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# Reconciling care and work with children in need of care in Denmark, Finland and Sweden

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## Abstract

Parents who have responsibility for a child in need of care and/or with disabilities continue to face major challenges in reconciling care and work – despite progress made with the introduction of certain reconciliation policy measures. These parents usually have to be particularly flexible in order to be able to address the additional needs of the child within their everyday life between employment and private life. This double burden legitimises the demand for and emphasises the importance of comprehensive measures to improve the possibilities for reconciliation of care and work for this specific group of caregivers. This working paper therefore examines the schemes and measures with which states support parents with children in need of care and/or disabilities in reconciling care and work. In this context, the following measures are central for better reconciliation: leave schemes, flexibilisation schemes and financial support.

Given the wide range of efforts towards achieving a good work-life balance in the Nordic countries, this working paper highlights good practice examples from Denmark, Finland and Sweden. Particular attention is paid to measures that promote partnership-based burden sharing between women and men.

Central findings are:

- In all three countries studied, parents with children in need of care and/or with disabilities are explicitly supported with models for the reconciliation of care and work.
- Parents are enabled to reduce their employment, to interrupt it for a long or short period and to apply for wage compensation or absence allowances.
- Parents of children in need of care and/or with disabilities also benefit from the general regulations which apply to all parents or to all employees (e.g. parental leave, amongst others).
- Compared to the European average, all three countries have a very high female employment rate, generous parental leave or flexible parental leave arrangements and a legal guarantee for childcare placement.
- Most measures also aim to promote a fair distribution of unpaid care work between women and men.
- In the literature as well as in social discourse, the focus of care provided by relatives (family caregivers) is clearly directed towards the care for elderly persons.
- “Family caregivers” of children in need of care are first and foremost seen as parents; their special needs are hardly noticed.
- The nursing and care of a child also includes education and the promotion of development as central components and is therefore not comparable to the care of an elderly person.
- The measures become less pronounced as the children grow older.

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## 1 Introduction

The reconciliation of care and work remains a challenge for many caregiving relatives in Europe, despite progress made in recent years with the introduction of certain reconciliation policies. This is particularly true for relatives, usually the parents, who take on responsibility for caring for a child in need of care (Kofahl et al. 2017: 25). The need of care for children is often associated with disabilities and rare or chronic illnesses.<sup>1</sup> The spectrum of impairments is broad and differs significantly from adult need for care (GKV-Spitzenverband 2013: 52f.).

In Germany, a total of 3.41 million people were in need of long-term care (within the meaning of care insurance) in 2017, including around 114,000 children and young people under the age of 15.<sup>2</sup> 98.3% of these young people were fully cared for at home. With just over 3% of the total number of people affected, children in need of care constitute a relatively small group (Statistisches Bundesamt 2018: 19).<sup>3</sup>

For parents with children in need of care, the common challenges of parenthood are intensified, as the (chronic) illness or disability creates special needs. Among the many challenges are: learning about the illness or disability, dealing with the child's needs/requirements, frequent appointments for therapies and medical visits and their reconciliation with employment, the financial burden of additional costs for treatments that are not covered by health insurance, financial losses due to the reduction in employment, finding childcare that is tailored to the child's needs, fear and worry about the health of one's own child and its future, little time for self-care and the care of other children.<sup>4</sup>

These specific challenges can have a negative impact on parents emotionally, health-wise and economically. For example, Kofahl et al. state: "Compared to parents of healthy children, parents of children in need of care and/or disabled children have significantly worse physical and mental health, a lower quality of life and a significantly worse economic situation due to career and employment slumps" (Kofahl et al. 2017: 25). Similarly, siblings also show signs of strain due to their sibling's need for care and can put additional strain on the family system (ibid.). Often, the impairment or illness of a child results in a separation of the parents, which then leads to a particularly high burden for – usually – single mothers who have to take on the

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<sup>1</sup> Besides chronic diseases, rheumatic diseases (e.g. cancer, diabetes, congenital heart defects) or rare diseases (muscular dystrophies, various neurodegenerative diseases) can also lead to a need for care. The most common disabilities in children are mental development disorders, physical disabilities and functional impairments of internal organs or limbs, congenital malformations or genetic defects. Multiple disabilities are often observed (GKV 2013: 52f.). In order to make it easier to deal with translations from international literary sources, this working paper refers to "children in need of care" or "children with disabilities", meaning children who require more time for nursing and care than "healthy" children. The two terms are used synonymously.

<sup>2</sup> The figure has almost doubled in Germany in the past ten years (compared to 2007: a total of 63,164 people under 15 in need of long-term care). The reason for this is the reform of the long-term care insurance system on 1 January 2017 as well as the introduction of a new concept of the need for long-term care and five levels of long-term care.

