ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives

Denmark

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Jon Kvist
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European Social Policy Network (ESPN)

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The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for the Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

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Summary / Highlights

Work-life balance measures in Denmark for working-age people with dependent relatives are fairly extensive, but mainly target care dependants rather than relatives. Care dependants have a right to compensation as far as possible for the lack of mental and physical functionality caused by their illness or disability. On the other hand, relatives have no legal obligation to take care of a care dependant.

Most work-life balance measures that take the form of in-kind benefits are locally provided by the 98 municipalities – including long-term care, personal assistants, and aids. The extensive long-term care system consists of both institutional care and home-based help. In institutional care there is a move to reduce permanent staff and to make residents care for themselves to a greater extent. In home-based help the trend is towards prevention and rehabilitation, also with an emphasis on self-care. Cuts in home-based help, however, increase strains on working-age relatives.

Care leave is available to friends and relatives. They get a care allowance if they take leave to care for someone with a terminal illness or a severe, chronic illness.

The care allowance in the case of terminal illness is 1.5 times the sickness benefit, with a ceiling of EUR 3,640 per month for those who take leave from their work. People outside the labour market get a flat-rate amount of EUR 2,010 per month. The benefit has no time limit, but is normally paid for 2-6 months.

In the case of someone with a severe, chronic illness, relatives are entitled to a care allowance paid by the municipality if the alternative is residential care or if the care involved amounts to a full-time job. The allowance is EUR 2,200 per month. The maximum benefit period is 6 months with a possible extension of 3 months. The period can be split into smaller units and can be shared with other eligible persons.

People aged 12-67 with a disability that reduces their level of functionality can apply for a companion to assist them for a number of hours per week. Disabled people above 18 years of age with a greater need for help can apply for a citizen’s personal assistant. The disabled person receives funding to hire someone according to a needs assessment. The person hired can be a relative.

Care dependants can get financial help to buy a car or modify a home, get costs related to a reduced level of functionality reimbursed, and buy a series of in-kind benefits at subsidised prices, e.g. food, technical devices, and aids. Working-age relatives often achieve a better work-life balance through such benefits for their care dependants.

Most benefits in kind that support relatives to care for dependants are not provided by public authorities but by voluntary organisations. In particular, patient organisations provide emotional, social, psychological, and practical help. The range of support from these and other non-governmental organisations (NGOs) is very great: but its effects on well-being and employment are largely unknown due to lack of data.

Despite more information and a growing number of studies on the effectiveness of certain interventions there is a lack of knowledge on the situation of relatives. Statistics exists on coverage and other aspects of long-term care, but not on the majority of in-kind and in-cash benefits provided at the local level to relatives and care dependants.

Overall, however, there is little doubt that extensive work-life balance measures in Denmark contribute to carers well-being and carers high employment.

Nevertheless, the special needs of relatives are still largely neglected. The policy recommendations of the organisation Carers in Denmark include better legal recognition and rights for carers in various domains, establishment of education for all carers, the provision of care consultants in all municipalities and hospitals, and rights to practical and psychological help. To the extent that such measures can be introduced, the physical and mental strain on the relatives of care dependants is likely to become smaller, and their work-life balance is likely to improve.

1 Description of main features of work-life balance measures for working-age people with dependent relatives

The Danish labour market and welfare model are mutually reinforcing. High labour force participation is key to financing an extensive welfare model. And, vice versa, the extensive welfare model enables traditional carers to reconcile work with care tasks.

Work-life balance measures include measures targeted at care-dependent people themselves, and measures − both in kind and in cash − targeted at working-age people with dependent relatives.

Working-age people have no legal obligations to take care of their dependent relatives. People with disabilities, including children, are entitled to compensation for the consequences of their reduced functional capacities. Taken together this means that formal care provision is extensive and that working-age people are assumed to be working full time. Formal care provision is therefore the main way in which the system supports work-life balance for people with care-dependent relatives. In addition, receipt of a care allowance is a right for every person – relative or friend − who takes leave to take care of a person who is either terminally or severely, permanently ill. Finally, a wide range of in-kind benefits support working-age people and dependent relatives, which, in turn, enable the former to achieve a better work-life balance.

Formal care is primarily provided at the local level by municipalities; care allowances are provided and financed centrally; and many of the in-kind benefits are provided by civil society (not least NGOs and patient group associations, often subsidised by public means).

