

**Services for Supporting  
Family Carers of Elderly People in Europe:  
Characteristics, Coverage and Usage**

**EUROFAMCARE**

**National Background Report  
for Denmark**



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## Summary of main findings

no information provided

## Introduction – an overview of family care

no information provided

## 1 Profile of family carers of older people

Demographic ageing and its social and economic consequences has been the subject of research in Denmark into the classic issues of ageing for at least two decades (for example, Leeson 1981a, 1981b, 1986a, 1986b, 1992, 2000a; Platz 1981; Hansen & Platz 1995; Leeson et al 1993; Leeson & LiliGREEN 1987). However, research focused solely on elucidating the role of the family as caregivers is decidedly more limited (Leeson 1989; Leeson & Hoffmann 1993; Leeson et al 1993). This makes providing profiles of – indeed any information relating to – family carers extremely difficult. The information we shall be able to present will be drawn from research studies relating more to the situation of older people and the formal services, which in some cases do touch on the situation of family carers. Chapter 7 provides data relating to older people in Denmark.

At this early stage, it should be underlined that the Danish research to be drawn upon (for example, Leeson et al (1993), Lewinter (1999) and Jensen (2002)) interestingly reveals that family carer is not a term, which family members helping older persons, use about themselves – thus the term primary caregiver is not one they would associate with themselves or the help and support they are giving to an older family member.

Familial networks are of significance as the role and importance of intergenerational relationships and the family seem to be increasing even in such a well-developed welfare state as the Danish where the role of the family in particular has otherwise been regarded as having been taken over by the public sector (Leeson 2000b).

As pointed out by Harper (2003), declining fertility and mortality levels and increasing longevity have led to the demographic ageing of all Western industrialised societies, but have not occurred as singular phenomena. Indeed, the factors, which have encouraged this demographic development in the 20<sup>th</sup> century and the factors, which are associated with demographic ageing, also influence other societal areas, while demographic ageing per se influences individual and social behaviour – nowhere more apparent than in relation to the family. Familial and social life are constantly being transformed, and familial organisation with kin groups pooling resources and functioning as a single coherent unit has changed as ideological, economic and social changes have driven control from the family unit towards the individual or towards other social institutions than the family. The kin connection to property and marriage has been destabilised by the move from family- to wage-based employment, which has encouraged individual autonomy in many of these decisions (Waite et al 2000). Recent Norwegian research does, however, imply that familial solidarity with regard to financial transfers is not decreasing, as is often claimed (Guldbrandsen and Langsether 2003). Urbanisation and technological change have almost revolutionised communication, social intercourse and en-

tertainment, dramatically undermining the role of the family in this respect. Furthermore, towards the end of the 20<sup>th</sup> century, new kin structures emerged: reconstituted or recombinant stepfamilies, ethnic minority families, single-parent families, cohabiting couples, all of which raised questions about individual roles and responsibilities within these new family structures.

In addition, societies are experiencing an *ageing of some life-transitions*, which when combined with the shift from a high-mortality / high-fertility to a low-mortality / low-fertility society have significant implications for both family structure and kinship roles (Farkas and Hogan 1995).

As populations age, the child-parent relationship moves from one of dependency to one of adult relationship. The common experience for many parents and children is moving towards one of around 60 years of joint life, with less than a third of this time spent in a traditional parent / dependent-child relationship (Riley 1983; Grundy 1999). Time spent as the daughter of a parent over 65 now exceeds the time spent as the parent of a child under 18 (Watkins et al 1987), but this should be viewed against the situation that while a high proportion of these persons aged 65 years and over previously were dependent to some degree on others, this is no longer the case. Dependence on children for help with daily living activities is now most likely to occur after age 80 (Ulhenburg 1995). The growing significance and length of old age and grandparenthood, however, places other and additional demands on the roles and relationships of adult women in particular (Zeilig and Harper 2000).

As family structures change, an older person in need of familial support may be faced with a complex of potential providers of support, whose familial ties vary considerably (Harper 2003), and in this respect the role of reconstituted or step families in caring for older adults is a central issue. There is only limited research, which elucidates these phenomena (Finch and Wallis 1994; Bornat et al 1998; Dimmock et al 2001; Haskey 1998), but the suggestion is that the complexities of the ensuing relationships do not lend themselves to any particular pattern or structure of care. The dominant care relationship of blood-related daughter for mother, found within non-reconstituted families, does, however, seem to remain central. Whilst there is a growing awareness of the possibilities of looser-knit, divorce-extended families, when it comes to 'the crunch' the availability of care will usually depend on access to close 'blood ties' (Dimmock et al 2001).

Older people and the family are often discussed in a dependency context, and there is indeed a wealth of literature on the concept of independence and the factors promoting or impeding this (Harper and Leeson 2002). The structures developed to support older people, even via the family, can be seen as operating within the concept of *structural dependency* (Townsend 1981), where it can be argued that support services for older people together with a number of other socio-economic constructs such as retirement and income maintenance defines a picture of older people based on dependency. However, the idea fo-

cuses on dependency arising from an economic disadvantage in old age and does not take into account or even allow the human factor. Baldwin et al (1993) argue that early-life structural inequalities in the economy rather than the supportive setting in later life can be the root of dependency in later life. The fact that older people adjust positively to their new situation is seen in the structural dependency context as older people's acceptance of social welfare outcomes – in other words, they accept there is no alternative.

A supportive relationship between older people and their family would most likely take place in the home setting, and it is striking how central *the home* is to the concept of independence both in policy terms but also in the statements of older people. Studies of the views of older people on the home and dependency reveal a desire to remain as independent as possible with the importance of the home as a place to express one's individuality as well as one's desire to retain control over one's own life (Means 1997). Among future cohorts of older people, the present home is seen as the most favoured accommodation in old age, even if it should become difficult to cope alone (Leeson 2000b).

Walker (1982) provides a comprehensive review of the different aspects of dependency and old age, covering life-cycle dependency, physical and mental dependency, political dependency, financial dependency, structural dependency, and the social construction of dependency in old age, and he points out that *the challenge confronting policy analysts is to examine the institutional processes which create and sustain dependency... (to) better understand and so counteract the development of dependency in old age*. Walker claims too that the growth and development of social services is based on restricted assumptions about the nature of dependency.

### 1.1 Number of carers

As appears from table 1, in Denmark, with approximately 700,000 inhabitants aged 67 years and over (67 years is the state pensionable age), 172,000 persons aged 67 years and over were in receipt of (long-term) home-help (Central Bureau of Statistics 2003), which is an increase of about 20,000 since 1992. To this can be added between 7000 and 8000 persons aged 67 years and over who receive short-term temporary home-help. The majority of these (long-term) home-help recipients live in their own homes – only 10,000 of the recipients are living in nursing homes or sheltered housing schemes. Almost 63 per cent of these 171,000 recipients of home-help are aged 80 years and over which means that 50 per cent of the Danish population aged 80 years and over are in fact receiving (long-term) home-help.

**Table 1: Recipients of (long-term) home-help according to age and number of hours per week. Thousands.**

Age	Under 2 hours	2-8 hours	8-12 hours	12-20 hours	20+ hours	Total
-67	18	8	2	1	2	31
67-79	39	15	3	3	4	64
80+	51	30	9	9	9	108
Total	108	53	14	13	15	203

Of course, the amount of home-help provided varies according to need and the number of hours increase with increasing age. Just over 50 per cent of recipients are in receipt of less than 2 hours per week, but the average number of hours received per week is 4.5 for those aged under 80 years and 6.1 for those aged 80 years and over. Almost 13,000 recipients aged over 67 years receive more than 20 hours per week. A staggering 1,080,000 hours of home help are delivered every week, of which 80 per cent was devoted to personal care with the remaining 20 per cent devoted to practical help in the home (cleaning, shopping and laundry). Of these 1.08 million hours of home-help per week, 60 per cent are delivered to persons aged 80 years and over (see table 2).

**Table 2: Number of (long-term) home-help hours per week, according to task and age of recipient, March 2003. Thousands.**

Age	Personal help and care	Practical tasks	Total
-67	106	32	138
67-79	225	63	288
80 and over	537	117	654
Total	868	212	1080

All of these figures include home-help provided (under recent legislation offering recipients a choice of provider) by private providers – in 54 local authorities (out of Denmark's almost 280) there were 153 private providers. In March 2003, 7200 persons chose private provision and of these 5900 received only practical help, 500 received only personal help and care, while 800 received both practical and personal help.

In March 2002, the equivalent of just over 45,000 persons full-time employees were working in home-help services in Denmark (including social-health workers), an increase of 6.3 per cent on the year before.

In a study elucidating the situation of older people aged 60 years and over in rural and urban areas in Denmark, Leeson (1999) reveals that while 15 per cent receive home-help services, 12 per cent of this group actually buy in private help services in the home (and receive no home-help) while an additional

3 per cent receive both public home-help services **and** buy in private services. In this same study, 4 per cent of the respondents are in receipt of meals on wheels.

More information on health and social care services for older people in general are provided in chapter 4.

The role of the family in counteracting much of the institutionalised dependency and in supplementing support services seems central even in the Danish context.

Having an extensive and supportive familial and social network can be crucial for an older person's ability to and opportunity for being able to cope from day-to-day in situations where challenges of old age can develop into problems of old age. Such networks comprise both informal (family, friends, neighbours, etc.) and formal (public sector support, such as home help) components. The importance of these networks can increase with increasing age, as it (may) gradually become increasingly difficult to cope without help. The network - and the individual's experience of the network - is therefore likely to be linked to an older person's quality of life.

In the welfare state of Denmark, public authorities play a significant supportive role as is evident from the home-help figures presented above (and supported additionally by the information in chapter 4) and as a consequence the family's contribution to providing care for older people is regarded as negligible (Leeson et al, 1993). However, it does seem increasingly that familial involvement in practical, social and emotional dimensions of caregiving in relation to older people is substantial (Lewinter 1999), although hard empirical evidence is scant.

However, despite public sector support and despite earlier assumptions (Leeson et al, 1993), the family does indeed still play a significant role and the importance of the family would seem to be increasing (Leeson 2001).

More than two (familial) generations under the same roof is certainly not a common occurrence in contemporary Denmark, although a substantial proportion of Danes do live in four-generation families (Leeson, 1988). Almost no one aged over 40 years lives with their parents (Leeson 2001) - a modest ½ % of generations aged 40-44 and 50-54 years in the late 1990s, for example.

Modern family patterns mean that children are not just children. Children may be children of current relationships, children from previous relationships and spouse's / partner's children from previous relationships. It seems reasonable to assume as a point of departure that all these children are part of a person's familial network in some way, and recent research reveals that the dissolution of existing partnerships and the formation of new partnerships do increase the potential number of children in the familial network (Leeson 2001).

Clearly, the older generations do have a larger number of children in the familial network than the younger generations - a result of the significant drop in fertility in the years after the Second World War and up to 1983, which cannot be counteracted by the modern family pattern with divorce, the formation of new partnerships and possibly the birth of more children.

If *children from current relationship* are considered, then there is a larger proportion of the generation in their 40s in childless relationships – 18 per cent of those in their 70s are childless compared with 32 per cent of those in their 40s (Leeson 2000). In addition to this generation-specific childlessness, 43 per cent of those in their 70s have at least three children from their current relationship, compared with just 13 per cent of those in their 40s.

As pointed out, studies and therefore statistics which could provide empirical evidence of the numbers of family carers and their characteristics is limited, coming completely from studies relating to the situation of older people rather than having family carers as their point of departure. In the following, therefore, we shall draw on survey data relating to older people, which contain information on carers.

In a study elucidating the situation of older people aged 60 years and over in rural and urban areas in Denmark, Leeson (1999) reveals that less than 1 per cent of the 1050 persons interviewed received help from family members or other members of social networks (friends, neighbours, volunteers) with personal care (bathing, dressing etc) (table 3).

**Table 3: Percentage of persons aged 60 years and over in receipt of various forms of help from their social network (family excl. spouse, friends, neighbours and volunteers), according to rural-urban situation.**

Type of help	Rural	Urban	Large Town	Total
Personal care	< 1	< 1	< 1	< 1
Cooking, cleaning and laundry	2	5	6	4
House repairs, gardening	21	18	23	21
Shopping	2	5	7	5
Financial support	< 1	< 1	1	< 1

Source: Leeson (1999)

As appears from table 3, if older people are in receipt of any help from this network, then it takes the form of help with the home and garden (21 per cent). Of those receiving this form of help, 63 per cent receive the help from children, 12 per cent from other family members (excl. spouse), 13 per cent from friends and 27 per cent from neighbours. If the forms of help are grouped, approximately 40 per cent of older females receive help from this network compared with approximately 17 per cent of males; approximately 25 per cent of those aged under 70 years receive help compared with 36 per cent of those aged 75

years and over; and while 16 per cent of older people not living alone receive help from this network, this compares with 40 per cent of older people living on their own. In absolute figures, these percentages translate into approximately 320,000 older people receiving help from family, friends, neighbours or volunteers.

## 1.2 Age of carers

The lack of studies focusing on family carers makes it difficult to give information on the age distribution of carers, but in this section, we shall present secondary information which at least may give an indication of the age of the carer in relation to the older person receiving help / care.

Lewinter (1999) has investigated the care situation of older people aged 75 years and over in receipt of home help in two regions of Denmark, giving also a rural-urban mix. In the rural area, interviews with 24 informal caregivers were obtained, and in the urban area 19 interviews were obtained. There is of course in this material no pretence of statistical robustness or representivity, but the data do give one of the few indications of the carer composition.

The composition of these carer interview samples is shown in table 4.

**Table 4: Characteristics of primary (family) caregiver in rural and urban areas of Denmark. Percentage.**

	Rural	Urban
<b>Relationship</b>		
Daughter	58	53
Son	17	11
Spouse	13	20
Grandchild	0	5
Other	12	11
<b>Gender</b>		
Male	22	21
Female	78	79
<b>Occupation</b>		
Male		
Pensioner	33	50
Unemployed	0	25
Employed	67	25
Female		
Pensioner	24	27
Unemployed	19	0
Employed	57	73

Source: Lewinter (1999)

As it appears, bearing in mind the small numbers involved and that these older people are in receipt of home-help, there are only moderate differences between rural and urban older people with regard to the characteristics of their caregivers. The daughter (including one daughter-in-law) is the primary caregiver in 53-58 per cent of cases, and it is thus hardly surprising that almost 80 per cent of caregivers are female.