<sup>3</sup> A query to the Federal Statistical Office has shown that there are no comparable figures of minors in need of care within the framework of official European statistics. Only statistics on "Own data on the use of care services at the patient's place of residence, by gender, age and degree of activity restriction" were available. However, only persons aged 15 and over are recorded in these statistics.

<sup>4</sup> <https://www.bu.edu/fsao/resources/parenting-children-with-special-needs/>

sole care of the child to be cared for (ibid.: 30). There are also indications, however, that family ties can become stronger in the face of these challenges and develop towards particularly closer relationships (ibid.: 25). Gender asymmetries often occur, with mothers taking on unpaid care work and fathers earning the family income – which in turn often entails a general loss of income for the family and does not contribute to gender equality (bpb 2020: 42).

The high burden on parents caused by care justifies the demand and stresses the importance of comprehensive measures to address and improve the reconciliation of care and work for this group of caregivers. This will be accounted for in this present working paper.

Crucial for better reconciliation in this context are **leave schemes**, **flexibilisation schemes** as well as **financial support** for caregivers.<sup>5</sup> Specifically, the eligibility conditions, the duration of the measures, the design and the amount of wage compensation or benefits are decisive in each case (Bouget et al. 2016).<sup>6</sup>

Building on the Observatory's 2017 overview on "Leave and financial support for family caregivers in EU Member States"<sup>7</sup>, this working paper focuses on reconciling care and work with children in need of care. Best practice models of governmental support for reconciling care and work with children in need of care from Denmark, Finland and Sweden will be presented.

The reconciliation of professional and private life also has many implications for gender equality, especially when it comes to the role of parents. Due to traditional gender norms, care responsibilities are very often taken over by women. This has implications for their access to the labour market and to paid employment, their career advancement, economic independence, equal pay and equal participation in decision-making and in society as a whole (Equinet 2018). Most parents with children under the age of 18 look after and bring up their children on a daily basis – this corresponds to 88% of mothers and 64% of fathers in the EU-28. A closer look at participation in the care of children and grandchildren by people of working age (18-64 years) shows that 84% of men, but only 66% of women are in employment. Data are also available for the care and nursing of a person (under 75 years of age) with disabilities or in need of care, but no explicit figures exist specifically regarding children with disabilities or in need of care (Eurofound 2017: 43f.).

The proportion of women in employment in the Nordic countries is higher than the global average, partly due to the commitment to equal rights in the workplace, subsidised childcare and generous parental leave. Due to the diverse investments in gender equality in the labour market in the Nordic countries, these three countries will be included in the analysis (Nordic

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<sup>5</sup> On specific groups of persons, see also: Reich, Nele / Reinschmidt, Lena / Hoyer, Sören (2017): (Wie) Kann häusliche Pflege im Angehörigenkreis aufgeteilt werden? Freistellungen und finanzielle Leistungen für die häusliche Pflege in ausgewählten europäischen Staaten; [https://www.beobachtungsstelle-gesellschaftspolitik.de/file/?f=c731415fbd.pdf&name=2017\\_Studie\\_Freistellungen\\_DE.pdf](https://www.beobachtungsstelle-gesellschaftspolitik.de/file/?f=c731415fbd.pdf&name=2017_Studie_Freistellungen_DE.pdf) (in German).

<sup>6</sup> On services for family carers, see also: Merkle, Maike (2018): Counselling services for family carers in Europe; <https://beobachtungsstelle-gesellschaftspolitik.de/f/1e3bfc3ede.pdf>.

<sup>7</sup> Hoyer, Sören / Reich, Nele (2017): Leave and financial support for family caregivers in EU Member States; <https://beobachtungsstelle-gesellschaftspolitik.de/f/04d661be68.pdf>.

Council of Ministers 2018: 3). The working paper will pay special attention to measures that promote the partnership-based division of work between women and men.

Chapters 2–4 will take closer looks at each of the three examined states. As a start, a short introductory section provides information on the general work-life balance, on existing family benefits (parental leave etc.) and on entitlements to childcare, in order to provide a comprehensive overview of the respective country and the general measures taken there. This is followed by a presentation of the respective existing schemes for better reconciliation, which are divided in this working paper according to three criteria:

- **Leave schemes** are measures which allow time off (paid or unpaid with different cost-sharing; employer, employee, state, families) of different duration (short-term, long-term) from work without losing the respective job (return guarantee).
- **Flexibilisation schemes** can mean that the scope of work remains the same, but flexible working arrangements in terms of time and place with the same wage or the reduction of weekly working time with corresponding loss of earnings are possible and, where appropriate, this loss of income is compensated for through public or insurance-covered benefits.
- **Financial support** is usually independent of employment but can help to ease the financial situation and thus provide more room for manoeuvre in terms of reconciliation.

