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Feasibility Study – Comparable Statistics in the Area of Care of Dependent Adults in the European Union

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Preface

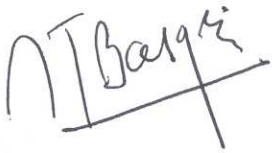
This feasibility study about comparable statistics in the area of care of dependant adults in the European Union has been conducted by Eurostat with the financial support of DG EMPL.

Indeed, the policy needs on the area of care of dependant adults were underlined on subsequent occasions. In 1999, the Council adopted conclusions which confirmed that "reconciliation of work and family life" would be one of the themes of the next review of the implementation of the Beijing Platform of Action by the Council of the European Union. The Presidency conclusions of the Stockholm European Council (23-24 March 2001) recognise that increasing employment rates demands active employment policies and invites the Council and the Commission to develop indicators on the provision of care facilities for children and other dependants by 2002. Furthermore, pillar IV of the Employment Guidelines 2002 under the guideline "Enabling women and men to reconcile work and family life" includes two objectives on adopting family-friendly policies and increasing the availability of care services for children and other dependants ; there are similar requirements under pillar VI of the Employment Guidelines 2003 "Gender equality".

The purpose of this feasibility study was to investigate the needs for statistics about care for dependant adults, to do an inventory and to analyse the existing data sources in Member States, at European level and in other international organisations and finally to make proposals for future developments. A special interest was put on elderly dependant persons. In fact, the existing indicator on elderly care to follow up the European Employment Strategy concerns "dependent elderly men and women (unable to look after themselves on a daily basis) over 75: Breakdown by: living in specialized institutions; who have help (other than the family) at home; and looked after by the family".

The project was finalised in summer 2003. It indicates that, on the basis of available data, it is difficult to obtain comparable statistics covering care services for dependant adults. Nevertheless, this study presents available data on the number and characteristics of dependant adults, on care provided by the family and by care services at home or in institutions and on characteristics of care providers as well as recommendations.

We have a great pleasure to present the results of this study which constitutes a step to improve the comparability of statistics in the area of care of dependant adults in the European Union.



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Feasibility study

COMPARABLE STATISTICS IN THE AREA OF CARE

OF DEPENDENT ADULTS IN THE EUROPEAN UNION

Final report - July 2003

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INTRODUCTION

Demographic (ageing of the population) and social (promotion of active participation in social life) developments have led policy makers to focus more on the needs of dependent people and the help available to them. The current study aims to meet demands concerning the number and characteristics of adult and elderly dependent persons and to make proposals concerning the elaboration of comparable statistics at a European level.

The report is divided in two parts. Part A presents the statistics and Part B describes the sources and the methodologies of national surveys.

Part A presents the collected data. It is divided into three sections. Section I presents the main characteristics of persons with long-term care needs. Section II presents information on informal care and Section III describes formal care. At the end of each section, we present a discussion of main issues and present recommendations for future action.

The definition of ‘dependency’ by the different national surveys keeps a central role in this part.

Part B presents the sources and the methods. We have adopted a standardised presentation. A standard form (fiche) describes each source of data and presents some comments.

An annex presents a glossary with the main terms and the classifications used.

A preliminary analysis of national data provides an estimation of the number of dependent people. As national statistics are not strictly comparable, we present also a narrower definition of dependency based on self-care needs. The data reveals that the rate of dependency increases sharply with age. According to the narrow definition, one could advance that there are about 7 million adult and elderly dependent persons in the EU. The study gives a special attention to 'dependent elderly men and women (unable to look after themselves on a daily basis) over 75'.

The study analyses extensively the nature and degree of dependency in the Member States. As we could expect, people with self-care dependency are less numerous than people with dependencies related to instrumental activities of daily living (housework, shopping, etc.).

This section concludes with a discussion on the best indicator to measure dependency and put forward proposals concerning the collection of comparable data at the EU level. The EU indicator and international classifications form the basis of the discussion.

Dependency and lack of support might lead to institutional care. Consequently, the distribution of dependent persons at home and in institutions retains our attention. Available statistics indicate that not all persons in institutions are dependent according to the narrow definition.

The main provider of help is the family. Women are more numerous than men in providing care to dependent persons. This might lead to a conflict between work and dependency care. There is little information on the characteristics of care providers. Consequently, we make a certain number of proposals for the collection of statistics concerning the needs of dependent persons living at home and the characteristics of carers.

Formal care (notably professional, paid help) is another important pillar for keeping dependent people in the community. We present available data concerning home help and the type of help used by dependent people living at home. Statistics on formal care are rare. Also, existing data poses a big problem of comparability across countries.

The study aims to help to improve the collection and comparability of statistics concerning dependent people and thus contributes in the elaboration of policies, which meet the demands of these persons.

In certain countries, the term 'care dependent person' is used; in other countries, we use the term 'persons with long term care needs'. In the following we use them as alternatives to represent the same concept.
For the sake of comparability, this study focus on statistics collected through surveys. Statistics from administrative sources are only exceptionally used. Concerning administrative data, social security is the main source and the statistics produced concern the number of persons receiving dependency allowances aiming to compensate for extra costs generated by long-term care needs. Professional help and care is thus often funded by social security and welfare systems. Consequently, in presenting formal help, a certain number of data refers to the number of beneficiaries of different long-term care and assistance schemes.

General context

Over the past three decades, the number of older people (aged 65 and over) in the European Community has significantly risen. All the signs indicate that this trend will continue in the future, and that in 2020 there will be approximately twice as many older people in the European Union as there were in 1960.

This structural change favours new demands on our societies, in particular with regard to health care and long-term care. Also, the fact that there are fewer children and more older people is changing the structure of care needs.

In this scenario of changing and growing needs for care, informal care cannot be relied upon to fill the gap. According to available information, the majority of informal carers are women (mothers, daughters, etc.) and this raises questions concerning the relation between work and family life.

A project “Care work in Europe: Current Understandings and Future Directions (CARING)", financed under the fifth framework programme of the European Community for research, technology development and demonstration activities (1998-2002) aims to contribute towards development of good quality employment in caring services.

Guideline 18 in the Employment guidelines 2002 on gender equality concerns “Reconciling work and family life”. The main objective of this guideline is to adopt family-friendly policies in order for women and men to be able to reconcile their work and family life. The reconciliation of work and family life is facilitated by the availability of care services for children and frail elderly people.

The Conclusions of the Lisbon summit of 23-24 March 2000 confirmed the need of making it easier to reconcile working life and family life. Existing statistics covering care services do not provide information to monitor and follow the developments in this area. The purpose of this feasibility study is to do an inventory and analyse the existing data sources in the Member States and finally to make proposals for future developments.

The study focuses on elderly people with a special interest on 'dependent elderly men and women (unable to look after themselves on a daily basis) over 75'.

In fact, the “Indicators on childcare and elderly care – coverage and targets set in 2002 NAPs” indicate that Indicator EO c10 concerns: “dependent elderly men and women (unable to look after themselves on a daily basis) over 75: Breakdown by: living in specialised institutions; who have help (other than the family) at home; and looked after by the family”.

The definition of the indicator uses a certain number of concepts, which have to be clarified before establishing a quantitative measure. In fact, the terms ‘dependency’, ‘daily basis’, ‘help’ etc. are used in different ways by the Member States. Even inside a Member State statistical definitions and administrative definitions might differ significantly. Consequently, the discussion of these terms takes an important place in the rest of the study.

The aim is not to promote research in this field but to use existing data and studies in order to establish concepts, which can be measured in a practical and unequivocal way.

The ECHI project proposed a design for a set of European Community Health Indicators. It proposes a list, which includes notably, chronic disease, functional limitations, activity limitations and a global activity limitations indicator. However, the general approach is dominated by a 'health status' perspective.

Recent work by the World Health Organisation has reoriented the policy perspective. The new International Classification of Functioning, Disability and Health (ICF) has abandoned the traditional causality: impairment - disability- disadvantage and has taken into account social and environmental factors. Activity (the execution of a task or action by an individual) and participation (involvement in a life situation) play a central role in the new classification.

Thus, there is a tendency to broaden traditional concepts and include aspects, which take into account needs for an active participation in society.

Furthermore, 'dependency' must be differentiated from acute sickness and temporary limitations. Dependency raises problems, which are expected to be long standing. Consequently, they require different solutions compared to temporary problems.

In the following the term 'dependency' does not refer to dependency on social protection, neither does it to the ratio of retired (or inactive people) to the working age (or active population). It refers to physical, mental, communication, etc. dimensions that will be developed further later on.

This means that the terms used below do not refer to national social protection schemes but to concepts used in national and European surveys. Many surveys share a certain number of common elements and approaches. This common trend is the result of the use of international classifications developed notably by the World Health Organisation. Proposals concerning the elaboration of comparable statistics make reference to the work done in the relevant international organisations.

PART A

STATISTICS CONCERNING DEPENDENT PEOPLE

SECTION I

CHARACTERISTICS OF DEPENDENT PEOPLE

Introduction

This part presents the data identified in the Member States.

The main sources of statistics are:

- Specific surveys on care dependency undertaken by the Member States
- Health Interview Surveys
- Other surveys including questions on related themes.

Most surveys on care dependency are related to disability surveys. Specific surveys on care dependency have been undertaken notably in France, Austria and the United Kingdom.

It is important to notice that age is an important criterion. There are an increasing number of surveys, which makes a distinction between adults of a working age and the elderly people.

In the first case, the dominant aspect is (re) integration in the labour market. The surveys focus on work-disability. Reported statistics concern impairments, disabilities and exceptionally handicaps[1]. In the case of the elderly people, the labour market dimension is absent and focus is put on long-term dependency. In this case, the survey aims to identify people who can do a certain number of activities and those who cannot or need help.

In all cases, there is a clear distinction between a temporary limitation and a permanent dependency. All surveys have filtering questions in order to identify a permanent status and a temporary one. Of course 'permanent' does not necessarily mean forever. Both in social security and in statistical approaches the term 'permanent' means a status/situation that is expected to last in general at least six months or one year.

This does not mean that temporary dependencies are not important in quantitative terms. The sum of all spells of temporary limitations might be important as it concerns the whole population.

Another important aspect is the ageing of the population, which raises questions very different from those put by disability in general in terms of health care, nature of assistance, etc.

Health Interview Surveys (HIS) are an important source of data. However, a first limitation relates to the classifications used. These surveys aim to collect information on health issues. Consequently, they use medical classifications that are restrictive for our goal. In fact, dependency and care may refer not only to health problems but also to social activities (e.g. go out, prepare a meal, make shopping, communicate, etc.). Meanwhile, a certain number of these surveys take into account this dimension. They include questions concerning limitations on daily activities.

There are a high number of surveys, which include questions relating to dependency and long term care of the elderly people. These statistics are often fragmentary and raise many problems of comparability. However, they present statistics in some interesting areas.

Surveys on Living Conditions and Time Budgets include questions concerning the time spent to take care of a dependent person. We encounter a comparability problem across countries, as well as a second problem related to the objectives of these surveys. The statistics report the time spent by a person to take care of someone. It does not present the number of persons cared for. The aim here is more to identify the characteristics and needs of the carer rather than the person cared for.

[1] See the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in the Glossary.

In general, the census 2000/2001includes questions on long-term care but the Member States have not yet published statistics on long-term care needs or supply. Also, past census did not exploit such information.

It is important to note, that the introduction of a long-term care insurance scheme has been an important incentive in some countries for the development of statistics on care dependent elderly people.

In the following, we present the main statistics identified in the Member States.

Chapter 1

Number of dependent people

Statistics on disability constitute an important source of statistics on care dependent persons. The European Community Household Panel (ECHP) presents the number of persons who are hampered in their daily activities by chronic physical or mental health problems, illness or disability.

However, not all persons with a disability are dependent persons. Notably, persons with a moderate disability might experience little need for help or assistance from a third party. A best proxy for people needing help in a wide sense might be 'severe' disability.

Concerning people aged 65 and over, about 21% of the population reports to be severely hampered in their daily activities (ECHP, 1999). Prevalence of severe disability is only 8% for persons aged 16 and over. This rate increases with age as will be developed in the next chapter. Table 1 presents the data for the EU countries.

The prevalence of disability is different across countries and might be explained notably by:

- subjective interpretations of the same question. In fact, the question is too general.
- socio-economic conditions (poverty levels, working conditions, rural/urban context, family ties, etc.).
- linguistic/cultural interpretations of the same concepts,
- etc.

The different waves of the ECHP provide estimates for severe limitations, which are generally stable, except for Belgium, Denmark and the United Kingdom.

However, not all persons with a severe limitation might be considered dependent. A severe limitation might indicate that some persons are doing a daily activity with some problems but do not necessarily need help. This might affect the quality of life but in a strict sense does not necessarily imply a regular and permanent help. For example a person missing an arm is considered in most Member States as severely disabled. Still, he is not considered as a dependent person. Similarly diabetes or hearts problems might restrict severely daily activities but do not always imply constant help. This however, might engender a need for occasional help. Consequently, the number of persons with severe limitations might be used as an upper limit for the number of dependent people.

Comparability across countries is reduced by the way the question is put. In fact, the degree of dependency has an important impact. As it will be discussed below, there are a high number of people with a slight need for long-term care. Their inclusion or not might affect significantly the reported estimates. Furthermore, self-assessment is subjective and comparison across individuals difficult.

In general, surveys focusing on disability report higher rates. In fact, countries using the International Classification of Impairments, Disabilities and Handicaps (ICIDH), elaborated by the World Health Organisation, centre on impairments or limitations, which do not always reveal a need for assistance.

Surveys using questions on Activities of Daily Living (ADL) limitations present statistics, which are more comparable. In fact, comparability is always enhanced if the interview uses a control list of activities rather than a general self-assessment question. However, not all of them use the same number of activities, as will be discussed later.

Another important problem arises from the distinction between need for care and effective provision of care. As one might expect, not all elderly persons with a long-term care need receive help or assistance. Consequently, the rate of elderly persons receiving care or assistance might be significantly lower compared to the rate of the elderly persons with care needs.

Yet from another point of view, many persons without need of help receive care notably from the family. Consequently, if we ask: "Did you receive help from the family, etc.", the reported rates might be very high.

Other factors may also have a significant impact and reduce comparability across countries. This might include:

- The organisation of care and assistance systems, and
- Cultural factors and lifestyle modes.

In many countries, the provision of home help is means tested. This means that administrative data excludes persons with high resources. Also, social welfare statistics often include the number of beneficiaries of assistance, which might be only a few hours per month. This means that persons with occasional need for help might be included in the reported statistics.

Also, a dependent person may live at home or in an institution. The choice of residence is not independent from dependency. Consequently, it is desirable to have a good representation of people in institutions in the sample.

In order to avoid these problems, we have selected the data according to a certain number of criteria. Of course, the quality of the data is the first criterion. Other criteria include:

- data from surveys covering the whole population (e.g. inclusion of institutions)
- clear reference to the concept of ‘need of help’,
- a minimum regularity of the need or the assistance provided,
- a permanent dependency (excluding acute sickness and short term severe disabilities).

Table 2 presents the main findings. Most surveys focus on elderly people but a certain number of surveys report dependency for young adults.

For comparability reasons, we have separated large from more strict definitions of dependency. Wide definitions include often activities of daily living (washing, dressing, transfer (to or from a bed or chair), going to the toilet, continence and eating) and instrumental activities of daily living (using the telephone, shopping, food preparation, housekeeping, laundry, travel, responsibility for own medicine and ability to handle finances). Narrow definitions of dependency focus on activities of daily living, notably personal care. Furthermore, they require a significant, or continuous or regular need for help.

We have tried to construct a narrow definition using personal care needs and a wider one including activities of daily living and instrumental activities of daily living. This was not always possible. In certain cases, we have released the severity of ADL limitations in order to present a wider definition.

Statistics generally cover people aged 65 and over. However, a certain number of surveys indicate that approximately 4% of the total adult population might be considered as dependent. This percentage is only indicative and is based on a relatively wide definition of dependency. For comparability reasons, we have excluded Denmark as the reported rate in table 2 gives ‘restriction’ which does not mean necessarily a long term need for help.

The different surveys give a clear relation between age and dependency prevalence. Consequently, the rates are much higher for the elderly persons. However, there is a high variation across countries for a

given age group. For information, we could say that the representative proportion of persons aged 65 and over who are dependent ranges approximately from 15 % to 16%. The proportion for persons aged 75 and over is approximately 25% to 26%. Data for Denmark and Austria might overestimate the number of dependent people. In fact, Denmark refers to limitations, while Austria gives intentionally a large definition.

The narrow definition provides a rate of about 2% for the total adult population (see table 3). For the age groups 65+ and 75+ there is a relatively big variation of prevalence.

The reported variations across countries require a deeper analysis of the methods and definitions used. In the following, we present the more salient aspects.

Belgium

Table 2 presents the wide definition. The authors (B2) distinguish: self-dependent persons, moderately care dependent, highly care dependent, and very highly care dependent. They use the Katz index (for persons less than 75 years, they use an approximate Katz index):

- Fully independent person: Katz index = 0.
- Moderately care dependent: Katz index = 1 or 2.
- Highly care dependent: Katz index = 3 or 4.
- Very highly care dependent: Katz index = 5 or 6.

We retain all care dependent persons e.g. persons who are not fully self-dependent. The data includes both persons in private households and in institutions. The estimation covers the Flemish Region.

For comparison, the Belgian Health Interview survey gives 23% for the age group 65 and over, and 33% for 75 and over (B1). It refers to 'Persons with severe limitations' and includes persons with at least one severe limitation among the following ten physical functions: getting in and out of bed, getting up sitting down, dressing/undressing, washing hands and face, eating and cutting food, going to the toilet, urinary continence, walking, hearing and seeing. The rate for persons 75+ is much higher than the estimate provided by the ECHP (1999) (see Table 1). However, the ECHP estimates for the previous years were significantly higher.

The narrow definition 'Highly care dependent (ADL)' includes only highly care dependent, and very highly care dependent people. Table 3 presents the data.

For comparison the proportion of people permanently bedridden, or from time to time and hampered at least from time to time in daily activities is 3% for the age group 15+, 8% for 65+ and 9% for 75+ (B1).

Denmark

Table 2 presents the number of persons with a very restricting long-standing illness.

Germany

The wide definition includes persons with a continuous dependency, daily need for care or a need for care several times a week. For comparison the number of registered disabled people aged 65 and over was 26%. The ECHP (1998) gives 25% for severely disabled aged 65+.

The narrow definition 'Persons needing regular care' includes persons with a continuous dependency or a daily need for care.

Continuous dependency includes persons who need help for all areas of body-care (leave the bed, use the toilet etc.) and are generally immobile. Continence, eating and drinking are the most common factors. Housework is entirely done by a third party.

Daily need for care includes persons who need help for daily hygiene (bath, shower, washing). Mobility and movements of body-parts are restricted (getting dressed etc.). Persons need help in order to do their housework.

Need for care several times a week includes persons who need help for some household-tasks, but are in general still able to cook.

The long term care insurance scheme reports that 12% of people aged 65 and over are beneficiaries of long term care as 23% of people aged 75 and over (1999, D1).

For comparison, in 1999, there were 3.405.470 severely disabled persons (with official certification) aged 65 and over. They were representing 26% of the same age group. Table 1 indicates that this rate is equal to the prevalence given by the European Community Household Panel.

Greece

The European Community Household Panel indicates that the prevalence of limitations (severely hampered persons) by age group in Greece follows a similar path as the EU average. Consequently, we have estimated the dependency rate by exploiting the EU average (see GR1).

Spain

Disability is defined as limiting the human capacity to the point of making a person's normal activity impossible or extremely difficult. The survey's definition of disability is based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH).

The wide definition presents the number of persons with performing housework limitations (housework, shopping and supervising supplies and services).

The narrow definition gives the proportion of persons with caring for oneself limitation. We retained persons with at least one of the following limitations:

- Needs assistance for caring for personal hygiene (washing oneself and taking care of one's appearance),
- Controlling bodily functions and needing assistance to use the toilet,
- dressing, undressing, grooming,
- eating, drinking.

In both cases, statistics include persons with severe disabilities and persons who can't do the activity.

France

The wide definition 'Persons dependent for at least one Activity of Daily Living' covers individuals who answered that they did need help for at least one of the activities of daily living. The survey uses the Katz-index that includes the activities washing, dressing, going to toilet and using it, lying / sitting down and getting up, continence, eat already prepared meals. The survey uses the International classification of Impairments, Disabilities and Handicaps.

It is important to note that the results stem from a survey based on two samples. The first covers persons in institutions and the second in private households.

The narrow definition 'Persons needing significant help' includes persons who have to restrict their activities seriously, or are not autonomous at home or are permanently in bed. They refer to daily normal activities.

Ireland

An overall measure of independence has been calculated from eight categories of daily activities (IRL1), yielding four levels of ability to maintain independence in activities of daily living (ADL):

- the person is completely self-sufficient
- the person is reasonable self-sufficient and experiences some minor and even major difficulties in performing ADL
- the person is still self-sufficient but has many major difficulties in performing ADL
- the person may be called ‘severely disabled’.

The wide definition covers people living in the community who are still self-sufficient but have many major difficulties in performing ADL, and persons who are classified as ‘severely disabled’. The narrow definition reports only the number of older people who are considered ‘severely disabled’ with ADL.

For comparison, the same survey reports that the proportion of older people usually needing help with one or more daily tasks is about 12%.

The rate is higher compared to the percentage of people with a severe limitation given by the ECHP. It is important to note that the latter provides a rate which is significantly lower compared to other Member States. This difference is not related to an age composition effect. The ECHP might underestimate the true value of severe disability.

National estimations (IRL1) indicate that we have to double the rate reported by the ECHP in order to arrive at comparable results with national surveys.

Italy

The index measuring the lack of self-sufficiency is privileged over that measuring the presence of handicaps. Consequently, reported limitations are close to the need of help. The survey uses the International classification of Impairments, Disabilities and Handicaps.

The wide definition 'Persons with serious Activities of Daily Living limitations' includes those who have the maximum degree of difficulty with the following activities: go to bed and get out of bed, sit down in and get up from a chair, washing, dressing, take a shower or a bath and eating.

The narrow definition Table 3) includes persons confined in bed, in a chair or at home. Confinement at home may be due both to physical and psychical problems.

Luxembourg

The socio-economic panel distinguishes five levels: complete autonomy, light loss of autonomy, loss of autonomy but not problematic, serious dependency and severe dependency (L1). Statistics on wide definition present the last two levels (serious and severe dependency). It is important to note that the statistics cover only persons who receive help. Consequently, needs might be higher.

Activities relate to: prepare a hot meal, shopping, climbing stairs, walk inside and outside home, carry an object, take the bus or the train, washing oneself and does not forget to take his medicine.

The narrow definition presents the number of care dependency insurance beneficiaries. Benefits are granted to persons needing the assistance of a third party to do the essential daily activities (L2).

Netherlands

Table 2 presents the wide definition based on activities of daily living. The Activities of Daily Living indicator refers to limitations in carrying out general daily activities. Since 1989 respondents are asked if they can: 'eat and drink', 'sit down in and get up from a chair', 'get into and out a bed', 'dress and undress', 'move to another room on the same floor', 'walk up and down stairs', 'go out and let themselves in again', 'move around outside', 'wash their face and hands' and 'wash themselves completely'. The figures present persons who are not able to do one or more of these activities or only with great difficulty.

We exclude people answering ‘with some difficulty’ but retain persons answering ‘with great difficulty’. This includes people who can do these activities, even with big difficulties, and consequently might not require a continuous help. These rates are close to the prevalence of severe disability.

The Dutch statistics give also the OECD indicator. It refers to limitations in the ability to communicate and move around (follow a conversation, read small print, carry an object weighing five kilos, bend down and pick something up from the ground, walk for 400 meters without stopping). The figures refer to people who reported not being able to do one or more of these activities, or only with great difficulty. This indicator gives 32% for people aged 65 and over. The inclusion of mobility limitations increases sharply the reported rates. This rate is higher than the prevalence of severe disability reported by the ECHP and lower than the prevalence of total disability.

The narrow definition includes people who can do the activities of daily living only with the help of others. The indicator refers to limitations in carrying out general daily activities and excludes instrumental activities.

Austria

Data refers to limitations in the autonomous performance of daily activities that lead to a need for regular or irregular care. A person that needs help for body-care activities at least several times a week is in need of regular care. People that are in need of irregular care are limited for some body-care activities and housework chores and need help at least once a week.

The wide definition 'Persons requiring help (large sense)' defines the need for help in a very wide sense including those persons that e.g. can’t iron anymore or that can’t bend down. Help is provided from time to time or in case of a need. The estimate is close to the ECHP estimate for severe disabilities.

The narrow definition 'Persons requiring regular help (ADL)' includes persons who can no longer do activities of daily living. Support and help is needed regularly.

Portugal

The wide definition 'Persons with severe mobility disabilities' covers persons with a severe reduction or limitation concerning personal mobility or moving objects. Personal mobility includes notably locomotion, displacement and use of transport.

The narrow definition 'Persons with severe ADL limitations' covers persons with a severe reduction or limitation concerning activities of daily living and manual dexterity such as open/close doors, switch on/off light, telephone, manipulate objects, etc.

Finland

The wide definition refers to 'Persons who feel unable to fulfil the demands of everyday life'. The answer distinguishes: never, seldom, every now and then, often and most of the time. The data presented here include ‘often’ and ‘most of the time’.

Sweden

The survey on living conditions (S1) produces different indicators for persons aged 65-84:

- Persons with physical disability: 22%
- Cannot take a short walk at a fairly quick pace: 19%
- Needs help with grocery shopping: 15%.

We have chosen ‘grocery shopping’ as a wide definition rather than those close to severe disability. Taking into account the results of other countries, this indicator is representative of instrumental activities, a relatively wide definition of dependency.

For comparison, in 1999, roughly 8% of people aged 65 and over were entitled to home help services in ordinary housing. The corresponding figure for those aged 80 and over was 20%. In 1980, almost 16% of persons aged 65 and over were entitled to home help services in ordinary housing (S2). This change indicates that social security statistics are very sensitive to restrictive policies concerning help and may not be used as an indicator of actual needs. Home help services include service tasks (e.g. cleaning and doing laundry, help with shopping, post office and bank errands and preparation of meals) and personal care (e.g. eating and drinking, getting dressed, personal hygiene and moving about).

United Kingdom

The data comes from the Health Survey for England. They use the WHO (World Health Organisation)-ICIDH protocol.

The wide definition 'Persons with a personal care disability' (2001) is based on the activities of daily living such as washing, dressing, feeding, using the toilet, and requiring help getting in and out of a bed or a chair.

The narrow definition 'Persons with a severe personal care disability' (2000) comes from the Health Survey for England. In accordance with the WHO (World Health Organisation)-ICIDH protocol, disability was measured across five domains: locomotor, personal care, sight, hearing and communication. For each domain, the level of severity was scored into none (0), moderate (1) and severe (2).

The criteria was given by the activities of daily living such as washing, dressing, feeding, using the toilet, and requiring help getting in and out of a bed or a chair. The persons who needed assistance with any of these tasks were classified as severely disabled on the personal care disability dimension.

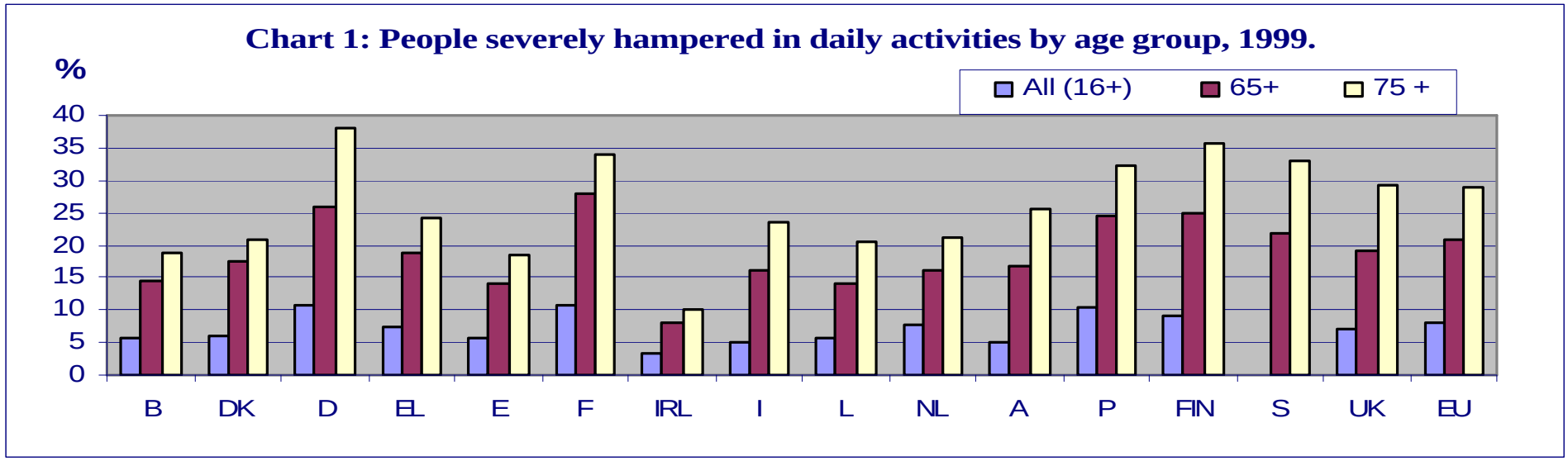
It is important to notice that the 2000 Health Survey for England includes two samples: one concerning private households and one covering care homes.

PEOPLE WITH SEVERE LIMITATIONS

Table 1: People severely hampered in daily activities by age group; Percentage of the same age group, 1999

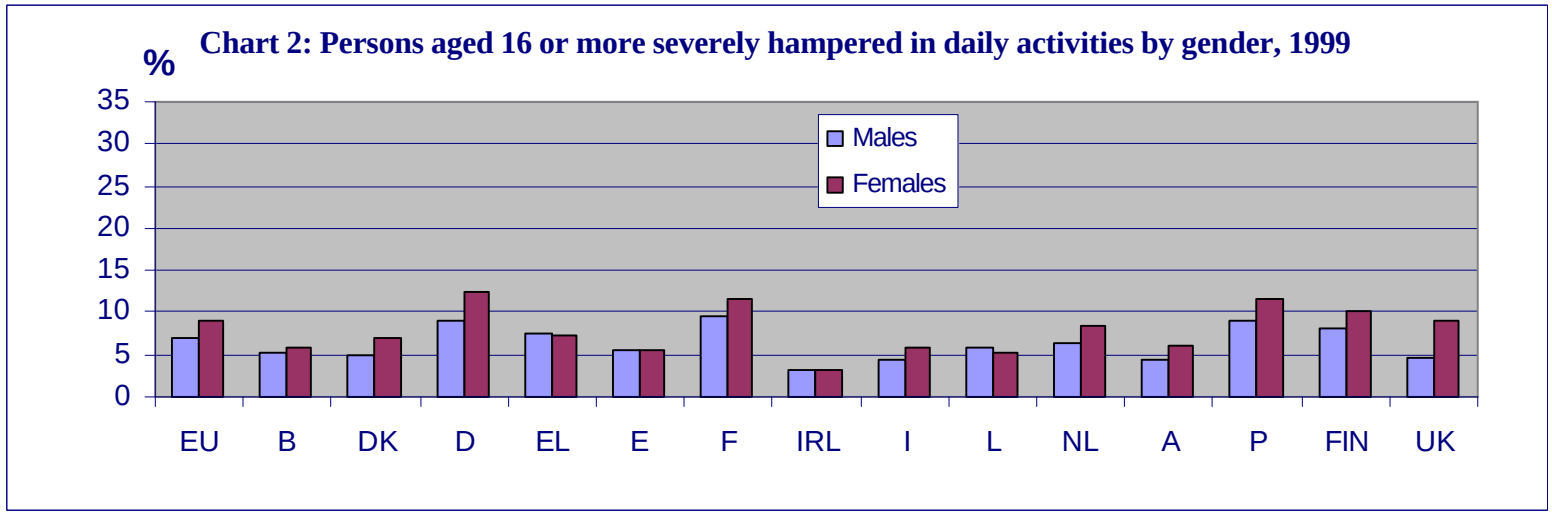
	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK	EU
	% (Percentage, same age group)															
Age																
All (16+)	6	6	11	7	6	11	3	5	6	8	5	10	9		7	8
65 +	14	18	26	19	14	28	8	16	14	16	17	25	25	22	19	21
75 +	19	21	38	24	19	34	10	24	20	21	25	32	36	33	29	29

Source: Eurostat (ECHP 1999) and S1. The data covers private households. The Irish data might underestimate the true value.
Note: For comparison the Survey of Income and Program Participation in the US gives: all (0+): 10%, 65+: 34%. [2]

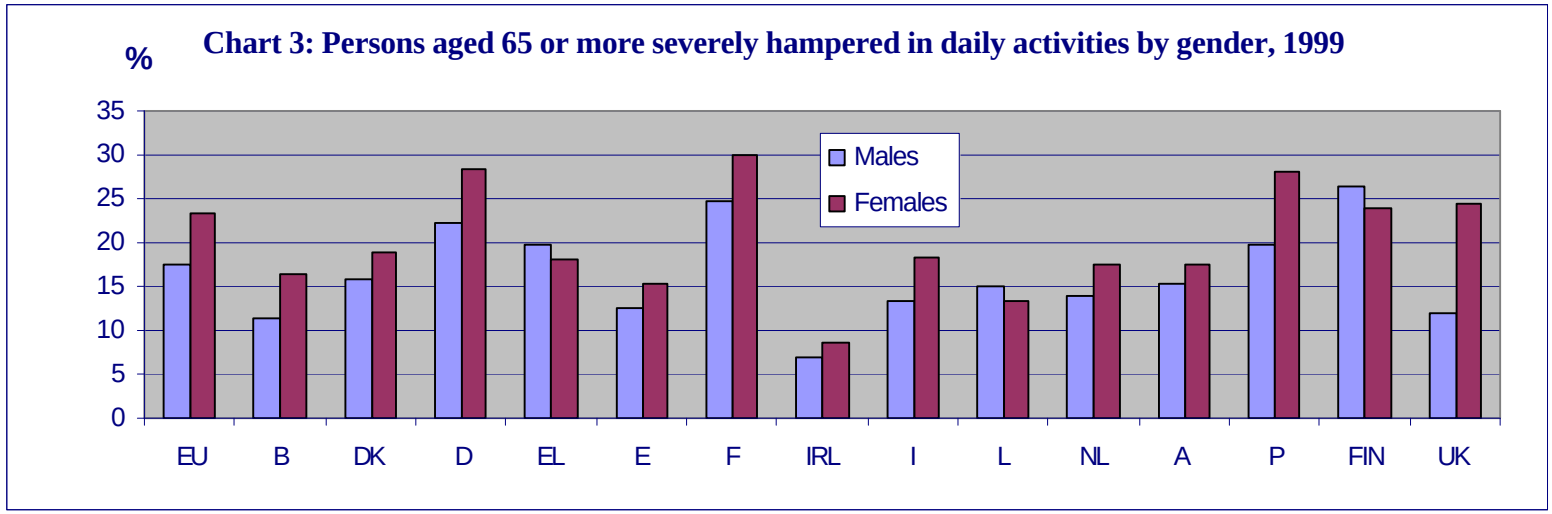


Source: Eurostat (ECHP 1999) and S1. Data covers private households.

[2] John M. McNeil, 'Americans with Disabilities: 1991-92; Data from the Survey of Income and Program Participation', Current Population Reports, Household Economic Studies, Bureau of the Census. 1994.



Source: Eurostat (ECHP 1999). Data for Luxembourg: 1996. Private households.



Source: Eurostat (ECHP 1999). Data for Luxembourg: 1996. Private households.

DEPENDENT PERSONS

Table 2: Prevalence of dependency as a percentage of the population covered of the same age group (Wide definition)

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK	
Definition	Persons with ADL limitations	Persons with very restricting long-standing illness	Persons needing regular care and help for housework	Persons with ADL limitations	Persons with performing housework limitations	Persons dependent for at least one ADL	Persons having major difficulties with ADL	Persons with serious ADL limitations	Dependent persons receiving help	Persons with ADL limitations	Persons requiring help (large sense)	Persons with severe mobility disabilities	Persons unable to fulfil demands of everyday life	Persons needing help (shopping)	Persons needing help (mobility)	Persons with a personal care disability
Year	1997	2000	1991/92	1999	1999	1998/99	2000	1999/00	1992	2000	1996	1995	2001	1996/97	1998	2001
Type of residence	All	All	Priv house	All	Priv house	All	Priv house	Priv house	Priv house	Priv house	All	All	Priv house	Priv house	Priv house	Priv house
Source	B2	DK1	D2	EL1	E1	F1	IRL1	I1	L1	NL1	A2	P2	FIN1	S1	UK3	UK1
Adults Age group	15+	16+				20+		25+		20+		All				
Men		10						2								
Women		13						4								
Total	**4**	**12**				**4**		**3**		**5***		**4**				
65+ Age group	60+	67+	65+	65+	65+	60+	65+	65+	60+	65+	65+	65+	65-84	65-84	65+	65+
Men		25			9	9	8	9	10				13		9	15
Women		27			20	12	18	15	14				12		19	17
Total	**17**	**26**	**19**	**14***	**15**	**11**	**14**	**12**	**12**	**18**	**26**	**14**	**12**	**15**	**15**	**16**
75+ Age group		80+	75+	75+	75+	80+	75+	75+	80+	75+	75+	75+	75-84	75-84	75+	75+
Men		29			19	23		17					17		14	18
Women		34			32	34		27					16		29	21
Total	**30**	**32**	**30**	**23***	**27**	**31**	**20***	**23**	**25**	**27**	**37**	**20**	**16**	**22**	**23**	**19**

Notes
For a description of the different concepts used in this table, see the discussion in the text.
*: Estimation.

DK	For comparison, the 1994 survey provided for 16+: 12,2%.
B	For comparison B1 gives for persons with a severe limitation in at least one of 10 ADL functions, in 2001: 15+: 7%; 65+: 23% and for 75+: 33%.
E	Data refers to disabilities.
NL	For the estimation see NL1. The observed prevalence for the age group 55+ is 13% (men: 8%, women: 17%). For comparison the proportion of people with severe limitations is 12,5% (16+) and 31,6% (65+), in 2000.
S	Total '65+' covers the age group 65-84 and '75+' covers 75-84.
FIN	Persons who feel unable to fulfil the demands of everyday life. Total '65+' covers the age group 65-84 and '75+' covers 75-84.

Note: For comparison the Survey of Income and Program Participation in the US gives for persons needing assistance for one or more IADL: all (15+): 4,5%, 65+: 17%. (John M. McNeil, 1994)

Table 3: Prevalence of dependency as a percentage of the population covered of the same age group (Narrow definition)

	B	D	E	F	IRL	I	L	NL	A	P	UK
Definition	Highly care dependent persons (ADL) or plus	Persons needing regular (personal) care	Persons with caring for oneself limitations	Persons needing significant help	Persons having severe difficulties with ADL	Persons confined in bed, in a chair or at home	Care dependent insurance beneficiaries	Persons needing help for ADL	Persons requiring regular help (ADL)	Persons with severe ADL limitations	Persons with a severe personal care disability
Year	1997	1991/92	1999	1991	2000	1999/00	2002	2000/2001	1996	1995	2000
Type of residence	All	Priv house	Priv house	Priv house	Priv house	Priv house	All	Priv house	All	All	All
Source	B2	D2	E1	F2	IRL1	I1	L2	NL1	A2	P2	UK1
Adults											
Age group	15+	40+		20+		6+				16+	
Men											
Women											
Total	**2**	**3**		**2**		**2**				**1**	
65+											
Age group	60+	65+	65+	65+	65+	65+	60+	65+	65+	65+	65+
Men			7		4	6					5
Women			10		11	11					5
Total	**8**	**7**	**9**	**8**	**8**	**9**	**5**	**7**	**6**	**4**	**5**
75+											
Age group	75+	75+	75+	75+		75+	80+	75+	75+	75+	80+
Men			14			12					10
Women			18			19					12
Total	**12**	**12**	**17**	**12**		**16**	**11**	**12**	**10**	**7**	**11**

Notes

For a description of the different concepts used in this table, see the discussion in the text.