In Leeson (2001), data relating specifically to help received by the generation of 70-74-year olds in Denmark reveals that at most 55 per cent receive help with certain tasks and that the primary providers of this help are spouses and children (table 5).

**Table 5: Percentage of 70-74-year olds receiving help with specific tasks according to primary provider.**

Task	Receive	Primary Provider			
		Spouse	Children	Public	Private
Cleaning	55	66	3	25	8
Repairs	43	23	50	0	11
Gardening	25	43	15	3	26
Transport	23	15	40	0	3
Shopping	17	90	0	0	0

Source: Leeson (2001)

The composition of family carers as illustrated in tables 4 and 5 indicates that the large proportion are daughters (53-58 per cent), and given the age of the older people in the studies (over 70 years), it is likely that the age of the carers is 50 years and over. Indeed, some of the qualitative evidence presented in Lewinter (1999) talks of a daughter aged 63 years as a caregiver for her parents, but otherwise, the age of such caregivers is conspicuously lacking in this work. Spouses account for 13-20 per cent of the carers, and again in view of the sample of older people in question, the age of these spouses is likely to be 70 years and over.

## 1.3 Gender of carers

See section 1.2 tables.

As reported by Lewinter (1999), the family members interviewed about family help are predominantly and overwhelmingly female, and even in the limited number of instances where a couple were helping (son / daughter-in-law or daughter / son-in-law) the tasks were clearly distributed among them according to gender (females doing washing, cleaning, shopping; males doing repairs, gardening and paperwork). Lewinter also points out (as was highlighted by Leeson et al (1993)) that these family caregivers are working women (table 1.4) and that those not working at the time of her study were pensioners them-

selves. Jensen (2002) finds in her qualitative study that spouses and children are the main providers of help and support.

It appears from table 4 that 78-79 per cent of family carers in Lewinter's study are females. The few cases in which the son was the main caregiver seem to be when there is no daughter / daughter-in-law or when these lived at some distance from the parent.

Clearly, the roles of females as family caregivers are determined to a great extent by the fact that female labour force participation rates in Denmark are some of the highest in the world. In addition, most have families of their own and many are grandparents, fitting nicely into the conceptual idea of *women in the middle* (Brody 1990) but with the added dimension of being actively employed in the workplace.

#### 1.4 Income of carers

As pointed out in the preceding sections (table 4 in particular), the majority of caregivers in Denmark appear to be employed, and if not they are pensioners themselves. The structure of the welfare state and in particular the public support services for older people in Denmark are built up around a familial network within which the adult family members are economically active in the formal labour market, and family caregiving activities therefore are in accordance with this – the simple fact that family carers are also workers.

There is no data available (or at least found, incl. contact with the Central Bureau of Statistics) on the income levels of carers, but because of the above-mentioned structure of care in the country, the most appropriate proxy is doubtless the income statistics for the population in general. National statistics (Central Bureau of Statistics 2003) reveal the gender bias in income levels – the average annual income for males in Denmark in 2002 was 267,000 DKK compared with 194,000 DKK for females. Of those with an annual average income of under 200,000 DKK, almost 60 per cent are females, and of those with an income of more than only 16 per cent are females.

In table 6 and 7, we present data on household income and household assets respectively for generations aged 45-49 years to 75-79 years, who will primarily comprise the caregiver generations.

**Table 6: Household income according to generation, 2002. DKK. Percentage.**

Income	75-79	65-69	55-59	45-49
Less than 100,000 DKK	12	5	1	1
100,000-200,000 DKK	48	31	11	5
200,000-300,000 DKK	22	32	13	11
300,000-400,000 DKK	5	12	12	14
400,000-500,000 DKK	2	6	21	16
More than 500,000 DKK	2	9	35	49

Source: Leeson (2004)

**Table 7: Household assets according to generation, 2002. DKK. Percentage.**

Assets	75-79	65-69	55-59	45-49
None	20	14	14	22
Less than 50,000 DKK	9	4	5	7
50,000-250,000 DKK	11	11	9	15
250,000-500,000 DKK	13	10	12	17
500,000-1,000,000 DKK	14	20	21	16
More than 1,000,000 DKK	33	40	37	23

Source: Leeson (2004)

The data show that household income in particular is age-dependent with 82 per cent of the oldest generation having a household income of less than 300,000 DKK compared with just 17 per cent of the youngest generation. The distribution according to household assets on the other hand seems to be less age-sensitive with between 23 and 40 per cent having assets in excess of 1 million DKK, and between 14 and 22 per cent having no assets.

#### 1.5 Hours of caring and caring tasks, caring for more than one person

Clearly with the Danish welfare structure and the provision of extensive public domiciliary services as outlined above, family caring is less likely than in some other countries to be a full-time job. This does not, however, mean that family carers do not feel the strain of caring and working at the same time.

Lewinter (1999) highlights two different patterns of family caregiving:

- *frequent, informal, short contacts* from family members living a short distance from the older person;
- *regular arranged visits* from family members with work commitments and / or living some distance away.

Family members do not regard themselves as caregivers to a large extent, as already mentioned above – they see themselves rather as having a social supportive role in relation to their older family members (parents) and practical tasks which they may help with are seen as a natural part of this supportive rather than caring role.

Visiting, keeping an eye on them and organizing events (birthdays, trips out and the like) are the main social supportive roles. Many tasks are not the responsibility of one person alone, and many of them are carried out in conjunction with things the carer is doing anyway for himself / herself. It is also difficult to distinguish between tasks that would be done anyway and tasks that relate to frailty and are therefore clearly supportive.

Tables 3 and 5 provide some information on the type of tasks carried out (and by whom) (Leeson 1999 and 2001), and Lewinter (1999) points out the division of labour between the family carer and the home-help: basic cleaning and personal care are the responsibility of the home-help while other tasks are shared according to the individual situation. Perhaps the most important role of the family is helping the older family members to remain socially active and included (take part in family events). This is also very clear from the limited qualitative data of Lewinter, which support those of Leeson (1999 and 2001) shown in tables 3 and 5. Of the older people interviewed by Lewinter, none receives personal care from family / informal carers – in fact, the overwhelming majority cope with this themselves (alone or as couples). The family / informal network helps with shopping, transport, laundry, and some cleaning.

### 1.6 Level of education and / or profession / employment of family carer

As already outlined, active employment of family carers is the norm in Denmark where labour force participation rates are high for both males and females until (early) retirement age. Table 4 reveals that female caregivers (the main caregiver) are likely to be employed or unemployed (73-76 per cent) – in other words they are not housewives. Table 8 presents labour force participation rates for males and females according to age and gender in 2002 for those aged 40 years and over (main age range for family caregivers).

**Table 8: Labour force participation rates in Denmark according to age and gender, 2002. Percentages.**

Age	Males	Females
40-44 years	89.7	87.2
45-49 years	88.7	85.9
50-54 years	88.0	83.2
55-59 years	84.0	72.3
60-64 years	45.3	25.5
65-66 years	21.5	9.2
All ages 16-66 years	81.2	74.3

As is clear from the labour force participation figures in table 8, there is not a substantial reserve army of carers outside the labour force with both male and female participation rates between 70 and 80 per cent prior to age 60 years after which early retirement is available (and popular). The state pension age is still 67 years (but will decline to 65 years). So that when eldercare (potential) responsibilities arise, the children-generation is likely to be considering (early) retirement anyway, and the possibility or reality of eldercare tasks will hardly influence this decision to leave the workplace.

Leeson (2004) reveals that the active generations aged 45-59 years still expect to leave the labour force as early as possible and expect to spend their hard-earned leisure time spending more time with their family. There is, however, an expectation to spend time helping parents (in-law) in the future (table 9).

**Table 9: Proportions expecting to spend time helping parents (in-law) in the future according to generation, 1997.**

	60-64	50-54	40-44
Yes	44	43	56
Maybe	8	20	22
No	49	31	17

Source: Leeson (2001)

Between 17 and 49 per cent of these (carer) generations **do not** expect to spend time helping their parents (in-law) in the future, and among these the main reasons given are that this is a task for the public authorities (between 10 per cent of the youngest generation to 39 per cent of the oldest), and that they are not expected to need the help of these children (in-law) (between 16 and 44 per cent).

Unemployment in the 40-66 years age group is low thereby eliminating the potential for a pool of carers among the unemployed. In the 40-49 year age group, unemployment rates are 6.5 and 6.8 per cent for males and females

respectively, and in the 50-66 year age group, they are 7.7 and 8.5 per cent for males and females respectively.

Denmark prides itself as a land with high levels of general education in the population, something which is borne out by the data in table 1.10. No data have been found relating to the educational levels of carers.

The education level data in table 1.10 exhibit an almost traditional generation-gender pattern with larger proportions of the older generations having only basic schooling (41 per cent of 65-69 year old males compared with 25 per cent of 40-44 year old males and 58 per cent of 65-69 year old females). Larger proportions of females at all tabulated ages have only basic schooling, but it is interesting to note that among females aged under 55 years, the proportions having medium-term higher education are approximately twice those of their male counterparts, while slightly larger proportions of males have long-term higher education (8 compared with 5 per cent).

The gender-specific differences observed in table 10 are more likely in Denmark to be attributable to childbearing and childcare rather than eldercare.

**Table 10: Highest level of education attained according to age and gender, 2002. Percentages.**

<b>Males</b>	<b>40-44</b>	<b>45-49</b>	<b>50-54</b>	<b>55-59</b>	<b>60-64</b>	<b>65-69</b>
Basic Schooling (8-10 years)	25	26	26	29	36	41
General Upper Secondary School	4	4	3	2	1	< 1
Vocational Upper Secondary School	1	1	1	< 1	< 1	< 1
Vocational Education & Training	42	44	46	42	39	38
Short-term Higher Education	5	5	5	4	3	2
Medium-term Higher Education	10	11	12	11	10	8
Long-term Higher Education	8	8	8	7	5	5

<b>Females</b>	<b>40-44</b>	<b>45-49</b>	<b>50-54</b>	<b>55-59</b>	<b>60-64</b>	<b>65-69</b>
Basic Schooling (8-10 years)	27	34	32	39	50	58
General Upper Secondary School	4	3	2	2	1	1
Vocational Upper Secondary School	1	< 1	< 1	< 1	< 1	< 1
Vocational Education & Training	34	30	39	35	30	26
Short-term Higher Education	5	5	4	3	3	2
Medium-term Higher Education	20	22	19	13	10	9
Long-term Higher Education	5	5	4	3	2	1

### 1.7 Generation of carer, relationship of carer to older person

Once again, hard evidence relating to these points is difficult to obtain and we are therefore forced to employ secondary indicative evidence. We have already seen in table 4 that the limited material from Lewinter (1999) indicates that the primary family caregiver is the daughter (in-law) – 53-58 per cent with 13-20 per cent identifying their spouse as the primary family caregiver. Only 5 per cent (in rural areas) identify a grandchild as the primary family caregiver.

In other words, despite the fact that increasing life expectancies (see chapter 7) mean that families of three generations are the norm and with an increasing

proportion of four generation families (Leeson et al 1988), the caregiving association is between parent-child or spouse-spouse generations. Only seldom is a one-removed generation (grandchildren) responsible as the primary family caregiver. This is also supported by the evidence from Leeson (2001) presented in table 5 above.

It is clear that the primary family caregivers – being spouses or daughters – are themselves either in old age or approaching old age. The children-generation carers are likely to be grandmothers themselves (Leeson 1988) and therefore in a double or even triple caring situation (parent – grandchild – own spouse), and intersecting these caring relationships is the likelihood of caring for the parent(s) of one's spouse too, as discussed above.

Interlinked with these close familial and generational caring associations are the reasons for caregiving and the related pressure felt by the caregiver. The reasons given by Danish family caregivers are that it is the obvious and natural action to take, albeit in a modified fashion – a feeling of reciprocity and fondness. The closeness of the relationship and the genuine feeling of reciprocity and fondness do, however, give rise to concern, strain and even burden. Concern about the older person's health. Strain arising from working and caring and having a life of one's own. Burden of the tense relationship rather than the actual caregiving.

### 1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc)

The proportion of older people living with their children in Denmark is negligible. The Danish Longitudinal Future Study (Leeson 2001) reveals that less than 5 per cent of those aged 60-75 years live with children (children of current or previous relationships), so the proportion of family carers living with older people is likely to be extremely low too. It should also be pointed out in this respect that an estimated 12 per cent of older people aged over 60 years have no surviving children (Leeson 1999), while 14 per cent have 4 or more surviving children as appears from the figures in table 11.

**Table 11: Distribution of people aged 60 years and over according to number of surviving children and children living in the locality, 1999. Percentage.**

	Persons	In locality
No children	12	56
1 child	16	27
2 children	35	11
3 children	23	4
4 or more children	14	2

Source: Leeson (1999)

The majority of persons have 2-3 surviving children (58 per cent), and the average number of surviving children for people aged 60 years and over is 2.2.

This same study (Leeson 1999) also illustrates the number of children living in the locality. The locality is defined as within a radius of 10 km. from the older person's home, which would enable frequent easy visits (see table 11). More than half of the older people in this study have no children living in the locality.

**Table 12: Household size for two generations of older people, 2002. Percentage.**

Household Size	75-79 years	65-69 years
<b>One person</b>		
Male	41	13
Female	69	47
<b>Two persons</b>		
Male	59	82
Female	31	51
<b>Three or more persons</b>		
Male	1	5
Female	0	2

Source: Leeson (2004)

Of course, none of these data necessarily preclude the possibility of an older person receiving care from the family, although not having children and not having children living close by may well prove to be a logistical and practical problem. As it appears from table 12, among persons aged 65-69 years and 75-79 years, while 13 per cent of males aged 65-69 years and 41 per cent of those aged 75-79 years live in single person households, the proportions for females are 47 and 69 per cent respectively in the two age groups. In addition, at most 5 per cent (of males aged 65-69 years) live in 3 person households. Almost 70 per cent of females aged 75-79 years live alone, which corresponds to the marital status figures given in chapter 7.

### 1.9 Working and caring

It is by now clear from the data presented that

- family caregiving is of a different kind and size from what may be experienced in countries with less well-developed public support services for older people living in their own homes;
- family carers (who do not regard themselves as carers per se) are either spouses or working daughters (in-law) – there is no reserve of economically inactive females;

- public services are the main provider of care and support for older people living in their own homes.