Chapter 5 offers an overview on all three states, aiming to facilitate comparability. This overview provides summarised information on eligibility conditions, duration of the measure, structure/design and the amount of the wage compensation or benefit of the individual schemes and benefits described in Chapters 2–4. Chapter 6 gives a short topical outlook on various initiatives at European level – with a focus on the EU Directive on work-life balance – which are intended to address and improve the reconciliation of care and work as well as the situation of children in need of care and their families in the EU member states. Chapter 7 offers a comparative conclusion, also with regard to the legal regulations regarding family care in Germany.

## 2 Denmark

The opportunities for the reconciliation of work and non-occupational activities are relatively well developed in Denmark. The standard working week is 37 hours, and at 2.3%, the number of employees who work very long hours per week is also very low compared to the OECD<sup>8</sup> average (11%). Among other measures, so-called “flex jobs” have been introduced, allowing employees to work at their own pace or to reduce their working hours. Such flex-job agreements are concluded for five years and must be re-approved after this period of time.<sup>9</sup>

Families with young children in Denmark receive comprehensive financial support and benefits from well-developed public care and education services. As a comparison: Denmark spends more than 4% of its gross domestic product (GDP) on family benefits and childcare, whereas the OECD average is at a mere 2.6%. Paid maternity leave is granted to female workers for four weeks before and 14 weeks after the birth. Fathers in Denmark are also entitled to two weeks’ paid paternity leave after childbirth. After that, mothers and fathers can split a total of 32 weeks of paid paternity leave. Children aged six months and over are entitled to a public childcare placement.<sup>10</sup> According to section 32 of the *serviceloven* (Social Services Act), children with disabilities who cannot attend a conventional day care centre are also entitled to a placement in a care facility. Municipalities are obliged to provide the required number of places in such facilities. According to paragraph 11, citizens have a right to counselling with regards to a disability of children (Danish Ministry for Children and Social Affairs 2018).

These comprehensive support services for families have, among other things, led to a comparatively high birth rate in Denmark in recent years of 1.7-1.8 children per woman. At the same time, the employment rate for women is one of the highest in the OECD, at 78%.<sup>11</sup>

Denmark offers support and certain supplementary allowances for children with disabilities, including a compensation for loss of income by parents and a subsidy for relevant additional costs related to the continuation of daily life with permanent impairments.<sup>12</sup> Based on available data, it is estimated that around 30-35,000 children and young people between 0 and 18 years of age, or their families, have received such support under the Social Services Act in 2016. The number of children and young people with disabilities receiving support increases with age. It is estimated that only a few hundred children aged zero receive support due to a disability, whereas the number is estimated at 2-3,000 people between the ages of ten and 18. In 2016, close to 10,000 persons received *tabt arbejdsfortjeneste* (compensation for loss of income) (Chapter 2.1) and about 20,000 received *merudgiftsydelse* (a grant for additional

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<sup>8</sup> Organisation for Economic Cooperation and Development.

<sup>9</sup> <http://www.oecdbetterlifeindex.org/topics/work-life-balance/>

<sup>10</sup> *ibid.*

<sup>11</sup> <http://www.oecdbetterlifeindex.org/topics/work-life-balance/>

<sup>12</sup> <https://ec.europa.eu/social/main.jsp?catId=1248&langId=en&intPagId=3638>

costs) (see [Chapter 2.2](#)) (Social- og Indenrigsministeriet 2019: 170f.). These two measures will be presented in the following chapters.

## 2.1 Flexibilisation schemes

Parents who care at home for their child under 18 years of age with a permanent disability or severe impairment can receive ***tabt arbejdsfortjeneste***<sup>13</sup> (**compensation for loss of income**). The prerequisite for receiving such compensation is to reduce or discontinue work altogether and to take over home care and/or provide for the child's education. The compensation for loss of earnings amounts to up to DKK 31.249<sup>14</sup> (about 2,400 euro) per month. The maximum amount corresponds to a loss of earnings for a 37-hour week. The compensation payment is based on the previous gross income and is taxable. There is no temporal limitation (OECD 2018: 26).

