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

Iceland

2016

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The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.

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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The system of long-term care (LTC) for working-age people with dependent relatives consists of **institutional care homes** (nursing homes or service homes for the disabled), **support and day care** facilities, as well as **leave provisions** for carers and **benefits** in cash and kind for carers or the dependent.

In 2011, the provision of services to individuals with disabilities (and their families) were moved from central government to local municipalities, some of which join together to form joint service areas. Rights and services are based on legislation no. 59 from 1992 with updates until 2012. Parents have legal responsibility to care for their children until age 18.

The Icelandic care services for the disabled or long-term patients, as well as for the frail elderly, are collectively the responsibility of the government, local authorities and third sector voluntary organisations (mainly not-for-profit). Government primarily provides framework legislation on rights and provisions, quality surveillance and finances the largest part of services (both at central and local level), but also for the third sector organisations.

About 0.5% of all individuals under age 65 live in institutions or service housing for disabled individuals and about 1% of the population 65 and under are disabled individuals that receive home help from municipalities. This is similar or higher than in the other Nordic countries.

Almost all (99.6%) disabled children and youth under age 18 live in their parents' or relatives' homes, but this changes significantly up the age scale. Living with parents/relatives is down to 46% for those 18-39 years of age and 3.7% for those 40-66 years of age. So the majority of disabled individuals gradually obtain independent housing conditions in special purpose institutions or service housing.

The first significant leave provision for carers of sick or disabled children is the right for employees to apply to their labour union's sickness fund for sickness pay for up to 9 months. This applies equally to their own illness or that of their children. This also applies for children with serious lack of capabilities/disabilities. The length of the leave can vary between sickness funds. It is longest for public employees but generally from 6 to 9 months for every 12 months in the private sector. During this leave the carer will enjoy 80% of former total pay (averaged over the last 6 months).

Social Security provides a universal carer's allowance ("*Umönnunargreiðslur*"). This compensation is for parents of disabled or long-term sick children, in cases of great caring needs and extra costs due to the illness (based on legislation 99/2007 and regulation 504/1997). This is financed by taxation, through the public social security system. Parents get a monthly tax-free payment, depending on an assessment of the severity and caring need.

The maximum allowance is equal to about 92% of the universal unemployment benefit (as of January 2016), which however is a modest sum (EUR 1,439). Many get less. The benefit is payable until the child reaches age 18 and qualifies for universal disability pension. This eases continued employment participation with breaks or reduced work volumes, at least in the first years after the onset of dependency. The low sum available means however that there is an incentive for parents to continue work at full pay if at all possible.

But in the overall picture it is institutional support that makes the greatest difference to the possibility of continued employment participation by individuals with dependent children or relatives in need of extensive care.

The big majority of Icelandic women caring for dependent family members are actively employed (92%) and caring activity is an uncommon, almost insignificant, reason for inactivity in the labour market. Hence the indication is that the LTC system in Iceland

succeeds to a large extent in facilitating employment participation of individuals aged 20-65 who have disabled family members in need of extensive care.

1 Description of main features of Work-Life Balance measures for working-age people with dependent relatives

1.1 Overall description of long-term care regime

On the whole, the system of long-term care (LTC) for working-age people with dependent relatives consists of **institutional care homes** (nursing homes or service homes for the disabled), **support and day care** facilities, as well as **leave provisions** for carers and **benefits** in cash and kind for carers or the dependent.

In 2011, the provision of services to individuals with disabilities (and their families) was moved from central government to local municipalities, some of which join together to form joint service areas. The rights and services are based on legislation no. 59 from 1992 (Lög um málefni fatlaðs folks) with updates until 2012. Parents have legal responsibility to care for their children until age 18.

The Icelandic care services for disabled or dependent persons, as well as for the frail elderly, are collectively the responsibility of the government, local authorities and third sector voluntary organisations (mainly not-for-profit). Central government primarily provides framework legislation on rights and provisions, quality surveillance and finances largest part of services (both at central and local level), but also for the third sector organisations. They frequently get contracts for service provision, with the government paying the operational costs, (such as charges on a per-bed/person-per-day basis). Voluntary organisations of individuals belonging to a particular disease group and the general organisations of the disabled (ÖBÍ) are particularly active in providing services to their members, including housing provisions[1]. Many service homes for the elderly are also of this third sector type, reflecting a very active relationship between the government, local authorities and the civil society voluntary sector in the provision of welfare services[2]. This form often has the added benefit of producing employment opportunities for people with disabilities. In addition to these formal services, significant informal services are also provided by relatives and neighbours (support families), which make a difference in a tightly knit small-scale society, such as the Icelandic one, which has about 330,000 inhabitants (Egilsdóttir and Sigurðardóttir 2009; Sigurðardóttir 2010; NOSOSKO 2015).