1.1 Overall description of long-term care regime

Denmark has probably the most extensive long-term care system for the elderly in the world. The goal of long-term care is to increase the quality of life for people in need of care and to increase their opportunities to take care of themselves. The long-term care system does not have an explicit goal of helping working-age people with dependent relatives to achieve work-life balance, but its contribution in this regard is significant.

The system is organised and financed at the level of local municipalities. Long-term care may be provided by way of residential (institutional) care facilities, special housing (typically with nurses attached), or home-based help. The 98 municipalities may deliver the services themselves or use private for-profit firms to provide them.

The system is to a large extent based on help provided in the homes of the elderly, in the form of personal and practical help.

In the last few years policies to support the elderly in their own homes have become more comprehensive. Until recently the strategy consisted mainly of providing help in elderly people's own homes, and of adjusting homes to their needs and capabilities. Now the emphasis in many municipalities is also on rehabilitation and prevention. Rehabilitation is aimed at getting elderly people to become physically and socially better able to take care of themselves. Prevention is enhanced by strengthening their physical, social, and cognitive functional capabilities. This prevention strategy even targets the non-elderly in some municipalities.

New forms of accommodation are another major development in institutional long-term care for elderly people. In particular there has been a marked growth of general elderly people's homes that are specially designed for the elderly but have no staff associated. Most recently there has been an emergence of private care accommodation that is a hybrid between elderly people's housing and ordinary rental accommodation with associated permanent staff.

Today there are thus five types of provision for the 75,333 people living in nursing and elderly people's homes:

- 4,680 people live in nursing homes *(plejehjemsboliger)*: i.e. institutions for elderly people with permanent staff and service areas.
- 943 live in sheltered housing *(beskyttede boliger)* connected to institutions for elderly people, with some having permanent staff and service areas and others operating on an emergency call-out basis etc.
- 37,705 live in elderly people's housing *(plejeboliger)*: i.e. homes for the elderly with associated staff and service areas.
- 31,290 live in general elderly people's homes *(almene ældreboliger)* that are designed to be suitable for people who are elderly or disabled, but without permanent staff or service areas.
- 715 live in private care accommodation *(friplejeboliger)*: i.e. rental accommodation for people with extensive needs for service and care with permanent staff and service areas, outside of the municipal sector. (Danmarks Statistik, 2016)

Which accommodation an elderly person resides in will depend on their needs, on local care policies, and on the vacancies available.

There is a variety of other support offered to people who cannot take care of themselves that relaxes the strain on the work-life balance of people with dependent relatives. These include general schemes such as the obligation for municipalities to offer food and schemes targeted at disabled people.

People who cannot cook for themselves can get help from the municipality. The municipality is obliged to provide food for those who cannot cook because their physical and mental functional capacity is temporarily or permanently reduced or because they have special social problems.

If the person is eligible after a substantive assessment, they are entitled to food in their own home, or to food that can be eaten at another place such as in the catering firm or in a day centre. The price for a main meal must not exceed EUR 7 (2016).

If the person lives in a nursing home or an elderly people's home, there is a ceiling on what the municipality can charge for food. The municipality must not charge more than EUR 465 per month (2016) or more than the cost of producing the food.

Disabled people with reduced functional capacity can apply for a companion *(ledsagerordning)* and citizens' personal assistance (*borgerstyret personlig assistance*, BPA).

The companion scheme is for people with reduced physical or mental functional capacity. The scheme is in addition to – not a replacement for – other help such as practical help in the home.

A disabled person applies for the companion from their municipality. The scheme is for people aged 12-67 years. If a person that turns 67 years has a companion scheme this will not be terminated.

A disabled person who has a greater need for help can apply for citizens' personal assistance, BPA. To be entitled to get a BPA a person must have a significant and permanent physical or mental reduction of functional capacity that necessitates substantial help or that cannot be met by other forms of personal and practical help.

Under the BPA scheme the disabled person hires and directs their own personal assistant(s). The disabled person can transfer the subsidy to a relative, a company or an association, which then takes care of administrative tasks. However, the person must be able on their own to manage their personal assistance on a daily basis.