The municipalities decide whether to grant support upon an individual assessment. One condition for receiving the benefit is the finding that the child's care by parents at home is most appropriate. Reasons for such an assessment may be the following: the child requires constant presence or supervision by a person, the child has many therapy and treatment appointments, it has to be assessed anew every day whether the child can leave the home with regard to pain and seizures, or the child cannot attend a day care centre or school due to a weakened immune system.<sup>15</sup>

It is also possible to receive this benefit only for a few hours per week, for example to accompany the child to treatments and therapies. Both parents can apply for the benefit and thus share the childcare tasks on a partnership basis.<sup>16</sup>

Self-employed people must prove their income by means of bank statements so that the municipality has a realistic basis for calculation. If the person has been unemployed for a long time before the application period, or if the person has no training, the calculation is based on the salary of a *hjemmehjælper* (domestic helper).<sup>17</sup>

If a pension plan is part of the parent's employment agreement, the compensation payment also includes pension rights. The contributions are calculated at 10% of the gross salary. The contribution may not exceed the amount paid by the previous employer. The municipality pays 2/3 and the beneficiary 1/3 of the ATP contribution.<sup>18,19</sup>

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<sup>13</sup> Paragraph 42 of the *serviceloven* (Social Services Act); <https://danskelove.dk/serviceloven/42>

<sup>14</sup> DKK is the abbreviation for Danish Kroner, the legal tender in Denmark.

<sup>15</sup> <https://sm.dk/arbejdsomraader/handicap/oekonomisk-stoette/tabt-arbejdsfortjeneste/>

<sup>16</sup> *ibid.*

<sup>17</sup> *ibid.*

<sup>18</sup> ATP is a supplementary pension scheme in Denmark. This supplementary pension is paid to most of the Danish population over the standard age limit, see also: <https://ec.europa.eu/social/main.jsp?catId=1107&langId=en&intPageId=4494>.

<sup>19</sup> [www.retsinformation.dk/eli/ta/2019/798](http://www.retsinformation.dk/eli/ta/2019/798)

If one parent loses their part-time work while he or she is receiving compensation for loss of income, there is the possibility of receiving a special supplementary benefit. This benefit can be granted for a maximum period of three months after the loss of employment. One of the conditions for the parent's entitlement is that he or she is insured against unemployment and is not entitled to unemployment benefit under unemployment insurance law. The benefit can amount to a maximum of 90% of the parents' previous employment income.<sup>20</sup>

## 2.2 Financial support

Parents can receive *merudgiftsydelse*<sup>21</sup> (a grant for additional costs) from the municipalities for expenses incurred due to the disability or illness of a child under 18 years of age. Eligible costs may include additional care, medicine, special nutrition, leisure activities and transport. A precondition for reimbursement is that the additional costs are a consequence of the child's impaired abilities and cannot be covered by other statutory benefits. The additional costs must amount to at least DKK 5,044 (about 675 euro) per year. The amount is tax-free and can be paid independent of family income.<sup>22</sup>

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<sup>20</sup> <https://sm.dk/arbejdsomraader/handicap/oekonomisk-stoette/tabt-arbejdsfortjeneste/>

<sup>21</sup> Paragraph 41 of the *serviceloven* (Social Services Act); <https://danskelove.dk/serviceloven/41>

<sup>22</sup> <https://www.borger.dk/familie-og-boern/Udsatte-boern-og-unge/boern-med-handicap>

### 3 Finland

Work-life balance is a key issue in Finland. Therefore, high standards are set in terms of the reconciliation of work and private life. Working hours per week are roughly in line with the European average – half of employees work between 35 and 40 hours per week.<sup>23</sup> Part-time work is relatively uncommon in Finland: 22% of working women and 11% of working men pursue part-time employment. Only 12% of women who work part-time have reduced their working hours because of care work.<sup>24</sup> In Finland, a mere 3.8% of workers have very long working weeks (50 hours or more), which is significantly less than the OECD average (11%).<sup>25</sup>

Finland is known for a high participation of both men and women in the labour market and an explicitly high female employment rate. Overall, 78% of men and 73% of women pursue gainful employment. While for men this is close to the EU-15 average, the proportion of employed women is much higher than the EU-15 average of 57%.<sup>26</sup>

Childcare in Finland is supported by various measures and entitlements, and structures have been created to improve the work-life balance of employees. The system in place in Finland includes maternity leave, paternity leave and parental leave. Maternity leave covers 105 working days and is paid. Between 30 and 50 days must be taken before the birth, including two weeks before and two weeks after the birth. Paternity leave covers 54 working days and is paid. It can be taken between one and 18 days while the mother is on maternity or parental leave. All remaining or available days can be taken in two blocks of time after parental leave and until the child is two years old. Paid parental leave is available to the family for a total of 158 working days. Parental leave can be taken flexibly: Each parent can take parental leave in two blocks (of at least 12 days) or on a part-time basis (if both parents take part-time parental leave at the same time) for at least two months at a time.<sup>27,28</sup>

After parental leave and until the child starts school, parents have the opportunity to choose between three state-subsidised types of childcare: Municipal day care, home childcare allowance and private day care allowance (see EU COM 2019a):

All parents have a right to have their child placed in a municipal day care centre. The fees for day care depend on the family's income: low-income families do not have to pay any fees. Childcare is provided either in day care centres or in the form of private day care.