In other words, working and caring are a natural partnership in Denmark, but the caring aspect of the partnership is one mainly of support with practical tasks in and around the home, enabling the older person in question to maintain an optimum degree of independence while receiving support from public services. While it is felt that the family does and should have a caring role in relation to older family members, it is equally felt that they should not have sole responsibility for providing for the practical needs – the family's role is seen primarily as social one while feeling secure that practical needs are being met by public services. This is reflected in the only organisation in Denmark, which is specifically established for family members of frail older people. Their main aim is to work for the establishment of a formal co-operative body whereby relatives and professional care staff can work together. Their aim is not primarily to secure improvements for (working) carers but to improve the quality of life of their old frail relatives. (See [www.pgruppen.dk](http://www.pgruppen.dk) - website for Paarerendegruppen for svage aeldre (Relatives of Frail Older People) in Danish).

However, having stated this, there is still the question of *strain* on family carers in Denmark, as pointed out in the work of Lewinter (1999), relating to combining employment and caring or to caring while suffering from ill-health one's self.

Employers are aware of this strain (Leeson & Hoffmann 1993) and exhibit a degree of flexibility in attempting to enable a working carer to manage both tasks (including managing their own family) without formal arrangements – the Danish way is to attempt to tackle situations individually as they arise. However, in contrast to childcare, eldercare does not have the same political awareness and attention.

### 1.10 General employment rates by age

As illustrated in table 8 (repeated below), labour force participation rates in Denmark are relatively high for both males and females at ages over 40 years. The majority of males aged between 30 and 66 years are working full time (37 hours or more per week), while much larger proportions of females in this age group are working part time (thereby potentially freeing up time for caregiving activities), as appears from table 13.

**Table 13: Labour force participation rates in Denmark according to age and gender, 2002. Percentages.**

Age	Males	Females
40-44 years	89.7	87.2
45-49 years	88.7	85.9
50-54 years	88.0	83.2
55-59 years	84.0	72.3
60-64 years	45.3	25.5
65-66 years	21.5	9.2
All ages 16-66 years	81.2	74.3

**Table 14: Distribution of labour force aged 30-66 years according to hours worked per week, 2003.**

Gender / Age group	Less than 15	15-36	37 or more
Males			
30-54 years	1	7	92
55-66 years	4	11	85
Females			
30-54 years	2	38	60
55-66 years	6	45	49

Interestingly, over three times as many males as females are still economically active after pensionable age (67 years) – 40,000 compared with 13,000 respectively, and at all ages over 40 years there are numerically more males than females economically active.

**Table 15: Employment rates in Denmark by occupational status, age and gender, 1996. Percentages.**

Occupational status	40-44	45-49	50-54	55-59	60-66	67+
<b>Males</b>						
Self-employed	11	13	16	18	33	61
Assisting spouses	< 1	< 1	< 1	< 1	< 1	< 1
Salaried employees	45	46	46	44	42	22
Skilled workers	20	19	17	15	9	3
Unskilled workers	20	18	18	20	14	9
Unspecified	4	4	3	3	2	3
<b>Females</b>						
Self-employed	4	5	6	6	12	31
Assisting spouses	1	2	4	5	10	9
Salaried employees	69	66	60	54	45	25
Skilled workers	1	1	1	1	1	< 1
Unskilled workers	20	22	23	26	19	8
Unspecified	5	4	6	8	3	27

In terms of occupational status, the data for 1996 (latest available) in table 14 show that in the age range 40 to 59 years males in the different age groups have similar distributions according to occupational status with approximately 45 per cent employed as salaried employees and 15-20 per cent as both skilled or unskilled workers. Between 11 and 18 per cent of males (increasing with increasing age) are self-employed. After age 60 years – at which point early retirement comes into effect – and age 67 years (pension age), it is seen that of those still in active employment the proportion in self-employment increases dramatically to 33 and then to 61 per cent after age 67 years. The occupational status distribution for females at the different tabulated ages is similar to that of males but at a different level – the proportion of salaried employees at each age up to age 60 years is significantly higher – from 54 to 69 per cent, highest at the youngest age tabulated. The proportion of skilled workers in each age group is far lower at just 1 per cent, as is the proportion of self-employed persons (between 4 and 6 per cent up to age 60 years). Again, the proportion self-employed among those still working after age 60 years increases to 12 per cent and then increases even more dramatically to 31 per cent among those aged 67 years and over.

### 1.11 Positive and negative aspects of care giving

Clearly then from the statistical profile which we have attempted to present in the above sections based on the relatively sparse data available on family carers in Denmark, the time spent caring for older relatives is spent rather more in a supportive rather than a caring role, and this time is limited and in most

cases has to fit into the schedules and routines of the family carer. Public services take the brunt of the caring responsibility for older people in their own homes (not to mention the care in institutional settings). However, as already pointed out, this relatively favourable situation for family carers in Denmark does not preclude them from feeling strain and concern in relation to their support of older family members. The family has a social role in relation to the frail older person and the practical tasks they inevitably perform for the older person fit into the framework of this role.

The work of Lewinter (1999) though limited in its empirical scope does highlight some of the positive and negative aspects of caring. The persons involved in these activities do not recognize themselves as caregivers and as such surely do not feel a burden of caring in the strict sense of the word. Exceptions are noted in Lewinter – especially in relation to ageing and ailing spouses who are providing substantial care and support and actually do regard themselves as carers while at the same time being concerned about their own health and well-being as well. In addition, those with substantial care tasks worry about what would happen if they could no longer care for the older person in question. Other concerns relate to ensuring (even controlling) that the work of the home-help was up to scratch.

Where sons / daughters were the primary family caregiver, they had in most cases positive relations with other siblings. Many carers express relief when public services take away some of the burden and strain and worry they feel – for example, handicap transport can relieve the carer of expensive and time-consuming visits.

The emotional aspects of caring are apparent, particularly with regard to *paying back* the care and support given by the older person to children earlier, and with regard to making caring a little easier – reciprocity and fondness seem to be the key words (Lewinter 1999).

The nature rather the practical content of the caring relationship determine the burden of the relationship. Even in situations where carers are performing lots of practical tasks and providing lots of social support, statements like “I love my mother...” and “She is such a nice person” are not uncommon (Lewinter 1999). Indeed, Eliasson (1996) talks of the hand, head and heart of caregiving, and especially the concept of heart and its interpretation is much discussed. The parent-child relationship can of course be strained by a feeling of guilt or of being manipulated, and it can then be discussed to what extent the carer in question is actually caring or simply carrying out caring tasks. Interestingly, in Lewinter’s material, none of the sons expresses feelings of guilt or bad conscience while they all expressed affection. All caregivers regardless of gender express a feeling of responsibility, which leads to reliability and commitment. In addition to this commitment though, there was a problem for family caregivers with accountability – there is no legislation in Denmark, which demands that children take care of or support their parents, and therefore there is no public

body to which one is accountable. Accountability seems to be between the family members and between the carer and his / her conscience, hence the sense of guilt expressed.

Do any of these problem areas lead to abuse of the older person being cared for by a family member? We have been unable to trace empirical evidence on this sensitive issue.

### 1.12 Profile of migrant care and domestic workers. Trends in supply and demand

Currently there are no official statistics on migrant care and domestic workers. However, as we saw in table 1.15 above, among the 70-74 year olds living in their homes, of those receiving help with cleaning tasks in the home (55 per cent) only 8 per cent pay for help; 11 per cent of those (43 per cent) receiving help with repairs pay for private help; 26 per cent of those (25 per cent) receiving help with gardening pay for private help and 3 per cent of those (23 per cent) receiving help with transportation pay for private help. In other words, the extent of private help is doubtless quite limited, and it is impossible to estimate the proportion of this private help which is being provided by migrant workers.

At the end of the 20<sup>th</sup> century, there were just less than 120,000 foreign workers in Denmark. This number had doubled since 1985.

However, there is a potential for migrant workers in this sector if we consider the statistics (Leeson 2004) and the debate about replacement migration and selective migration. Approximately 260,000 foreign citizens were resident in Denmark at the turn of the 21<sup>st</sup> century, and of these 21 per cent were from other EU Member States; 8 per cent were from EFTA countries; 20 per cent were from central and Eastern European countries and 24 per cent were from Asia.

### 1.13 Other relevant data or information

no information provided

## 2 Care policies for family carers and the older person needing care

To illustrate the policy structure in Denmark relating to carers and older people needing / receiving care, we shall briefly elucidate the relevant legislation in place.

The Danish welfare state has three primary characteristics:

- universalism,
- primarily tax-financed provision,
- single string provision.

The Danish welfare model has the following administrative and responsibility structure:

- National government develops the legislative framework for social and health policies and redistributes tax income to regional and local authorities responsible for health and social provisions respectively.
- Regional (county) authorities are responsible for health care services, which include hospitals, GPs, non-hospital based medical specialists, dentists, physiotherapists etc.
- Local (municipal) authorities are responsible for the provision of social care, including home help.

A universal state old age pension scheme was introduced in Denmark as early as 1891. Today, this old age pension is available to everyone aged 67 years and over (to be reduced to 65 years) and eligibility is based on number of years of residence rather than labour force participation. Various early retirement schemes were introduced from the end of the 1970s and the main one is now regarded as an integrated feature of the welfare provision. Today, there are approximately 700,000 recipients of the Danish state old age pension (includes Danish old age pensioners living abroad) and the annual cost of these pensions in 2001 was almost 60 billion DKK (Socialministeriet 2002).

Denmark is perhaps the single European country that has progressed furthest with deinstitutionalisation of older people with legislation in 1987 more or less putting a (formal) stop to the construction of conventional (residential) nursing homes. Instead, legislation encouraged the development of independent specialised housing for older people with care and support services being provided in the home. Table 15 illustrates the development in the number of specialised housing units for older people 1999-2003. The total number of units for older people has increased only slightly from 88,000 in 1999 to 91,000 in 2003. Approximately 48,000 of this total are linked into extensive care services. The deinstitutionalisation is seen clearly from the decline in the number of nursing home places from 31,000 in 1999 (had been 38,000 in 1994) to only

24,000 in 2003. Not clear from the table is the fact that the number of sheltered housing units has declined too – from 4640 in 1999 (had been 5257 in 1994) to 3572 in 2003. The “lost” nursing home places have been replaced by independent housing units for older people – their number has increased from 32,000 in 1999 (had been 18,000 in 1994) to almost 43,000 in 2003.

**Table 16: Number of specialised housing units for older people, 1999-2003. Thousands.**

Specialised housing units	1999	2000	2001	2002	2003
Nursing home places	31	30	28	26	24
Sheltered accommodation	5	4	4	4	4
Independent units	32	35	38	40	43
Other types of housing for older people	20	20	20	20	20
<b>Total</b>	<b>88</b>	<b>89</b>	<b>90</b>	<b>89</b>	<b>91</b>

Source: Socialministeriet and Central Bureau of Statistics

The level of care provision available to older people in the different types of housing presented in table 15 can vary and the Central Bureau of Statistics operates with three categories of levels of care provision: A (24 hour services, in most cases on site, and common facilities), B (care and support at the level of domiciliary services) and C (practical support at the level of domiciliary services). The breakdown of the housing for older people according to these levels of care and support provision is shown for 2002 in table 16.

**Table 17: Housing for older people according to level of care and support provision, 2002.**

Specialised housing units	Level A	Level B	Level C
Nursing home places	25,737	65	0
Sheltered accommodation	2,750	1,337	18
Independent units	17,665	17,436	4,530
Other types of housing for older people	1,468	3,214	15,193
<b>Total</b>	<b>47,620</b>	<b>22,052</b>	<b>19,741</b>

Source: Socialministeriet and Central Bureau of Statistics

All but 65 nursing home places out of almost 26,000 have the highest level of provision. This is true for 67 per cent of sheltered accommodation and 45 per cent of the independent units. In 2002, there were almost 5000 places designated specifically for persons suffering from dementia – this figure has been increasing steadily in recent years.

As mentioned, home care provision is the responsibility of local authorities, and as seen in table 1 above, 172,000 persons aged 67 years and over are in receipt of (long-term) home-help, with the vast majority of these living in their own homes. As of January 1<sup>st</sup> 2003, home-help recipients have more choice

with regard to the service provider (it previously having been the public services only). At the same time, more flexibility has been introduced with regard to the tasks carried out by the home-help so that the home-help and the recipient can determine which tasks are to be done (within reason and in accordance with the tasks the recipient has been screened to receive).

As of July 1<sup>st</sup> 1998, local authorities were obliged to offer every person aged 75 years and over a preventive home visit – prior to this date it had only covered persons aged 80 years and over. The visit is designed to create a sense of security and well-being, provide advice on public services, and to help older people maintain their independence and functional capacity for as long as possible. These visits have been extremely successful (Hendriksen & Vass 2003).

Both the number of persons being offered the preventive home visit and the number of persons receiving a visit have increased quite dramatically in recent years, as appears from table 17. Surprisingly, the number of persons declining the offer has also increased dramatically since 1997.

**Table 18: Preventive home visits, 1997-2001. Number of offers and number of visits. Thousands.**

	1997	1998	1999	2000	2001
Number of persons receiving offer	107	169	185	229	238
Numbers declining all offers	37	68	78	85	96
Numbers receiving one or more visits	70	101	107	144	142
Number of visits carried out	91	127	145	183	184

Source: Socialministeriet and Central Bureau of Statistics.

From 1994 to 1999, the number of full-time employed persons working in the (public) care sector for older people had remained more or less constant at approximately 92,000 but has since increased steadily and in 2002 the number employed amounted to almost 100,000 full-time employees (there are certain dissimilarities in methods of defining and calculating after 1999, so that the exact figures may not be completely comparable). From 2001 to 2002, the percentage growth in the number of full-time employees in the care sector for older people at 4.4 per cent was more than three times the growth in the number of older people aged 80 years and over in that year (1.4 per cent). Of the total number of employees, as appears from table 18, the vast majority - 85 per cent - are engaged in care functions for older people in institutional settings or in their own homes, 11 per cent in support functions (kitchen, cleaning, caretaker etc) and 4 per cent in administration.

**Table 19: Employees in the care sector for older people by employment category, full-time employees, 2001-2002.**

Employment category	2001	2002
Management and administration	3150	3705
Care	81497	84899
Nurses	9846	9765
Physiotherapists etc	2416	2700
Social and health assistants	25951	26141
Home helps, social and health workers	42423	45101
Other	861	1194
Support functions	10947	11232
<b>Total</b>	<b>95594</b>	<b>99836</b>

Source: Central Bureau of Statistics (2002)

The exact costs of public care services for older people are not immediately available as the figures compiled include recipients of home-help under age 67 years, as do nursing home costs. However, net service costs in 2002 amounted to 30.5 billion DKK.

