



Research note

Gender equality and long-term care at home

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Gender equality and long-term care at home

Abbreviations

Member State abbreviations

BE	Belgium
BG	Bulgaria
CZ	Czechia
DK	Denmark
DE	Germany
EE	Estonia
IE	Ireland
EL	Greece
ES	Spain
FR	France
HR	Croatia
IT	Italy
CY	Cyprus
LV	Latvia
LT	Lithuania
LU	Luxembourg
HU	Hungary
MT	Malta
NL	Netherlands
AT	Austria
PL	Poland
PT	Portugal
RO	Romania
SI	Slovenia
SK	Slovakia
FI	Finland
SE	Sweden
UK	United Kingdom
EU-28	28 EU Member States

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Introduction

The EU is currently experiencing unprecedented demographic changes. The share of the population above 65 years old in the EU is expected to increase from 20 % in 2019 ⁽¹⁾ to 29 % by 2080 and the percentage of people above 80 years will more than double to 13 % ⁽²⁾ in that time. A rapidly ageing population leads to an ever-growing need for long-term formal and informal care. In 2017, one in four people in the EU had a long-term disability, a greater number of that group being women (27 %) than men (22 %) ⁽³⁾. Another population group in need of long-term care is families with children who have a disability. In 2017, about 5 % of families with children had a child or children with disabilities (i.e. long-standing, potentially severe limitations on usual activities due to health problems) ⁽⁴⁾. Given this context, the EU will face major challenges in meeting long-term care needs in a financially sustainable way and in ensuring that care is affordable without endangering the quality of services or the lives of carers and those being cared for (European Commission, 2017d).

Challenges related to long-term care are highly gendered. Due to their longer life expectancy, more women than men are in need of long-term care services and are therefore more affected by the availability and quality of services. In the EU, an absolute majority of professional employees in the care sector are women. Women are also more likely to provide informal care to their family members when formal services are insufficient. Informal care is one of the main reasons behind women's lower employment rate and higher rate of inactivity in the labour market. It has also been proven to have negative effects on informal carers' quality of life and their work-life balance (Riedel and Kraus, 2011; Szebehely and Meagher, 2017; United Nations (UN) Women, 2017).

The European Pillar of Social Rights ⁽⁵⁾ and its initiative on a new start to support work-life balance endorses everyone's right to accessible, good-quality and affordable formal long-term care services and, in particular, to home care and community-based services. Although deinstitutionalisation and prioritisation of formal home-based long-term care is high on the political agenda, home care services remain underdeveloped and difficult to access in many EU Member States (Spasova et al., 2018). Across the EU, nearly every third household lives without adequate professional home care services. Long-term care relies heavily on informal care, with evidence indicating that the number of informal carers is twice that of formal carers (European Commission, 2014). Certain groups of the population experience greater difficulty in accessing formal long-term care services, including people with low income, people who are poorly educated, migrants and women of ethnic minorities (Corsi, Crepaldi and Samek Lodovici, 2009). As a result, households are forced to provide care themselves or, in some Member States, to outsource care to domestic workers, who are very often migrant women, or even to go without adequate care at all.

This research note focuses on formal home-based care across the EU. In terms of the care recipient's perspective, it looks at different aspects of long-term care that determine women's and men's opportunities to access long-term care services. Children with disabilities, adults with disabilities and older people are the three groups of (potential) care recipients covered in this study. In terms of the perspective of the carer, this study focuses on the quality of employment in the formal home-based care sector.

⁽¹⁾ Eurostat, Population on 1 January by broad age group and sex, 2019 (demo_pjanbroad).

⁽²⁾ Eurostat, Population projections, 2015 (proj_15ndbims).

⁽³⁾ Eurostat, Health variables of EU-SILC, 2017 (hlth_silc_06).

⁽⁴⁾ Eurostat, ilc_hch13.

⁽⁵⁾ European Pillar of Social Rights (https://ec.europa.eu/commission/sites/beta-political/files/social-summit-european-pillar-social-rights-booklet_en.pdf).

1. Formal home-based long-term care: what is it and why is it important?

1.1. What is formal home-based long-term care?

Long-term care is ‘a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent ... care’ (European Commission, 2014). Long-term care services can be formally performed by paid professionals either in an institution (e.g. a nursing home or a residential care home) or at home, or can be performed informally by family members, relatives, friends or other people. The majority of countries rely heavily on informal care, although the need to develop formal long-term care services is recognised (Spasova et al., 2018).

Formal institutional or residential care is provided to long-term care recipients staying in congregate institutions, such as nursing or care homes, or long-stay hospitals (Galik, 2013; Organisation for Economic Co-operation and Development (OECD), 2019). The residents at such institutions are usually isolated from the broader community; they lack control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the residents’ individual needs (European Platform for Rehabilitation (EPR), 2018). It is also a more expensive form of care, particularly for recipients with a lower level of disability (Genet et al., 2011; Rostgaard et al., 2011). In the case of children, institutionalised care can also mean institutions such as orphanages or children’s homes, where chil-

dren with disabilities are more likely to be placed than other children.

To improve quality of life and the efficiency of social care systems, the EU is moving towards the deinstitutionalisation of long-term care and supporting independent living at home through formal home-based or community-based care instead. As defined by the European Expert Group on the Transition from Institutional to Community-based Care (EEG), independent living ‘refers to people being able to make choices and decisions as to where they live, who they live with and how they organise their daily life’ ⁽⁶⁾. It is regarded as a more cost-effective solution that provides better care outcomes for the recipients compared to institutionalised care and, most importantly, reflects people’s preference for home-based care. Home-based care may include assistance with tasks such as housekeeping, shopping, getting dressed, bathing and preparing and eating meals, along with psychological support and helping the recipient participate in social activities (Rostgaard et al., 2011). It may also include nursing services provided by medical professionals. These services make it possible for older people to remain independent for longer.

In addition to formal home-based care services, independent living may also require ensuring the accessibility of the living environment – accessible transport, availability of technical aids and accessible information and communication – along with life and job coaching and access to other community-based services. It entails recognition of and support for family carers, including the need to help maintain or improve their quality of life ⁽⁷⁾.

⁽⁶⁾ EEG, From institutions to living in the community, ‘Community-based care – Terminology’ (<https://deinstitutionalisation.com/terminology/>).

⁽⁷⁾ *Ibid.*

1.2. Accessibility of formal home-based long-term care and its impact

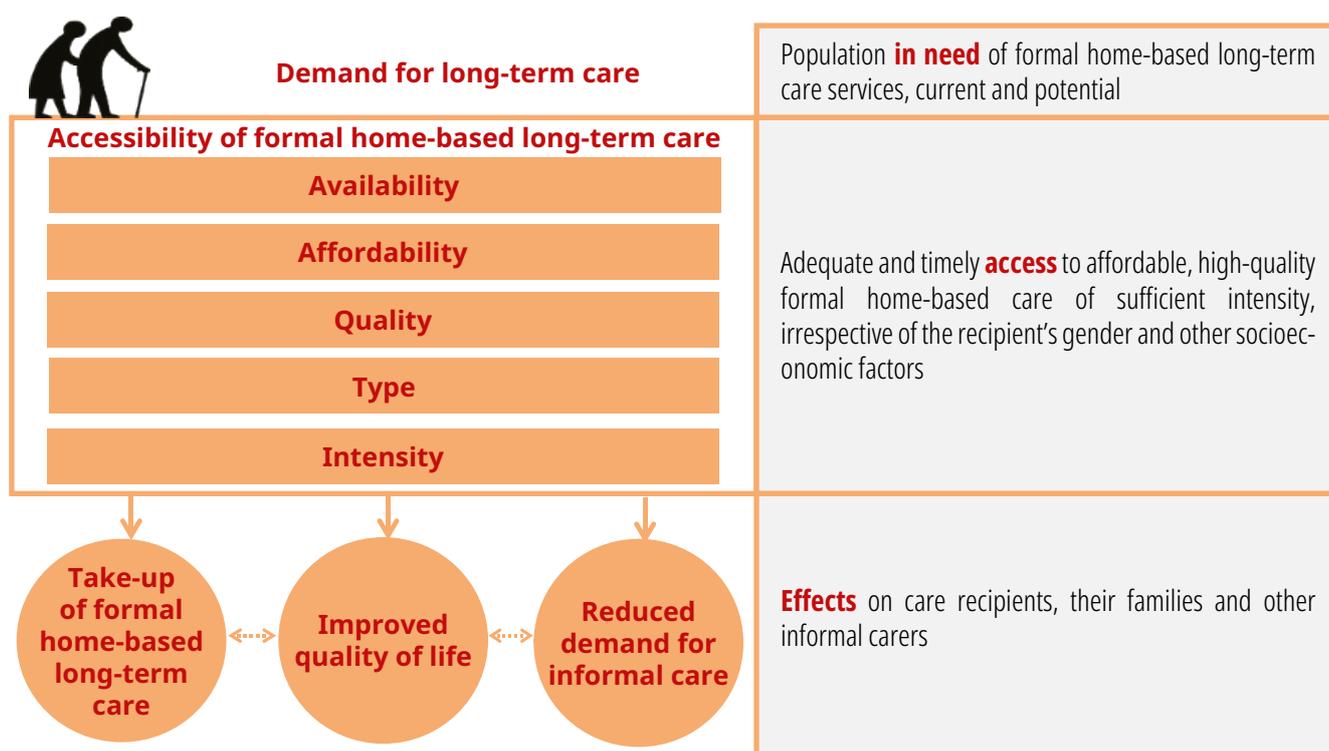
The accessibility of services, i.e. whether individuals in need of and willing to receive formal home-based long-term care can actually access adequate services, is crucial for preserving the well-being and dignified life of the people in need. The accessibility of formal home-based care depends on how many and what kinds of services are available, how affordable they are, what the quality of the services is and if the intensity of care is adequate (see Figure 1). The European Commission recognises three main objectives for long-term care services (EPR, 2018), which are as follows.

- **Universal access.** Access to services should be affordable to all; it should not depend on income or wealth.
- **High quality.** Services should focus on more comprehensive quality assurance that includes issues such as patients' rights.

- **Long-term sustainability.** Services should mitigate the likely increase in long-term care demand by making use of preventive approaches and technological developments.

If the formal home-based long-term care is inadequate in any of these aspects, people and families will be forced to find other solutions, i.e. institutionalised care (e.g. hospitals, mental healthcare facilities, orphanages) or informal care provided by family, friends, neighbours or other people. Low access to formal home-based care has a particularly strong impact on women, both as potential recipients of care and as informal carers. More women than men assume informal long-term care responsibilities at least several days a week, and in some cases every day. Overall, women represent 62 % of all people providing informal long-term care to older people or people with disabilities in the EU (EIGE, 2019). Women of pre-retirement age (50–64) are most likely to be providing long-term care. In the EU in 2016, 21 % of women and 11 % of men of pre-retirement age were providing informal long-term care every day or several

Figure 1: Accessibility of formal home-based long-term care services



Source: EIGE's creation.

days a week (compared to 13 % of women and 9 % of men aged 25–49). The unequal distribution of informal care between women and men greatly affects women's opportunities in the labour market, especially in pre-retirement age, leading to gender inequalities in pay and pension and increased risks of poverty and ill health (EIGE, 2019).

Provision of informal long-term care has a significant effect on work–life balance: it can lead to withdrawal from the labour market and have an impact on the health and well-being of the carer. Informal carers may be subjected to considerable stress as they try to balance work and family duties, especially when most have received no training in caring for people with disabilities or the elderly (European Commission, 2013b). This lack of training may in turn have an impact on the health and well-being of those in need of care. Where recipients have high-level care needs the informal carers need external support (Dorin et al., 2016).

Unpaid care work and the provision, affordability and quality of formal care services are key factors in determining whether women enter into and stay in employment and the quality of the jobs they perform. In the EU in 2018, care responsibilities were preventing 7.8 million women (aged 20–64) from entering the labour market, compared to 460 000 men ⁽⁸⁾. The contribution of unpaid care work – carried out mostly by women – to economic growth remains largely invisible.

Not all people in need of care have families living close enough to provide them with regular care. This means that a shortage of formal care services may lead to a situation where the recipient's care and support falls below the minimum standard. A survey of German care recipients showed that the men receiving care

are most often cared for by their wives while women – very often widows – live alone and need a wider social network and more frequent professional care (Dorin et al., 2016).

Children too are involved in caring for family members who are elderly and/or have disabilities, girls more often so than boys. Although the comparative data on young carers is very scarce, evidence from national sources shows that in European countries an estimated 2–8 % of children aged 5–17 are carers for family members who are ill or have disabilities (Chikhradze, Knecht and Metzing, 2017). For instance, in Ireland, the 2016 census showed that 3 800 children under 15 years were involved in providing care to others, accounting for 1.9 % of all carers. Half of the children providing unpaid care were under 10 years old (Psychosocial Support for Promoting Mental Health and Wellbeing among Adolescent Young Carers in Europe (ME-WE), 2019). In such cases, children are involved in all areas of care – just as adult informal carers are – and their responsibilities increase with age (Chikhradze, Knecht and Metzing, 2017). Girls are more often involved in long-term care than boys. A study carried out in Austria showed that the share of young carers who are girls is higher than the share of adult carers who are women (Nagl-Cupal et al., 2014).

Regular and intense responsibilities to care for adult family members have a strong impact on the lives of children. They miss out on opportunities to participate in society and spend most of their time at home. Young carers are often invisible, partially out of fear of being taken away from their home and fear of stigmatisation by their peers and teachers (ME-WE, 2019). Service providers tend to focus on the people who need care, rather than on supporting carers, including children.

⁽⁸⁾ Number of people in the inactive population, not seeking employment, mainly for reasons of looking after children or incapacitated adults. EIGE's calculations, based on Eurostat, EU-LFS (2018) (lfsa_igar; demo_pjangroup).

2. How is long-term care approached in public policy?

In light of demographic changes across EU Member States, addressing the challenges posed by an ageing population has become a necessity for the European Union. The increasing need for long-term care also poses a significant challenge to achieving gender equality, given that women continue to be the main providers of informal and formal care and that long-term care services remain insufficient across many Member States (EIGE, 2020). In the broader context of EU policies geared towards building a strong social Europe, gender equality features among the key principles of the European Pillar of Social Rights, and work–life balance has become a key priority in EU policy, most recently marked by the directive on work–life balance for parents and carers.

EU policies in the areas of social protection, health and long-term care aim at ensuring access to adequate and affordable long-term care provided by qualified professionals in a sustainable manner ⁽⁹⁾. Forward-looking policies and the development of sustainable models of long-term care provision are crucial instruments in removing the barriers keeping informal carers, especially women, away from the labour market. In this regard, the Social Protection Committee (SPC), together with the European Commission, introduces new ways to provide more adequate and sustainable long-term care services in ageing societies, by investing, for instance, in preventive care, rehabilitation and age-friendly environments (European Commission, 2014).

The European Commission has recognised achieving active and healthy ageing as a major societal challenge facing all EU countries, but also as an opportunity for Europe to establish itself as a global leader in providing innovative

solutions. Active ageing is defined by the European Commission as ‘helping people stay in charge of their own lives for as long as possible as they age and, where possible, to contribute to the economy and society’ ⁽¹⁰⁾. In 2011, the Commission launched the European innovation partnership in active and healthy ageing, which promotes greater autonomy and participation in paid employment of older people as a way to reduce demand for long-term care. By bringing together all relevant actors from across different policy areas and through the involvement of all levels of the innovation chain, the partnership is expected to foster innovation and digital transformation in the field of active and healthy ageing. For example, this initiative highlights the potential of digitalisation of health and care – carried out in a gender-neutral way – in helping informal carers to reconcile employment with caring for dependent relatives. To harness the potentially transformative effect on the division of informal care, digitalisation and smart home technologies should be more broadly investigated from a gender perspective (Wilson, Hargreaves and Hauxwell-Baldwin, 2014).

To support EU countries in monitoring active ageing outcomes, the European Commission, together with the United Nations Economic Commission for Europe, has developed the Active Ageing Index, measuring the realisation of older people’s potential in terms of employment, participation in social and cultural life and independent living, along with the enabling environment. The Commission also publishes a triennial ageing report, which looks at the long-term economic and fiscal implications of Europe’s ageing population, including a section on long-term care, determinants of expenditure and long-term projections. However, those tools

⁽⁹⁾ European Network of National Human Rights Institutions (2017), ‘Overview: long-term care in Europe’ (<http://ennhri.org/news-and-blog/overview-long-term-care-in-europe/>).

⁽¹⁰⁾ European Commission, ‘Employment, social affairs & inclusion – Active ageing’ (<https://ec.europa.eu/social/main.jsp?langId=en&catId=1062>).

do not include a gender analysis of the specific challenges experienced by women and men nor a cost analysis of gender inequalities in informal care in an ageing society.

The European Pillar of Social Rights specifically underlines the importance of access to good-quality and affordable long-term care services across all EU Member States, and in particular to home care and community-based services. Deinstitutionalisation and prioritisation of formal home-based long-term care is high on the political agenda across the EU. For example, the European disability strategy 2010–2020 encourages the transition from institutional to formal home-based services, although it does not consider the specific challenges and long-term care needs of women and men with disabilities. The 2017 progress report on the European disability strategy (European Commission, 2017a) has no gender focus, nor is there any indication that a gender mainstreaming approach was applied when collecting evidence on the EU situation (EIGE, 2020).

The need for deinstitutionalisation reforms has also been recognised in the European semester. The European Commission convened the EEG, a coalition of stakeholders representing people with care or support needs. They published the 'Common European guidelines on the transition from institutional to community-based care' (EEG, 2012) and the 'Toolkit on the use of European Union funds for the transition from institutional to community-based care' (EEG, 2014). In 2017, two thirds of EU Member States either adopted a dedicated strategy on deinstitutionalisation or included measures for deinstitutionalisation in a broader disability strategy (European Union Agency for Fundamental Rights (FRA), 2018).

Although not explicitly mentioned, the deinstitutionalisation process, along with the push for independent living, has its cornerstone in the Convention on the Rights of Persons with Disabilities (CRPD) ratified by the European Union and its Member States in a mixed agreement. Article 19 of the CRPD enshrines the right of people with disabilities to 'live in the community, with choices equal to others', and requires

states to 'take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community' by ensuring that '[p]ersons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance' (FRA, 2017; UN, 2006).

