# Profile of disability in elderly people: estimates from a longitudinal population study

Medical Research Council Cognitive Function and Ageing Study (MRC CFAS) and Resource Implications Study (RIS MRC CFAS). Writing committee: David Melzer, Brenda McWilliams, Carol Brayne, Tony Johnson, John Bond

Department of Community Medicine, University of Cambridge, Institute of Public Health, Cambridge CB2 2SR
David Melzer, *clinical senior research associate*
Brenda McWilliams, *research associate*
Carol Brayne, *lecturer in epidemiology*
Medical Research Council Biostatistics Unit, University of Cambridge, Institute of Public Health
Tony Johnson, *medical statistician*
Centre for Health Services Research, University of Newcastle upon Tyne NE2 4AA
John Bond, *professor of health services research*
Correspondence to: Dr Melzer dm214@medschl.cam.ac.uk

*BMJ* 1999;318:1108–11

## Abstract

**Objectives** To provide estimates of the numbers of cognitively impaired and physically disabled elderly people in England and Wales, subdivided by a range of sociodemographic, dependency, care receipt, and survival variables, to support debates on the form and funding of health and welfare programmes.
**Design** Interviews at baseline and 2 year follow up plus data on resource use extracted from records for those with disability.
**Subjects** 10 377 people aged 65 years and over in Cambridgeshire, Newcastle, Nottingham, and Oxford. All estimates weighted to population of England and Wales in 1996.
**Results** 11% of men and 19% of women aged 65 and over were disabled, totalling 1.3 million people; 38% of these were aged 85 or over and a similar percentage were cognitively impaired. Overall, more than 80% of elderly disabled people needed help on at least a daily basis. Over a third of people with limitations to daily activity living in private households were wholly or partly dependent on formal services for help. 63% of disabled elderly people used acute hospitals during the 2 year follow up, 43% as inpatients. 53% of those with cognitive impairment and limitations to daily activity were living in institutions.
**Conclusions** Very elderly people and those with cognitive impairment make up a large proportion of those in need of long term care. A large proportion of even the most disabled elderly people currently live outside institutions and depend on formal services as well as informal care givers. Disabled elderly people use acute hospitals extensively, underlining the interrelations between acute and long term care.

## Introduction

With the historic rise in life expectancy during this century, the human life span is now divided into four ages: the first is an age of dependency, childhood, and education, the second is an age of independence, maturity, and responsibility, and although the third age is considered a period of fulfilment for physically and mentally fit people in retirement, the fourth age is associated with disability and dependence.[1] The size and pattern of the fourth age is of critical importance not only for the quality of life of elderly people but also because disability is closely associated with use of health and social services.[2] The rising costs of the fourth age have precipitated policy discussion across the developed world,[3] a national plan in Japan,[4] reform of long term care funding in Germany,[5] and the appointment of a Royal Commission in the United Kingdom.

The pattern of disability in the elderly population in England and Wales was last studied in detail in 1986.[6] This study showed rising rates of disability with age and significantly higher rates for women. The patterns of disability associated with cognitive impairment, however, have been less clear.[7 8] Accurate national estimates of the numbers of cognitively impaired and physically disabled elderly people, subdivided by a range of sociodemographic, dependency, care receipt and survival variables are needed to support debates over the form and funding of government health and welfare support and for local service planning. The Medical Research Council's cognitive function and ageing study and resource implications substudy provide a basis for contemporary estimates. This longitudinal cohort study of elderly people began in 1991-2, and follow up data from the first 2 years provide estimates of the use of the range of provisions to those who are disabled.

## Subjects and methods

### Study design

A full description of the study design can be found elsewhere.[9] Briefly, random population samples of people in their 65th year and above were obtained from Family Health Service Authority lists in six areas of England and Wales (although data on resource use were collected in only the four sites included in this analysis). Sites were chosen as representing the main national variation in urban-rural differences, regional heterogeneity, and the presence of academic groups experienced in population studies. Ethical approval was obtained in each study site.