The present Danish pensions system comprises three pillars:

- the tax-financed state pension scheme (including the supplementary pensions);
- labour market pensions;
- private voluntary pensions.

Although the last two of these pillars are becoming increasingly widespread, it is still the (obligatory) tax-financed state pension, which is the cornerstone of the Danish pensions system. State pensionable age is 67 years for both males and females, but legislation from 1999 will lower this to age 65 years as of 1 July 2004 for persons reaching age 60 years after 1 July 1999. This legislation should be viewed along with legislation, which increased the age of eligibility for early retirement to 62 years. The full state pension is available to persons, who have resided permanently in the country for 40 years between age 15 and 67 years. Pensions are reduced proportionately for persons not meeting this 40 years of residence requirement and such persons residing in the country as pensioners are then eligible for top-up support.

The state pension comprises a basic pension and a supplementary allowance (higher for single persons). In addition, old age pensioners may receive various additional allowances: personal allowance, heating allowance, housing allowance, for example. The basic pension and supplementary and housing allowances are income dependent.

The number of state pensioners resident in Denmark peaked in 1993 at almost 712,000. This figure has declined steadily to approximately 690,000 but with

the lower pensionable age of 65 years as of 1 July 2004, the number will increase rather dramatically in the next 15 years, reaching almost 1.1 million in 2020 – an annual increase of between 13,000 and 28,000.

State expenditure on the state old age pension amounted to approximately 62 billion DKK in 2003. By 2007, it is estimated that the introduction of the lower pensionable age will increase pension expenditure by 8.5 billion DKK.

## 2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people

As outlined in some detail in this report, and as reflected in the research cited, the Danish welfare model and therefore national policy framework is based on the tax-financed provision of support (and care) services for citizens of all ages *in accordance with their needs*. Thus, it is fair to say that in Denmark there is a clearly stated policy of care and support for dependent older people, but the Danish Social Service Legislation also incorporates the family in various aspects of this support, as is indicated in the following, which highlights those parts of the legislation which refer to the family and network in any way.

According to paragraph 1 part 3 of the Social Service Legislation, support in accordance with this legislation is based on *individual responsibility for one's self and one's family*.

Furthermore, in accordance with paragraph 67a of this legislation the local or regional authority is obliged to determine whether or not there are relatives (or others), who can act on behalf of the older person (in relation to representing the older person in an advocacy role).

Paragraph 71 part 60 states that the local authority shall consider an older person's situation in total when determining the type and amount of help to be provided – due attention should be paid to the person's *network* and it is assumed that *other members of the household participate in support in the home*. Part 96 of paragraph 71 points out that in certain cases it may be advisable that a relative assists in completing the application forms (and all applicants should be made aware of this possibility).

Paragraph 72 states that the local authority is obliged to provide respite help to spouses, parents or other close relatives caring for a physically or mentally disabled person.

Paragraph 103a provides for a working person wishing to care for a close family member (with significantly and permanently reduced physical or mental capacity or with a chronic illness) in the home to be employed to carry out this caring role by the local authority on condition that:

- the alternative is 24-hour care outside the home or the care need corresponds to a full-time job;

- all parties agree to this arrangement and the content of the arrangement;
- the local authority has no cause to oppose that the carer in question cares for the older person.

Paragraph 104 provides for persons wishing to care for a close relative, who wishes to die at home, to receive compensation for lost wages on condition that medical treatment is deemed hopeless and that the condition of the person in question does not require admission to hospital or nursing home. The person to be cared for at home must also agree to this arrangement.

In recent years, the family has become openly more active - as witnessed by the establishment of the National Association of Relatives of Frail Older People – but this is primarily in order to ensure that the services provided are of a high quality and that the quality of life of their older relatives is maintained.

### **2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important? Do minority groups have different ideologies?**

Recent research attempts to elucidate attitudes to whom should be responsible for providing care and support for older people in different situations – the older person and his / her partner, family, public services or others (Colmorten et al 2003). We shall present in this section some of the pertinent results from this study in order to shed light on the Danish expectations and ideology about care of older people – and herewith on expectations and ideology relating to family care. The study involves interviews with 1287 older people aged 76 years and over in eight local authorities representing sparsely and more densely populated areas of the country. In addition focus groups in each local authority have been held with relatives on the one hand and various service provision actors on the other hand (senior management from the local authorities, representatives of older people's organisations and voluntary organisations working with older people).

However, before presenting these results, it is perhaps worth repeating the trends from the work of Lewinter (1999) in which the relationships between the home-helps and the family were analysed and discussed. It was from that work that it became clear that all parties had more or less the same appraisal of the caring situation – that practical tasks were the responsibility of the home-help while the family although also engaging in practical tasks did this as a natural part of their interaction with the older family member and did not regard themselves as carers – indeed their role was more of a social supportive nature.

Colmorten et al (2003) echo these sentiments in their results. The majority of older people – 61 per cent – feel that older people should receive home-help even though they may be able to do the cleaning themselves. However, they do not issue a carte-blanc for the allocation of home-help: 68 per cent do

not feel that all older people over the age of 75 years should receive home-help irrespective of need.

Since the end of the 1980s the Danish system has uniquely provided home-help free of charge regardless of the recipient's economic situation. Despite this, older people do not regard free home-help as a natural component of the social service provision – 64 per cent feel that older people should pay for the practical help they receive from the local authority if they are in an economic position to do so.

Clearly, it is felt that the local authority is responsible for the provision of practical help. It is more difficult, however, when it is a question of social and psychological support. For example, only 20 per cent of respondents feel that public services should meet the social needs of an older person (*needing someone to talk to...*).

There is a strong dismissal of the idea that others should take on more tasks in relation to caring and supporting older people thereby relieving local authorities of the responsibility and the tasks (costs). In response to the question "*Do you feel that the family, friends, neighbours and voluntary organisations should help more so that the local authority does not need to provide so much support?*" only 17 per cent answered in the affirmative.

Thus, although it is not felt that local authorities should provide (free) care and support in every situation, it is felt equally strongly that civil society should not and cannot take on the responsibility of the local authority and provide help that would relieve the authorities of some of the tasks they perform at present.

As well as these general questions relating to local authority tasks, Colmorten et al (2003) present the older respondent focus groups and the family / actors focus groups with a number of vignettes in which older people in different situations need help.

All agree that in the case of a married couple where one of the couple needs help then the spouse should be responsible for helping with practical tasks and with personal care tasks. It is interesting to note that it is felt that male spouses should be less responsible for helping their wives than female spouses for helping their husbands.

In relation to older people without a spouse to help, then the older people and the family feel that it is the responsibility of the local authority to help with tasks in the home and to ensure that the older person gets out of the house and is socially active (interesting in view of Lewinter's findings that the family's role is one of ensuring social participation), while the family is expected to help with contacting public bodies and with financial matters. They do not feel that the family, friends or neighbours should be responsible for helping with practical tasks or with personal care.

On the other hand, the actors (local authorities and organisations) do feel that the family should be more active in helping with practical tasks to the extent that they are able and that the local authority should only intervene if and when the spouse, the family or other parts of the informal network are no longer able to help.

There is thus clearly a conflict between the expectations of the actors on the one hand and the expectations of older people and their families on the other hand.

The only practical task that older people themselves feel older people should purchase from a private provider is *window cleaning*. However, they do feel that those able to afford it should contribute to the cost of help from the local authority – a view shared by the family and the actors. The role of organisations in relation to helping older people seems to be at the level of supporting their social participation (helping them to go for walks, for example).

In terms of personal care, almost no-one in the study feels that children (or others) should be responsible.

Interestingly, there is a discrepancy between general and specific expectations. In general terms (that is, talking about other older people), older people in the study feel that the local authority should be responsible. In specific terms (that is, talking about their own expectations), there is a feeling that they will cope on their own – and seek help from family or buy in help if they unexpectedly should need help.

As far as intergenerational support and reciprocity are concerned, there is then in Denmark a clear expectation that local authorities provide help while children are not expected to and moreover do not expect to have to provide practical and personal care help. However, as pointed out by Lewinter and by the home-helps in her study, the family *does* have a role in supporting older people and especially in helping them maintain their social role (within the family).

Furthermore, the Danish social welfare model is in many ways based on the ultimately impersonal expression of intergenerational reciprocity and solidarity – it is after all financed via taxation paid predominantly by younger working generations on the understanding that they will benefit when they age from this same reciprocity and solidarity between the young and old generations – the so-called social contract between generations.

The cultural context of the family and the role of the family – especially as family structures change – is important when considering expectations with regard to family responsibility (Harper 2003). Contact with family members and the value of the family has been on the increase in Denmark over the last 15 years and the supportive role of the family in relation to older people is increasingly acknowledged (Leeson 2001). Familial expectations in relation to various forms of support and care for older people among immigrant groups in Denmark is elucidated in Leeson (1989), and from this work it appears that 38 per

cent of immigrants (Turkish, Yugoslavian, Pakistani and Moroccan) aged 50-69 years expect to be able to live with their children in old age, 16 per cent expect financial help from their children, and 37 per cent expect practical help from their children. In addition, among the adult children of these same immigrants 60 per cent do not want their parents to have to go into a nursing home, and of these 79 per cent would prefer to look after them themselves, but of these 48 per cent admit that they will be unable to do so if that should become a reality.

### **2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?**

The information provided in the following is taken from a ministerial publication on social policy in Denmark (Socialministeriet 2002).

In Denmark, a social anticipatory pension is payable to persons aged 18 to 67 years (65 years as of 1 July 2004) whose capacity for work is materially reduced for physical, mental or social reasons. This is a passive financial allowance, which demands that all possibilities to develop and apply an individual's capacity to work have been exhausted. An applicant must have lived in the country for at least 10 years after the age of 15 years (Danish nationality is not a prerequisite).

Local authorities provide personal and practical help as discussed above, but they also provide general care services whose aim is to promote network formation and self-activation via for example day centre activities, contacts with voluntary organisations etc. Assistance is provided to carry out personal care and practical tasks in the home, which the older person is unable to perform. In addition, assistance to maintain physical and mental skills is provided. Personal care and practical help is provided on the basis of an assessment of an individual's functional capacity and needs. Local authorities are responsible for determining the content and scope of such services and also grant the funds required in accordance with general political resolutions on levels of service.

Legal entitlements to care benefits are restricted to compensation for caring for a dying relative (compensation for lost earnings) for a period on the condition that medical assessment shows that hospital treatment is futile. However, as of 1 January 2003 legislation allows older people (and their families) to decide whether help with personal care and practical tasks (determined on the basis of a local authority assessment) should be provided by the local authority, a private person, or an authorised private service provider. In theory, this allows the older person to choose a family member as the private service provider with payment for the provision coming from the local authority. This has been the case for some time in relation to practical help but will now also encompass personal care tasks.

### 2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psycho-social support or similar)?

As is clear from the discussions and data presented thus far, local authorities are responsible for providing, financing and managing care for older people – both in their own homes and in institutional settings. Hospital care is the responsibility generally of county authorities.

The Danish welfare model is based on the fundamental principle that citizens have rights in the event of social problems (unemployment, illness or dependency). All citizens regardless of labour force participation are entitled to social security benefits and social services, which are financed (mainly) from general taxation. The public sector as mentioned is responsible for the provision of these benefits and services although it co-operates with private and voluntary bodies to promote social welfare. Welfare policy is designed to provide services for children, dependent older people and disabled people and interconnect family and working life. There is a high degree of decentralisation of social responsibilities to local government and these authorities have great powers of autonomy in the Danish model with regard to implementing social policy.

Danish social policy has three pillars:

- extended care and service functions: care for dependent older people, family policy, activation, rehabilitation and preventive measures;
- initiatives targeting particular groups: persons with physical and mental disabilities, socially excluded groups and groups at risk of social exclusion, mentally ill people, alcohol and drug addicts, the homeless;
- transfer payments: old age pensions, social anticipatory pensions, maternity benefits, cash assistance and other special benefits.

Although the public sector is responsible for the majority of welfare tasks (and are not carried out by private service providers, voluntary organisations or families), certain public social services are contracted out to private entrepreneurs. Health care provision is primarily a public task with 85 per cent of health care costs financed through general taxes. The public health care reimbursement scheme embraces all residents and is financed by (county) taxes. Primary care services are available free of charge to everyone.

Local and county authorities cannot finance all of their welfare and social service activities via taxation, so this source of revenue is supplemented by central government transfers.

Family policy makes no mention of older people and family carers – it is devoted entirely to families and dependent children (Socialministeriet 2000).

As mentioned above, recent legislation allows older people who have been assessed as needing help with personal care and / or practical tasks are now in a position to choose whether this help should be provided by the local au-

thority, a private person (could be a family member) or a private service provider. The local authority is obliged to draw up agreements on provision with all public and private bodies wishing to provide these services and fulfilling the requirements of the local authority. The local authority does, however, remain responsible for the home-help services and is therefore responsible for ensuring that providers meet standards requirements. This choice also extends to *meals-on-wheels* in as much as an older person receiving this service can choose to have meals delivered to their home, to eat at the local day centre or to eat at any other local authority approved restaurant.

It is, however, important to underline that this increased freedom of choice on the part of the user does not relieve the local authority of its quality responsibility, its financial responsibility or its managerial responsibility. Complaints are also handled centrally.

And as discussed earlier in the report, a relative wishing to care full-time for an older person in the home can in accordance with certain conditions be employed by the local authority to do this.

### 2.1.4 Is there any relevant case law on the rights and obligations of family carers?

The only legislatively stipulated rights are the above-mentioned right to compensation for lost earnings in case of caring for a dying relative, and the right to employment as a carer when certain conditions are met.

### 2.1.5 What is the national legal definition of old age, which confers rights (eg pensions, benefits etc)?

Perhaps what could be regarded as the legal definition of old age (if such a definition exists) is the age at which one is entitled to a state old age pension – at present 67 years but 65 years as of 1 July 2004. This entitlement to a full pension is also linked to residence requirements as outlined earlier in this report. However, in social terms *old age* is increasingly perceived at an earlier age – closer to 60 years. This would seem to be linked to the trend in early retirement, thereby defining old age as a function of one's (age-related) participation in the labour force. This would seem to open the sluice gates for a veritable labyrinth of *old ages* as more and more people are employed in jobs, which have their own pensions and retirement schemes, some of which kick in at relatively *young* ages.