The municipality grants the disabled person an amount that matches the costs of hiring a personal assistant, irrespective of whether the person acts as employer or transfers the money to a relative, a company or an association. The amount granted is designed to cover the wage costs of the personal assistant based on an individual assessment of personal needs over the day and the week and on the qualification required of the personal assistant. The BPA scheme is not meant to give the disabled person any extra income or expenses. The BPA amount is for budgeted costs, with not-budgeted costs covered based on invoices. The latter costs relate to personal assistants' illness and the illness of the children of personal assistants (parents in general have the right to two paid days of leave with their children, which employers pay), insurance, and costs to meet legal requirements concerning the working environment etc.

The disabled person applies for a BPA from the municipality. The scheme is for people above 18 years of age, with no upper age limit.

Carers under both the companion scheme and the citizens' personal assistance scheme are paid according to wage tariffs set by collective agreements. If the carer needs formal qualifications the wages are regulated by agreements that give wage supplements related to the level of experience and the time in the day and week when care is provided.

It is important to note, in the context of the topic of this report, that disabled people can hire relatives to be their personal assistants. This obviously transforms some of the otherwise unpaid care undertaken by relatives into paid care.

1.2 Description of carers' leave

People who take leave in order to provide care are entitled to a taxable cash benefit, the care allowance *(plejevederlaget)*. There are two forms of care allowance, one for cases of terminal illness and one for cases of significant and permanent illness.

The care allowance in the case of terminal illness is for people who want to take care of someone who is dying in their own home. A doctor must certify that hospital treatment would serve no use, and that the person's condition does not require them to move to a hospital, nursing home or elderly care institution. Also the sick person must agree on the arrangement.

Both friends and relatives are eligible for the care allowance in cases of terminal illness. People both inside and outside the labour market can get the allowance. Those inside the labour market include wage earners and the self-employed. Those outside the labour market include students and retired people.

For people inside the labour market the amount of the care allowance is 1.5 times the sickness benefit that the person would have been entitled to. There is an absolute and a relative ceiling for the care allowance. The absolute ceiling is EUR 840 per week (2016), equal to 1.5 the maximum sickness benefit. The relative ceiling is that the allowance cannot exceed previous income.

People who are outside the labour market are not entitled to sickness benefit and it is thus not possible to give them a care allowance using the formula for sickness benefits. Instead they get a flat-rate amount of EUR 2,010 per month (2016). In very special situations it is possible for the municipality to award a higher care allowance. People receiving the care allowance cannot at the same time get study grants, old age pensions or other social security benefits.

There is no building up of social security contributions on the part of those providing care.

If two or more people share caring responsibilities, the care allowance can be distributed among them proportionately to their share of care. There is no fixed limit to the benefit period: but prognoses are often short, within a range of 2-6 months, and the allowance expires two weeks after the death of the care-dependent person.

The other care allowance is for people in work who take leave to take care of ill relatives. This care allowance is for relatives of a person who is significantly and permanently ill or has a severe chronic or long-lasting illness that requires care in the home. The care allowance is a right for those who qualify. The municipality is obliged to hire someone to provide care in the home if the alternative is residential care or if the amount of care is equal to a full-time job. The care allowance takes the form of a wage of EUR 2,220 per month (2016). In addition the carer builds up pension contributions of 12% per month, with 4% paid by the insured carer (deducted from the wage) and 8% by the municipality on top of the wage. The maximum benefit period is 6 months, but this period can be extended with up to 3 months in special circumstances. The period can be split up into spells of one month. If the employer agrees, the care periods can be split into even shorter spells. The allowance can be shared among more people if they fulfil the conditions for employment by the municipality.

The employer gets the care allowance if they continue to pay the full wage during the care leave.

Although the care allowance is paid to people providing care in the home of a care-dependent person, the carer remains entitled to the allowance if the latter goes into hospital or respite care.

1.3 Description of carers’ cash benefits

Besides the care allowance, described in section 1.2, there are cash benefits that compensate for the loss of income from work for parents of disabled children, and various earmarked cash benefits that reimburse certain expenditures.

Parents of disabled children can get compensation for loss of work income if the parent has to care for the child at home or accompany the child to examinations or treatments related to the disability. The child’s disability must imply a severe and permanent reduction of functional capacity or be a significant and chronic illness. The size of the compensation is determined on the basis of previous gross earnings. The maximum compensation for loss of income in a 37 hour week is EUR 3,920 per month (taxable). There are no time limits on compensation for loss of income.

The other cash benefits that may benefit carers are earmarked for special purposes related to the care and needs of a care-dependent person. Municipalities can provide financial support in respect of expenses related to medical articles etc. if these are not reimbursed elsewhere and if a relative, municipality or hospice takes care of a terminally ill person. The support is not means-tested and is paid to the terminally ill person or their relatives based on invoices.