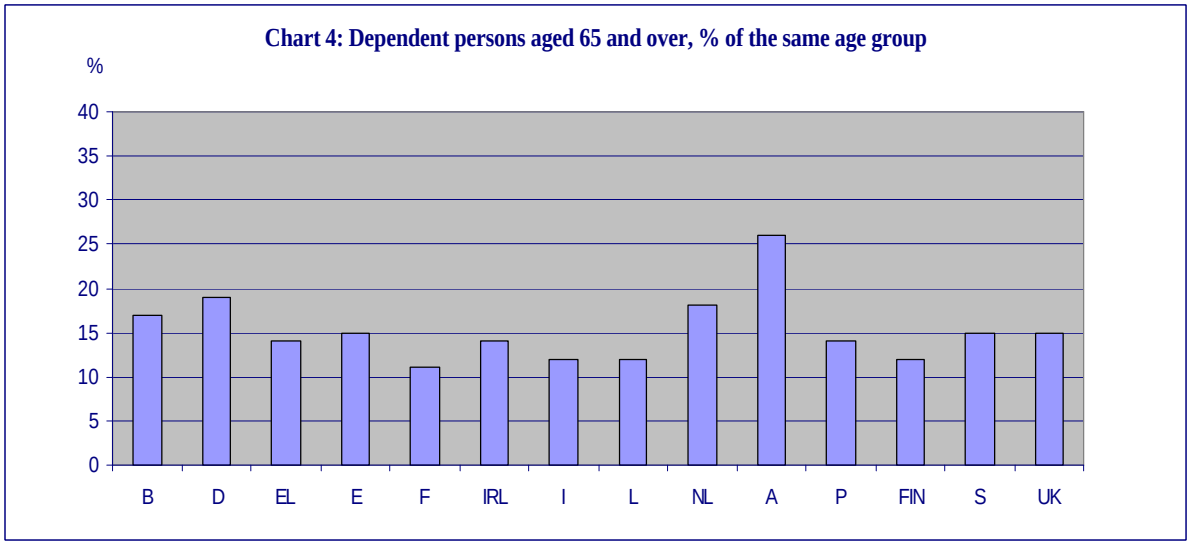
B For comparison the proportion of persons permanently bedridden, or from time to time and hampered at least from time to time in daily activities is: 15+: 3%; 65+: 8% and 75+: 9%.

E Data refers to disabilities.

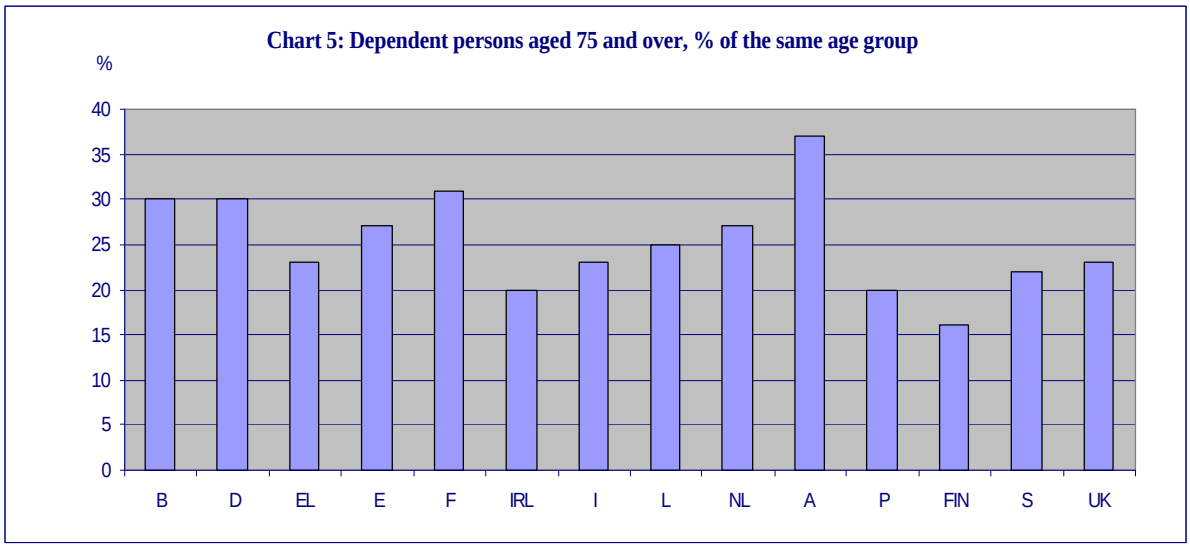
F Persons with serious restricted activities, not autonomous at home, and bedridden.

UK Persons with a serious personal care disability: Age groups: 65-79 and 80+. Data refers to England.

For comparison, the Survey of Income and Program Participation in the US gives for persons needing assistance for one or more ADL: 2%, (15+), and 8% (65+) (John M. McNeil, 1994).



Note: See Table 2 for the definitions, the population covered, the sources and the explanatory notes.
The survey for Austria has adopted a relatively wider definition.



Note: See Table 2 for the definitions, the population covered, the sources and the explanatory notes.
The survey for Austria has adopted a relatively wider definition.

Chapter 2

Distribution by age group

The previous chapter presented two indicators of dependency for the total population and for elderly people. On several occasions we noted that the proportion of people who are dependent increases strongly with age. The present chapter presents this relation in more details.

Age is important since the needs and expectations of individuals are influenced by age. A person of a working age might have work expectations, which are absent for persons aged 65 and over. Of course both might expect some form of assistance, which might enable them to do the essential activities of daily living and if possible participate actively in social life.

First we present in Chart 6 the prevalence of moderate and severe limitations in the EU by age group. The chart reports the percentage of people hampered in their daily activities (moderate or severe limitation) and the percentage of people who are severely hampered by age group. This serves only as a reference to the following, which presents the proportion of dependent people by age group. As we have noted above, the percentage of persons with a severe limitation might serve as an indication of the upper limit of the prevalence of dependency.

Tables 4 and 5 present the prevalence of dependency by age group. Again we distinguish between a wide and a narrow definition of dependency.

The tables reveal that a first problem relates to the use of different age groups. However, this does not hide the general trend across ages.

A second problem concerns the nature of data. Disability and health-related surveys (notably DK) report higher rates. These rates measure severe disability rather than dependency. In fact, as it was noted in the previous chapter, these statistics refer to severe disabilities, and a severe limitation might not necessarily generate a dependency. In terms of Chart 6, this means that these large concepts are close to severe limitations.

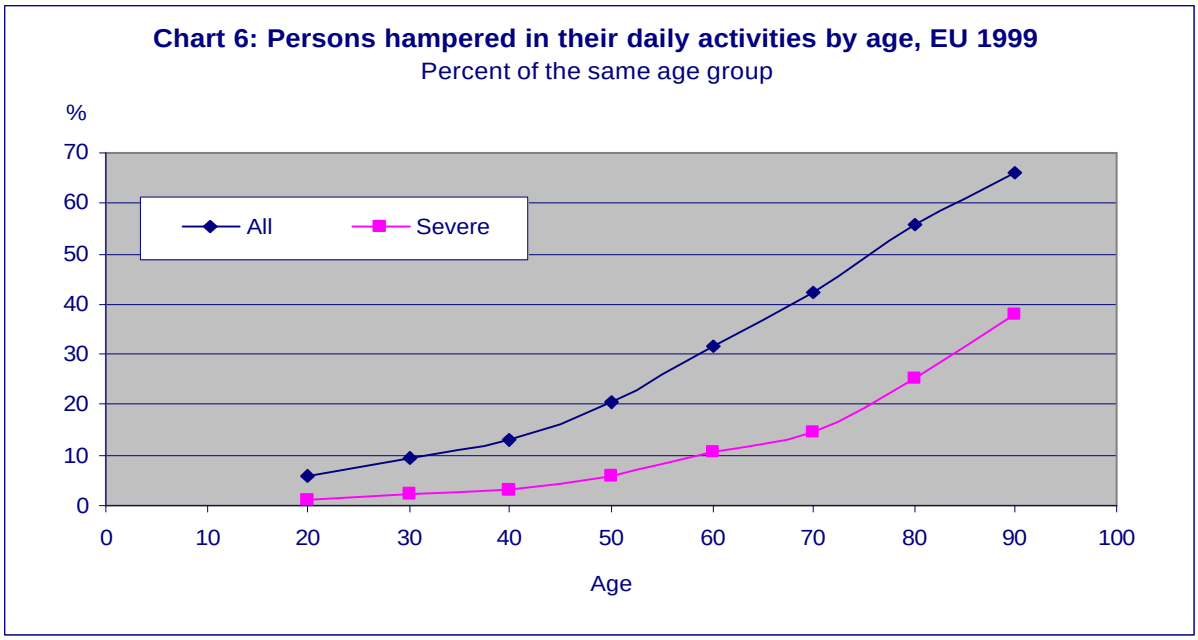
An important distinction concerns the frequency of needs and the degree of dependency. Surveys which use a wide definition of dependency e.g. Austria (Table 4) report rates which are close to the prevalence of severe disability.

On the contrary a narrow definition (Table 5) gives a much lower dependency rate.

To summarise, we can say that differences in dependency prevalence by age group may stem notably from:

- differences in methodology (only a few surveys cover institutions),
- differences in the reference year,
- differences in the definition of dependency (nature of activities covered),
- differences in the definition of the degree of dependency (regular needs, daily needs, etc.).

Available data indicates that the dependency rates for women are higher. However, this is partly or totally due to the longer life expectancy of women.



Source: Eurostat (ECHP, 1999). Private households.

Table 4: Prevalence of dependency by age group, as a percentage of the population covered of the same age group (Wide definition)

	B	DK	D	E	F	I	L	NL	A	P	FIN	S	UK
Definition	Persons with severe ADL limitations	Persons with very restricting long-standing illness	Persons needing regular care and help for housework	Persons with performing housework limitations	Persons dependent for at least one ADL	Persons with serious ADL limitations	Dependent persons receiving help	Persons with ADL limitations	Persons requiring help (large sense)	Persons with severe mobility disabilities	Persons unable to fulfil demands of everyday life	Persons needing help (shopping)	Persons with a personal care disability
Year	2001	2000	1991/92	1999	1998/1999	1999/00	1992	2000/2001	1996	1995	2001	1996/97	2001
Population	All	All	Priv house	Priv house	All	Priv house	Priv house	Priv house	All	All	Priv house	Priv house	Priv house
Source	B1	DK1	D2	E1	F1	I1	L1	NL1	A2	P2	FIN1	S1	UK1
20-24		3			1								1
25-29	3	6				1				1			2
30-34					1								
35-39	2									1			4
40-44					2								
45-49	4	14				1				3			6
50-54					4								
55- 59	7					2		5		7		5	11
60-64					5		8	6	14				
65-69	15	24	8	6		5		8	15	10	9	9	13
70-74			12	10	9			16	22		8		
75-79	33		19	16		12	12	23	29	20	16	22	17
80-84		32	30	26	26	35	25	35	40		20		
85-89			55	45					45				31
90 +					53								
Total (65+)	**23**	**26**	**19**	**15**	**11**	**12**	**12**	**19**	**26**	**14**	**12**	**15**	**16**
Total (75+)	**33**	**32**	**30**	**27**	**31**	**23**	**25**	**28**	**37**	**20**	**16**	**22**	**19**

Notes
For a description of the different concepts used in this table, see the discussion in Chapter 1 and 2.

B: Persons with at least one severe limitation among the ten physical daily activities and sensory functions. Last age group: 75+.
DK: Persons with very restricting long-standing illness; the age groups are: 16-24, 25-44, 45-66, 67-79 and 80+. Totals refer to 67+, 67-79 and 80+.
E: Data concerns disabilities. For comparison the percentage of people (65+) with a severe limitation concerning the activities of daily living is 15%. Last age group: 85+.
F: Persons dependent for at least one ADL: Age groups: 20-29, etc. and 90+. Totals refer to 60+ and 80+.
For comparison the number of persons in private households who received help was: 20% (65-69), 22% (70-74), 35% (75-79), 55% (80-84), 70% (85-89) and 85% (90+.
I: provisional data by age group. Age groups: 25-44, 45-54, 55-64, 65-74, 75-79, 80+.
L: Age groups: 60-69; 70-79; 80+. Totals: 60+, 60-79 and 80+.
NL: The last age group refers to 80+. These are pooled data combining 2000 and 2001.
A: The percentage by age group of persons needing care follows a similar path as the one for persons requiring regular help. Last age group: 85+.
FIN: Persons who feel unable to fulfil the demands of everyday life. The Age groups are: 65-69, 70-74, 75-79 and 80-84.Total 65+ cover 65-84 and 75+ covers 75-84.
S: Total '65+' covers 65-84 and '75+' covers 75-84.
UK: Persons with a personal care disability. For comparison the survey in 2000 concerning the elderly gives a rate of 16% for all people aged 65+ but does not provide information on younger adults. Age groups: 16-24, 25-34, etc. and 85+. Data refers to England.

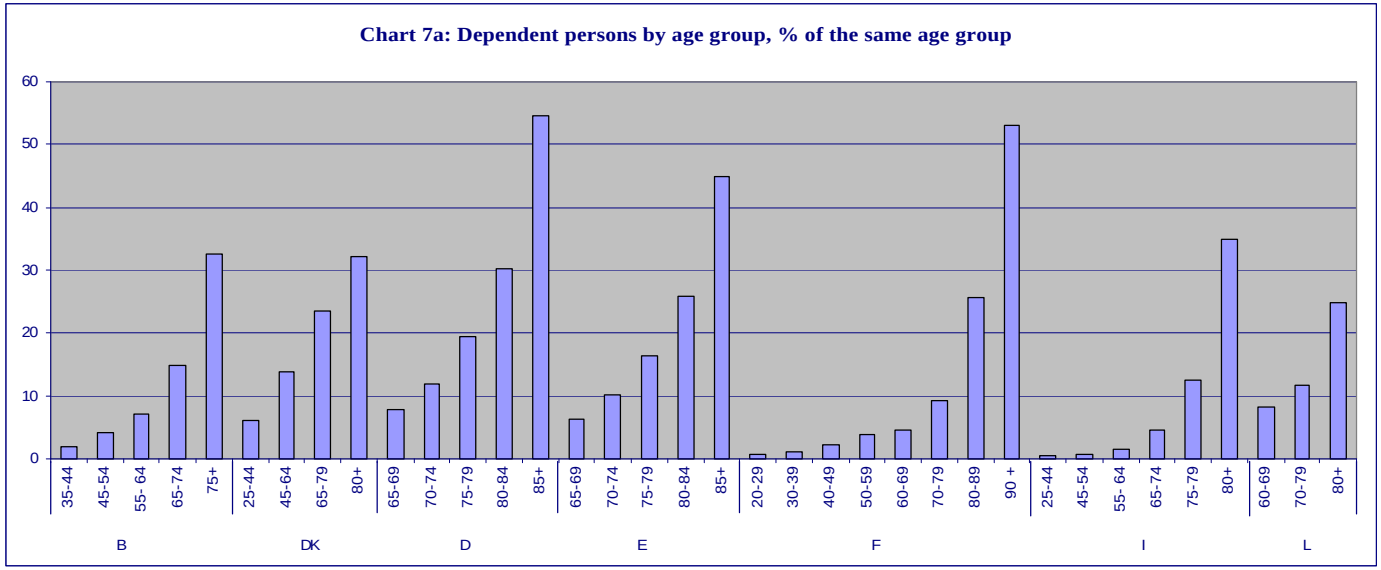
Table 5: Prevalence of dependency by age group, as a percentage of the population covered of the same age group (Narrow definition)

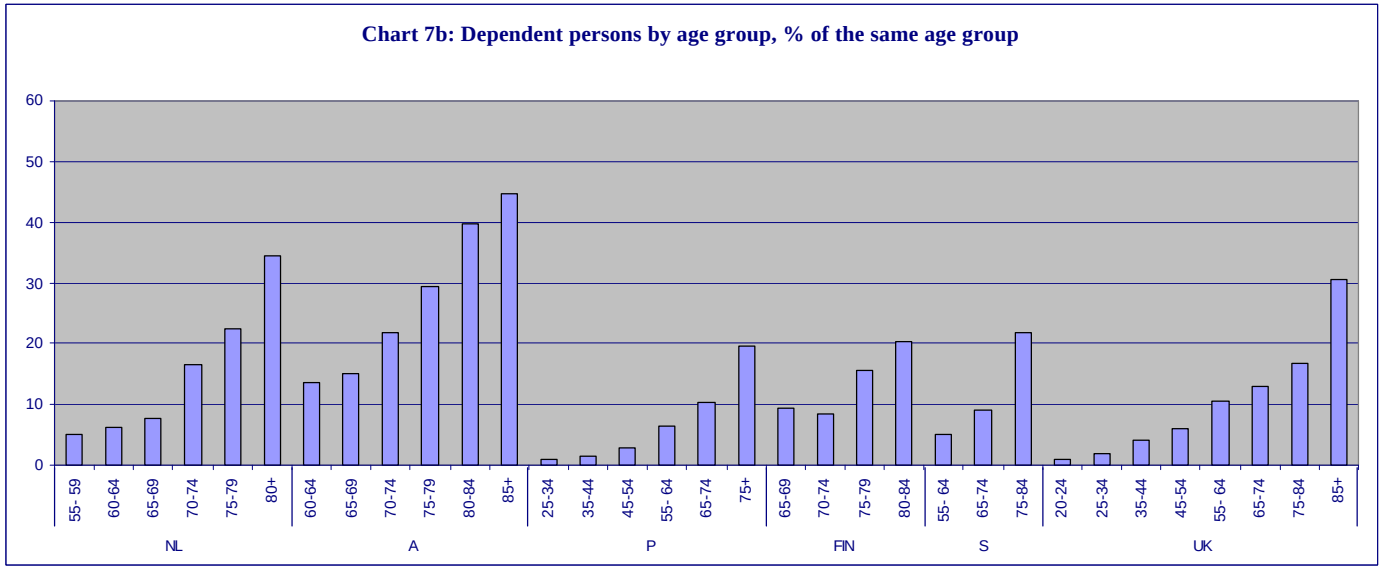
	B	D	E	F	I	L	NL	A	P	UK
Definition	Persons bedridden (from time to time)	Persons needing regular (personal) care	Persons with caring for oneself limitations	Persons needing significant help	Persons confined in bed, in a chair or at home	Care dependent insurance beneficiaries	Persons needing help for ADL	Persons requiring regular help (ADL)	Persons with severe ADL limitations	Persons with a serious personal care disability
Year	2001	1991/92	1999	1991	1999/00	2002	2000/2001	1996	1995	2000
Population	All	Priv house	Priv house	Priv house	Priv house	All	Priv house	All	All	All
Source	B1	D2	E1	F2	I1	L2	NL1	A2	P2	UK1
20-24				1					0	
25-29				1						
30-34	2			0	0	0			0	
35-39				1						
40-44	3			1	0				1	
45-49	5			0		0				
50-54		1		2	1				1	
55- 59	5			2			1			
60-64				4	1	1	1	1	2	
65-69	7	2	3	4	2		2	2	3	3
70-74		3	5	6	4	5	5	4		
75-79		6	8	8	8		9	6		
80-84	9	11	15	10				10	7	
85-89		26	33	23	25	11	16	16		11
90 +										
Total (65+)	**8**	**7**	**9**	**8**	**9**	**5**	**7**	**6**	**4**	**5**
Total (75+)	**9**	**12**	**17**	**12**	**16**	**11**	**12**	**10**	**7**	**11**

Notes

For a description of the different concepts used in this table, see the discussion in Chapter 1 and 2.

B: Permanently bedridden or from time to time and hampered at least from time to time in daily activities.
E: Data concerns disabilities.
F: Persons needing help: persons with serious restricted activities, not autonomous at home and bedridden.
L: Age groups: 19-39; 40-59; 60-69; 70-79; 80+.
P: Age groups: 16-24, 25-34, etc. and 75+.
UK: Persons with a serious personal care disability: Age groups: 65-79 and 80+. Data refers to England.





See Table 4 for the sources, the population covered, the definitions and the explanatory notes.

Chapter 3

Nature of dependency

Previous chapters presented a summary description of a certain number of global indicators chosen for each country. This chapter presents and discusses the nature of dependency used by the Member States in the different surveys.

In the following, we present a summary of the relevant parts of the questionnaires. This will enable the reader to better understand and assess the data reported in the next table 6 and 7.

Tables 6 and 7 are a simplified version of the International Classification of Functioning (WHO).

Belgium

Within the disabilities concerning the most elementary activities of daily life such as getting up, washing oneself, dressing, etc., the survey makes the distinction between those who can do it 'with difficulty' and those 'who necessitate the help of someone else' (B1).

The respondents were asked to value (on a 100 points scale) the physical functions they are still able to perform such as walk (the score100 = no limitation), go up and down stairs, carry a shopping bag, etc. In general, the survey estimates severe limitation, moderate limitation and no limitation. In this case, we have retained persons with severe limitations.

Main questions include:

- mobility; to get up, to lie down; to sit, to get up; go to the toilet.
- to dress, to undress; to wash hands and face; eat and cut food; bite and chew hard food; continence
- hearing
- seeing.

In certain cases, in the following tables, we have completed the survey data with estimations on care dependency based on ADL limitations (B2). The authors distinguish: self-dependent persons, moderately care dependent, highly care dependent, and very highly care dependent.

They use the Katz index (for persons less than 75 years, they use an approximate Katz index):

- Fully independent person: Katz index = 0.
- Moderately care dependent: Katz index = 1 or 2.
- Highly care dependent: Katz index = 3 or 4.
- Very highly care dependent: Katz index = 5 or 6.

Denmark

Data includes persons who have difficulties in doing the different activities, notably:

- follow a normal conversation
- speak (judgement of the interviewer)
- walk 400 m without resting
- walk up and down the stairs from one floor to another without resting
- carry without difficulties 5 kg (e.g. shopping bag)

Germany

The autonomous performance of activities distinguishes doing the activity ‘with difficulties / need of help' and ‘impossible’. The data reported here includes both levels. This means that the data might be broader compared to other countries. The definition of dependency covers chronic diseases, complaints or handicaps, certified severe disability, use of medical-technical aids, long-term dependency on care or help, confined to bed.

The different types of limitations concern:

- Personal Care and Hygiene: Take a bath; take a shower/to wash oneself; take a bath; get dressed/undressed; brush the hair; continence; use the toilet; organise medication.

- Food: Cook; organise medication; cut the food; eat.

- Household performance: Clean the home; go shopping; organise finances; heat the place.

- Mobility at home: Climb stairs; walking in the home; go to bed/get out of bed; sit down/get up.

- Communication/Mobility outside home: Use public transport; visit people; orientate outside home; use telephone.

- Other: be alone for hours.

This last question has also been used in French surveys in order to measure mental/psychological dependency.

The German National Health Examination and Interview Survey has a bloc of questions with some ADL activities. However, the statistics are not comparable with those of other countries, since they distinguish: a) limited a lot, b) limited a little, and c) not limited at all.

Spain

The severity grade of a disability relates to the difficulty (no, moderate, severe and total difficulty) in performing daily activities. Disability is defined as limiting the human capacity to the point of making a person’s normal activity impossible or extremely difficult. The survey uses the International Classification of Impairments, Disabilities and Handicaps (WHO).

Unlike previous data, present data refers to disabilities and not to persons. A person may declare several disabilities.

People (65+) with a severe or total disability by limitations of activities of daily living include:

- seeing: disability in receiving any image; disability in overall visual tasks; disability in detailed visual tasks; other visual disabilities.

- hearing: disability in receiving any sound; disability in hearing loud sounds; disability in hearing speech.

- communicating: communicating through speech; communicating through alternative languages; communicating through non-signing gestures; communicating through conventional reading and writing.

- learning, applying knowledge and performing tasks; recognising people, objects and orienting oneself in space and time; remembering information and recent and/or past events; understanding and carrying out simple commands and/or performing simple tasks; understanding and carrying out complex commands and/or performing complex tasks.

- getting around: changing and maintaining different body positions; getting up, lying down, standing or sitting; getting around inside the home.

- using arms and hands: moving-carrying light objects; using utensils and tools; manipulating small objects with hands and fingers.

- getting around outside the home: getting around without a means of transportation; getting around using public transport; driving one's own vehicle.

- caring for oneself: caring for personal hygiene without assistance: washing oneself and taking care of one's appearance; controlling bodily functions and using the toilet without assistance; dressing, undressing, grooming; eating, drinking.

- performing housework; shopping and supervising supplies and services; preparing meals; washing and ironing clothes; cleaning and maintaining the house; looking after the welfare of other family members.

- relations with other people: maintaining affectionate relationships with close family members; making and keeping friends; dealing with co-workers, superiors and subordinates.

France

The data covers individuals who responded that they did need help for doing the activity in question:

- Self-care: Washing (body hygiene); dressing and undressing; cut food; eating and drinking processed food.

- Elimination: ensure hygiene as well as faecal and urine elimination: use the toilet; control stools and urines.

- Mobility: confined in bed, in the room, inside the home.

- Changing position: get in and out of bed; get seated and get up from a chair.

- Moving inside the home: move about in all the rooms on the same floor; go up and down one flight of stairs; use the lift.

- Moving outside: go out of the home; longest distance one can cover on his own without stopping and being seriously bothered.

- Shopping (direct or mail order buying): do shopping; carry a five-kilo object on a ten-meter distance (for example a shopping bag or a school bag).

- House chores and management; cook; common house chores (dishwashing, laundry, ironing, cleaning); fill in plain forms; manage to order/take a taxi, or use public transportation; take the medicines prescribed by the doctor.

- Distance communication (using means of communication, phone, bell, alarm).

Coherence (conversing and/or behaving sensibly): communicate with relatives.
Orientating (finding one's bearings in time, moments of the day and places): forget the time of a day; find his/her way when going out.

- Sight (see well close to, recognise the face of someone 4 meters away), hearing (hear a conversation), speech.

- Being supple and handling objects: cut toenails, use hands and fingers; open/close a door, turn taps on and off; bend over and pick up an object on the floor (such as a shoe).

Published statistics present grouped data in certain cases.

Ireland

Functional ability was measured using the Stanford health assessment Questionnaire (HAQ). Respondents were asked to rate their ability to perform seventeen daily tasks within eight activity categories in the past week on a four point-scale – 'without difficulty', 'with some difficulty', 'with much difficulty' or 'unable to do so'. An overall measure of independence (ranging from 0-3) can be calculated from the eight categories, yielding four levels of ability to maintain independence in activities of daily living (ADL):

- 0 - 0,5: the person is completely self-sufficient;
- 0,51-1,25: the person is reasonable self-sufficient and experiences some minor and even major difficulties in performing ADL;
- 1,26-2,00: the person is still self sufficient but has many major difficulties in performing ADL;
- 2,10-3,00: the person may be called 'severely disabled'.

The eight categories included:

- Personal care (wash and dry entire body, take a bath, get on/off the toilet, dress, shampoo hair, care of feet and toenails).

- Arising ability (stand up from an armless chair, get in and out of bed).

- Eating and drinking (prepare meals, make a cup of tea, cut meat, lift a full cup of glass to mouth, open a new milk cartoon).

- Walking ability (walk outdoors on flat ground, climb up 5 stairs).

- Reach ability (reach up and get down a five pound object, bend down and pick up clothing from the floor).

- Grip ability (open car doors, open jars previously opened, turn taps on/off).

- Activity ability (do messages, shopping, etc; get into/out of car; do housework).

- Cognitive ability (manage own affairs-pay bills; remember daily tasks).

We retain only persons who are unable to do the activity. Data concerning big categories refers to persons who usually need help for one or more tasks in the category.

Italy

The survey focuses on:

- Confinement: Forced to always remain in bed even if someone is available to help him/her get up; Forced to always sit in a chair or armchair even if someone is available to help him/her walk; Forced to always stay at home without being able to go out for physical or psychological reasons.

- Mobility: Can walk 200 metres or more by him/herself without stopping and without getting too tired, climbing stairs, ability to bend down to pick up a shoe from the floor, go to bed and get out of bed without help, sit down in and get up from a chair without help, and get dressed and undressed without help.

- Self care: Take a bath or a shower, wash his/her hands and face without help, eat without help (even cutting the food without help), manage to chew without difficulty, prepare meals, take medicine by him/herself, and incontinence.

- Communication / Sensory: Watch a television program at a high volume; recognise a friend 1 meter away; Speak without difficulty.

- Instrumental activities: Use the telephone, do shopping, take care of his/her home, wash his/her clothes, use means of public transport, and manage his/her own finances.

In the following table we report cases where he/she can do the activity only with the help of someone. In certain cases we add the two situations: ‘with big difficulties’ and ‘total inability’. This aims to increase comparability with other countries (for example concerning the capacity to speak, ability to bend down to pick up a shoe from the floor and climbing stairs).

Luxembourg

The survey distinguishes five levels: complete autonomy, light loss of autonomy, loss of autonomy but not problematic, serious dependency and severe dependency. Data includes the last two levels (persons with a serious or severe dependency). It is important to note that the data covers only persons who receive help. Consequently, needs might be higher.

Netherlands

The Dutch data distinguishes: No difficulty, with some difficulty, with big difficulties and only wit help. We report the last two dimensions. In presenting the degree of dependency, we make the distinction between the two dimensions. The data might be higher compared to other more restrictive definitions but the numbers concerning only those who need help are small and consequently the reported estimators less efficient.

We do not report information on incontinence since this statistic reports the number of persons who in the latest 12 months suffered from involuntary urine losses and consequently is not comparable with other data.

The ADL (Activities of Daily Living) indicator refers to limitations in carrying out general daily activities. Since 1989 respondents are asked if they can: 'eat and drink', 'sit down in and get up from a chair', 'get into and out a bed', 'dress and undress', 'move to another room on the same floor', 'walk up

and down stairs', 'go out and let themselves in again', 'move around outside', 'wash their face and hands' and 'wash themselves completely'.

The figures present people who are not able to do one or more of these activities, only with great difficulty, and with some difficulty. We report data only for the first two categories.

The Netherlands is the only Member State to report the OECD indicator. For people aged 65 and over, the indicator gives 31,6% (2000). The figure refers to people who reported not being able to do one or more of these activities, or only with great difficulty. For comparison the ADL indicator gives 19%.

The OECD indicator refers to limitations in the ability to communicate and move around; Respondents are asked if they can do the following:

- follow a conversation in a group of 3 or more persons (if necessary with a hearing aid),
- read small print in a newspaper (if necessary with glasses or contact lenses),
- recognise a face at a distance of 4 meters (if necessary with glasses or contact lenses),
- carry an object weighing five kilos (e.g. a bag of shopping) a distance of 10 meters,
- from upright position, bend down and pick something up from the ground, walk for 400 meters without stopping (if necessary with a stick).

The Longitudinal Ageing Study Amsterdam (LASA) (NL2) measures the time needed to:

- Take off a cardigan,
- Walk three meters back and forth,
- Get up from a kitchen chair five times without arms folded.

Data concerning the number of respondents who were not able to perform the test are similar to the ones reported in table 6.

Austria

Interviewed persons responded to the following questions:

Which of the following activities can you do without the help of a third party, only with the help of a third party, not at all:

- getting up and down,
- washing and getting dressed,
- walking in the house,
- eating and drinking,
- easy household tasks – clearing up, doing the dishes, preparing meals,
- difficult household tasks – vacuum cleaning, doing the laundry, hanging up laundry, cleaning the windows,
- going shopping,
- going out and making visits.

Reported statistics in the table include 'only with the help of a third party' and ' not at all'.

Portugal

The health survey reports persons with a long term disability concerning:

- Confinement: always in bed; always bound to a chair; confined to the house

- Mobility: lie down and get up from bed; sit down and get up from a chair; go and use toilet; pick up something from the ground; can walk on a flat terrain without discomfort; climb and go down 12 steps.
- Personal care: get dressed and undressed; wash face and hands; eat (cut food and bring food and drinks to mouth) and incontinence.
- Sensory / communication: listen to TV or radio; distinguish forms and recognise friends; difficulties to speak.

Concerning personal care the answer is: alone, without difficulty; alone with difficulty; with help. We have retained persons who answer 'with help'.
Concerning sensory functions and certain mobility questions the answers are different. In this case, we have retained 'cannot / not at all'. Concerning incontinence we have chosen the stricter definition: at least once per week.

Finland

The survey covers ability to:

- read a newspaper
- hear a conversation
- manage tasks which require good memory and mental effort
- use stairs
- handle matters outside home
- walk outside
- carry heavy things
- cook
- do housework.

The answer distinguishes, in general, ability to do the activity: without difficulties; alone, but it is difficult; yes, if somebody helps; and no, not even with help. Statistics in the following table include the last two degrees.

Sensorial abilities distinguish: No; Yes, but it is difficult; Without difficulties. The data retained includes only those who answer 'No'.

Sweden

The Swedish survey presents data on the following aspects/activities:

- Difficulties to carry heavy objects
- Difficulties to grip, e.g. turn on tap
- Difficulties to climb stairs
- Difficulties to get onto a bus
- Can not take a short walk at a fairly quick pace
- Can not get up from a chair

- Physical disability
- Impaired hearing
- Impaired eyesight
- Seriously impaired working capacity

- Need of care: Need of personal assistance indoors; Need of personal assistance outdoors; Has/in need of taxi services for disabled

- Needs help with: cleaning; grocery shopping; cooking; laundry; bath or shower; getting up or getting to bed.

United Kingdom

The indicator 'Persons with a severe personal care disability' (2000) comes from the Health Survey for England. In accordance with the WHO (World Health Organisation)-ICIDH protocol, disability was measured across five domains: locomotor, personal care, sight, hearing and communication. For each domain, the level of severity was scored into none (0), moderate (1) and severe (2).

- Locomotor disability includes: Difficulty walking 200 meters; Difficulty climbing 12 stairs; Difficulty picking up shoes.

- Personal care disability includes: Difficulty getting in / out of bed; Difficulty getting in / out of chair; Difficulty dressing / undressing; Difficulty washing; Difficulty feeding self; Difficulty getting to / using toilet.

In general, a person may answer: No difficulty; Moderate difficulty; Severe difficulty.

The indicator 'Persons needing help' (1998) covers private households in Great Britain.

The survey reports persons usually unable to manage on their own, for the following activities:

- Mobility: Going out of doors and walking down the road; Getting up and down stairs and steps; Getting around the house; Going to the toilet; Getting in and out of bed.

- Self-care: Bathing, showering, washing all over; Dressing and undressing; Washing face and hands; Feeding; Cutting toenails.

- Domestic tasks: Household shopping; Wash and dry dishes; Clean windows inside; Jobs involving climbing; Use a vacuum cleaner to clean floors; Wash clothing by hand; Open screw tops; Deal with personal affairs; Cook a main meal; Prepare a snack; Make a cup of tea

Comments

Most surveys focus on mobility, self-care and domestic life.

Activities of daily living (ADL) include self-care activities, such as bathing, dressing and feeding oneself. Most Member States focus on the following items:

- washing,
- dressing,
- transfer,
- going to the toilet,
- continence and
- eating.

However, the same denomination often hides different measures. For example washing may refer to wash face and hands, or showering or bathing. It is clear that there is a big difference between the three questions. The last one is the most restrictive and might present the lowest percentage.

Transfer may refer notably to:

- transfer from a bed to a chair, or
- sitting down, standing up.

Walking may refer to:

- walking 100 meters without resting; or
- walking 400 meters without resting;

Going to the toilet refers in many surveys to a mobility problem and notably the capacity to maintain a body position, while use the toilet refers often to a continence problem. In the latter case, the reported rates may vary sharply according to the question. The question "Did you have a problem during the last month" will give a very high rate in comparison to the question "Do you have every day …".

Eating sometimes is combined with problems related to the use of hands (for example cut food) while in other cases it has a very restrictive sense.

Watching, listening and speaking are included in most surveys. It is important to note that all report difficulties concerning these functions. As one could expect the reported rates are relatively high. On the other hand some surveys report total inability.

Recent EU policies on improving the quality of life of the elderly people and improving equal opportunities in social and leisure activities has put emphasis on social and cultural participation.

There is an increasing tendency to include Instrumental Activities of Daily Living (IADL). They include domestic activities such as cooking, shopping and house keeping.

Communication and relations with others are items, which are more difficult to measure, and only a few surveys have included them. They are called to take a higher importance in the future for the following reasons:

- they are important determinants of social participation, and
- they might be important factors for certain persons in their decision to enter into an institution.

Communication is taken into account, but big differences exist across countries (Germany: use the telephone, visit people; DK: follow a normal conversation; E: maintaining relations with other people; F: coherence, communicate with relatives; A: making visits; etc.).

Table 6: Nature of dependency. Number of elderly persons with a specific dependency as a percentage of the population covered of the same age group.

		B	DK	D	E	F	IRL	I	L	NL	A	P	FIN	S	UK
	Definition	Persons with severe limitations	Persons who have difficulties	Dependent persons	Persons with a severe disability	Persons needing help	Persons unable to do the activity	Persons with serious difficulties	Persons receiving help	Persons with severe limitations	Persons needing help	Persons needing help	Persons needing help	Persons needing help	Persons needing help
	Age group	65+	60+	65+	65+	60+	65+	65+	60+	65+	60+	65+	65-84	65-84	65+
	Year	2001	1994	1991/92	1999	1998/99	2000	1999/00	1992	2000/2001	1998	1998/99	2001	1996/97	1998
	Population covered	All	All	Pr. House.	Pr. House	All	Pr. House.	Pr. House.	Priv house	Priv house	Priv house	Priv house	Priv house	Priv house	Priv Hous
	Source	B1	DK1	D2	E1	F1	IRL1	I1	L1	NL1	A1	P1	FIN1	S1	UK3
I	**Mobility**	11					10	17	6						
a	Changing body positions (sitting down, standing up, getting into/out of a seat)	4		6	6	3	4	7		3	4	4		4	2
b	Maintaining a body position				4										
c	Go to/use the toilet	2		5	3	3	3					4			1
d	Lifting and carrying objects		*32*			5	8	17		11		9	16		
e	Hand and arm use			5	7	2	8							*10*	2
f	Walking		*33*		7		4	10		2		2	6	*19*	
g	Climbing stairs		*30*	18		7	5	18		16	12	7	6	*24*	9
h	Moving around														
	-Inside the home	11		6	5	3		5		4	3	6		2	1
	-Outside the home			17	14	17				9			9	6	12
II	**Self-care**	14			6		16	13					12		
a	Washing	5		10	5	8	5	4	3	5	7	5		4	7
b	Caring for body parts			5			10								30
c	Toileting (incl. continence)	13		5		3						13			
d	Dressing	6		10	5	6	3	7		3		5			3
e	Eating	3		3	} 1,9	1		4		0	} 2,6	3			1
f	Drinking					3									
g	Looking after one's health			6		3									
III	**Domestic life**														
a	Preparing meals			11	8	6	7		4				9	8	7
b	Doing housework			20	12	13	11		7		13		23	17	10
c	Shopping			19	9	21	10			20	22			15	14
IV	**Communication**				2	1									1
a	Speaking		*5*			0		2		1		4			
b	Conversation		*26*							9					
V	**Sensory experiences & solving problems**							4							
a	Watching	1			6	3		2		3		2	2	*6*	3
b	Listening	2			4	2		3				2	4	*29*	2
c	Solving problems / making decisions			11	7		7						7		6
VI	**General tasks and demands**														
a	Understanding tasks				3	13			4				8		
b	Handling stress														
c	Memory / orientation			10		2	5								
VII	**Community and social life**			14	5						16				
VIII	***Total reference population 1.000s***	*1,730*	*1,040*	*12,795*	*6,435*	*12,072*	*426*	*10,049*	*75*	*2,164*	*1,547*	*1,627*	*707*	*1,353*	*9,282*

Notes

The table indicates that in Belgium 4% of persons aged 65 and over are dependent for mobility activities.
Numbers in Italics refer to difficulties.
'Total reference population' presents the total number of persons (private households and establishments). The reader has to use with caution these numbers as a certain number of estimates cover only people living in private households.