The CRPD addresses the issue of children with disabilities, in Articles 7 and 23 specifically, stating that their best interest comes first and that 'States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting' (UN, 2006). The European Commission recognised the importance of supporting families and of promoting alternative care possibilities as part of the 2013 EU recommendation 'Investing in children: Breaking the cycle of disadvantage' (European Commission, 2013a). Furthermore, those values were included as a key element of its social investment package, reaffirmed in 2017 by staff working document 'Taking stock of the 2013 recommendation on "Investing in children: Breaking the cycle of disadvantage"' (European Commission, 2017b) and a progress report. Importantly, the recommendation makes explicit reference to the fact that fighting child poverty and exclusion must be underpinned by gender mainstreaming. In the same year, the Council of the European Union adopted the 'Revision of the EU guidelines for the promotion and protection of the rights of the child (2017) – Leave no child behind' (Council of the European Union, 2017), recognising that by implementing a systems-strengthening approach the most vulnerable children, including children with disabilities, will have their rights protected. It highlights the importance of promoting alternative care for children and providing them with appropriate support to enable them to participate in community life and to access mainstream services across all Member States in line with the UN guidelines for the alternative care of children (UN, 2010).

Long-term care is a cross-cutting issue affecting different policy areas, such as social protection

and inclusion and healthcare. The gender mainstreaming across different areas of EU policy, including the implementation of Europe 2020 and the European semester, is fragmented and lacks a systematic approach. Even where gender equality objectives are included, a cross-cutting

gender mainstreaming approach is often missing. For instance, while the European Pillar of Social Rights includes a gender-specific principle, it lacks a gender dimension across some of its key principles, such as long-term care (EIGE, 2020).

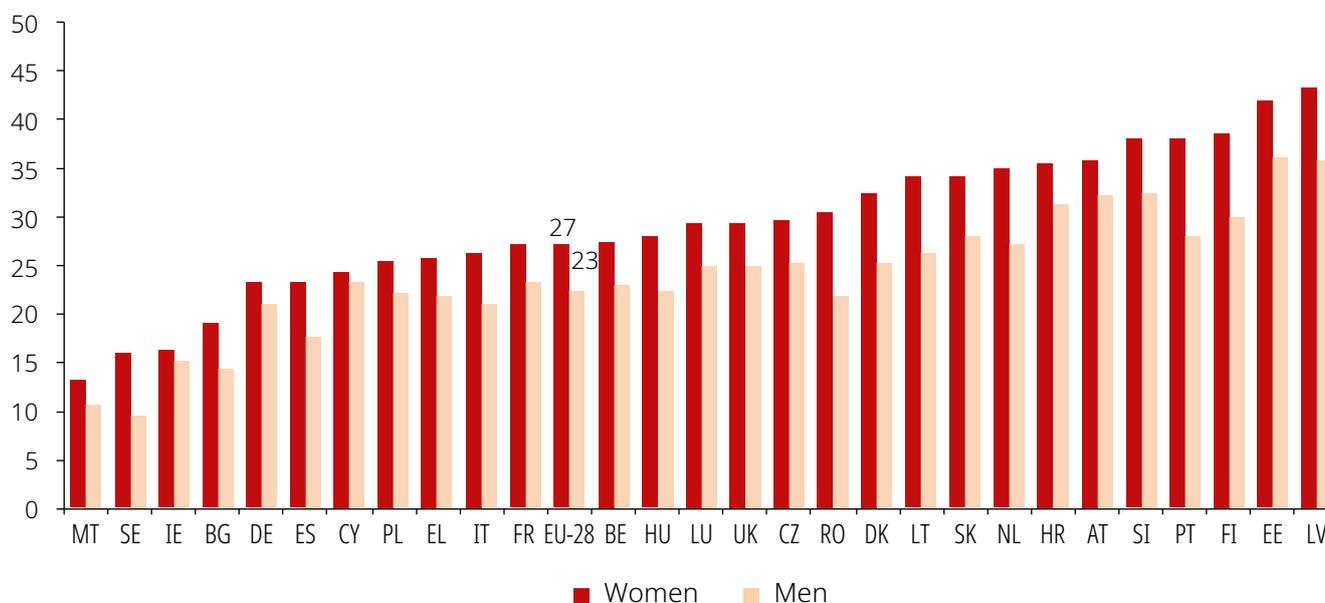
3. Who needs home-based long-term care?

Understanding who in society is most in need of long-term care, especially home-based, is essential not only in order to ensure that adequate services are designed and developed but also in order to evaluate the extent to which needs are met. The underlying assumption in this study is that people who have some kind of disability are (potentially) in need of help and long-term care. Disability is a complex, evolving and multi-faceted concept that can be defined and measured in various ways ⁽¹⁾. The following sections highlight the segments of the EU population that ‘experience limitations in their usual activities due to health problems’, as is measured by the European Union statistics on income and living conditions (EU-SILC), the main EU-wide survey providing information on home-based long-term care.

3.1. Older people and adults with disabilities

In the EU, one in four adults report being limited or very limited in their daily activities as a result of a health problem. While such limitations affect 12 % of the population in Malta, the highest burden of disability is observed in Latvia, with 40 % of adults reporting limitations ⁽²⁾. As shown in Figure 2, in all EU countries, women are more likely than men to experience limitations on daily activities due to health problems (27 % of women compared to 23 % of men). At the national level, the largest gender differences are seen in Portugal (10 percentage points (p.p.)), Romania (9 p.p.), Finland (9 p.p.), Latvia, Lithuania and the Netherlands (8 p.p.).

Figure 2: Percentage of women and men with long-standing limitations on their usual activities due to health problems, by gender (16 +, EU-28, 2018)



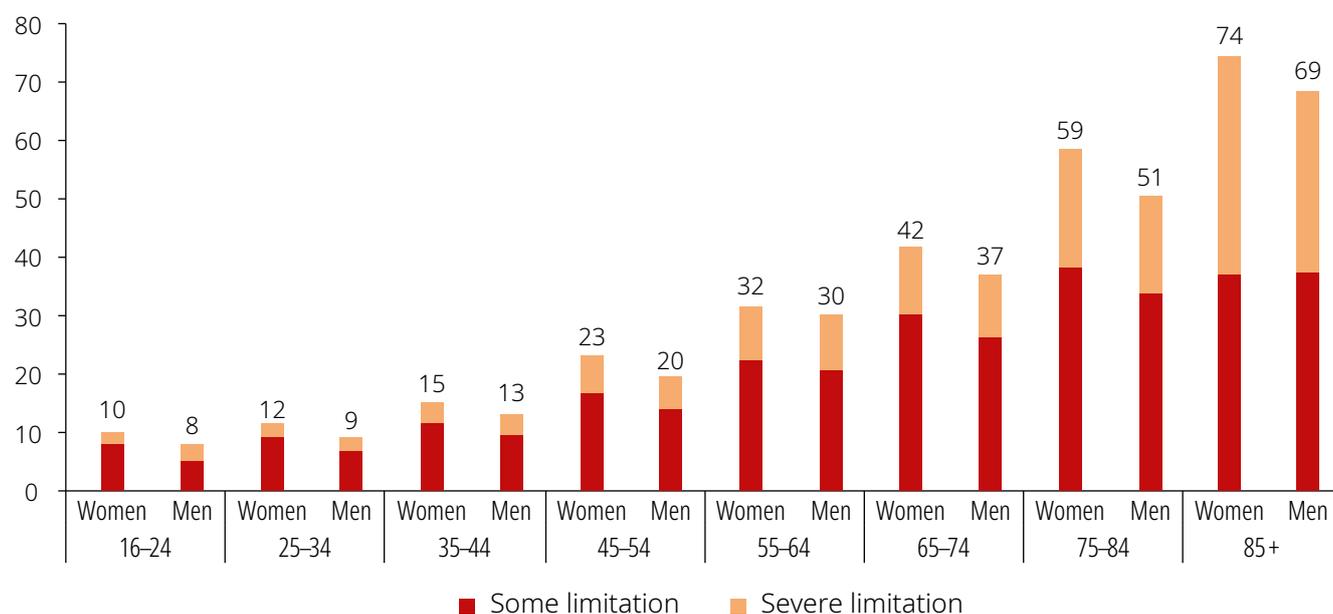
Source: Eurostat, EU-SILC, 2018 (hlth_silc_06).

NB: Respondents were asked: ‘For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?’ An activity is defined as: ‘The performance of a task or action by an individual’; activity limitations are therefore defined as ‘The difficulties the individual experiences in performing an activity’. Respondents who answered ‘Yes, strongly limited’, ‘Yes, limited’ and ‘No, not limited’ were counted for this figure. Answers of ‘Yes, strongly limited’ and ‘Yes, limited’ were grouped.

⁽¹⁾ See for instance Eurostat, ‘Disability statistics introduced’ (https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Disability_statistics_introduced).

⁽²⁾ Eurostat, Health variables of EU-SILC, 2018 (hlth_silc_06).

Figure 3: Percentage of women and men limited in their usual activities due to health problems, by age group and severity of difficulty experienced (EU-28, 2018)



Source: Eurostat, EU-SILC, 2018 (hlth_silc_06).

NB: Data labels refer to the total percentage of women and men of each group reporting some or severe health limitations.

In the majority of EU countries, the share of people with long-standing limitations has increased since 2008 ⁽¹³⁾. Only seven countries (DE, IE, ES, IT, HU, SK and SE) have seen the share of people experiencing limitations decrease. Such trends reflect the fact that gains in life expectancy in the past decades have been accompanied by an increase in the occurrence of chronic diseases that can limit a person's ability to handle certain daily activities and lead to an increasing need for long-term care (European Commission, 2013b).

In the EU, while women enjoy a higher life expectancy – 83.5 years compared to 78.3 years for men (a difference of 5.2 years in 2017) – this advantage is partially offset by the fact that

women spend more years in ill health. According to data from 2016, for example, women in the EU spent on average approximately 20 years of their lives in poor health compared to 16 years for men (EIGE, 2019).

An analysis of the burden of disability by gender and age shows that although one in four adults at the EU level are affected by limitations ⁽¹⁴⁾, this applies to only 9 % of people under 25 compared to 40 % of people aged 65–74 (see Annex). The prevalence of limitations increases with age and affects women and men differently; within such a context, any analysis of the needs for long-term care must consider not only age and gender but also the severity of the limitations (Figure 3).

⁽¹³⁾ Belgium, Bulgaria, Czechia, Denmark, Estonia, Greece, France, Cyprus, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Austria, Poland, Portugal, Romania, Slovenia, Finland and the United Kingdom (Eurostat, 2018 (hlth_silc_06)).

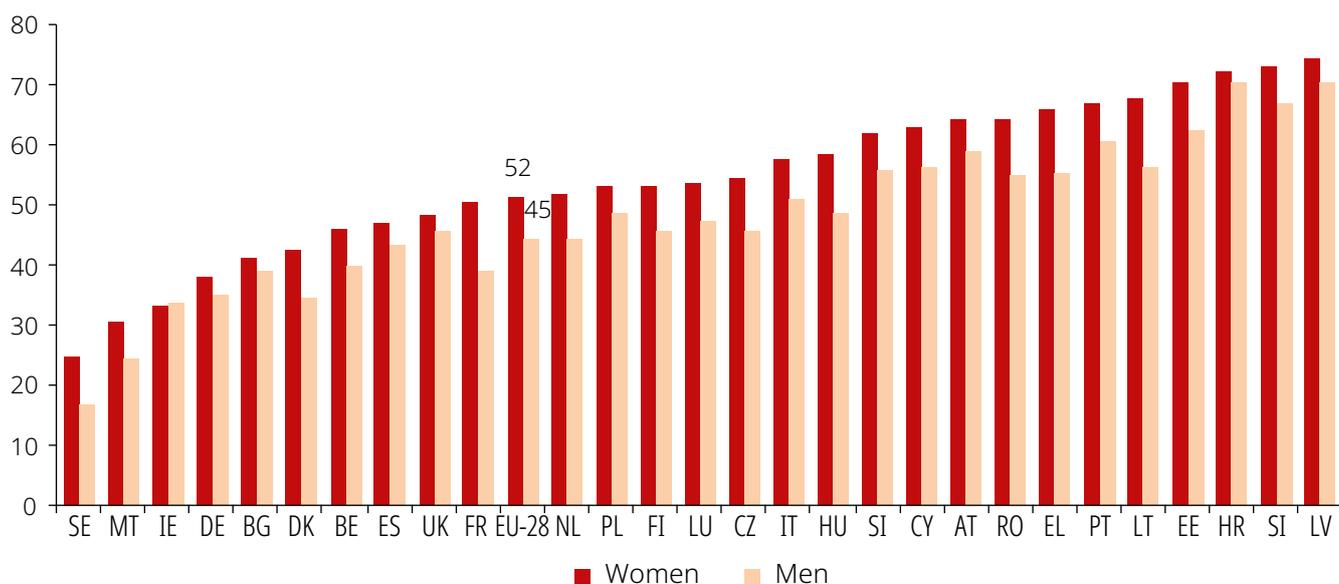
⁽¹⁴⁾ Eurostat, Health variables of EU-SILC, 2018 (hlth_silc_06).

Women are likely to be over-represented among people in need of long-term care for two main reasons. First, due to their higher life expectancy, women represent a larger share of the older population. Second, research shows that women are more likely to report symptoms of ill health than men. In addition, they are on average affected by disabilities at a younger age than men and affected by chronic conditions to a greater degree (World Health Organization (WHO), 2011). This is due to a whole host of reasons, including unmet needs for medical examinations, poor working conditions, low socioeconomic status or gender-based violence (Garcia-Moreno and Watts, 2011). The gender-based differences in disability reported could be explained not only by objective differences in health conditions, but also by gender norms. Normative masculinity is closely associated with physical strength, rational thinking and independence, while admitting and reporting illness, seeking treatment and discussing symptoms is often found to be more socially acceptable for women (Caroli and Weber-Baghdiguan, 2016; Emslie, Hunt and Macintyre, 1999; Swain et al., 1994).

Those factors account for the fact that gender differences in limitations on everyday activities are higher among the older age groups as highlighted in Figure 3. For instance, among individuals aged between 55 and 64 years, the share of women limited in their everyday activities is only 2 p.p. higher than that of men (32 % of women compared to 30 % of men). Among individuals aged between 75 and 84 years, the difference between the share of women and men limited in everyday activities rises by 8 p.p. (59 % of women compared to 51 % of men).

Figure 4 presents the share of women and men aged 65 and over experiencing some limitations or severe limitations on their everyday activities due to a health problem. In nearly all Member States, except for Ireland, more women than men aged 65 and over experience limitations on their daily activities due to health problems, ranging from 25 % of women in Sweden to 75 % in Latvia. In 19 Member States, the majority of women of this age group suffer these limitations. The share of men of this age experiencing such limitations ranges from 17 % in Sweden to 71 % in Latvia.

Figure 4: Percentage of women and men aged 65 + limited in their usual activities, by gender (EU-28, 2018)



Source: Eurostat, EU-SILC, 2018 (hlth_silc_06).

NB: Respondents were asked: 'For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?' An activity is defined as: 'The performance of a task or action by an individual'; activity limitations are therefore defined as: 'The difficulties the individual experiences in performing an activity'. Respondents who answered 'Yes, strongly limited', 'Yes, limited' and 'No, not limited' were counted for this figure. Answers of 'Yes, strongly limited' and 'Yes, limited' were grouped.

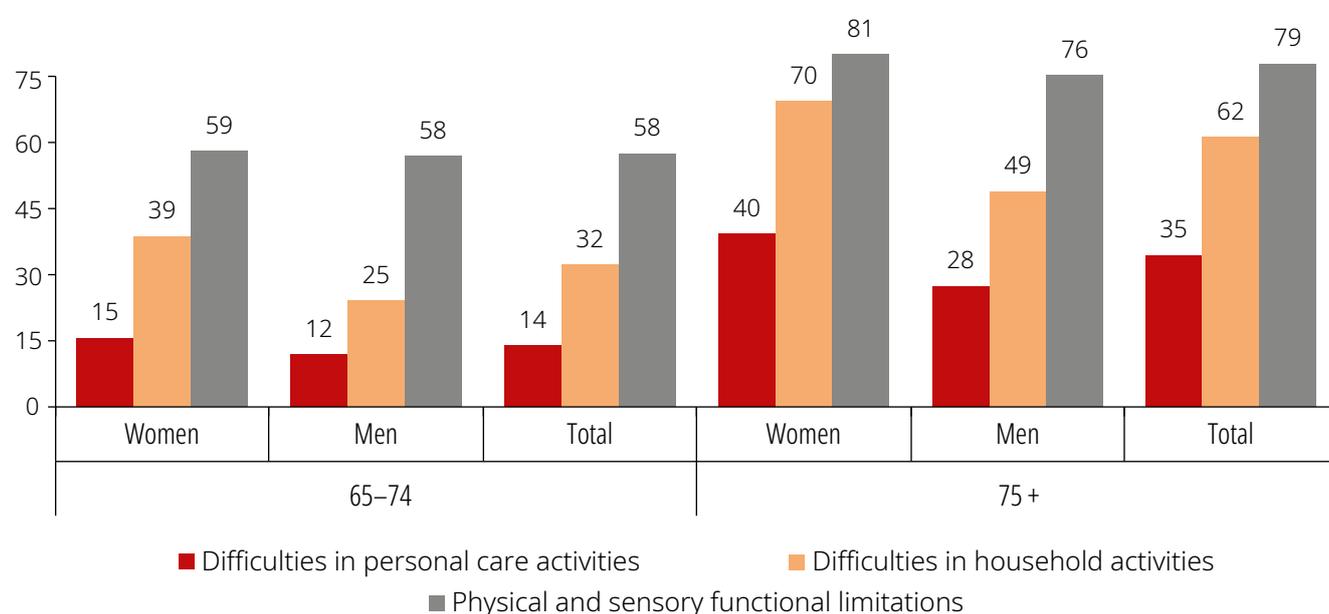
Women and men differ not only in their overall probability of experiencing limitations on everyday activities but also in the nature of such limitations. The European health interview survey (EHIS) distinguishes three general types of limitations: physical and sensory functional limitations (e.g. on seeing, hearing and walking), difficulties in personal care activities (e.g. feeding oneself, bathing) and difficulties with household activities (e.g. preparing meals, shopping, housework) (Figure 5). Many more women than men indicated having difficulties in carrying out household activities, in particular those aged 75 and over.