Municipalities can also reimburse 50% of expenses in relation to necessary aids that are consumption goods that cannot be seen as part of normal households. The latter criterion excludes, for example, computers.

Parents of children with permanently reduced physical or mental functional capacity can get support to buy, or make special interior modifications to, a car. Normally, the support takes the form of an interest-free loan which is not to be paid back in full.

The private, supplementary health insurance scheme, denmark *(danmark)*, subsidises user payments for the private care of a person in the terminal phase of illness in their own home, provided by a general practitioner or authorised nurse. The subsidy is 50% of costs with a ceiling of EUR 1,600 (2016). Denmark has 2.3 million insured members out of a total population of 5.3 million. This benefit helps carers to arrange for death to take place in a familiar setting, and thus increase the well-being of the carer. The public sector does not provide terminal care by general practitioners in people’s own homes. However, many people in the terminal phase of an illness receive nursing and palliative care in their own home.

1.4 Description of carers' benefits in kind

There is a range of in-kind benefits to support carers of people with dependent relatives, including transport, respite support, training, counselling, psychological support, advice and information, and other in-kind benefits.

Transport to doctors and hospitals may in special situations be supported by the municipalities.

The municipalities must offer two types of respite support to spouses, parents or other close relatives who take care of a person with reduced physical or mental functional capacity. Replacement care is offered in the home, whereas relief is offered outside the home, e.g. in a nursing home. Replacement care in the home is seen as permanent home help and is free.

The length of the relief period depends on the purpose. It might be recurring weekends and holidays, and it might be from shorter periods up to periods of several months. Carers must pay for the relief period, with different prices between municipalities; although the prices must not be so high that the carer cannot cover rent and other expenses related to their permanent accommodation. In Rudersdal municipality, for example, the relief period typically lasts up to five weeks per year and each day costs EUR 20 (2016).

Some municipalities have counsellors for relatives with care responsibilities. In larger municipalities these counsellors may be the working relatives of people with a specific diagnosis, e.g. dementia, whilst other municipalities have counsellors working with relatives who themselves are in need of care. The counsellors typically offer individual talks with relatives; opportunities to join networks with other relatives; thematic evenings and café meetings on relevant topics; educational programmes for the relatives of people with specific illnesses; and courses where relatives also learn how to take good care of themselves. Finally, counsellors can give advice on the support and other opportunities for help that are offered by the municipality, and which may be difficult to navigate for people new to the situation.

Groups of relatives may meet to discuss specific needs or problems. They may be managed by professionals or volunteers, or they may be completely autonomous. Often the initiative to set up a group is taken by a municipality, a voluntary centre in municipalities or by an association for patients. Support groups are most often thematically organised. For example there are groups on cancer and dementia. Support groups can promote self-help; facilitate exchange of ideas; allow access to practical advice and knowledge; and provide a community in which it is possible for carers to talk about difficult emotions, gain a better understanding about their situation, and help them to live their lives under the conditions in which they find themselves.

Relatives of people who are in need of care have their own organisation, Carers in Denmark *(Pårørende i Danmark)*. The organisation offers information and tools that enable carers to care; gathers knowledge about carers' needs and suggests how these needs can be met; cooperates with national and local politicians on initiatives for carers; helps carers get better at looking after themselves and at overcoming difficult situations; works to promote the health and well-being of carers; and supports networking between carers.

Carers in Denmark is a member of the European umbrella organisation for carers, EuroCarers. EuroCarers is organizing the European project, InformCare (previously Innovage), which provides information and advice to carers in the EU countries (EuroCarers, 2016).

There are also many patient associations providing vital support to relatives of people with, for example, brain damage, dementia, and Parkinson's disease (see, respectively, Hjerneforeningen, 2016; Alzheimerforeningen, 2016; Parkinson, 2016). Finally, the special interest organisations for elderly people, DaneAge (Ældresagen), and disabled people, *(Dansk Handicap Forbund, DH)*, also provide support to relatives.

The Impartial Consultative Service for People with Disabilities *(Den Uvildige Konsulentordning på Handicapområdet*, DUKH) provides free advice to disabled people and their relatives in different languages. This concerns parents of disabled children, help to parents with reduced functional capacities, and relatives of adults with a disability or serious/terminal illness (Den Uvildige Konsulentordning på Handicapområdet, 2016).