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<sup>23</sup> <https://businessculture.org/northern-europe/finland-businessetiquette/work-life-balance-2/>

<sup>24</sup> <https://eurocarers.org/country-profiles/finland/>

<sup>25</sup> <http://www.oecdbetterlifeindex.org/topics/work-life-balance/>

<sup>26</sup> <https://businessculture.org/northern-europe/finland-businessetiquette/work-life-balance-2/>

<sup>27</sup> <https://ec.europa.eu/social/main.jsp?catId=1248&langId=en&intPageId=3640>

<sup>28</sup> In 2021, the parental allowance will be reformed in Finland. The total entitlement is to be increased from the current 11.5 to 14 months. Each parent is entitled to 6.6 months of paid parental leave (6-day benefit system), of which up to 69 days can be transferred to the other partner. The changes are introduced, among other things, in order to provide a more gender-neutral entitlement to parental allowance and thus improve gender equality. Single parents are entitled to receive the allowance for the entire period (AGF 2020: 3).

Parents of children under three years of age who are not placed in a municipal day care centre but are looked after at home can apply for *kotihoidon tuki* (a home childcare allowance).

Parents who hire a caregiver or use a private provider to look after a child not yet of school age can apply for *yksityisen hoidon tuki* (a subsidy for private day care).

For parents of children with disabilities, there are, in addition to measures for all parents, further support measures in the form of leave and flexibility schemes as well as financial benefits, which will now be described in the following [Chapters 3.1](#), [3.2](#) and [3.3](#).

### 3.1 Leave schemes

For the care and nursing of a sick child or a child with disabilities, an application may be filed for ***erityishoitoraha* (compensation for loss of income in the form of a so-called special care allowance)**. The conditions for applying for the allowance at Kela<sup>29</sup> are that the child in need of care is under 16 years of age and that the person caring for the child is unable to carry out their regular work because of the care provided, as he or she must participate in the therapy or rehabilitation of the child. The allowance may be applied for with regards to one's own child, but also for the child of the spouse/partner or for an adopted child.<sup>30</sup>

The allowance is paid for up to 60 working days per year during home care, hospitalisation or rehabilitation. The allowance can be claimed for a further 30 days for medical reasons. Such reasons may include continuous treatment, dialysis or palliative care. If both parents must be present in the event of hospitalisation or during rehabilitation, the care allowance may be paid to both parents. The respective doctors' opinion is sufficient for the needs assessment. The days are added up and can thus be applied for spread over the entire calendar year.<sup>31</sup>

Since 1 January 2020, the special care allowance has been calculated on the basis of annual income. The past twelve calendar months before the beginning of the incapacity for work are taken as a basis of calculation. If the income is very low, the minimum amount is paid. The allowance is considered taxable income. The benefit cannot be paid if other benefits (this includes maternity, paternity and parental benefits as well as sickness benefit) are received for the same period.<sup>32</sup> The minimum amount was 24.64 euros per day in 2018 (Social Security Administration 2018: 114).

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<sup>29</sup> *Kela* is the Finnish social insurance institution, a government agency that provides social insurance cover for all people living in Finland at different stages of life. The social insurance benefits provided by Kela include family benefits, health insurance, rehabilitation, unemployment insurance, social assistance, housing benefits, financial assistance for students, disability benefits and basic pensions.

<sup>30</sup> <https://www.kela.fi/web/en/special-care-allowance?inheritRedirect=true>

<sup>31</sup> *ibid.*

<sup>32</sup> *ibid.*

### 3.2 Flexibilisation schemes

All parents of a child in first or second grade have a legal right to part-time leave. If the working time does not exceed 30 hours per week, there is a claim to ***osittainen hoitoraha***<sup>33</sup> (a **partial care allowance**). A condition for the allowance is that the parent must have worked for at least six months in the previous twelve months.<sup>34</sup> Children with disabilities are subject to extended compulsory education and attend school one year longer. If a child falls under this extended compulsory schooling, one parent may receive a partial care allowance for one additional year – for example, already during pre-school or until the child has completed its third primary school year (Kalliomaa-Puha/Kangas 2016: 5f.). The partial care allowance can be paid to both parents if they each reduce their working hours and take over the care of the child at different times of the day. The allowance is only paid for one child at a time and cannot be paid at the same time as the flexible care allowance (see below).<sup>35</sup> The lump sum in 2019 was 96.89 euros per month and is subject to tax (Kela 2019: 9).