The sample was stratified by age group (65-74 years and 75 years and over) and equal numbers were randomly selected from each stratum sufficient to produce an interviewed sample of around 2500 people in each of the areas included in this analysis.[9] The study incorporated a two stage prevalence survey with 2 year longitudinal follow up to establish incidence rates.

All subjects were screened with a structured initial interview in their own homes by trained fieldworkers using laptop computers. The refusal rate for the screening interview was 18% overall.[9] Data were collected using structured schedules for accommodation, household composition, help provided to the respondents, social networks, health, functional ability, carers' health, and impact of caring. The use of services by the disabled elderly group was monitored over a 2 year period by concurrent structured review of service records.[10]

Datasets have been released for analysis at various stages of the cognitive function and ageing study and are labelled by their version number. In version 4.0 of

the dataset used here, information on prevalence screening for the four resource sites was available for 10 377 people; of these 1446 were classified as disabled and were included in the resource implications study; service monitoring data were available on 1391 people. No important differences were found in demographic structure or prevalence of cognitive impairment between the sites.[9]

**Scales and classification**

The modified Townsend activities of daily living scale covers washing all over, cutting toenails, getting on a bus, going up and down stairs, doing heavy housework, going shopping and carrying heavy bags, preparing and cooking hot meals, reaching an overhead shelf, and tying a good knot in a piece of string. [11 12] Scores are: 0, if the person can perform the activity with no difficulty; 1, if the person can perform the activity but with difficulty; and 2, if the person needs help to perform the activity. Totalled scores ranged from 0 (no incapacity), to 1 or 2 (slight incapacity), 3-6 (some incapacity), 7-10 (appreciable incapacity), 11 or more (severe incapacity). Severe incapacity might describe a person who needs help to do at least two of the activities and has some difficulty with all of the rest.

Subjects were classified as cognitively impaired if the automated geriatric examination computer assisted taxonomy (AGECAT[13]) measure of organic psychiatric illness at screening was ⩾3: a majority of these people have dementia. People were classified as physically disabled if they scored ⩾11 on the Townsend scale.[11] Those with both characteristics are referred to as having combined disability.

The interval of need for care is a classification based on the lapsed time between periods when the subject may need help with essential activities. [11 14] The categories for classification are independent, long interval (needing care less often than daily), short interval (needing care at some time every day), and critical interval (needing care or supervision continuously). People were allocated to the interval categories on the basis of daily living functioning (from the Townsend scale) and their score in the mini-mental state examination.[15] For example, a typical person categorised as critical interval would be bedbound or chairbound, or unable to get to or use the toilet, or have severe cognitive impairment. Anyone with severe cognitive impairment (mini-mental state score $<10$) was considered to need critical interval care regardless of their physical dependency.

## Results

Table 1 shows the estimated numbers of disabled elderly people by type of disability, age, and sex. Using the study definitions, there were an estimated 1.3 million disabled elderly people in England and Wales (15.7% of those aged 65 and over, 95% confidence interval, 15.1% to 16.3%). These and subsequent estimates were weighted by sex and 5 year age groups to reflect the population structure of England and Wales in 1996,[16] and calculation of confidence intervals took account of each age and sex weighted group separately. Prevalence rates were lower in men (10.6%, 9.7% to 11.5%) than in women (19.2%, 18.3% to 20.1%).

**Table 1** Estimated numbers of cognitively impaired or disabled elderly people in England and Wales by age group, sex, and type of disability

| | 64-74 years | | 75-84 years | | ⩾85 years | |
|---|---|---|---|---|---|---|
| **Disability** | **Men** | **Women** | **Men** | **Women** | **Men** | **Women** |
| Physical only | 68 000 | 122 000 | 82 000 | 257 000 | 43 000 | 232 000 |
| Cognitive only | 32 000 | 29 000 | 45 000 | 57 000 | 20 000 | 61 000 |
| Combined | 14 000 | 11 000 | 26 000 | 57 000 | 27 000 | 99 000 |

Data on 0.4% of people missing.