All individuals with reduced capabilities have access to such special housing, but there may be significant waiting times in some areas, counted in years. The institutional system and the home help provisions (nursing and caring assistants) are perhaps the most important aspect of the LTC system for facilitating employment participation by individuals of working age who have dependent children or relatives. The following tables and graphs show the extent and characteristics of the use of institutional services and home help.

[1] See for example www.obi.is; www.saa.is; www.sjalfsbjorg.is.

[2] See for example Sólheimar (http://www.solheimar.is/en/); also www.hrafnista.is; www.eir.is; www.grund.is; http://www.island.is/efriarin/busetumal/hjukrunarheimili-umsokn.

Table 1: Disabled people under age 65 living in institutions or service housing in Iceland and other Nordic countries in 2014.

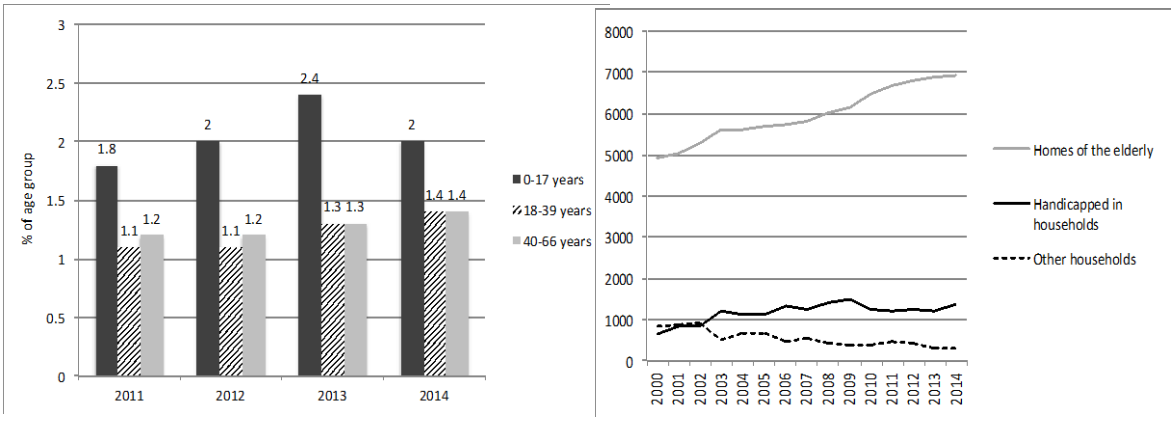
	Denmark	Finland	Iceland	Norway	Sweden
Disabled living in institutions or in service housing					
(% of population under age 65):	0.2	0.5	0.5	0.7	0.5
Disabled receiving home help					
(% of population under age 65)	0.6	0.1	1.0	1.1	0.3

Institutiona are nursing homes or homes for the long-term ill. Service housing is sheltered housing, service flats or collective housing (sambýli). Source: NOSOSKO 2015.

In the Nordic community Iceland has for some years had the reputation of having a relatively large number of long-term-care beds in institutions, especially for the elderly, as well as providing home help to a great extent in comparative terms (Ólafsson, 2015). Here we profile the situation for people with disabilities who are under age 65.

About 0.5% of all individuals under age 65 lived in institutions or service housing for disabled individuals in 2014. That was a similar proportion to Finland and Sweden, higher than in Denmark and lower than in Norway. Iceland and Norway however had the highest proportion of this age group receiving home help in 2014, about 1-1.1%. The proportions for Finland, Sweden and Denmark were significantly lower.

Figure 1: Persons with disabilities receiving any services from municipalities 2011-2014 (left diagram), by age group, and numbers of household types receiving home-help 2000-2014 (right diagram).