Aids and welfare technology can help to increase the functional capacity of people with physical or mental disabilities. This makes the person more self-reliant and more autonomous. Aids and welfare technology can also support many of the routine tasks that are today taken care of by welfare professionals and relatives. This increases the well-being of the carers and improves their work-life balance.

People in need of care, and their relatives, can apply for aids such as beds, wheelchairs, special cutlery, and adjustments to the home to facilitate care in the home, e.g. installation of an elevator or an alignment of doorsteps. Municipalities have different policies on the extent to which they help in these situations. Carers and the cared for can get help to apply and, if necessary, appeal against decisions related to care support from the patient organisations DaneAge, DUKH or Copenhagen Legal Help (which despite its name gives advice to citizens in the whole country).

As part of its contribution to knowledge-based social policy, the National Board of Social Services *(Socialstyrelsen)*, runs an online database, Assistive Technology Data, which gives information on aids according to target groups, sales agencies, principal court cases, and more (Socialstyrelsen, 2016).

2 Analysis of the effectiveness of work-life balance measures for working-age people with dependent relatives

Danish work-life balance measures for working-age people with dependent relatives are integral parts of the Danish welfare model and flexicurity model. They consist of a wide range of social and health services that are key to the Nordic welfare model. They are part of the universal social services in the flexicurity model that come together with loose employment protection and accessible, generous benefits, and extensive active labour market policies, to create a flexible and secure labour market. In this report we focus on work-life measures for working-age people with caring responsibilities arising from a severe, chronic or terminal illness or disability that reduces a dependant’s physical or mental functional capacity, irrespective of age.

The general move towards evidence-based policy making is also widely observed in the field of care for people with reduced physical and mental functional capacity. Studies in this area focus on specific interventions and their cost-effectiveness and comparative costs and benefits. However, the studies do not cover the effects on the working-age relatives of care-dependent people. Nor can general policy conclusions be derived from the findings from the study of specific interventions. For example, studies on the use of Critical Time Intervention or Assertive Community Treatment cannot provide general conclusions that can be transferred to a policy field. Instead our analysis must rest on more general data on the various measures.

The analysis of the effectiveness of work-life balance measures thus rests in part on the quality and availability of relevant data. Whereas data is very good for long-term care there is very little data on measures for working-age people themselves, such as care leave and in-kind benefits. Moreover, there is generally no data on take-up of benefits, including long-term care, care allowances, and other in-cash and in-kind benefits.

2.1 Assessment of individual measures

As described above, the long-term care system consists of homes for the elderly and help provided in an elderly person’s own home by nurses and social workers. Although no take-up statistics exist, waiting time may be a proxy indicator of unmet need. On average the waiting time for nursing homes and elderly people’s homes increased from

20 to 26 days between 2011 and 2014. In total, 37 out of 98 municipalities have a waiting time that exceeds one month (Danmarks Statistik, 2016). There is no available data on waiting times for relatives' in-kind benefits.

The coverage of long-term care is well documented. In 2015 75,333 people lived in nursing and elderly people's homes (Danmarks Statistik, 2016). The number living in such homes has been stable since 2011, but as the average age of the population has risen, the relative share of the elderly among residents of the homes has gone down. Thus between 2011 and 2015 the total number elderly people in nursing and elderly people's homes went down by 3% at the same time as the number aged above 65 years in the general population grew by 10%.

The gradual shift away from institutional care to home-based help that started in 1987 has also meant that on average people residing in institutional care are older and frailer. In 2014 the share of elderly in institutional care was 5.4% of persons aged 75-79 compared with 6.2% in 2011. In the same period from 2011 to 2014 the similar share fell from 12.5% to 11.0% for persons aged 80-84, from 23.0% to 21.1% and from 41.4% to 39.7% (Danmarks Statistik, 2012, 2014, 2015). When only very old and frail people, are in institutional care it means that a larger amount of care is provided in the homes, in part by the relatives of those dependent on care.

Even more marked is the shift from nursing homes to elderly housing since 1987. The number of people living in nursing homes has gone down from 49,088 in 1987 to only 4,680 in 2015 (Danmarks Statistik, 2012, 2016). Conversely, the number living in elderly people's homes has increased from 3,356 in 1987 37,705 in 2015.