B	II: Activities of daily living; IIe: includes arms use limitations.
DK	If: Walk 400 m without resting; Id: Carry 5 kg without difficulties.
D	If: to organise medication; IIb: Brush the hair; VII: Visit people.
E	Ib: Changing and maintaining a body position; If: Getting around; Vc: looking after the welfare of other family members; VIa: Learning and applying knowledge.
F	Ia: Lying down /getting up from a bed. For comparison getting into/out of a seat: 2,4%; Ie: for comparison cut food: 4%. Id: Pending and taking an object. We did not report, 'cut toenails': 22,0%. Vic: Refers to memory, for comparison orientation: 1%.
IRL	I: Walking ability; Ie: grip ability; II: Personal grooming; IIa: Take a bath: 8%; IIb: Care of feet and toenails; Vc: manage own affairs (pay bills)
I	I: includes walking, climbing stairs, bending and Ia; Ia: getting into and out of bed; Id: Pending and taking shoes; If: Can walk only a few steps; Iha: Confined at home; II: Includes activities of daily living; IIa: Needs the assistance to wash hands and face. For comparison 12,5% need assistance for shower or bath; IIe: Needs help to eat and cut food; V includes sight, hearing and speech; Va: See and recognise at 4 meters. The data include both 'with big difficulties' and 'total inability' in the following cases: capacity to speak, ability to bend down to pick up a shoe from the floor and ability to climb stairs.
L	The nature refers to the type of assistance. Data refers to persons with a serious or severe dependency receiving often or daily help. VIa: Administrative procedures.
NL	Ia: getting in and out of bed. The corresponding rate for getting in and out of a chair is 3,6%. If: move to another room on the same floor; for comparison, walk for 400 meters without stopping: 13,9%. IIa: Wash oneself completely. For comparison the prevalence for washing face and hands is 0,6%. Va: Recognise a face at a distance of 4 meters. For comparison read small print in a newspaper: 7%. IIIc: Carry an object weighting 5 kilos a distance of 10 meters.
A	IIa: Washing includes dressing; VII: To go out to visit
P	Persons needing help; for comparability reasons, we have added persons confined in bed to all mobility (except 'constrained in house', where it was included), washing and dressing items. Ia: Lie down and get up from bed; Id: Pick up something from the ground; Ih: Constrained to the house; IIc: At least once per week; IIe: Includes arms use. Persons with a serious disability; Id: Intolerance, resistance; III: Open doors, use of telephone, use of arms, coordination, etc.
FIN	II: Demands of everyday life. V: Difficulties (including inability) are: to read a newspaper: 23,6% (M: 20,9 and W: 25,4); to hear a conversation: 35% (M: 41% and W: 31%). VIa: Ability to handle tasks outside home.
S	Ia: Cannot get up from a chair. The percentage of getting up / going to bed is 2,2%; Laundry: 13,3% (M: 14,1 and W: 12,7) Ih: Has/is in need of taxi service for disabled: 18,1%.
UK	Persons needing help (General Household Survey). It covers Great Britain. Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own. IIa: Refers to bathing, showering, washing all over. Washing face and hands: insignificant percentage. IIb: Cutting toenails; If: Wash and dry dishes IIIa: Cook a main meal: 5% and prepare a snack: 2%; The table does not include: clean windows inside: 19% (M: 12% and W: 24%), Jobs involving climbing: 28% (M: 19% and W: 35%), Wash clothing by hand: 8% (M and W: 8%) A certain number of data comes from the Health Survey for England (2000) covering all persons (including institutions). The survey defines 'Persons with a severe disability'. These numbers are: IV, Va and Vb. The remaining data is similar to the one presented here.

Table 7: Nature of dependency by gender. Number of elderly men/women with a specific dependency as a percentage of the population covered of the same sex and age group.

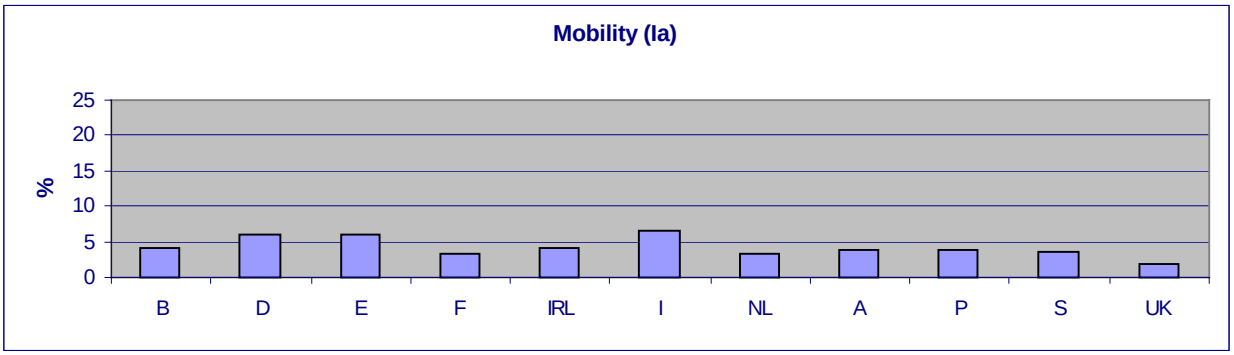
		B		DK		E		F		I		A		P		FIN		S		UK			
	Definition	Persons with severe limitations		Persons who have difficulties		Persons with a severe disability		Persons needing help		Persons with a serious disability		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons with severe disabilities	
	Age group	65+		60+		65+		60+		65+		60+		65+		65-84		65-84		65+		65+	
	Year	2001		1994		1999		1998/99		1999/2000		1998		1998/99		2001		1996/97		1998		2000	
	Population covered	All		All		Priv Hous		All		Priv Hous		Priv Hous		Priv Hous		Priv Hous		Priv Hous		Priv Hous		All	
	Source	B1		DK1		E1		F1		I1		A1		P1		FIN1		S1		UK3		UK1	
	Sex	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**
I	**Mobility**	7	13							12	21											10	14
a	Changing body positions (sitting down, standing up, getting into/out of a seat)	4	4			4	7	2	4	5	8	4	4	4	4			3	4	1	3	2	3
b	Maintaining a body position					3	5																
c	Go to/use the toilet	2	3			2	4	2	4					4	4					1	1	2	3
d	Lifting and carrying objects			*18*	*43*			3	3	13	21			9	10	11	20						
e	Hand and arm use					5	8	1	2									*5*	*15*	1	2		
f	Walking			*26*	*39*	5	8			7	12			2	2			*16*	*21*			6	8
g	Climbing stairs			*24*	*36*			4	9	13	22	10	13	6	8	4	8	*19*	*28*	6	12	8	12
h	Moving around																						
	-Inside the home					4	6	2	4	3	6	3	4	5	7			1	2	1	1		
	-Outside the home					11	17	17	22							5	7	3	8	6	16		
II	**Self-care**					5	7			9	15					13	12					5	5
a	Washing	3	6			4	6	6	9	3	4	7	7	5	5			4	4	5	9	1	2
b	Caring for body parts																			22	36		
c	Toileting (incl. continence)	10	14					2	3					9	16								
d	Dressing	4	7			4	5	5	7	6	8			6	5					3	3	4	4
e	Eating	2	4			} 1,5	} 2,1	1	1	3	4	} 2,5	} 2,6	4	3					0	1	1	1
f	Drinking							2	3														
g	Looking after one's health							3	4														
III	**Domestic life**																						
a	Preparing meals					5	9	8	6							13	6	10	7	6	7		
b	Doing housework					6	14	12	13			12	13			20	25	15	19	5	13		
c	Shopping					6	12	21	26			18	25					10	18	8	18		
IV	**Communication**					2	2	1	2													1	2
a	Speaking			*6*	*5*			0	1	2	2			5	3								
b	Conversation			*29*	*23*																		
V	**Sensory experiences & solving problems**									3	5												
a	Watching	1	1			5	6	3	4	1	2			2	3	2	2	*6*	*7*	*24*	*30*	3	3
b	Listening	2	3			4	4	2	2	3	3			2	2	5	4	*37*	*24*	*27*	*20*	2	2
c	Solving problems / decisons					5	9									8	5			4	7		
VI	**General tasks and demands**																						
a	Understanding tasks					2	4	10	15							8	9						
b	Handling stress																						
c	Memory / orientation							1	3														
VII	**Community and social life**											13	18										

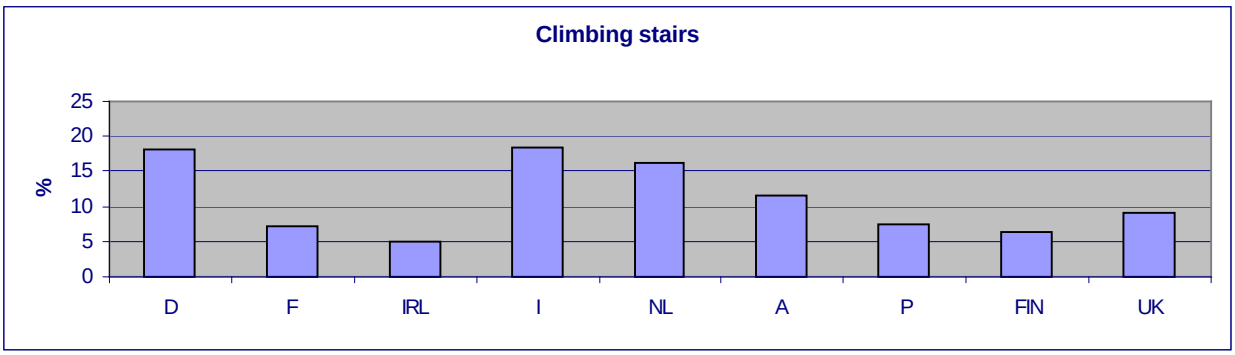
Notes

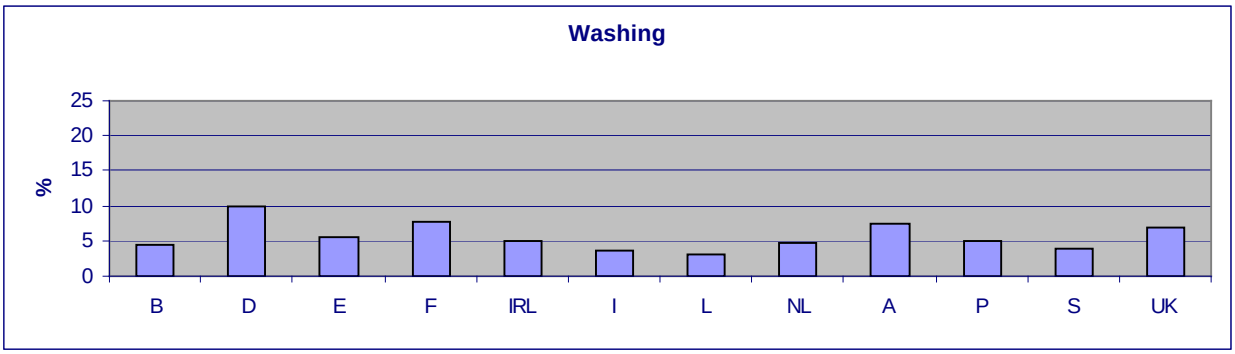
The table indicates that in Belgium 7% of men aged 65 and over are dependent for mobility activities.
Numbers in italics refer to difficulties.

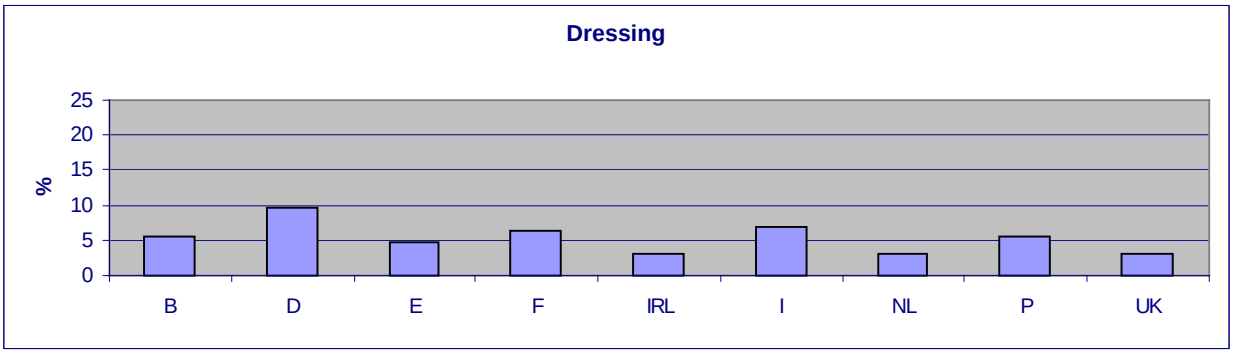
B	IIe: Includes arms use limitations.
DK	If: Walk 400 m without resting; Id: Carry 5 kg without difficulties.
D	If: To organise medication; IIb: Brush the hair; VII: Visit people.
E	Ib: Changing and maintaining a body position; If: Getting around; Vc: Looking after the welfare of other family members; VIa: Learning and applying knowledge.
F	
I	I: Includes walking, climbing stairs, bending and Ia; Ia: Getting into and out of bed; Id: Pending and taking shoes; If: Can walk only a few steps; Iha: Confined at home; II: Includes activities of daily living; IIa: Needs the assistance to wash hands and face; IIe: Needs help to eat and cut food; V: Includes sight, hearing and speech; Va: See and recognise at 4 meters.
A	IIa: Washing includes dressing; VII: To go out to visit
P	Persons needing help; For comparability reasons, we have added persons confined in bed to all mobility (except 'constrained in house', where it was included), washing and dressing items. Ia: Lie down and get up from bed; Id: Pick up something from the ground; Ih: Constrained to the house; IIc: At least once per week; IIe: Includes arms use.
FIN	II: Demands of everyday life. V: Difficulties (including inability) are: to read a newspaper: 23,6% (M: 20,9 and W: 25,4); to hear a conversation: 35% (M: 41% and W: 31%). VIa: ability to handle tasks outside home.
UK	Persons needing help (General Household Survey). It covers Great Britain. 'Eyesight' and ' Hearing' refer to difficulties, while the remaining refers to inability to manage on their own. IIa: Refers to bathing, showering, washing all over. Washing face and hands: insignificant percentage. IIb: Cutting toenails; If: Wash and dry dishes IIIa: Cook a main meal: 5% and prepare a snack: 2%; The table does not include: clean windows inside: 19% (M: 12% and W: 24%), Jobs involving climbing: 28% (M: 19% and W: 35%), Wash clothing by hand: 8% (M and W: 8%) Persons with a severe disability (Health Survey for England) The survey covered only England. The reference population is the total UK.

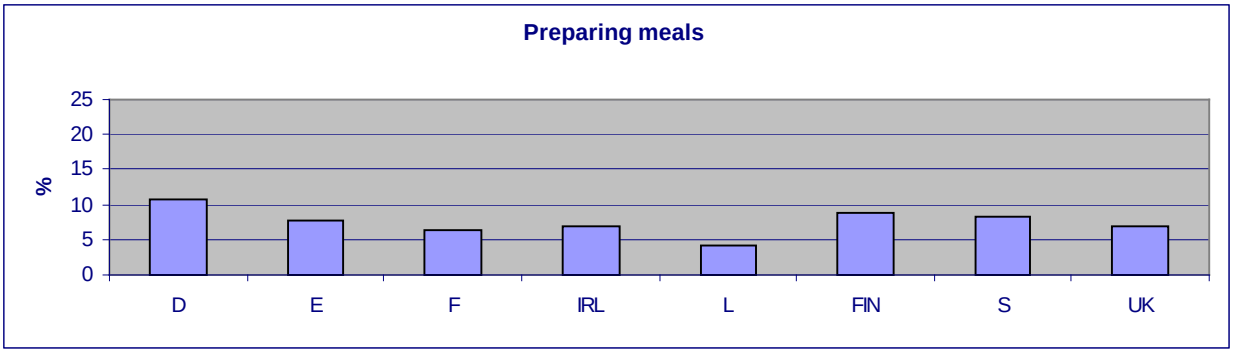
Chart 8: Nature of dependency. Number of elderly people with a specific dependency as a percentage of the population covered of the same age group.

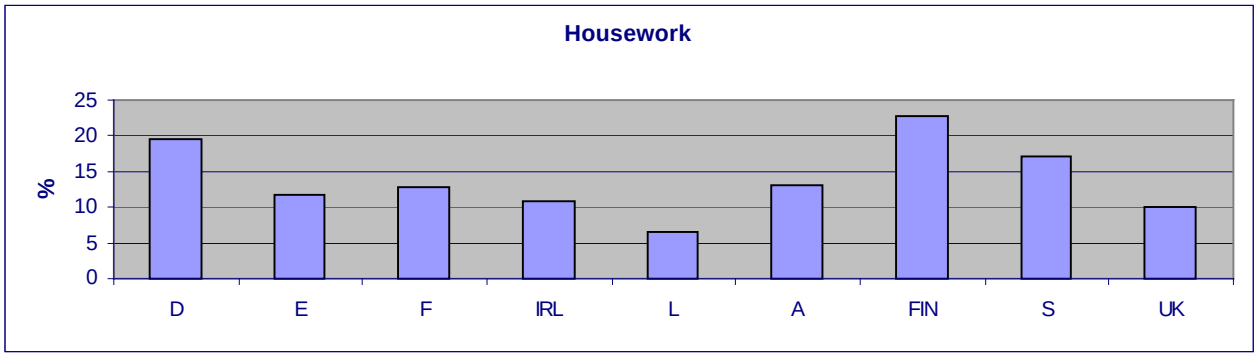


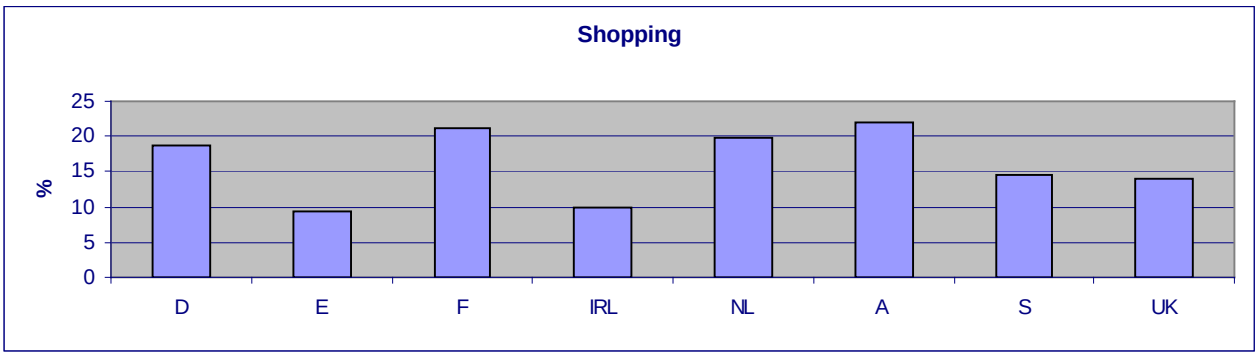


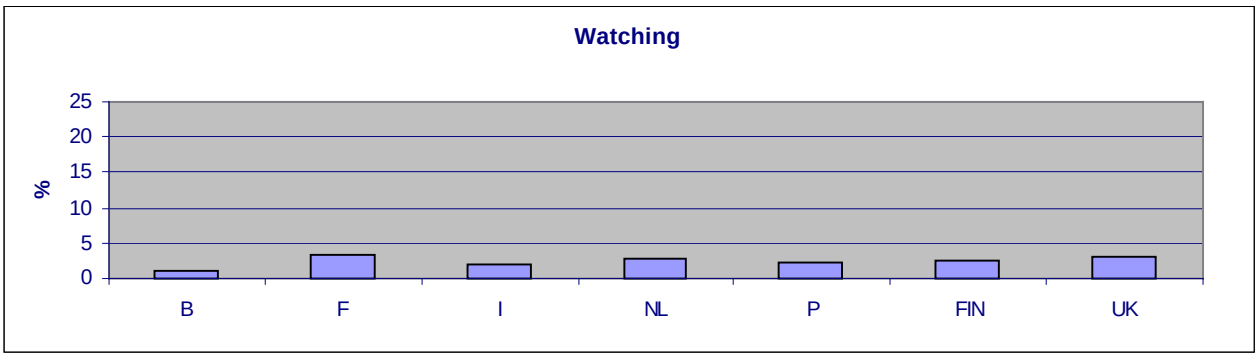


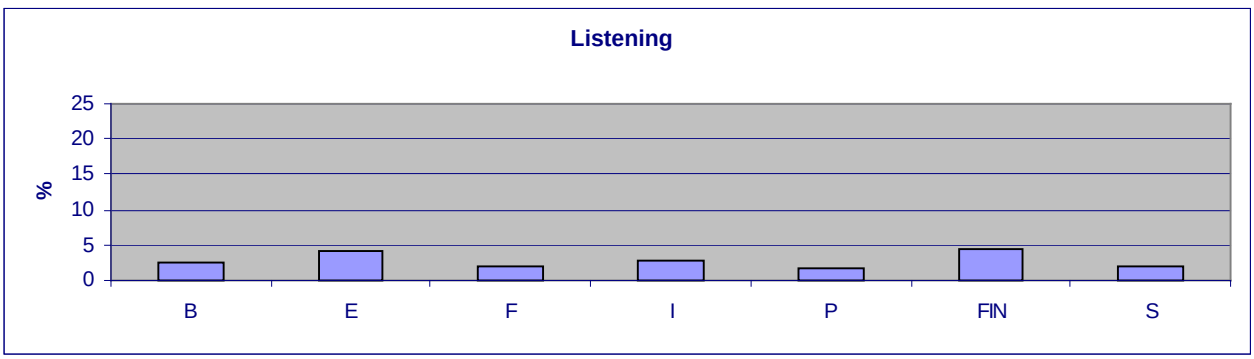












Note: See Table 6 for definitions, population covered, explanatory notes and sources.

Chapter 4

Nature of dependency by age group

In Chapter 2 we presented the evolution of dependency with age. The present chapter describes the evolution of each specific dependency by age group.

In general, all types of dependency follow a similar path of increase with age.

In general, the number of self-care dependencies is lower at all ages compared to mobility and domestic life activities (see Table 8)

Table 8 presents the same surveys as those presented in previous chapters. A small difference concerns Italy. Previous table was reporting cases where he/she can do the activity with the help of someone. In certain cases we reported cases ‘with big difficulties’ and ‘total inability’ (for example concerning the capacity to speak). The prevalence by age group in the present table presents persons with limitations and includes ‘people with a little difficulty’ in certain cases.

Table 8: Nature of dependency by age group. Number of elderly persons with a specific dependency as a percentage of the population covered of the same age group.

		B		DK		D		E		F		I		NL		A		P		FIN		S		UK	
	Definition	Persons with severe limitations		Persons who have difficulties		Dependent persons		Persons with a disability		Persons needing help		Persons with a disability		Persons with severe limitations		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons needing help	
	Age-group	65-74	75+	60-79	80+	65-79	80+	65-74	75+	60-79	80+	65-74	75+	65-74	75+	65-74	75+	65-74	75+	65-74	75-84	65-74	75-84	65-74	75+
	Year	2001 (1997)		1994		1991/92		1999		1998/99		1999/00		2000/2001		1998		1998/99		2001		1996/97		1998	
	Population covered	All		All		Priv.Hous		Priv.Hous		All		Priv.Hous		Priv.Hous		Priv.Hous		Priv.Hous		Priv.Hous		Priv.Hous		Priv.Hous	
	Source	B1, B2		DK1		D2		E1		F1		I1		NL1		A1		P1		FIN1		S1		UK3	
I	**Mobility**											9	34												
a	Changing body positions (sitting down, standing up, getting into/out of a seat)	3	11			4	12	7	16	1	12	3	17	2	5	3	7	2	6			3	5	2	2
b	Maintaining a body position							4	11																
c	Go to/use the toilet					2	11			1	11							2	7					1	1
d	Lifting and carrying objects			*19*	*47*			6	12	3	15			7	17			6	15	9	29				
e	Hand and arm use					3	13	3	15	1	5											*9*	*13*	1	3
f	Walking			*28*	62									1	4			1	4	3	12	*12*	*29*		
g	Climbing stairs			*25*	*58*	13	34			3	25			10	24	8	20	4	13	3	11	*18*	*32*	5	15
h	Moving around																								
	-Inside the home	7	17			4	14	5	15	1	12			2	7	2	6	3	11			1	3	1	1
	-Outside the home					11	37	14	32	10	49			5	14							2	10	6	19
II	**Self-care**	13	15					4	17			5	23							9	16				
a	Washing					6	22	3	15	4	25			2	8	5	13	2	10			2	7	4	11
b	Caring for body parts					3	12																	21	43
c	Toileting (incl. continence)					3	12	1	8	1	10							10	19						
d	Dressing					6	20	3	13	3	20			2	5			3	10					2	4
e	Eating					1	7	1	5	0	4			0	1	2	4	2	6					1	1
f	Drinking									1	10														
g	Looking after one's health					3	15			2	11														
III	**Domestic life**																								
a	Preparing meals	2	8			6	25	4	18	4	19									5	16	5	13	4	11
b	Doing house work	3	19			13	39	7	24	9	33					9	23			13	40	11	26	5	16
c	Shopping					12	38	7	23	13	57			12	29	16	37					9	22	7	22
IV	**Communication**							2	8	1	5													0	4
a	Speaking			*3*	*14*			1	3	0	1			1	2			3	5						
b	Conversation			*21*	*50*									6	13										
V	**Sensory experiences & solving problems**											2	7												
a	Watching							7	17	2	4			1	5			1	5	1	4	*3*	*10*	2	7
b	Listening							6	17	1	2							1	3	3	7	*25*	*34*	1	6
c	Solving problems / decisons					6	28	2	8											4	11			3	10
VI	**General tasks and demands**																								
a	Understanding tasks (simple)							1	4	9	34									4	14				
b	Handling stress																								
c	Memory / orientation					5	24	2	8	1	7														
VII	**Community and social life**					8	32	3	9							11	29								

Notes

The table indicates that in Belgium 3% of persons aged 65 to 74 years old are dependent for mobility activities.
Numbers in italics refer to difficulties.

B Ia: Limited to a chair; Ih: Limited to house/garden; II: Activities of daily living; III: Refer to the Flemish region, 1997.

DK If: Walk 400 m without resting; Id: Carry 5 kg without difficulties.

D Ih: Outside the home: use public transport; IIb: Brush the hair; VII: Visit people.

E II: Caring for oneself; VIc: Refers to remembering information and recent events; Recognising people and orientation: 0,9% and 5%. Washing and ironing: 5,2% and 20,7%.

The data here refers to disabilities. Previous tables present persons with a severe disability.

F Ie: For comparison cut food: 1,9% and 14,1%. II: Demands of everyday life.

I I: Includes walking, climbing stairs, bending and Ia; Ia: Confined in bed, in a chair or at home; II: Includes activities of daily living; Due to a filter question on confinement in bed or a chair, this percent might be underestimated.
V: Includes sight, hearing and speech.

NL Ia: Getting in and out of bed. If: Move to another room on the same floor; For comparison, walk for 400 meters without stopping: 7,9% and 21,4%.
IIa: Wash oneself completely. For comparison the prevalence for washing face and hands is 0,3% and 1%. Va: Recognise a face at a distance of 4 meters. For comparison read small print in a newspaper: 5,3% and 9,1%.
IIIc: Carry an object weighting 5 kilos a distance of 10 meters.

A IIa: Washing includes dressing; VII: To go out to visit …

P Persons needing help; For comparability reasons, we have added persons confined in bed to all mobility (except 'constrained in house', where it was included), washing and dressing items.
Ia: Lie down and get up from bed; Id: Pick up something from the ground; Ih: Constrained to the house; IIc: At least once per week; IIe: Includes arms use.
Persons with a serious disability; Id: intolerance, resistance; III: open doors, use of telephone, use of arms, coordination, etc.

FIN VIa: Ability to handle tasks outside home.

S Ih: Has/is in need of taxi service for disabled: 9,2% and 30,2%.

UK Persons needing help (General Household Survey).
It covers Great Britain. Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own.
Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own.
IIa: Refers to bathing, showering, washing all over. Washing face and hands: insignificant percentage. IIb: Cutting toenails; If: Wash and dry dishes
IIIa: Cook a main meal: 5% and prepare a snack: 2%; The table does not include: clean windows inside: 19% (M: 12% and W: 24%),
Jobs involving climbing: 28% (M: 19% and W: 35%), Wash clothing by hand: 8% (M and W: 8%)
Data concerning 'Communication', 'Watching' and 'Listening' comes from the Health Survey for England. They refer to persons with a severe disability (UK1)
The latter survey covered only England.

Table 9: Dependent persons aged 65 to 74, by gender. Number of men/women with a specific dependency as a percentage of the population covered of the same sex and age group.

		DK		E		F		I		A		P		FIN		S		UK			
	Definition	Persons having difficulties		Persons with a disability		Persons needing help		Persons with a disability		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons with severe disabilities	
	Age group	60-79		65-74		60-79		65-74		65-74		65-74		65-74		65-74		65-74		65-79	
	Year	1994		1999		1998/99		1999/00		1998		1998/99		2001		1996/97		1998		2000	
	Population covered	All		Priv Households		All		Priv Households		Priv Households		Priv Households		Priv Households		Priv Households		Priv Households		All	
	Source	DK1		E1		F1		I1		A1		P1		FIN1		S1		UK3		UK1	
	Sex	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**
I	**Mobility**							7	10											8	8
a	Changing body positions (sitting down, standing up, getting into/out of a seat)			5	8	1	2	3	4	3	2	2		2		2	3	1	2	2	2
b	Maintaining a body position			3	5																
c	Go/use to the toilet					1	1					2		1				1	1	1	1
d	Lifting and carrying objects	*23*	*19*	4	7							6		6	7	10					
e	Hand and arm use			3	3	1	1									*4*	*13*	1	1		
f	Walking	*33*	*28*									1		1	3	3	*11*	*13*		4	5
g	Climbing stairs	*30*	*25*			2	4			8	8	3		3	2	4	*17*	*20*	3	7	6	7
h	Moving around																				
	-Inside the home			3	6	1	2			2	2	2		3			1	0	1	0		
	-Outside the home			11	16	12	12										2	3	4	9		
II	**Self-care**			4	4			4	5						10	8				3	3
a	Washing			3	3	5	4			6	4	2		2			3	2	3	5	1	0
b	Caring for body parts																		14	27		
c	Toileting (incl. continence)			1	1	1	1					6		3								
d	Dressing			3	3	4	3					4		2					2	3	2	2
e	Eating			1	1	0	0			2	2	2		1					0	1	1	0
f	Drinking					1	1															
g	Looking after one's health					2	2															
III	**Domestic life**																				
a	Preparing meals			3	4	6	3								7	2	6	4	4	4		
b	Doing housework			4	10	10	8			10	9				11	15	9	12	3	7		
c	Shopping			4	8	15	16			14	17						7	11	5	9		
IV	**Communication**			2	2	1	1													0	0	
a	Speaking	*3*	*3*	1	1	0	0					4		2								
b	Conversation	*25*	*18*																			
V	**Sensory experiences & solving problems**							1	2													
a	Watching			6	8	2	2					1		1	2	1	*3*	*3*			2	2
b	Listening			6	6	1	1					1		0	3	3	*34*	*18*			1	0
c	Solving problems / decisons			2											6	3			3	3		
VI	**General tasks and demands**																					
a	Understanding tasks (simple)			1	1	8	9								4	3						
b	Handling stress																					
c	Memory / orientation			2	2	1	1															
VII	**Community and social life**			2	3					11	11											

Notes

The table indicates that in Spain 5% of men in the 65 to 74 age group are dependent for changing a body position.
Numbers in italics refer to difficulties.

DK If: Walk 400 m without resting; Id: Carry 5 kg without difficulties.

D Ih: Outside the home: use public transport; IIb: Brush the hair; VII: Visit people.

E II: Caring for oneself; VIc: Refers to remembering information and recent events.
The data here refers to disabilities. Previous tables present persons with a severe disability.

F Ie: Cut food.

I I: Includes walking, climbing stairs, bending and Ia; Ia: Confined in bed, in a chair or at home; II: Includes activities of daily living; Due to a filter question on confinement in bed or a chair, this percent might be underestimated.
V: Includes sight, hearing and speech.

A IIa: Washing includes dressing; VII: to go out to visit

P Persons needing help; For comparability reasons, we have added persons confined in bed to all mobility (except 'constrained in house', where it was included), washing and dressing items.
Ia: Lie down and get up from bed; Id: Pick up something from the ground; Ih: Constrained to the house; IIc: At least once per week; IIe: Includes arms use.

FIN II: Demands of everyday life. VIa: Ability to handle tasks outside home.

S Ia: Getting up / going to bed is 1,4% and 0,9%; Ih: Has/is in need of taxi service for disabled: 8,2% and 10,1%.

UK Persons needing help (General Household Survey).
It covers Great Britain. Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own.
Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own.
IIa: Refers to bathing, showering, washing all over. Washing face and hands: insignificant percentage. IIb: Cutting toenails; If: Wash and dry dishes
IIIa: Cook a main meal: 5% and prepare a snack: 2%; The table does not include: clean windows inside: 19% (M: 12% and W: 24%),
Jobs involving climbing: 28% (M: 19% and W: 35%), Wash clothing by hand: 8% (M and W: 8%)
Persons with a severe disability (Health Survey for England)
The survey covered only England. The reference population is the total UK.

Table 10: Dependent persons aged 75 and over by gender. Number of men/women with a specific dependency as a percentage of the population covered of the same sex and age group.

		DK		E		F		I		A		P		FIN		S		UK			
	Definition	Persons having difficulties		Persons with a disability		Persons needing help		Persons with a disability		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons needing help		Persons with severe disabilities	
	Age group	80+		75+		80+		75+		75+		75+		75-84		75-84		75+		80+	
	Year	1994		1999		1998/99		1999/00		1998		1998/99		2001		1996/97		1998		2000	
	Population covered	All		Priv. House		All		Priv. House		Priv. House		Priv. House		Priv. House		Priv. House		Priv. House		All	
	Source	DK1		E1		F1		I1		A1		P1		FIN1		S1		UK3		UK1	
	Sex	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**	**M**	**W**
I	**Mobility**							24	40											20	29
a	Changing body positions (sitting down, standing up, getting into/out of a seat)			13	18	8	14	12	19	8	7	7	7			4	6	2	3	5	8
b	Maintaining a body position			8	12																
c	Go to/use to the toilet					7	13					7	7					1	2	3	8
d	Lifting and carrying objects	*47*	*47*	10	14							15	15	20	34	*15*	*42*				
e	Hand and arm use			12	17	3	6									*7*	*17*	2	4		
f	Walking	*58*	*64*									4	4	9	13	*24*	*32*			13	18
g	Climbing stairs	*52*	*61*			15	29			17	21	12	14	9	13	*22*	*39*	10	19	16	25
h	Moving around																				
	-Inside the home			12	17	7	15			5	6	9	12			1	4	0	2		
	-Outside the home			25	36	51	57									5	14	10	25		
II	**Self-care**			14	18			17	27					17	16					10	12
a	Washing			13	17	18	27			14	13	10	9			5	8	9	13	3	5
b	Caring for body parts																	36	48		
c	Toileting (incl. continence)			7	9	7	12					15	21								
d	Dressing			11	13	14	23					10	9					3	4	9	9
e	Eating			4	5	2	4			4	4	7	6					0	1	2	4
f	Drinking					7	11														
g	Looking after one's health					9	12														
III	**Domestic life**																				
a	Preparing meals			14	20	19	20							25	11	16	11	11	11		
b	Doing housework				23	27	37			22	23			39	41	23	28	10	19		
c	Shopping			17	27	60	66			31	41					15	26	14	27		
IV	**Communication**			7	8	4	6													2	5
a	Speaking	*21*	*11*	3	3	0	1					6	4								
b	Conversation	*55*	*47*																		
V	**Sensory experiences & solving problems**							7	8												
a	Watching			16	18	3	5					4	5	4	4	9	*11*			9	6
b	Listening			17	16	2	2					3	4	9	6	*40*	*30*			5	7
c	Solving problems / decisons				8									13	9			7	11		
VI	**General tasks and demands**																				
a	Understanding tasks (simple)			3	4	26	38							15	14						
b	Handling stress																				
c	Memory / orientation			6	9	4	10														
VII	**Community and social life**			7	11					23	32										

Notes

The table indicates that in Spain 13% of men aged 75 and over are dependent for changing a body position.
Numbers in italics refer to difficulties.

DK If: Walk 400 m without resting; Id: Carry 5 kg without difficulties.

D Ih: Outside the home: use public transport; IIb: Brush the hair; VII: Visit people.

E II: Caring for oneself; VIc: Refers to remembering information and recent events.
The data here refers to disabilities. Previous tables present people with a severe disability.

F Ie: Cut food

I I: Includes walking, climbing stairs, bending and Ia; Ia: Confined in bed, in a chair or at home; II: Includes activities of daily living; Due to a filter question on confinement in bed or a chair, this percent might be underestimated.
V: Includes sight, hearing and speech.

A IIa: Washing includes dressing; VII: To go out to visit somebody.

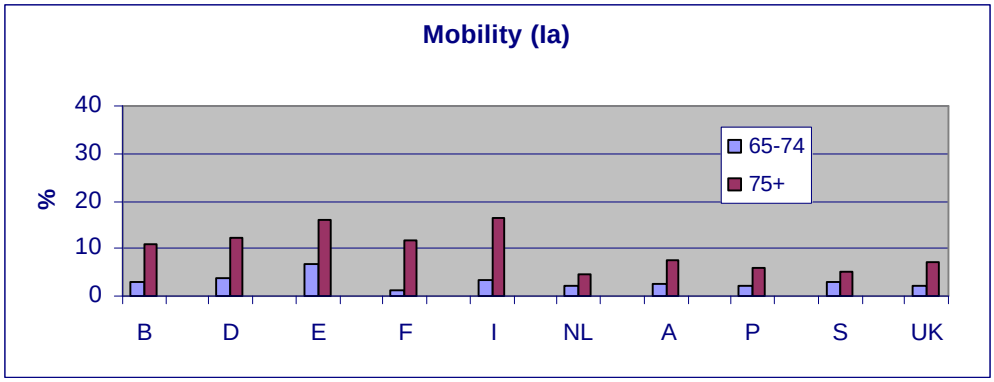
P Persons needing help; For comparability reasons, we have added persons confined in bed to all mobility (except 'constrained in house', where it was included), washing and dressing items.
Ia: Lie down and get up from bed; Id: Pick up something from the ground; Ih: Constrained to the house; IIc: At least once per week; IIe: Includes arms use.

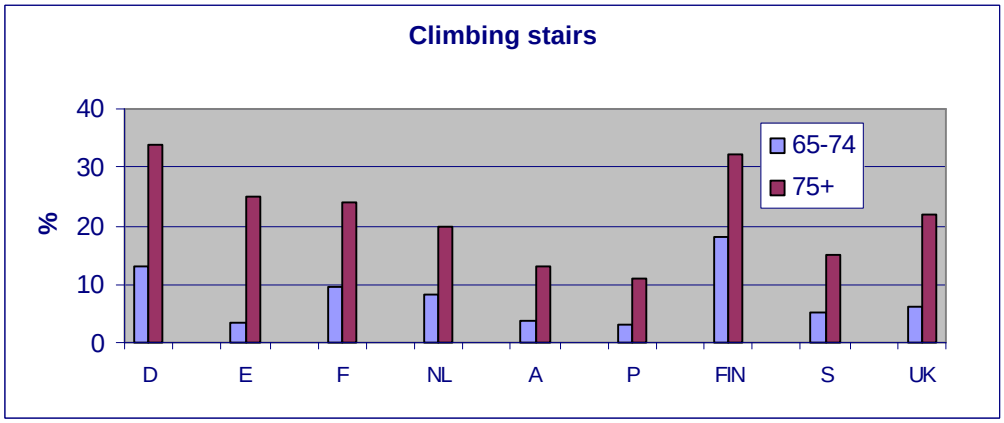
FIN II: Demands of everyday life. VIa: Ability to handle tasks outside home.

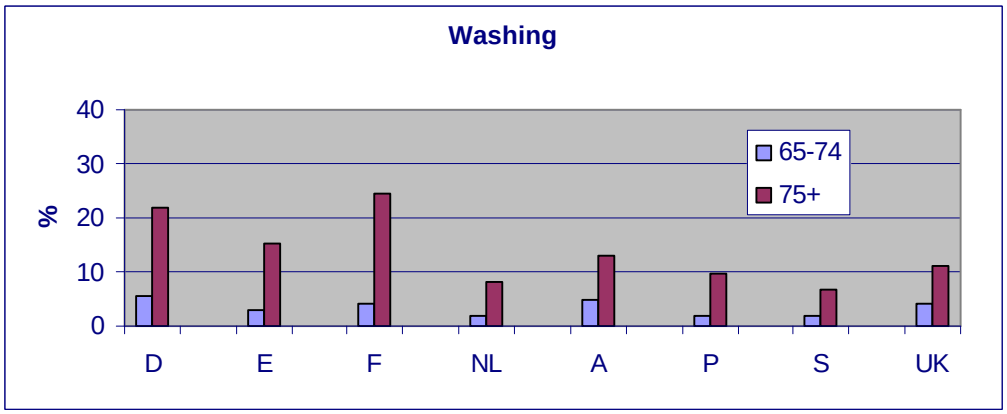
S Ia: Getting up / going to bed is 2,4% and 4,5%; Ih: Has/is in need of taxi service for disabled: 18,3% and 38,3%.