Source: Statistics Iceland

Figure 1 gives an overview of the extent of the services provided by municipalities to persons with disabilities. The left hand diagram shows the development of overall services received, by age groups, from 2011 to 2014. The service is most often directed at the youngest individuals, aged 0-17, while the proportions of service receipt for 18-39 and 40-66 year olds are simiar but at a lower level. The right hand diagram shows the number of households with handicapped individuals which received home help in comparison with the elderly and others. There was not a significant increase in the number of households with handicapped individuals receiving home help between 2006

and 2014, while the number of elderly receiving home help increased significantly. Home help can cover nursing, general services, cleaning, food on wheels and the like.

In table 2 we analyse the residential situation of persons with disabilities or long-term illness receiving care services from municipalities in 2014, by age categories.

There we see that for the whole group, just under half lived with parents/relatives (48.5%), about 11% lived in their own housing and 3% rented in the general market. The rest lived in facilities specifically provided for this group or rental housing from non-profit welfare organizations. This is however very age dependent, as columns 2 to 5 show.

Almost all disabled children and youth under age 18 live in their parents' or relatives' homes, but that changes significantly up the age scale. Living with parents/relatives is down to 46% for those 18-39 years of age and 3.7% for those 40-66 years of age. So the majority of disabled individuals gradually obtain independent housing conditions, either in special purpose institutions (about a third) or rented accommodation (another third). About 23% of the 40-66 year olds lived in their own accommodation. For disabled individuals aged 67 and over the rate for own accommodation was 39% on average and the biggest part of the rest lives in special purpose accommodation for the elderly or disabled. The elderly as a whole have a much higher rate of own accommodation.

Table 2: Persons with disabilities receiving service from municipalities in 2014, by type of residence and age.

	Total	0-17 years	18-39 years	40-66 years	67 years and older
Total	100	100,0	100,0	100,0	100,0
Single dwelling facilities for disabled	5.2	0.1	4.4	10.9	8.9
Other assisted living facilities for disabled	11.1	0.1	13.7	21,0	11.1
Assisted living facilities for elderly	1	-	-	0.8	11.8
Retirement homes for elderly	0.5	-	-	0.8	4.5
Rented dwelling municipal ownership	11.2	0.2	15.9	19.8	7,0
Rented dwelling owened by non-profit organisations	5.3	-	5.6	10.1	9.6
Lives with parents/relatives	48.5	99.6	46,0	3.7	1.3
Rented dwelling general market	3	-	5.8	4.2	1,0
Owner occupied dwelling	11	-	4.9	23.3	38.5
n.a.	3.2	-	3.8	5.5	6.4

Source: Statistics Iceland

From age 30-39 most disabled obtained housing outside the orbit of parents or relatives. Home nursing and home help are of major importance for these groups, as indeed they are for parents caring for young disabled in their homes.

With rights being universal, and taking account of the types of disabilities and special needs, this aspect of the LTC system for the disabled is the most important for making it possible for family members of working age to undertake active employment, fully or partly. But waiting for the proper conditions to materialise may take years and impose a large care work toll the the from family members of working age. Universal access to nursing homes and home help/nursing for the elderly also means that the burden of caring for disabled elderly parents is primarily solved by institutional means. Regular visits outside working time are however the norm in such situations.

Other support measures are also of importance, such as family support, respite and day care facilities, which provide rest and relief for caring families. So do some leaves provisions.

1.2 Description of carers' leaves

The most significant leave provision for carers of sick or disabled children is the right of employees to apply to their labour union's sickness fund for sickness pay for up to 9 months. This applies equally for their own illness. The length of the leave can vary between labour unions, each of which has a sickness fund for its members (it is longest

for public employees but generally from 6 to 9 months for every 12 months in the private sector).

During this leave, the carer (who must have previously worked full time for at least 6 months) will enjoy 80% of their former total pay (averaged over the last 6 months). This provision is cumulative with the right to retain pay for up to 1-3 months (depending on length of service to the employer) during one's own or one's child's sickness.

Most employees are members of labour unions (85-90% - cf. Ólafsdóttir and Ólafsson 2014) and they all enjoy this right.

In addition employees enjoy the right to retain the employment relationship in case of sickness or accidents in the family, even if they take an unpaid leave from their job (legislation 19/1979). There is often the possibility to reduce working hours, for example to 50%, with 50% pay. There are no formal leave provisions for carers of elderly relatives, since institutional provisions are generally universal.