Social benefits are otherwise largely independent of age being available to independent (read: potentially in employment) adults aged between 18 and 67 (65) years. There is in this policy an implication that persons under the age of 18 years and over the age of 67 (65) years are dependent and fall under the jurisdiction of other social policies.

As the concepts of modern retirement and the modern retiree encroach upon the scene and older people as a group increase in size, influence and spending power, various other (non-public) age-related benefits appear, usually providing discounted access to a variety of leisure pursuits (travel, museum entrance fees etc etc) and other services (for example, a campaign running at present in Denmark offering age discount on spectacles: age 60 years, 60 per cent discount!).

## 2.2 Currently existing national policies

As already discussed in some detail in the above sections of the report, the Danish welfare model is based on the fundamental principle that citizens have rights in the event of social problems (unemployment, illness or dependency). All citizens regardless of labour force participation are entitled to social security benefits and social services, which are financed (mainly) from general taxation. The public sector as mentioned is responsible for the provision of these benefits and services although it co-operates with private and voluntary bodies to promote social welfare. Welfare policy is designed to provide services for children, dependent older people and disabled people and interconnect family and working life. There is a high degree of decentralisation of social responsibilities to local government and these authorities have great powers of autonomy in the Danish model with regard to implementing social policy.

Danish social policy has three pillars:

- extended care and service functions: care for dependent older people, family policy, activation, rehabilitation and preventive measures;
- initiatives targeting particular groups: persons with physical and mental disabilities, socially excluded groups and groups at risk of social exclusion, mentally ill people, alcohol and drug addicts, the homeless;
- transfer payments: old age pensions, social anticipatory pensions, maternity benefits, cash assistance and other special benefits.

### 2.2.1 Family carers?

Family policy makes no mention of older people and family carers – it is devoted entirely to families and dependent children (Socialministeriet 2000).

The only legislatively stipulated rights are the above-mentioned right to compensation for lost earnings in case of caring for a dying relative and the right to employment by the local authority as a full-time carer of a close relative when certain conditions are met.

### 2.2.2 Disabled and / or dependent older people in need of care / support?

Although the public sector is responsible for the majority of welfare tasks (and are not carried out by private service providers, voluntary organisations or families), certain public social services are contracted out to private entrepreneurs. Health care provision is primarily a public task with 85 per cent of health care costs financed through general taxes. The public health care reimbursement scheme embraces all residents and is financed by (county) taxes. Primary care services are available free of charge to everyone.

Local and county authorities cannot finance all of their welfare and social service activities via taxation, so this source of revenue is supplemented by central government transfers.

Recent policy allows older people, who have been assessed as needing help with personal care and / or practical tasks, to choose whether this help should be provided by the local authority, a private person (could be a family member) or a private service provider. The local authority is obliged to draw up agreements on provision with all public and private bodies wishing to provide these services and fulfilling the requirements of the local authority. The local authority does, however, remain responsible for the home-help services and is therefore responsible for ensuring that providers meet standards requirements. This choice also extends to *meals-on-wheels* in as much as an older person receiving this service can choose to have meals delivered to their home, to eat at the local day centre or to eat at any other local authority approved restaurant.

It is, however, important to underline that this increased freedom of choice on the part of the user does not relieve the local authority of its quality responsibility, its financial responsibility or its managerial responsibility. Complaints are also handled centrally.

In Denmark, a social anticipatory pension is payable to persons aged 18 to 67 years (65 years as of 1 July 2004) whose capacity for work is materially reduced for physical, mental or social reasons. This is a passive financial allowance, which demands that all possibilities to develop and apply an individual's capacity to work have been exhausted. An applicant must have lived in the country for at least 10 years after the age of 15 years (Danish nationality is not a prerequisite).

Local authorities provide personal and practical help as discussed above, but they also provide general care services whose aim is to promote network formation and self-activation via for example day centre activities, contacts with voluntary organisations etc. Assistance is provided to carry out personal care and practical tasks in the home, which the older person is unable to perform. In addition, assistance to maintain physical and mental skills is provided. Personal care and practical help is provided on the basis of an assessment of an individual's functional capacity and needs. Local authorities are responsible for

determining the content and scope of such services and also grant the funds required in accordance with general political resolutions on levels of service.

Legal entitlements to care benefits are restricted to compensation for caring for a dying relative (compensation for lost earnings) for a period on the condition that medical assessment shows that hospital treatment is futile. However, as of 1 January 2003 legislation allows older people (and their families) to decide whether help with personal care and practical tasks (determined on the basis of a local authority assessment) should be provided by the local authority, a private person, or an authorised private service provider. In theory, this allows the older person to choose a family member as the private service provider with payment for the provision coming from the local authority. This has been the case for some time in relation to practical help but will now also encompass personal care tasks. Employment by the local authority as a full-time carer of a close relative is also possible in certain cases.

As is clear from the discussions and data presented thus far, local authorities are responsible for providing, financing and managing care for older people – both in their own homes and in institutional settings. Hospital care is the responsibility generally of county authorities.

### **2.2.3 Working carers: are there any measures to support employed family carers (rights to leave, rights to job sharing, part-time work etc.)?**

As far as working carers are concerned, there is only one piece of specifically targeted legislation, which provides compensation for lost earnings in case of caring for a dying relative.

However, as pointed out in Leeson & Hoffmann (1993), this lack of central government legislation does not prevent local agreements in the workplace being made to support working carers of older people. The general consensus then – and there is no evidence to suggest this may have changed since – was that individual applications from a working carer would be considered individually and that in most cases the parties would attempt to reach some kind of agreement (for example, with regard to flexibility, care leave etc etc). This situation does, however, mean that the situation of working carers with regard to combining working and caring can differ significantly dependent on the individual employer.

Finally, it should also be added that there is no tradition for government in Denmark to interfere in workplace agreements – these are the responsibility of the trade unions and the employers.

## **2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people?**

Central government policy in relation to dependent older people (and to family carers if there were any such policy) is then the responsibility of the autonomous local and regional authorities as far as implementation is concerned. This local government autonomy does allow for a degree of local and regional variation in the way in which central policies are implemented. This may mean that dependent older people in exactly the same situation would be treated differently in different local authorities in respect of the amount of practical support provided and even financial allowances in addition to the state old age pension.

Central government in the health and social policy fields outlines so-to-speak the overall framework within which provision should be made for all citizens resident in the country – local autonomy then allows for different interpretations of the ways in which this provision is best provided (within the financial constraints provided by central tax income and local tax income). For example, it may be central policy that no-one waits more than 6 months for a hip-replacement once a decision has been made that they should have one. How this is put into practice and affects the individual patient can differ significantly from one region to another. Likewise, an older person may elect to enter residential care (once screened for this) in an area other than her area of residence (as legislation allows) – to be closer to family, for example – but this may be easier in some areas than others.

## **2.4 Are there differences between local authority areas policy and / or provision for family carers and / or older people?**

As is clear from section 2.3 above, policy is a central government issue, while provision is a local / regional issue (within the framework and guidelines of this policy).

Comments in section 2.3 apply.

### 3 Service for family carers

As is eminently clear from the content of this national report so far, services for family carers of dependent older people in Denmark are in a direct sense few and far between. However, this is not the case indirectly in as much as the public support to the family carer is in fact provided to the dependent older person, thereby (in theory at least) relieving the family carer of the primary onus of practical care and support and allowing them as all parties seem to agree to provide social and emotional support. It remains a point of debate in the country, however, whether this social and emotional support is forthcoming (Jensen 2002; Colmorten et al 2003), although research does show that family members are providing support and feel happy (obliged) to do so (Lewinter 1999; Jensen 2002) and that the importance of family values is increasing (Leeson 2004 forthcoming). Almost everywhere, however, practical care and support is expected to be provided by the public sector (Colmorten et al 2003).

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)			X	X				
Counselling and Advice (e.g. in filling in forms for help)			X	X		X		X
Self-help support groups		X				X		X
“Granny-sitting”		X				X		X
Practical training in caring, protecting their own physical and mental health, relaxation etc.	X							
Weekend breaks	X							
Respite care services		X		X				
Monetary transfers		X		X				
Management of crises	X							
Integrated planning of care for elderly and families (in hospital or at home)		X		X				
Special services for family carers of different ethnic groups	X							
Other								

In the above table, it is difficult to differentiate in all cases where the services are specifically for a family carer and where they are for an older person. In cases where non-statutory bodies are attributed as providing a service, these would primarily refer to the three organisations mentioned below, but also others (Red Cross and various religious organisations), providing voluntary services.

#### 3.1 Examples

There are three organisations in Denmark, which directly or indirectly work with and for relatives of dependent older people. The first one (Aeldremobiliseringen – Danish Association of Senior Citizens) is an umbrella association of local and regional older people’s and pensioners’ organisations. The second one (Aeldre Sagen – DaneAge Association) is a national (individual) member organisation working with and for older people. Both of these work indirectly with family carers in as much as they provide social support activities (for older people). The third organisation (Paarøerendegruppen for svage aeldre – National Association for Relatives of Dependent Older People) is pressure group working as already mentioned not for family carers but for the dependent older people on behalf of relatives. In all cases, the activities of the organisations in relation to dependent older people coincides with national policy – it is to ensure that public services of the highest quality are provided to those in need when and where they need them.

However, one direct service developed by one of these organisations (DaneAge) provides volunteer-based respite services for families with an older person suffering from dementia. The organisation trains volunteers to be able to provide such services in the home.

In fairness, there is also a wide variety of initiatives at the local level, which may be carried out by local groups of national voluntary organisations or may be carried out by purely local groups. Whatever, these initiatives and the services provided will often be subsidised by public money and carried out in close co-operation with local community services to support older dependent people. Such support may be provided in the home; may be provided in an institutional setting; or may be designed to help older people take part in activities outside the home. The above-mentioned scheme from DaneAge to train volunteers to provide support and breaks from caring for families with an older person suffering from dementia is one of the few (if not the only one) aimed specifically at supporting the family rather than the older person.

## 4 Supporting family carers through health and social services for older people

In the preceding sections of this report, the Danish social services model has been described in some detail in relation to the services available for older people and their families. The service structure in Denmark is needs led with the focus on the older person, although as described above, legislation does incorporate the family in a number of cases. Despite the well-developed social and health care support services, the value of the networks of older people should not be underestimated (Leeson 1999, 2001; Audun-Olsen 2000; Jensen 2002). Much of the information in this chapter comes from the official publication of the Ministry of the Interior and Health (2002).

### 4.1 Health and social services

#### 4.1.1 Health services

As a public provision, health care is financed almost exclusively (85 per cent) through taxation and is the responsibility mainly of regional authorities working closely with local and central government. The health service comprises:

- primary health care
- and the hospital sector.

The health care service has three political and administrative levels: national, regional and local. The aim of the service is to provide services as close to the user as possible so that services are provided by the lowest possible administrative level. There are 275 local authorities in Denmark (including Copenhagen and Frederiksberg) and the provision of health care is one of many tasks they are responsible for. As already mentioned, these local authorities are responsible for most social services (including residential nursing homes and specialised housing for older people), but they are also responsible in the health care field for district nursing, public health care, school health care and child dental care. Hospitals are the responsibility of the 14 regional counties (hospitals in Copenhagen and Frederiksberg, as the capital region, are run by the Copenhagen Hospital Co-operation), as is the practising sector (except in Copenhagen and Frederiksberg where they are the responsibility of the two local authorities there). The organisation and provision of health services at the regional level is determined regionally with due attention being paid to local conditions and without central government interference. At the national level, the responsibility of the state is to co-ordinate and advise and determine national health policy goals and strategies. Every four years, the local and regional authorities are required to draw up a health care plan designed to improve co-ordination and efficiency of the different administrative levels of

health care provision. There is a trend towards relieving hospitals of social care.

#### 4.1.1.1 Primary health care

The primary health care sector deals with general health problems, is usually the first point of contact for an individual and comprises:

- GPs, practising specialists, practising dentists, practising therapists and district nurses all of whom are responsible for care and treatment;
- Preventive health schemes, health care and child dental care.

GPs act as gatekeepers in as much as they are usually the first point of contact for a client and it is their task to ensure that clients are referred to the required / needed treatment. Hospital examination and treatment usually require referral from a GP, the exceptions being in the case of an accident or an acute illness. Specialist treatment also requires GP referral. GPs also refer clients to the other health professionals working with the health service and arrange for the provision of district nursing.

All residents in Denmark are covered by the public Health Care Reimbursement Scheme, which is financed through taxation at the county level. Persons aged 16 and over choose between Group 1 and Group 2 insurance (differences highlighted later in relation to the different services available). The vast majority of citizens are in Group 1 (97.5 per cent).

In Denmark in 2000, there were 3466 GPs which corresponds to 0.65 GPs per 1000 inhabitants or 1600 patients per GP. Group 1 persons have the right to free medical help from their GP (or another GP in a different area if they are temporarily in that area). Group 2 persons receive only part of the cost of GP medical treatment.

The public Health Insurance Scheme pays for all or part of specialist treatment. Group 1 persons receive free specialist treatment referred by their GP, and Group 2 persons receive only a subsidy but may visit a specialist without prior GP referral. There are approximately 800 specialists corresponding to 0.14 per 1000 inhabitants.

Inhabitants can choose their own dentist from among the 2691 practising dentists (in 2000). Reference for treatment from a GP is not necessary. Those aged 18 years or over receive subsidised preventive and dental treatment, while for those under 18, the partly disabled or those with serious mental / physical disabilities receive free dental treatment.

Physiotherapy, which has been referred by a GP, is subsidised (those with serious physical disabilities may receive free therapy). There are approximately 1400 physiotherapists in the country. Subsidised treatment from a chiropractor is available from the country's approximately 450 chiropractors – referral from a GP is not necessary.

District nursing must be provided free of charge by local authorities when this service has been deemed necessary by a GP. All local authority residents have a right to district nursing. Appliances and aids for those in receipt of district nursing are also available free of charge. The aim of district nursing is to allow those with a temporary or chronic illness or those close to dying the possibility to remain in their own homes.

The reimbursement system for prescribed medicines is based on individual needs and individual consumption. Some medicines available without a prescription are only subsidised for old age pensioners, disability pensioners, early retirees or those suffering from long-term illnesses.