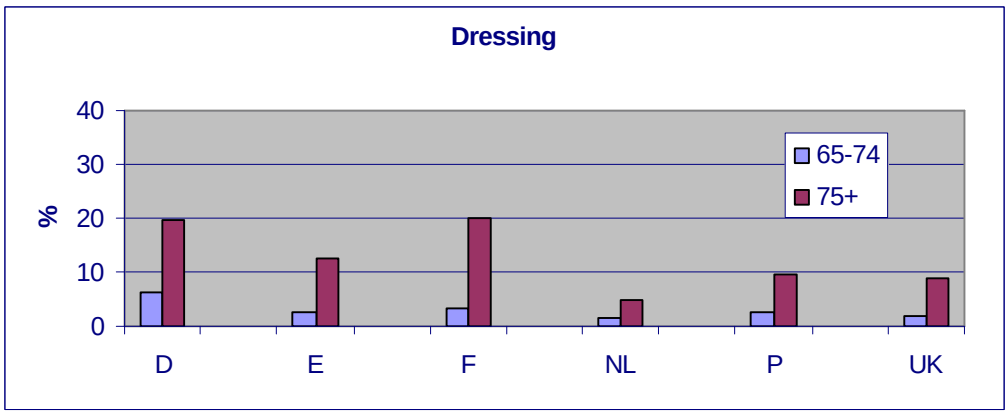
UK Persons needing help (General Household Survey).
It covers Great Britain. Eyesight and hearing refer to difficulties, while the remaining refers to inability to manage on their own.
IIa: Refers to bathing, showering, washing all over. Washing face and hands: insignificant percentage. IIb: Cutting toenails; If: Wash and dry dishes
IIIa: Cook a main meal: 5% and prepare a snack: 2%; The table does not include: clean windows inside: 19% (M: 12% and W: 24%),
Jobs involving climbing: 28% (M: 19% and W: 35%), Wash clothing by hand: 8% (M and W: 8%)
Persons with a severe disability (Health Survey for England)
The survey covered only England. The reference population was the total UK.

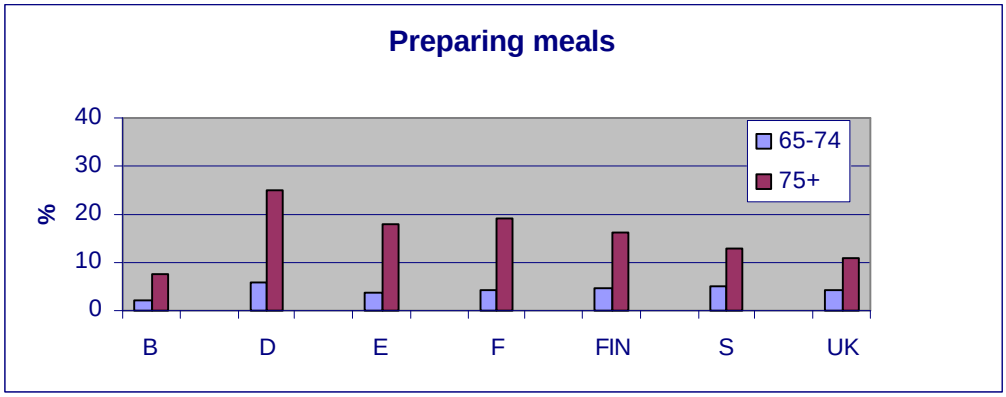
Chart 9: Nature of dependency by age group. Number of people with a specific dependency as a percentage of the population covered of the same age group.

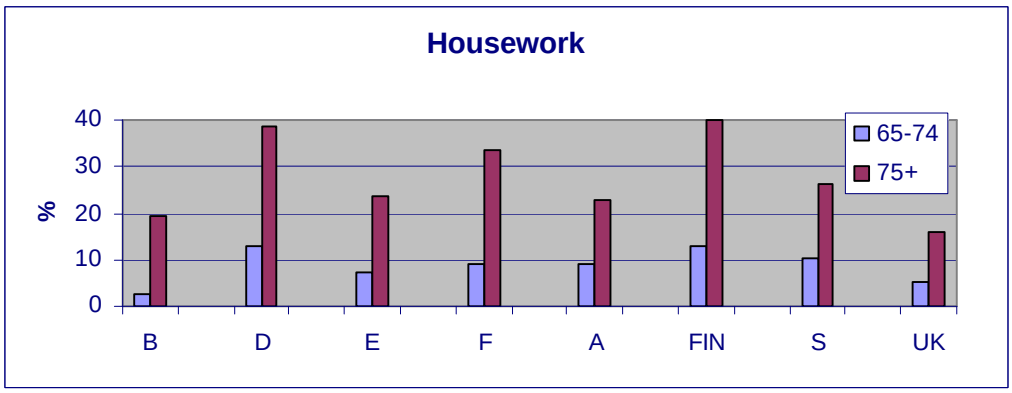


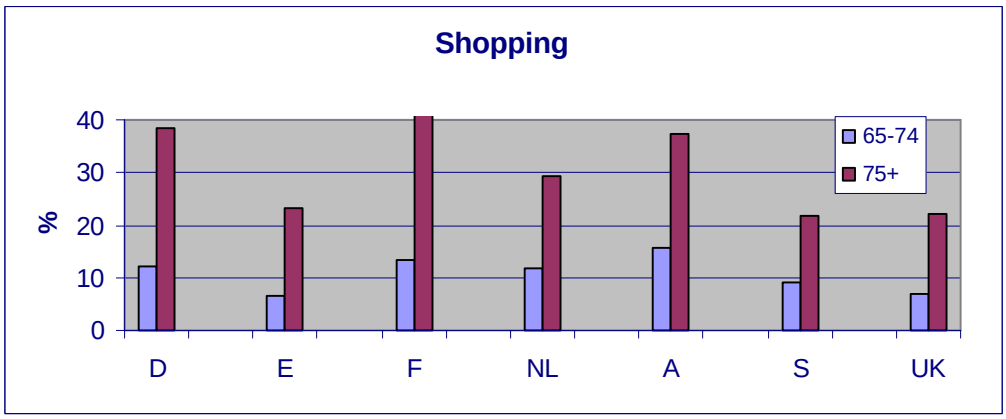












Note: See Table 8 for definitions, population covered, explanatory notes and sources.

Chapter 5

Nature and degree of dependency

As noted above, the Katz index has six items: washing, dressing, transfer, going to the toilet, continence and eating. For each item, we distinguish four cases. Let's take washing. A person able to wash without assistance receives a score of zero points. A person needing assistance in washing lower part of body receives one (1) point, etc. A fully self-dependent person has a total score of zero (0), etc.

- Full self-dependent person: Katz index = 0,
- Moderately care dependent: Katz index = 1 or 2,
- Highly care dependent: Katz index = 3 or 4,
- Very highly care dependent: Katz index = 5 or 6.

The simplicity of the Katz index explains its widespread use. But the use is often restricted to the nature of items retained. The rating is rarely used.

Most surveys focus on the ability to do these activities with or without help. In this case the surveyed person has to answer whether he/she needs help or not. In other cases, we distinguish:

- No help,
- Some help,
- Significant help, and
- Rely totally to another person.

In the following table we retain only the last two possibilities and the distinction 'need help' or 'impossible to realise the activities'.

The Dutch data distinguishes: No difficulty, with some difficulty, with big difficulties and only with help. We report the last two dimensions.

Including occasional need for help raises the rates significantly and gives estimates close to persons with severe limitations and in certain cases even higher rates.

There is some argument to advance that a high number of elderly people experiences light or moderate care needs and a small number faces a severe dependency.

The time spent per week or month to assist the dependent person is another indicator of the degree of dependency. Another one, which is used, is the frequency of help. Some data will be presented in the next Section.

Table 11: Nature of dependency by degree (Need help/Impossible) (Percent of the same age group)

		B		D		E		F		IRL		NL		A		FIN		UK	
	Definition	Persons with a limitation		Dependent persons		Persons with a disability		Dependent persons		Persons with ADL difficulties		Persons with severe limitations		Persons needing help		Persons needing help		Persons with a severe disability	
	Age group	65+		65+		65+		60+		65+		65+		60+		65-84		65+	
	Year	2001		1991/92		1999		1990		2000		2000/2001		1998		2001		1985	
	Population covered	All		Private house.		Private house.		Private house.		Private house.		Private house.		Private house.		Private House.		Private House.	
	Source	B1		D2		E1		F3		IRL1		NL1		A1		FIN1		UK1	
	Degree of dependency	**Moderate**	**Severe**	**Need help**	**Imp.**	**Need help**	**Imp.**	**Need help**	**Imp.**	**Much diff.**	**Imp.**	**Big diff.**	**Need help**	**Need help**	**Imp.**	**Need help**	**Imp.**	**Need help**	**Imp.**
I	**Mobility**	*16*	*11*					4	2									4	2
a	Changing body positions (sitting down, standing up, getting into/out of a seat)	*15*	*4*	5	1					2	4	3	1	3	1				
b	Maintaining a body position																		
c	Go to/use the toilet	*7*	*2*	3	2					2	3								
d	Lifting and carrying objects									4	8	8	3			6	11		
e	Hand and arm use			3	2	8	6			1	4							3	2
f	Walking					12	3			2	4	2	1						
g	Climbing stairs			14	4					4	5	11	5	8	4	4	3		
h	Moving around																		
	-Inside the home			5	2							3	2	3	1				
	-Outside the home			7	10	17	10					5	4			4	2		
II	**Self-care**	*27*	*14*			10	5									8	5	3	2
a	Washing	*6*	*5*	6	4					2	5	2	3	7	1				
b	Caring for body parts			3	2					3	10								
c	Toileting (incl. continence)	*4*	*13*	4	1													1	1
d	Dressing	*14*	*6*	7	2					2	3	2	1						
e	Eating	*6*	*3*	2	1							0	0	2	0			0	0
f	Drinking																		
g	Looking after one's health			3	3														
III	**Domestic life**							13	4										
a	Preparing meals			5	6					2	7					4	5		
b	Doing housework			9	10	17	*27*			5	11			6	7	10	13		
c	Shopping			8	11					1	10	6	14	11	11				
IV	**Communication**					2	2											1	1
a	Speaking											1	0						
b	Conversation											7	2						
V	**Sensory experiences & solving problems**																		
a	Watching	*9*	*1*			7	2					1	1					2	1
b	Listening	*19*	*2*			4	1											2	1
c	Solving problems / decisions			5	7	5	3			2	7					5	2		
VI	**General tasks and demands**																		
a	Understanding tasks (simple)															6	3	1	1
b	Handling stress																		
c	Memory / orientation			4	6					2	5							0	0
VII	**Community and social life**			7	7	1	8							9	8			1	1

Notes

The table indicates that in Germany 5% of persons aged 65 and over need the assistance of a third party to change a body position, and 1% cannot do it at all (exactly 1,4%).
Degree of dependency. The categories are: 'Need help' or 'Impossible'. In certain cases we have 'Big difficulty' instead of 'Need help'.
Data in italics refers to difficulties and are not comparable with other countries

B	Ia: To get up, to lie down; IIe: Eat and cut food.
D	The distinction is 'Difficult' and 'Impossible'. Ih: Outside the home: use public transport; IIb: Brush the hair; VII: Visit people.
E	The distinction is 'Severe' and 'Impossible'. Contrary to previous tables, data here refers to disabilities and not to persons. If: Getting around; Vc: Learning, applying knowledge.
F	The data refers to dependent and very dependent persons. I: Refers to physical dependency (mobility and self-care). III: Refers to dependency for domestic life activities (including administrative tasks). Domestic tasks include: shopping, cooking, housework, heavy housework and administrative tasks. Each activity has a specific weight.
IRL	Ie: Open car doors. 'Much diffic' means much difficulty.
NL	Ia: Getting in and out of bed. If: Move to another room on the same floor; for comparison, walk for 400 meters without stopping: 4,7% and 9,3%. IIa: Wash oneself completely. Va: To recognise a face at a distance of 4 meters. For comparison read small print in a newspaper: 2,9% and 4,1%. IIIc: Carry an object weighting 5 kilos a distance of 10 meters. 'Big dif/ty' means big difficulty.
A	IIa: Washing includes dressing; VII: To go out to visit somebody.
FIN	II: Demands of everyday life. VIa: Ability to handle tasks outside home.
UK	Need help: Persons with a disability degree of 7-8. Impossible: Persons with a disability degree of 9-10. Ie: Dexterity. For comparison 'reaching and stretching' gives 1,8% and 1,2%. VIc: Consciousness. VII: Behaviour.

Chapter 6

Nature of dependency, degree and age

As noted earlier the number of severe limitations relative to light limitations increases with age.

Table 12 presents the nature of dependency by degree and age group for each type of long-term care needs.

Table 12: Nature of dependency by degree and age group (Need help/Impossible) (Percent of the same age group)

		D				E				NL				A				FIN				UK			
	Definition	Dependent persons				Persons with a disability				Persons with severe limitations				Persons needing help				Persons needing help				Persons with a severe disability			
	Age group	65-79		80+		65-74		75+		65-74		75+		65-74		75+		65-74		75-84		65-74		75+	
	Year	1991/92				1999				2000/2001				1998				2001				1995			
	Population covered	Priv. Households				Priv. Households				Priv. Households				Priv. Households				Priv. Households				Priv. Households			
	Source	D2				E1				NL1				A1				FIN1				UK1			
	Degree of dependency	Need help	Imp.	Need help	Imp.	Need help	Imp.	Need help	Imp.	Big difficulty	Need help	Big difficulty	Need help	Need help	Imp.	Need help	Imp.	Need help	Imp.	Need help	Imp.	Need help	Imp.	Need help	Imp.
I	**Mobility**																					3	1	5	3
a	Changing body positions (sitting down, standing up, getting into/out of a seat)	3	1	9	3					2	0	4	1	2	0	6	1								
b	Maintaining a body position																								
c	Go to/use the toilet	2	1	7	4																				
d	Lifting and carrying objects									6	3	11	5					4	5	9	20				
e	Hand and arm use	2	1	8	6	5	3	12	11													2	1	3	2
f	Walking					7	1	19	7	1	0	3	1												
g	Climbing stairs	11	2	22	12					8	2	15	9	6	3	14	6	2	2	8	4				
h	Moving around																								
	-Inside the home	3	1	10	4					2	1	4	3	2	1	4	2								
	-Outside the home	6	5	12	25	11	9	26	11	3	2	8	6					2	2	8	4				
II	**Self-care**					4	2	19	10									6	3	10	7				
a	Washing	4	2	12	10					1	1	3	6	5	0	12	1					3	1	5	3
b	Caring for body parts	2	1	7	5																				
c	Toileting (incl. continence)	2	1	9	3																	1	1	2	2
d	Dressing	5	1	14	5					1	1	3	2												
e	Eating	1	0	5	1					0	0	0	0	2	0	4	1					0	0	0	0
f	Drinking																								
g	Looking after one's health	1	1	6	9																				
III	**Domestic life**																								
a	Preparing meals	3	3	10	15													2	3	7	9				
b	Doing housework	7	6	14	25	9	11	29	43					4	3	10	13	7	6	15	25				
c	Shopping	7	6	12	27					4	8	8	22	9	7	17	21								
IV	**Communication**					1	1	3	6													1	1	2	2
a	Speaking									1	1	1	0												
b	Conversation									5	1	9	4												
V	**Sensory experiences & solving problems**																								
a	Watching					4	1	11	3	0	1	3	2									1	1	3	2
b	Listening					2	1	6	2													1	1	3	2
c	Solving problems / decisions	3	3	10	18	2	1	9	6									3	1	7	4				
VI	**General tasks and demands**																								
a	Understanding tasks (simple)																	2	2	9	6	1	1	2	2
b	Handling stress																								
c	Memory / orientation	2	3	10	14																	0	0	0	0
VII	**Community and social life**	5	4	13	19	1	3	4	13					6	5	15	13					1	1	1	2

Notes

The table indicates that in Germany 3% of people aged 65 to 79 need the assistance of a third party to change a body position, and almost 1% cannot do it at all.
Degree of dependency. The categories are: 'Need help' or 'Impossible'. In certain cases we have 'Big difficulty' instead of 'Need help'.

D	Difficult/Impossible. Ih: Outside the home: use public transport; IIb: Brush the hair; VII: Visit people.
F	Domestic tasks: Age 70-74: dependent 9% and very dependent 1%; Age 80+: dependent 32% and very dependent 12%..
E	Severe/Impossible. The data refers to disabilities, not persons. If: Getting around; Vc: Learning, applying knowledge.
NL	Ia: Getting in and out of bed. If: Move to another room on the same floor; For comparison, walk for 400 meters without stopping gives for 65-74: 2,6% and 5,3%; for 75+: 7,2% and 14,2%. IIa: Wash oneself completely. Va: Recognise a face at a distance of 4 meters. IIIc: Carry an object weighting 5 kilos on a distance of 10 meters.
A	IIa: Washing includes dressing; VII: To go out to visit.
FIN	II: Demands of everyday life. VIa: Ability to handle tasks outside home.
UK	Need help: Persons with a disability degree of 7-8. Impossible: Persons with a disability degree of 9-10. Ie: Dexterity. For comparison 'reaching and stretching' gives 1,4% and 0,9% for the age group 65-74, and 2,4% and 1,7% for the age group 75+. VIc: Consciousness; VII: Behaviour.

Chapter 7

Place of residence

The distribution of elderly people living at home or in an institution depends notably from the following factors:

- Nature and degree of dependency,
- Available help,
- Policy concerning institutionalisation, and
- Socio-cultural elements.

Table 13 "Share of population aged 65 and over in institutions (Mid 90s)" presents the number of elderly people in formal long-term care institutions, as a percentage of the total elderly population.

Statistics are estimates made by the Organisation for Economic Co-operation and Development using different sources, including a questionnaire to the Member Countries (Source: OECD1). The author notes that the statistic includes formal long term care institutions as the increased diversity in lodging makes it difficult to isolate nursing homes. "Estimates may vary according to the concept chosen for institutions (sheltered housing, hotels for the elderly, medical homes). Normally, the concept described should include only staffed homes".

The author notes that the data needs to be interpreted with caution. "Between residences which are almost like hotels, with medical care available only in case of emergency, and nursing homes offering the full range of medical care, there are establishments offering varying degrees of medical care". "The types of accommodation arrangements are extremely diverse. Mostly public in the Nordic countries, they are mixed in continental Europe".

In the Nordic countries, during the 60s and 70s, a place in an institution was considered as a right of the elderly persons. The result was an active policy of developing places in institutions. This policy was later challenged and reversed. Living at home with the necessary help became the priority. This partly explains the relatively higher rate in the Nordic countries (see Table 13).

In Mediterranean countries, where infrastructures (staffed homes) are not developed, the number of dependent people living in institutions seems to be lower.

In Great Britain, the General Household Survey 1998 (UK3) gives for people aged 65 and over:

- 90% live in private households, and
- 10% in sheltered accommodation. Sheltered housing is defined as having a warden on premises or a central alarm system. This excludes communal establishments such as nursing homes and hospitals. Half of these sheltered housing have a resident warden.

Comparison across countries has to take into account that certain institutions may include persons who are not dependent. This is notably true when the definition includes rest homes.

The previous data covers all people. The focus of our study is the number of dependent persons at home and in institutions. Table 14 presents some data.

Available statistics are poor and are not comparable.

Statistics available for Portugal are not presented in the table. They cover all persons with a disability in private housing (99%) and in collective housing (1%). Collective institutions include educational, hospitals, other providing assistance, religious, military and others (P2).

Table 15 presents the distribution of dependent persons by age and type of residence. Data for Germany and Luxembourg cover beneficiaries of long term insurance. The table indicates that the share of institutions increases sharply with age. But even for persons aged 90 and over, the majority of people live at home.

Table 13 : Share of population aged 65 and over in institutions (Mid 90s)

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK
Share of pop aged 65 and over in institutions (mid 90s)	6,4	7,0	6,8	-	2,9	6,5	5,0	3,9	6,8	8,8	4,9	-	6,9	8,7	5,1

Source: OECD1 and FIN2

Note: Includes formal long-term care institutions. The authors note that "Estimates may vary according to the concept chosen for institutions (sheltered housing, hotels for the elderly, medical homes). Normally, the concept described should include only staffed homes".

Table 14: Dependent persons by type of residence

	D	F	NL	L	UK
Definition	Persons with a need for long-term care (law on long-term care insurance)	Elderly dependent persons (grille Colvez)	Dependent persons (sensory and ADL)	Recipients of care dependency insurance	Persons with a locomotion disability
Age	60+	60+	65+	60+	60+
Year	1999	1998/99	1999	2002	1985/86
Source	D1	F1	NL3	L2	UK2
Persons living at home (Private households)					
%	**68**	**74**	**75**	***55***	***91***
N	1.158.608	1.053.000	355.025	*3.135*	*3.000.030*
Persons living in institutions					
Institution	Institutions for elderly	Institutions for elderly and other institutions	Institutions for elderly and nursing homes	Institutions for elderly	Communal establishments
%	**32**	**26**	**25**	***45***	***9***
N	543.191	364.000	115.804	*2.515*	*292.000*

Numbers in italics are not comparable with data from other countries (L and UK).

Institutions

D Home-care, full-time and part-time institutional services

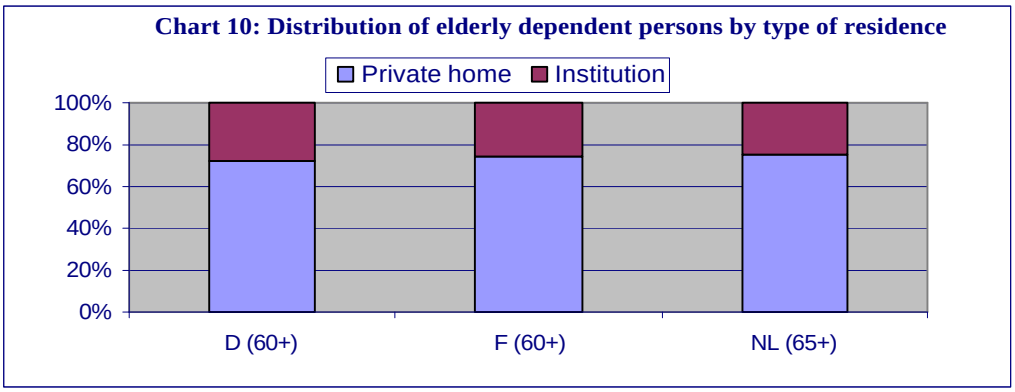
L Residential and day care homes. They include a minority of persons aged 40 to 60 years old.

F Residential homes for elderly, services for long term care in hospitals, institutions for disabled and psychiatric units. For comparison the total number of elderly persons in institutions is about 498.000. About 115.000 are not dependent and for 19.000 persons the information is missing. The Katz index gives: 447.000 dependent persons for at least two activities living at home and 250.000 in institutions.

NL Homes for the elderly (recognised), Nursing homes, Homes for mentally disabled persons, Mental hospitals, and Family replacement homes (notably for persons with sensorial disabilities).

UK Great Britain. Communal establishments.

Chart 10: Distribution of elderly dependent persons by type of residence



Sources: see Table 14.

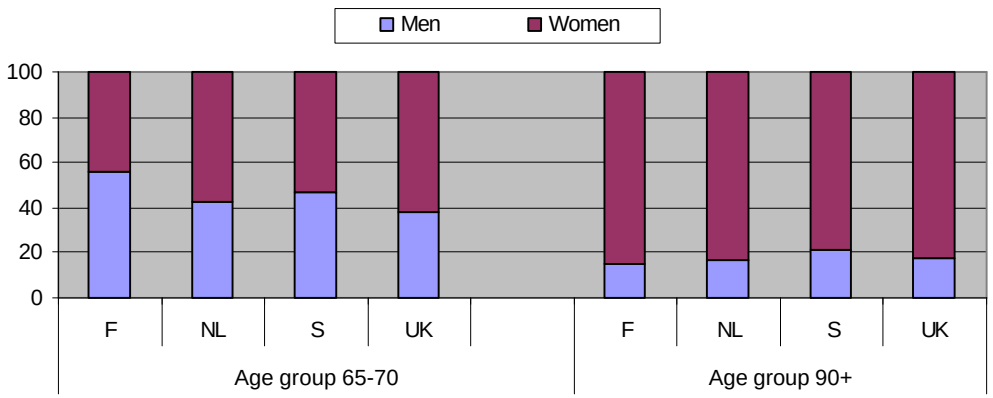
Table 15: Persons by type of residence and age group

	F		**D**		**L**		**NL**		**A**		**S**		**UK**	
	Total population		Persons needing long term care		Beneficiaries of long term care insurance		Total population		Total population		Total population		Total population	
Year	1998		1999		2002		1999		2000		2000		2000	
Source	F1		D1		L2		NL1		A2		S2		UK1	
	Private	Institution	Private	Institution	Private	Institution	Private	Institution	Private	Institution	Private	Institution	Private	Institution
Age	All		15+		40+		65+		All		All		65+	
All	**99**	**1**	***72***	***28***	***55***	***45***	**95**	**5**	**98**	**2**	**92**	**8**	**96**	**4**
60-65	99,3	0,7	*78,0*	*22,0*	*73,4*	*26,6*	99,8	0,2	98,8	1,2				
65-70			*79,1*	*20,9*			99,1	0,9	98,1	1,9	98,6	1,4	99,6	0,4
70-75	97,9	2,1	*77,8*	*22,2*	*65,4*	*34,6*	97,0	3,0	96,1	3,9			99,0	1,0
75-80			*72,8*	*27,2*			90,6	9,4	92,5	7,5	95,3	4,7	97,4	2,6
80-85	87,8	12,2	*68,4*	*31,6*	*47,6*	*52,4*	77,8	22,2	87,0	13,0	89,1	10,9	93,4	6,6
85-90			*63,4*	*36,6*			61,7	38,3	79,0	21,0	75,9	24,1	84,0	16,0
90 +	69,3	30,7	*56,7*	*43,3*	*35,9*	*64,1*	49,1	50,9	70,8	29,2	53,7	46,3	69,0	31,0

Notes
Numbers in italics are not comparable with data from other countries (D and L).

D Home-care, full-time and part-time institutional services
L Residential and day care homes.
F Homes for elderly and other institutions (healthcare and welfare institutions)
NL Homes for elderly
A Public housing (institutions for elderly and care dependent)
S Special housing
UK England. Care homes (residential and nursing)

Chart 11: Distribution of persons in establishments by gender and age



Sources: see Table 15.

Chapter 8

Dependency by type of residence

Belgium

The UFSIA-DSSB survey of the elderly people (B2) indicates that some 38% of the elderly residing in rest homes had no ADL-limitations. Only 7% of these elderly people without ADL-limitations had no IADL-limitations either.

A survey done by Vanden Boer L. (B2) in Flanders, in 1993, finds out that 16% of the service-flat residents were self-sufficient. About 67% of service-flat residents had some need for assistance, 13% had considerable need for assistance and 4% a serious need for assistance.

France

The indicator 'Persons dependent for at least one Activity of Daily Living' covers individuals who responded that they did need help for at least one of the activities of daily living. The survey uses the Katz-index that includes the activities washing, dressing, going to toilet and using it, lying / sitting down and getting up, continence, eat already prepared meals (F1).

The survey of homes for the elderly provides that 37% of residents have ‘no or a small dependency’. The proportion of clients with ‘no or small dependency’ is 42% in residential homes and 2% in long-term nursing homes (F5). Furthermore, 65% of residents in care homes have ‘no or small psychical’ dependency. This proportion is 20% in long-term nursing homes.

Ireland

The statistic concerning persons in private households gives the number of older people who have a difficulty with ADL (IRL1).

The estimate of persons in long-stay institutions (IRL3) covers Health boards (geriatric home, Welfare home, and private nursing home). Dependent persons exclude the 'Low Dependency' category. This category refers to people who need some support in the community and the more independent residents in residential accommodation who require little nursing care. They are usually mobility independent but may use a walking stick and have difficulty climbing stairs.

The distribution of residents indicates that about 39% of ‘Welfare Homes’ patients are characterised by a low dependency and thus might not be considered as dependent in a strict sense.

From the medico/social status criterion (i.e. the main reason for residence) about 13% of resident patients report social reasons. Other reported statuses are: chronic illness, rehabilitation and disability/handicap. The group reporting 'social reasons' is concentrated in Welfare homes. However, this category might include drug-addicted persons, etc.

NL

For private households, we take 18% of persons 65+ (see Table 2). Van Herten et al (NL3) present the prevalence of dependency by age group and type of institution (Nursing homes and Homes for the elderly).

The dependency rate of persons aged 75-79 years is:

- Nursing homes: men 66,4%, women 75,2%.
- Homes for the elderly: men: 55,0%, women: 60,8%.

De Klerk (NL3) reports that almost 100% of nursing homes' residents and 71% of 'Homes for the elderly' residents make use of professional help. However, this might overestimate dependency as some persons might use these services, which are defined in a broad way, once in a while.

The distribution of residents in homes for the elderly is:

Always in bed	5,3%
Totally dependent on help	26,2%
Partially dependent on help	45,7%
No physical assistance	22,7%
Total	100 %

This gives a dependency rate of about 77%, which is significantly higher than the two rates presented above. However, we may note that a certain number of partially dependent persons might not very often use help. Consequently, this rate might be considered as an upper limit.

UK

The United Kingdom data refers to England. It relates to persons with a severe disability.

The survey distinguishes severe disability by type of care home: Residential homes (70%), nursing homes (91%), dual registered homes (85%). 55% in care homes needed assistance with one or more self-care tasks but only 3% in private households.
Prevalence of severe disability for 65+: 16%. Care homes: men 69%, women: 79%.

Table 16: Prevalence of dependency by type of residence

	B	F	IRL	NL	UK
Definition	Persons with severe ADL limitations	Dependent for at least one ADL activity (Katz)	Dependent persons	Dependent persons (mainly ADL)	Persons with a severe disability (England)
Source	B2	F1	IRL1, IRL3	NL1, NL3	UK1
Age	60+	60+	65+	65+	65+
Year	1999/01	1998/99	2000	1999/2000	2000
% of persons living at home who are dependent					
Private households	14	9	15	18	13
% of persons living in institutions who are dependent					
Institutions	78	63	89	68*	77

Notes

*: Estimation.

B Flemish region. Rest homes and nursing homes
Private households: All persons with severe ADL limitations in 2001.
Institutions: Dependency according to the health insurance criteria (personal care and dementia) in 1999.

F Dependent for at least one ADL activity (Katz):
Washing, dressing, go to and use the toilet, get in/out of bed and get in/out of a chair, incontinence, and eat prepared food.
The survey of homes for the elderly provides that 37% of residents have 'no or a small dependency'.
The proportion of clients with 'no or small dependency' is 42% in residential homes and 2% in long-term nursing homes (F5).

IRL Institutions include Health boards (geriatric home, Welfare home, and private nursing home)
About 5% of long-stay patients are less than 65 years age.
About 13% of patients residents report social reasons as a medico/social status.
The remaining people report a chronic illness, rehabilitation or disability/handicap.

NL For private households, we take 18% of persons 65+ (see Table 2)
Institutions: persons with a severe sensory or ADL limitation (NL3). Van Herten et al. give the dependency rate of persons aged 75-79 years:
- Nursing homes: men 66,4%, women 75,2%.
- Homes for the elderly: men: 55,0%, women: 60,8%.

De Klerk (NL3) reports that almost 100% of nursing homes' residents and 71% of 'Homes for the elderly' residents make use of professional help.

UK Residential homes, nursing homes, dual registered homes.
Severe disability by type of care home:
Residential homes (70%), nursing homes (91%), dual registered homes (85%).
55% in care homes needed assistance with one or more self-care tasks but only 3% in private households.
Prevalence of severe disability for 65+: 16%. Care homes: men 69%, women: 79%.

Discussion and recommendations

a. Comparability of existing surveys

Identified data reveals that comparability presents the following problems:

- The definition of dependency varies across countries,
- The methods and classifications used to measure dependency are different;
- The same term may contain different concepts.

Despite these differences, many Member States use classifications, which are close to WHO classifications and Activities of Daily Living. Most Member States focus on the following items:

- washing,
- dressing,
- transfer (getting in/out of bed/chair),
- going to the toilet,
- continence and
- eating.

Watching and listening is included in most surveys. It is important to note that all report difficulties concerning these functions. The notion of help here is difficult to apply. The important point here is the availability of different degrees of limitations, which enables us to identify the extent of assistance required.

Recent policies on improving the quality of life of disabled and elderly people have put emphasis on social and cultural participation. Furthermore, improving equal opportunities in social and leisure activities has led many countries to take into account both the provision of services and the elimination of barriers.

There is thus an increasing tendency to include in the surveys questions concerning:

- activities related to domestic life (cooking, shopping and house keeping), and
- mobility in a larger extent (moving outside the home, etc).

They are called to take a higher importance in the future for the following reasons:

- they are important determinants of social participation, and
- they might be important factors for certain persons in their decision to enter into an institution.

Mobility poses the problem of barriers and environmental accommodation. The rate of dependency might be very sensitive to public policies. In fact, the provision for example of an accessible public transport might reduce significantly the number of people who declare that they need help to use public transport.

Communication, general tasks and demands, and social life are considered important but are more difficult to measure. Consequently, only a few surveys have included them.

Number of dependent persons

Following previous comments it is interesting to see the implications of the Indicator EO c10 concerning: 'dependent elderly men and women (unable to look after themselves on a daily basis) over 75'.

If we interpret the indicator in a strict sense to mean only personal self-care dependency, we have to notice that there are a significant number of dependent people below the age of 75 years.

As discussed above, available statistics are not comparable. However, they deliver a certain number of lessons, which may characterise current tendencies. Concerning the number of dependent persons, identified data indicates that an approximate estimation for the different age groups might be (see Table 5[3]):

- age group 20-59: 1%,
- age group 60-75: 3%
- age group 75+: 12%

This data uses the narrow definition and ought to be considered as minima. They give the following approximations:

- 2,1 million persons aged 20 to 59 years,
- 1,6 million persons aged 60 to 75 years, and
- 3,2 million persons aged 75 and over.

These numbers indicate that the majority of highly dependent people are less than 75 years old. Consequently, a relevant estimator ought to take all age groups into account.

As noted above, the number of persons with a severe disability might be considered as an upper limit for the number of dependent people. Chart 12 presents both the proportion of people who are severely hampered in their daily activities and the proportion that are dependent (narrow definition).

Furthermore Table 17 indicates that the number of elderly people is going to increase in the coming years. This means that the number of persons aged 65 and over with a severe disability is expected to increase significantly.

The definition of the EU indicator

If we interpret the indicator in a strict sense, it means that we have to include mainly self-care and basic transfer activities (washing, dressing, transfer (getting in/out of bed/chair), going to the toilet, continence and eating).

This means that a person who needs help to accomplish at least one of these activities may be considered as dependent. This strict interpretation leads to the Katz index.

The Katz index (ADL) has six items: washing (bathing), dressing, transfer (to or from a bed or chair), going to the toilet, continence and eating. The index covers tasks, which people need to be able to perform to survive without help. They were initially used for clinical purposes and may be sufficient in certain institutional settings. They are considered too restrictive for a person living in the community.

In order to take into account these critics, the Lawton and Brody index (IADL) includes 8 Instrumental Activities of Daily Living: using the telephone, shopping, food preparation, housekeeping, laundry, travel, responsibility for own medicine and ability to handle finances. These activities are considered to be necessary for living a more or less normal life without help.

Communication, general tasks and demands, and social life are considered important by most but pose a methodological problem of measurement.

[3] Different definitions of average for the age group 65-74 range from 3% to about 3,5%. The different definitions of average for the age group 75+ are close to 12%.

The EU indicator requires inability to look after oneself on a daily basis. If we consider that for example shopping or the ability to take his/her medication are prerequisites for the ability to look after oneself, then we must take into account these activities. In fact, instrumental activities enter indirectly in the definition as they make possible the implementation of the basic daily activities (eating, etc).

Social security definitions in the Member States take into account IADL activities, considering that they are essential for an independent living. However, the nature of these activities as well as conditions imposed upon them (minimum number or hours needed) differs greatly across countries and inside a country between different services.

In deciding the granting of certain services promoting independent living, the Member States use notably the following criteria:

- B Use of ADL-related scales (bathing, dressing, transfer and/or toileting).
- DK Activities of daily life including eating, dressing, bathing, toileting, continence, walking, cooking, shopping, cleaning and transportation.
- D Assistance in special life situations (participation, integration, care).
- E Most essential acts of life including personal care, domestic activities, shopping, communication and coherence, etc.
- F Lack of autonomy in ordinary daily activities including dressing, toileting, etc.
- I Basic daily tasks.
- NL ADL and IADL activities, including limitations concerning living or moving in and outside the dwelling.
- A Daily activities, mobility, etc.
- S Daily activities include both ADL and IADL activities.
- UK Need care notably for bathing and washing.

It is clear that many Member States include instrumental activities in their assessments of needs. Of course, a person who cannot make his/her shopping in a big city may not be considered as fully dependent. In fact, most of the national social security schemes impose a minimum number of hours.

The frequency of the activity is an important element. The indicator use the term 'on a daily basis'. The question then is how to take into account these activities in the definition of dependency. One possibility might be to assign a weight to each of these activities.

A person receives '1' or '0' depending whether he/she is not able to do or is able to do each of the basic activities (washing, dressing, transfer-getting in/out of bed/chair, going to the toilet, continence and eating). A person unable to do at least one of these activities is considered dependent and receives at least one point.

For the remaining activities we may assign a weight to each activity. The weight may depend on the frequency of each activity. Time-use surveys might for example provide information for the calculation of these weights. In a simplified version, if we assign the weight '0,33' to each activity, then a person might be considered dependent if he/she is unable to do three of the instrumental activities.

Concerning self-care, we assumed that the person is able/unable to do the activity. The situation might be more complicated if we assume that he/she needs help every day, every week, once in a while, etc. Again we may assign a specific weight to each answer.

A certain number of methodological problems might arise in the definition of questions concerning communication general tasks and demands, and social life.

Dependent persons in institutions

Data ought to include both dependent persons in private households and in institutions. As noted above, not all persons in residential homes for the elderly may be considered as dependent persons.

In designing the sample of a survey, a special attention ought to be given to include all dependent persons. Furthermore, given the high diversity of institutions (protected homes, care homes, nursing homes, etc.) a fair representation ought to be guaranteed.

On the other hand, restricting the sample on private households might be undesirable as a big number of people aged 80+ live in institutions. The choice of a residence is not independent from the nature and degree of dependency.

The inclusion of people in institutions might imply the elaboration of two questionnaires one for people living in private households and one for those living in institutions. In fact, a certain number of questions might have no relevance for people in establishments, notably those concerning Instrumental Activities of Daily Living (shopping, etc.).

The collection of reliable data for people aged 80+ would require a special attention on methodologies and samples. The non-response rate might be a function of dependency.

Elements of a European survey

Previous discussion indicates that a future survey at a European level might include the following activities of the WHO classification (ICF):

1. Mobility
    a. Changing basic body position (getting in/out of a seat/bed, bending)
    b. Maintaining body positions (use the toilet)
    c. Transferring oneself (transferring oneself while sitting or lying: from a chair to a toilet seat)
    d. Carrying, moving and handling objects (lifting and carrying objects, hand and arm use)
    e. Walking and moving around (walking short and long distances, climbing steps)
    f. Moving around using transportation (moving around within the home, moving around outside the home, use public transport)
    g. Other

2. Self-care
    a. Washing oneself
    b. Caring for body parts
    c. Toileting
    d. Dressing
    e. Eating
    f. Drinking
    g. Looking after one’s health
    h. Other

3. Domestic life – Household tasks
    a. Preparing meals
    b. Doing housework (light housework)
    c. Other

4. Communication
    a. Speaking
    b. Conversation / Discussion

5. Sensory experiences
    a. Watching (recognise a face or read a newspaper or watch a television programme)
    b. Listening (listen to radio, etc.)

6. General tasks and demands
    a. Undertaking single (manage his/her own finance, etc.)
    b. Memory

7. Community and social life

The classification ought to include questions enabling us to identify contextual factors, which constitute barriers to participation. For example, the need of assistance in going out might result from the absence of accessible transport services. In this case either we say that the person needs assistance or we propose to adapt the existing transport services. The latter case might simply require the presence of a bus with low stairs or an easy entry.

Concerning the degree of dependency, ICF proposes the following scale:

- No difficulty
- Mild difficulty
- Moderate difficulty
- Severe
- Complete difficulty
- Other / Not specified

An alternative scale based on the need of assistance could be:

- I can do it without any assistance and with no difficulty
- I can do it without any assistance but with some difficulty
- I can do it without any assistance but with much difficulty
- I need some assistance
- I need much assistance
- I can not do it at all
- Other.

However, this might create practical problems and might be difficult to incorporate in certain national questionnaires. As many surveys have a first filter question on the presence or not of any difficulty, it might be more interesting to keep this question and add a follow up question determining the nature of help. Consequently, if the interviewee answers positively in the filter question, the next question could focus on the needs for each activity:

- I can do it without any assistance but with difficulty
- I need some assistance
- I need much assistance
- I can not do it at all
- Other.