Since many work places are small in the Icelandic context, there is often considerable flexibility and consideration in cases of this kind, such as those requiring flexible work time and reduced work volume.

If a person of working age, who is not a pensioner, cares for an elderly or invalid spouse, he/she can apply for a caring allowance from social security, to compensate for reduced work participation. This allowance is called the "Spouse and care allowance for the elderly" (Maka- og umönnunarbætur aldraðra) and provides a modest compensation.

1.3 Description of carers' cash benefits

Social Security provides a universal carer's allowance ("*Umönnunargreiðslur*"). These are compensations for parents of disabled or long-term sick children, in cases of great caring needs and extra cost due to the illness (based on legislation 99/2007 and regulation 504/1997). This is financed by taxation, through the public social security system.

Parents receive a monthly tax-free payment, depending on the assessment of the severity and caring need. The provision grades the support into 5 groups, depending on severity of sickness/disability and extent of caring needs (separately for disabled/retarded children and for long-term sick children). The following table provides the sums for the disabled/retarded, which are discrete for each case and taka account of family conditions.

Table 3: Amount of care allowance for parents of disabled children, January 2016. Sums in Euros.

	Caring need:		
Severity:	**100%**	**50%**	**25%**
Grade 1	1,118.9	559.5	279.7
Grade 2	951.1	481.2	279.7
Grade 3	783.3	391.6	279.7
Grade 4	0	0	279.7
Grade 5	0	0	0

Source: Social Security Administration

Given that these are tax-free payments, the amount is more valuable than might seem at first glance. The maximum is equal to about 92% of the universal unemployment benefit (as of January 2016), which however is a modest sum compared to wages. The benefit is payable until the child reaches age 18 and qualifies for disability benefit.

The allowance is not paid if the child is cared for outside the home (in an institution) and if it is in respite service (rest care with a support family or in an institution) for more than 8 days consecutively the allowance is reduced.

Parents also have a right to discretionary supplements for outlays related to the child's special needs (medical services and medications, equipment etc.) and are required to provide proof of that extra cost (receipts for special costs incurred).

There is also a provision called "Parental allowance for long-term sick or seriously disabled children, when parent stops working". This is payable for up to 6 months if a working parent stops working (after 14 days from child's certification of sickness or disability). The amount is maximum 80% of average total earnings for the previous 4-6 months – up to a limit that is near average pay in the labour market. This right is only provided after the applicant has fully utilised his/her right to retaining pay from their employer and has fully used their union sickness fund rights. So with full compensation a parent can have such support for up to 15-18 months (depending on length of service with the present employer), i.e. jointly for sickness pay from employer, union sickness benefit and Parental Allowance from Social Security.

Parents who are in full education have a comparable Parental Allowance right for up to 3 months (if they were active in employment for at least 6 months before starting of present education programme). Parents who are outside the labour market have a less generous right to some minor financial support, if they cannot work or study due to the child's condition and caring needs.

During the support period time has in general to be spent on caring for the child instead of working or studying. Recipients of these allowances have to be resident in the country.

Lastly, there are provisions for individuals of working age caring for a spouse who is a pensioner, most often a disability pensioner (Maka- og umönnunarbætur). This is primarily aimed at compensating reduced work participation, caused by caring for the spouse. The carer and pensioner have to live together. The carer may not be a pensioner himself/herself. If the carer is 67 years of age and stops working but has an occupational pension below ISK 230,000per month (EUR 1,611) he/she has a right to an income-tested supplement from Social Security, up to a limit. A couple may not however own net assets worth more than ISK 8 million (EUR 56,000). On the whole, these support measures are primarily effective for the lower income population and those with fewer net assets.

Seriously disabled individuals (disability pensioners) have a right to a grant for buying a car every 5 years, and a supplementary subsidy on the operating costs of a car (petrol, maintenance etc.).

1.4 Description of carers' benefits in kind

Parents have a right to respite support, either from a support family or caring institution. Support families get paid by the local municipality, between ISK 11,330 and ISK 19,015 per 24 hours (EUR 73-133), depending on caring needs (3 levels).

The National Association of Intellectual Disabilities (Þroskahjálp) provides counselling, training and psychological support to families of carers, as do the Municipality Social Services and the counsellors of the Social Security Administration (TR). The same applies to information on rights and benefits and assessments of caring needs.