#### 4.1.1.2 Acute hospital and tertiary care

As mentioned, there has been a move away from hospitals providing social care which has resulted in a continuous decline in the average length of hospitalisation and the number of bed days and an increase in the number of out patients being treated in out patient clinics. Thus, from 1980 to 2000 the number of somatic hospitals fell from 117 to 71 and the number of beds from 31,000 to 19,000. Bed days declined from almost 8.5 million in 1980 to less than 6 million in 2000 and the average length of stay declined from 9.4 to 5.3 days. The number of out patients has increased from 3.1 million to 5.5 million.

Similarly, the number of psychiatric hospitals fell from 16 to 12 in that same period, beds from almost 11,000 to just over 4000, bed days from 3.3 million to 1.4 million, while the number of out patients has increased from 230,000 to 574,000.

Hospital services are provided by the county councils (and the Capital) free of charge to residents of the county and to temporary residents. In some instances – and especially in the case of specially hospitals – private hospitals also have agreements with the county to provide services. In 1993 it was made possible for Danes to choose freely the hospital at which they required treatment, and as of mid 2002 this choice has been extended to private hospitals and clinics in Denmark and abroad **if** the waiting time for treatment is more than two months (provided the chosen hospital / clinic has an agreement with the counties) – the costs will be covered by the county in question or by the state.

In addition to the public hospitals and the private hospitals, which have agreements with the public providers, a number of private hospitals exist where patients can purchase treatment outside the public health service sector – this paying sector comprises approximately 0.2 per cent of the total service.

Table 19 illustrates the number of health sector staff in hospitals in 1999 (Ministry of the Interior and Health 2002).

**Table 20: Health sector staff in hospitals, 1999.**

Doctors	10,158
Nurses	28,194
Other trained nursing staff	12,789
Assisting staff (physiotherapists etc)	15,441
Others	19,271
<b>Total</b>	<b>85,853</b>

Source: Ministry of the Interior and Health (2002)

In 2002, 670,000 persons were admitted to hospital (corresponding to almost 1.12 million admissions) and they totalled 5.6 million bed-days. Of the 670,000 persons admitted to hospital, 232,000 corresponding to 35 per cent were aged 60 years and over with 77,000 of these aged 80 years and over. This group aged 60 years and over accounted for 58 per cent of all bed-days, however (source: Danish National Bureau of Statistics Databank).

The co-ordination of hospital services is discussed in detail by Lund Nielsen & Skaarup Arrevad (2003).

#### 4.1.1.3 Are there any long-term health care facilities?

Long-term health care facilities are to be found within the hospital sector and with the nursing home sector.

#### 4.1.1.4 Are there hospice / palliative / terminal care facilities?

Again these facilities will be found predominantly within the existing overall health care sector, although a limited number of hospice facilities do exist.

#### 4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?

Strictly speaking, family carers (or the family in general) are not expected to play an active role in in-patient health care. Indeed, anecdotal evidence suggests that the family would prefer to be more involved (i.e. informed). In relation to residential nursing home settings, authorities are obliged to establish a *relatives' council* – the aim is to improve dialogue and involvement of relatives of residents.

#### 4.1.2 Social services

As already mentioned, although there are centrally determined guidelines on the provision of health and social services in Denmark, the actual provision is the responsibility of local and regional authorities (as well as part-financing through local and regional taxation) and this does mean that there is local and regional variation in provision (as is also reflected in the range of variation in local tax levels from approximately 15 to approximately 25 per cent). The so-

cial system in Denmark has been described above and at this stage, we shall merely comment again that the system has the following broad characteristics:

- universalism based on residence;
- tax financed (at local, regional and central level);
- public responsibility.

In addition, the public sector, where applicable, co-operates with the voluntary and private sectors to promote social welfare, and measures are designed to actively support rather than passively maintain. A central element is the involvement of users (re senior citizens' councils).

Again, broadly speaking, Danish social policy involves extended care and service functions (care for dependent older people, family policy, activation, rehabilitation and preventive measures), initiatives targeting special groups (persons with mental and physical disabilities, socially excluded persons and persons at risk of social exclusion), and transfer payments.

Danish social policy in the field of ageing is based on continuity in an individual's life, the optimal use of an individual's resources, and autonomy and self-determination of the individual.

#### 4.1.2.1 Residential care

Denmark is perhaps the single European country that has progressed furthest with deinstitutionalisation of older people with legislation in 1987 more or less putting a (formal) stop to the construction of conventional (residential) nursing homes. Instead, legislation encouraged the development of independent specialised housing for older people with care and support services being provided in the home. Table 20 illustrates the development in the number of specialised housing units for older people 1999-2003. The total number of units for older people has increased only slightly from 88,000 in 1999 to 91,000 in 2003. Approximately 48,000 of this total are linked into extensive care services. The deinstitutionalisation is seen clearly from the decline in the number of nursing home places from 31,000 in 1999 (had been 38,000 in 1994) to only 24,000 in 2003. Not clear from the table is the fact that the number of sheltered housing units has declined too – from 4640 in 1999 (had been 5257 in 1994) to 3572 in 2003. The “lost” nursing home places have been replaced by independent housing units for older people – their number has increased from 32,000 in 1999 (had been 18,000 in 1994) to almost 43,000 in 2003.

**Table 21: Number of specialised housing units for older people, 1999-2003. Thousands.**

Specialised housing units	1999	2000	2001	2002	2003
Nursing home places	31	30	28	26	24
Sheltered accommodation	5	4	4	4	4
Independent units	32	35	38	40	43
Other types of housing for older people	20	20	20	20	20
<b>Total</b>	<b>88</b>	<b>89</b>	<b>90</b>	<b>89</b>	<b>91</b>

Source: Socialministeriet and Central Bureau of Statistics

The level of care provision available to older people in the different types of housing presented in table 20 can vary and the Central Bureau of Statistics operates with three categories of levels of care provision: A (24 hour services, in most cases on site, and common facilities), B (care and support at the level of domiciliary services) and C (practical support at the level of domiciliary services). The breakdown of the housing for older people according to these levels of care and support provision is shown for 2002 in table 21.

**Table 22: Housing for older people according to level of care and support provision, 2002.**

Specialised housing units	Level A	Level B	Level C
Nursing home places	25,737	65	0
Sheltered accommodation	2,750	1,337	18
Independent units	17,665	17,436	4,530
Other types of housing for older people	1,468	3,214	15,193
<b>Total</b>	<b>47,620</b>	<b>22,052</b>	<b>19,741</b>

Source: Socialministeriet and Central Bureau of Statistics

All but 65 nursing home places out of almost 26,000 have the highest level of provision. This is true for 67 per cent of sheltered accommodation and 45 per cent of the independent units. In 2002, there were almost 5000 places designated specifically for persons suffering from dementia – this figure has been increasing steadily in recent years.

##### 4.1.2.1.1 Basic data on older people in specialised housing / care units

Table 22 illustrates the age distribution of residents in specialised housing / care units for older people.

**Table 23: Age distribution of residents in specialised housing / care units for older people, 2003.**

	60-66	67-74	75-79	80-89	90+	Total
Nursing home places	908	2115	2948	10639	6048	22658
Sheltered accommodation	187	432	462	1563	701	3345
Independent units	2228	5897	6873	18109	6633	39740
<b>Total</b>	<b>3323</b>	<b>8444</b>	<b>10283</b>	<b>30311</b>	<b>13382</b>	<b>65743</b>

Source: Danmarks Statistik 2003: Nyt fra Danmarks Statistik nr. 356

The total number of almost 66,000 older people in either a nursing home, sheltered housing or independent specialised housing corresponds to approximately 6 per cent of the total population aged 60 years and over.

#### 4.1.2.1.2 Criteria for admission

Admission to one of these units is based on individual need and appraisal. Residents receive their pensions and benefits and pay for services according to the same rules as persons living in their own homes. This is an attempt to ensure equal treatment of older people in their own homes and older people in nursing homes or specialised housing. Older people in social housing or specialised (service) housing may receive individual housing benefits to which there is no limit.

#### 4.1.2.1.3 Public / private / NGO status

Residential nursing homes are usually financed and managed by the local authority. However, a limited number of homes may be co-financed (at point of construction) by a private organisation / NGO and managed by these organisations in accordance with an agreement with the local authority, which remains responsible for financing. For residents, this management structure does not influence their status (financially).

#### 4.1.2.1.4 Does residential care involve the participation of carers or work with carers?

Through the establishment of *relatives' councils* relatives (family carers) are encouraged to take a more active part in the day-to-day management and activities of the home, but this does not include providing care. Some homes do make use of volunteers to provide social and emotional support to residents.

#### 4.1.2.2 Community care services

Community care services are an integral part of the health and social care provision of the local and regional authorities as described in detail elsewhere in the report. Certain social supportive tasks are also provided by voluntary organisations, as mentioned.

#### 4.1.2.2.1 Home-help

As appears from table 23, in Denmark, with approximately 700,000 inhabitants aged 67 years and over, 172,000 persons aged 67 years and over were in receipt of (long-term) home-help, which is an increase of about 20,000 since 1992. To this can be added between 7000 and 8000 persons aged 67 years and over who receive short-term temporary home-help. The majority of these (long-term) home-help recipients live in their own homes – only 10,000 of the recipients are living in nursing homes or sheltered housing schemes. Almost 63 per cent of these 171,000 recipients of home-help are aged 80 years and over which means that 50 per cent of the Danish population aged 80 years and over are in fact receiving (long-term) home-help.

**Table 24: Recipients of (long-term) home-help according to age and number of hours per week. Thousands.**

Age	Under 2 hours	2-8 hours	8-12 hours	12-20 hours	20+ hours	Total
-67	18	8	2	1	2	31
67-79	39	15	3	3	4	64
80+	51	30	9	9	9	108
<b>Total</b>	<b>108</b>	<b>53</b>	<b>14</b>	<b>13</b>	<b>15</b>	<b>203</b>

Source: Danish National Bureau of Statistics

The amount of home-help provided varies according to need and the number of hours increase with increasing age. Just over 50 per cent of recipients are in receipt of less than 2 hours per week, but the average number of hours received per week is 4.5 for those aged under 80 years and 6.1 for those aged 80 years and over. Almost 13,000 recipients aged over 67 years receive more than 20 hours per week. A staggering 1,080,000 hours of home help are delivered every week, of which 80 per cent was devoted to personal care with the remaining 20 per cent devoted to practical help in the home (cleaning, shopping and laundry). Of these 1.08 million hours of home-help per week, 60 per cent are delivered to persons aged 80 years and over (see table 24).

**Table 25: Number of (long-term) home-help hours per week, according to task and age of recipient, March 2003. Thousands.**

Age	Personal help and care	Practical tasks	Total
-67	106	32	138
67-79	225	63	288
80 and over	537	117	654

Source: Danish National Bureau of Statistics

All of these figures include home-help provided (under recent legislation offering recipients a choice of provider) by private providers – in 54 local authorities

(out of Denmark's almost 280) there were 153 private providers. In March 2003, 7200 persons chose private provision and of these 5900 received only practical help, 500 received only personal help and care, while 800 received both practical and personal help.

In March 2002, the equivalent of just over 45,000 persons full-time employees were working in home-help services in Denmark (including social-health workers), an increase of 6.3 per cent on the year before.

From 1994 to 1999, the number of full-time employed persons working in the public care sector for older people had remained more or less constant at approximately 92,000 but has since increased steadily and in 2002 the number employed amounted to almost 100,000 full-time employees (there are certain dissimilarities in methods of defining and calculating after 1999, so that the exact figures may not be completely comparable). From 2001 to 2002, the percentage growth in the number of full-time employees in the care sector for older people at 4.4 per cent was more than three times the growth in the number of older people aged 80 years and over in that year (1.4 per cent). Of the total number of employees, as appears from table 25, the vast majority - 85 per cent - are engaged in care functions for older people in institutional settings or in their own homes, 11 per cent in support functions (kitchen, cleaning, caretaker etc) and 4 per cent in administration.

**Table 26: Employees in the care sector for older people by employment category, full-time employees, 2001-2002.**

Employment category	2001	2002
Management and administration	3150	3705
Care	81497	84899
Nurses	9846	9765
Physiotherapists etc	2416	2700
Social and health assistants	25951	26141
Home helps, social and health workers	42423	45101
Other	861	1194
Support functions	10947	11232
<b>Total</b>	<b>95594</b>	<b>99836</b>

Source: Central Bureau of Statistics (2002)

#### 4.1.2.2.2 Personal care

As is clear from the information provided thus far, personal care is provided by public services (and by family carers), and of course this form of care can also be purchased from private providers.

#### 4.1.2.2.3 Meals service

Meals services are also part of the services provided by public bodies with residential homes also preparing meals for older people in the community. Meals facilities are also available in day centres.

#### 4.1.2.2.4 Other home care services

In theory, public services are designed to provide the practical support needed to enable an older person to remain (active) in his / her own home for as long as possible. Clearly, there are services that local public services do not provide (e.g. what can be described as handyman services around the home) – such services may be provided by a local voluntary organisation or purchased from a private provider.

Aids in the home are provided in accordance with individual need and assessment.

#### 4.1.2.2.5 Community care centres

Organisations such as DaneAge with its nationwide network of local and regional groups offers a wide range of voluntary activities and a similarly wide range of social activities for its members ([www.aeldresagen.dk](http://www.aeldresagen.dk)).

#### 4.1.2.2.6 Day care

no information provided

#### 4.1.2.3 Other social care services

Counselling is provided by organisations and there is a well-developed structure of public complaints and advice bodies.

Medical and technical aids are provided by the public services on the basis of individual need and assessment.

There appear to be no structures providing courses for family carers.

#### 4.2 Quality of formal care services and its impact on family care-givers: systems of evaluation and supervision, implementation and modelling of both home and other support care services

Accountability with regard to the quality of care provided lies well and truly with the local authority even in the present situation, in which recipients of care may choose a provider other than the public provider.

In addition, a framework of mechanisms, which allow the recipient (or relatives) to complain and appeal, is in place.

Organisations representing older people are invariably critical of the levels of care (quantity and quality) provided and of the bureaucracy of complaints and appeals procedures.