This section has highlighted that the prevalence of long-standing health limitations among adults is high in most EU countries and on the rise compared to previous decades. Both the prevalence and severity of health limitations increase with age and tend to disproportionately affect women. The steadily growing care needs rep-

resent a significant long-term challenge for the national health and social protection systems.

While the data presented above refers to people who are living at home, large numbers of people fall outside of the scope of such statistics because they reside in various types of institutions, such as care homes for the elderly or medical facilities. A study published in 2007 estimated that 1.2 million people with disabilities were living in institutions across the EU. One of the key reasons for the high numbers of people being placed in institutions is the paucity of community-based services and support (Mansell et al., 2007). Therefore, it is fair to assume that more people would use home-based services if they were available. However, there is no data on how many of those receiving care in institutions would in fact be able to live independently if adequate home-based formal long-term care were available.

Figure 5: Percentage of women and men aged 65 + with moderate or severe limitations on their activities, by age group (EU-28, 2014)



Source: Eurostat, EHIS, 2014 (hlth_ehis_ha1e; hlth_ehis_pc1e; hlth_ehis_pl1e).

NB: (a) The data on limitations on personal care activities shows the share of women and men experiencing difficulties in at least one personal care activity, including eating, getting in and out of bed or a chair, dressing and undressing, using a toilet and bathing or showering, based on the self-reported answers of the population aged 65 and over. (b) The data on limitations on household activities shows the share of women and men experiencing difficulties in at least one household activity, including preparing meals, using the telephone, shopping, managing medication, carrying out light housework, carrying out occasional heavy housework, taking care of finances and performing everyday administrative tasks, based on the self-reported answers of the population aged 65 and over. It should be noted that there may be reasons other than health problems behind difficulties in doing household activities. (c) The data on physical and sensory functional limitations refers to the extent of the severity of at least one limitation self-reported by the population aged 65 and over on functions involving vision, hearing and walking. Respondents evaluated the extent of their difficulties on the following scale: 'no difficulty', 'some difficulty' (referred to in this study as 'moderate difficulties'), 'a lot of difficulty' and 'cannot do at all' (both referred to as 'severe difficulties').

3.2. Children with disabilities

Another population group in need of long-term care is families with children with disabilities. The number of children with long-term conditions across the EU has been rapidly increasing in the last decade (Nightingale et al., 2019). This trend can be explained by advances in medical knowledge and technologies that make it possible to identify chronic illnesses in children with greater accuracy, and which have in turn improved survival rates of children with disabilities (Isaacs and Sewell, 2003). Additionally, children's health can be more accurately assessed by monitoring them over a longer period of time, which can lead to a higher number of disabilities being reported for their age group (Nightingale et al., 2019).

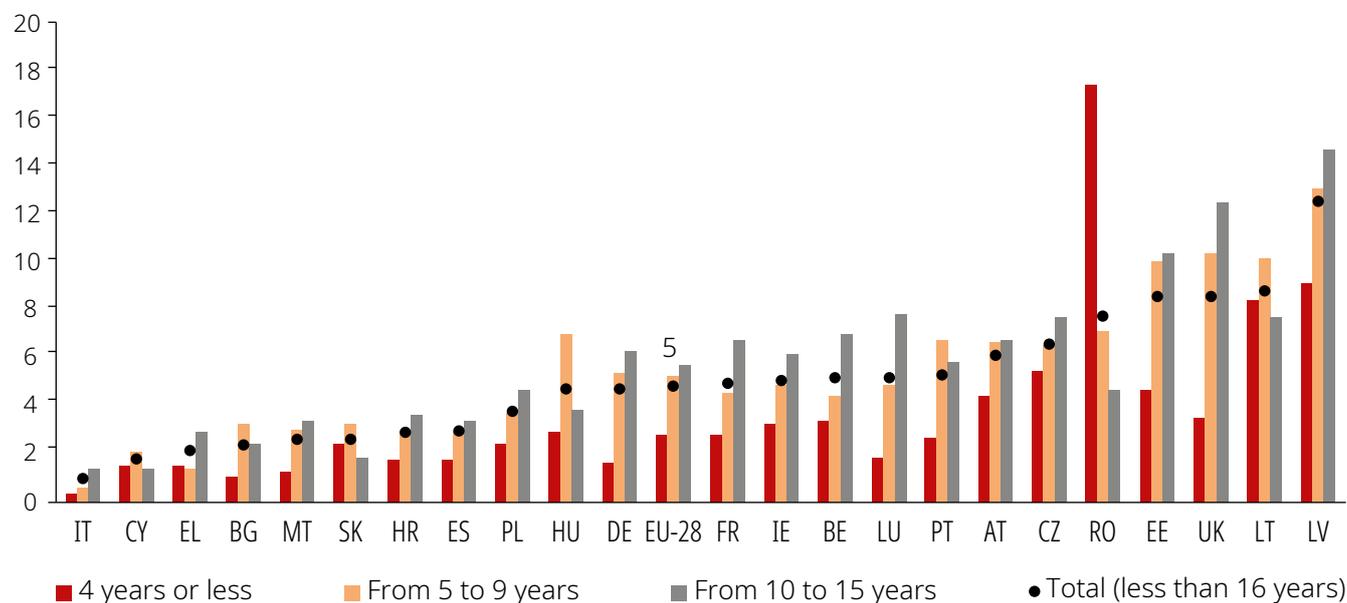
In 2017, about 5 % of EU families with children had a child or children with disabilities (i.e. some or severe long-standing limitations on

usual activities due to health problems) ⁽¹⁵⁾. This average masks significant diversity between EU countries, with less than 1 % of households in Italy, 8 % of households in Estonia and the United Kingdom, 9 % in Lithuania and 12 % in Latvia reporting having children with moderate or severe limitations ⁽¹⁶⁾.

As shown in Figure 6, many children are born with disabilities, with 3 % of families with children younger than 4 years reporting experiencing moderate or severe limitations ⁽¹⁷⁾. The number of households with children with disabilities increases as children get older. In the EU, disabilities in children affect 5 % of families with children aged 5–9 and 6 % of families with children aged 10–15.

In the EU in 2017, as much as 9.4 % of girls and young women and 7.4 % of boys and young men aged 16–24 had a disability ⁽¹⁸⁾.

Figure 6: Percentage of households with children who have moderate or severe limitations on their activities due to health problems, by age and country (EU-28, 2017)



Source: Eurostat, 2017 (ilc_hch13).

NB: Data for Denmark, the Netherlands, Slovenia, Finland and Sweden is missing.

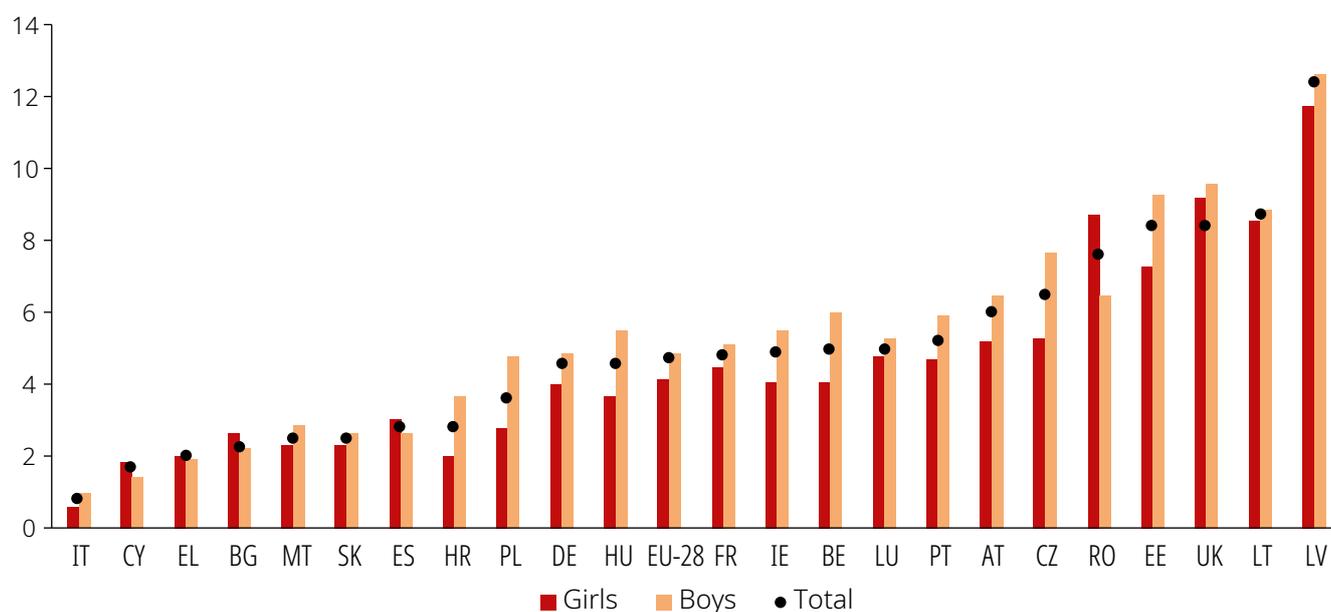
⁽¹⁵⁾ Eurostat, ilc_hch13. Relates to children aged 16 years and younger.

⁽¹⁶⁾ *Ibid.*

⁽¹⁷⁾ Eurostat, ilc_hch13.

⁽¹⁸⁾ Eurostat, Health variables of EU-SILC, 2017 (hlth_silc_12).

Figure 7: Percentage of girls and boys with limitations on their activities due to health problems, by country (< 16, EU-28, 2017)



Source: EIGE's calculations based on Eurostat, EU-SILC, 2017 (ad hoc module).

NB: Figure covers variable RC020T: 'Limitation in activities because of health problems (child)': 1. 'Severely limited'; 2. 'Limited but not severely'; 3. 'Not limited at all'. Countries are arranged in ascending order of the total prevalence of limitations among both girls and boys. Data for Denmark, the Netherlands, Slovakia, Finland and Sweden is missing.

As seen in Figure 7, there are slight gender differences in the prevalence of disabilities among children, with boys being more likely to be affected in 19 Member States⁽¹⁹⁾. About 4 % of girls and 5 % of boys under 16 experience health limitations in the EU. The largest gender differences are seen in Belgium, Czechia, Estonia, Hungary and Poland, with boys experiencing a prevalence of limitations 2 p.p. higher than girls.

Children limited in their everyday activities are more likely to live in a single-parent household (Di Giulio, Philipov and Jaschinski, 2014; Loft, 2011). In 2017 across the EU, 4 % of all children with a disability lived with two parents and 7 % lived with one parent⁽²⁰⁾. This is mostly due to higher separation rates among parents of children with disabilities (Di Giulio, Philipov and Jaschinski, 2014; Hogan, 2012) meaning that daily care responsibilities fall entirely on the shoulders of one parent, mostly mothers

(Di Giulio, Philipov and Jaschinski, 2014; Levine, 2009).

Lone parents raising children with disabilities have especially high needs for formal long-term care services. If those services are unavailable, parents may need to withdraw from the labour market to become full-time carers for their children (Di Giulio, Philipov and Jaschinski, 2014) with negative, often long-term financial implications. Women are at a greater disadvantage considering the fact that they make up almost 85 % of all single-parent households in the EU (EIGE, 2016). In many countries, children with disabilities continue to be institutionalised (Crowther, 2019).

In addition, the level of poverty is known to be higher among lone parents. Almost half (49 %) of lone mothers and a third (32 %) of lone fathers are at risk of poverty or social exclusion (EIGE, 2016). This lack of financial resources is one of the main reasons behind unmet needs for long-term care (EIGE, 2016).

⁽¹⁹⁾ Slovakia, Lithuania, Italy, the United Kingdom, Luxembourg, France, Malta, Latvia, Germany, Portugal, Austria, Ireland, Croatia, Hungary, Belgium, Poland, Estonia and Czechia.

⁽²⁰⁾ Eurostat, ilc_hch13.

4. Access to long-term care services and gender impact

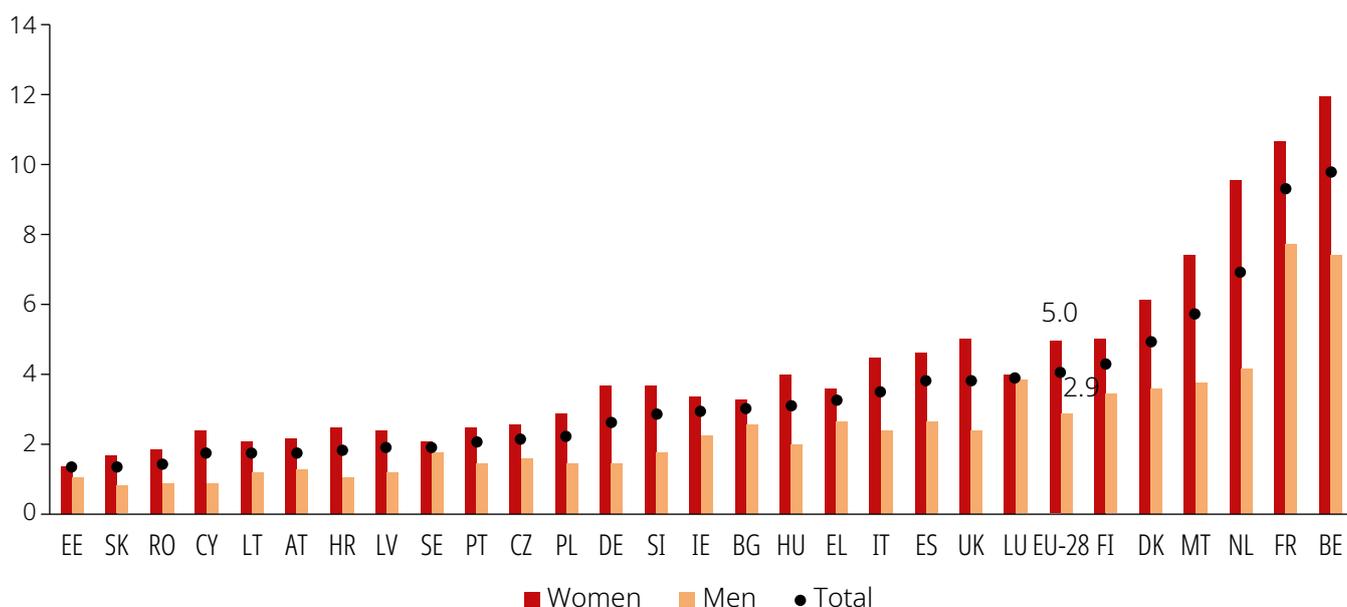
4.1. Use and users of formal home-based long-term care services

Although a quarter of the adult population in the EU has reported having long-standing limitations on their day-to-day activities due to health problems (Figure 4), the use of professional home care is not very high. According to the latest available data, across the EU, only 5 % of women and 3 % of men aged 15 + used such services in 2014 (Figure 8). The overall use of services varies from 10 % in Belgium to just above 1 % in Estonia, Slovakia and Romania of the adult population. The fact that these percentages are well below the total share of people with disabilities in society is the first indication that there is a shortage of home care services.

In all countries, there are more women than men among home care service recipients. In the Netherlands, where the largest gender gap (5 p.p.) is found, 10 % of women versus 4 % of men report that they have received home care.

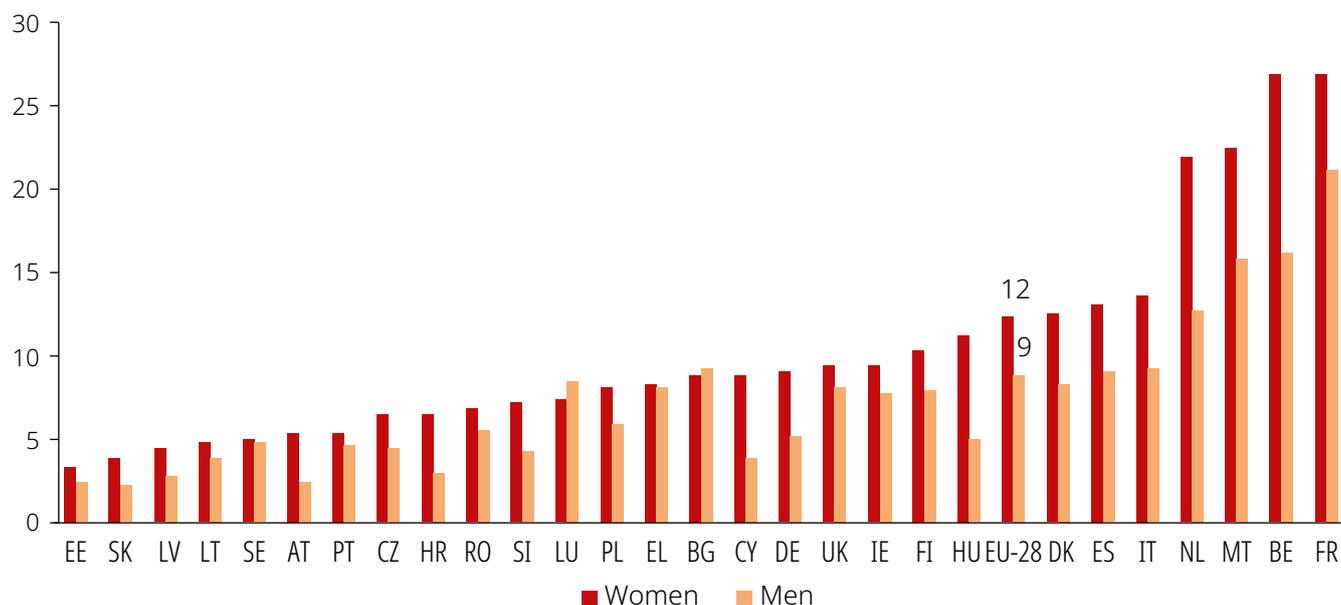
The highest use of professional home care services is observed among people who are above 75 years old. In the EU in 2014, on average 20 % of women and 14 % of men aged 75 and over used home care services (Figure 9). People in this group are most in need of formal care, as they are most likely to have a disability. They also are most likely to live alone, with no one in the household to provide them with informal help and care. Due to their longer average life expectancy, this is more common for the women of this age group than the men.