Women accounted for 72% of the disabled group, with the preponderance of women becoming more pronounced with age. Cognitive impairment was present in over a third of all disabled elderly people (38.3%, 36.0% to 40.6%), and these were more or less equally divided between the cognitive only or combined categories. People aged 85 and over made up 37.6% (35.6% to 39.7%) of the total number with disability.

A good summary of overall level of dependence was the critical interval of need for care. Of the 1.3 million disabled elderly people, 3% (35 576) were independent, 14% (171 586) needed care less often than daily, 62% (778 401) needed care at some time every day (short interval) and 21% (268 863) needed care or supervision continuously (critical interval).

Only 1% of the subjects who were not disabled by study definitions lived in institutional care. However, 17% of those with only cognitive impairment, 18% of those with only physical disability, and 52.8% (47.3% to 58.3%) of those with combined disability lived in institutions. Overall, 46% of all those living in institutions had diagnostic levels of cognitive impairment. By contrast, accommodation with a warden provided care for only 9% of those with combined disability and catered for many people who were not classified as disabled. The proportions of disabled elderly people living alone or in institutions increased sharply with age, especially among women—56% of institutional places for the disabled were filled by people aged 85 or over and 79% were filled by women.

Table 2 shows the proportions of each disability group in the community by type of help received and type of helper. Although most of the care required involved household tasks, 38% of those with combined disability received help with personal care tasks. Most of this help was supplied by informal care givers, but the contribution of formal community support including, for example, home help, care workers, meals on wheels, and community nurses, was far from insignificant. Formal services were the sole reported source of support for 29% of people who were physically disabled only and 23% of those with combined disability, and these services complemented informal support in a further 10% and 11% respectively.

Over the 2 year period of follow up from baseline interview (undertaken in subjects in the resource implications study only, which excludes those without disability), 63.2% (60.7% to 65.8%) used acute hospitals, with 43% doing so as inpatients. Rates of acute hospital use were even higher in disabled people living in the community (table 3). Cognitive impairment was associated with relatively lower use of all forms of hospital care. For those living in the community there was also a small decrease in use of all hospi-

**Table 2** Percentage (number, in thousands) of each disability group by type and source of receipt of help for those living outside institutions

| Variable | Not disabled (n=6880)* | Disability type: Physical only (n=657)* | Disability type: Cognitive only (n=203)* | Disability type: Combined (n=110)* | All elderly people (n=7849)* |
|---|---|---|---|---|---|
| Receiving help | 40.9 (2816) | 86.9 (571) | 48.7 (99) | 80.3 (88) | 45.5 (3574) |
| Type of help received: | | | | | |
| Personal and household | 0.8 (52) | 28.7 (189) | 1.9 (4) | 37.6 (41) | 3.6 (286) |
| Personal only | 0.2 (14) | 2.2 (15) | 0.0 (0) | 0.0 (0) | 0.4 (29) |
| Household only | 40.0 (2749) | 56.0 (368) | 46.8 (95) | 42.7 (47) | 41.5 (3259) |
| Type of helper: | | | | | |
| Spouse only | 28.7 (1976) | 26.3 (172) | 20.7 (42) | 21.2 (23) | 28.2 (2214) |
| Other informal | 5.0 (358) | 22.0 (142) | 12.5 (25) | 25.3 (28) | 7.0 (553) |
| Mixed (including formal) | 0.9 (65) | 9.9 (65) | 1.6 (3) | 11.0 (12) | 1.9 (145) |
| Formal services only | 6.1 (417) | 29.1 (191) | 13.9 (28) | 22.8 (25) | 8.4 (662) |

Source: Subjects from cognitive function and ageing study completing baseline interview (n=10 377) weighted by sex and 5 year age groups, and population of England and Wales in 1996.
*Estimated.

tal services with age, with 72% of those aged 65 to 74 using hospital care compared with 71% aged 75 to 84 and 63% of those aged 85 and over.