One possible alternative could be to follow the following path:

- Question on the presence of a difficulty or a limitation. If the answer is positive,
- Question whether the limitation is moderate or severe. If the answer is positive,
- Question on the nature of need by type of activity. Questions on sensory experiences might have a different structure, as the formulation of needs could be different.

Member States express the view that new questions ought to preserve continuity with existing instruments and hence guarantee longitudinal comparability of national data. From this point of view, one ought to take into account the path of the different filters used in national surveys.

An important dimension is the amount of time required per week and the periodicity. This could provide a more objective indicator for the degree of care dependence. The periodicity might indicate whether assistance is needed:

- Once a week,
- Several times a week,
- Once/twice per day,
- Several times a day.

Periodicity will enable us to retain only persons with a significant dependency and exclude the occasional need for help.

Finally, as it was noted in the general introduction, the survey ought to retain only long-term (permanent) dependencies. A criterion might be an expected duration of six months or more.

A survey at a European level might be organised in two ways. A specific survey covering all aspects might be organised at a European level. This might be the more costly solution. Another possibility might be the extension of existing national surveys.

The second solution might be preferable since all Member States organise surveys with similar questions. The preparatory work here will consist in harmonising existing surveys at least for a common bloc of questions.

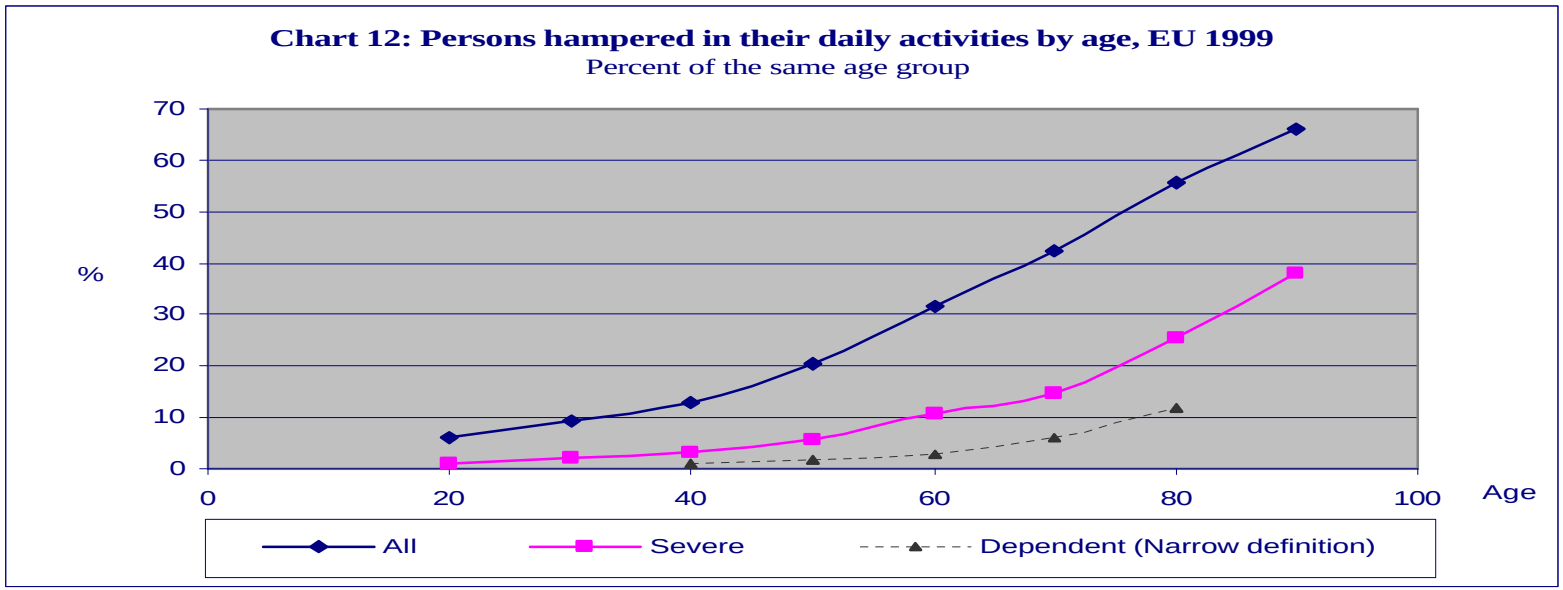
The different surveys, which might support a common module on care dependency, are the European Community Household Panel survey and the National Health Interview surveys.

The survey "Statistics on Income and Living Conditions" (SILK), previously European Community Household Panel survey, could include a simplified module on the characteristics of dependent people. This is the less costly solution but the information might be very general. The module could focus on ADL activities.

A more elaborated module on the characteristics of dependent people and the nature of care/needs provided could be included in the national Health Interview Surveys. For many countries this would require only the harmonisation of existing questions and the adoption of a common classification. This seems to be the best solution and probably the less expensive if we take into account the final product. Furthermore, a certain number of Member States are exchanging information on the implementation of the WHO classifications (notably ICF)[4]. In fact, the EUROHIS project aims to promote the use of common instruments in health interview surveys in Europe. The project is coordinated by WHO. The project has focussed on health indicators but is expected to begin work on the use of ICF.

As a conclusion, we can say that a certain policy of harmonisation of existing surveys might be the most efficient solution.

[4] It is interesting to note the Survey of Health, Ageing and Retirement in Europe project (SHARE). It aims notably to study the link between health status and socio-economic status, the dependency risk and retirement decisions. The study is coordinated by OECD. It focuses on cross-national differences of ageing-related diseases and the way to improve health care systems.



Source: Eurostat (ECHP 1999) and Table 5.
Note: Table 5 gives approximately (narrow definition): 1%; 3%, and 12%. The remaining points on the chart are extrapolations based on an exponential fit.

Table 17: Severely hampered people by age group (ECHP); Absolute number and percentage change

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK	EU
	Absolute numbers, 1000															
65+ (1999)	244	139	3.434	339	923	2.599	33	1.666	9	343	210	400	191	336	1.795	12.662
65+ (2020)	293	191	4.520	432	1.092	3.339	52	2.222	12	515	279	467	294	449	2.323	16.480
% change	*20*	*37*	*32*	*27*	*18*	*28*	*55*	*33*	*41*	*50*	*33*	*17*	*54*	*34*	*29*	*30*
	Absolute numbers, 1000															
75+ (1999)	135	79	2.176	169	519	1.426	19	1.041	5	201	144	211	116	258	1.272	7.771
75+ (2020)	171	97	3.248	272	687	1.764	26	1.650	8	279	205	267	166	323	1.585	10.748
% change	*26*	*24*	*49*	*61*	*32*	*24*	*37*	*58*	*59*	*39*	*43*	*27*	*43*	*25*	*25*	*38*

Source: The estimation uses ECHP (1999) and Eurostat projections for the total population (see Eurostat, "Statistiques sociales européennes: Démographie"; Thème 3, Population et conditions sociales, 2001). % change: percentage increase between 2020 and 1999.
Note: The Irish data might underestimate the true number

SECTION II

INFORMAL CARE

Introduction

Care may be provided by professionals or by informal sources. The informal sector includes mainly the family, relatives, friends and neighbours. The next chapter will discuss the meaning of the term 'informal'.

A question concerns the frontier between help considered to be convenience assistance and help considered to be dependency care. The frequency and the time spent by the carer might be relevant criteria. But someone has still to fix these values. Comparison of the criteria used by national social security systems could provide an indication here. The problem is that these criteria differ across countries and inside a country across services.

Another possibility might be to measure the time and frequency of care provided among members of households without dependent persons and to take this quantity as a critical level. Help over this amount could be considered as help related to dependency.

The family may provide the bulk of care in certain countries. It is consequently interesting to identify the characteristics of both the persons receiving informal care and the characteristics of the carers.

Another question concerns care allowances. In certain countries elderly persons have a right to:

- the funding of personal assistance provided by a professional (contribution to cost, partial payment, credit, reimbursement, etc.) or
- an amount of money which he can use to pay a relative or any other informal carer.

It often concerns home nursing, e.g. assistance in activities such as personal hygiene, dressing, etc. In such cases, we might have a nominal shift of informal care towards formal care.

Also, a family carer may receive different types of support (for example: social security contributions of the carer are paid by public authorities, if the amount of assistance is over 14 hours per week, in Germany; the carer receives an allowance if he/she lodges a dependent person in Spain; an allowance or a set of services is provided to the carer, in Sweden and the United Kingdom). These measures may affect the amount of help provided by the family.

The goal here is not to present an analysis of such measures but to keep in mind that different factors might influence the amount of help provided by the family apart from socio-cultural elements.

We consider that operations, which generate an official transaction and are registered (directly or by estimation) in the national accounts, ought to be characterised as a formal activity. All other operations ought to be included in the informal sector. Consequently, a free help supplied by a charity employing a staff ought to be included in the formal sector. In fact, the freely available service gives rise to a paid work, which is included in the national accounts.

From this perspective a family member providing help ought to be considered as informal help. On the contrary, the same person if public authorities support him/her financially, ought to be considered as formal carer, at least for this part of care, which corresponds to the financial counterpart.

Given this precision, we have to acknowledge that it is not possible to identify correctly the distinction between formal and informal. The best proxy which can be used in a questionnaire is whether help is paid or not (directly or indirectly). What is important here is to have a clear classification of carers, which has a meaning for the interviewed person. Existing classifications do not seem to pose any serious problem in the comparability of collected data. The use of paid/free service seems to be a workable instrument.

Chapter 1

Characteristics of people receiving informal care

a. Analysis by country

This chapter aims to present data concerning informal care to dependent persons. This means that data related to temporary limitations and acute sickness ought to be excluded. However, this was not always possible.

France

The survey distinguishes between professional and non-professional help.

Informal care includes any care not directly provided by a professional sector – i.e., a medical, social service, or institutional sector. Informal care thus excludes services provided by professionals and volunteers working for non-profit organisations. Professional care includes notably, medical and paramedical professionals, cleaning personnel, educators and non-lucrative associations.

Non-professional carers include the family (partner, child, grand child, brother/sister, other), friends and neighbours, person sharing the residence, and servant or salaried living with the beneficiary.

The nature of help retained includes activities such as self-care, mobility, cleaning, ironing, shopping, administrative procedures, taking care and defending the interests of the beneficiary, etc. This means that the frequency might be at least once a week and even less in certain cases. Consequently, the definition is very broad and one might expect high rates.

In fact, data in Table 18 indicates that the number of elderly persons (60+) receiving care from a non-professional is higher compared to the number of persons needing help for at least one ADL (Katz) activity.

Netherlands

In 1999, about 9% of private households received informal help (NL4). This rate was stable during the last ten years. For comparison, about 8% received individual help (from an employee or a nurse) and 7% benefited from Home care (including personal care, housework, etc.). This data covers all persons and all types of informal care. It is important to note that this data includes persons who receive help but may not be considered as dependent.

Among persons aged 65 years and over receiving at least one type of help (informal, individual or home care):

- 25% received only informal help, and
- 11% received informal care and Home care.

Austria

Concerning informal care, interviewed persons responded to several questions (A3):

a. Your household provides care for whom – chief of household (COH), husband / wife of COH, mother-in-law of COH, father-in-law of COH, children-in-law of COH, sister or brother-in-law of COH, grandparents of COH, other relatives or friends?

b. Which household member provides care for persons aged 60 and more?

c. How many hours per week (travel included) of help are given by your household for a person aged 60 or more: until 1 hour, 2-3 hours, 4-5 hours, 6-10 hours, 11-19 hours, more than 20 hours?

d. For which activity do members of your household help persons aged 60+: personal care, medical care, going shopping, preparation of meals, cleaning up, washing and ironing, other household tasks, making provisions, going out?

e. How often do you provide care / help: every day, several times per week, once a week, less often, never?

The data reports persons with physical limitations who receive help by family, friends, home help and others. They distinguish daily help, once a week, regularly, not often, never, not known. In the following table we present help provided by the family, relatives and friends. We distinguish help provided daily and help provided at least once a week.

Furthermore, we have added help provided by the family and the friends. This might involve double counting if a person receives help both from the family and the friends. However, this overestimation might be low as the number of friends providing help is very small.

The survey makes the distinction between help provided by household members and social services. It does not refer explicitly to formal and informal.

Sweden

For Sweden, we dispose only of an estimation done by Johansson et al. (S4). It includes family help with ADL-functions. The authors advance that increased inputs from families match the decline of public services, that is, a 'reverse' substitution has recently been taking place.

UK: Family Resource Survey (UK5)

An individual is recorded as receiving care if he receives care from another person in the household and/or from someone outside the household. They are counted only once no matter how many people provide care to them.

Informal care is defined as giving and receiving help on an informal basis, that is, not as part of a paid job. The authors note that what should be counted as care is not prescriptively defined.

The data gives the frequency of help: continuously, several times a day, once or twice a day, several times a week and once a week. In the following table we distinguish daily help (at least once a day) and at least once a week.

Concerning persons receiving care available data does not distinguish between formal and informal help.

The data for England (General Household Survey, 1994; source: UK3) indicates that 46% of elderly persons without dependency receive an informal help.

Consequently, it is important to have a filtering question before to put the question: Do you receive any help? This might involve a question on "Do you have any limitations …". If the person answers "Yes", then the question on help might be relevant.

Dependent persons

Only the Austrian data presents the rate of dependent persons receiving informal help. Data for other countries refers to the total population.

French data indicates that more than three-quarters of all dependent seniors receive informal help (F4).

Concerning United Kingdom, if we assume that all daily care (11% in Table 18) is provided to persons with long standing limiting illness, then the proportion of persons with a long standing limiting illness who receives care amounts to 25%. This could be compared with the Austrian data, but we know that our hypothesis is not correct. As a certain number of persons without dependency receive help from the family, the rate ought to be lower.

The General Household Survey for England (UK1) indicates that the percentage of persons unable to perform one or more domestic tasks that receives informal help is 85%. The percentage of elderly persons unable to perform one or more personal care tasks that receives informal help is 76%. The percentages are high because there is no constraint on the frequency.

Table 18: Persons receiving informal care, as a percentage of the population of the same age group.

	F	**IRL**	**A**		**S**	**UK**		
Definition of beneficiaries and care	Persons receiving care from a non-professional (private households)	Persons receiving a high level of informal help (age: 65+)	Persons with physical limitations receiving daily help from family and relatives	Persons with physical limitations receiving help at least once a week from family and relatives	Persons receiving help with ADL functions	Persons receiving daily care	Persons receiving help at least once a week	
Source	F1	IRL1	A3		S4	UK5		**Source**
Year	1999	2000	1995		2000	2000/01		**Year**
20-24	2							**20-24**
25-29						1	2	**25-29**
30-34	2		3	5				**30-34**
35-39						2	2	**35-39**
40-44	4		4	6				**40-44**
45-49						3	4	**45-49**
50-54	7		6	8				**50-54**
55-59						4	5	**55-59**
60-65	13		8	12		6	7	**60-65**
65-69						7	10	**65-69**
70-74	21		16	25				**70-74**
75-79						14	24	**75-79**
80-84	48		42	59				**80-84**
85-89						28	49	**85-89**
90+	70							**90+**
65+	**22**	**21**	**18**	**27**	**-**	**11**	**18**	**65+**
75+	**51**	**-**	**42**	**59**	**37**	**17**	**29**	**75+**

Notes

In France, 22% of persons living at home, aged 65+ receive care from a non-professional.

F: Age-groups: 20-29; …; 80-89; 90+. Totals refer to 60+ and 80+.

A: Age groups: 30-39; …; 70-79, 80+. Totals refer to 60+ and 80+.
The percentage of persons receiving daily help from friends is less than one percentage point except for persons aged 70-79: 1,2% and 80+: 3,5%.

S: The survey covers only persons 75+.

UK: The % of persons aged 65+ unable to perform one or more domestic tasks receiving informal help is 85%. The % of elderly persons unable to perform one or more personal care tasks receiving informal help is 76% (General Household Survey, England, 1994).

b. Informal / Formal help

Another important aspect is that many persons may receive help from different sources (see Tables 19 and 20). In fact, many persons cumulate informal help with formal home services.

In France, the data indicates that a significant proportion of people without dependency receive some kind of regular help. Furthermore, among those who receive help an important number combines help from different sources. Table 19 presents the sources of care by degree of dependency. We have retained the two most used indicators in France: the 'Colvez' and the 'Isoressources group' index.

An isoressources group is a group of people requiring a comparable volume of assistance, measured in man-hours. The groups are numbered from 1 to 6 by decreasing level of dependency. Group 1 mainly comprises individuals who have lost their mental, bodily, motor, and social independence, and thus require a continuous presence of caregivers. On the other extreme, the individuals in group '5' need ad-hoc care (usually home help) and those in group 6 are persons who remain independent in all daily-living activities. On the other hand, the 'Colvez' classification distinguishes four levels.

In Sweden, a fifth of the older people who are helped by their families also use home help services (see table 20).

In the Netherlands, among persons 65 years old and over receiving at least one type of help (informal, individual paid or home care): 25% received only informal help, 11% combined informal care and Home care, and about 6% received another combination of different types of help (NL4).

An important discussion concerns the substitutability or complementarity between formal and informal help.

Analysis of different surveys provides mixed results. In certain cases formal and informal seem to be substitutes and in other cases they seem to be complementary. The Swedish study noted above finds that increased inputs from families match the decline of public services, that is, a 'reverse' substitution has recently been taking place in Sweden.

Complementarity might arise in situations where the formal sector provides personal care services and leaves to the family the provision of instrumental activities (shopping, etc.).

Following a study, in France, the lower the average hourly price of formal care, the longer the hours received. However, formal and informal care volumes vary too much from one dependent person to another to be able to determine the extent to which these two types of care are substitutes (F4). Furthermore, it seems that total hours of care increase with dependency and isolation.

Research in the US indicates that "as long as a person has faculties of comprehension, spousal care is a viable and often used substitute. For all individuals, male and female, without comprehension limitations, marriage cuts the probability of nursing home entrance by more than half. Only for the most severely disabled people, who suffer from an inability to understand or communicate, is spousal care not an important substitute"[5].

[5] Lakdalla, D., and Philipson, T., "Aging and the Growth of Long-Term Care", NBER Working Paper Series, N° 6980, 1999.

Table 19: Source of care received by dependency level (France),

France, 1999; Persons aged 60 and over.

Type of care/Degree of dependency	Severe (GIR 1, 2 and 3)	Moderate (GIR 4)	Little or no (GIR 5 and 6)
Informal care alone	30	53	51
Formal and informal care	63	40	25
Professional care alone	7	7	24
TOTAL	100	100	100
Percent of elderly persons receiving help	100	99	25

Note: For the definition of 'GIR' see 'AGGIR' in the Glossary. '6' means self-sufficient.
The data includes only private households.
Source: F1.

France, 1996; Persons aged 65 and over.

Type of care	Extreme dependency (Adjusted Colvez 1 & 2)	Moderate dependency (Adjusted Colvez 3)	Little dependency (Adjusted Colvez 4)
Informal care alone	53	54	41
Formal and informal care	30	29	24
Formal care alone	16	17	35
Total	100	100	100

Note: For the definition of the type of care see 'Colvez' in the glossary. Private households.
Source: F4

Table 20: Source of care received by persons 75+ in need of help (Sweden), 2000.

Type of support	All	Live alone	Co-resident
Informal care only	66	47	88
Both informal care and Home Help	16	24	7
Home Help services only	18	28	5
Total	100	100	100

Note: Persons residing in the Community.
Source: S4.

c. Classifications of informal care

The different surveys distinguish between different types of carers. In general they avoid the terms formal and informal, contrary to academic works. The relationship to the person being cared for can be:

D	E	F	A	UK(1)	UK(2)
Wife/ husband /partner	Partner	Partner	Spouse/partner	Spouse	Parent
Daughter / son	Daughter/Son	Child	Daughter (in-law)	Parents	Partner/spouse/ cohabitee
Sister / brother	Sister/Brother	Grandchild	Son (in-law)	Children	Son / Daughter
Daughter-in-law	Mother/Father	Other ascendant	Other female relative	Other relatives	Brother / Sister
Other relatives	Other relative	Brother/sister	Other male relatives	Others	Other relative
Friends, neighbours	Employee	Other relative	Female friends		Non relative
Others	Friends and neighbours	Friend, neighbour	Male friends		
	Guests	Other person (no relative)	Social services including volunteer		
	Social services (volunteer)	Employee	Other persons (paid domestic aid)		
	Other relations		Not known		
	Not known				

Statistics on informal care by type of relationship between the carer and the beneficiary are presented below.

d. Co-resident / Other household

Table 20 makes an interesting differentiation: whether the beneficiary of informal care is living alone or resides with the carer.

A British survey (UK5) distinguishes between whether the informal carer lives in or outside the household.

Also, the General Household Survey (UK3) asks who gave the help: Spouse or partner; Other household member; Non-household relative; Friend/neighbour; NHS or personal social services; Paid help; and Other.

If the person usually gets help from someone outside the household, he is asked who is the person: Son; Daughter; Brother; Sister; Other relation; Friend/Neighbour; Social services; District nurse/ Health visitor; Paid Help; Other.

Finally, the German data makes a distinction between help received at home and help received in an institution. They don't present informal and formal help.

It is important to note that help may be provided to another household, without being able to distinguish the beneficiary inside the household (e.g. cleaning the house), while in other cases, the member of the household can be identified (e.g. washing a person).

Chapter 2

Type of informal care

The previous chapter presented the number of (dependent) persons receiving informal help. This chapter will analyse the nature of this help.

It is important to note that ideally the data ought to exclude care for temporary and acute sickness. For example, available Dutch data (NL4) indicates that among the informal carers, 9% of carers provide help to persons with chronic sickness, 15% provide care to persons temporarily sick, 6% provide care to persons at a terminal stage, etc. Data ought to eliminate informal care provided to temporarily sick persons. However, available information does not always makes this distinction.

Type of informal care provided

Table 21 indicates that in the majority of cases, informal help concern instrumental activities like shopping and household tasks.

Both constitute important activities of independent living at home and maintenance in the community.

Statistics are not comparable since they adopt different points of view (dependent person or carer).

Frequency

Table 22 presents the frequency of informal care. The data is only indicative since the definitions and the frequencies used are not strictly comparable.

Hours are important in surveys aiming to study the link between needs and social security benefits. For example, modelling Social Security benefit entitlement is central to the “Family resources survey” (UK5), notably for policy evaluation and costing of policy options.

The time spent for caring varies sharply across countries. The high importance of permanent care need in Germany might be the result of the population covered. In fact reported statistics cover beneficiaries of the long term insurance scheme, and thus more dependent persons compared to people in general surveys.

Provider

We have very little information on the preferences of older people concerning the nature of the care provider. A recent study in Ireland (HeSSOP, IRL1) asked older people about their preferences for long-term care. In the case of housekeeping care (cleaning, cooking, shopping and so on), 54% of the respondents said that they preferred to receive this type of care from family, friends or neighbours. The percentage of respondents preferring professional care providers was slightly higher (23%) in the case of personal care services (bathing, dressing and so on), with 50% preferring their family, friends or neighbours. The most popular living at home situation was the current home with involvement of the health board through the provision of respite care services. This data has only an indicative value and may not be extrapolated to other countries. In fact, preferences might depend upon the availability of market services, the quality of such services, the cost of these services, traditions, etc.

A survey among Danish elderly people[6] revealed that there is an agreement among older people, relatives and parties involved with older people that in cases regarding couples the non-dependent spouse is responsible for assisting with both practical tasks and personal care. Furthermore, neither older people nor relatives think that family, friends and neighbours should be burdened with the responsibility of assisting older people with practical tasks or personal care.

In the Netherlands, a study concerning the reasons for entering a nursing home, a care home or a protected form of housing indicates that the inability to receive the necessary help from the family and the friends was a main reason to enter a nursing home and an important reason to enter a care home for the elderly. On the contrary, this was not an important reason to enter a protected form of housing (NL4).

Table 21: Type of care provided / received in %

	F	**NL**	**A**	**S**	**UK**
Definition	Type of non-professional care given	Distribution of private households receiving informal help by type of help	Households with help for elderly	Distribution of type of care	Carers with main person cared for
Source	F1	NL4	A1	S1	UK4
Year	1999	1999	1998		2000
Type of care given / received (in %)					
personal care	25	27	28		26
medical help	36		28		22
going shopping	52		59	37	
preparing meals			30	19	
household tasks	42	73	95	39	71
going out	28		18		52
financial matters	67		45		39
others	39				

Note: Percentages might not add up to 100, because one carer might provide several types of care. Also, the dependent person may receive different types of help. Statistics are not comparable since they adopt different points of view (dependent person or carer).

F 25% of non-professional help supplied by non-professionals concern personal care.
NL 27% of private households receiving informal help benefit from services concerning personal care.
A 28% of households with help for elderly people receive services concerning personal care.
S 37% of care provided concerns personal care;
UK 26% of carers provided help concerning personal care.

F: Financial matters: defense of rights / administrative help; Others: keeping company
NL: The categories of help are very large.
S: Data comes from different studies exploiting the same survey.

[6] "An Old Person Needs Assistance. Who should provide it?", Colmorten, E. et al., Institute of Local Government Studies, 2003.

Table 22: Frequency of informal help received

	D	E	A		S	UK
Definition	Dependent persons (all ages) cared for at home (dependency level I)	Disabled persons aged 65+ receiving informal care	Time spent on informal caring	Informal care provided to persons aged 60+	Elderly being cared for by relatives	Households members aged 60+ receiving care
Source	D3	E1	A1	A1	S1	UK5
Year	1999	1999	1998	1998	1980-1998	2000-2001
(in %) both sexes						
once a week	8		12	6	24	13
several times/week	10	15	19	10		22
once a day	15	17	19			20
twice a day	13	16	25	22	5	
several times/day	25	9				23
permanent	22	42	26			23
never	4			49	55	
not often				13	15	
not known	3	2				
	100	100	100	100	100	100
(in %) men						
once a week	8					11
several times/week	9	11				18
once a day	10	17				20
twice a day	12	15				
several times/day	27	10				23
permanent	27	45				28
never	5					
not often						
not known	3	1				
	100	100				100
(in %) women						
once a week	8					17
several times/week	11	16				25
once a day	17	17				20
twice a day	14	16				
several times/day	24	9				20
permanent	19	41				19
never	4					
not often						
not known	3	2				
	100	100				100

Notes

D	**E**	**A**	**A**	**UK**
Once a week (housework)	Several times /week: < 7 hours	Once a week: -1 hour		Continuously
Several times/week	Once a day: 7-14	Several times/week: 2-5 hours	Once a week	Several times a day
Once a day	Twice per day: 15-30	Once a day: 6-10 hours	Several times/week	Once/twice a day
Twice a day	Several times /day: 31-40	Several times/day: 11-19 hours	Daily	Several times a week
3 times a day/more	Permanently: 40+	Permanent: 20+ hours	No help	Once a week
Permanent	Not known			
Not known				

D: The data includes formal and informal help.
UK: The data includes formal and informal help.

Chapter 3

Distribution by sex and age of informal carers

Previous chapters presented the characteristics of dependent persons. The following chapters will present the characteristics of carers.

As noted above, this chapter aims to present data concerning carers of dependent persons. This means that care related to temporary limitations and acute sickness ought to be excluded. Furthermore, we exclude data concerning childcare, maternity care, and related forms, as they are not part of this study.

It is important to note that we identified data only for Austria and Sweden. The data for the remaining countries covers all carers. Consequently, they are not comparable with Austria and Sweden.

The gender breakdown indicates that the majority of carers are women.

Data in Great Britain indicates that women were more likely to be carers than men were but the difference was not marked, 14% compared with 11%. However, since there are more women than men in the total adult population of Great Britain, it is true that the number of women caring is considerably greater than that of men, 3,3 million compared with 2,4 million (UK3). This gives 42% men and 58% women.

Authors note (UK3):

- Women looking after someone outside the household 10%, men 7%;
- 5% of adults looked after parents and 3% cared for friends and neighbours
- The peak age for caring was 45-64. 20% of adults in this age group were providing informal care.

Additional data for Germany indicates that, more than 1.7 million people were using nursing services offered by the Long Term care insurance. 74% lived in their own homes and, the rest in nursing homes. 83% of those giving care at home are women[7].

In Ireland, 30% of carers are aged over 65 years (IRL1) and the majority of carers are in the age group 45-68. The survey reports that 8% of older people are the main person providing care for someone else.

In the Netherlands, 10% of persons 18 years old and over provide informal help (NL4). This statistic is relatively large as it includes help to non-dependent persons. About 17% of persons 45 to 54 years old and 19% of 65-74 provide informal help.

[7] Federal Statistical Office, “Health Report for Germany: Abridged Version”, Statistisches Bundesamt, 1998.

Table 23: Distribution of informal carers by sex in %

	D	E	F	IRL	A	S	UK	
Definition	Carers	Carers	Carers	Carers of older people	Carers for elderly with a long-term need for care	Carers of older people (75+) who live alone and have needs with ADL functions	Adult carers (16-64)	Carers
Source	D4	E1	F1	IRL1	A1	S4	UK2	UK3
Year	2002	1999	1999	2000	2000	2000	1989	1995
Distribution of carers by sex in %								
Men	20	26	36	33	20	27	35	42
Women	80	74	64	67	80	72	65	58
Total	100	100	100	100	100	100	100	100

Table 24: Informal carers by age group

	D	E	NL	A	UK	
Definition	Carers for persons depending on care	Carers providing care to a person needing special attention	Informal carers (aged 18+)	Carers for persons aged 60+	Informal adult carers	Carers
Source	D2	E1	NL4	A1	UK2	UK3
Year	1996	2000	1999	1999	1989	1995
Age-distribution of carers in %						
18-29	2	10	16	31	23	32
30-44	17	15	16	38		
45-50	49	20	20			48
50-64		23	22		37	
65-74	21	15	19	30	24	20
75+	10	17	7		16	
Total	100	100	100	100	100	100

Notes

E: The age groups are: 18-24, 25-34, 35-44, 45-54, 55-64 and 65+.
NL: Age groups: 18-34, 35-44, 45-54, 55-64, 65-74, and 75+.
A: Age-groups: -39, 40-59, 60+
UK: Age-groups: -50, 50-64, 65-74, 75+
UK: The General Household Survey 1995 (UK3) gives: carers aged 16-44: 32%, 45-64: 48% and 65+: 20%.

Chapter 4
Relationship of informal carers to persons cared for

As indicated in the first chapter of this section, the family is the main provider of informal care.

Spouse/partner and daughters appear to be the most important groups of informal care providers.

We present below certain key aspects of the British General Household Survey (UK3).

Concerning all carers, we may note the following:

- Carers looking after someone in their own household: 52% were caring for a spouse; 22% was caring for parents and parents in law.
- Carers looking after someone in other household: over a half (55%) were looking after parents or parents in law; just over a fifth (22%) were looking after friends and neighbours.

Co-resident carers constitute about 25% of carers. Certain advance that co-resident care involves often a heavier involvement for the carer. Also, this indicates that there might be differences between spouse carers and daughters/sons carers.

About 13% of all persons aged 65 and over were carers.

From the point of view of dependent persons:

- Persons being cared for by someone in the same household: 54% were aged 65 or over;
- Persons being cared for by someone in a different household: 85% were aged 65 or over.

The general Household Survey (UK3), 1998, notes that the most common source of help with mobility, self-care and domestic tasks was the respondent's husband, wife or partner, providing help in about half of cases. Other common sources of help were other household members and non-household relatives. Apart from getting in and out of bed, for which 20% of respondents used personal social services, only a small proportion used help from anyone other than a household member or relative outside the household.

In Spain (E1), there is a significant difference concerning the origin of help between elderly men and women with disabilities. About 45% of men receive assistance from a partner and 21% from a daughter. In comparison, the rates for women are 15% and 37% respectively. This might be partly due to the longer life expectancy of women.

Concerning the number of hours provided to persons with disabilities:

- Help provided by social services and the market concentrates relatively more in assistance, which last less than 7 hours per week.
- Help provided by partners and daughters concern in the majority of cases help, which lasts more than 30 hours per week.

However, this information does not indicate whether the two forms are substitutes or complements.

About 21% of adult population provides care to elderly persons requiring special attention. The rate is 25% for women and 17% for men. About 31% of persons 45 to 54 years old are carers.

Table 25: Relationship of carer to person cared for in %

	D	E	F	IRL	A	S	UK
Definition	Carer for persons aged 65-79	Principal carer of persons 65+ with disabilities	Non-professional carers	Carers for older people	Personal care for people aged 60+	Carers of older people (75+) who live alone and have needs with ADL functions	Carers for persons aged 65+ (GB)
Source	D2	E1	F1	IRL1	A1	S4	UK3
Year	1996	1999	1999	1994/2000	1998	2000	1995
spouse / partner	61	23	29	25	36	-	19
son (in-law)	2	6	35		10	13	43
daughter (in-law)	30	32		34	26	33	
sister / brother		3	4			53	
other relatives	6	15	25		6		37
friends / neighbours	2	2	7	12	9		
volunteers / employees		12	0		2		
others		7	0		4		
not known					7		
Total	100	100	100	100	100	100	100

Note
Similar results are found in the Netherlands (NL4).

Classifications used	D	E	F	IRL	A	SW	UK
	Wife	Partner	Partner	Different sources	Spouse/partner	Daughter(s)	Spouse
	Husband	Daughter	Child		Daughter (in-law)	Son(s)	Parent/parent in-law
	Partner	Son	Grandchild		Son (in-law)	Female relative	Child (any age)
	Daughter	Sister/brother	Other ascendant		Other female relatives	Male relative	Other relative or friend
	Son	Other relatives	Brother/sister		Other male relatives		
	Sister/brother	Friends, neighbours	Other relative		Female friends	The study focuss on older people (75+) who live alone and have needs with ADL functions	Dependent's relationship to carer
	Daughter-in-law	Employees	Friend, neighbour		Male friends		
	Other relatives	Social services	Other person (no relative)		Social services including volunteer		
	Friends, neighbours	Others	Employee		Other persons e.g. paid domestic aid		
	Others				not known		

Chapter 5

Employment status of informal carers

From an equal opportunities perspective it is important to know whether the carer participates in the labour market or is unable to work due to care constraints.

German and Austrian statistics indicates that providing care might have an adverse impact on labour participation. Caregivers are over-represented among the 'not working' (Germany) and 'part-time work / work per hour' (Austria).

However, a certain number of authors consider that the relationship between employment and care is not straightforward (UK3). Caring responsibilities can impact upon employment, but the employment status may also influence an individual's propensity to care.

The Austrian data indicates that the higher the time spent for providing care, the lower the proportion that works. But this correlation does not reveal the direction of causality.

Different econometric studies have analysed the relation between caring and part-time work[8]. However, most of them do not distinguish caring for children and caring for adults and elderly persons.

As we saw before (see Table 24), there is a concentration of carers for dependent persons in the age group 50 to 64. The European Community Household Panel (Eurostat, 2001) provides a certain number of statistics, which makes the distinction between 'looking after a child' and 'looking after someone other than a child'.

The following charts present a comparison between the employment rate of persons 50 to 64 years old looking after someone other than a child and persons not doing so. The charts distinguish between men and women. The data relates to 1998. It is important to note that data relates to the employment rate and not to the labour participation.

The results indicate that caring might have an important adverse effect on the employment of older workers. However, this ought to be interpreted with caution as many econometric studies indicate that several factors may intervene in which case it is difficult to discriminate among correlated variables. From another point of view, 'looking after someone' might act as a proxy for other characteristics. In any case, the results indicate that further research into this direction is desirable.

Several Member States have established allowances in favour of caregivers. J. Jenson and S. Jacobzone undertook a qualitative review of the impact of various types of care benefits on women caregivers[9]. They note that "instituting such allowances does not seem to have the effect, which some feared, of lowering women's labour participation. However, nor does it mean that they represent a way to promote gender equality, as they do not change the gender distribution of caring work".

The Labour Force Survey includes a group of questions of interest:

- reason for working part time, and
- reasons for not participating in the labour market

[8] "Le travail à temps partiel féminin et ses déterminants", Bourreau-Dubois, C., Guillot, O., et Jankeliowitch-Laval, E., *Economie et statistique*, N° 349-350, 2001 – 9/10.

[9] Jenson, J. and Jacobzone, S., "Care allowances for the frail elderly and their impact on women care-givers", *Labour Market and Social Policy* – Occasional Papers N° 41, OECD, 2000.

The respondent has a set of choices. However, the grouping of reasons does not enable us to distinguish 'care for an adult'.

Only the United Kingdom has introduced a question concerning reasons for not looking for work where they distinguish:

- caring for children,
- caring for dependent adult relative, and
- other.

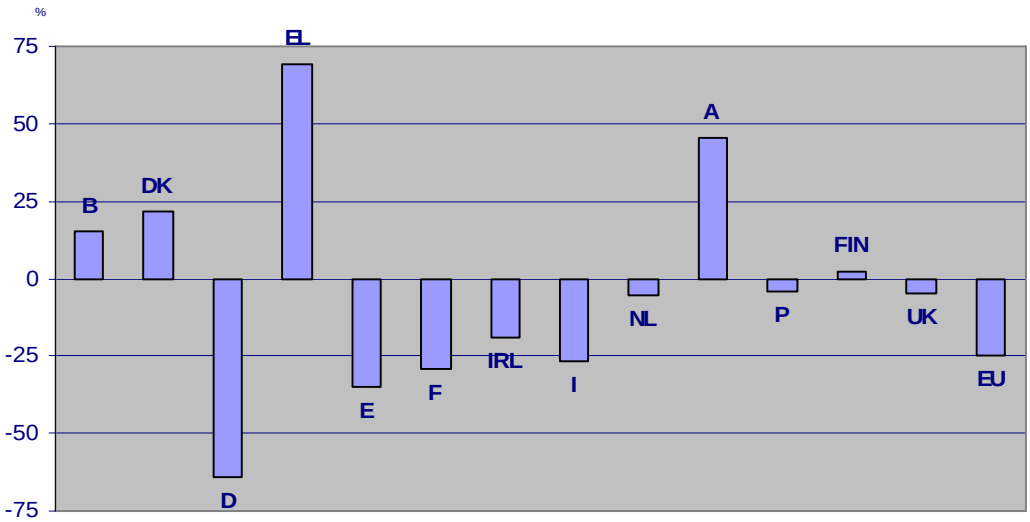
The result of the UK experience might be interesting for the definition of a EU approach.

Table 26: Informal carers by employment status in %

	D	**A**	**UK**
Definition	Carer for a person with a constant need for care	Main Carer (working)	Adults who were carers
Age	18-64	18-64	16-64
Source	D2	A3	UK4
Year	1996	1997	2000
%			
not working	77	-	27
work per hour	5	22	
part-time work	7	64	18
full-time work	10	14	54
Total	100	100	100

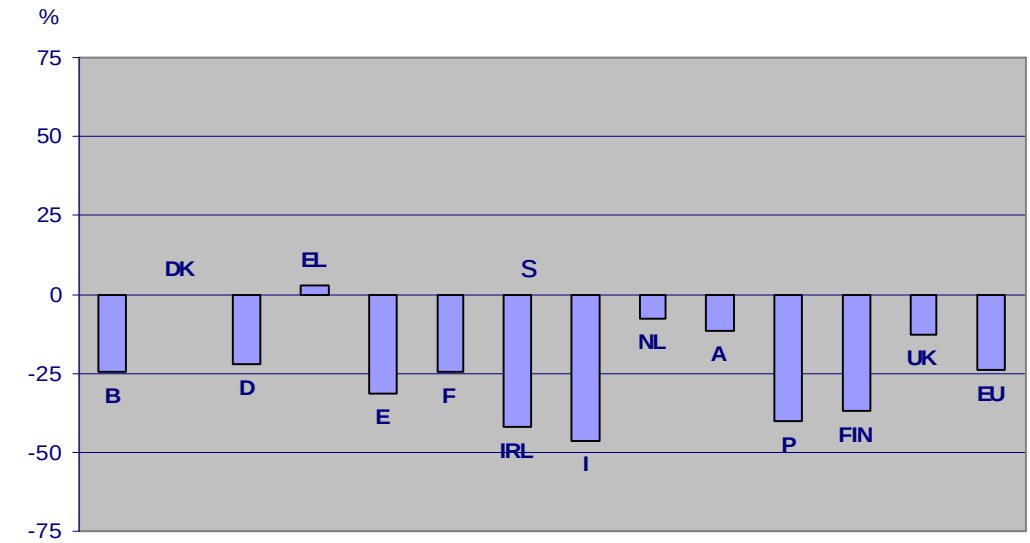
Note: The data is only indicative and not comparable**.**

Chart 13a: How much lower is the employment rate of women caring for someone other than a child over those non-caring? (age group: 50-64)



%: (Employment rate of carers - Employment rate of non-carers)/(Employment rate of non-carers) in percent.
Source: Eurostat (ECHP 1998)

Chart 13b: How much lower is the employment rate of men caring for someone other than a child over those non-caring? (age group: 50-64)



%: (Employment rate of carers - Employment rate of non-carers)/(Employment rate of non-carers) in percent.
Source: Eurostat (ECHP 1998)

Discussion and recommendations

The review of available data indicates that Household tasks are the main type of care provided by the informal carers. Going shopping is the second largest need. Both constitute important activities of independent living at home and maintenance in the community.