Figure 8: Percentage of women and men using home care services, by gender and country (15 +, EU-28, 2014)



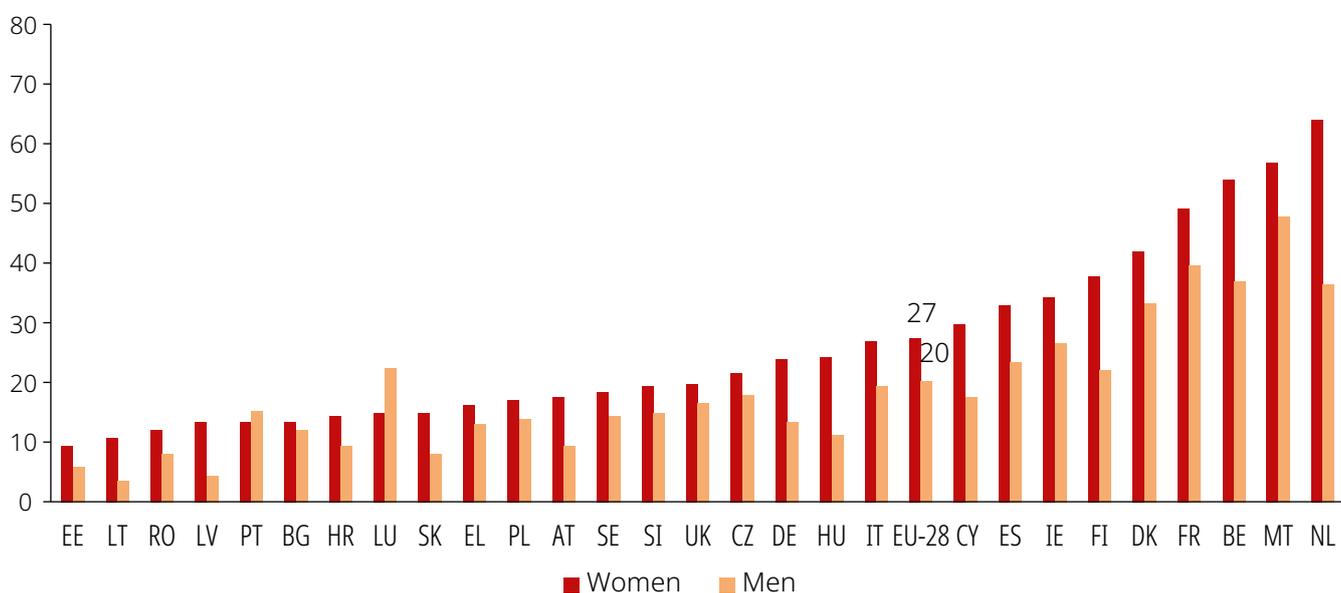
Source: Eurostat, EHIS, 2014 (hlth_ehis_am7e).

Figure 9: Percentage of women and men with limitations on everyday activities who use home care services, by gender and country (15 +, EU-28, 2014)



Source: Eurostat, EHIS, 2014 (hlth_ehis_am7d).

Figure 10: Percentage of women and men limited in everyday activities who use home care services, by gender and country (75+, EU-28, 2014)



Source: Eurostat, EHIS, 2014 (hlth_ehis_am7d).

Out of those with a disability, 15 % of women and 9 % of men indicated that they received formal home-based long-term care services in 2014. The remaining people with disabilities therefore relied on informal care, provided either by family and friends or by individuals such as migrant workers, paid unofficially and

with no formal 'carer' status. The country differences vary from between 27 % of women and 21 % of men in France to between 3 % of women and 2 % of men in Estonia reporting receiving formal home-based long-term care services. The largest gender gap can be found in Belgium (11 p.p.).

Older people with disabilities, particularly those aged 75 and over, show higher use of formal home care services than the rest of the population. On average, 27 % of women and 20 % of men in this group in the EU received home care services in 2014. The use of services ranges from 64 % of women and 37 % of men in the Netherlands (a gender gap of 28 p.p.) to 9 % of women and 6 % of men in Estonia. Portugal and Luxembourg are the only countries where men of 75 and over with disabilities are more likely to receive formal home care services than women of the same group. Overall, 62 % of women and 54 % of men in this age group report that they experience limitations on their usual activities in the EU-28 (2018) (see Annex, Indicator 1).

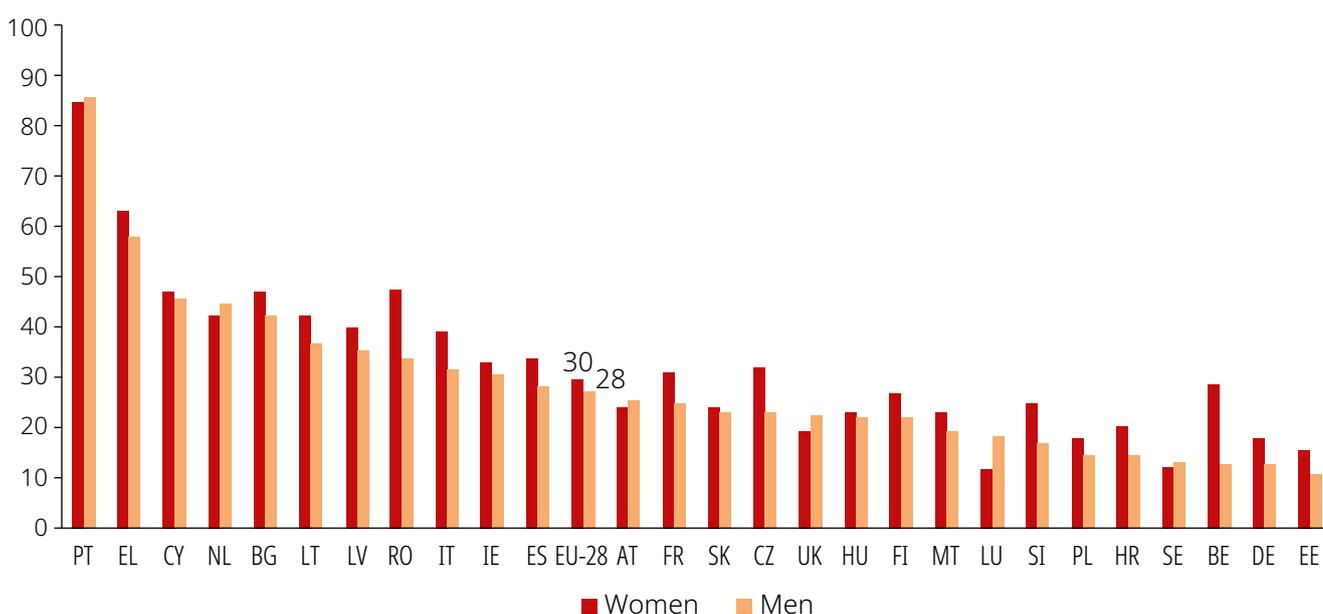
Not everyone who experiences some limitations on their everyday activities needs or wants formal care. Such people are either living independently in an environment adjusted to their needs or are receiving sufficient informal care from their family. Some evidence suggests that women and men prefer different kinds of long-term care. For instance, men favour home-based long-term care provided by their spouse while

women prefer professional support or institutional long-term care. Overall, little is known about what older people consider appropriate long-term care (Carvalho et al., 2019).

In the EU, about 29 % of households reported unmet needs for professional home care services in 2016 (EIGE, 2019). The reporting of unmet needs was slightly higher in the households where a woman responded to the survey (30 %) rather than a man (28 %). Women are more likely than men to report an unmet need for professional home care services in all but six Member States (LU, NL, AT, PT, SE and UK). Nearly a quarter of women and men live in households which rely on informal care that may be either insufficient or unsuitable/not the preferred arrangement of either the carer or the care recipient. This information relates to the household as a whole and does not reflect the gender of the person in need of help.

The share of people with unmet needs is linked to the overall level of gender equality in society. The highest levels of gender inequalities in the use of time, as measured by the Gender Equal-

Figure 11: Percentage of women and men reporting unmet household needs for professional home-based care services (in households with at least one individual limited in everyday activities), by gender and country (16 +, EU-28, 2016)



Source: EIGE (2019) based on Eurostat, EU-SILC, 2016 (ad hoc module).

NB: Figure covers variable HC240: 'Unmet needs for professional home care' – i.e. whether there are household members who require professional home care, but are not provided with any or are provided with less than they require. The possible answers were 'Yes' and 'No'. Respondents who chose 'Yes' were counted for this figure.

ity Index, are recorded in the Member States with higher unmet needs for professional home care services (e.g. EL, PT). Member States with the best gender equality in the use of time (e.g. SE) have fewer households with unmet needs for professional home care (EIGE, 2019).

4.2. Availability of formal home-based long-term care

The existence of formal home-based long-term care services is an obvious precondition for those services being accessible to the potential recipients. For the services to be fully available, the demand needs to be met by an adequate supply provided by public, private or other kinds of entities in a timely manner (Riedel and Kraus, 2011). The supply of formal long-term care services (both home-based and residential) does not meet the demand in most EU countries and the availability of formal home-based services is lower than that of residential care (Spasova et al., 2018).

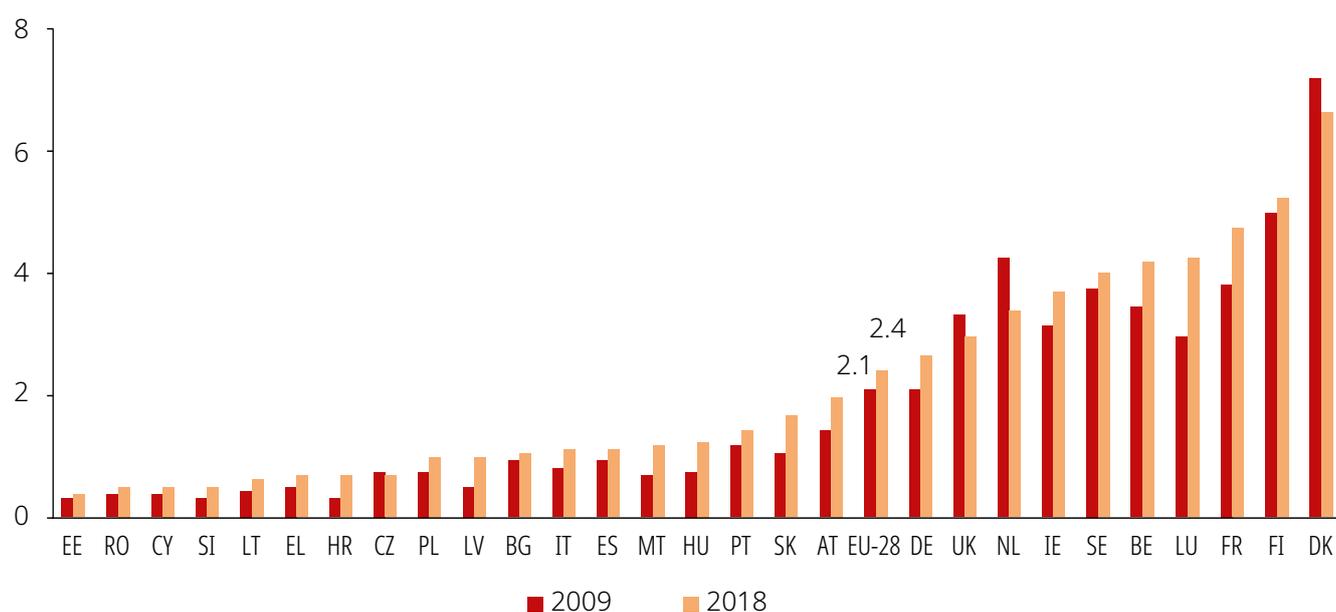
Home-based long-term care services often fall within the scope of both social and healthcare

services, offered by a mix of state, local and private providers. This adversely affects the quality of available comparable data on the provision of the services or the number of service providers.

In 2018, social workers involved in providing services without accommodation (i.e. at home or in the community) comprised 2.4 % of the workforce in the EU (over 5.5 million people) compared to 2.1 % in 2009 (Figure 12). Comparative 2018 figures vary across Member States, from just 0.4 % in Estonia and 0.5 % in Cyprus and Romania to 4.7 % in France, 5.2 % in Finland and 6.7 % in Denmark in 2018. In all Member States, except for the Netherlands, Denmark and the United Kingdom, the number of social workers has increased over the past 10 years.

On average in the EU, for every 100 adults with disabilities there are 5 social workers who provide some kind of service outside of residential care (Figure 13). There are about 20 adults with disabilities per social worker. The highest potential recipient-social worker ratios are found in Denmark, Ireland and Sweden while the lowest ratios are found in Estonia, Romania and Slovenia. However, these statistics should be interpreted with

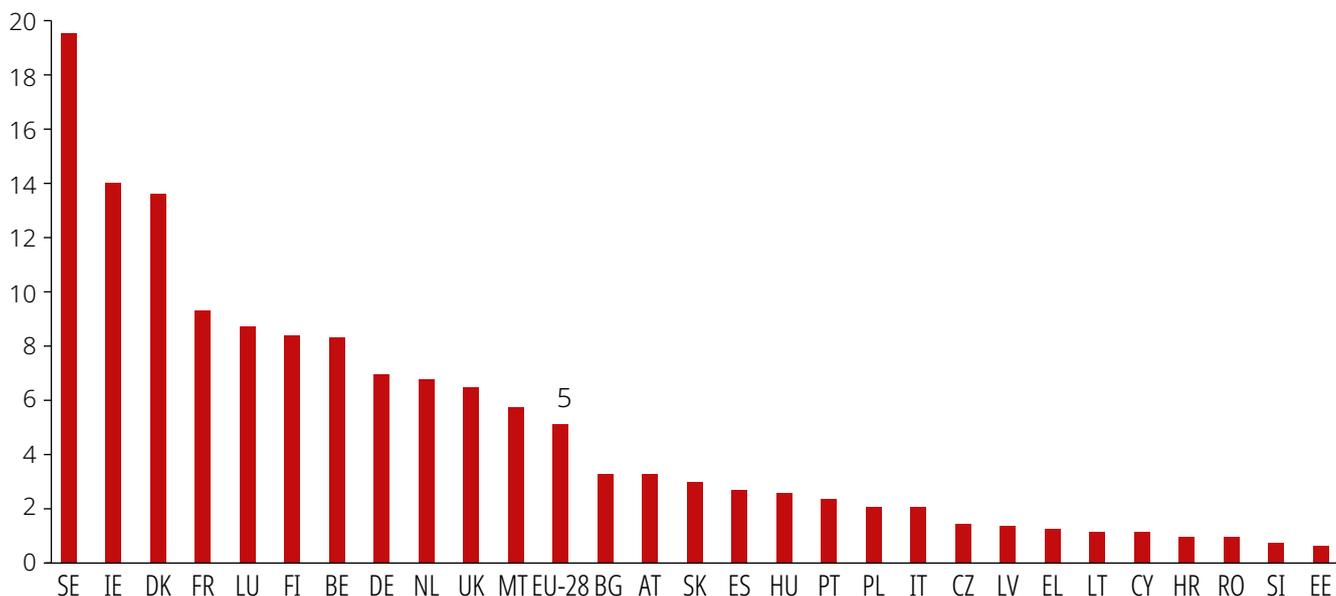
Figure 12: Percentage of total workforce comprised of employees performing social work activities without accommodation, by country (EU-28, 2009, 2018)



Source: Eurostat, 2009 and 2018 (lfsa_egan22d).

NB: Covers employees performing social work activities without accommodation (i.e. not in institutions, but at home or in the community), as defined by the statistical classification of economic activities in the European Community (NACE) category 88 (Eurostat, 2008).

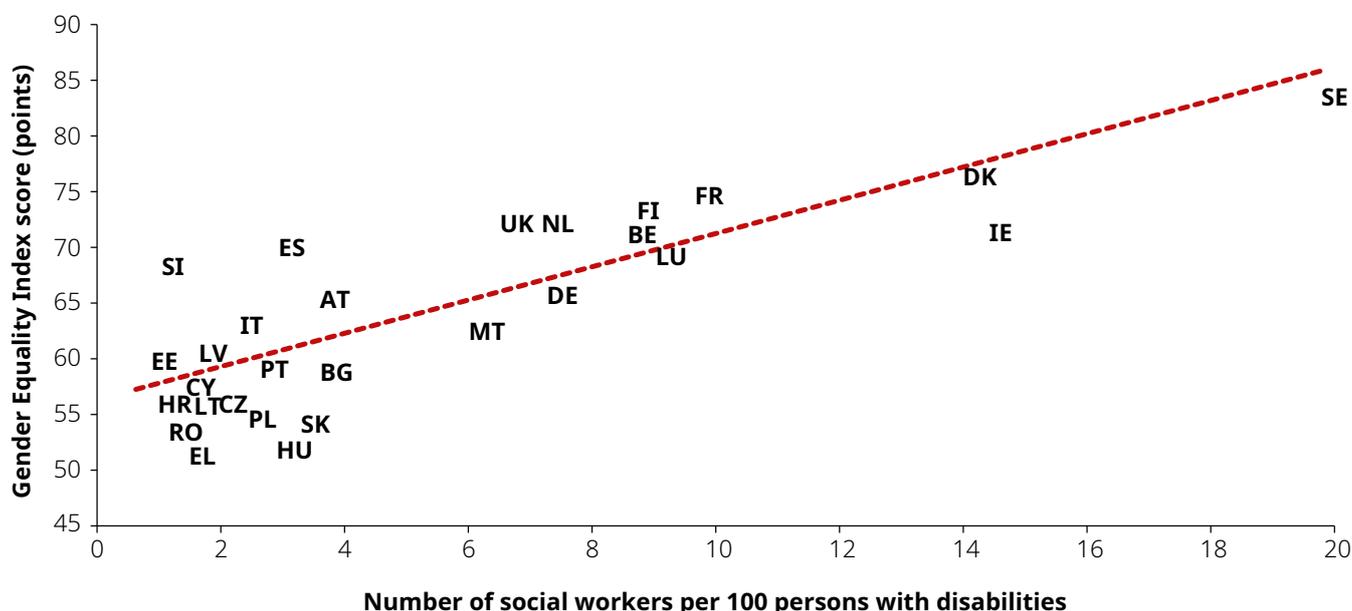
Figure 13: Number of employees performing social work activities without accommodation per 100 people aged 16 + with disabilities, by country (EU-28, 2018)



Source: EIGE’s calculations based on Eurostat, 2018 (hlth_silc_06; demo_pjan; lfsa_egan22d).

NB: Calculated as a ratio of the number of employees performing social work activities without accommodation (i.e. not in institutions, but at home or in the community), as defined by NACE category 88 (Eurostat, 2008), to the size of the population with disabilities (defined as the number of people limited in everyday activities) (hlth_silc_06; demo_pjan).