Families of disabled individuals have rights to subsidies on the cost of special equipment (Hjálpartæki) from Icelandic Health Insurance (SÍ).

During the past 5 years **NPA service** (Notendastýrð persónuleg aðstoð – e:User-directed personal assistance) has been offered in some municipalities as an experimental project. The experimental period is due to end in 2016, but the provision is likely to be legalised as part of the legislation on the rights of disabled individuals (law 59/1992) This is aimed at individuals with very high service needs (for example MND patients etc.). The long-

term sick/disabled individuals receive an allowance to pay for caring services, undertaken by assistants who come into their home and work in principle under the direction of the dependent individual. The carers work according to a collective agreement and their pay is in the region of what prevails for low paid service jobs.

Lastly, individuals with disabilities have general access to transportation services provided by municipalities. These facilitate independent living as well as participation in work, education and community for the individuals themselves and their families. This is paid for by the user but significantly subsidised.

2 Analysis of the effectiveness of work-life balance measures for working-age people with dependent relatives (max 4 pages)

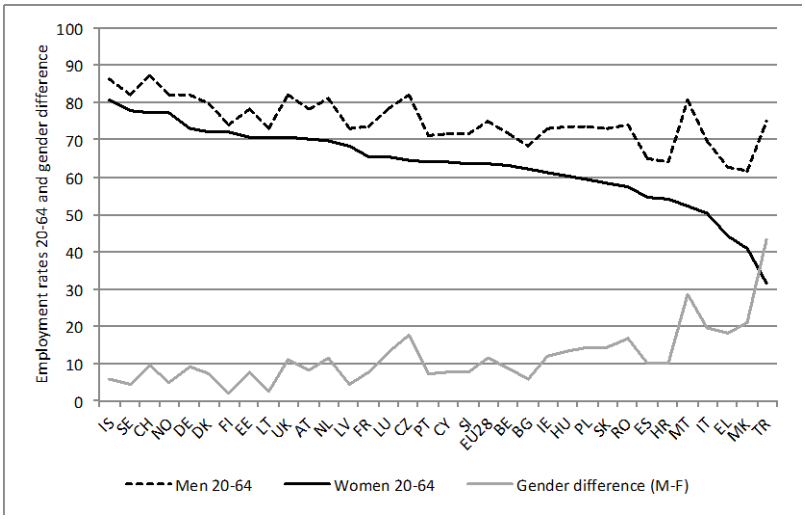
As indicated in tables 1 and 2 above, about 0.5% of the population under age 65 are disabled individuals who live in institutions or service flats. About 1% of the population under age 65 is disabled **and** receives formal home help from municipalities' Social Services. Disability pensioners aged 65 and under are however about 7.5% of the population of working age (TR 2014).

Figures from Statistics Iceland indicate that about 48% of persons with disabilities receiving some care services are living with their parents or relatives. This is however primarily applicable to the youngest disabled individuals. After age 18 the proportion living with parents gradually declines and by age 40-66 the average is less than 4%.

While it may be very trying to wait for the proper facilities for individuals that are cared for in the homes of parents or relatives, the great majority are eventually cared for in some form of institutional care facilities or in service housing. This facilitates full or partial work participation by individuals of working age with dependent family members.

Leave provisions, home help and caring benefits/allowances generally ease the caring work done in parents' homes and most likely facilitates further continued work participation by caring parents or spouses. The leaves are temporary and the benefits/allowances are moderate and are therefore not likely to have any significant work-disincentive effects. While this has not been researched in depth, the figures on employment participation of individuals of working age in Iceland – and work participation of women specifically – are amongst the highest seen in Europe and have been so for a long time. Figure 2 gives an overview of employment participation and gender differences in Iceland and in other EU countries.

Figure 2: Employment rates for age group 20-64 and gender difference in 2014.



Source: Eurostat

Icelandic women of working age have the highest employment rate while Icelandic males share that status with Swiss males. The gender difference in employment rates in Iceland is accordingly amongst the lowest.

Employment participation of people with disabilities in Iceland has also been amongst the highest seen amongst OECD-countries (Hannesdóttir, Thorlacius and Ólafsson 2010).

Hence the indication is that the LTC environment in Iceland helps individuals of working age who have dependent individuals in their household to maintain employment participation, full or partial.