The EU indicator might be interpreted to favour a rather narrow definition of dependency. However, taking into account instrumental activities and moderate dependencies might have very important implications for the carers. In fact, persons with the most severe personal care dependencies tend to die fairly soon. They do not seem to be the heaviest nursing homes users[10]. On the other hand, persons with moderate needs seem to be the heaviest users of nursing home care. As moderately dependent persons constitute an important share of nursing home residents, they are likely to be cared for at home by an informal carer. In fact, they are more numerous and live longer. This means that moderate dependencies might have a significant impact on informal carers and this ought to be taken into account. Restricting ourselves into a very restrictive definition of dependency might exclude an important number of informal carers.

Concerning carers, data in Great Britain indicates that carers looking after someone in their own household and carers looking after someone in another household might have different characteristics and thus different needs.

German and Austrian statistics indicate that providing care might have an adverse impact on labour participation. Caregivers are over-represented among the 'not working' (Germany) and 'part-time work / work per hour' (Austria). However, a certain number of authors consider that the relationship between employment and care is not straightforward. Caring responsibilities can have an impact upon employment, but the employment status may also influence an individual’s propensity to care.

Some results indicate that caring might have an important adverse effect on the employment of older workers. However, this ought to be interpreted with caution as many econometric studies indicate that several factors may intervene in which case it is difficult to discriminate among correlated variables.

Furthermore, concerning allowances to care, social security and welfare measures indicate that "instituting such allowances does not seem to have the effect, which some feared, of lowering women’s labour participation. However, nor does it mean that they represent a way to promote gender equality, as they do not change the gender distribution of caring work". These results need to be studied further.

Informal care is defined as giving and receiving help on an informal basis, that is, not as part of a paid job. This appears to be a workable criterion.

Guidelines concerning the questions of surveys

Certain surveys report that the number of persons receiving care is higher compared to the number of persons needing help. Consequently, it is important to have a filtering question before to put the question: Do you receive any help? This might involve a question on “Do you have any limitations …”. If the person answers “Yes”, then the question on help might follow. By the same way, we exclude some forms of convenience help.

Concerning the carers a bloc of questions ought to collect information on their characteristics and the implication on equal opportunities. This bloc of questions ought to collect information on:

[10] Lakdalla, D., and Philipson, T., “Aging and the Growth of Long-Term Care”, NBER Working Paper Series, N° 6980, 1999.

- gender and age distribution;
- type of care provided;
- the relationship of the informal carer to the person cared for;
- the employment status of the carer (full time, part time)
- periodicity of care provision (continuously, several times a day, once or twice a day, several times a week and once a week);
- desired working time in the absence of any constraint concerning the dependent person;
- etc.

An individual ought to be recorded as receiving care if he receives care from another person in the household and/or from someone outside the household. They ought to be counted only once no matter how many people provide care to them.

The survey ought to precise whether the beneficiary of informal care is living alone or resides with the carer.

The survey might ask in a first step who gave the help. For example: Spouse or partner; Other household member; Non-household relative; Friend/neighbour; NHS or personal social services; Paid help; etc.

If the person usually gets help from someone outside the household, he ought to be asked who is the person: for example: Son; Daughter; Brother; Sister; Other relation; Friend/Neighbour; Social services; District nurse / Health visitor; Paid Help; etc.

Questions concerning the carers fit well in the Labour Force Survey but they pose some problems in a health interview survey. In the latter, this kind of information ought to be collected only indirectly, which is questionable. The person receiving the informal care or another person in the household ought to provide information concerning the informal care provider.

Concerning the Labour Force Survey, this might require only marginal adaptations of existing questionnaires. The proposed modifications are already introduced in the United Kingdom and the first lessons might be interesting for other countries.

Labour Force Survey includes a group of questions of interest:

- reason for working part time, and
- reasons for not participating in the labour market

The respondent has a set of choices. It is thus important to distinguish the following:

- caring for children, and/or
- caring for dependent adult, and/or
- other.

This will provide some information at a marginal cost. Full modules on carers could follow the analysis of the first results.

SECTION III

FORMAL CARE

Introduction

In general, formal care corresponds to professional care. It is a 'paid' service. However, this does not hold for all surveys. In each case, we will indicate how these services are treated in the different surveys.

As formal is often associated with ‘professional’ or ‘paid’ service, this implies that a significant part of these services are related to the social protection system. Consequently, many studies report administrative statistics, which are based on the number of beneficiaries of different services paid by the public sector. For example, home help is an important service paid by local authorities. In Denmark, Finland and Sweden this is a municipal matter. A financial support is provided towards payment of personal assistance and help to manage the household.

In France, the formal sector includes any service provided directly by a professional sector – i.e., a medical, social service, or institutional sector (F1). In the United Kingdom, most surveys favour the ‘paid’ or not criterion.

The nature of services paid or provided by public authorities has an important impact on certain data. For example, a ‘cleaning lady’ might be considered as professional care if it is provided by a local authority service. On the contrary, the same service might be included in the informal sector if the dependent person pays it. Normally a cleaning person ought to be included in the formal sector, if it generates a transaction, which is officially registered or declared.

Chapter 1

Formal care and place of residence

Table 27 presents persons aged 65 and over living outside the institutions and receiving home help. In general, home help includes personal care, and housekeeping. However, in several cases other types are included. This makes the comparability across countries very difficult.

We present a selection of statistics aiming to be as close as possible to a set of common criteria. At this end, each time it was possible we retained:

- long term care, and
- a minimum amount of time in order to exclude persons receiving for example for only one or two hours of help per week.

We have completed our data with estimations provided by the OECD. The OECD notes that home help might include notably day care, respite care, visiting nurses and home helps (OECD3). The OECD estimations use different sources, including a questionnaire to the Member countries.

OECD has also estimated the "Share of population aged 65 and over receiving formal help at home (Mid 90s)" (OECD2). It includes population aged 65 and over receiving formal help at home, including district nursing, and help with Activities of Daily Living. The authors note that home care should include all home care services, including district nurses services, excluding medical visits. This data presents the total number of beneficiaries and might include persons who are not dependent or are only temporary beneficiaries. Estimations did by OECD use different sources, including a questionnaire to the Member countries. The author notes that existing estimates for long term care in OECD Health Data are somewhat lower but do exclude a considerable share of long-term care programmes.

The Nordic Social-Statistical Committee (NOSOSCO) notes that statistics concerning home help in the Nordic countries are not easily comparable (DK2). It indicates that the extent of assistance is determined on the basis of individual needs and may vary from a few hours per month to several hours per day. The assistance is a municipal matter and is provided by municipal or privately employed staff. In all Nordic countries, people with severe disabilities may be granted financial support towards payment of personal assistance and help to manage the household (personal care and housekeeping).

In order to improve comparability across countries, we have retained only people receiving a minimum amount of help. For example,

- 10 hours or more per month in Sweden. In fact, of all elderly persons (65+) receiving home help, about 39% receive help of 1 to 9 hours per month.
- 4 hours or more per week in Denmark. The number of recipients aged 67+ receiving 3 hours or less of help per week is about 63% of all the beneficiaries.
- At least once per week in Austria.

It is important to note that data might overestimate the number in the following cases:

- some questionnaires ask about the use of services in the last month. This means that persons with a temporary dependency might be included. Also, some persons use home help but do not consider themselves as dependent persons.
- Administrative statistics report the number of beneficiaries. Similarly, persons with a temporary dependency or very low need frequency might be included.

Previous tables cover all persons. Statistics focusing on dependent persons are rare and not comparable.

In Belgium (Flanders), about 40% of persons aged 60+ with ADL-limitations receive personal care, cleaning services and meals on wheels (B2).

In Germany, the long term care insurance scheme reports 2,02 million care dependent persons (of all ages). 573.000 dependent persons receive care in 8.900 nursing homes. 1,44 million dependent persons receive care in private households. 1,03 million of them get only informal care. The others (415.000) get additional or exclusive care by the 10.800 care services (D1).

In France, half of the dependent elderly receive care from professionals. Two-thirds of dependent seniors living alone receive professional care as opposed to half of those living with a partner and 40% of those sharing accommodation with other family members (F4).

In the United Kingdom (GB) 45% of persons aged 65+ needing help to go outdoors and walk down the road use home help (from Local Authorities and private services).

The French HID survey finds that the number of all elderly persons (60+) receiving care from a professional is 14%. This rate is higher than the rate of persons needing help for at least one ADL (Katz) activity (11%). This indicates that some persons use professional services but are not considering themselves as dependent.

Finally, Table 28 presents the rate of persons receiving formal help by age group. The data covers all persons except for Germany.

The Danish data reports the number of people who received help from municipal or privately employed staff during a year. For comparability reasons, in certain tables we have excluded the short-term beneficiaries e.g. persons who received help ranging from 1 to 3 hours per week. For comparison, Sweden reports the number of people who per 31 December (1 November for 1999) had been granted home help. Help may stem from municipal or privately employed staff.

Table 27: Share of population aged 65 and over receiving home help (includes only significant long term help)

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK
	1997	1998	1995		2001	1998/99	1996	1995	1992	1996	1995	1992	2001	2001	1998
Source	B2	DK2	O1		E2	F1	IRL2	OECD2	L1	O1	A1	OECD3	FIN3	S2	UK3
Share of pop aged 65 and over receiving home help	5	9	5	-	2	7	4	3	7	10	5	1	8	8	5

Notes:

The data excludes occasional non-regular help and help to persons who may not be considered as dependent persons

OECD includes notably day care, respite care, visiting nurses and home helps. Other countries include mainly housekeeping and personal care.

B: Home help use by all elderly persons (60+) in the Flemish area is about 4% (B2). OECD estimates that 5% of the elderly (65+) receive formal help at home (OECD2).

DK: Persons aged 67+. Persons in ordinary housing with home-help services: 25%. Help may stem from municipal or privately employed staff (DK2). The number of recipients aged 67+ with 3 hours or less of help per week is about 63% of the beneficiaries.

D: Professional home care 3% and help with domestic work from the domestic service agencies 2%. OECD estimates that 10% of elderly (65+) receive formal help at home, but this includes all persons whatever the amount of help received (OECD2).

E: About 1% of the same age group benefit from the public tele-assistence service. OECD reports also a rate of 2% (OECD3). It includes public, private non-profit and private home care services.

F: Persons aged 60+. Domiciliary care amounts to 6% in 1992 (O1). OECD estimates that 6% of elderly receive formal help at home, for mid 90s (OECD2).

IRL: Home helps by the health boards and voluntary agencies subsidised by the health boards (IRL2). For 2000, the number is estimated at 20.000 persons: 4,7%. It includes home helps and home care attendants.

NL: Housekeeping and personal care. Includes specialised care and domestic care. Age group: 60+.

L: Persons aged 60+ receiving regular help. It includes housework and personal care. The total might involve double counting and informal help (L1).

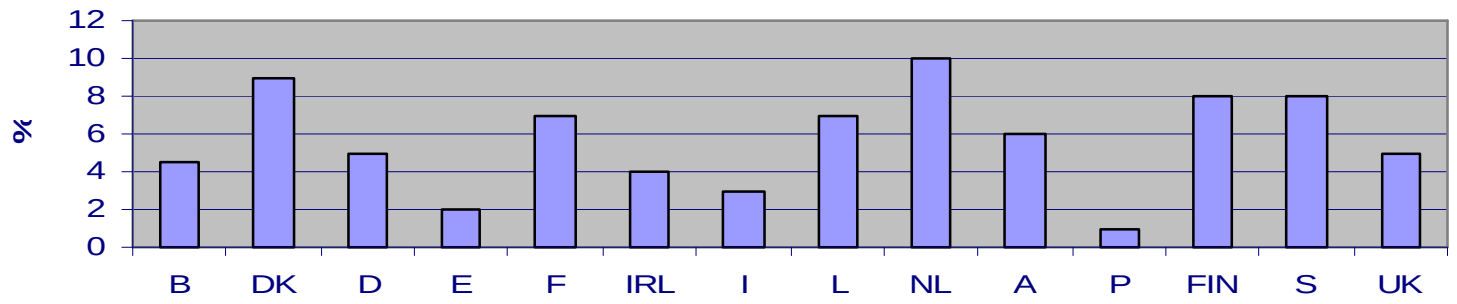
A: Persons 60+ receiving daily or weekly help from social services (A1). An additional 0,8%receives help less than once per week.

FIN: Persons having regular home care services (Home help service or home nursing) (FIN3). Persons 65+ in ordinary housing with home-help services: 11% (FIN2).

S: Persons in ordinary housing with home help services (from municipal or privately employed staff) (S2). Persons who receive home help (in relation to ADL) in 2000: 8% (S4).

UK: Covers Great Britain. The % includes only persons receiving and needing help. If we take into account all persons who report use of home help in the previous month, we obtain: Home help from local authorities: 4%. Use of private domestic help amounts to 9%. In 1991, the rates were respectively 9% (LA) and 4%. (Private).

Chart 14: Persons receiving Home help, as a percentage of the same age group



Source: see Table 27 for the definitions, the explanatory notes and the sources.

Table 28: Persons receiving formal help

	DK	D	F	FIN	S
Definition	Persons receiving formal help	Beneficiaries of long-term care insurance	Persons receiving help from a professional	Persons receiving formal help	Persons receiving formal help
Year	1999	1999	1999	1999	1999
Population	All	All	Pr. House.	All	All
Source	DK2	D1	F1	FIN2	S3
20-24			0		
25-29					
30-34			1		
35-39					
40-44			2		
45-49					
50-54			3		
55-59					
60-64		2	4		
65-69	7	3		5	3
70-74		5	14		
75-79	36	11		14	10
80-84	64	21	41	44	22
85-89		38			41
90 +		60	62		68
Total (65+)	**28**	**12**	**13**	**16**	**14**
Total (65-74)	7	4	4	5	3
Total (75+)	**52**	**23**	**23**	**30**	**24**

Notes

DK: Persons receiving formal help. Data includes persons receiving 1+ hour of help. Age groups: 67-74, 75-79 and 80+. Certain statistics regroup 67-74 and 75-79 age groups. For these we have assumed a split similar to other Nordic countries.

D: Beneficiaries of long-term care insurance, including households chores at least several times a week (D1).

F: Persons receiving help from a professional living in private households. 'Total 65+' refers to 60+; '65-74' to 60-70; and '75+'refers to 70+.

FIN: Persons receiving formal help. The age groups are: 65-74; 75-79; and 80+. Total: 65+.
Certain statistics regroup 75-79 and 80-84 age groups. For these we have assumed a split similar to other Nordic countries.

S: Persons receiving formal help: Age groups: 65-74; 75-79; 80-84; 85-89 and 90+.

Chapter 2

Type of formal care

The data in the next table indicates that the classifications used are different and put serious problems of comparability.

Germany

Care facilities include home-care and full-time and part-time institutional services that are certified within the framework of the law on long-term care insurance (D1).

Austria

The data are the result of a written interview with beneficiaries of dependency allowances and a certain number of direct interviews.

Sweden

The importance of the different sources of formal help for persons aged 65 and over in 1999 was as follows (S2):

- 8% Municipal Home Help;
- 1% Private home help (approximation),
- 3% Home nursing care,
- 3% Daytime activities,
- 3% Short-term help.

A person may benefit from several forms of formal help at the same time.

UK

The General Household Survey asks a question on who is providing care. If the person gets usually help from someone outside the household, he is asked who is the person:

Son
Daughter
Brother
Sister
Other relation
Friend/Neighbour
Social services
District nurse/ Health visitor
Paid Help
Other

Personal social services include:

District nurse / health visitor
Home help (LA)
Home help (private)
Meals-on-wheels
Day centre

Table 29: Number of persons using formal help by type of help, in percentage of the same age group.

	B		A	FIN	S	UK	
Definition	All persons	Persons with ADL-limitations	Beneficiaries of dependency allowances (services at home)	All persons	All persons	All persons (GB)	Dependent persons (Need help to go outdoors and walk down the road) (GB)
Source	B2		A3	FIN1	O1	UK3	
Age	60+		60+	65-84	65+	65+	
Year	1997		1995	2001	1996	1998	
Care-use in % of the same age group							
Nursing / Personal care	4	13	10	14		5	19
Medical services			8		17		
Housework / Domestic	8	13	17			13	45
Transport / Mobility				5	23		
Administrative services							
Visiting service / company	0	2	6				
Food / Meals on wheels	4	15	14	4	1	5	11
Others	5	12	23			3	11

Notes

Data are not fully comparable.
In Belgium: 4% of all persons aged 60+ , and 13% of persons with ADL limitations receive nursing/personal care.

A: Covers services at home.

S: Includes only social services. The percentage for Home help is: 17%.
We present below additional data concerning older persons (65+), in 1989 (Source: O1). They result from the following question: Who provides help with ... in %;
- Cleaning: Local authority 51%, Spouse: 26%, Children: 12%.
- Shopping: Local authority 38%, Spouse: 28%, Children: 30%.
- Visit toilet: Local authority 57%, Spouse: 36%, Children: 0%.

UK: Data on voluntary organisations is not included.
Dependent persons are defined as persons needing help to go outdoors and walk down the road.
Housework / domestic services include Local authority home help (4% all, and 23% dependent persons) and private home help (9% and 22%). The addition (4+9%, and 23+22 %) might involve double counts.

Classifications used

B
Home help
Cleaning service
Meals-on-wheels
Informal care
Day centre
Help from local employment agencies
Other

F
Personal care
Mobility within house
Leaving house
Defence of rights/interests
Medical services
Administrative help
Shopping
Housework
Keeping company

A
Nursing services
Home help services
Meals on wheels / Food services
Visiting service
Medical service
others

FIN
Basic Service
Meals on wheels
Transport service
Help with bathing

UK3
District nurse/health visitor
Local auth. home help and home care
Private home help
Meals-on-wheals
Lunch club
Day centre
Voluntary organisation (not reported)

Discussion and recommendations

Statistics concerning formal help are not comparable across countries. Available statistics often rely on administrative registers. Consequently they include persons who receive help from public services directly or indirectly.

This data includes all beneficiaries, even those who benefit a few hours per month or for a short period of time. Furthermore, these statistics might include activities like gardening, small repair works, etc. which may not be included in the definition of dependency.

As these statistics are collected for the follow up of certain welfare schemes, they follow national legal definitions. Consequently, it is difficult to achieve comparability.

Different attempts to elaborate comparable statistics notably by the Organisation for Economic Cooperation and Development (OECD) or the Nordic Social-Statistical Committee (NOSOSCO) note the difficulties to elaborate comparable data.

Collection of comparable statistics through a survey ought to include a minimum set of questions on the type of services used. This might include paid help concerning:

- Personal care (ADL activities)
- Nursing services
- Mobility within house
- Mobility outside the house
- Housework
- Shopping
- Meals on wheels
- Visiting service
- Administrative help
- Etc.

The survey ought to focus on dependent persons. Consequently, a filtering question ought to precede the questions on the type of formal care.

An elaborated questionnaire might focus on the type of services:

- used ,
- not used and not needed, and
- not used but needed.

The type of provider (notably public) can be generated through administrative statistics. Furthermore, many persons might not be able to answer whether the provider is public or private. Consequently, the nature of the provider does not seem to be a relevant question.

ANNEX TO SECTION III

FIN Clients having home help services and home nursing by type of service and age				
	Total	both	home help	home nursing
Total				
45-64	6.313	1.411	3.610	1.292
65-74	10.054	2.760	4.709	2.585
75-84	25.119	7.396	11.555	6.168
85+	16.822	5.653	8.158	3.011
Total	60.869	17.378	30.155	13.336
in % of clients				
45-64	10	8	12	10
65-74	17	16	16	19
75-84	41	43	38	46
85+	28	33	27	23
Total	100	100	100	100
Mean age	76,2	79,0	74,4	76,6

Source: FIN3

Note

Statistics are based on discharge reports (reports to be made for each discharged client) and on client census reports (to be filled in for all clients in care on the census day). Reports and censuses concern persons that receive

- Institutional care and housing services with 24-hour assistance;
- Housing services with part-time assistance; and
- Home care

Sweden Persons (65-84) who get help from... in % of those who need help					
	All	Men	Women	Living alone	Cohabitants
Other member of the household					
Daily	39	50	32	3	75
Every week	8	5	10	2	13
More seldom	1	2	1	2	0
Receives no help	52	44	57	93	11
Relative outside the household					
Daily	5	5	5	9	1
Every week	24	19	28	35	13
More seldom	15	11	18	21	9
Receives no help	55	65	49	35	76
Other private help					
Daily	0	0	0	0	0
Every week	2	1	2	3	0
More seldom	7	4	8	9	5
Receives no help	92	95	89	89	95
Municipal help including medical care					
Daily	13	14	12	21	5
Every week	12	10	13	16	7
More seldom	6	4	8	10	3
Receives no help	69	72	67	53	86
Other help (except personal assistant)					
Daily	1	0	1	1	0
Every week	1	0	1	1	0
More seldom	1	0	1	1	1
Receives no help	98	100	97	97	99
Personal assistant	0	0	0	0	0
Total population in 1000*	269	102	165	134	134
Number of interviews	441	172	265	213	224

Source: S1

UK

Proportion of disabled adults who received different services in the last year by severity category and age: adults living in private households (1989)

Type of service received	Severity category 1-2	3-4	5-6	7-8	9-10	All Adults
	Proportion of disabled adults who received each service					
65-74						
LA home help	6	8	20	20	28	12
Meals on wheels	0	2	2	5	2	2
Laundry service	0	1	0	1	4	1
Incontinence service	0	0	1	1	4	1
Night sitting service					1	0
Mobility/technical officer for the blind		0	0	1	1	0
Social worker	2	3	8	12	22	6
Voluntary services	1	1	1	2	2	1
Visiting service	0	0	1	1	1	0
Private domestic help	3	3	3	4	4	3
Private nursing help	0		0		2	0
Other services	1	1	1	2	3	1
Any of the above	12	15	29	36	55	21
Base	1017	622	462	288	144	2533
75+						
LA home help	17	28	41	43	30	31
Meals on wheels	5	6	11	17	11	9
Laundry service		1	2	2	5	1
Incontinence service			0	2	5	1
Night sitting service			0	1	1	0
Mobility/technical officer for the blind		1				
Social worker	2	4	7	10	12	6
Voluntary services	1	2	2	2		1
Visiting service	0	0	0	1		0
Private domestic help	6	7	7	7	4	7
Private nursing help	0		1	2	3	1
Other services	0	1	1	2	2	1
Any of the above	27	38	51	58	50	42
Base	864	719	715	566	317	3181

Source: UK2

General conclusions

The review of national surveys reveals that current data presents a certain number of comparability problems. However, despite these differences, available statistics reveal a certain number of tendencies across the Member States.

The results of the different surveys enable us to give a gross approximation of persons considered dependent according to the European indicator EO c10 concerning: 'dependent elderly men and women (unable to look after themselves on a daily basis) over 75'.

If we interpret the indicator in a narrow sense to mean only personal with a self-care dependency, an indicative approximation of the proportion of dependent people by age group might be:

- age group 20-59: 1%,
- age group 60-75: 3%
- age group 75+: 12%

These percentages constitute minima levels. Still, we have to notice that there are a significant number of dependent people below the age of 75 years.

In fact, in absolute terms, the indicative estimations are:

- 2,1 million persons aged 20 to 59 years,
- 1,6 million persons aged 60 to 75 years, and
- 3,2 million persons aged 75 and over.

From the point of view of carers, this means that providing help to dependent people less than 75 years old might be as important as it is for persons aged 75 and over. Previous statistics do not cover dependent children as our study covers only adults and elderly people.

If we interpret the indicator in a narrow sense, it means that we have to include mainly self-care and basic transfer activities (washing, dressing, transfer - getting in/out of bed/chair, going to the toilet, continence and eating). This strict interpretation leads to the Katz index, but this index is generally considered too restrictive for a person living in the community.

In order to take into account these critics, Instrumental Activities of Daily Living have been included in several surveys. These activities are considered to be necessary for living a more or less normal life without help. In fact, many Member States take into account these activities in deciding upon the granting of assistance to dependent persons.

Communication, general tasks and demands, and social life are considered important by most national social services but these activities pose a methodological problem of measurement.

Data ought to include both dependent persons in private households and in institutions. As noted above, not all persons in residential homes for the elderly may be considered as dependent persons. And the choice of a residence is not independent from the nature and degree of dependency.

The discussion indicated that a future survey at a European level might include the following activities of the WHO classification (ICF): 1) Mobility, 2) Self-care, 3) Domestic life – Household tasks, 4) Communication, 5) Sensory experiences, 6) General tasks and demands and 7) Community and social life.

Member States express the view that new questions ought to preserve the continuity with existing instruments and hence guarantee longitudinal comparability of national data. Furthermore, this harmonisation strategy ought to promote comparability of data concerning the socio-economic situation of dependent persons.

A survey at a European level might be organised in two ways. A special survey covering all aspects might be organised at a European level. This might be the more costly solution. Another possibility might be the extension and harmonisation of existing national surveys.

The second solution might be preferable since all Member States organise surveys with similar questions on activity limitations. The preparatory work here will consist mainly in harmonising existing surveys, at least for a common bloc of questions.

A short simplified module could be included in the European survey “Statistics on Income and Living Conditions” (SILC). This simplified version could be organised in regular intervals.

The review of available data indicates that household tasks are the main type of care provided by the informal carers and women constitute the big majority of informal carers. It is important to note that restricting ourselves into a very narrow definition of dependency might exclude an important number of informal carers.

Some results indicate that caring might have an important adverse effect notably on the employment of older workers. However, this ought to be interpreted with caution and needs to be investigated further in relation with the impact of allowances granted to carers.

Concerning carers, a bloc of questions could be designed to collect information on their characteristics and the implication of caring on equal opportunities.

Questions concerning the carers fit well in the Labour Force Survey but they pose some problems in a health interview survey. In the latter, this kind of information could be collected only indirectly, which is questionable.

Available statistics on formal help often rely on administrative registers. Surveys in this field are scarce. Further research here needs to improve our understanding of what are the desires of dependent people and what are the best ways to meet these demands.

PART B

STATISTICAL METHODS AND SOURCES

Introduction

This part presents in the form of record sheets, the statistical methods and sources for the data given in Part A.

The statistics were obtained from:

- National sources: mainly statistical offices and ministries; and
- International institutions: mainly from Eurostat.

Each record sheet is made up of the following elements:

- **Definition:** The definition of dependency and other concepts analysed in this study, as presented in the statistical series;

- **Source**: The institution which collected the quantitative data;

- **Years:** It presents the reference period e.g. the year during which the data is collected and the frequency of collection.
We report only the years for which we have exploited the statistical data (and previous years). Consequently, this is not an exhaustive list of years. Our goal is not to present a history of these surveys. Furthermore, we do not report recent years for which we do not possess data or the results are not of interest to our study.
The term 'annual data' means, for instance, that in theory, we expect to have data for each year. However, owing to delays in publication, the last few years may be missing.

- **Population:** It indicates whether the survey covers private households or institutions.

- **Method:** It presents the methodology utilised for the collection and the exploitation of the statistical series.

- **Publication:** The original publication from which the statistics are taken or, where non-published information is concerned, the institution responsible.

- **Commentary:** Provides comments and additional information for the interpretation of statistics.

- **Tables:** Lists the tables in Part A of the report, which present the statistics for the record sheet in question.

BELGIUM

B1. Health Interview Survey

Definition

Activity limitation

The survey considers different indicators.

The first determines if the person suffers from a long-term illness or handicap. The survey distinguishes permanent and temporary limitations. Then, the respondents were asked to value (on a 100 points scale) the physical functions they are still able to perform such as walk (the score100 = no limitation), go up and down stairs, carry a shopping bag, etc.

Within the disabilities concerning the most elementary activities of daily life such as getting up, washing oneself, dressing, etc., the survey makes the distinction between those who can do it 'with difficulty' and those 'who necessitate the need of someone else'.

Persons with a severe disability

Persons with at least one severe limitation among the following ten functions: getting in and out of bed, getting up sitting down, dressing/undressing, washing hands and face, eating and cutting food, going to the toilet, urinary continence, walking, hearing and seeing.

Social participation restriction

The survey uses here the notion of 'mobility handicap' expressed by confinement, e.g. 'stay at home', 'stay sitting in a chair', or 'stay in bed'.

Source Institut Scientifique de la Santé Publique – Institut National de Statistique

Years 1997, 2001.

Population All

Methodology The sample of 12.111 persons was chosen randomly on the base of the National Register Book of the population. No exclusion was made as to the nationality or as to the group of age. Certain questions however were just asked to persons aged 15 years or more. The sample includes isolated persons.

The first part is dedicated to the state of health in general. Follows questions on physical troubles, the impact of problems of mental health, emotional troubles on well being and on the quality of life. These topics are treated in the survey through the use of two questionnaires: The “General Health Questionnaire” and the “Symptom Checklist-90-Revised”.

The survey also studies the consequences of the physical or psychological problems on daily life. Respondents also have been questioned about recent disabilities i.e. which have occurred within the last 2 weeks.

Publication “Enquête de Santé par Interview Belgique 2001”, Institut Scientifique de la Santé Publique, IPH/EPI Reports nr 2002 – 22 & 25.

Comments The exploitation of the results distinguishes physical disability and mental health.

Tables : 4, 5, 6, 7, 8, 11.

B2. Dependent persons in care homes

Definition Care dependent persons in rest homes and nursing homes.
The study distinguishes:
- Category 0: Independent persons, not suffering from dementia
- Category A: Assistance in washing and dressing + persons suffering from dementia with no functional limitations
- Category B: Assistance in washing and dressing and assistance in getting to the toilet and/or assistance in transfer + persons suffering from dementia needing assistance in washing and dressing
- Category C: Assistance in washing, dressing, getting to the toilet, moving about and assistance in eating and/or incontinence + persons suffering from dementia meeting criteria of category B.

Care dependency
The authors distinguish: self-dependent persons, moderately care dependent, highly care dependent, and very highly care dependent.
Persons 75+: Use of Katz index.
- Fully independent person: Katz index = 0.
- Moderately care dependent: Katz index = 1 or 2.
- Highly care dependent: Katz index = 3 or 4.
- Very highly care dependent: Katz index = 5 or 6.

Persons less than 75 years: Use of an approximate Katz index.

Source National Sickness and Invalidity Insurance Institute (RIZIV)
Health Interview Survey (see B1)
Department of Sociology and Social Policy, University of Antwerp (UFSIA)

Years 1999 (RIZIV)
1997 (see B1)
1994 (UFSIA-DSSB)

Population All Flemish population.

Methodology Estimation by the authors using the number of persons in rest homes and nursing homes provided by the National Sickness and Invalidity Insurance Institute.

For persons aged less than 75 years, they use the Health Interview Survey, 1997. For persons aged 75 or over, they use the UFSIA-DSSB-1994 survey.

In order to calculate the totals for persons aged 60 and over, we have used as weights for the different age groups, the distribution of the total population by age group.

Publication Breda, J. and Geerts, J., “Care dependency and non-medical care use in Flanders”, Archives of Public Health, 2001, 59, p. 329-346.

Comments By exploiting the results of the Health Interview Survey (1997) and other special surveys, the authors estimate the percentage of care dependent individuals in the Flemish Region to be 11,6% for persons aged 60-74 and 30,1% for 75+, in 1997. These estimates include moderately, highly and very highly care dependent persons.

The authors note that the UFSIA-DSSB survey of the aged reports that some 38% of the elderly residing in rest homes had no ADL-limitations. Only 7% of these elderly people without ADL-limitations had no IADL-limitations either.

A survey done by Vanden Boer L. (Vanden Boer L., "Functional status and the care network among elderly residents of sheltered housing", Archives of Public Health, 1997, 55, p. 63-85) of 620 residents of service flats and serviced housing complexes in Flanders, in 1993, finds that 16% of the service-flat residents turns out to be self-sufficient. About 67% of service-flat residents had some need for assistance, 13% had considerable need for assistance and 4% a serious need for assistance.

Tables 2, 3, 8, 16, 27.

DENMARK

DK1. Danish Health and Morbidity Survey

Definition Persons with very restricting long-standing illness. However, detailed data refers to difficulties.

Physical mobility includes notably:
- Walking up and down a stair case from one floor to another without resting;
- Walking 400 meters without resting and carrying 5 kg.

Communication skills include:
- Difficulty in reading a newspaper,
- Ability to hear a conversation between several individuals, and
- Ability to talk without difficulty.

Source National Institute of Public Health

Years 1987, 1991, 1994, 2000

Population All

Methodology The Danish Health and Morbidity Surveys (SUSY) are established by interviewing randomly selected Danes extracted from the Danish Civil Registration System. Each interview is carried out in the residence of the interviewee. After completing an interview, a postal questionnaire is handed out in order to be completed at convenience. It covers Danes adults aged 16 years or older.

All in all 22.486 adult persons were invited, 16.690 (74,2%) were interviewed and 14.278 (63,5%) returned a postal questionnaire, in 2000. The overall sampling fraction was 0,54% ranging between 0,36% and 2,35% in the 15 counties.

The data for 1994 was collected in three waves. Every wave was containing a random sample of about 2000 individuals. 4668 individuals completed the interview equalling 78% of the random sample.

Estimations of prevalence in the entire population use stratified (weighted) computations.

Publication **"**Sundhed & Sygelighed I Danmark 2000 & udviklingen siden 1987", Statens Institut for Folkesundhed, København, 2002.

"Danish Health and Morbidity Survey 1994", http://www.susy.si-folkesundhed.dk/

Comments The years of healthy life lost at 60 years old measures the life expectancy of a 60-year-old man minus the number of years in states of reduced functioning. The expected number of years of healthy life lost for a 60-year-old man decreased from 5,3 in 1987 to 4,1 in 2000. The decrease among women was slightly less – from 8,4 to 7,7 years.

Tables 2, 4, 6, 7, 8, 9, 10.

DK2. Persons receiving help

Definition Persons **(**Households) receiving help in ordinary housing, and in institutions and service housing. Home help includes personal and practical help.

Institutions include nursing homes, homes for the long-term ill and old people's homes. Service housing includes sheltered homes, service flats, collective housing, housing where special care is provided, etc. Elderly people may also, be offered long-term medical treatment in hospital wards – often in the so-called geriatric wards. There are special wards in some nursing homes.

Source Nordic Social-Statistical Committee (NOSOSCO)
Statistics Denmark

Years Annual data

Population All

Methodology Home help
Number of people who received help from municipal or privately employed staff.

Until 1998, recipients were calculated as households, from 1999 as persons.

In 1998, there were 201.500 recipients. The number of beneficiaries in 2001 was 203.000 persons. The average number of hours allocated for permanent home help is about 5 hours per week in 2001. The number of recipients aged 67+ who received permanent home help in 1998 was 172.463 (25% of the same age group). The distribution of beneficiaries by hours of help was:

- 63% received 1-3 hours per week;
- 13% 4-6 hours per week;
- 13% 7-12 hours per week;
- 11%. 13+ hours per week:

For comparability purposes, when we refer to dependent beneficiaries, we exclude the first group (1-3 hours per week).

Dependent people in institutions or service housing
Number of people living in institutions or service housing.

In order to take into account only persons requiring assistance we have taken 50% of the age group 67-74, 60% for 75-89, 70% for 80+. These are non-weighted averages of dependent persons in institutions in Belgium, France and the United Kingdom.

For home help, the age groups are: 67-79 and 80+. For institutions the age groups are: 67-74, 75-79 and 80+. We had to split the home help component into 67-74 and 75-79. We took into account comparable rates in other Nordic countries and the weights of the respective age groups.

Publication "Social Protection in the Nordic Countries", Nordic Social-Statistical Committee (NOSOSCO), Copenhagen, 2001.

"The social Sector in Figures 2002", Ministry of Social Affairs, Copenhagen.

Comments The Nordic Social-Statistical Committee (NOSOSCO) notes that statistics concerning home help in the Nordic countries are not easily comparable. It indicates that the extent of assistance is determined on the basis of individual needs and may vary from a few hours per month to several hours per day.

The assistance is a municipal matter and is provided by municipal or privately employed staff.

In all Nordic countries, people with severe disabilities may be granted financial support towards payment of personal assistance and help to manage the household.

Tables 27, 28.

GERMANY

D1. Beneficiaries of long-term care insurance

Definition

Activities of daily living

Personal hygiene: washing, showering, bathing, dental hygiene, combing your hair, shaving, going to the bathroom
Eating: eating, and preparing food so that it is bite-sized and ready to eat
Mobility: getting out of and going to bed, getting dressed and undressed, walking, standing, climbing stairs, leaving and getting back to your home without assistance
Housekeeping: grocery shopping, cooking, cleaning, dishwashing, changing and washing linen and clothing, heating the home

Care dependency

Level 1: considerable need of care, requiring help at least
- Once a day with personal hygiene, eating, or with a minimum of two activities from one or more types of activity, and
- Several times a week help with household chores

Level 2: severe need of care, requiring help at least
- Three times a day with personal hygiene, eating or getting around, and
- Several times per week with household chores

Level 3: extreme need of care, requiring
- Round-the-clock help every day with personal hygiene, eating or getting around, and
- Help several times a week with household chores

Care facilities

Care facilities include home-care and full-time and part-time institutional services that are certified within the framework of the law on long-term care insurance (Pflegeversicherungsgesetz SGB XI)

Source Statistisches Bundesamt

Years Data was collected for the first time in December 1999; is collected twice a year.

Population All

Methodology The aim of the data collection is to obtain information concerning offer and demand of care provision. Data collection includes therefore on the one-hand persons who are care-dependent and on the other hand institutions and home help services including their staff.

Definitions are based on the law on long-term care insurance, Pflegeversicherungsgesetz SGB XI (§ 109.1 in relation with BGBI. I. S. 2282 of 24.11.1999). Statistics must be provided by private and public health insurance companies and by the concerned care facilities (legal obligation under BGBI. I. S. 2282).

Statistics include 2,02 million care dependent persons. 10.800 care services and 1,03 million informal carers care for 1,44 million dependent persons. 573.000 dependent persons receive care in 8.900 nursing homes.

Publication Statistisches Bundesamt, Kurzbericht : Pflegestatistik 1999. Deutschlandergebnisse, Bonn, 2000

Comments -

Tables 14, 15, 28.

D2. Help and care dependent persons in private households

Definition

Restrictions of activities

Persons were asked if the following indicators of restrictions were relevant to them

- Continuous diseases, complaints or handicaps
- Certified severe disability
- Use of medical-technical aids
- Long-term dependency on care or help
- Confined to bed

If one of these categories applied, persons were asked on restrictions of activities and instrumental activities of daily living.

Dependency on care and help

The autonomous performance of activities is impossible or the person depends on help. Generally, care-dependency is due to several restrictions that concern whole blocks of activities.

1. Continuous dependency
   Persons need help for all areas of body-care (leave the bed, use the toilet etc.) and are generally immobile. Continence, eating and drinking are the most common factors. Housework is entirely done by a third party.
2. Daily need for care
   Persons need help for daily hygiene (bath, shower, washing). Mobility and movements of body-parts are restricted (getting dressed etc.). Persons need help in order to do their housework.
3. Need for care several times a week
   Persons need help for some household-tasks, but are in general still able to cook.

Informal carers

The informal carer is the main carer in private households. One carer might give several types of care or help.

Employment situation

Principal carers aged 18-64 in private households.

Source Statistisches Bundesamt

Years 1991/92

Population Private households.

Methodology The survey is based on two samples of the population of East and West Germany: a household sample (B) for the whole population and a sample of elderly persons aged

70 and more (A) living in private households. The sample excludes persons living in institutions.

The sample 'A' follows a survey of 1986 in West Germany. In order to add East German data, supplementary addresses were drawn out of the population register. Sample 'B' was formed along the Random-Route-Procedure.

Sample 'B' is based on 22.644, sample 'A' on 3.092 households. Both samples include 60.938 persons. The survey was done from November 1991 until February 1992. Data projections were made in relation to the population structure of 1989.