Figure 14: Correlation between Member States’ number of social workers per 100 people with disabilities and Member States’ Gender Equality Index scores (EU-28, 2017)



Source: EIGE’s calculations based on EIGE (2019) and Eurostat, 2018 (hlth_silc_06; demo_pjan; lfsa_egan22d).

caution because these social workers are not only addressing the needs for home-based or community care of people with disabilities, but also providing support to other groups of people (e.g. migrants, youths, homeless people).

The availability of social services such as social work has clear implications for gender equality. The better the availability of formal services, the less the burden falls on families to provide care and support to their family members with dis-

abilities. Since care responsibilities in the family, in line with enduring stereotypes, are still typically taken on by women – and even by girls of a young age – the need for informal care limits the opportunities for women in other areas of life.

At the national level, there is a clear link between the overall level of gender equality, measured by the Gender Equality Index, and the number of social workers providing care without accommodation per person with a disability (Figure 14). Countries such as Denmark, Ireland and Sweden have the highest availability of social work services as well as high Gender Equality Index scores. In eastern European countries, the scores are lower on both counts.

Even with sufficient services in place, certain groups of people still face many barriers that potentially limit the actual accessibility of the home-based long-term care. First, services may not be equally available geographically, and in particular rural and sparsely populated areas are likely to be disadvantaged (Corsi, Crepaldi and Samek Lodovici, 2009). When considering older women and men (aged 65 and older) living alone, at the EU level there are no notable differences between the use of services in cities, towns, suburbs and rural areas. However, significant differences in the availability of services may exist at the national level. There are some countries where rural areas have significantly more care users (e.g. BE, LU, SK and FI) than cities, but there are also countries where cities have the lowest availability of services for single older women and men (e.g. PT and FI) ⁽²¹⁾.

All Member States can and do set criteria and rules regarding eligibility for their social services. Eligibility for publicly funded long-term care services can be subject to the care needs of the person, their income and assets and the availability of family carers. Publicly funded services may only be available through insurance schemes and therefore only to those who are or have been active in the labour market, thereby excluding those in precarious jobs from accessing the public service provision. Women

are more likely to be inactive or in precarious jobs and are therefore more likely to be ineligible for publicly funded services. Eligibility criteria may also exclude people without residency or citizenship, the long-term unemployed and the homeless. In recent years, several EU Member States have tightened their eligibility criteria by restricting services to those individuals with serious care needs (e.g. IE, EL, HU, SW, UK) (Spasova et al., 2018).

Public formal long-term care in several EU Member States is reserved for citizens who do not have family support (e.g. BG, EL, LV, PL, UK) (Spasova et al., 2018). Although it is crucial to improve the quality of life of these people (e.g. elderly women and men living alone), this policy approach disadvantages informal carers – who are most often female family members – who often have no choice but to carry the burden of care. Families often have a legal responsibility to provide care to their adult members. In some countries, such as Sweden, families do not have a legal responsibility to provide care to their adult members (Meagher and Szebehely, 2013). Nevertheless, a Swedish study showed that the likelihood of receiving formal home help was lower for those living with their spouse and/or with children (Larsson, Kåreholt and Thorslund, 2014).

To adequately assess a person's care needs, a standardised procedure is needed to ensure the unbiased allocation of care, which is crucial where services are in short supply. Formal assessment tools also need to be impartial and inclusive, for instance of different kinds of disabilities and special needs (e.g. mental health issues). Evidence exists showing the presence of gender bias in such assessment procedures. For instance, in certain circumstances women have to 'exhibit greater levels of disability' than men before formal long-term care services are granted (Gruneir et al., 2013). Another study revealed that care managers were more likely to grant less care if the requests were sent by women than if they were sent by men (Jakobsson et al., 2016). Gender biases in the provision of formal long-term care clearly require more research.

⁽²¹⁾ Eurostat, ilc_ats13.

4.3. Affordability of formal home-based long-term care

The availability of formal home-based long-term care services does not guarantee that they are universally affordable. Affordability depends on the cost of the services, available public funding or subsidies and individual or household income. In 2016, in most EU countries, over half of the care recipients needed to pay for their formal home-based long-term care services. Nursing care is more likely to be free of charge than home help or personal care services in the EU (European Foundation for the Improvement of Living and Working Conditions (Eurofound), 2019).

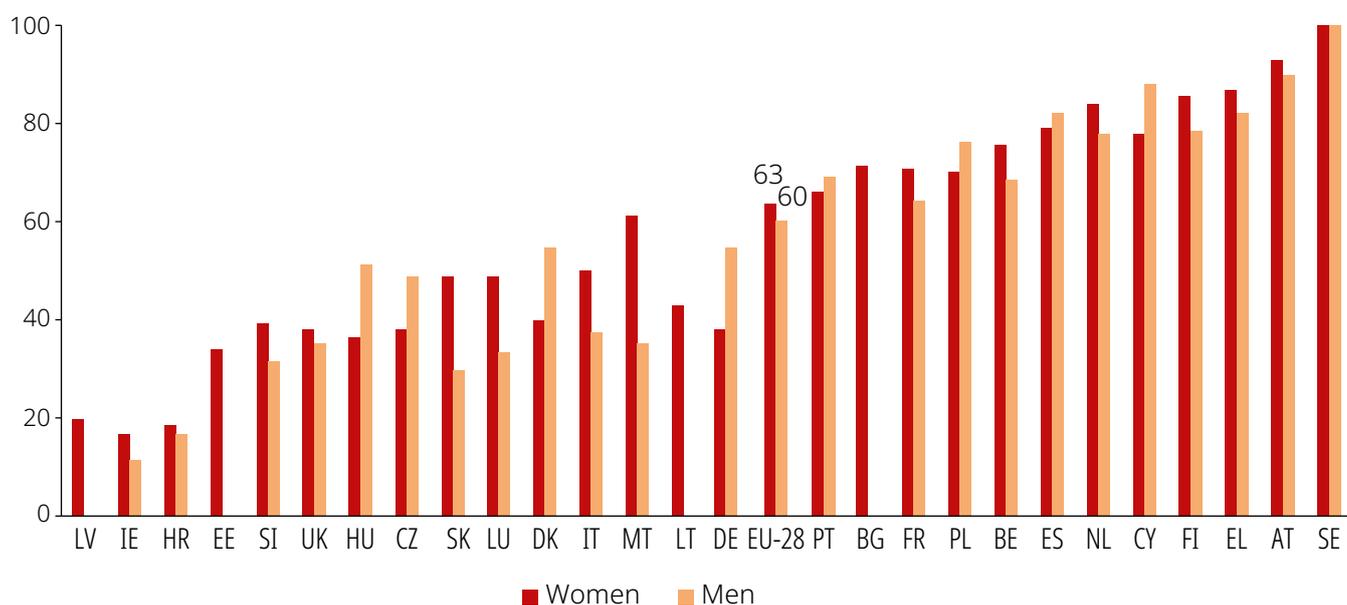
In some countries, such as Latvia, Ireland and Croatia, less than 20 % of the households pay for home-based long-term care services. In other countries, such as Sweden, all care recipients make a financial contribution to the service. In Austria, Greece, Finland, Cyprus and the Netherlands, receiving the services free of charge is unusual, with over 80 % of households needing to pay for them.

Although payment applies in nearly all countries, it is not clear how expensive or affordable such services are for the recipients. Quite often, the

services are highly subsidised and the fees for the households are not very high or are means-tested, i.e. free of charge for those with the lowest levels of income. The eligibility for the benefit (in e.g. CY, HR, PT) and the amount received (in e.g. ES, FR, SK) can depend on the income of the beneficiary (Spasova et al., 2018). Long-term care services (including both home-based and institutional) in the EU are more likely to be free of charge for those in the lowest income quartile (58 %) (Eurofound, 2019). In some Member States, this benefit is reserved for people with severe disabilities (e.g. CY, EL, HR, HU, RO, SK) (Spasova et al., 2018).

The link between the availability, free of charge, of services and the overall availability of the long-term care services is not straightforward. In 2016, over half (52 %) of households reported unmet needs for professional home-based services due to their inability to afford them (see Figure 14). The lowest share of people who were unable to afford the services was in Sweden, where no free services are available (see Figure 15). Concurrently, in Austria, Greece and Cyprus, where long-term care services are also paid for by the majority of recipients, a large share of households with unmet needs for professional home care services reported being unable to afford them.

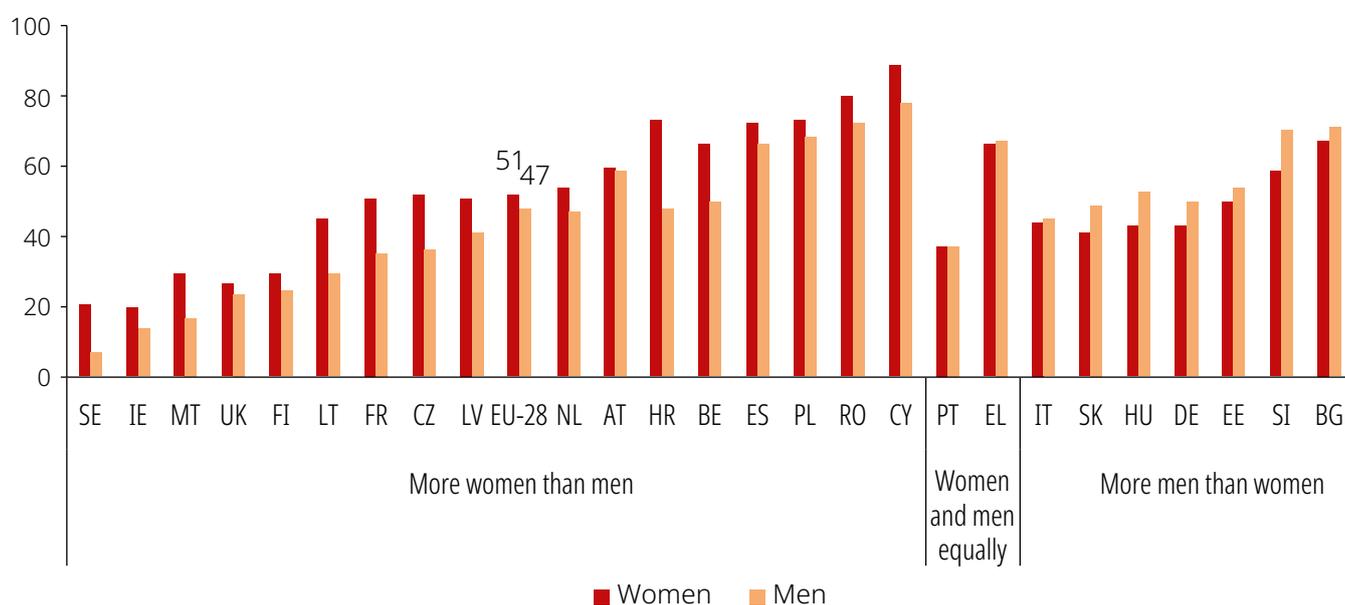
Figure 15: Percentage of women and men reporting that their household needed to pay for the formal home-based long-term care services they received, by gender and country (EU-28, 2016)



Source: EIGE's calculations based on Eurostat, EU-SILC, 2016 (ad hoc module).

NB: Data for women and men in Romania and for men in Bulgaria, Estonia and Lithuania is missing due to small sample sizes.

Figure 16: Percentage of women and men living in households where inability to afford services was the main reason for the household's unmet needs for professional home care services, by gender and country (EU-28, 2016)



Source: EIGE's calculations based on Eurostat, EU-SILC, 2016 (ad hoc module).

NB: Figure covers variable HC250: 'Main reason for not receiving (more) professional home care services'. The possible answers were '1. Cannot afford it'; '2. Refused by person needing such services'; '3. No such care services available'; '4. Quality of the services available not satisfactory'; '5. Other reasons'. The respondents who chose '1' were counted for this figure. Data for Denmark and Luxembourg is not available due to small sample sizes.

Available statistics on the affordability of the services do not provide a good overview of gender differences. While the data reveals how many women and men are living in households that cannot afford the services due to financial reasons, it does not show the gender balance of those left without professional home care services. It is also unknown how much of the formal home-based long-term care services are financed by the recipients themselves and how much are financed by their families. It would be reasonable to assume that due to the gender pay gap, gender pension gap and their relatively limited economic independence, women are more likely to encounter financial obstacles.

4.4. Quality of formal home-based long-term care

The quality of care is multidimensional. It encompasses factors concerning how the care is delivered (e.g. training of professionals), the process of the care provision (e.g. individual approach, ensuring timely and adequate services) and the outcomes (e.g. changes in care recipients' physical or mental health, independence, behaviour or knowledge, along with their overall quality of life) (Donabedian, 1988). In 2010, the SPC released a voluntary European quality framework for social services and defined high-quality services as those meeting the following conditions: a wide range of services

must be available, easily accessible, affordable to the individual, provided continuously for the duration of the time they are needed and focused primarily on benefiting the user (SPC, 2010). The WHO connects the quality of care services directly with the achievement of desired care outcomes. High-quality care must be safe, effective, timely, efficient, equitable and people centred (WHO, 2016). Given that an increasing share of the population is in need of formal long-term care services, all EU countries are facing challenges in finding sustainable ways of ensuring that formal home-based long-term care services are affordable and offer full coverage without compromising the quality of the care.

The quality of formal home-based care services remains one of the key challenges in long-term care (Spasova et al., 2018). The home-based care sector is mostly unregulated and unmonitored in a majority of the Member States, in contrast with residential care services where some measures are applied across the EU (on-site inspections, requirements and standards, licencing, etc.) (Spasova et al., 2018; Szebehely and Meagher, 2017). Formal home care service quality can also be negatively affected by poor working conditions for professional carers as, due to their high workload, tired carers are not always able to provide services that meet the highest standards (Leichsenring, Billings and Nies, 2013) (see Section 5 for more information on professional carers' working conditions).

At the policy level, insufficient coordination between the social and healthcare sectors is another element that may contribute to the low quality of formal home-based services. In most EU countries, responsibilities for regulation, funding and service provision are shared between the health and social care sectors, with powers granted to the national, regional and local levels. The two policy sectors often

lack sufficient integration and coordination, which can have a negative impact on the overall accessibility and quality of the services (Spasova et al., 2018).

Data about the quality of formal home-based care is scarce. Of all the EU level surveys reviewed here ⁽²²⁾, only the European quality of life survey (EQLS) includes a question specifically designed to measure the quality of home-based care services, and the number of respondents who are users of home-based long-term care services is too small to carry out reliable and comparative analysis across all EU Member States. However, EQLS also includes a broader question about the experience of direct and indirect users ⁽²³⁾ of residential and/or home-based care to evaluate the quality of several aspects of the long-term care services (see Table 1). On average, taking into account all four aspects of long-term care quality, the highest user satisfaction is found in Malta, Romania and Ireland, while Cyprus has the lowest (Eurofound, 2019). It is likely that the quality rating of the overall long-term care system in the country (both residential and home care) is also a good reflection of the trends in quality of home-based care services.

The quality of most of these aspects of formal home-based services is somewhat less likely than the affordability of the services to be affected by the gender of the carer or care recipient. However, since the care is provided in an isolated home environment, the care recipients are more likely to experience abuse or neglect, which may involve aggressiveness, rough handling, threats, physical violence, sexual harassment or even abuse from their carer. This is especially likely when care recipients live alone and is more likely to affect women than men due to their longer life expectancy (Hawes, 2003; Post et al., 2010; WHO, 2011). Home-based care recipients may also be subjected to economic violence, especially when care by family members is compensated by the state or local community.

⁽²²⁾ EU-SILC, EU-LFS, EHIS, EWCS, EQLS, SHARE and OECD health statistics.

⁽²³⁾ I.e. both people who personally received long-term care and people who stated that someone close to them had received such care in the last 12 months.

Table 1: User satisfaction with aspects of care provision in long-term care services (EU-28, 2019)

	Quality of the facilities and equipment	Expertise and professionalism of staff	Personal attention given	Being informed or consulted about care	Average user satisfaction
MT	8.4	8.4	8.6	8.7	8.5
RO	8.7	8.5	8.2	8.7	8.5
IE	8.7	8.5	8.2	8.2	8.4
PL	8.3	8.2	8.2	8.2	8.2
SI	8.2	8.3	8.1	8.1	8.2
ES	7.7	8.2	8.3	8.2	8.1
FI	8.2	8.1	7.9	8.0	8.1
EE	7.9	7.8	7.9	8.4	8.0
FR	7.6	7.8	7.9	7.5	7.7
DK	8.7	7.7	7.5	6.8	7.7
BE	7.7	7.7	7.7	7.6	7.7
DE	7.9	7.7	7.6	7.5	7.7
HU	7.5	7.7	7.4	8.0	7.7
SE	8.0	7.5	7.4	7.5	7.6
LU	8.2	7.5	7.3	7.3	7.6
AT	7.5	7.7	7.4	7.6	7.6
SK	7.8	7.4	7.3	7.7	7.5
NL	7.5	7.4	7.4	7.3	7.4
LV	7.5	7.5	7.2	7.3	7.4
HR	6.9	7.4	7.5	7.3	7.3
LT	7.8	7.1	7.1	7.2	7.3
PT	6.6	7.4	7.3	6.8	7.0
UK	6.7	6.9	6.9	7.0	6.9
CZ	7.2	6.5	6.2	6.7	6.6
EL	6.1	6.6	6.7	6.7	6.5
BG	6.4	6.0	7.1	6.4	6.5
IT	6.1	6.5	6.4	6.2	6.3
CY	5.3	5.6	5.7	5.6	5.5
EU-28	7.4	7.5	7.4	7.3	7.4

Source: Eurofound (2019) based on EQLS, 2016.

NB: Users comprise both care recipients themselves and someone close to them. At the individual level, an average of the quality ratings of four different aspects of care was calculated by Eurofound. Respondents were asked to rate their satisfaction with each quality aspect of long-term care service used on a scale of 1–10, where 1 = 'very dissatisfied' and 10 = 'very satisfied'.