The long-term care system is currently undergoing a process of retrenchment and reorganisation. Retrenchment takes the form of fewer benefits offered to fewer people. In this way retrenchment results in less formal care, more care given by working-age relatives, or both.

Reorganisation of long-term care concerns an increased focus on prevention and rehabilitation. To the extent that prevention and rehabilitation increase functional capacity, this results in a reduction in the need for care and thus in the care needing to be given formally and by working-age relatives.

Austerity made the Parliament adopt stricter regulation of municipalities' finances. In turn the municipalities were even more prudent than required by the Parliament. As a result there has been a *de facto* retrenchment of home-based help even in the absence of explicit policies at the central or local level. In total the number of home help hours in Denmark went down by 37,801 per week between 2011 and 2015 – equal to a reduction of 7.4% or nearly 2 million hours per year (Danmarks Statistik, 2016).

Unfortunately, there are no systematic evaluations of how individual measures affect the employment or well-being of carers and dependent relatives. There are many studies on the self-reported perceptions of the quality and quantity of individual measures, in particular of long-term care, including home help (see Kvist, 2016).

Although the long-term care system is largely free or heavily subsidised there is a skew profile in the care that relatives provide according to their income. Proportionately more people from low-income groups are involved in caring on a weekly basis than those from higher-income groups. For example, 8.7% of people from the lowest income quartile are involved in caring either every day (1.7%), several days a week (1.0%) or once or twice a week (6.0%). In comparison only 3.4% from the highest income quartile are involved in caring either every day (0.3%), several days a week (0.8%) or once or twice a week (2.3%). The rich, however, see their care relatives more often than poor persons with shares of, respectively, 16.1% and 9.0%. It seems safe to conclude that visits at this frequency reflect care of a more social nature and are not the personal or practical help that is needed on a daily basis (Eurofound, 2012).

In 2014 municipalities spent EUR 25.8 million on care allowances and cash benefits to pay for medical articles needed in the care of terminally ill people in their own home (Danmarks Statistik, 2016).

Unfortunately, there is no publicly available data on the number of people who take up care allowances. However, large differences can be expected in the coverage, amount, and quality of in-kind benefits as these are organised by 98 municipalities and a large number of NGO's and patient organisations.

The well-being of carers and the cared for has a strong gender profile. This is clear from objective measures and subjective measures. Indicators on life expectancy and quality-of-life years show that men on average live for fewer years than women but that men have fewer years with a bad quality of life. In 2013 Danish women had a life expectancy of 20.4 years at age 65, which was less than the European Union (EU) 28 average of 21.3 (Eurostat, 2016). For men life expectancy was 17.7, which was also less than the EU 28 average, of 17.9. At age 65 women could expect 12.7 healthy life years, which was markedly higher than the EU 28 average of 8.6. Men could expect 11.6 healthy life years, which was better than the EU 28 average at 8.5 but worse than Danish women. Whereas men could expect 6.1 years of bad health in old age, women could expect 7.7 years.

The overall life satisfaction of Danes is 8 on a scale from 0 to 10. Together with Sweden and Finland this is the highest level in the EU. In sum it seems that the extensive provision of social, education, and health services in the Nordic countries does not compromise the general life satisfaction of the population and has a positive influence on the number of disability-free years in old age, although longevity still lags behind neighbouring EU countries.

2.2 Assessment of overall package of measures and interactions between measures

The Danish labour market and work-life balance measures reinforce each other. High employment results in more taxes, which in turn contribute to the financing of work-life measures. Conversely, work-life measures result in more carers being able to work, thus increasing employment.

The extensive long-term care system helps to explain the comparatively low proportion of Danes who are involved in caring for their elderly or disabled relatives. Denmark has the lowest share of men and women relatives, both at 1.3%, who provide care on a daily basis (Eurofound, 2012).

The division of care labour between the state and civil society, most notably families, is in part conditioned by history and culture, demography, and the extent of formal care. In Denmark the expectation is that the state, i.e. municipalities, provides most of the care that is related to medical and personal care. The family and civil society is expected to take care of more social aspects of care.

The best indicator for the division of labour is probably the day-to-day care of elderly and disabled relatives. If the formal provision of care is high, we would expect comparatively low levels of family relatives involved in care, and vice versa. The low share (1.3%) of both men and women caring for their elderly and disabled relatives indicates that Denmark in comparative terms has a large long-term care sector with high take-up. Within the 1.3% are to be found people on care leave and those with disabled children, besides those involved in social and practical care, the latter including a growing number of immigrants with a different culture and norms about care of relatives.