Publication "Hilfe- und Pflegebedürftige in privaten Haushalten", Schneekloth U. et al, Bonn, 1996.

Comments -

Tables 2, 3, 4, 5, 6, 8, 11, 12, 24, 25, 26.

D3. Microcensus: care dependency in the framework of the long-term care insurance

Definition

Care dependency

Persons answered the following questions:

- Do you need help for body-care, nutrition, movements, mobility, housework?
- How often do you receive help? Once a day; Twice a day; Three times a day and more; All the time; Not known; No help
- Do you receive allocations of the long-term care insurance?
- For which level of dependency do you receive benefits? Level 1; Level 2; Level 3; Not known; No benefits

Disability

Disability is the consequence of a restricted functionality with a minimum duration of six months, based on a physical, mental or emotional health status that deviates from the typical health-status of the specific age group. Normal characteristics of ageing are hence not considered as a disability.

Persons, whose degree of disability amounts to at least 50, are considered to be severely disabled. Persons with a degree of less than 50 are considered as moderate disabled. The degree of disability reflects the extent of the restriction of functionality. The scale rises in grades of ten from 20 until 100.

Persons answered the following questions:

- Was a handicap testified or did you apply for such an official recognition?
- What is the degree of the officially recognised handicap? Under 25 %; 25-29 %; 30-39 %; … 90-99 %; 100 %

Source Statistisches Bundesamt

Years Annual data – the questions about care and disability every four years.

Methodology The microcensus covers 370.000 households with 820.000 persons. All households in certain districts are questioned. A quarter of chosen districts are replaced every year. Households participate hence during 4 years in the census.

The microcensus consists of a basic module with yearly periodicity and additional modules that appear every four years. The module on care dependency is such an additional module and will be included the next time in April 2003.

Results of the care-module are based on the sample of the Microcensus of April 1999. The framework for extrapolations was the Pflegestatistik. Definitions are, as in the Pflegestatistik, based on the law on long-term care insurance, Pflegeversicherungsgesetz SGB XI.

Results of the module on disability are based on the sample of the Microcensus of April 1999. The framework for extrapolations was the Schwerbehindertenstatistik (Statistics of severely disabled). Definitions are based on the law on severe disability, Schwerbehindertengesetz.

Publication Heiko Pfaff, Sonderbericht: Lebenslagen der Pflegebedürftigen – Pflege im Rahmen der Pflegeversicherung – Deutschlandergebnisse des Mikrozensus 1999

Heiko Pfaff, "Lebenslagen der Behinderten – Ergebnis des Mikrozensus 1999", in Wirtschaft und Statistik 10 / 2002, S.869 – 876.

Comments -

Tables 22.

D4 4th Report on the situation of elderly

Definition The report covers very old persons, defined as elderly aged 80 and more.

Source Federal Ministry of Family, Elderly, Women and Youth.

Years 2002

Population -

Methodology The estimation was done by the Federal Ministry of Family, Elderly, Women and Youth. The Ministry installed an expert commission for the topic: "Risks in high age under consideration of dementia – challenges for politics".

Publication Bundesministerium für Familie, Senioren, Frauen und Jugend, Vierter Bericht zur Lage der älteren Generation in der Bundesrepublik Deutschland. Risiken, Lebensqualität und Versorgung Hochaltriger – unter besonderer Berücksichtigung Dementieller Erkrankungen, Berlin 2002.

Comments -

Tables 23.

ELLAS

Definition Persons with limitations of Activities of Daily Living.

Source Estimations by the author.

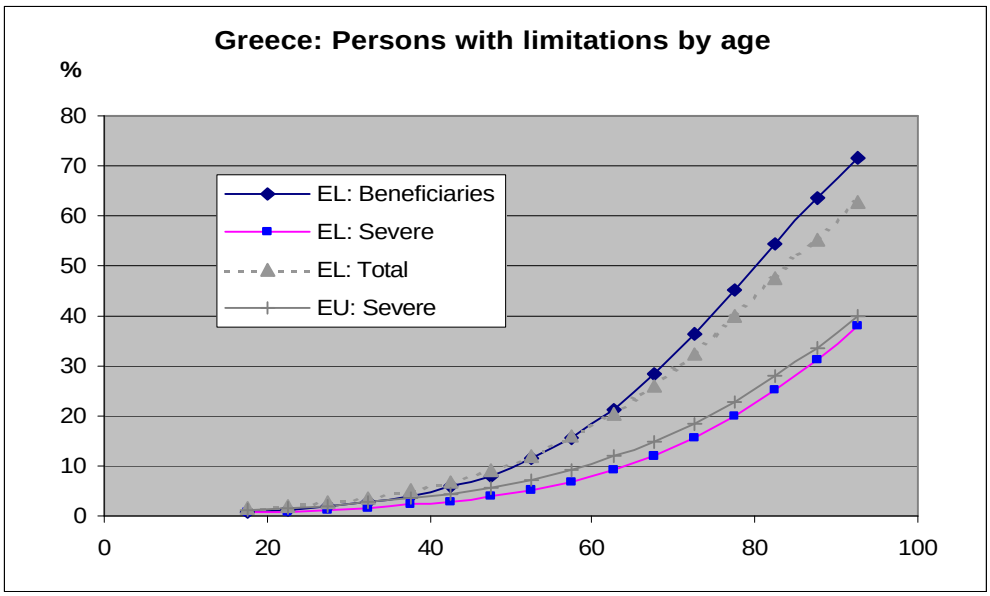
Years 1999

Population All

Methodology The European Community Household Panel (ECHP) generally gives an estimation of the total number of people hampered in daily activities by any physical or mental health problem, illness or disability lower compared to other European countries. Similar results are found for Ireland and Italy. This estimation for Greece is close to the number of persons receiving a disability related benefit. In fact, the following chart indicates that the number of beneficiaries of a disability related benefit (EL: Beneficiaries) is close to the number of people who are severely or moderately hampered (EL: Total). Similar results are found for Italy.

Concerning severe disabilities, the ECHP estimation for Greece is close to the EU average (see chart), but slightly lower. The situation in Greece appears thus very close to the EU average. Consequently, in order to estimate the number of persons with ADL limitations, we have taken the average (geometric mean) of the national estimates presented in Table 2. Furthermore, in order to take into account the slight difference between Greece and the EU average, we have taken 90% of this average.

Finally, we obtain approximately 14% (age group: 65+) and 23% (age group: 75+).



Publication -

Comments Concerning the estimation of beneficiaries of disability related benefits, we have used the data presented in "Disabled People: Statistical Data", S. Grammenos, Eurostat, 2nd Edition, 1995.

Table 2.

SPAIN

E1. Impairment, Disabilities and Handicaps

Definition

Number of dependent persons

The survey's definition of disability is based on the *International Classification of Impairments, Disabilities and Handicaps (ICIDH)*. Disability is defined as limiting the human capacity to the point of making a person's normal activity impossible or extremely difficult. For example, a difficulty to speak, understand, communicate, move, take care of oneself etc.

Distribution by nature of needs

The survey's definition of disability is based on the *International Classification of Impairments, Disabilities and Handicaps (ICIDH)*.

Distribution by degree of dependency

The severity grade of a disability relates to the difficulty (no, moderate, severe and total difficulty) in performing activities of daily living: changing the position of the body; getting up and lying down; getting around inside the home; getting around without a means of transportation; washing oneself; controlling bodily functions; dressing oneself; eating and drinking; shopping, preparing meals, washing and ironing clothes, cleaning and maintaining the home and looking after the welfare of other family members.

Informal carers

The study includes the following classification of the carers: husband or wife/son or daughter/brother or sister/father or mother/other relative/ friends or neighbours/host/other relation It also mentions if the carer lives in the same household or if he or she lives outside, as well as the number of hours devoted to help.

Formal help

The study distinguishes the help coming from 'employees' and from 'social services'.

Source Instituto Nacional de Estadistica (INE)

Years 1986, 1999

Population Private households

Methodology The survey addresses the population living in households. The sample includes 80.000 households, that is 220.000 people. Information was collected in the second quarter of 1999. The survey established three age groups, 0-5 years, 6-64 years and 65+ years.

Only disabilities taking their origin in a well-defined impairment were taken into account. Exception was made for the ones due to a process of natural degeneration. A disability is considered as 'long-term disability' if it is implicit in the impairment (e.g.. in case of mental retardation), or if it has been lasting for at least 1 year. A disability entirely compensated by a technical relief, will not be retained. Let us note moreover that with regard to the group 'less than 6 years of age', certain impairments are not yet translated into disabilities.

The variables used for the group 'more than 64 years' are the same as for the group 'between 6 and 64 years '. However, the exploitation of these variables was made independently.

We can point out that in a first stage of the survey, questions were addressed to all the members of the household. The aim was to define the type and composition of the household. Information was requested about the education level, about the professional situation, the type of relationship between the persons living in the household, also about the internment in a public establishment within the last 12 months, etc.

Publication INE (2001) : Encuesta sobre Discapacidades, Deficiencias y Estado de Salud 1999: Avance de resultados, Madrid

Comments The characteristics of carers providing help was provided by CIS.

Tables 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 22, 23, 24, 25.

E2. Beneficiaries of home help

Definition Number of beneficiaries of home help provided by public services. Help includes care and domestic tasks.

Source Instituto Nacional de Estadistica (INE)

Years Annual

Population -

Methodology Administrative data. Number of beneficiaries.

Publication INEbase.

Comments About 76.000 persons aged 65 and over are beneficiaries of public tele-assistence services. It represents about 1% of the same age group.

The Survey on Disabilities (E1) reports that about 138.000 persons with disabilities receive help from social services and the market. This represents 2% of the population aged 65+.

OECD reports the rate of elderly people receiving home help. It amounts to 2% (OECD3). It includes public, private non-profit and private home care services.

Tables 27.

FRANCE

F1. Handicaps-Disabilities-Dependencies

Definition

Impairments, Disabilities and Handicaps

The study uses the International classification of Impairments, Disabilities and Handicaps (WHO). The relationship of diseases and handicaps is described in terms of the Wood-Sequence.

Disabilities are a restricted ability, or a lack, of ability, to perform normal activities or more complex ones. Normal activities include physical activities such as standing up, getting up, or walking up a staircase, and mental activities such as memorising. Complex activities include dressing, using the telephone, and conversing with several persons. Disabilities are generally due to one or more impairments.

Disadvantages denote a restricted ability, or a lack of ability, to fulfil a social role that the person may seek to perform or that society expects of the person. Such roles include attending school, doing work, communicating with other people, and parenting.

Persons living in institutions

Institutions consist of healthcare and welfare institutions accommodating handicapped persons and seniors suffering from functional impairments. This category primarily includes homes for seniors and handicapped adults, teenagers, and pre-teenage children. Psychiatric institutions were added.

Degree of dependency

Data covers individuals who responded that they did not or that they did need aid for each of the activities of daily living. The study uses the Katz-index that includes the activities washing, dressing, going to toilet and using it, lying / sitting down and getting up, continence, eat already prepared meals.

Informal care

Any care not directly provided by a professional sector – i.e., a medical, social service, or institutional sector. Informal care thus excludes services provided by professionals and volunteers working for non-profit organisations.

Colvez-indicator / Formal help

The Colvez-indicator classes persons in four groups:

1. Limited to bed or chair
2. Not limited to bed or chair but needing help for toilet or dressing
3. Persons needing help to leave their home or institution, but who don't belong to level 1 or 2
4. Other persons who are considered to be not dependent

Data covers persons who belong to the first three levels. Types of residence include establishments for elderly, other establishments and private households.

Source Institut national de la statistique et des études économiques (INSEE : National Institute of Statistics and Economic Studies).

Years 1998/99 and 2000/01.

Population All

Methodology The Handicaps-Disabilities-Dependency (HDD) project has four main goals: (1) to provide framework data, (2) to establish forecasts and estimate flows, (3) to make the most of existing sources, and (4) to meet local players' information needs. The first objective required a survey of both the institutional population and private households. The second required tracking the survey respondents over time. This called for two surveys—each with its tracking procedure—and even three surveys, since the definition of the HDD survey sample of private households demanded a prior large-scale filtering of the total population using the criteria of the Daily Life and Health survey (hereafter DLH; in French, Vie Quotidienne et Santé: VQS).

Persons living in institutions
16.000 individuals in 2000 pension homes, homes for disabled and psychiatric institutions were questioned in two waves in 1998 and in 2000; the questionnaire covers the three dimensions of a handicap: deficiency, incapacity and disadvantage.

Persons living in private households
Persons living in private households required a two-stage survey. The first filtering stage serves merely to count the people concerned and select those for subsequent interview. The second stage serves to describe respondents' disabilities, the origins or causes of these disabilities, and any limiting consequences on participation in the main areas of social activity.

A filtering survey requires a sample eight to ten times larger than the population to be interviewed and described. The sample for the HDD survey's household section was set at 20.000 people. The preliminary filtering operation – i.e., the DLH – thus had to cover at least 160.000 people representative of the French population living in private dwellings.

The sample for the preliminary filtering did finally amount to 400.000 persons. These persons received a written questionnaire in 1999. 359.000 answers were exploited. 20.000 persons were finally interviewed in two waves in 1999 and 2001.

Formal help
C. Aliaga and N. Dutheil (F1) report that 3.230.000 persons aged 60+ living at home received a regular help. This represents 28% of the same age group.

About 50% of these beneficiaries receive a professional help or a combination of professional and informal help. Consequently, 14% of persons aged 60+ receives formal care. Among those receiving formal help, about one third receives at least care from a paramedical worker (nurse, kinesitherapist, etc.). This means that about 5% of persons aged 60+ receives at least a paramedical service. We consider this as an important indicator for self-care dependency.

Furthermore, the average duration of help is almost 7 hours, but 50% of the beneficiaries receive help, which lasts less than 3 hours per week. This means that 7% of the population aged 60+ receives a regular and significant formal help. In fact, we consider that we have to exclude those receiving care of less than 3 hours per week. This help might be convenience help or include help that is dominated by cultural patterns (e.g. cleaning services). This is further sustained by the fact that among those who receive professional help 86% use a cleaning man/woman or an auxiliary help.

Finally, we consider that the rate of 7% is the best indicator.

Publications "Enquête Handicaps - Incapacités - Dépendance en Institution en 1998: Résultats détaillés", Goillot, C., and Mormiche P., 2001.

"Enquête Handicaps – Incapacités - Dépendance auprès des personnes vivant en domicile ordinaire en 1999: Résultats détaillés", Goillot, C., and Mormiche P., 2002.

"Aider les personnes âgées à vivre à domicile: nature des aides et conséquences pour l'entourage", Aliaga, C., and Dutheil, N., Protection sociale 9, Données Sociales 2002-2003, INSEE, p. 635-640.

"Le nombre de personnes dépendantes d'après l'enquête Handicaps-incapacités-dépendance", C. Colin and V. Coutton, Etudes et résultats N° 94, décembre 2000, drees.

Comments The survey retains the relationship of diseases and handicaps as described in the Wood-Sequence. Diseases (in the broad sense, i.e. including accidents and other mental and physical traumas) are the first link in the chain. They are susceptible to diagnosis and medical treatment. Impairments denote any loss (such as amputation or sclerosis) or dysfunction of a body part (limb, muscle or organ) or of the brain. They generally result from a disease or trauma. A similar and more commonly used notion is 'invalidity'.

For information, we present below the distribution according to the Colvez index:

Elderly dependent persons (Colvez indicator)				
	Home	Institutions for elderly	Homes for disabled and psychiatric	Total
Level1 (confined in bed or chair)	105.000	118.000	2.000	225.000
Level 2 (need for washing and dressing)	300.000	99.000	4.000	403.000
Total severe dependency	405.000	217.000	6.000	628.000
Level 3 (need to go out)	648.000	135.000	6.000	789.000
Total dependency	1.053.000	352.000	12.000	1.417.000
Level 4 (non dependent)	10.509.000	111.000	4.000	10.624.000
Unknown dependence level	34.000	17.000	2.000	53.000
Total 60+	11.586.000	480.000	18.000	12.084.000

Level1 (confined in bed or chair)	47	52	1	100
Level 2 (need for washing and dressing)	74	25	1	100
Total severe dependency	64	35	1	100
Level 3 (need to go out)	82	17	1	100
Total dependency	74	25	1	100
Level 4 (non dependent)	99	1	0	100
Unknown dependence level	64	32	4	100
Total 60+	96	4	0	100

Tables 2, 4, 6, 7, 8, 9, 10, 14, 15, 16, 18, 19, 21, 23, 25, 27, 28.

F2. Survey on Health and Medical Care (ESSM)

Definition Handicap
Persons who are handicapped or have some troubles or difficulties in every day life.

Degree of impairment

No trouble (discomfort), very small trouble, trouble but has a normal life, has to restrict his activities, restricted or slow activity, no autonomy at home, permanently in bed.

Degree of dependency
For daily activities the interviewee could answer: can do the activity a) with no difficulty; b) with many difficulties.

Mobility disability
Persons who declare having trouble (discomfort) to stand up, to go out. The statistic is large as it includes all levels of discomfort.

Confined at home
Persons who may not stand up or may do it sometimes.

Source National Institute of Statistics and Economic Studies **(**Institut national de la statistique et des études économiques: INSEE).

Years 1980, 1991.

Population Private households

Methodology Representative sample of ordinary households in Metropolitan France. The sample is drawn from the census. Every interviewee received five visits, one every three weeks.

Publication "Enquêtes décennales sur la Santé et les Soins Médicaux 1980-1991", Centre de Recherche en Economie de la Santé (CREDES).

Comments -

Tables 3, 5.

F3. Living conditions

Definition Physical dependency
Need for assistance for the following activities: eat, washing oneself, dressing, mobility (getting out of bed, of the room, of the house), climb stairs. Weighting of the different activities takes into account the frequency of help required (occasional, regular, permanent).

Dependent for domestic life activities
Need for assistance for the following activities: shopping, preparing meals, cleaning, and administrative tasks. Weighting of the different activities takes into account the frequency of help required (occasional, regular, permanent).

Source National Institute of Statistics and Economic Studies **(**Institut national de la statistique et des études économiques: INSEE).

Years 1990

Population Private households. Age: 60 and over.

Methodology The survey centred on income and living conditions. It took place during 1989 and 1990. The representative sample included 8.071 private households with at least one person aged 60 or more.

Publication "Aisance à 60 ans, dépendance et isolement à 80 ans", M. G. David and C. Starzec, INSEE PREMIERE, N° 447 – Avril 1996, INSEE.

Comments We did not retain data concerning people 'moderately autonomous'.
The survey gives for persons 60 years and over: 3,7%, 3,6% and 1,1% persons of the same age group needing respectively help for standing up, climbing a stair and washing oneself.

Tables 11.

F4. Household Living Conditions

Definition Dependency
Adjusted Colvez classification (See Glossary: 'Colvez').

Source National Institute of Statistics and Economic Studies **(**Institut national de la statistique et des études économiques: INSEE).

Years 1996

Population Private households.

Methodology The national 'Household Living Conditions' panel survey collected information on 14.845 individuals (2.211 of whom were elderly) living at home. Two extensions were added to this survey. The Paris area extension used the same methodology to collect information on 2.479 individuals (251 of whom were elderly). The Eure-et-Loir extension was designed to study care received by seniors and was based on an abridged questionnaire. This second extension collected information from 1.058 aged individuals. The national survey and the two extensions were combined to form a preliminary sample of 3.520 seniors, 1.509 of whom answered the Kish questionnaire on dependency care.

Households are asked among other questions about the informal and formal care they receive (excluding dependency care). Dependency care data is collected by a Kish questionnaire.

Dependency care focuses on essential daily activities (by excluding activities assumed to be characteristic of convenience care). The methodology prevents a reduced volume of care from having an influence on the receipt of formal and informal care.

Publication "Caring for the dependent elderly: More Informal than Formal", Breuil-Genier, P., INSEE Studies, no 39, September 1999.

Comments The author estimates that one in ten people aged 65 and over cannot get out without help.

Total hours of care increase with dependency and isolation. The lower the average hourly price of formal care, the longer the hours received. Formal and informal care

volumes vary too much from one dependent person to another to be able to determine the extent to which these two types of care are substitutes.

Tables 19.

F5 Survey of residential institutions for elderly people (EHPA)

Definition Residents of care homes for the elderly people.

Source Ministry of Employment and Solidarity.

Years 1992, 1994, 1996

Population Residents of homes for elderly persons

Methodology The survey takes place every two years. It aims to identify the activities, structures and the personnel of the residential homes for elderly people. Every four years a specific module collects information on the characteristics of clients.
A specific survey on health institutions collects information on long-term nursing homes.

Publication "Annuaire des statistiques sanitaires et sociales: 2000", Collection Etudes et statistiques ; Direction de la recherche, des études, de l'évaluation et des statistiques (DREES) ; La Documentation Française, 2001.

Comments In 1996, there were about 600.600 persons aged 65+ in care homes for the elderly and long-term nursing homes. They represented about 6,6% of the total population.

There is a big difference between the clients of residential homes for the elderly (542.026 persons) and long-term nursing homes (77.195 persons). Physical dependency is as follows:

Physical dependency 31 December 1994

	Residential homes for elderly	Long-term nursing	Total
Confined in bed/chair	12	52	17
Help for washing and dressing	31	41	32
Help to go out of the institution	15	5	14
No or small dependency	42	2	37
Total	100	100	100

Psychical dependency 31 December 1994

	Residential homes for elderly	Long-term nursing	Total
Psychical dependency	35	80	40
No or small dependency	65	20	60
Total	100	100	100

Psychical dependency includes problems related to behavioural troubles and orientation in space and time.

Tables -

IRELAND

IRL1. Persons needing help

Definition Older people living in the community who have a difficulty with ADL.

Available data reports persons having:
- Mostly minor difficulties with ADL
- Major difficulties with ADL, and
- Severely impaired.

The authors report also, the number of persons usually needing help with one or more daily tasks.

Source Different sources (notably Health and Social Services for Older people in Ireland - HeSSOP)

Years -

Population -

Methodology Analysis of different sources.

Most data comes from the analysis of a sample of 937 people aged over 75 years living in the community (HeSSOP). Functional ability was measured using the Stanford health assessment Questionnaire (HAQ). Respondents were asked to rate their ability to perform seventeen daily tasks within eight activity categories in the past week on a four point-scale – 'without difficulty', 'with some difficulty', 'with much difficulty' or 'unable to do so'. An overall measure of independence (ranging from 0-3) can be calculated from the eight categories, yielding four levels of ability to maintain independence in activities of daily living (ADL):

- 0-0,5: the person is completely self-sufficient
- 0,51-1,25: the person is reasonable self-sufficient and experiences some minor and even major difficulties in performing ADL
- 1,26-2,0: the person is still self sufficient but has many major difficulties in performing ADL
- 2,1-3,0: the person may be called 'severely disabled'.

The eight categories included are:

1. Personal care
2. Arising ability
3. Eating and drinking
4. Walking ability
5. Reach ability
6. Grip ability
7. Activity ability
8. Cognitive ability

Different European surveys (Eurobarometer and ECHP) report generally relatively low prevalence disability rates for Ireland. Given these statistics and the estimate reported by HeSSOP, we consider that a good estimate for the prevalence of dependency for people aged 75 and over might be around 20%.

Publications "Carers", Ageing in Ireland Fact File No. 9, 2002, National Council on Ageing and Older People.

"Supporting Carers: A Social Policy Report", COMHAIRLE, July 2002.

Comments The Department of Health (1997) estimates that the number of persons aged 65 years and over in long term institutional care is 5%.

Tables 2, 3, 6, 11, 16, 18, 23, 25.

IRL2. Home help service

Definition Recipients of Community Welfare Services. It includes home helps employed by the health boards and by voluntary agencies subsidised by the health boards and provided to the older persons.

Source Department of Health and Children

Years Annual

Population Administrative data

Methodology Administrative data, number of recipients for year ended 31 December.

Publication "Health Statistics 1999", Prepared by Information Management Unit, Department of Health and Children.

Comments The number of physically handicapped who used home help services was 1.401 persons in 1996.

The National Physical and Sensory Disability Database (NPSDD) covers only people less than 66 years old.

Tables 27.

IRL3. Long-Stay Units

Definition Dependency
Low Dependency: This category refers to people who need some support in the community and the more independent residents in residential accommodation who require little nursing care. They are usually mobility independent but may use a walking stick and have difficulty to manage stairs.

Medium Dependency: Person whose independence is impaired to the extent that he or she requires residential care because the community does not provide the appropriate support and nursing care required by the person. Mobility is impaired to the extent that the person requires supervision or a walking aid.

High Dependency: Independence is impaired to the extent that the person requires residential care but is not bed bound. The person may have a combination of physical and mental disabilities, may be confused at times and be incontinent. He/she may require a walking aid and physical assistance to walk.

Maximum Dependency: People whose independence is impaired to the extent that he/she requires nursing care. The person is likely to be bed bound, to require assistance with all aspects of physical care and may be ambulant but confused, disturbed and incontinent.

Nursing homes:
A private nursing home is run as a private business for the care and maintenance of dependent persons, running on a profit-making basis.

A voluntary nursing home is run by a charitable non-profit making organisation in which patients are not maintained for the personal profit of the proprietors.

Number of beds: Total bed complement at 31.12.2000 excluding respite beds.
Number of respite beds: Allocated for the planned admission of dependent persons for short periods of time in order to assist carers in their task of caring.

Source Department of Health and Children

Years 1996-1998

Population Institutions (Long stay units)

Method Survey of long-stay units/nursing homes. In 2000, 384 questionnaires out of 562 were returned.
Number of patients in residence at 31.12.2000, including occupants of respite beds.

Publication "Long-Stay Activity Statistics 2000", The Information management Unit, Department of Health and Children.

Commentary The majority of patients in long-stay units were female (66,5%).

- 11,0% have been categorised as low dependency
- 20,5%: medium dependency,
- 29,8%: high dependency,
- 38,6%: maximum dependency.

Tables 16.

ITALY

I1. Health conditions of the population and recourse to health services

Definition

Disability

The index measuring the lack of self-sufficiency is privileged over that measuring the presence of handicaps. Use of the International Classification of Impairments, Disabilities and Handicaps (ICDH, 1980).

Activity of Daily Living (ADL)

Use of the OECD list of domains concerning the ability to implement in an autonomous way the essential activities of daily living. They take into account three dimensions:

- Activities of daily living: go to bed and get out of bed, sit down in and get up from a chair, washing, dressing, take a shower or a bath and eating.
- Mobility: walk, climbing stairs, take an object from the ground; Confinement refers to permanently confined to bed, chair or at home.
- Communication: speaking, sight and hearing.

Degree

It ranges from absolute incapacity to implementation without problems.
Persons with a sight, hearing and speech disability refer to difficulties.

Source Istituto Nazionale di Statistica (ISTAT)

Years 1986-1987, 1999-2000

Population Private households. Age: 6+.

Methodology The survey 1999-00 on health conditions of the population and access to health services covers about 140.000 individuals living in 52.300 households, representative of the Italian resident population. Persons currently living in hospitals or institutions are not interviewed. The information was supplied by a member of the family and in 72% of the cases it is the individual itself that answered the questions. Disability statistics were collected only for population aged 6 years and over.

Statistics concerning prevalence by age group are provisional.

Publication

"Le condizioni di salute della popolazione: Indagine Multiscopo sulle famiglie 'Condizioni di salute e ricorso ai servizi sanitari' Anni 1999 – 2000'", Istituto Nazionale di Statistica, 2002.

"Indagine Multiscopo sulle Famiglie – Anni 1987-91 – La condizione degli anziani", Istituto Nazionale di Statistica, 1994.

"Indagine Multiscopo sulle Famiglie – Anni 1987-91 – I disabili", Istituto Nazionale di Statistica, 1995.

"Relazione sullo stato sanitario del Paese 2000", Ministerio della Salute, 2001.

"Relazione sulla condizione dell'anziano, 1989/90", Presidenza del Consiglio dei Ministri: Dipartimento per gli Affari Sociali, Roma, 1992.

Comments The "Report on the State of Health in the Country 2000" presents non-standardised data.

The Multipurpose Survey on Family gives the number of persons needing:
a) Help from time to time,
b) Continuous help.

Tables 2, 3, 4, 5, 6, 7, 8, 9, 10.

LUXEMBOURG

L1. Socio-economic panel

Definition Dependency
The survey distinguishes five levels: complete autonomy (O), light loss of autonomy (1), loss of autonomy but not problematic (2), serious dependency (3) and severe dependency (4).

Source Centre d'Etudes de Populations, de Pauvreté, et des Politiques Socio-économiques (CEPS).

Years Annual

Population All private households.

Method Available data refers to 1992. In 1992, the Socio-Economic Panel (PSEL) covered 5.191 persons, of which 1.081 were aged 60 years and over. Questions concerning dependency and care focus on persons aged 60 years and over (1.039 answers).

In 2000 the survey included a module on care and services rendered between generations.

Publication "Les personnes âgées dépendantes en ménage privé: contribution au groupe de travail sur la dépendance", A. Kerger, Document de recherché n° 9439, CEPS, 1994.

Commentary The questions focussed on activities such as: prepare a hot meal, shopping, climbing stairs, walk inside home and outside home, carry an object, take the bus or the train, washing oneself and does not forget to take his medicine

Tables 2, 4, 6, 27.

L2. Long term care insurance

Definition Dependent persons
Need of regular help for the essential activities of daily life.

Source Ministère de la Sécurité Sociale

Years Annual

Population All

Methodology Number of beneficiaries of the law 19.06.1998 concerning the dependence insurance. Statistics refer to 30 June 2002.

Publication Unpublished data.

Commentary -

Tables 3, 5, 14, 15.

NETHERLANDS

NL1. Permanent Survey on Life Conditions

Definition

Physical disabilities

Physical disabilities are surveyed with the aid of two instruments: the OECD (Organisation for Economic Cooperation and Development) indicator for persons aged 16 years and older and the ADL (Activities of Daily Living) indicator for persons aged 55 years or more.

OECD indicator

The OECD indicator refers to limitations in the ability to communicate and move around; Respondents are asked if they can do the following:

- Follow a conversation in a group of 3 or more persons (if necessary with a hearing aid),
- Read small print in a newspaper (if necessary with glasses or contact lenses),
- Recognise a face at a distance of 4 meters (if necessary with glasses or contact lenses),
- Carry an object weighing five kilos (e.g. a bag of shopping) a distance of 10 meters,
- From upright position, bend down and pick something up from the ground, walk for 400 meters without stopping (if necessary with a stick).

The figures refer to people who reported not being able to do one or more of these activities, or only with great difficulty.

ADL indicator

The ADL (Activities of Daily Living) indicator refers to limitations in carrying out general daily activities. Since 1989 respondents are asked if they can: 'eat and drink', 'sit down in and get up from a chair', 'get into and out a bed', 'dress and undress', 'move to another room on the same floor', 'walk up and down stairs', 'go out and let themselves in again', 'move around outside', 'wash their face and hands' and 'wash themselves completely'.
The figures present persons who are not able to do one or more of these activities, only with great difficulty, and with some difficulty. We report data only for the first two categories.

Mobility

Percentage of persons who have problems moving around.

Incontinence

Percentage of persons who in the latest 12 months suffered from involuntary urine losses (incontinence).

Source Centraal Bureau voor de Statistiek

Years Annual

Population Private households

Methodology The POLS (Permanent Onderzoek Leefsituatie) aims at providing permanent information about different life topics for the Netherlands population taken in private

households. The survey covers the total population. The sample was taken in the local administration register and included 9.323 respondents in 1999 and 9.877 in 2000.

The questions are divided in different modules each one focusing on a certain subject. The different modules are subjected only to one part of the respondents, in exception of the base module. This latter provides ground information i.e. about age, sex, education, etc. as well as some general information about health.

Data about long-term impairments is based on written report by the persons themselves. Interviewees are asked if they suffer from or have suffered during the last 12 months from long-term impairments taken of a list of 24.

The table concerning physical limitations stems from questions on the base of the OECD-indicator.

The question on ADL limitations covers only persons aged 55+. In order to estimate the prevalence for all adults (20+), we have first run a logistic regression on the observed rates. The good results in terms of R^2 (0,9), DW (2,1) and heteroscedasticity test (nR^2=0,6) must not make us forget that the number of observations is very limited. The estimated rates applied to the number of persons living in private households gives a global rate for persons aged 20+ equal to 4,5%. This has only an indicative value. For comparison the estimation for the age group 65+ is 18, 5 and the observed 18,6%.

Publication Vademecum gezondheidsstatistiek Nederland 2001, Centraal Bureau voor de Statistiek, Voorburg/Heerlen, 2001.

Http://statline.cbs.nl

Comments In certain tables we present pooled data combining 2000 and 2001. This increases the efficiency of the reported estimators. In calculating the prevalence for grouped ages, use was made of the 2000 population distribution.

Tables 2, 3, 4, 5, 6, 8, 11, 12, 15, 16.

NL2. Longitudinal Ageing Study Amsterdam (LASA)

Definition Functional limitations
It is based on:
- Ability to walk up and down 15 steps of a staircase without stopping,
- Use public or private transport, and
- Cut one's own toenails.

We retain as dependency the case where all three activities are done with difficulty.

Performance tests measure the time needed to:
- Take off a cardigan,
- Walk three meters back and forth,
- Get up from a kitchen chair five times without arms folded.

We report only the number of respondents who were not able to perform the test.

Source Ministry of Health, Welfare and Sports.

Years 1992/93, 1995/96 and 1998/99.

Population All persons aged 55-85.

Methodology The Longitudinal Ageing Study Amsterdam (LASA**)** covers a representative sample of institutionalised and non-institutionalised population of individuals aged 55-85.

No refreshment samples are drawn at wave II and wave III. Wave I covered 2.925 individuals, wave II: 2.204 individuals, and wave III: 1.717 individuals. Short interviews were organised as well as interviews by telephone.

Publication "An Econometric Analysis of the Mental-Health Effects of Major Events in Life of Elderly Individuals", Lindeboom, M., Portrait, F., and van den Berg, G., Discussion Paper No. 398, IZA, Bonn, 2001.

Comments The authors argue that institutionalisation has negative effects on both emotional well-being and cognitive abilities.

For information, dependency defined as difficulty to perform all three functional limitations (walk up and down 15 steps of a staircase without stopping, use public or private transport, and cut one's own toenails) gives 11% for persons aged 55-85.

Tables -

NL3. Institutional care

Definition Persons in:
- Homes for the elderly (recognised),
- Nursing homes,
- Homes for mentally disabled persons,
- Mental hospitals
- Family replacement homes (notably for persons with sensorial disabilities), etc.

Available statistics often do not distinguish between different institutions. For comparability purposes, each time it was possible, we have retained only persons in homes for the elderly. In all cases, we have excluded other institutions such as religious, prisons and boarding schools.

Dependency
Persons in institutions with very serious limitations in hearing, seeing, mobility and/or ADL activities.

Source Centraal Bureau voor de Statistiek

Years Annual data

Population -

Methodology Number of residents, 1 January. The population consists of persons whose accommodation and daily needs are provided by for by a third party on a professional basis.

Estimation of the number of dependent persons (65+).

Private households: we take 18% of persons 65+ (POLS, source: NL1.)
Institutions: In 1999, there were about 230.000 persons in institutions. About 170.000 persons were aged 65 and over (excluding religious institutions, prisons and boarding schools). They represent 8% of the same age group. Van Herten et al (cited in rivm, 2003) present the prevalence of dependency by age group and type of institution (Nursing homes and Homes for the elderly). We suppose a prevalence rate for all elderly persons outside nursing homes similar to the one of residents of 'Homes for the elderly'.

De Klerk (cited in rivm, 2002) reports that almost 100% of nursing homes' residents and 71% of 'Homes for the elderly' residents make use of professional help. This might overestimate dependency as some persons might use once in a while these services.

De Klerk defines dependency as persons using:
- Personal care services (eat and drink, get out/in the bed, washing oneself, dressing, etc.),
- Nursing services (medicine, caring wounds, etc),
- Light housework (shopping, ranging, dust, etc.),
- Mobility (going up/down stairs, mobility outside the home, etc.).

Publication "Vademecum gezondheidsstatistiek Nederland 2001", Centraal Bureau voor de Statistiek, Voorburg/Heerlen, 2002.

"Lichamelijk functioneren: Omvang van het probleem", Nationaal Kompas Volksgezondheid, rivm, Bilthoven, 2003.

"Verpleeghuis- en verzorgingshuiszorg: Vraag en gebruik", Nationaal Kompas Volksgezondheid, rivm, Bilthoven, 2002.

"Statistical Yearbook 2002", Statistics Netherlands, Voorburg/Heerlen, 2003.

Comments Persons in 1999:

- Homes for the elderly (recognised):	108.207
- Nursing homes:	33.145
- Homes for mentally disabled persons:	28.653
- Mental hospitals:	11.607
- Family replacement homes, etc.:	36.000
- Other institutions (Religious, prisons and boarding schools):	12.895
- TOTAL	230.507.

In 2001, there were 218.784 persons (79.209 men and 139.838 women).

Tables 14, 16.

NL4. Informal help

Definition Informal help includes non-paid help provided by the family, friends and neighbours.

Individual help includes help from an employee or a nurse.

Home care includes personal care, housework, alphahelp, maternity, nutrition and diet, advice, provision of technical aids, etc.

Source Analysis of different sources.

Years -

Population -

Methodology Analysis of different sources.

Publication "Informele hulp: Aanbod", Nationaal Kompas Volksgezondheid, rivm, Bilthoven, 2003.

"Informele hulp: Vraag en gebruik", Nationaal Kompas Volksgezondheid, rivm, Bilthoven, 2003.

"Thuiszorg: Vraag en gebruik", Nationaal Kompas Volksgezondheid, rivm, Bilthoven, 2003.

Commentary -

Tables 21, 24.

AUSTRIA

A1. Microcensus

Definition

Activities of daily living

Interviewed persons responded to the following questions:

a. Which of the following activities (getting up and down, washing and getting dressed, walking in the house, eating and drinking, easy household tasks – clearing up, doing the dishes, preparing meals – difficult household tasks – vacuum cleaning, doing the laundry, hanging up laundry, cleaning the windows – going shopping, going out and making visits) can you do without the help of a third party, only with the help of a third party, not at all.
b. Are you not able to perform body care due to impairment of vision, hearing, mobility or of a chronic disease and do you receive help of a family member, parents, friends, social services or other persons? Do also indicate how often you are helped – once a week, less often, never.

Informal care

Interviewed persons responded to several questions:

a. Your household provides care for whom – chef of household (COH), husband / wife of COH, mother-in-law of COH, father-in-law of COH, children-in-law of COH, sister or brother-in-law of COH, grandparents of COH, other relatives or friends?
b. Which household member provides care for persons aged 60 and more?
c. How many hours per week (travel included) of help are given by your household for a person aged 60 or more: until 1 hour, 2-3 hours, 4-5 hours, 6-10 hours, 11-19 hours, more than 20 hours?
d. For which activity do members of your household help persons aged 60+: personal care, medical care, going shopping, preparation of meals, cleaning up, washing and ironing, other household tasks, making provisions, going out?
e. How often do you provide care / help: every day, several times per week, once a week, less often, never?

Informal care

It refers to persons aged 60+ with a long-term need for care.

Source Österreichisches Statistisches Zentralamt

Years Irregular periods

Population Private households

Methodology Participation is obligatory, except for supplementary programs. The sample includes 33.600 private households in 800 municipalities (60.000 persons). One eighth of the sample is replaced every three months. Projection on the total population takes into account the evolution of the population by region, sex, age and nationality.

Whenever it was possible, we have corrected the estimates for non-response, notably in cases where the non-response rate was known and relatively high.

Publication Bundesministerium für Soziale Sicherheit und Generationen: Ältere Menschen – Neue Perspektiven : Seniorenbericht 2000: Zur Lebenssituation älterer Menschen in Österreich, Wien.

Österreichisches Statistisches Zentralamt, Personen mit körperlichen Beeinträchtigungen. Ergebnisse des Mikrozensus Juni 1995. Beiträge zur österreichischen Statistik Heft 1.276, Wien 1998

Pomezny, W., Häufigkeit bezahlter Hilfe in Privathaushalten. Ergebnisse des Mikrozensus März und September 1992, in: Statistische Nachrichten 4/1994, pp.336

Statistik Österreich: Lebenssituation älterer Menschen. Ergebnisse des Mikrozensus Juni 1998, Beiträge zur österreichischen Statistik, Heft 1.340, Wien, 2000

Vötsch W., Personen mit körperlichen Beeinträchtigungen: Wobei benötigen sie Unterstützung. Ergebnisse des Mikrozensus Juni 1995, in: Statistische Nachrichten 8/1997

Vötsch W., Personen mit körperlichen Beeinträchtigungen: Wer hilft? Ergebnisse des Mikrozensus Juni 1995, in: Statistische Nachrichten 9/1997, 743-748

Vötsch, W., Haushalte: Unterstützung für Senioren. Ergebnisse des Mikrozensus-Sonderprogramms Juni 1998, in: Statistische Nachrichten 11/1999, pp.959

Wiedenhofer B., Gesundheitliches Befinden von Senioren. Ergebnisse des Mikrozensus-Sonderprogramms Juni 1998, in: Statistische Nachrichten 2/2000, pp.112

Wiedenhofer B., Unentgeltliche Hilfeleistung bei der Betreuung von Erwachsenen. Ergebnisse des Mikrozensus März und September 1992, in: Statistische Nachrichten 6/1994, pp.509

Comments -

Tables 6, 7, 8, 9, 10, 11, 12, 21, 22, 23, 24, 25, 27.