4.5. Long-term care for children with disabilities

Children with disabilities represent a unique group of long-term care recipients. Their care needs are specific and usually arise from congenital diseases, rather than from acquired illnesses. In most cases, children's health limitations are described as long-standing and

requiring intensive long-term care services, including continuous monitoring of their health. This makes them reliant on long-term care services for their whole life, with parents playing an indispensable role in both the formal and informal care processes. Moreover, children with disabilities usually require specific types of care services, such as those of a childminder, psychologist, educator or highly qualified

healthcare worker. The complex care needs of children with disabilities pose great challenges for national long-term care systems in the EU in terms of the accessibility, affordability and quality of services.

Informal care provided by parents remains the main type of care received by children with disabilities (Elias, Murphy and the Council on Children with Disabilities, 2012; Knox and Bigby, 2007; Stein, 2001). This is mainly due to the dominant societal expectation that parents of children with disabilities (and especially mothers) should be primarily responsible for the child's care (Stein, 2001), especially when long-term care services for children with disabilities are insufficient. Professional care services (including home-based care) are usually only provided in addition to intensive informal care already provided by family members (Yantzi, Rosenberg and McKeever, 2007).

There is no information available on the funding and cost of the services provided to children. In general, none of the EU Member States provide fully funded long-term care services, hence additional out-of-pocket contributions are often

needed (Eurofound, 2019). Families with children with disabilities (and especially lone parents) face a higher risk of poverty or have financial difficulties in affording services more often than other families (Di Giulio, Philipov and Jaschinski, 2014). Access to such services is also challenging in rural areas, which often have limited nursing and social care resources (Elias, Murphy and the Council on Children with Disabilities, 2012).

In cases where a child has a severe disability and limited access to home-based long-term care services, parents may face a difficult decision on whether to place the child into permanent institutional care or fully dedicate themselves to informal care, with potentially negative consequences to their economic well-being and overall quality of life. According to the Academic Network of European Disability Experts (ANED), in many European countries children with disabilities are placed into institutional care significantly more often than able-bodied children (Crowther, 2019). Member States have made progress in reducing the number of children in institutional care settings; however, children with disabilities are often left behind in this process (Crowther, 2019).

5. Providers of formal home-based long-term care

5.1. Who are the main providers of formal home-based long-term care?

The actual social value of care work is high and is recognised as both an important aspect of economic activity and an indispensable factor contributing to the well-being of individuals, their families and societies (Stiglitz, Sen and Fitoussi, 2017). In reality, the value of informal care to economic growth is invisible and not recognised, and formal care work usually belongs to the lowest-paid and lowest-valued professions. Formal home-based care can significantly improve the well-being of care recipients and reduce demand for residential care (ILO, 2018; Spasova et al., 2018). The overall aim of the home-based carer's tasks is to increase the care recipient's quality of life and independence by providing help with everyday tasks (European Commission, 2013b). However, formal carers are not a homogeneous group as they differ based on work functions, qualifications and the types of care they provide. Some different types of formal carers are as follows.

- **Providers of nursing care**, who often have medical qualifications (e.g. nurses) and who help with basic medical needs such as wound dressing, pain management, medicine consumption and regular health monitoring.
- Home-based **personal carers**, who often have no formal health-sector qualifications, and who help with everyday personal care activities such as walking, eating, bathing

or getting dressed, and with domestic tasks such as shopping, cleaning and cooking.

- **Domestic workers**, who mostly assist with domestic tasks and who usually enter into a direct employment relationship with the care recipients; they can be distinguished as an additional subgroup of home-based personal carers (ILO, 2018; Colombo et al., 2011).

Women are heavily over-represented among all types of formal home-based carers (ILO, 2018). In 2018, 4.5 million of the 5.5 million EU workers in the economic sector known as 'social work activities without accommodation' ⁽²⁴⁾ were women ⁽²⁵⁾. They represented around 82 % of the workforce in this sector – a gross over-representation given that women make up less than half (46 %) of the total EU workforce ⁽²⁶⁾. Over the last 10 years, the share of women in social work has remained unchanged despite the overall increase of the number of workers in this sector (see Figure 17). Moreover, out of all the women in the workforce, 4.3 % were performing social work activities without accommodation, compared to only 0.8 % of men ⁽²⁷⁾. This data, however, covers the broader scope of social work, encompassing all social work activities provided to various groups of recipients at home or in the community.

In the EU-28, it is estimated that a third of social workers – about 1.8 million people – provide specifically home-based professional care to people with disabilities and to older people, and only about 300 000 of these are men (17 %) ⁽²⁸⁾ (Figure 18).

⁽²⁴⁾ NACE category 88 (Eurostat, 2008 (<https://ec.europa.eu/eurostat/documents/3859598/5902521/KS-RA-07-015-EN.PDF>)).

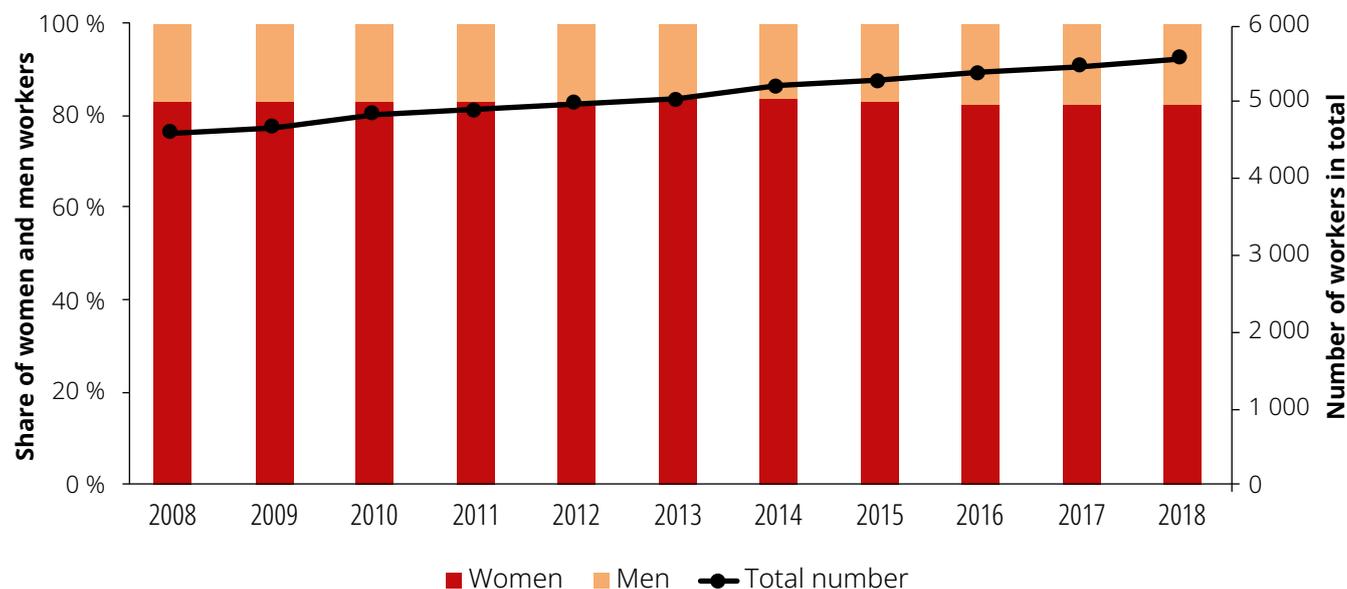
⁽²⁵⁾ Eurostat, EU-LFS, 2018 (lfsa_egan22d).

⁽²⁶⁾ EIGE's calculations based on Eurostat, EU-LFS, 2018 (lfsa_egan22d).

⁽²⁷⁾ *Ibid.*

⁽²⁸⁾ EIGE's calculations based on Eurostat, EU-LFS, 2018.

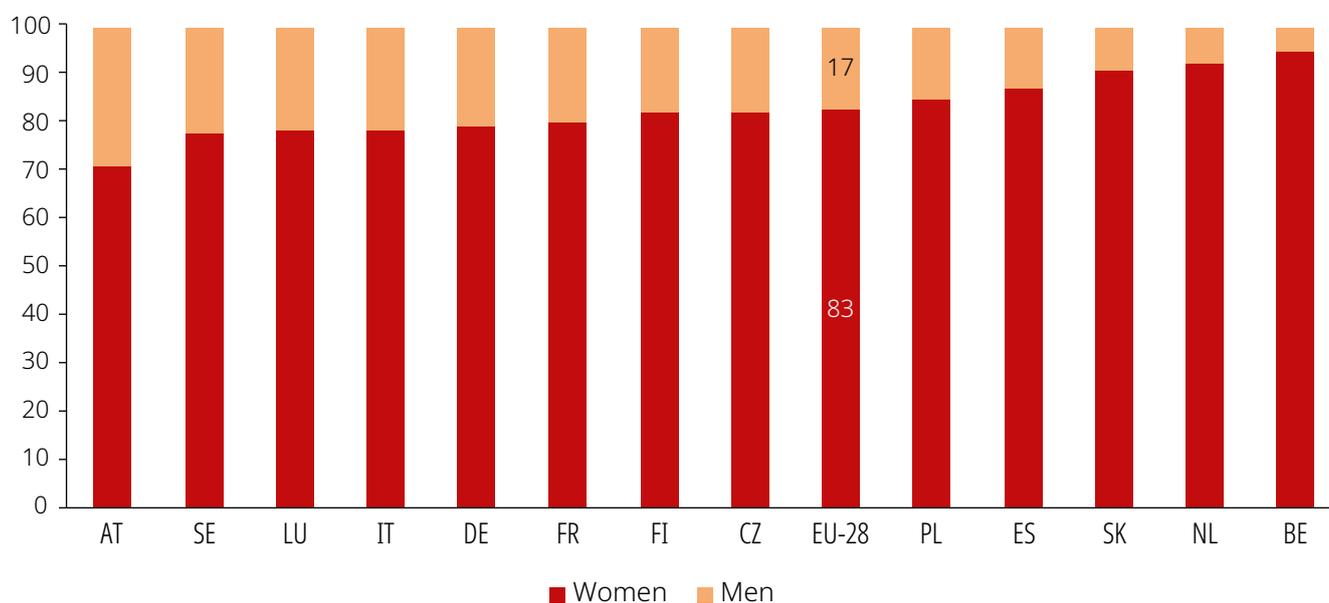
Figure 17: Number of total workers and share of women and men workers in the sector of social work activities without accommodation (NACE 88), by year (15 +, EU-28, 2018)



Source: Eurostat, EU-LFS, 2018 (lfsa_egan22d).

NB: NACE category 88 includes not just social work activities without accommodation for the elderly and disabled, but also other social work activities without accommodation (e.g. social, counselling, welfare, refugee, referral and similar services, youth work, day facilities for the homeless and vocational rehabilitation of the unemployed) (Eurostat, 2008).

Figure 18: Percentage of women and men working in the sector of social work activities without accommodation for the elderly and disabled (NACE 88.1), by country (15 +, EU-28, 2018)



Source: EIGE's calculations based on Eurostat, EU-LFS, 2018.

NB: Data for the rest of the EU-28 is not reliable due to small sample sizes. NACE 88.1 'Social work activities without accommodation for the elderly and disabled' includes social, counselling, welfare, referral and similar services that are aimed at helping the elderly and disabled in their homes or elsewhere and are carried out by government offices, private organisations, national or local self-help organisations and specialists providing counselling services. It includes visits to the elderly and disabled, day-care activities for the elderly or for adults with disabilities, and vocational rehabilitation and habilitation activities for disabled people provided that the education component is limited (Eurostat, 2008).

Data on this particular group of employees at the national level is scarce. Large-scale comparative population surveys available in Europe can only cover such a small group of workers adequately in half of the Member States. Austria stands out from these countries, with 29 % of its professional home-based long-term care workers being men, while in Belgium, the Netherlands and Slovakia the share of men remains below 10 % in 2018 (Figure 18).

Women with low or medium-level education and migrant women are more likely to work in the long-term care sector (especially as personal carers) (OECD, 2019). According to the OECD, few EU countries require personal care workers to hold a minimum level of education or have licenses/certifications, therefore personal care workers do not always have sufficient knowledge or training to deliver high-quality care (OECD, 2019). In recent years, the growing demand for long-term care workers and significant differences in pay and working conditions between different countries has induced an influx of mainly women migrant workers. Foreign-born carers play an especially important role in southern European countries and in Austria (European Commission, 2012). Over-qualification is a rather common phenomenon among skilled migrant women working in the care sector (e.g. qualified medical nurses) (European Commission, 2017c; ILO, 2018), who encounter difficulties in validating their qualifications and therefore tend to face a higher risk of being disadvantaged by unfair recruitment practices (Cangiano et al., 2009).

5.2. Difficult working conditions for formal carers

Employment in the formal care sector is often described as low quality and precarious (Colombo et al., 2011; ILO, 2018; Spasova et al., 2018). In many EU countries formal care work is characterised by:

- high work intensity (e.g. high emotional demands and high workload);
- adverse social environment (e.g. high risk of abuse, harassment and under-appreciation);

- atypical work hours (e.g. working at night and/or at weekends, frequent changes to work hours);
- low income.

High workloads and high levels of stress are prevalent in the formal care sector (ILO, 2018; Spasova et al., 2018). Home-based care workers often carry out complex tasks that involve taking on different roles and responsibilities such as those of a social worker, household helper, nurse and assistant in day-to-day activities. Many of the care tasks involve a great deal of physical exertion, such as maintaining tiring or painful positions and lifting or moving other people, which can have negative effects on the carer's physical health in the long term. For example, muscular pain and exhaustion are described as common health problems among many professional carers (Elwér, Aléx and Hammarström, 2012).

Carers and care recipients usually engage in a healthy and satisfactory relationship; however, it can also become very demanding and emotionally fraught, especially in cases where recipients have psychological or mental problems (Elwér, Aléx and Hammarström, 2012; ILO, 2018). The high emotional burden placed on care workers increases their risk of mental health problems such as mental fatigue or depression (Colombo et al., 2011). Moreover, care workers report some of the highest levels of violence and harassment compared to other industries and sectors (Eurofound, 2015; Lippel, 2016). In 2012 a German survey among care staff revealed that 56 % had experienced physical violence and 78 % had experienced verbal aggression in the 12 months preceding the survey (Schablon et al., 2012). Because of the isolated environment of the care recipient's home, home-based care workers face a higher risk of being subjected to adverse social behaviour by care recipients or their family members compared to residential carers working in institutions. Due to the composition of the social care workforce, such abuse and violence disproportionately affect women, in particular migrant women working as domestic workers (ILO, 2018).

Formal home-based carers are highly likely to have atypical work hours, which are found to have negative effects on workers’ work–life balance, overall health and subjective well-being (Eurofound, 2017; ILO, 2018).

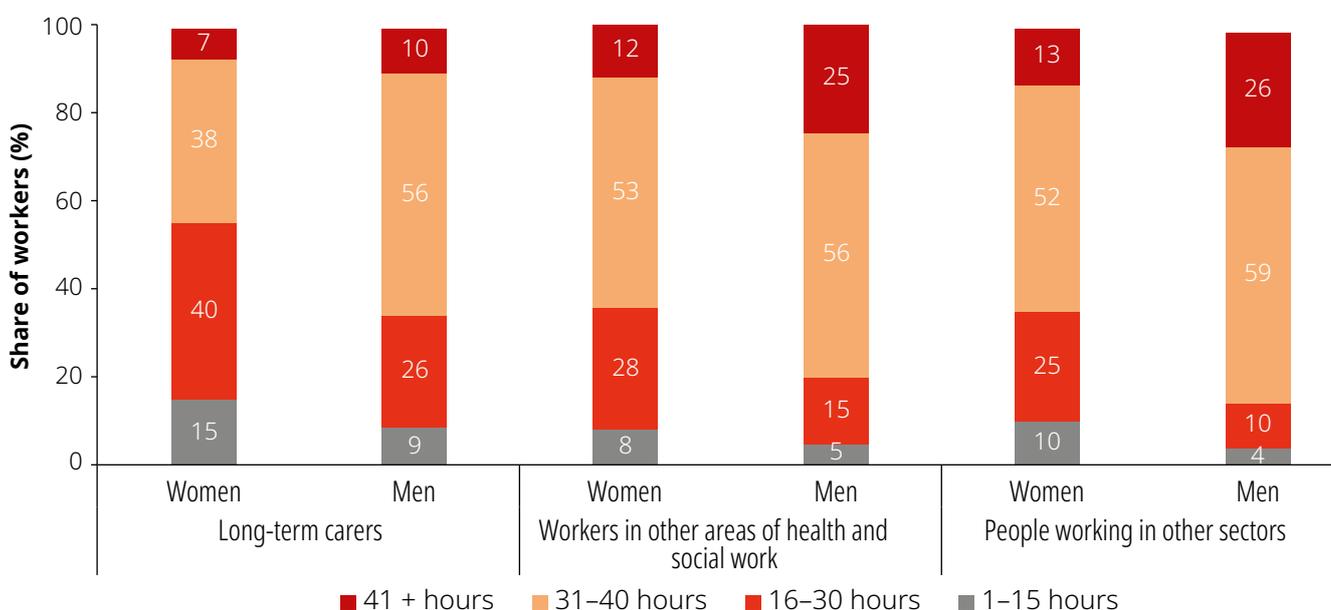
In 2018, in the EU-28, the employees providing home-based long-term care to the elderly and people with disabilities were predominantly working shorter hours than the rest of the EU workforce. Of the workers in this field, 55 % of women and 35 % of men worked less than 30 hours a week. Part-time work is much more common for long-term carers than for other employees in Europe, even those in other areas of health and social work activities (Figure 19).

A study in Sweden found that some carers’ decision to work part-time is strategic: it allows them to accommodate both work and family life despite the high workload and atypical and irregular work hours in the sector (Elwér, Aléx and Hammarström, 2012). Although part-time

employment can have positive effects by allowing carers to rest and spend more time on family and social commitments, it also has a negative effect on their current and future incomes (Elwér, Aléx and Hammarström, 2012). Of those providing home-based long-term care, 15 % of women and 9 % of men work very short hours – up to 15 hours per week (Figure 19). This can be considered precarious employment that may lead to a very low income.

In 2011, an OECD analysis of home-based carers’ wages in 16 European countries revealed that low-skilled carers were likely to earn less than the national average wages (European Commission, 2012). In 2018, over half (51 %) of women and 42 % of men providing professional home-based long-term care in the EU-28 reported having a monthly income falling within the lowest income deciles (Figure 20). Only 4 % of women and 10 % of men in these jobs report having income that can be regarded as high (8th to 10th decile).