Flexibility in working places is also likely to prevail, given that many work places are relatively small and tightly knit socially. Iceland was not included in the Eurofound Quality of Life Survey, but older data (1990 and 2005) indicate that there was considerable flexibility with regards to organising working time and taking short-term leaves without too many consequences for work security or pay (Stefán Ólafsson 1990; Guðmundsdóttir 2001; Bjarnason 2009).

2.1 Assessment of individual measures

2.1.1 Carers' leaves

There is a lack of data about the extent and characteristics of carer's leaves.

2.1.2 Carers' cash benefits

In 2014, 4,830 individuals with disabilities were receiving some form of services from municipalities or other services. About 2,151 were receiving Care Allowance (CA) cash benefit (*Umönnunarbætur*) in that year, or about 45% of service recipients.

In principle, every individual with disabilities has the right to services and care so the system is universal in character, but due to the partial use of institutional care and the modest sums involved, take-up is not universal or complete at any one time.

A long time may pass before the transition of caring and residence from parental homes to institutional or service flats is accomplished, and that also explains why everyone does not get Caring Allowance at any point in time. It is primarily parents of young disabled or long-term sick individuals who get the Caring Allowance. They do not qualify for the Caring Allowance after their dependent is cared for in institutions. The indication is thus that effective coverage and take-up are relatively high. Only a part of the overall caring time can however be covered due to the conditionality of the allowance.

About 0.2% of pensioners receiving social security benefits get the Spouse and Carer's Allowance for the elderly.

2.1.3 Carers' benefits in kind

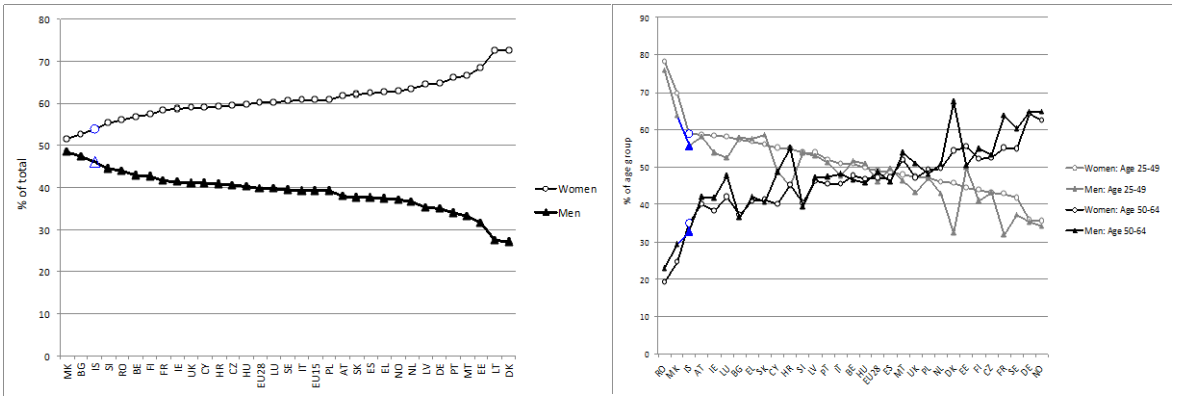
There is a lack of data on take-up and coverage of carer's benefits in kind.

2.2 Assessment of overall package of measures and interactions between measures

On the whole the carer's leaves and benefits in cash and in kind are particularly important for carers of dependent family members immediately after a child or a related adult (spouse or parent) is certified as having severe disabilities, has a serious accident or becomes seriously ill. These facilitate fundamental adjustments within the family until the disabled child reaches age 18 (and qualifies for disability pension) and this eases continued employment participation with breaks or reduced work volumes, at least in the first years after the onset of dependency. The low sum available means that there is an incentive for parents to continue work if possible.

But in the overall picture, it is institutional support that makes the greatest difference to continued employment participation by individuals with dependent children or relatives in need of care.

Figure 3: Proportion of women and men regularly taking care of relatives/friends aged 15 or more and in need of care (left diagram), and broken down by age groups (right diagram).