A number of studies over the years reveal an overall picture among older people receiving home-help services, for example, of satisfaction (for example, Hansen & Platz 1995, 1996; Leeson 1999; Bunnage et al 2001; Hansen 1999). However, a more recent study of older people's experiences with the new legislation allowing them more freedom of choice reveals that older people are acutely unaware of their possibilities (Aeldre Sagen 2004) and innovative research earlier had revealed quite dramatic flaws in the quality of life of older people in residential care (Christophersen 1999). Even so, generally speaking, older people do seem to be content with their general situation (Leeson 1999, 2004; Jensen 2002).

#### **4.2.1 Who manages and supervises home care services?**

As described in detail elsewhere in this report, the management and supervision of home care services are the responsibility of the local authority. Complaints and appeals frameworks are in place.

#### **4.2.2 Is there a regular quality control of these services and a legal basis for this quality control?**

Within the auspices of the responsible local authority departments, services are controlled. In addition, the local government research institute (AKF) carries out evaluation and monitoring of services in local authorities – especially in relation to changes in procedure.

#### **4.2.3 Is there any professional certification for professional care workers? Average length of training?**

Professional care workers are public employees (civil servants) and are organized mainly in FOA (The Danish Trade Union for Public Employees), comprising almost 60 per cent of that union's membership of almost 200,000 members. This union plays a central role in broad policy issues relating to the care sector (for example, private provision of care services, ethical issues) and is active in relation to training issues, the quality of care and the perception of the care sector. The level of training of care workers in Denmark is relatively high and has undergone several improvements over the course of the last 10-15 years. In order to increase workforce flexibility, the original five course training scheme was replaced by a single basic training system in 1991. The system has phases which offer trainees the option to work on completion of basic training or to continue with further education. The idea behind the combination of work and training was to increase motivation for further training and to address recruitment problems in the care (for older people) sector.

More recent reforms have increased the level of coordination between employment and education. Training is between 14 and 20 months to be able to provide domestic work, and over 95 per cent of those working with older people have this level of training. As of 2002, training for social and health care helpers has been extended by two months and new subjects introduced. Training is conditional on having secured employment with local / regional authorities. During training, trainees receive a salary as a trained working care worker.

#### **4.2.4 Is training compulsory?**

Yes and is furthermore conditional on having secured employment with local / regional authorities, who therefore determine recruitment levels.

#### **4.2.5 Are there problems in the recruitment and retention of care workers?**

The number of social and health care helpers and assistants completing their training increased by just over 10 per cent from 1995 to 1998. Although there is already relatively great emphasis on care sector training, it is often argued that more attention should be paid to the quality of training (Johansson & Cameron 2002).

Females make up 90 per cent of the care workforce. The improved training mentioned above was designed to attract more young (males) people to the care sector, where care for older people is regarded as the least attractive. Efforts to recruit male staff have focused on the needs in homes for persons with mental disabilities and in psychiatric hospitals.

### **4.3 Case management and integrated care**

Health and social care services provided for older people in Denmark are substantially integrated and merged in delivery, having adopted such an approach to avoid professional conflict (social workers vs. nurses) and to encourage and allow case management flexibility (Walker & Maltby 1997). This extensive coordination comprises multi-disciplinary teams, decentralization of service responsibility bringing services as close as possible to the user; cross-care setting work; common training programmes (Smith 2003).

#### **4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?**

The work of Lewinter (1999) and Jensen (2002) and Christophersen (1999) witness an interaction between relatives and professional carers, which in many ways can be regarded as the seeking of advice – or at least the active involvement in the situation of the older family member. The initiative to set up

relatives' councils in care homes can also be seen as a means whereby advice can be sought and professionals and relatives interact to the benefit of the older person.

## 5 The Cost-Benefits of Caring

According to the Central Bureau of Statistics' Databank, Danish GDP in 2003 current prices was 1400 billion DKK.

### 5.1 What percentage of public spending is given to pensions, social welfare and health?

Total public expenditure amounts to approximately 60 per cent of GDP with approximately 50 per cent of this amount allocated to public welfare schemes (health and social services sector and the labour market). The social sector accounts for approximately 15 per cent of GDP.

It is perhaps worth noting that approximately one third of the total workforce are employed in the public sector with three quarters of these employed by local or county authorities.

The break down of social expenditure is 65 per cent in transfer payments and the rest in services.

The service field expenditure is distributed as follows:

- Day-care facilities for children – 32 per cent
- Special schemes for children and young people – 11 per cent
- Home care and nursing homes for older people / disabled people – 37 per cent
- Residential accommodation and services for people with disabilities and mental illnesses – 18 per cent
- Social services for homeless people and alcohol and drug addicts – 2 per cent

The transfer payment expenditure is distributed as follows:

- Coverage of lost wages and additional expenses related to caring for a disabled child in the home – 1 per cent
- Old age, partial retirement and anticipatory pension – 67 per cent
- Individual housing benefits – 6 per cent
- Cash assistance, activation benefits, assistance towards medical treatment etc. – 11 per cent
- Rehabilitation benefits, flexible working arrangements and sheltered employment – 4 per cent
- Maternity benefits and child allowance – 5 per cent
- Sickness benefits – 6 per cent

In 2002, the cost of social services was 407.6 billion DKK. Generally, social services are tax financed. However, there is a certain degree of user payment, which may differ among local authorities. Costs for older people are difficult to specify in detail because of the above-mentioned integration and coordination of services.

## **5.2 How much – private and public – is spent on long term care?**

In 2002, the total net expenditure on services for older people (includes personal and practical support, home nursing, preventive home visits, nursing homes and sheltered housing etc) was 30.5 billion DKK.

Residents do as described elsewhere in the report rent.

There is no private provision of social services (apart from services which are out sourced from local authorities – this is still funded from public funds).

## **5.3 Are there additional costs to users associated with using any public health and social services?**

User payments in relation to public health services are discussed in chapter 4 of the report. Social services for older people are 100 per cent tax financed. Personal and practical help in the home is free of charge.

## **5.4 What is the estimated public / private mix in health and social care?**

In addition to the public hospitals and the private hospitals, which have agreements with the public providers, a number of private hospitals exist where patients can purchase treatment outside the public health service sector – this paying sector comprises approximately 0.2 per cent of the total service.

There is no private provision of social services (apart from services which are out sourced from local authorities – this is still funded from public funds).

## **5.5 What are the minimum, maximum and average costs of using residential care in relation to average wages?**

As of January 1<sup>st</sup> 1995, residents in nursing homes, sheltered housing etc received their old age pension in full (prior to this they had only received a monthly allowance of *pocket money*, their pension being withheld to cover the costs) and hereafter have to pay rent.

In 2000, the Ministry for Social Affairs published figures which revealed that a single old age pensioner residing in a nursing home had 1914 DKK after paying for the full service facilities in the home (tax, rent, electricity, heating,

meals, laundry etc) compared with 825 DKK (2000 prices) prior to the change in legislation.

User payment depends on the resident's financial assets and income and may vary significantly among local authorities, as the costs depend on the levels of service and user payments determined by the local authorities.

## **5.6 To what extent is the funding of care for older people undertaken by the public sector?**

As already discussed, funding is tax financed and 100 per cent covered by the local authority (albeit with user payment in homes as described above).

## **5.7 Funding of family carers**

In accordance with the Consolidation Act on Social Services, persons attached to the labour market who wish to take care of a close relative with substantially and permanently impaired physically or mental function or a serious chronic disease or other illness of long duration at home shall be engaged by the municipal authority under certain conditions. Such a person shall be engaged on a salary amounting to 14,875 DKK per month. The total employment period cannot exceed 6 months.

In accordance with this same legislation, persons caring for a close relative wishing to die at home will under certain conditions be eligible for a constant care allowance (1.5 times sick benefit). This is independent of the financial standing of the carer or the family.

### **5.7.1 Are family carers given any benefits for their care? Are these means tested?**

See previous section.

### **5.7.2 Is there any information on the take up of benefits or services?**

The numbers of older people receiving services and benefits is presented elsewhere in the report. For family carers, no information has been found.

### **5.7.3 Are there tax benefits and allowances for family carers?**

See above.

### **5.7.4 Does inheritance or transfers of property play a role in caregiving situations?**

In view of the Danish situation relating to family carers, this is unlikely.

## 5.7.5 Carers' or users' contribution to elderly care costs

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
General practitioner	X					
Specialist doctor	X <sup>1</sup>					
Psychologist	X <sup>2</sup>		X			
Acute Hospital	X					
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)	X					
Day hospital	X					
Home care for terminal patients	X					
Rehabilitation at home						
Nursing care at home (Day / Night)	X					
Laboratory tests or other diagnostic tests at home						
Telemedicine for monitoring						
Other, specify: home help	X					

<sup>1</sup> Referral necessary by the general practitioner

<sup>2</sup> Referral necessary by the general practitioner or privately paid

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care / old people's home	X					
Temporary admission into residential care / old people's home in order to relieve the family carer	X					
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)	X					
Laundry service	X					
Special transport services	X					
Hairdresser at home						
Meals at home	X					
Chiropracist / Podologist	X					
Telerecue / Tele-alarm (connection with the central first-aid station)	X		X <sup>3</sup>			
Care aids	X					
Home modifications	X					
Company for the elderly	X <sup>4</sup>					
Social worker						
Day care (public or private) in community centre or old people's home	X					
Night care (public or private) at home or old people's home	X		X			
Private cohabitant assistant ("paid carer")	X <sup>5</sup>					
Daily private home care for hygiene and personal care			X			
Social home care for help and cleaning services / "Home help"	X		X			
Social home care for hygiene and personal care	X					
Telephone service offered by associations for the elderly (friend-phone, etc.)	X					
Counselling and advice services for the elderly	X					
Social recreational centre						
Other, specify						

<sup>3</sup> Provided by Falck, for example.

<sup>4</sup> Provided by voluntary organisations.

<sup>5</sup> In accordance with the legislation outlined in the report.

c. Special services for family carers	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring	-	-	-			
Telephone service offered by associations for family members	-	-	-			
Internet Services	-	-	-			
Support or self-help groups for family members	-	-	-			
Counselling services for family carers	-	-	-			
Regular relief home service (supervision of the elderly for a few hours a day during the week)	-	-	-			
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)	-	-	-			
Assessment of the needs	X	-	-			
Monetary transfers	-	-	-			
Management of crises	X	-	-			
Integrated planning of care for the elderly and families at home or in hospital	-	-	-			
Services for family carers of different ethnic groups	-	-	-			
Other, specify	-	-	-			

## 6 Current trends and future perspectives

The public sector will continue to provide the bulk of (tax-financed) services for older people, and as is discussed elsewhere in this report, this is the wish of older people and their families too. However, that does not mean that the family has no role, as also discussed elsewhere, and trends indicate that the value of the family as a supportive institution is increasing.

### 6.1 What are the major policy and practical issues debated on family care of older people from the carers' point of view? Are older people and / or carer abuse among these issues?

There is little debate about family care of older people in Denmark – simply because as should be clear from this report it is not a widespread phenomenon. Debate focuses more on the services provided for older people in their own homes, on the situation of older people in nursing homes, and on older people and the health services.

As far as older people living in their own homes are concerned, the provision of quality services is almost constantly being debated and elucidated and most of the larger organisations working for and with older people are active in this area. Aeldre Sagen (DaneAge) has been particularly active in relation to the provision of home help and the achievement of legislation allowing flexibility in choice and improving quality.

The quality of life of older people in nursing homes is also an ever-present issue, and the relatively new organisation for relatives of frail older people (Paarøerendegruppen for svage ældre) was established against a backdrop of among other things significant differences in the levels of provision among local authorities.

In the health sector, waiting lists are a major cause for concern – especially but not exclusively in relation to older people. While politicians focus on reducing waiting lists, organisations call for action in relation to dementia, convalescence, training, and death and dying.

The abuse of older people has received little attention.

### 6.2 Do you expect there to be any changing trends in services to support family carers?

As mentioned, it is clearly an expectation and a political aim to maintain and develop public service provision, allowing an older person to remain active in his / her home for as long as he / she wishes. Pressure groups in the country are geared to supporting these developments rather than supporting the family in a caring role – that is hardly seen as a viable option.

Government is looking seriously at the services it provides for older people in their own homes – in particular the practical help provided.

There is also increasing awareness of the need for emotional and psychological support for older people living in their own homes to avoid and counteract the danger of isolation and the problems that brings. Policy would probably seek to support the work of voluntary organisations in this field (as in the existing work of many of these local and national organisations).

### **6.3 What is the role played by carer groups / organisations, pressure groups?**

This has been discussed and outlined several places elsewhere in the report.

### **6.4 Are there any tensions between carers' interests and those of older people?**

There does not appear to be any conflict in this area.

### **6.5 State of research and future research needs**

More research is needed in the following areas:

- Family carers in migrant groups.
- The consequences of changing family structures on the role of the family in relation to older people.
- Elder abuse is an unresearched area, both in formal and informal settings.
- Dementia: GPs still have a disturbing lack of knowledge about dementia and preventive measures need to be developed and evaluated.
- The use of migrant workers in the formal and informal care sectors.
- The use of technology to support older people and reduce their isolation.

### **6.6 New technologies**

no information provided

### **6.7 Comments and recommendations**

With so much being initiated in the field of care provision, validated evaluation procedures need to be developed which take into account the complex issue of *user satisfaction*. Research methods to elucidate the quality of life of those frail older people unable to express their own wishes need to be developed and tested.

Research into health and social care communication could improve the methods whereby services are accessed and provided.

Research into the transition from independence to dependence is weak and should be strengthened with a view to developing further preventive measures across the life course.

## 7 Appendix to the National Background Report for Denmark

### 7.1 Socio-demographic data

Socio-economic development in Denmark has influenced the lives of the present generations of older people and has been quite different from that experienced by younger generations. If we broadly consider by way of illustration, the generations aged between 45 and 80 years of age today, it may be enlightening to briefly describe the socio-economic conditions experienced at different phases of life by the different generations to ascertain a mini-history of contemporary Denmark.

The oldest of these generations was born into a world undergoing dramatic change in both political and social terms. Europe was in the process of rebuilding war-torn nations, and in the wake of the post-war boom came the peacetime crisis with uncertain economic and labour market conditions. Enormous rural-urban changes were taking place, both with regard to the distribution of the population but also with regard to the distribution of labour between the agricultural and industrial sectors. The *peasant culture* was under serious pressure.