In the 2 years after initial interview, 10% of the whole group of elderly people died, but rates were far higher in those with cognitive impairment (25%), physical disability (26%), or combined disability (48%).

## Discussion

Throughout the developed world, the funding of care for disabled elderly people has become a highly publicised political issue. In the United Kingdom, total public expenditure on long term care is already estimated to account for 3.6% of the gross domestic product,[17] and some have suggested that overall costs might rise as high as 10.8% by 2030.[18] Not surprisingly, UK governments have undertaken a series of reforms in this area, including narrowing access to NHS continuing care and thereby extending means testing.[19] In future policy debates, estimates of the numbers and types of people who need long term care should be central.

**Table 3** Percentage (number, in thousands) of disabled elderly people (living outside institutions) by use of hospital and community services during 2 year follow up period

| Variable | Disability type: Physical only (n=550)* | Disability type: Cognitive only (n=170)* | Disability type: Combined (n=96)* | All disabled (n=818)* |
|---|---|---|---|---|
| Any hospital contact: | 71.4 (392) | 61.8 (105) | 64.0 (61) | 68.5 (561) |
| Acute | 49.1 (270) | 38.2 (65) | 54.4 (52) | 47.5 (389) |
| Outpatient | 58.1 (319) | 42.9 (73) | 36.1 (35) | 52.3 (428) |
| Day hospital | 8.1 (44) | 11.2 (19) | 14.7 (14) | 9.6 (78) |
| Community nursing services† | 56.8 (312) | 38.4 (65) | 59.5 (57) | 53.0 (434) |
| Social worker | 9.8 (54) | 11.8 (20) | 15.5 (15) | 10.8 (89) |
| Specialist community services‡ | 59.6 (327) | 36.5 (62) | 56.7 (54) | 54.2 (444) |
| Day centre | 12.8 (70) | 14.6 (25) | 19.4 (19) | 13.9 (114) |
| Any above community services | 86.5 (475) | 64.2 (109) | 80.5 (77) | 80.8 (661) |
| Home care services§: | 55.3 (303) | 31.9 (54) | 52.4 (50) | 49.8 (408) |
| Meals on wheels | 22.3 (123) | 12.4 (21) | 22.2 (21) | 20.2 (165) |
| Home help | 47.1 (259) | 25.2 (43) | 43.4 (42) | 41.9 (343) |

Source: Subjects from resource implications study (n=1391) weighted by sex and 5 year age groups, and population of England and Wales in 1996.
Data on resource use on those without disability were not collected in this study.
*Estimated.
†Doctor and community nurses (including psychiatric and Marie Curie nurses), health visitors, and continence advisors.
‡Chiropodists, physiotherapists, audiologists, and occupational therapists.
§Meals on wheels, laundry, home help, private domestic help, and incontinence service.

### Comparison with general household survey estimates

Several problems with the estimates presented above should be noted. The four areas included in the study are diverse, but are not fully representative of England and Wales. However, comparisons of study estimates for 1991 with those produced by the nationally representative general household survey for the same year[20] mostly show remarkable similarity, for example, in the proportion of people living at home who had no difficulty with particular tasks. However, reported proportions of elderly people who were living in residential or nursing home care in 1994 were marginally higher than study estimates for that year.[21] These differences may be the result of having no study sites in the retirement areas of the country. However, government policy aims to reduce rates of elderly people living in nursing and residential homes and thus the estimates presented give a picture that is appropriate for future care planning.

### Implications

In considering the results, it is important to remember that disability is not an attribute that is clearly present or absent, but rather a matter of degree. While policy makers may like to classify people as fit or disabled, in need or not, in reality a full spectrum of disability is present, from slight to very severe. This lack of a natural cut off point between those in need of long term care and those not in need of long term care has obvious implications for establishing workable eligibility criteria for long term care funding. It also means that providers of care have substantial scope to offer services to comparatively less disabled groups, thus expanding the size and cost of long term care programmes.