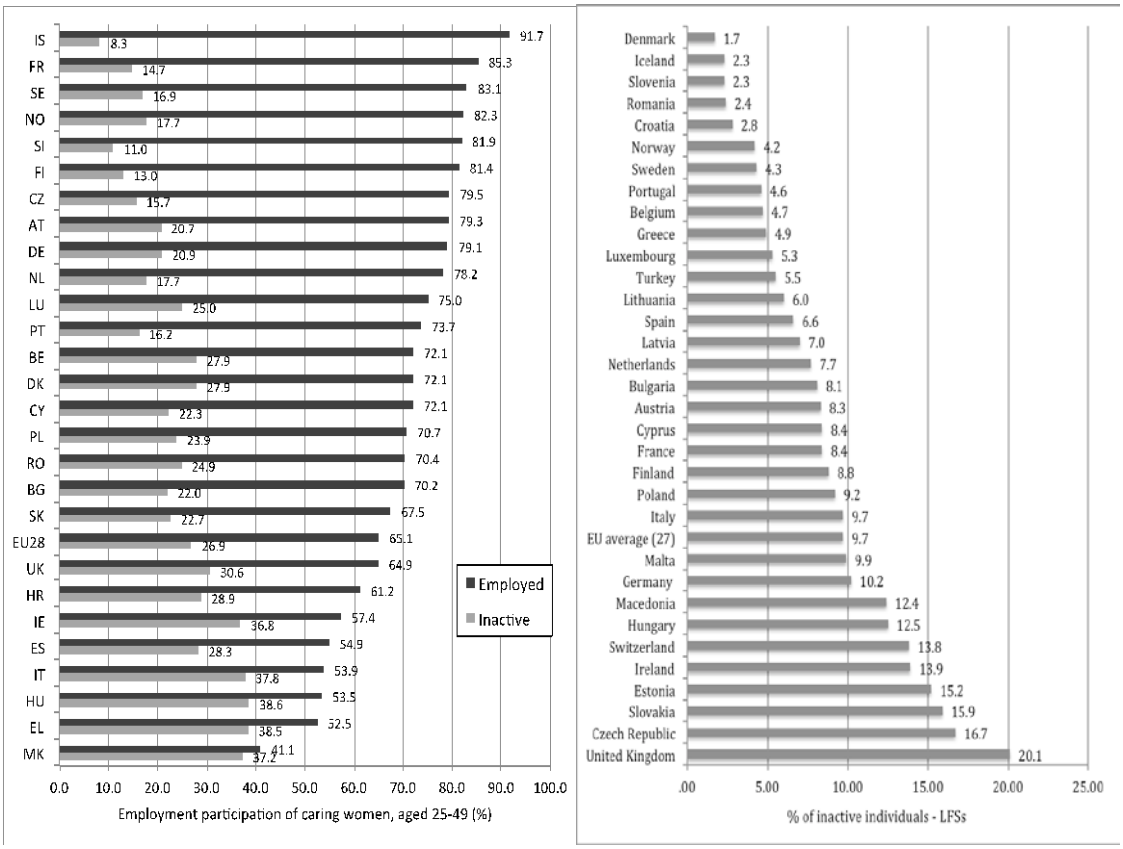
Source: Eurostat EU-SILC, Ad Hoc Module 2010

Figure 3 indicates that just over half of Icelandic women and just under half of Icelandic men regularly take care of dependent relatives/friends aged 15 or more. The gender difference is small in Iceland but the level of women's carer activity seems to be low by EU comparisons, i.e. the third lowest for women but the third highest for males. That picture however changes when we look at the age distribution of carer activity (right hand diagram). There we see that Icelandic women and men at ages 25-49 have the third highest carer activity rates, after Romania and Macedonia. The age group 50-64 has however the third lowest carer rates in Iceland.

The explanation for this difference between age groups lies in the role of institutional care. Most carer parents at ages 25-49 have children with caring needs who are aged 25 and under, and they are primarily cared for in parents' homes, as we showed in table 2. When parents have reached age 50-64, their dependent younger family members will have been gradually provided for in institutional or special service housing facilities.

This conclusion is further supported by the data in figure 4, which shows the employment status of women carers at ages 24-49, i.e. the proportion of women carers who are employed and the proportion who are inactive. Icelandic women carers at this age have the highest employment participation rate and the lowest inactivity rate amongst European nations. Iceland's lead on this front is substantial at 91.7%, while the runner-up countries (France, Sweden, Norway, Slovenia and Finland) range from 81.4% to 85.3%.