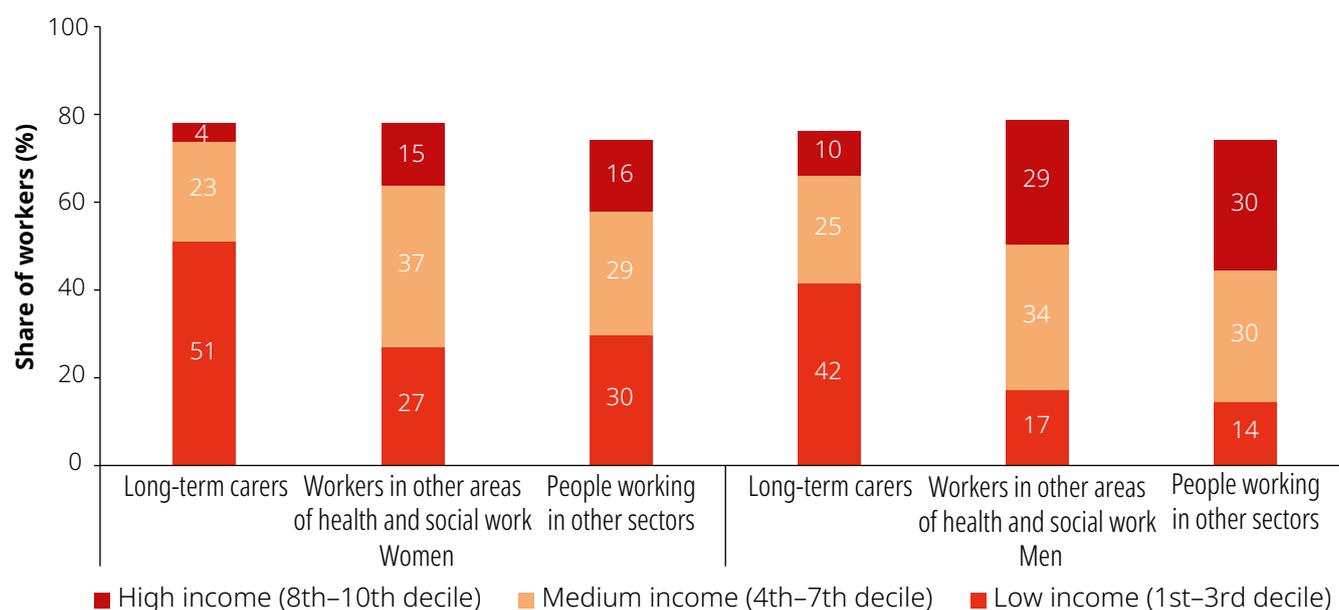
Figure 19: Employed people in different sectors by the length of their working week (in hours, % of employees in the sector, 15 +, EU-28, 2018)



Source: EIGE’s calculations based on Eurostat, EU-LFS, 2018.

NB: Long-term carers are defined as those performing ‘social work activities without accommodation for the elderly and disabled’, in accordance with NACE subcategory 88.1. Workers in other areas of health and social work are those performing functions that fall into all other subcategories of NACE 88, ‘social work activities without accommodation’ (Eurostat, 2008). Data for long-term carers working more than 60 hours per week is not available.

Figure 20: Monthly take-home pay from main job (in income deciles) of workers, by economic activity and gender (15 +, EU-28, 2018)



Source: EIGE's calculations based on Eurostat, EU-LFS, 2018.

NB: Long-term carers are defined as those performing 'social work activities without accommodation for the elderly and disabled', in accordance with NACE subcategory 88.1. Workers in other areas of health and social work are those performing functions that fall into all other subcategories of NACE 88, 'social work activities without accommodation' (Eurostat, 2008). The shares of workers do not add up to 100 % because not all employees revealed their income.

Low pay not only negatively affects the attractiveness of the sector, but also has a negative impact on the economic independence and overall well-being of carers. Migrant personal care workers in round-the-clock live-in arrangements are also particularly vulnerable to financial exploitation, as they are unable to exit the employment relationship (ILO, 2018).

Improvement of employment quality in the for-

mal home-based care sector would likely contribute to the overall levels of gender equality in the Member States. Since women make up the majority of professional carers, improved working conditions in the care sector would benefit them most. It is also likely that improved employment quality, especially higher wages, would attract more men to the care sector, make the balance of women and men in the sector more even and mitigate the shortage of professional carers.

6. How can progress in formal home-based long-term care be monitored?

Monitoring the developments in the provision of formal home-based long-term care services in the EU Member States from a gender equality perspective requires consistent, comparable data. Currently, available data sources on EU Member States provide fragmented information and do not allow definitive conclusions to be drawn on the potential relationship between formal home-based care and gender equality. EIGE reviewed multiple EU-level surveys (namely EU-SILC, European labour force survey (EU-LFS), EHIS, European working conditions survey (EWCS), EQLS, survey of health, ageing and retirement in Europe (SHARE) and OECD health statistics) and while all of them provide some insights, they have some limitations. The key challenges concerning the data relevant for the monitoring of formal home-based services are as follows.

1. Much of the relevant data on the availability and quality of long-term care services is collected at the household level, which makes a gender analysis impossible. The indicators proposed are disaggregated by gender, but they do not actually provide information on the gender of the care recipients (only about the gender of the household respondent). This is an issue for Indicators 5 and 6 on accessibility, and Indicators 7 and 8 on affordability of home-based care services (see Table 2).
2. Data on long-term care of older people is more readily available than that of children or adults with disabilities. For instance, EHIS only asks detailed questions about difficulties in carrying out various daily activities if the respondent is older than 65. Similarly, SHARE data only covers the population over 50. Data gaps are especially large in the case of children with disabilities. While the provision of childcare is monitored by several surveys, it is not possible to identify whether the care is being provided to children with disabilities.
3. Long-term care is monitored more rarely than other health or social services. For instance, EU-SILC includes questions about health or dental care services received by respondents in their primary surveys (implemented annually), but questions concerning long-term care were asked only in the ad hoc module of 2016 (collected every 5 years or even less often).
4. As for data on care recipients, the four most suitable data sets are EHIS, EU-SILC (especially the ad hoc module of 2016), EQLS and SHARE. However, all of them have limitations and disadvantages. EHIS collects information on the use of care services at home at the individual level, but the data is only collected about once every 5 years (the latest data available is from 2014). Information for the EU-SILC module 'Access to services' is also only collected every 5 years and most of the relevant questions are collected at the household level. Therefore, the analysis of gender or age differences between care recipients is limited. The SHARE survey only covers people older than 50. EQLS has several questions that are very useful and suitable for the analysis of long-term care, but the sample size of this survey is relatively low, which makes estimates for many Member States unreliable and therefore not suitable for monitoring at the national level.
5. Difficulties in identifying professional home-based carers complicate the monitoring of their employment quality. Ideally, formal home-based carers would be classified using the International Standard Classification of Occupations category 5322, 'home-based personal care workers' or NACE category 88.1 'social work activities without accommodation for the elderly and disabled'. However, due to the fact that home-based long-term care workers make up only a small proportion of

all professions, the EU-LFS sample size is not sufficient to provide reliable data for monitoring developments in the EU Member States on the characteristics and working conditions of this group. As an alternative, Indicator 10 provides a gender division of workers in NACE category 88, which includes all social workers without accommodation – a much broader category. There is no data on the employment conditions (Indicators 11.1–11.4). Only a selec-

tion of working conditions which are considered important to monitor are mentioned.

Taking into account the advantages and limitations of different EU level surveys, the mix of the aforementioned surveys could be used to monitor different aspects of home-based long-term care presented in this report (see Table 2). Filled-in data tables of the proposed indicators are included in the annex.

Table 2: List of indicators to monitor home-based long-term care

Aspect of long-term care	Title of indicator	Data source
Care recipients		
Care needs	Indicator 1: Percentage of women and men limited in usual activities, by age group (16 +, EU-28, 2018)	EU-SILC
	Indicator 2: Percentage of children limited in activities due to health problems, by gender (< 16 EU-28, 2017)	EU-SILC, 2017 (ad hoc module)
Prevalence of formal home-based care	Indicator 3: Percentage of women and men, with some or severe level of activity limitation, using home care services (15 +, EU-28, 2014)	EHIS, 2014
Availability of formal home-based long-term care	Indicator 4: Number of employees performing social work activities without accommodation per 100 people limited in their everyday activities (16 +, EU-28, 2018)	EU-SILC, EU-LFS and population statistics
Accessibility of formal home-based care services	Indicator 5: Percentage of people reporting unmet household needs for professional home care services, by gender (16 +, EU-28, 2016)	EU-SILC, 2016 (ad hoc module)
	Indicator 6: Prevalence (in percent) of each of the main reasons for the household needs for professional home care services going unmet, by gender of the household respondent (16 +, EU-28, 2016)	EU-SILC, 2016 (ad hoc module)
Affordability of formal home-based long-term care services	Indicator 7: Percentage of people who report that their household needed to pay for the formal home-based long-term care services they received, by gender (16 +, EU-28, 2016)	EU-SILC, 2016 (ad hoc module)
	Indicator 8: Percentage of people who report that their household faced difficulties in paying for the formal home-based long-term care services they received, by gender (16 +, EU-28, 2016)	EU-SILC, 2016 (ad hoc module)
Quality of formal home-based long-term care services	Indicator 9: Average ratings by care recipients of the quality of the formal home-based long-term care services they received, by gender (18 +, EU-28, 2016)	EQLS
Carers		
Individuals working as formal home-based carers	Indicator 10: Percentage of women and men among formal home-based carers (15 +, EU-28, 2018) Applies to home-based carers identified with NACE category 88, 'social work activities without accommodation'	EU-LFS
Employment quality of formal home-based carers	Indicator 11.1: Working at weekends Indicator 11.2: Working at night Indicator 11.3: Exposure to violence at work Indicator 11.3: Participation in education and training Indicator 11.4: Monthly (take-home) pay from main job Applies to home-based carers identified with NACE category 88.1, 'social work activities without accommodation for the elderly and disabled'	No data currently available

Conclusions

Long-term care needs are on the rise and affect women disproportionately

Population ageing leads to fast-growing needs for long-term care and potentially adds to women's already disproportionate burden of unpaid care responsibilities, given that long-term care services are insufficient across the EU. Although the challenges of long-term care have been on the EU policy agenda for some time, the policies seldom contain a gender equality perspective.

The prevalence of health limitations among adults is high in most EU countries, increases with age and **affects women disproportionately**. Due to their higher life expectancy, more women than men are dependent on long-term care. In addition, the vast majority of formal and informal carers are women. The **growing care needs represent a significant long-term challenge for national health and social protection systems**, but also for the achievement of the EU's overall aims to combat social exclusion and discrimination and to promote equality between women and men.

Nearly every tenth person – more men than women – enters adulthood with health limitations

Although the prevalence of disability is highest among older people, about **8 % of young women and 10 % of young men aged 16–24 start off their adulthood with some or severe limitations on their everyday life**. Due to specific and complex needs, their parents may need to forgo employment and engage in full-time informal care. **Children with disabilities often live in single-parent families** – with lone mothers more often than lone fathers – **who are at greater risk of poverty and may have financial difficulties accessing professional care services**.

The care needs of young women and men with disabilities differ significantly from the needs of older people. Young people with disabilities need lifelong support and care to acquire independence, gain an education, integrate into the labour market and prevent possible deepening of their disabilities and dependence. The specific needs of girls and boys and young women and men in need of long-term care should be more broadly addressed in long-term care policies.

Shortage of formal long-term care puts economic independence of women at risk

The availability of formal long-term care services varies greatly in the EU Member States. Across the EU, only a quarter of households with people with disabilities receive formal home-based long-term care services. Long-term care therefore relies heavily on the support provided by informal carers. **Nearly a third of women and men in the EU live in households with unmet needs for professional care**. Certain groups of women are particularly disadvantaged in accessing the services, such as those who are not covered by social insurance schemes, have a lower income or are disadvantaged due to gender biases in the need assessment process.

The shortage of adequate formal home-based care leads to several adverse consequences. It can cause extensive engagement in informal care by family members or friends, avoidable institutionalisation or insufficient care and poor quality of life for those in need of care. Most often, **women in the family take over the care responsibilities – often starting from a very young age – and this puts their economic independence at risk**. A responsibility to provide care is one of the main reasons keeping women out of the labour market or in part-time employment and leading to potentially severe economic and health consequences (gender

pay gap, gender pension gap, risk of poverty, ill health, etc.).

Informal carers need support and their contribution to economy needs to be recognised

The deinstitutionalisation process in the EU moves care from institutions to home. Providing care to people who are severely ill or have disabilities can have a negative impact on carers' health and well-being, particularly if they are lacking in adequate training and support. Besides adult family members, **many children are involved in providing care to family members who are ill or have disabilities** and this has a major impact on their quality of life, education and mental health. Gender roles in care start emerging at very early age – girls, more often than boys, are the ones to take on the care of their relatives who are chronically ill or have disabilities, along with other household tasks.

Developing **support structures and services for formal care at home needs to go hand in hand with supporting family members who provide informal care**. These measures should be designed and coordinated so as to allow family members to freely choose how to arrange the care and to what extent the family will use professional services to achieve an adequate work-life balance. The role of informal carers is vital: it needs to be acknowledged and valued.

Policy targets, action and data collection need to be extended to children with disabilities

With the development of medicine and technology, the number of children with disabilities is on the rise, with about 5 % of EU families having a child with disabilities. **Children need complex and integrated services to support their development**, prevent deepening of their disability and support their future independence. Children with disabilities grow up to be adults

with disabilities: they are dependent on long-term care services throughout their lives.

Children with disabilities are mostly dependent on care by their parents, although the evidence on the services provided to children with disabilities is very scarce. Care for children with disabilities is very demanding and may lead to intense work-life conflict, stress and low quality of life for informal carers. **Without adequate services, parents (mostly mothers) of children with severe disabilities may face a difficult choice on whether to place their child into permanent institutional care or fully dedicate themselves to providing informal care** at home, thereby risking falling out of the labour market and into poverty and social exclusion.

The same difficult decision applies to adults with disabilities, whose institutionalisation may sometimes be prevented with adequate support and home-based care services – a more cost-effective solution that often provides better health outcomes and higher quality of life. Overall, over 1 million Europeans with disabilities live in institutions (FRA, 2018). People with intellectual disabilities along with younger people with disabilities appear to face a higher degree of institutionalisation (ANED, 2010).

Better remuneration required for long-term carers to compensate for difficult working conditions

A lack of service providers has been seen as one of the reasons behind the scarcity of home-based long-term care services. Social workers who provide services outside of institutionalised care make up just over 2 % of the workforce in the EU, covering not only the needs for home-based and community-based long-term care of older people and people with disabilities, but also other disadvantaged groups (e.g. youths, refugees).

The majority of people engaged in social work in the EU are women. In 2018, women comprised 4.5 million out of the 5.5 million professional social workers providing care outside of

institutional settings in the EU. The actual value of both formal and informal care is not adequately recognised in society. **Working conditions in the formal care sector are often difficult and precarious, characterised by high work intensity, atypical work hours, adverse social environment and low income.** Currently, information on the actual working conditions of the people providing home-based long-term care services in different Member States is scarce. In order to improve the working conditions and secure adequate pay, policies should recognise the precariousness of jobs in the care sector in the majority of Member States and to acknowledge the need for good-quality comparable data on working conditions in this sector.

Ambitious and gender-specific policy goals are needed

Targets should be set in order to effectively monitor progress in the provision of formal home-based long-term care – similar to the targets on the provision of childcare (the ‘Barcelona objectives’). The targets should cover

not only long-term care provided to older people and adults with disabilities, but also to children with disabilities. This study proposes a set of indicators that could be used to capture the complexity of the accessibility of care. In addition to measuring the overall level of need for care, Member States should also collect data and regularly map the situation regarding the availability, affordability and quality of the services. In order to achieve positive care outcomes, care must be safe, effective, timely, efficient, equitable and people-centred (WHO, 2016).

Since long-term care, both formal and informal, is a highly gendered issue, a **gender perspective needs to be introduced when setting the targets and significantly strengthened in data collection.** Current high-quality and comparable statistics on the use of home-based long-term care in the EU is lacking a gender perspective as most of the information is collected at the household level. This puts limitations on researching gender inequalities in the field of formal home-based long-term care, especially in terms of availability, affordability and quality of services.

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Annex

Indicator 1: Percentage of women and men limited in usual activities, by age group (16 +, EU-28, 2018)

	Total (≥ 16)			16-64			65-74			75 +		
	Total	Women	Men									
EU-28	25.0	27.3	22.6	17.9	19.2	16.6	39.6	41.7	37.1	59.0	62.3	54.4
BE	25.3	27.6	23.0	19.8	21.2	18.4	34.7	35.4	34.0	53.8	56.9	48.9
BG	16.8	19.1	14.3	9.2	9.6	8.8	31.2	32.6	29.3	51.2	55.3	44.2
CZ	28.0	29.8	25.2	18.6	19.8	17.0	42.7	44.0	40.7	66.4	69.2	61.0
DK	29.0	32.5	25.3	25.4	29.4	21.4	37.6	39.2	35.8	44.7	44.7	44.8
DE	22.3	23.3	21.2	17.7	18.4	17.0	31.1	31.7	30.4	42.4	44.8	39.9
EE	39.7	42.1	36.3	29.9	29.7	30.1	60.2	62.6	56.1	77.1	78.5	73.0
IE	15.8 ^p	16.4 ^p	15.3 ^p	11.9 ^p	12.4 ^p	11.4 ^p	27.3 ^p	26.6 ^p	28.1 ^p	42.4 ^p	42.6 ^p	42.2 ^p
EL	24.0	25.7	22.0	10.6	11.0	10.1	48.7	50.8	46.2	77.8	79.7	75.4
ES	20.7	23.4	17.8	13.5	14.5	12.4	33.4	36.9	29.5	58.8	63.8	51.4
FR	25.3	27.2	23.4	18.4	19.7	17.0	37.3	38.0	36.5	59.0	59.5	58.4
HR	33.5	35.5	31.4	22.0	21.5	22.4	62.2	63.4	60.8	81.6	84.4	76.6
IT	23.8	26.4	21.0	12.9	13.4	12.3	40.8	43.7	37.7	67.6	71.5	61.6
CY	24.0	24.5	23.3	16.0	15.4	16.7	51.2	52.7	49.5	73.0	80.2	64.0
LV	40.1	43.5	35.8	29.0	30.1	27.8	64.9	65.7	63.6	83.0	83.6	81.3
LT	30.6	34.1	26.3	19.4	20.2	18.6	57.0	58.2	54.9	74.2	75.9	70.0
LU	27.2	29.4	25.1	22.2	24.3	20.0	42.9	45.3	40.5	64.8	67.1	62.6
HU	25.4	28.1	22.5	16.7	17.6	15.7	46.9	48.7	44.3	68.1	71.1	63.1
MT	12.0	13.2	10.8	7.6	7.8	7.4	22.5	24.0	20.8	37.8	42.3	31.9
NL	31.3	35.1	27.3	26.1	29.7	22.6	43.7	46.9	40.3	56.4	59.5	52.3
AT	34.1	35.9	32.2	27.3	27.9	26.7	51.2	52.6	49.7	71.5	74.3	67.0
PL	24.0	25.5	22.2	16.3	16.1	16.6	41.1	42.8	38.8	64.5	67.5	58.5
PT	33.6	38.2	28.2	23.5	26.7	20.0	55.2	60.6	48.6	71.8	75.1	66.4
RO	26.5	30.7	21.9	16.5	18.7	14.4	55.2	60.2	48.6	72.6	75.0	68.4
SI	35.4	38.1	32.6	28.7	30.2	27.2	52.1	51.9	52.4	70.4	75.5	62.3
SK	31.3	34.3	28.1	22.0	23.6	20.4	65.1	65.5	64.6	84.8	84.8	84.6
FI	34.3	38.8	30.0	28.5	32.3	25.0	42.7	44.7	40.7	61.8	66.6	55.0
SE	12.8	15.9	9.7	10.1	12.6	7.8	16.9	20.1	13.4	26.5	30.3	21.3
UK	27.3 ^p	29.5 ^p	25.0 ^p	21.8 ^p	23.8 ^p	19.7 ^p	37.6 ^p	38.7 ^p	36.5 ^p	55.4 ^p	56.9 ^p	53.4 ^p

Source: Eurostat, EU-SILC, 2018 (hlth_silc_06).