Any improvements in living conditions that may have occurred in the 1930s came to an abrupt halt with the outbreak of the Second World War and the German occupation of Denmark, and in the immediate post-war period there was yet again a period of rebuilding Europe with accompanying currency crises and labour market unrest. In that same period, demography began to show signs of unrest and turmoil too. As we shall see, the baby-boom plummeted to a baby-bust, a minor resurgence in the 1960s and a deeper baby-bust in the mid 1980s. Economic growth and the growth in consumption potential were accompanied by perhaps one of the most dramatic social changes of modern times: the changing status of women in the home and the work place. In the mid 1960s, less than 50 per cent of females aged 25-50 years were in the labour force, but by the end of the 20<sup>th</sup> century this figure had reached 90 per cent in Denmark.

The role of the family was professionalised and became a task of the public sector. An increasing proportion of the country's resources were needed to provide care, security and social support to its citizens. The oil crises of the 1970s put the welfare state to its hitherto most serious test – there was a real fear that a whole generation would be left to unemployment. However, towards the end of the 20<sup>th</sup> century, new concerns were being aired for the future of the welfare state as private pension schemes, privatisation of care and even health insurance become part of everyday life.

### 7.1.1 Profile of the elderly population – past trends and future projections

In considering the demographic profile of the elderly population, it is pertinent to by way of introduction to consider the broader demographic backdrop in Denmark. In mid-2003, the size of the Danish population was approximately 5.4 million people with 14.9 per cent aged over 65 years and 4 per cent aged over 80 years, and by the year 2050 this is expected to have fallen to 5.3 million 23.8 per cent aged 65 years and over (Central Bureau of Statistics 2003).

#### 7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

Across the more developed world – and increasingly across the developing world too - the shadow of mortality has been lifting during the 20<sup>th</sup> century, the result being that each new generation can expect to live longer than previous generations.

Table 26 illustrates the development in life expectancies in Denmark at selected ages from the beginning to the end of the 20th century.

**Table 27: Life expectancies at age 0, 65 and 75 years in Denmark, 1900-2002. Males / Females.**

	Age		
	0	65	75
1900	51.7 / 55.2	12.5 / 13.6	6.9 / 7.5
1981-1982	71.4 / 77.4	13.8 / 17.7	8.3 / 10.7
2001-2002	74.7 / 79.2	15.3 / 18.2	9.1 / 11.3

Source: National Statistics

At the turn of the 20<sup>th</sup> century, life expectancies at birth in Denmark were 51.7 years for males and 55.2 years for females - a difference between life expectancies at birth of 3.5 years. This difference remains but decreases at ages 65 (1.1 years) and 75 years (0.6 years). By the turn of the 21<sup>st</sup> century, the difference in life expectancies at each of the tabulated ages has actually increased to 4.5 years at birth, 2.9 years at age 65, and 2.2 years at age 75, with females having a life expectancy at birth of 79.2 years and of 11.3 years at age 75 years. In Europe, only Ireland has a life expectancy at birth lower than the Danish level (73 years for males and 78.5 years for females). Most recently, mortality has increased for both males and females in the age group 30-40 years, and in the first year of life for females (Central Bureau of Statistics 2003).

In its most recent population forecast, the National Bureau of Statistics assumes that mortality will continue to decline over the whole period until 2050, so that by that year life expectancies at birth will have reached 81 years for males and 84 years for females.

### 7.1.1.2 Percentage of > 65 year-olds in total population

As is well known, the demographic ageing of a population is a result of the development in fertility and mortality with fertility levels declining substantially and life expectancies and longevity increasing likewise substantially (as outlined in section 7.1.1.1 above). According to Day (1995), fertility is the most evasive demographic component in terms of explanations for its development over time. As most European countries, Denmark came through a completion of the classical demographic transition in the first half of the 20<sup>th</sup> century and entered post war what has been called the second demographic transition (van de Kaa 1987). Fertility levels reached replacement levels in the 1930s and 1940s but apart from a short-lived baby-boom in the mid 1960s, fertility moved down from its replacement level plateau. In the mid 1980s, Danish fertility hit its lowest at less than 1.5. Enduringly low levels of fertility, as we can see in table 27, would lead inevitably to population decline without compensatory international immigration (Davis 1986).

**Table 28: Total fertility rates in Denmark, 1960-2000.**

1900	1920	1940	1960	1970	1980	1990	1995	2000	2003
4.14	3.29	2.22	2.57	1.95	1.55	1.67	1.80	1.77	1.73

Note: The total fertility rate is the average number of children that would be born alive to a woman during her lifetime if she were to pass through and survive her childbearing years conforming to the age-specific fertility rates of a given year.

Source: Council of Europe (2001), Leeson (2001), Central Bureau of Statistics DK Databank

Despite a period of modest increase towards the end of the 1980s and much of the 1990s, fertility levels in Denmark remain below replacement level. The fertility decline of the last forty years of the 20<sup>th</sup> century was accompanied by changes in associated behaviour (table 28) such as marriage patterns, divorce patterns, family structures, age at birth of first child, use of contraception methods. The postponement of childbearing - always a natural control of fertility - has been particularly strong and in Denmark the average age of women at first birth has increased steadily and continually from the middle of the 1960s and to the final years of the 20<sup>th</sup> century, when fertility had even shown signs of a (temporary) increase.

**Table 29: Development in fertility-related behaviour in Denmark, 1960-2000.**

	1960	1965	1970	1975	1980	1985	1990	1995	2000
Age at birth of 1st child	23.1	22.7	23.8	23.9	24.6	25.7	26.4	27.4	28.1
Crude marriage rates	7.8		7.4		5.2		6.1	6.6	7.2
Total female 1 <sup>st</sup> marriage rate	1.0		0.8		0.5		0.6	0.7	0.7
Female mean age at 1st marriage	22.8		22.8		24.6		27.6	29.0	29.5

Source: Council of Europe (2001), Central Bureau of Statistics (2003)

In Denmark, it is clearly a case of delaying the birth of the first child and of limiting the number of children, reproductive behaviour made possible by widespread, efficient and easily accessible methods of contraception, including access to free abortion.

In relation to the mean age at first birth, however, the period measure for Denmark increases from 23.1 years in 1960 to 28.1 years in 2000, but for the generation of women born in 1935, this mean age was 26.2 years, and for the generation born in 1955 it is 26.8 years, a more modest increase. Despite the more modest development in terms of generational measures it is still unlikely that generations of women born after the 1950s will attain completed fertility levels that exceed replacement level fertility (Chesnais 1990).

As fertility and mortality have developed as outlined above, society has aged and the proportion of the total population aged over 60 years - by which age the large proportion of a generation will have retired from the labour market - has increased from around less than 10 per cent at the turn of the 20<sup>th</sup> century to more than 20 per cent at the beginning of the 21<sup>st</sup> century (table 29).

**Table 30: Population development in Denmark, 1900-2003. Percent-ages.**

Year	Age Group			Total pop.(mill)
	0-19	20-59	60+	
1900	43.6	46.5	8.9	2.5
1960	33.5	51.1	15.4	4.6
2003	24.4	55.2	20.4	5.4

As the Danish population has aged, so too has the older population in what is termed the *double-ageing* of the population (table 30). The proportion of the older population aged 80 years and over has increased from approximately 9 per cent in 1900 to approximately 20 per cent in the year 2003.

**Table 31: Development in the older age groups in Denmark, 1900-2003. Percentage of total old age group in each age group.**

Year	60-79 years	80 years and over	Total
1900	91	9	241.000
1960	90	10	702.000
2003	80	20	1.046.000

A more detailed breakdown of the age and gender distribution of the older population aged 60 years and over is shown in table 31.

**Table 32: Age and gender distribution of the older population in Denmark as of 1 July 2003.**

Age	Males	Females	Total
60-	144586	147466	292052
65-	198823	224241	432064
75-	112363	167493	279856
85-	27505	65201	92706
95-	1103	4650	5753
100 and over	91	504	595
<b>Total</b>	<b>484471</b>	<b>609554</b>	<b>1094025</b>

The 2003 population forecast from the Central Bureau of Statistics (2003) assumes, as pointed out above, that mortality will continue to decline and life expectancies at birth reach 81 years for males and 84 years for females. Fertility assumptions operate with different fertility levels and different development regimes for immigrants from developing countries (and their descendants) and the remainder of the population. For the immigrant group, fertility is expected to decline from 2.75 at present to 2.1 in 2030; for descendants, fertility is expected to increase from 1.71 at present to 1.85 in 2030; and for the rest of the population, fertility is expected to increase to 1.8 in 2030. After 2030, the attained level of fertility in each of the three groups remains constant. Migration assumptions vary for the different citizen groups. The results of the forecasts are shown in table 32.

**Table 33: Population development in Denmark according to age and gender, 2003-2050. Thousands.**

Age / Gender	2003	2030	2050
<b>A) Males</b>			
0-19	669	616	596
20-59	1478	1321	1279
60-64	145	181	140
65-79	266	409	372
80 and over	73	148	205
<b>Total</b>	<b>2631</b>	<b>2675</b>	<b>2592</b>
<b>B) Females</b>			
0-19	636	586	567
20-59	477	1322	1274
60-64	147	186	46
65-79	318	445	411
80 and over	145	214	272
<b>Total</b>	<b>2723</b>	<b>2752</b>	<b>2670</b>
<b>C) Total Population</b>			
0-19	1305	1202	1163
20-59	2955	2643	2553
60-64	292	367	286
65-79	584	854	783
80 and over	218	362	477
<b>Total</b>	<b>5354</b>	<b>5427</b>	<b>5262</b>

The proportion of the Danish population aged 60 years and over is forecast to increase from 20 per cent and 1.09 million in 2003 to 29 per cent and 1.6 million in 2030 and 29 per cent and 1.5 million in 2050. However, the ageing of the older population is such that while 20 per cent of that population is aged 80 years and over in 2003, it is expected to increase to 23 per cent in 2030 and to 31 per cent in 2050. This population ageing and double ageing is equally pronounced for males and females – the proportion of the male population aged 60 years and over is expected to increase from 19 to 28 per cent and that of the female population from 22 to 31 per cent. It is interesting to note – perhaps especially in relation to a care and support perspective – that the number of persons aged 100 years and over is expected to increase from 595 in 2003 to 2215 in 2030 and to 8529 in 2050 – in other words an increase of fourteen fold. Of the almost 9000 centenarians in 2050, two thirds will be female.

#### 7.1.1.3 Marital status of > 65 year-olds (by gender and age group)

Table 33 illustrates the marital status of older people in Denmark as of July 1<sup>st</sup> 2003.

The comprehensiveness of the Danish registration system means that traditional marital status classifications as shown in table 7.7 include contemporary union phenomena. Therefore, *widowed* comprises widows in a traditional sense but also the surviving partner from a partnership; *divorced* comprises divorced in a traditional sense but also after the dissolution of a partnership; *married* comprises married in a traditional sense but also partnerships; while *single* comprises single in a traditional sense and in the sense that one has not been in a partnership.

**Table 34: Marital status of older people in Denmark according to age and gender, 2003.**

Age / marital status	Males	Females	Total
<b>60-64 years</b>			
Widowed	5725	18321	24046
Divorced	19756	23715	43471
Married	108187	99153	207340
Single	10918	6277	17195
<b>Total</b>	<b>144586</b>	<b>147466</b>	<b>292052</b>
<b>65-79 years</b>			
Widowed	32106	113785	145891
Divorced	26137	35436	61573
Married	191030	153275	344305
Single	17570	14774	32344
<b>Total</b>	<b>266843</b>	<b>317270</b>	<b>584113</b>
<b>80 years and over</b>			
Widowed	25837	103704	129541
Divorced	3747	10094	13841
Married	39135	21551	60686
Single	4323	9469	13792
<b>Total</b>	<b>73042</b>	<b>144818</b>	<b>217860</b>
<b>Older population aged 60 years and over</b>			
Widowed	63668	235810	299478
Divorced	49640	69245	118885
Married	338352	273979	612331
Single	32811	30520	63331
<b>Total</b>	<b>484471</b>	<b>609554</b>	<b>1094025</b>

Of the total population aged 60 years and over, 56 per cent are *married* with 27 per cent *widowed* and 6 per cent *single*. This marital status distribution is of course highly age-specific: while 59 per cent of those aged 80 years and over are *widowed* this is the case for only 25 per cent of those aged 65-79 years and 8 per cent of those aged 60-64 years. In addition, there is a strong gender

dependence: of the *widowed* population aged 60 years and over, 80 per cent are females (and there is no significant age dependence) and 39 per cent of females aged 60 years and over are widowed compared with 72 per cent of females aged 80 years and over, 13 per cent of males aged 60 years and over and 35 per cent of males aged 80 years and over.

### Household composition

Being widowed, divorced or single in old age does not of course necessarily mean living alone, but that does seem to be the situation for most (see table 34 below).

**Table 35: Household size according to age and gender, 2002. Percent-age.**

Household size	75-79	65-69	55-59	45-49
<b>1 person:</b>				
Males	41	13	6	4
Females	69	47	26	19
<b>2 persons:</b>				
Males	59	82	75	54
Females	31	51	67	52
<b>3 or more persons:</b>				
Males	1	5	10	29
Females	0	2	8	30

Source: Leeson (2004)

#### 7.1.1.4 Urban / rural distribution by age

The Danish population of approximately 5.4 million in mid-2003 is more or less equally distributed between urban areas and rural areas with 1.2 million inhabitants in the Greater Copenhagen area alone. While 20.4 per cent of the total population are aged 60 years or over, the population of the Capital (Copenhagen + Frederiksberg) comprises 16.3 per cent aged 60 years and over.

#### 7.1.1.5 Disability rates

It is estimated that over 100,000 persons suffer from dementia, and in 2003, almost 270,000 persons were in receipt of a social pension (under the age of 67 years).

#### 7.1.1.6 Income distribution

In 2002, average income for females was 194,000 DKK and for males 267,000 DKK.

Persons aged 75 years and over have an annual expenditure of 91,000 DKK compared with 134,000 DKK for those aged 18-64 years, and just over 100,000 DKK for those aged 65-74 years.

A household with two persons aged under 65 years have an annual average income of 270,000 DKK compared with 133,000 DKK for households with two persons aged 70-74 years. However, this older group receives on average 120,000 DKK in transfer payments as well as 18,000 DKK in indirect support (medical help, hospital, home help etc).

Source: National Bureau of Statistics 2003.

#### 7.1.1.7 Ethnic groups

no information provided

#### 7.1.1.8 Home ownership

Among households aged 65 years and over, 62 per cent own their own homes with 38 per cent living in rented accommodation.

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