On this basis Denmark has a comparatively well-functioning long-term care sector and health system. However, this is not to say that there are no strains on relatives arising from the needs of care dependants. Indeed relatives play a central role in navigating the complex system of public provision, which differs between municipalities, as those in need of care may be unable to do so themselves. At the same time relatives often face obstacles when seeking to act on behalf of their care dependants (see also policy recommendations below). Hence, if we move away from the numbers on coverage and take-up of long-term care, and focus on the qualitative experience of family carers, the picture changes. Indeed the vast number of patient organisations and their extensive advice and support services for carers show that carers have needs that are not covered by public provision.

In addition, the labour market is flexible in that 45% of both men and women do not have fixed start and finish times in their work (Eurofound, 2015). In comparison the same is true for 34% of women and 44% of men in the EU overall. This flexibility may help relatives to find time to care for elderly and disabled people without compromising their participation in the labour market.

Although the same share of men and women have no fixed working time, the gender-segmented nature of the labour market and the persistent gender pay gap still makes it more economically advantageous for families to have the woman take care of elderly and disabled relatives.

Even though Denmark does not provide regular statistics on the employment rate of working-age people with care-dependent relatives, more general statistics may provide important insights into the general workings of the system. Employment rates for persons, in particular for women as traditional carers, may be the best indicator. And if we want to focus on care dependents that are ill we may get the best proxy for older workers which is defined by Eurostat as persons aged 55-64 years. In 2014, the employment rate of Danish women aged 55-64 was 57.6% compared with 45.0% for women in the EU on average (Eurostat, 2016). This may indicate that the overall working of the Danish care system contributes to employment, since women in this age group have traditionally been expected to take the main burden of caring for dependent relatives. As the employment rate of older men is 63.2% in Denmark, and 51.8% in the EU overall, one may add that the system also works for men. But when comparing the employment rates of older men and women we can see that there is a marked gender gap, suggesting that, also in Denmark, work and care are not shared equally between the sexes.

2.3 Policy recommendations

The relatives of people whose functional capacity is physically and mentally reduced make a significant contribution to the well-being and quality of life of those who are dependent on care. Relatives are an important source of care for children, elderly people, the severely ill, and disabled people. At the same time many relatives providing care suffer both physical and mental strain.

Due to an ageing population and budget constraints, in the foreseeable future the role of relatives is likely to become even more important, rather than the reverse. The debate on who should care for whom, in which ways and under what conditions, will continue. Some on-going reforms are focused on how to improve collaboration with civil society. A similar focus could be adopted on the contribution and situation of working-aged relatives.

In the case of dementia, for example, the National Board of Social Services initiates and collects systematic research on how to strengthen the collaboration between relatives, volunteers, and voluntary organisations. The findings are used as the basis for guides to authorities on how to collaborate with relatives. Similar initiatives could be applied to the relatives of other groups of chronically ill and/or disabled people.

Fully adopting a life-course perspective on health, ageing, and disability might be another impetus for reforms. The emphasis on prevention and rehabilitation is already evident in many recent policy reforms – for example, long-term care, disability pensions, and sickness benefits –and in many cost-effectiveness and cost-benefit analysis of methods applied in social work. The impact of policy reforms in a life-course perspective on the work-life balance of working-age people with care- dependent relatives and on those who depend on care could be made more transparent.

The potential of this approach can be illustrated by reference to the strong gender profile of carers' well-being. Men have shorter life expectancy on average than women, who more often outlive their partner. In part for this reason most of the relatives caring for their partner in old age are women (the same is true in the other so-called gender-friendly Nordic countries). At the same time, women have more years of bad health in old age than men, and often these women cannot get care from a partner. As ageing and health is a life-long process, one policy recommendation could be that more emphasis should be placed in earlier life stages on men's physical health and on women's social networks. Working-age men could, for example, be called to regular medical checks, since men are less likely than women to contact their doctor. Working-age women could get help establish and maintain social networks to prevent solitude in old age. Such a life-course perspective on ageing and health could help to reduce the number of those who depend on care by others, as well as improving the well-being of care dependants and their relatives.

An even greater emphasis on evidence-based studies, along with better knowledge dissemination to municipalities, clients, and relatives, might promote upward convergence, as some solutions constitute win-win situations for all involved.