***Joustava hoitoraha*** (flexible care allowance) can be applied for if the mother or father does not work more than 30 hours a week and is caring for a child under three years of age. This allowance cannot be combined with other support benefits and can only be claimed for one child per family. However, the parents can both receive the flexible care allowance if they both reduce their working hours and take over care at different times.<sup>36</sup> The amount of the allowance depends on the hours worked by the parent and can be either 160.80 euros or 241.19 euros<sup>37</sup> per month (Kela 2019: 9).

### 3.3 Financial support

Children and youths under 16 years of age with a long-term illness or disability can receive ***alle 16-vuotiaan vammaistuki*** (a **disability allowance**). The disability allowance is paid by Kela if the care and nursing of a child with a long-term illness or disability results in an above-average burden and higher care costs compared to a healthy child of the same age. The entitlement is not based on the diagnosis of the illness or the severity of the disability, but on an assessment of the need for support. The need must exist for at least six months.<sup>38</sup>

The allowance can be paid at three levels: the basic rate, the average rate and the maximum rate. The amounts of support in 2020 are 93.05 euros, 217.13 euros and 421.04 euros per month. Income or assets have no influence on the level of disability benefits. The benefits are not subject to tax.<sup>39</sup>

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<sup>33</sup> Also translated *allowance for home care*.

<sup>34</sup> According to the *työsopimuslaki* (Employment Contracts Act) (55/2001)4 4:4§.

<sup>35</sup> <https://www.kela.fi/osittainen-hoitoraha?inheritRedirect=true>

<sup>36</sup> <https://www.kela.fi/joustava-hoitoraha?inheritRedirect=true>

<sup>37</sup> The amounts of the allowance cited here were valid in the year 2019.

<sup>38</sup> <https://www.kela.fi/web/en/disability-allowance-for-children>

<sup>39</sup> *ibid.*

The allowance can be granted for a fixed period or until the age of 16. It may then be followed by *16 vuotta täyttäneen vammaistuki* (a disability allowance for persons aged 16 or over).<sup>40</sup>

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<sup>40</sup> *ibid.*

## 4 Sweden

Regarding the reconciliation of work and family life, Sweden is considered one of the most successful societies in the European Union (EU). The Swedish government has put in place various measures to facilitate an improved reconciliation of work and private life, including flexible working time arrangements for parents with young children, generous family benefits, and measures to share care work in a more gender-equal way. Family policy in Sweden aims to support the dual income family model. This also results in employment rates for women in Sweden being among the highest in the EU.<sup>41</sup> The share of working mothers with children aged zero to 18 years is also the highest in Europe, at around 82% (OECD 2016: 2).

According to data from the EU Labour Force Survey (EU LFS), 4.3% of the Swedish population in the 15-64 age group currently not working cite childcare or care for other people unfit for work as the main reason for their own inactivity/non-employment. Broken down by gender, the figures are 7.5% for women and 0.4% for men. These figures are well below the EU average (overall: 9.6%; women: 15%; men: 1.2%) (Schön/Johansson 2016: 13).

Parents are each entitled to 240 days of paid parental leave, which can be taken either during the first 18 months or until the child is eleven years old.<sup>42</sup> 90 days are not transferable, while the remaining days can be transferred to the other parent. The first 13 months of parental leave are remunerated at around 80% of the last income (parental allowance) and are considered taxable income. For the remaining days there is a flat-rate amount of SEK 180<sup>43</sup> (about 17 euros) per day. Parents have a high degree of flexibility in taking parental leave: they can take their parental leave as part-time or full-time, combine it with paid or unpaid parental leave, take it in several blocks of time and do so together for up to 30 days. Mothers can start claiming and receiving parental allowance 60 days before the calculated date of birth.<sup>44</sup>

In addition to the general possibility of using flexible working hours in many workplaces in the form of flexitime, which can also help to improve reconciliation<sup>45</sup>, parents with children under the age of eight have the right to reduce their normal working hours by up to 25% – without wage compensation – in order to look after the child/children. The right enshrined in the *Föräldraledighetslagen* (Parental Leave Act) is only applicable if the parents do not receive parental allowance at the same time.<sup>46</sup>

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<sup>41</sup> <https://ec.europa.eu/social/main.jsp?catId=1248&langId=en&intPagId=3658>

<sup>42</sup> Applicable to children born after 1 January 2014. For children born before 2014, the limit is the seventh birthday.

<sup>43</sup> SEK is the abbreviation for Swedish Kroner, the legal tender in Sweden.

<sup>44</sup> <https://ec.europa.eu/social/main.jsp?catId=1130&langId=en&intPagId=4808>

<sup>45</sup> [https://www.bc.edu/content/dam/files/centers/cwf/research/publications3/executivebriefingseries-2/ExecutiveBriefing\\_Work-LifeinSweden.pdf](https://www.bc.edu/content/dam/files/centers/cwf/research/publications3/executivebriefingseries-2/ExecutiveBriefing_Work-LifeinSweden.pdf) p.4f.