In this study we have chosen a fairly restrictive cut off point of severe limitation to activities of daily living and diagnostic levels of cognitive impairment, as evidenced by the large proportion of the group who needed daily or more frequent help. The results clearly show that women, the oldest old, and cognitive impairment, especially in institutional care settings, are important both numerically and in decisions about policy. However, the results also show that even in the most dependent subgroups needing constant care and attention, the majority of disabled elderly people live in

**Key messages**

- Disability is not present or absent, but rather a matter of degree. On the restrictive study definitions for disability 1.3 million elderly people in England and Wales are classified as disabled or cognitively impaired
- 38% of disabled elderly people have cognitive impairment
- People aged 85 years and over and those with cognitive impairment combined with limitations in activities of daily living make up a large proportion of those needing institutional care or intensive home support
- Formal community services were the only source of support for 29% of physically disabled elderly people and 23% of those with combined disability in the community
- 43% of disabled elderly people were admitted to acute hospitals during the 2 year follow up period

the community supported by both formal and informal caregivers. Two policy points arise from this. Firstly, that the terms of funding of long term care might easily influence the choice of setting, either encouraging elderly people to stay at home alone, move in with others or, as happened in the 1980s,[22] go into institutional care. Secondly, that if people are asked to fund elements of their own future care, women now aged 40, for example, will have to finance care which many may only need in 40 or more years time. Given the relative lack of resources available to most women in this age group, personal funding would be difficult to achieve in practice.

Another feature of the data is the considerable overlap between acute hospital and long term care, with 43% of disabled elderly people being admitted and 63% having some contact with acute hospitals in the 2 years after initial interview. There is thus a strong case for long term care arrangements that encourage cooperation with acute care,[3 23] including incentives for the provision of services aimed at preventing the need for admission as well as improving arrangements for early discharge and rehabilitation.

We thank the subjects, the project team of the resource implications study, and the fieldworkers.

Funding: The Medical Research cognitive function and ageing study was funded by the Medical Research Council and Department of Health. The analyses reported were funded by a grant from the Anglia and Oxford research and development programme.

Competing interests: None declared.

Guarantors: DM (content of paper), CB (overall study), JB (data on resource use), TJ (analysis), and BMcW (analysis).

Contributors: Study Management Group: T Arie, J Bond, C Brayne, JRM Copeland, NE Day, M Devakumar, ME Dewey, M Esiri, O Goddard, B Gregson, J Grimley Evans, FA Huppert, M Jepson, AL Johnson, DWK Kay, C McCracken, I McKeith, K Morgan, J Morris, C Parker, ES Paykel, and N Walker. National coordinators: C McCracken and GP Slegg. Cambridge: C Brayne, FA Huppert, J Nickson, and ES Paykel. Gwynedd: JRM Copeland, M Devakumar, ME Dewey, and S Jones-Evans. Liverpool: JRM Copeland, ME Dewey, P McKibbin, and P Saunders. Newcastle: A Fairbairn, S Hrisos, J Illing, DWK Kay, and I McKeith. Nottingham: T Arie, J Levings, K Morgan, and C Parker. Oxford: J Grimley Evans and O Goddard. Medical Research Council Biostatistics Unit: C Gill, AL Johnson, D Mathewson, MA McGee, J Nickson, and N Walker. Analysis subcommittee: C Brayne, JRM Copeland, NE Day, ME Dewey, C Gill, B Gregson, FA Huppert, J Illing, AL Johnson, DWK Kay, D Mathewson, C McCracken, MA McGee, K Morgan, J Nickson, C Parker, ES Paykel, and N Walker. Instrument subcommittee: J Bond, C Brayne, JRM Copeland, NE Day, ME Dewey, C Gill, B Gregson, J Grimley Evans, FA Huppert, AL Johnson, DWK Kay, C McCracken, I McKeith, K Morgan, P Saunders, and N Walker. Local administrators and support staff: B Ackerly, V Gilgeous, L Hughes, V Jackson, J Pollock, and A Scott.