There are numerous other policy initiatives that could help to improve the situation of working-age people with care-dependent relatives. To the extent that such initiatives mitigate or prevent some of the current physical and mental strains on working-age people, this is likely to improve not only their well-being but also their employment and productivity.

The organisation Carers in Denmark points to three issues that could improve the situation of carers, namely: education of carers, a carer consultant in all municipalities, and improvement of the quality of respite offers (Carers in Denmark, 2016).

Care education should be offered to all those with dependent relatives. The education should focus on:

- *skills* to undertake care tasks such as medicine security, move techniques, aids, and nutrition;
- *knowledge* that enables relatives to navigate social legislation, legal questions related to warrants and guardianship, and other relevant topics; and
- *competences* that enable relatives to cope in their new life situation and to take care also of their own physical and mental health.

These ideas relating to the care education come from the municipal patient schools. Patient schools teach patients how to better manage their life with illness, e.g. persons with diabetes learn how to take medicine, live healthier lives etc.

Few municipalities have a care consultant. A care consultant mainly helps people get the right care and inform the care dependant and relatives about their possibilities for support in the municipality. Carers in Denmark suggests that their work should be evaluated, that municipalities should be required to hire consultants, and that a national standard should be established for care consultants and their possible tasks.

The scope of respite support varies between municipalities. However, according to Carers in Denmark, most of the respite offers are of bad quality. The offers should be improved to reach the same quality of care as that offered to people in residential care. Respite homes should be bookable, fully furnished, and should contain all necessary aids. Finally, there should be a national minimum for the number of respite weeks.

Next to these cardinal proposals, Carers in Denmark (2016) proposes to give carers additional rights in a number of areas, i.e. inclusion, practical help, own time, own life, and recognition. The aim is to improve the situation of carers and to make them partners in the care and treatment of their dependent relatives.

Relatives should get rights to inclusion. The rights of relatives to be involved in the management of their relatives' cases should become more transparent and enforceable; education for social and health staff should include knowledge on how to collaborate with relatives; relatives should be offered talks with doctors respecting their secrecy; clear guidelines should be issued on care dependants' transitions, e.g. from children to adulthood at age 18 or after an illness; and all hospitals should have relative consultants.

Relatives' rights to practical help should be strengthened. Primary relatives who live with a sick person should be individually assessed for practical help in the same way as single people. The practical help should be more flexible, and should enable relatives who undertake certain tasks to free resources to be used on other tasks. Relatives should always participate in the first meeting with the municipality along with a care consultant from the municipality. Relatives should be involved in the discharge of patients and given the necessary aids in advance of discharge.

Relatives' rights to own time should be improved. Caring days should be introduced for the relatives of disabled adults , chronically ill people, and those with life-threatening diseases. Care leave should be extended beyond the current 6 months plus 3 months and it should be possible to take up care leave on a part-time basis.

Relatives' rights to their own life should be strengthened. There should be a single digital access point to all benefits of relevance to relatives, irrespective of whether they are provided by national, regional, local, or NGO agencies. Information on the number of non-paid carers, i.e. relatives with regular caring tasks, should be made publicly available by the national statistical agency. Relatives – adults and children – should be given a right to psychological help after the expiration of the current 12 months rule (following the establishment of a diagnosis).

Relatives' rights to recognition should be increased. There should be a registration system for relatives who care for dependants, to enable health authorities to monitor the care provided and to make alternative arrangements where care is inadequate. Formulating a policy on relatives should become mandatory for municipalities and encouraged for companies.

Finally, in order to properly assess the quality and effectiveness of various measures in relation to to working-age carers, *more data and evidence* is needed. In this regard, the general move to evidence-based policy should be welcomed as it entails better documentation underlying policies. For relatives it is particularly important that this information is also used to inform policy-making and that the information is made publicly available.

Because municipalities are responsible for many of the services and benefits for those needing care, there are large differences in work-life balance for working-age people who are in an identical situation with regard to their care dependants but who happen to live in different municipalities. Inequalities in work-life balance measures are inevitable in a system based on local provision, and it is recommended that more use should be made of minimum standards in order to stimulate a process of upward convergence. To this end *more studies* are needed to inform policy-making, along with the additional data and evidence called for above. In the light of the human and economic costs involved it is surprising that greater efforts are not put into such studies. The European Commission may have a role to play in this area, as a funder of studies and broker of evidence – a halfway house between academia and policy-makers.

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