<sup>46</sup> <https://www.forsakringskassan.se/arbetsgivare/foraldraledighet/foraldraledig-medarbetare>

In addition, the Swedish welfare system includes an extensive childcare system that guarantees all children aged one to six years a placement in a public day care centre. The cost of such childcare depends on the parents' income level.<sup>47</sup>

In Sweden, municipalities have been obliged to support family caregivers since 2009. The design is up to the municipalities themselves. Thus, the offers vary from local support centres and short-term care services with regard to information, talks, and counselling services such as for instance the “family carer advisors” (Reinschmidt 2018).

Parents and children with disabilities can receive different types of benefits. The following measures and schemes are described in [Chapters 4.1](#) and [4.2](#): the two leave schemes *Kontakt dagar* (contact days) and *tillfällig föräldrapenning* (temporary parental benefit) as well as the two financial support schemes *omvårdnadsbidrag* (caregiving allowance for children with disabilities) and *merkostnadsersättning* (allowance to cover extra costs).

## 4.1 Leave schemes

***Kontakt dagar* (contact days)** are a benefit for parents with children under 16 years of age covered by the LSS Act.<sup>48</sup> By applying for contact days, parents can take part in training courses or information events – for example to gain more knowledge about how to better support their own child – but also in all activities organised by the pre-school or school. For this, they may be released from work.

Ten contact days per child per year can be applied for. The contact days are remunerated with about 80% of the income. Contact days can also be requested for a quarter, half or three quarters of a working day. The prerequisite for remuneration is an income that is recognised as the basis for calculating sickness benefit. Both parents can receive compensation for the same child and the same period. In addition, since 2010, contact days can also be used by other people who are not the biological parents, such as the partner of a parent or by foster parents<sup>49</sup> (EU COM 2019b: 38f.).

Parents whose children are 12 years of age or older and are covered by the LSS Act can apply for ***tillfällig föräldrapenning* (temporary parental benefit)** if one parent (or any other legal guardian) is unable to go to work due to the child's illness. Such temporary parental allowance is a compensation for lost income and can even be applied for if the parent was unable to look for employment due to care work for the child. Temporary parental benefit is calculated on the basis of income and corresponds to the amount of sickness benefit. It therefore also amounts to around 80% of income. The maximum period of entitlement is 120 days per year and per child and can be claimed until the child is 21 years old. In special cases – serious mobility problems or attendance of the secondary level of a specialised school – the temporary parental

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<sup>47</sup> [https://www.bc.edu/content/dam/files/centers/cwf/research/publications3/executivebriefingseries-2/ExecutiveBriefing\\_Work-LifeinSweden.pdf](https://www.bc.edu/content/dam/files/centers/cwf/research/publications3/executivebriefingseries-2/ExecutiveBriefing_Work-LifeinSweden.pdf)

<sup>48</sup> LSS: *lagen om stöd och service för vissa funktionshindrade* (Law on support for people with certain functional impairments) (1993:387); [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa\\_sfs-1993-387](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387).

<sup>49</sup> <https://www.forsakringskassan.se/privatpers/funktionsnedsattning/om-ditt-barn-har-en-funktionsnedsattning/kontakt dagar>

allowance can be claimed until the child is 23 years old. If care allowance is already being received for the same care needs, no temporary parental allowance can be claimed (EU COM 2019b: 38f.).

Parents with a seriously ill child under the age of 18 can receive the temporary parental allowance for an unlimited period. This applies in particular if there is a substantial danger to the child's life. The temporary parental allowance can also be paid in connection with the death of a child (Wissenschaftliche Dienste des Deutschen Bundestages 2019: 11).

## 4.2 Financial support

Sweden reformed its social benefit regulations in 2019 and introduced two separate allowances for children with disabilities and their parents respectively. The original *vårdbidrag* (care allowance for a child with disabilities) can no longer be claimed from 1 January 2019. Instead, ***omvårdnadsbidrag* (caregiving allowance for children with disabilities)** and ***merkostnadsersättning* (allowance to cover extra costs)** were introduced.

For children with disabilities or illnesses, parents (or other legal guardians) can apply for a care allowance if the disability or illness results in additional costs for care and assistance compared to children of the same age without impairments. The period in which the additional care effort is incurred must be at least six months (EU COM 2019b: 36f.).