1 Laslett P. *A fresh map of life: the emergence of the third age*. London: Macmillan Press, 1996.
2 Fried LP, Guralnik JM. Disability in older adults: evidence regarding significance, etiology, and risk. *J Am Geriatr Soc* 1997;45:92-100.
3 Wiener J. Long term care reform: an international perspective. In: *Health care reform: the will to change*. Health Policy Studies number 8. Paris: Organisation for Economic Cooperation and Development, 1996.
4 Bass S, Morris R, Oka M. *Public policy and the old age revolution in Japan*. New York: Haworth Press, 1996.
5 Schulte B. Social protection for dependence in old age: the case of Germany. In: Eisen R, Sloan F, eds. *Long term care: economic issues and policy solutions*. Boston: Kluwer Academic, 1996;149-70.
6 Martin J, Meltzer H, Elliot D. Report 1. *The prevalence of disability among adults*. London: HMSO, 1988.
7 Department of Health. *Health of elderly people: an epidemiological overview*. Volume 2. London: HMSO, 1992.
8 Melzer D, Ely M, Brayne C. Cognitive impairment in elderly people: population based estimate of the future in England, Scotland and Wales. *BMJ* 1997;315:462.
9 The Medical Research Council cognitive function and ageing study (MRC CFAS). Cognitive function and dementia in six areas of England and Wales. *Psychol Med* 1998;28:319-35.
10 Resource Implications Study of the Medical Research Council Cognitive Function and Ageing Study (RIS MRC CFAS). Mental and physical frailty in older people: the costs and benefits of informal care. *Ageing Soc* 1998;18:317-54.
11 Bond J, Carstairs V. *Services for the elderly: a survey of the characteristics and needs of a population of 5,000,000 old people*. Scottish Home and Health Studies number 42. Edinburgh: Scottish Home and Health Department, 1982.
12 The Medical Research Council Cognitive Function and Ageing Study. The description of activities of daily living in five centres in England and Wales. *Age Ageing* 1998;27:605-13.
13 Copeland J, Dewey M, Griffiths-Jones H. A computerised psychiatric diagnostic system and case nomenclature for elderly subjects: GMS and AGECAT. *Psychol Med* 1986;16:89-99.
14 Isaacs B, Neville Y. *The measurement of need in old people*. Edinburgh: Scottish Home and Health Department, 1975.
15 Folstein M, Folstein S, McHugh P. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;313:1419-20.
16 Office of Population Census and Surveys. *National population projections:1994-based (OPCS monitor PP2 96/1)*. London: OPCS, 1996.
17 Bone M. *Trends in dependency among older people in England*. London: Office of Population Census and Surveys, 1995.
18 Nuttall SR, Blackwood RJL, Bussell BMH, Cliff JP, Cornall MJ, Cowley A, et al. Financing long-term care in Great Britain. *J Inst Actuaries* 1994;121:1-53.
19 Impallomeni M, Starr J. The changing face of community and institutional care for the elderly. *J Public Health Med* 1995;17:171-8.
20 Jarvis C, Hankock R, Askham J, Tinker A. *Getting around after 60: a profile of Britain's older population*. London: Stationery Office, 1996.
21 House of Commons Health Committee. *Long term care: future provision and funding. Third Report*. London: Stationery Office, 1996.
22 Grundy E, Glaser K. Trends in, and transition to, institutional residence among older people in England and Wales, 1971-1991. *J Epidemiol Community Health* 1997;51:531-40.
23 *Royal Commission on the funding of long term care with respect to old age: long term care—rights and responsibilities*. London: Stationery Office, 1999. (Cmnd 4192-1.)

*(Accepted 18 February 1999)*

*Endpiece*

## Prejudices

Few people are capable of expressing with equanimity opinions which differ from the prejudices of their social environment. Most people are even incapable of forming such opinions.

Albert Einstein