NB: Flags: p = provisional data.

Indicator 2: Percentage of children limited in activities due to health problems, by gender (< 16, EU-28, 2017)

	Total	Girls	Boys
EU-28	4.7	4.2	4.9
BE	5.0	4.1	6.0
BG	2.2	2.6	2.2
CZ	6.5	5.3	7.7
DK	—	—	—
DE	4.6	4.0	4.9
EE	8.4	7.3	9.3
IE	4.9	4.1	5.5
EL	2.0	2.0	1.9
ES	2.8	3.0	2.6
FR	4.8	4.5	5.1
HR	2.8	2.0	3.7
IT	0.8	0.6	1.0
CY	1.7	1.8	1.4
LV	12.4	11.8	12.7
LT	8.7	8.6	8.9
LU	5.0	4.8	5.3
HU	4.6	3.7	5.5
MT	2.5	2.3	2.9
NL	—	—	—
AT	6.0	5.2	6.5
PL	3.6	2.8	4.8
PT	5.2	4.7	5.9
RO	7.6	8.7	6.5
SI	—	—	—
SK	2.5	2.3	2.6
FI	—	—	—
SE	—	—	—
UK	8.4	9.2	9.6

Source: Eurostat, EU-SILC, 2017 (ilc_hch13) and EIGE's calculations based on the EU-SILC, 2017 microdata.

NB: '—' = data not available or not published due to reliability problems.

Indicator 3: Percentage of women and men, with some or severe level of activity limitation, using home care services (15 +, EU-28, 2014)

	Total	Women	Men	Gap
EU-28	10.8	12.3	8.8	3.5
BE	22.2	26.9	16.2	10.7
BG	9.0	8.8	9.2	- 0.4
CZ	5.6	6.5	4.5	2.0
DK	10.5	12.5	8.4	4.1
DE	7.3	9.1	5.2	3.9
EE	2.9	3.3	2.4	0.9
IE	8.7	9.5	7.7	1.8
EL	8.3	8.4	8.2	0.2
ES	11.5	13.2	9.1	4.1
FR	24.4	27.0	21.2	5.8
HR	5.0	6.5	3.0	3.5
IT	11.9	13.7	9.2	4.5
CY	6.8	8.9	3.9	5.0
LV	3.9	4.5	2.8	1.7
LT	4.5	4.9	3.9	1.0
LU	8.0	7.4	8.6	- 1.2
HU	8.6	11.2	5.1	6.1
MT	19.5	22.5	15.8	6.7
NL	18.0	21.9	12.8	9.1
AT	4.1	5.3	2.4	2.9
PL	7.2	8.2	6.0	2.2
PT	5.1	5.4	4.7	0.7
RO	6.4	6.9	5.5	1.4
SI	5.9	7.2	4.2	3.0
SK	3.3	4.0	2.3	1.7
FI	9.2	10.4	7.9	2.5
SE	4.9	5.0	4.8	0.2
UK	8.8	9.4	8.1	1.3

Source: Eurostat, EHIS, 2014 (hlth_ehis_am7d).

Indicator 4: Number of employees performing social work activities without accommodation per 100 people limited in their everyday activities (16 +, EU-28, 2018)

EU-28	5.2
BE	8.4
BG	3.4
CZ	1.5
DK	13.7
DE	7.0
EE	0.6
IE	14.2
EL	1.2
ES	2.7
FR	9.4
HR	1.0
IT	2.1
CY	1.2
LV	1.4
LT	1.2
LU	8.8
HU	2.7
MT	5.8
NL	6.8
AT	3.4
PL	2.1
PT	2.4
RO	1.0
SI	0.8
SK	3.1
FI	8.5
SE	19.7
UK	6.5

Source: EIGE's calculations based on Eurostat, EU-SILC, 2018.

NB: NACE category 88 'Social work activities without accommodation' was used to define employees performing social work activities without accommodation (Eurostat, 2008).

Indicator 5: Percentage of people reporting unmet household needs for professional home care services, by gender (16 +, EU-28, 2016)

	Women	Men	Gap
EU-28	29.9	27.5	2.4
BE	29.0	12.8	16.2
BG	47.3	42.6	4.7
CZ	32.1	23	9.1
DK	—	—	—
DE	17.8	12.6	5.2
EE	15.5	10.8	4.7
IE	33.2	30.8	2.4
EL	63.5	58.4	5.1
ES	34.1	28.1	6.0
FR	31.0	25.0	6.0
HR	20.4	14.4	6.0
IT	39.1	31.4	7.7
CY	47.2	46	1.2
LV	40.3	35.6	4.7
LT	42.7	36.9	5.8
LU	11.5	18.2	- 6.7
HU	23.1	22.2	0.9
MT	23	19.4	3.6
NL	42.6	44.9	- 2.3
AT	24.1	25.5	- 1.4
PL	17.7	14.6	3.1
PT	85.3	86	- 0.7
RO	47.8	34	13.8
SI	25.1	17	8.1
SK	24.1	23.2	0.9
FI	26.7	22.1	4.6
SE	12.1	13	- 0.9
UK	19.3	22.4	- 3.1

Source: EIGE's calculations based on Eurostat, EU-SILC, 2016 (ad hoc module).

NB: '—' = data not available or not published due to reliability problems.

Indicator 6: Prevalence (in percent) of each of the main reasons for the household needs for professional home care services going unmet, by gender of the household respondent (16 +, EU-28, 2016)

	Cannot afford services			Services refused by person in need			No such care services available			Quality of available services not satisfactory			Other		
	Women	Men	Gap	Women	Men	Gap	Women	Men	Gap	Women	Men	Gap	Women	Men	Gap
EU-28	51.2	47.3	3.9	7.6	8.3	- 0.6	14.0	15.4	- 1.4	3.3	3.5	- 0.2	23.8	25.5	- 1.7
BE	66.2	50.0	16.2	2.9	3.2	- 0.3	6.4	28.8	- 22.4	5.0	0.0	5.0	19.6	18.1	1.5
BG	67.6	71.6	- 4.0	6.4	5.1	1.3	14.1	13.7	0.4	2.4	3.4	- 1.0	9.5	6.2	3.3
CZ	51.8	36.4	15.5	12.8	14.0	- 1.1	11.4	5.5	5.9	1.6	5.0	- 3.3	22.3	39.2	- 16.9
DK	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
DE	43.1	50.0	- 7.0	14.4	5.7	8.6	3.9	12.0	- 8.1	0.0	2.3	- 2.3	38.7	30.0	8.7
EE	49.5	53.2	- 3.8	1.6	4.6	- 3.0	32.2	26.8	5.4	0.6	0.0	0.6	16.1	15.4	0.8
IE	19.1	13.7	5.4	6.7	8.3	- 1.6	26.7	31.6	- 5.0	20.0	3.8	16.2	27.6	42.6	- 15.0
EL	66.5	67.0	- 0.4	25.1	23.2	1.9	5.0	4.9	0.1	1.8	1.7	0.0	1.6	3.3	- 1.7
ES	72.4	66.7	5.8	3.9	2.8	1.1	9.4	10.0	- 0.7	0.7	2.1	- 1.4	13.6	18.4	- 4.8
FR	50.6	34.7	15.9	9.7	13.6	- 3.9	7.7	7.4	0.3	4.0	0.8	3.2	28.0	43.6	- 15.6
HR	73.1	48.1	25.0	0.9	3.9	- 3.0	14.2	23.7	- 9.5	5.6	5.2	0.4	6.2	19.2	- 13.1
IT	44.0	45.2	- 1.1	2.1	2.7	- 0.7	34.0	36.3	- 2.3	4.6	5.1	- 0.5	15.3	10.7	4.6
CY	88.8	77.8	11.0	6.3	10.5	- 4.2	1.0	0.0	1.0	2.8	4.3	- 1.5	1.1	7.4	- 6.4
LV	51.2	40.7	10.4	16.4	12.3	4.1	16.7	22.4	- 5.7	4.0	7.2	- 3.2	11.7	17.4	- 5.7
LT	44.4	29.1	15.3	17.4	13.9	3.5	8.0	4.4	3.6	3.8	9.3	- 5.5	26.4	43.4	- 16.9
LU	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
HU	43.3	52.9	- 9.5	25.0	33.1	- 8.1	20.5	6.5	14.0	3.8	0.0	3.8	7.4	7.6	- 0.1
MT	29.1	17.0	12.1	8.6	8.3	0.4	0.0	6.9	- 6.9	2.4	4.9	- 2.5	59.9	63.0	- 3.1
NL	53.4	46.4	7.0	3.1	3.2	- 0.1	15.3	13.4	1.9	1.1	2.1	- 1.0	27.1	34.9	- 7.8
AT	59.9	58.1	1.8	18.5	14.5	4.0	4.8	10.3	- 5.5	1.9	0.0	1.9	14.9	17.1	- 2.1
PL	73.2	68.0	5.2	5.9	11.1	- 5.3	7.4	11.7	- 4.3	6.1	2.3	3.8	7.5	7.0	0.5
PT	37.3	37.1	0.2	8.5	10.0	- 1.4	6.1	10.0	- 3.9	2.3	1.2	1.0	45.8	41.6	4.1
RO	80.2	72.6	7.6	4.5	7.2	- 2.8	11.2	16.8	- 5.6	0.0	0.0	0.0	4.1	3.4	0.7
SI	58.5	70.0	- 11.5	8.1	4.7	3.4	11.4	11.0	0.4	3.2	1.0	2.2	18.8	13.3	5.5
SK	41.0	49.1	- 8.1	17.7	27.1	- 9.4	14.4	6.4	8.0	1.7	0.0	1.7	25.3	17.5	7.8
FI	29.7	24.0	5.7	3.4	2.8	0.6	22.6	28.2	- 5.6	2.5	2.1	0.3	41.8	42.9	- 1.0
SE	20.8	6.8	14.0	6.9	3.2	3.6	12.9	13.7	- 0.8	0.0	22.3	- 22.3	59.5	54.1	5.4
UK	26.7	23.7	3.0	8.8	10.7	- 1.9	14.8	14.3	0.5	5.6	7.6	- 2.0	44.1	43.8	0.3

Source: EIGE's calculations based on Eurostat, EU-SILC, 2016.

NB: '—' = data not available or not published due to reliability problems.

Indicator 7: Percentage of people who report that their household needed to pay for the formal home-based long-term care services they received, by gender (16 +, EU-28, 2016)

	Total	Women	Men	Gap
EU-28	62.0	63.4	59.9	3.5
BE	72.2	75.5	68.6	6.8
BG	68.1	71.2	—	—
CZ	41.7	38.3	49.0	- 10.7
DK	44.6	40.0	54.8	- 14.8
DE	48.1	38.3	54.8	- 16.5
EE	31.3	33.6	23.4	10.2
IE	14.6	16.5	11.2	5.3
EL	84.9	86.8	82.3	4.4
ES	79.0	79.0	82.4	- 3.4
FR	68.5	70.8	64.5	6.3
HR	17.5	18.4	16.8	1.6
IT	44.9	50.0	37.4	12.6
CY	82.7	78.1	88.0	- 10.0
LV	14.5	19.8	0.0	19.8
LT	46.9	42.5	—	—
LU	43.1	48.5	33.2	15.3
HU	41.5	36.0	51.3	- 15.4
MT	45.6	61.2	35.3	26.0
NL	81.8	83.9	77.8	6.1
AT	91.9	93.0	89.6	3.4
PL	71.8	70.2	76.1	- 5.9
PT	67.4	66.2	68.8	- 2.6
RO	—	—	—	—
SI	36.1	39.2	31.7	7.5
SK	41.9	48.8	29.5	19.3
FI	83.3	85.8	78.4	7.4
SE	100.0	100.0	100.0	0.0
UK	36.9	38.2	35.3	2.9

Source: EIGE's calculations based on Eurostat, EU-SILC, 2016.

NB: '—' = data not available or not published due to reliability problems.

Indicator 8: Percentage of people who report that their household faced difficulties in paying for the formal home-based long-term care services they received, by gender (16 +, EU-28, 2016)

	Total	Women	Men	Gap
EU-28	52.8	53.5	46.3	7.2
BE	50.6	52.1	51.7	0.5
BG	78.2	80.1	—	—
CZ	84.3	83.2	85.6	- 2.4
DK	31.4	31.8	40.1	- 8.3
DE	39.1	33.2	37.7	- 4.5
EE	68.6 ^u	—	—	—
IE	47.2	43.5	—	—
EL	93.3	93.1	95.8	- 2.7
ES	70.9	74.9	64.5	10.5
FR	42.4	47.4	31.3	16.2
HR	82.5 ^u	—	—	—
IT	81	87.5	78.8	8.7
CY	92.3	92.4	92.4	0.0
LV	76.8 ^u	—	—	—
LT	94.1 ^u	—	—	—
LU	34.1	37.9	—	—
HU	80.8	95.5	—	—
MT	39.5	35.6	—	—
NL	36.9	38.8	35.1	3.7
AT	58.6	62.3	53.0	9.3
PL	82.2	84.8	—	—
PT	80.4	86.1	71.9	14.2
RO	—	—	—	—
SI	66.5	61.7	82.6	- 20.9
SK	94.5	89.1	—	—
FI	24.8	27.9	26.4	1.6
SE	26.9	30.7	27.1	3.7
UK	45.2	45.2	41.7	3.5

Source: Eurostat (ilc_ats16) and EIGE's calculations based Eurostat, EU-SILC, 2016
 NB: '—' = data not available or not published due to reliability problems. Flags: u = low reliability.

Indicator 9: Average ratings by care recipients of the quality of the formal home-based long-term care services they received, by gender (18 +, EU-28, 2016)

	Total	Women	Men	Gap
EU-28	7.8	7.7	7.9	- 0.2
BE	8.1	8.0	8.2	- 0.1
BG	—	—	—	—
CZ	7.2	—	—	—
DK	8.9	8.4	9.3	- 0.9
DE	7.9	7.8	—	—
EE	—	—	—	—
IE	—	—	—	—
EL	—	—	—	—
ES	—	—	—	—
FR	7.9	7.8	8.0	- 0.2
HR	—	—	—	—
IT	6.3	6.0	6.7	- 0.7
CY	—	—	—	—
LV	7.6	7.3	—	—
LT	—	—	—	—
LU	8.5	8.7	—	—
HU	8.5	8.6	—	—
MT	8.7	8.7	—	—
NL	7.7	7.8	—	—
AT	—	—	—	—
PL	—	—	—	—
PT	—	—	—	—
RO	—	—	—	—
SI	8.1	8.1	—	—
SK	—	—	—	—
FI	8.6	—	—	—
SE	8.5	8.1	—	—
UK	—	—	—	—

Source: EIGE's calculations based on Eurofound, EQLS, 2016.

NB: '—' = data not available or not published due to reliability problems. Care recipients are defined as those respondents who answered 'Yes, I have' to question 68a, 'Have you ... used [formal nursing care services at your home] in the last 12 months?' and/or to question 68b, 'Have you ... used [formal home help or personal care services in your home] in the last 12 months?'. Respondents were asked to rate their satisfaction with each quality aspect of long-term care service used on a scale of 1-10, where 1 = 'very dissatisfied' and 10 = 'very satisfied'.

Indicator 10: Percentage of women and men among formal home-based carers (15 +, EU-28, 2018)

	Women	Men
EU-28	82.4	17.6
BE	83.3	16.7
BG	85.7 ^u	14.3
CZ	83.3	16.7
DK	79.5	20.5
DE	75.1	24.9
EE	—	—
IE	84.2	15.8
EL	83.8	16.2
ES	84.7	15.3
FR	86.0	14.0
HR	—	—
IT	83.6	16.4
CY	—	—
LV	—	—
LT	—	—
LU	80.5	19.5
HU	88.8	11.2
MT	—	—
NL	90.4	9.6
AT	77.4	22.6
PL	88.6	11.4
PT	90.5	9.5
RO	82.0 ^u	18.0
SI	68.8 ^u	31.3 ^u
SK	91.0 ^u	9.0
FI	89.6	10.4
SE	77.8	22.2
UK	80.4	19.6

Source: EIGE's calculations based on Eurostat, EU-LFS, 2018 (Ifsa_egan22d).

NB: '—' = data not available or not published due to reliability problems. Flags: u = low reliability. NACE category 88, 'Social work activities without accommodation' was used to define employees providing social work activities without accommodation (Eurostat, 2008).

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