost of, long term care provision.

Having considered the various data sources in Part I, we describe the multiple state model used to carry out the projection in Part II.

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