Figure 4: Left diagram: Employment status of women carers, aged 25-49: Employed or inactive (%). Right diagram: Proportion of inactive individuals at working ages caring for children or incapacitated adults, in 2014



Source: Eurostat EU-SILC Ad Hoc Module 2010 and EU-SILC 2014 and Eurostat LFS.

Given the generally high employment rate for women and men in Iceland the overall proportion of inactive individuals of working ages is low in the country. So is the proportion of inactive individuals that give the reason for their inactivity as caring for children or incapacitated adults in the family. On the right hand side of the figure we see the proportion of the inactive individuals that are caring for children or incapacitated adults. Iceland has the second lowest rate of caring as a reason for inactivity (2.3% of the inactive individuals), after Denmark (1.7%).

So the majority of Icelandic women caring for dependent family members are actively employed and caring activity is an uncommon reason for inactivity in the labour market. The conclusions for women at ages 25-49 in figure 4 apply similarly to women aged 50-64 and to men as well.

In general there is a high workload on Icelandic homes, due to high employment participation of both parents and relatively long working-hours for males. The fertility rate is also relatively high, meaning that there are slightly more children on average in Icelandic homes than in most European households (Eydal 2012 and Stefánsson 2012). Icelandic homes have relatively few hours spent on housework, compared to other Western societies (Þórsdóttir 2012), due to high rates of use of child care and pre-school, as well as to a high level of mechanisation of housework.

In that context it would be expected that when a family has a child with long-term illness or disabilities that needs to be cared for in the home, the pressure on employment participation should be large. Institutional support and leave provisions and caring benefits soften such pressures. Still, given that families with dependent individuals

needing a high level of care are a small proportion of the whole population of households, it does not seem to negatively affect the overall degree of satisfaction with home life.

Hence Þóra K. Þórsdóttir (2012, pp. 301-322) found a relatively high rate of satisfaction with home life and a low rate of stress arising from home life. This is despite the fact that on the whole many working individuals, men and women, report frequent conflicts between work and family life. About a third of working individuals report that they have a number of times been so tired after work that they have had difficulty performing necessary tasks in the home. This applies to households in general. The outcome is no doubt much more difficult for working households also caring for dependent individuals.

In the context of the high workload that inevitably is associated with households with two earning individuals and the need to care for a dependent family member, the outcome that the great majority of family carers are actively employed indicates that the role of the support system for LTC in Iceland is working relatively well.

Institutional support plays the greatest role in relieving the long-term situation, but the leaves provisions and caring benefits are import for adjustments in the short-term after the caring need arises and may last until the disabled child reaches age 18.

In general the individuals with disabilities and long-term illnesses have a lower level of life satisfaction than the general population, scoring 6.2 on a scale of 1-10, compared to the average of 8.0 for the general population (Hannesdóttir 2010). This is primarily related to the illnesses and disabilities and the burdens associated with them. Even satisfactory facilities for institutional care do not compensate for that.

Lastly it should be mentioned that those engaged in caring activities in institutions and special service housing facilities are generally low paid and often work under significant pressure. That applies equally to those serving the disabled and the elderly in general (Svansdóttir 2012 and ASISP Iceland 2012).

2.3 Policy recommendations

The support group National Association of Intellectual Disabilities (Þroskahjálp) has recently raised the issue of inadequate provision of service housing for individuals with long-term incapacities. The complaint is that the waiting time for provision of such residential care is too long. Not enough special purpose housing is built, but the situation varies somewhat between municipalities.

Given our conclusion about the large role that this and other institutional support plays for the care of the individuals concerned, as well as for facilitating employment participation of their family members, one can recommend further efforts in this direction.

There is also an unfulfilled need for NPA (User Directed Caring Assistance) in Iceland. It does not involve many individuals but the needs of those involved are great indeed, as is the pressure on their families.

Lastly one could recommend improved conditions and pay for professional care workers, providing both home help and institutional services. Better conditions and pay are likely to improve both the supply of individuals willing to do such work and could increase the stability and quality of their services.

The present Minister of Social and Housing Affairs appointed a task force to formulate a new family policy. The proposals of the group were recently published on the ministrys' website. While the plan has not been put to parliament, it contains many useful ideas for improving conditions for families caring for a dependent member in need of care (Tillaga til þingsályktunar um fjölskyldustefnu til ársins 2020, see here).

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