A2. Report for the Austrian Chapter des Club of Rome

Definition Care dependent persons:
Limitations in the autonomous performance of daily body-care that lead to a need for regular or irregular care. A person that needs help for body-care activities at least several times a week is in need of regular care. People that are in need of irregular care are limited for some body-care activities and housework chores and need help at least once a week.

Persons dependent on help (large sense)
The need for help is defined in a very wide sense including those persons that e.g. can't iron anymore or that can't bend down. Help is provided from time to time or in case of a need.

Persons dependent on help (restricted sense)
The degree of need of help is higher and includes persons who can't climb stairs anymore, who can no longer dress themselves etc. Support and help is needed regularly.

Source Österreichisches Bundesinstitut für Gesundheitswesen (ÖBIG)

Years -

Population -

Methodology This publication is not a survey, but a report that is based on several sources.

Publication ÖBIG (Österreichisches Bundesinstitut für Gesundheitswesen): Alte Menschen in Österreich: Lebensverhältnisse, Probleme, Zukunftsperspektiven – Bericht an das Austrian Chapter des Club of Rome, Wien, 1998

Comments -

Tables 2, 3, 4, 5.

A3. Consequences of the long-term care provision system

Definition Activities of daily living
Number of persons who consider that they could not do the enumerated activities without the help of a third person.

Informal care
Percentage of carers who provide care for a certain number of hours per week with a remunerated activity

Source Badelt Ch. et al., Analyse der Auswirkungen des Pflegevorsorgesystems, Wien 1997

Years 1995

Population All

Methodology Written interviews with 3.120 beneficiaries of dependency allowances. 1.498 dependent persons and 1.396 carers were interviewed. 6,6% of dependent persons were less than 40 years old.

Publication Badelt Ch. et al., Analyse der Auswirkungen des Pflegevorsorgesystems, Wien 1997

Comments -

Tables 18, 26.

PORTUGAL

P1. National Survey on Health

Definition Persons declaring suffering a long-term disability.

The health survey reports persons with a long term disability concerning:

- Confinement: always in bed; always bound to a chair; confined to the house
- Mobility: lie down and get up from bed; sit down and get up from a chair; go and use toilet; pick up something from the ground; can walk on a flat terrain without discomfort; climb and go down 12 steps.
- Personal care: get dressed and undressed; wash face and hands; eat (cut food and bring food and drinks to mouth); incontinence.
- Sensory / communication: listen to TV or radio; distinguish forms and recognise friends; difficulties to speak.

Degree
Concerning personal care the answer is: alone, without difficulty; alone with difficulty; with help. We have retained persons who answer 'with help'.
Concerning sensory functions and certain mobility questions the answers are different. In this case, we have retained 'cannot / not at all'.
Concerning incontinence we have chosen the stricter definition: at least once per week.

Source Department of Health – National Health Institute

Years 1998-99

Population Private households.

Methodology The national health survey covered private households and excluded institutions. The survey took place during October 1998 and September 1999. The representative sample covered 21.808 households.

Questions concerning long-term disability covered persons aged 10 and over.

The survey presents first people who are confined and then (excluding confined individuals) persons with long-term disabilities (for example: persons not confined in bed/chair but needing help to walk on a flat terrain). In these cases, we have added both in order to arrive at the total estimate.

Publication "Inquérito Nacional de Saúde: Dados gerais; Continente 1998-1999", Ministerio da Saúde: Instituto Nacional de Saúde, 2001.

Comments The rate of persons 65+ who have difficulties to 'wash hands and face' amounts to 9%. The rate of those needing help amounts to 5%. Concerning 'climbing and going down 12 stairs' the rates are respectively: 42% and 7%.

If we add those confined in bed/chair we obtain the total of persons with difficulties in 'climbing and going down 12 stairs'. It is about 45%. This could be a good proxy for the proportion of persons with a disability.

Tables 6, 7, 8, 9, 10.

P2. National Survey on Impairments, Disabilities and Handicaps

Definition

Persons with severe mobility disabilities
Persons with a severe reduction or limitations concerning personal mobility or moving objects.

Persons with severe ADL limitations
Persons with a severe reduction or limitations concerning activities of daily living such as open/close doors, switch on/off light, telephone, manipulate objects, etc.

Collective housing
Collective institutions include educational, hospitals, other providing assistance, religious, military and others.

Source National Rehabilitation Secretariat

Years 1995

Population All households.

Methodology The sample covered 47.020 families representing 142.112 persons.

Publication "Inquérito Nacional ás Incapacidades, Deficiências e Desvantagens : Resultados Globais", Secretariado Nacional de Reabilitação, Lisboa, 1996.

Comments This survey yields disability prevalence rates, which are slightly lower to the ECHP (1996) estimates. For comparison, concerning persons aged '65-74', the present survey gives a prevalence of disability of 37%, while the ECHP gives 48%.

Tables 2, 3, 4, 5.

FINLAND

FIN1. Health survey

Definition The indicator refers to "Persons who feel unable to fulfil the demands of everyday life". The answer distinguishes never, seldom, every now and then, often and most of the time. The data presented here includes 'often' and 'most of the time'.

Source National Public Health Institute

Years 2001; Health Behaviour among elderly has been monitored since 1985

Population Private households. Age: 65-84.

Methodology The purpose of the survey was to obtain information about living conditions, health status and lifestyle and coping with daily activities among 65-84 year old citizens of Finland. Random samples of 300 persons from each five-year age group of men and women were drawn from the National Population Register. Out of 2.400 persons 2.388 were contacted by mail. 83% of men and 80% of women responded.

Publication "Health Behaviour and Health among Finnish Elderly, Spring 2001, with trends 1993-2001", National Public Health Institute.

Comments -

Tables 2, 4, 6, 7, 8, 9, 10, 11, 12.

FIN2: Persons receiving help

Definition Households receiving help in ordinary housing and in institutions and service housing.

Institutions include nursing homes, homes for the long-term ill and old people's homes. Service housing includes sheltered homes, service flats, collective housing, housing where special care is provided, etc. Elderly people may also, be offered long-term medical treatment in hospital wards – often in the so-called geriatric wards. There are special wards in some nursing homes.

Source Nordic Social-Statistical Committee (NOSOSCO)

Years Annual data

Population All

Methodology Home help
Number of people (head of household) who received help during a year. Help may stem from municipal or privately employed staff.

Dependent people in institutions or service housing
Number of people (head of household) aged 65 years and older living in institutions or service housing.

In order to take into account only persons requiring assistance we have taken 50% of the age group 65-74, 60% for 75-89 and 70% for 80+. These are non-weighted

averages of dependent persons in institutions in Belgium, France and the United Kingdom.

For home help, the age groups are: 65-74, 75-84 and 85+. For institutions the age groups are: 65-74, 75-79 and 80+. We had to split the home help component into 75-79 and 80-84. We took into account comparable rates in other Nordic countries and the weights of the respective age groups.

Publication "Social Protection in the Nordic Countries", Nordic Social-Statistical Committee (NOSOSCO), Copenhagen, 2001.

Comments The Nordic Social-Statistical Committee (NOSOSCO) notes that statistics concerning home help in the Nordic countries are not easily comparable. It indicates that the extent of assistance is determined on the basis of individual needs and may vary from a few hours per month to several hours per day.

The assistance is a municipal matter and is provided by municipal or privately employed staff.

In all Nordic countries, people with severe disabilities may be granted financial support towards payment of personal assistance and help to manage the household.

Tables 13, 28.

FIN3. Beneficiaries of help/care

Definition Number of beneficiaries of different dependency provisions

Source Research and Development Centre of Health and Social Affairs (STAKES)

Years 2001

Population All

Methodology Statistics are based on discharge reports (reports to be made for each discharged client) and on client census reports (to be filled in for all clients in care on the census day). Reports and censuses concern persons that receive

- Institutional care and housing services with 24-hour assistance;
- Housing services with part-time assistance; and
- Home care

The total number of social welfare clients on 31 December 2001 was 135.000 persons. 88.000 persons of this group were aged 75 years and more.

Publication **"**Institutional Care and Housing Services on Social Welfare", Research and Development Centre of Health and Social Affairs (STAKES), 2002.

Comments **-**

Tables 27.

SWEDEN

S1. Survey on living conditions

Definition The survey produces different indicators for persons aged 65-84, notably:

- Persons with physical disability
- Needs help with different activities of daily living
- Difficulties with certain instrumental activities of daily living, and
- Impairments for sensory activities.

Source Official Statistics of Sweden **(**Socialstyrelsen)

Years 1996/97

Population Private households. Module: 65-84.

Methodology The questionnaire is a module of the Survey on living conditions. The first Survey on living conditions was done in 1974. Different modules have been added throughout the years and are repeated with a periodicity of 5 to 8 years.

Data is collected throughout the year. Results are an average of two years. 112.404 people aged 20-84 were interviewed. 40.829 of those interviewed were aged 55-84.

Publication "Äldres levnadsförhållanden 1980-1998", Rapport nr 93, Statistiska centralbyrån – Socialdepartementet – Socialstyrelsen, 2000.

Comments The prevalence of physical disability provided by the present survey is 22% (age: 65-84). The estimations provided by the ECHP and the present survey give similar results for 65+ and 75+.

Tables 1, 2, 4, 6, 7, 8, 9, 10, 21, 22.

S2. Care for the elderly

Definition Statistics focus on persons aged 65 and over living in ordinary housing, persons living in retirement homes or hospitals, people with home-help services and home medical care, persons with attendance allowance, with personal assistance, companion service, relief service in the home, short stay away from home and persons in residences with special services and daily activities.

Source Official Statistics of Sweden **(**Socialstyrelsen)

Years 2001

Population Persons aged 65 and over.

Methodology Statistics were collected by the municipalities who are obliged to respond. The collection took place in October 2001.

Beneficiaries of permanent and short-term care in retirement homes or other living arrangements risk to be counted twice. Some municipalities may also interpret *retirement homes* or *service homes* as *ordinary living arrangements* and might

therefore class people in the wrong category. One municipality (Göteborg) could not distinguish persons with home sick care from those with ordinary home care services and did hence only report the former category.

Publication "Äldre – vard och omsorg år 2001", Socialtjänst 2002:3, Socialstyrelsen.

"Policy for the elderly", Ministry of Health and Social Affairs, Sweden, Fact sheet N° 4, Mars 2001.

Comments The publication notes that all the municipalities have responded to the request, but have not always been able to answer all the questions. The authors note that there is also a risk of different interpretations of terminology by the different municipalities.

Tables 15, 27.

S3. Persons receiving help

Definition Persons receiving help in ordinary housing and in institutions and service housing.

Institutions include nursing homes, homes for the long-term ill and old people's homes. Service housing includes sheltered homes, service flats, collective housing, housing where special care is provided, etc. Elderly people may also, be offered long-term medical treatment in hospital wards – often in the so-called geriatric wards. There are special wards in some nursing homes.

Source Nordic Social-Statistical Committee (NOSOSCO)

Years Annual data

Population All

Methodology Home help
Number of people who per 31 December (1 November for 1999) had been granted home help and who live in their own house or flat. Help may stem from municipal or privately employed staff.

Dependent people in institutions or service housing
Number of people aged 65 years and over living in institutions or service housing, as per 1 November 1999. People staying on a short-term basis are included in the age group 65+.

In order to take into account only persons requiring assistance we have taken 50% of the age group 65-74, 60% for 75-89 and 70% for 80+. These are non-weighted averages of dependent persons in institutions in Belgium, France and the United Kingdom.

The age groups are: 65-74, 75-79 and 80+.

Publication "Social Protection in the Nordic Countries", Nordic Social-Statistical Committee (NOSOSCO), Copenhagen, 2001.

Comments The Nordic Social-Statistical Committee (NOSOSCO) notes that statistics concerning home help in the Nordic countries are not easily comparable. It indicates that the

extent of assistance is determined on the basis of individual needs and may vary from a few hours per month to several hours per day.

The assistance is a municipal matter and is provided by municipal or privately employed staff. In all Nordic countries, people with severe disabilities may be granted financial support towards payment of personal assistance and help to manage the household.

Home help in Sweden provides help with household tasks (shopping, cooking, cleaning, etc) and personal care tasks (getting in and out of bed, bathing, toileting, eating, (un)dressing, and outdoor walks).

Tables 28.

S4. Old-age care

Definition Family care (informal care)
Persons who receive at least weekly help or monitoring by household member, neighbour, close friends or acquaintance (year 1975).
Persons who receive help with ADL-functions (years 1994 and 2000).

Home help
Estimates are restricted to help concerning activities of daily living (ADL).

Source Statens Offentliga Utredningar (SOU).

Years 1994, 2000.

Population Community-residing population aged 75 and over.

Methodology Two surveys were commissioned by the National Board of Health and Welfare (1994, 2000) to assess the situation of older people. These nationally representative surveys over-sampled men and the oldest age groups, so all the reported pooled estimates are corrected by weighting by the authors. Number of interviews: 1.379 (1994) and 1.466 (2000). The first survey had a drop out rate of 27%, the second 30%.

Publication "State provision down, offspring's up: the reverse substitution of old age care in Sweden", Johansson, L., Sundström, G., and Hassing, L. B., *"Ageing & Society"*, 22, 2003, p. 1-13, Cambridge University Press.

"The Shifting Balance of Long Term Care in Sweden", Sundström, G., Johansson, L., and Hassing, L. B., The Gerontologist, Vol. 42, No 3, p. 350-355.

Comments The authors advance that increased inputs from families match the decline of public services, that is, a 'reverse' substitution has recently been taking place. The authors challenge also the so-called substitution thesis.

Tables 18, 20, 23, 25.

UNITED KINGDOM

UK1. Health Survey for England.

Definition

Disability

In accordance with the WHO-ICIDH protocol, disability was measured across five domains: locomotor, personal care, sight, hearing and communication. For each domain, the level of severity was scored into none (0), moderate (1) and severe (2). A summary disability score was then calculated which took the highest value of 0, 1 or 2 in order to assess overall physical disability levels across care homes. (The WHO developed a series of questions designed to estimate the percentage of the population experiencing different levels of severity: a lower and a higher level).

Dependency

The criteria was given by the activities of daily living such as washing, dressing, feeding, using the toilet, and requiring help getting in and out of a bed or a chair. The persons who needed assistance with any of these tasks were classed as severely disabled on the personal care disability dimension of the WHO protocol.

Care Homes

Five categories of care homes were chosen to be eligible for the sample, on the grounds that these types of home were most likely to contain older residents. The categories were public (local authority) residential homes, private nursing homes, dual registered homes, private residential homes and private small residential homes.

Source Great Britain Department of Health

Years Annual.

Population Private households (England), except 2000.

Methodology The main focus of the Health Survey for England 2000 was on the health of older people, defined for this purpose as persons aged 65 and over, although the survey also included interviews with children and with adults below the age of 65. It included the private household population as well as residents (aged 65 and over) in residential care and nursing homes.

Thus, the population surveyed is the population aged two and over living in England. There was no over-sampling of adults aged 65 and over. Older people living in care homes were included in a special sample in the 2000 survey, but residents in other types of institutions were not included. A random sample of 6840 addresses was selected from the Postcode Address File, interviews with 7988 adults were obtained. 1677 were aged 65 and over. Where there were more than two children aged 2-15, only two (selected at random) were interviewed.

The sample concerning care homes was selected from Laing and Buisson's Care Home and Hospital Information database (CHIC). In homes with six or fewer residents aged 65 and over, all residents were interviewed; otherwise, six were randomly selected for interview. 544 homes co-operated in the survey. Interviews were made with 2493 residents. Of the 2493 interviews, 1273 were carried out via a proxy informant.

Concerning private households, data was collected at two levels: household and individual. The interview with informants from the private household sample included the question modules, which are asked in most years in the Health Survey such as general health and longstanding illnesses, use of health services, cigarette smoking, psychosocial health and accidents. Questions on disability were also included. In the private household sample, all adults aged 65 and over were eligible for the second stage of the survey, a nurse visit.

Information about longstanding illnesses was also collected during the survey. Concerning care homes, data was collected at two levels: care home and individual. In care homes around half of those selected could not be interviewed in person. In these cases the interview was carried out with a proxy (nurse). In addition to the interviews with private household and care home residents, a short interview was carried out with care home managers.

As to the sampling of the different types of care homes, local authorities homes were chosen as the primary sampling units. Within these, 677 care homes were selected systematically with probability proportional to the number of beds in the home. A pre-decided total of care homes were selected in each category. In each care home, up to six residents aged 65 and over were selected at random. A resident had to be resident in the home for at least three months or to be expected to be resident for at least three months.

In 2001, the Health Survey for England dedicates a section to deal about the latest estimates of the prevalence of disability among those living in private households in England.

Interviews were obtained with 15.647 adults (aged 16 and over) and 3.993 children (aged under 16), residents in 9.373 households. In this report, the 2001 sample has been combined with the equivalent sample of the population resident in private households in HSE 2000 to improve the precision of estimates.

Publication Health Survey for England 2000.
Health Survey for England 2001.
www.official-documents.co.uk

Commentary -

Tables 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 15, 16.

UK2. Survey on disability and care

Definition Disabled adults
Persons aged 16 and over who, owing to the impairment of any mental or physical structure or function, experience significant restrictions in their ability (or a total lack of ability) to carry out the normal activities of life, taking age into account. The minimum threshold for this definition was fixed relatively low to enable data to be collected on a wide range of cases.

In general, the definitions of the International Classification of Impairments, Disabilities and Handicaps were used.

Source Office of Population Censuses and Surveys (O.P.C.S.)

Years 1985/1986

Population All (Great Britain)

Methodology The survey covered people aged 16 or more, living at home or in community establishments in Great Britain. It took place in 1985 for the former and in 1986 for the latter.

Adults living at home

The first stage was to ask the occupants of 100.000 private addresses to fill in a questionnaire to identify persons who had a) difficulty carrying out everyday activities and b) health problems.

Approximately 80.000 questionnaires were sent out by mail and 20.000 distributed personally by the enumerators. In the first group (of 80.000 addresses), the response rate from permanent residents was 82 % and in the second group 86%.
Of those households that did not return the questionnaire, approximately 1.500 was chosen for an additional investigation. 81% of the households in this latter group subsequently provided the information requested by the enumerators.

The second stage was for the enumerators to visit those persons restricted in their everyday activities who had been identified during the first stage (by the questionnaire). Thus approximately 18.000 were contacted for an interview.

80% of those persons were interviewed, whilst 9% of the adults identified were not interviewed because of changes, which occurred between the mailing of the questionnaire and the date scheduled for the visit.

Adults living in establishments

A questionnaire was sent to all (community) establishments where disabled adults were likely to be living permanently. Establishments that accepted people for short stays were eliminated. Such people were included with those living at home.

A total of 1.408 institutions were contacted by post. Approximately 63&% of these (892) had four or more permanent residents prepared to cooperate. Finally, 3.533 full interviews were carried out in 570 establishments.

Total estimate

The survey estimated the number of disabled adults at 6.202.000. The confidence interval, with a 95% probability threshold, was 6.202.000 +/- 169.000.

Publication The prevalence of disability among adults, J. Martin, H. Meltzer and D. Elliot, O.P.C.S. surveys of disability in Great Britain: Report 1: Office of Population Censuses and Surveys / Social Survey Division, HMSO, London, 1988

Disabled adults: Services, transport and employment, J. Martin, A. White and H. Meltzer, O.P.C.S. surveys of disability in Great Britain: Report 4: Office of Population Censuses and Surveys / Social Survey Division, HMSO, London, 1989

The financial circumstances of disabled adults living in private households, J. Martin and A. White, O.P.C.S. surveys of disability in Great Britain: Report 2: Office of Population Censuses and Surveys / Social Survey Division, HMSO, London, 1988

Comments The survey defined disability in relation to a certain number of activities, which the disabled person is not able to do. This does not correspond with the definition used in the Disabled Persons (Employment) Act.

Tables 14, 23, 24.

UK3. General Household Survey

Definition Persons usually unable to do tasks by themselves **(**Module on elderly: 65+)

Sheltered accommodation
Sheltered housing is defined as those having a warden on premises or a central alarm system. Sheltered housing excludes communal establishments such as nursing homes and hospitals.

Source Office for National Statistics – Social Survey Division

Years The module was included in the GHS in 1980, 1985, 1991, 1994 and 1998

Population Private households (Great Britain). Age: 65+ for the module.

Methodology The Study was carried out as part of the 1998 General Household Survey.

3.082 people aged 65 and over were interviewed about their living circumstances, their health, their ability to perform a range of domestic and other tasks, and the use they make of health and social services.

57% (1.745 persons) were women and 43% (1337 persons) were men. As the GHS only covers private households, the sample of elderly people is not representative of the elderly population as a whole. Households with at least one person aged 65 and over are referred to as 'elderly households'.

The proportion of GHS respondents in each five-year age group declined with increasing age, from 31% in the 65-69 age group to 8% aged 85 and over.

Since no suitable list of private households exists, the GHS selects a sample of addresses while households are identified at the interviewing stage. For the 1998 GHS 13.248 addresses were selected from the Postcode Address File, of which 1575 were ineligible. The remaining addresses yielded a sample of 11.831 households. Personal or proxy interviews were conducted with all adult members at 72% of these households, 23% did not wish to take part and 4% could not be contacted.

Information is collected throughout the year by personal interview with all adult members (aged 16 or over) in the sample of private households.

Publication "People aged 65 and over: Results of an independent study carried out on behalf of the Department of Health as part of the 1998 General Household Survey", Ann Bridgewood, Office for National Statistics – Social Service Division

"Informal Carers: results of an independent study carried out on behalf of the Department of Health as part of the 1995 General Household Survey", The Stationary Office, 1998

Comments Just over three-fifths (61%) of elderly people said they had a longstanding illness; 42% said this limited their activities in some way. This proportion remained relatively stable between 1980 and 1998.

Concerning dependency, with the exception of jobs involving climbing, there has been little change over the years in the proportion unable to perform domestic tasks unaided.

Use of home help in the month before the interview: Home help from local authorities: 4%. The use of private domestic help amounts to 9%. In 1991, the rates were respectively 9% (LA) and 4%. (Private). These estimates might include short-term beneficiaries and persons not considered dependent.
For comparison, in 2000, the number of persons receiving an attendance allowance was a 1.250.000 beneficiary. This represents about 14% of the population aged 65 and over. The attendance allowance is a non-contributory, non-income related benefit paid to people over the age of 65 who need help with personal care or need a lot of looking after. It aims to compensate the extra cost of care. Consequently, it might include people who rate not dependent on a long-term base.

Tables 2, 6, 7, 8, 9, 10, 23, 24, 25, 27.

UK4. Carers 2000

Definition The definition of care in the report is based on respondents' answers. Carers are defined as people who were looking after, or providing some regular service for a sick, disabled or elderly person living in their own or another household. All types of caring tasks for any number of hours were included.

Certain types of caring have been excluded: volunteer for a charity or other organisation; those caring for someone receiving care in an institution; those providing financial support only; and those caring for someone with a temporary illness or disability (as defined by the respondent).

Source Office for National Statistics – Social Service Division

Years 2000, five-yearly intervals since 1985.

Population Private households (Great Britain)

Methodology The survey on the extent and nature of care giving is a part of the General Household Survey (GHS). Fieldwork for the GHS is conducted on a financial year basis, with interviewing taking place continuously throughout the year. The results are based on a nationally representative sample of adults living in private households in Great Britain. A sample of 13,248 addresses is selected each year from the Postcode Address File.

In 2000/01, this produced a sample of 12393 eligible addresses. Interviews were achieved at 8221 households, representing a response rate of 67%. Since the 1994 survey, interviews have been conducted using computer-assisted personal interviewing (CAPI) on laptop computers, with the addition from 2000 of telephone

interviews (CATI) with those people for whom proxy data had been collected. The software is BLAISE.

Publication **"**Carers 2000", National Statistics, London: The Stationery Office.

Comments -

Tables 21, 26.

UK5. Family resources survey

Definition Persons receiving care
An individual is recorded as receiving care if they receive care from another person in the household and/or from someone outside the household. They are counted only once no matter how many people provide care to them.

Informal care
Giving and receiving help on an informal basis, that is, not as part of a paid job.

Source Department for Work and Pensions

Years Periodic survey. Last: 2000/2001

Population Private households in Great Britain.

Methodology The survey uses a stratified clustered probability sample drawn from the Royal Mail's small users Post Code Address File. The sample covered about 24.000 households and included 55.801 individuals. The overall response rate was 65%.

The survey took place between April 2000 and March 2001. Respondents are asked if anyone in the household provides care to any one in the household and/or to anyone living outside the household. Questions are then asked about who is receiving the help or being looked after. There are then follow-up questions for each person named about that provides the help and the frequency. The follow up questions are only asked for those receiving help at least once a week.

The publication reports household members receiving care by frequency of help. The publication reports the prevalence of long-standing illness.

Publication "Family Resources Survey: Great Britain 2000-2001", edited by N. Butt et al., National Statistics, Department for Work and Pensions.

Comments The authors note that what should be counted as care is not prescriptively defined.
Carers are counted only once, even if they look after more than one individual.
Modelling Social Security benefit entitlement is central to the survey, notably for policy evaluation and costing of policy options.

Tables 18, 22.

OECD

OECD1: Elderly people in institutions

Definition Population aged 65+ in institutions.
Includes formal long-term care institutions.

Source Organisation for Economic Co-operation and Development (OECD).

Years Different years according to country. In general, mid 90s.

Population Population aged 65+ in residential care.

Methodology Estimations done by the OECD using different sources, including a questionnaire to the member Countries. The author notes that data includes formal long term care institutions as the increased diversity in lodging makes it difficult to isolate nursing homes. "Estimates may vary according to the concept chosen for institutions (sheltered housing, hotels for the elderly, medical homes). Normally, the concept described should include only staffed homes". For Denmark the concept of older persons refers mostly to over 67. In the Netherlands, some of the residential accommodation is provided within hospitals.

Publication "Ageing and care for frail elderly persons: An overview of international perspective", S. Jacobzone, Labour Market and Social Policy – Occasional papers N° 38, OECD, 1999.

Comments The author notes that the data needs to be interpreted with caution. "Between residences which are almost like hotels, with medical care available only in case of emergency, and nursing homes offering the full range of medical care, there are establishments offering varying degrees of medical care". "The types of accommodation arrangements are extremely diverse. Mostly public in the Nordic countries, they are mixed in continental Europe".

Tables -

OECD2: Elderly people receiving formal help at home

Definition Population aged 65 and over receiving formal help at home, including district nursing, and help with Activities of Daily Living.

Home care should include all home care services, including district nurses services, excluding medical visits.

Source Organisation for Economic Co-operation and Development (OECD).

Years Different years according to country. In general, mid 90s.

Population Population aged 65+ living at home.

Methodology Estimations done by the OECD using different sources, including a questionnaire to the Member countries.

Publication "Ageing and care for frail elderly persons: An overview of international perspective", S. Jacobzone, Labour Market and Social Policy – Occasional papers N° 38, OECD, 1999.

Comments The author notes that existing estimates for long term care in OECD Health Data are somewhat lower but do exclude a considerable share of long-term care programmes.

Tables 27.

OECD3. Elderly people receiving home help

Definition Persons aged 65 and over remaining outside the institutions and receiving home help. Home help might include notably day care, respite care, visiting nurses and home helps.

Source Organisation for Economic Co-operation and Development (OECD).

Years Different years according to country. In general, beginning 90s.

Population Population aged 65+ living at home.

Methodology Estimations done by the OECD using different sources, including a questionnaire to the Member countries.

Denmark refers to persons aged 67+ receiving home help.
Spain includes public, private non-profit and private home care services.
Netherlands refers to administrative statistics.

Publication "Social protection for dependent elderly people: Perspective from a review of OECD countries", Labour Market and Social Policy Occasional Paper, N° 16, OECD, 1995.

Comments The publication does not provide further information on the questionnaire and the replies of the different countries.

Tables 27.

OTHER SOURCES

O1. Caring for people

Definition Home help

France:	Housework. Home nurses provide personal care.
Germany	Personal care and domiciliary care.
Netherlands	Housekeeping and personal care. Includes specialised care and domestic care.

Source Different sources according to country and type of information.

Years Different years.

Population -

Methodology Administrative data, surveys and personal communications to authors.
Home help for France is an estimation done by Lebeaupin. Administrative statistics are used for Germany and for the Netherlands.

Publication "Caring for Children and Older People: A comparison of European Policies and Practices", Rostgaard, T. and Fridberg, T., Social Security in Europe 6, The Danish National Institute of Social Research 98:20, Copenhagen, 1998.

Comments The authors present data concerning institutional accommodation for people aged 65 and over. Denmark: 4,5%; England: 5%; Finland: 3%; France: 4,5%; Germany: 5%, Netherlands: 9% and Sweden: 5%.

We do not report data on 'sheltered housing' as they might not concern significant numbers of dependent people. Sheltered accommodation aim to promote independent living for older people who are mainly able to perform basic tasks, but who may still need some regular help or security, e.g. by being linked to an alarm system.

Tables 27.

Summary of main sources

Country	Survey	Source	Year	Sample	Ref.
Belgium	Health Interview Survey	Institut Scientifique de la Santé Publique	2001	All 12.111 persons	B1
Denmark	Health and Morbidity Survey	National Institute of Public Health	2000	All 22.486 adults	DK1
Germany	Administrative data	Statistisches Bundesamt	1999	Beneficiaries of care insurance	D1
	Help and care dependency survey	Idem	1991/92	Private households 60.938 persons	D2
	Microcensus	Idem	1999	All 820.000 persons	D3
Greece	-	-	-	-	-
Spain	Survey on Impairments, Disabilities and Handicaps	Instituto Nacional de Estadistica	1999	Private households 220.000 persons	E1
France	Survey on Handicaps-Disabilities-Dependencies	Institut national de la statistique et des études économiques	1999/01	All 20.000 and 16.000 in Institutions	F1
	Survey on Health and Medical Care	Idem	1991	Private households	F2
	Household Living Conditions Panel survey	Idem	1996	Private households 14.845 persons	F4
Ireland	Functional ability of older people	Health and Social Services for Older people in Ireland	2000	Private households 837 persons 65+	IRL1
	Survey of Long-stay units	Department of Health and Children	1998	Institutions	IRL2
Italy	Health conditions and access to health services	Istituto Nazionale di Statistica	1999/00	Private households 140.000 persons	I1
Luxembourg	Socio-economic panel	CEPS	1992	Private households 5.191 persons	L1
Netherlands	Permanent Survey on Life Conditions	Centraal Bureau voor de Statistiek	2000	Private households 9.877	NL1
Austria	Microcensus	Österreichisches Statistisches Zentralamt	1996	Private households 60.000 persons	A1
Portugal	National Survey on Health	Department of Health	1998/99	Private households 21.808 households	P1
	Survey on Impairments, Disabilities and Handicaps	Nat. Rehabilitation Secretariat	1995	All 142.112 persons	P2
Finland	Health survey	National Public Health Institute	2001	Private households 2.400 persons	FIN1
Sweden	Survey on living conditions	Statistics Sweden	1996/97	Private households 112.404 persons	S1
	Care to the elderly (Administrative data)	Idem	2001	All (Persons 65+) Beneficiaries / care	S2
United Kingdom	Health Survey for England	GB Department of Health	2001	Private households Except 2000: 7.988 and 2493 in instit.	UK1
	General Household Survey (GHS)	Office for National Statistics	1998	Private households 3.082 persons 65+	UK3
	Survey on carers Module of the GHS	Idem	2000	Private households 12.393 addresses	UK4
	Family Resources Survey	Department for Work and pensions	2000/01	Private households 55.801 persons	UK5

Notes

Source: It presents the main partner. Sample: The numbers refer generally to persons and not households. All: Includes persons in institutions.

ANNEX A

GLOSSARY

Activities of daily living

Activities of daily living (ADL)

They include self-care activities, such as bathing, dressing and feeding oneself. The Katz index is the most often used index.

Instrumental activities of daily living (IADL)

They include domestic activities such as cooking, shopping and house keeping.

Katz index (ADL):

This index has six items: washing (bathing), dressing, transfer (to or from a bed or chair), going to the toilet, continence and eating. For each item, we distinguish four cases. Let's take washing. A person able to wash without assistance receives a score of zero points. A person needing assistance in washing lower part of body receives one (1) point, etc. A fully self-dependent person has a total score of zero (0), etc..

- Full self-dependent person: Katz index = 0,
- Moderately care dependent: Katz index = 1 or 2,
- Highly care dependent: Katz index = 3 or 4,
- Very highly care dependent: Katz index = 5 or 6.

Lawton and Brody index (IADL):

This index includes using the telephone, shopping, food preparation, housekeeping, laundry, travel, responsibility for own medicine and ability to handle finances.

AGGIR

The French "Isoressources Group Gerontological Independence grid" (AGGIR or GIR) is designed to evaluate the workload associated with the dependency of seniors (over 60 years old) living at home and in institutions. It is based on ten discriminating elements concerning coherence, bearings, washing the top and bottom half of the body, dressing, (top, middle and bottom), eating, urinary and faecal elimination, transfers, getting around indoors and outdoors, and communicating over distances.

An 'isoressources' group is a group of people requiring a comparable volume of assistance, measured in man-hours. The groups are numbered from 1 to 6 by decreasing level of dependency.

Group 1 mainly comprises individuals who have lost their mental, bodily, motor, and social independence, and thus require a continuous presence of caregivers. On the other extreme, the individuals in group '5' need ad-hoc care (usually home help) and those in group '6' are persons who remain independent in all daily-living activities (cited above).

A multi-disciplinary team of doctors and social services professionals does the assessment. Depending on what the senior does, does not do or partially does in these ten areas, he/she is classed in one of the six isoressources groups. The team fills in an evaluation grid, which is processed by a software program that determines the respondent's isoressources group.

Care

Carer

A person who supports a dependent person. Often used to designate the non-professional, benevolent provider of care and assistance.

Community-based care

Any type of care, supervision and rehabilitation outside the hospital by health and social workers based in the community (Atlas, 2001). Community care is associated with provision of services and care at home rather than in an institution.

Institutional care

Care in institutional settings (notably, rest and nursing homes), also called residential care. Currently, priority is given in a certain number of countries (e.g. Nordic countries) to favour the return to the community / 'disinstitutionalisation'.

Colvez classification

This classification distinguishes four levels[11]:

Level 1: Bedridden and chairridden
Level 2: Not bed or chairriden but helped to wash and dress
Level 3: Neither bed/chairriden nor helped to wash and dress but helped to get out of the house
Level 4: Independent.

Three additional categories (bearings in time and space, behaviour, and help with bearings and behaviour) are used to refine this classification by dividing each of the first four categories into two sub-categories according to level of psychological dependency.

In order to take into account care received by slightly dependent individuals, the adjusted Colvez classification adds a new level (4): the individual is assisted in activities of daily living (shopping, housework, etc.).

Disability adjusted life years (DALYs)

Quality adjusted life years (QALYs) is a summary measure of health gain that combines life expectancy and quality of life. A year in full health is assigned a weight of one and a state that is considered equivalent to death is assigned a value of zero. Health states that lie between these two limits will be given a weight that lies between zero and one. For example, a given status of health (e.g. living with a chronic disease) may be assigned a weight of 0,75. Living for 20 years with a chronic disease would then be considered equivalent to 15 QALYs (20x0,75=15). A policy preventing chronic disease would lead to a health gain of five QALYs (A. Shiell et al., 2002). Disability is one candidate health state and the measure is called DALY.

Disability free life expectancy (DFLE)

Number of years of projected life expectancy that will be spent free of disability. Disability free life expectancy is important because it indicates not only the increase in the number of years but also the quality of life during these additional years.

International Classification of Diseases (Tenth Revision)

ICD-10 is a classification of health conditions (diseases, disorders, injuries, etc.). Functioning and disability associated with health conditions are classified in ICF. Consequently, ICD-10 and ICF are complementary.

[11] "Caring for the Dependent Elderly : More Informal than Formal" , P. Breuil-Genier, INSEE Studies, n° 39, September 1999.

International Classification of Functioning, Disability and Health (ICF)

ICF constitutes a revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). ICF was endorsed by the Fifty-fourth World Health Assembly for international use on 22 May 2002 (WHO, 2001). It defines components of health and some health-related components of well being (such as education and labour). It presents two basic lists:

Part 1. Functioning and Disability
  a) Body Functions and Structures, and
  b) Activities and participation
Part 2. Contextual factors
  a) Environmental factors
  b) Personal factors.

Part 1. terms replace the formerly used terms 'impairment', 'disability' and 'handicap'. ICF also lists environmental factors that interact with all other constructs.

Body functions	Body structures
Body functions are the physiological functions of body systems (including psychological functions), 1. Mental functions 2. Sensory functions and pain 3. Voice and speech functions 4. Functions of the cardiovascular, haematological, immunological and respiratory systems 5. Functions of the digestive, metabolic and endocrine systems 6. Genitourinary and reproductive functions 7. Functions of the skin and related structures	Body structures are anatomical parts of the body such as organs, limbs and their components. 1. Structures of the nervous system 2. The eye, ear and related structures 3. Structures involved in voice and speech 4. Structures of the cardiovascular, immunological and respiratory systems 5. Structures related to the genitourinary and reproductive systems 6. Structures related to movement 7. Skin and related structures

Activities and participation	Environmental factors
Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. 9. Learning and applying knowledge 10. General tasks and demands 11. Communication 12. Mobility 13. Self-care 14. Domestic life 15. Interpersonal interactions and relationships 16. Major life areas 17. Community, social and civic life	Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives 1. Products and technology 2. Natural environment and human-made changes to environment 3. Support and relationships 4. Attitudes 5. Services, systems and policies

Impairments are problems in body functions or structure such as significant deviation or loss.
Activity limitations are difficulties an individual may experience in involvement in life situations.

International Classification of Impairments, Disabilities and Handicaps (ICIDH)

ICIDH published by the World Health Organisation (WHO) distinguishes: impairment, disability and handicap (WHO, 1980).

Impairment	Disability
Any loss or abnormality of psychological, physiological or anatomical structure or functions. 1. Intellectual impairments 2. Other psychological impairments 3. Language impairments 4. Aural impairments 5. Ocular impairments 6. Visceral impairments 7. Skeletal impairments 8. Disfiguring impairments 9. Generalised, sensory, and other impairments	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner of or within the range considered normal for a human being. 1. Behaviour disabilities 2. Communication disabilities 3. Personal care disabilities 4. Locomotor disabilities 5. Body disposition disabilities 6. Dexterity disabilities 7. Situational disabilities 8. Particular skill disabilities 9. Other activity restrictions

Handicap

A disadvantage, for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for the individual.
The term handicap refers to the relation between a person with his environment. It involves a limitation of scope to participate in community life on an equal footing with others.

Kuntzmann's score

This measure is used to assess the dependency of a person.
Nine indicators describe five fields (human resources requirements, getting around, continence, psychological state and care needs). These are used to ascribe a dependency score of 0 to 10.

Prevalence

Proportion of cases of a given social/medical condition at any one time in the population studied.
Incidence is the proportion of people contracting/acceding the condition in question over a specified period of time. The first refer to a stock and the second to a flow.

ANNEX B

NOTE ON METHODOLOGY

Calculations of % by age group (65+ and 75+)

We have always used rates given in the original publications. In exceptional cases, where we have only absolute numbers (number of answers), we have estimated first the rate for each age group and then for 65+ and 75+.

For weighting purposes, we have used the population data included in the publications; otherwise we have used the average population by five-year age groups provided by Eurostat.

Estimations

*: Means that the estimation is done by the author.

Charts

In general, charts present non-rounded data.

Rounding

Excel rounds 0,5 at the upper unit.
If the original publication rounds up 1,45 to 1,5; then the introduction of 1,5 into Excel will give 2.

Sources

Sources of the data are described in record sheets (fiches). They are presented in Part B by country. The first letter identifies the country and the second the N° of the fiche.

Zero

Due to rounding up, ‘0’ means less than 0,5.