Both parents can each receive childcare allowance for the same child. The benefit can be divided equally between the parents. Entitlement to the benefit is reviewed at least every two years and can be claimed retroactively for up to three months. The care allowance can be received from the birth of the child until the age of 18.<sup>50</sup>

Following an assessment by the Swedish social insurance agency, the determined need for support and assistance is assigned to one of four levels. The amount of the care allowance for 2020 is 2,464 SEK (about 233 euros) in level 1, 4,927 SEK (about 465 euros) in level 2, 7,391 SEK (about 698 euros) in level 3 and 9,854 SEK (about 931 euros) in level 4.<sup>51</sup> The care allowance can be used for direct care, support and supervision, practical help in everyday life but also for special training (EU COM 2019b: 36f.).

The number of parents receiving care allowance for children with disabilities has increased by more than 70% since 2000. The greatest increase was recorded for parents of children with mental health problems. In 2003, the age limit for childcare benefit was raised from 16 to 19 years, which increased the number of people receiving childcare benefit. In 2015, there were about 55,000 persons in Sweden receiving childcare allowance (Schön/Johansson 2016: 10).

In addition, ***merkostnadsersättning* (an allowance to cover extra costs)** can be claimed if extra costs arise due to disability or illness. This allowance can be claimed for children but also by adults with disabilities (EU COM 2019b: 37).

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<sup>50</sup> <https://www.forsakringskassan.se/privatpers/funktionsnedsattning/om-ditt-barn-har-en-funktionsnedsattning/vardbidrag>

<sup>51</sup> *ibid.*

Compensation can be claimed and used to pay for additional costs incurred as a result of the child's impairments, which amount to at least SEK 11,825 (about 1,117 euros) per year. The reimbursement of additional costs per child ranges from SEK 1,183 (about 112 euros) to up to SEK 2,759 (about 261 euros) per month.<sup>52</sup>

Again, also regarding this allowance, both parents can receive the benefit for the same child. The allowance can be divided equally between the parents. The cost allowance can be claimed retroactively for up to three months. The right to the allowance is reviewed at least every four years.<sup>53</sup>

The allowance to cover extra costs has been simplified compared to the previous benefits and now defines more clearly and transparently which costs can and cannot be reimbursed (EU COM 2019b: 37).

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<sup>52</sup> <https://www.forsakringskassan.se/privatpers/funktionsnedsattning/om-ditt-barn-har-en-funktionsnedsattning/merkostnadsersattning-for-barn>

<sup>53</sup> *ibid.*

## 5 Overview on leave and flexibilisation schemes as well as financial support

Schemes and benefits	Denmark	Finland	Sweden
<b>Leave schemes</b>	/	<i>erityishoitoraha</i> (compensation for loss of income in the form of the special care allowance)	<b>1 Kontaktdagar (contact days)</b> <b>2 tillfällig föräldrapenning (temporary parental allowance)</b>
<ul style="list-style-type: none"> <li>Prerequisite / eligibility condition</li> </ul>		Parents cannot perform their regular work due to the care and participation in the therapy/treatment or rehabilitation of a sick child or a child with disabilities under the age of 16.	<p>Re 1: By applying for contact days, parents can take part e.g. in school events of their children (under 16 years of age) covered by the LSS Act and are released from their employment during this time.</p> <p>Re 2: One parent (or other guardian) cannot pursue his or her own employment due to an illness of the child (from the age of 12) covered by the LSS Act.</p>
<ul style="list-style-type: none"> <li>Duration</li> </ul>		Up to 60 days per year, a further 30 days are possible if medically necessary (in case of palliative care or very serious illness).	<p>Re 1: Parents can apply for ten contact days per year (also for a quarter, half, or three quarters of a working day).</p> <p>Re 2: The maximum period of entitlement is 120 days per year and per child until the child reaches the age of 21 (in special cases up to 23 years of age). Parents with a seriously ill child under the age of 18 can receive the temporary parental allowance for an unlimited period of time (e.g. for palliative care.)</p>
<ul style="list-style-type: none"> <li>Design</li> </ul>		If the presence of both parents is required, the allowance may be paid to both parents.	Re 1: Both parents can receive compensation for the same child and the same period.

			Re 2: Temporary parental allowance is a compensation for loss of parental benefit and cannot be combined with care allowance.
<ul style="list-style-type: none"> <li>Wage compensation</li> </ul>		The allowance is calculated on the basis of the annual income. If the income is very low, the minimum amount is paid, which in 2018 was 24.64 euros per day. The allowance is considered taxable income.	<p>Re 1: The contact days are remunerated with about 80% of the income. The prerequisite is an income that is recognised for receiving sickness benefit.</p> <p>Re 2: Temporary parental benefit is calculated on the basis of income and corresponds to the amount of sickness benefit, and thus amounts to around 80% of income.</p>
<b>Flexibilisation schemes</b>	<b><i>tabt arbejdsfortjeneste</i></b> <b>(compensation for income losses)</b>	<b>1 osittainen hoitoraha (partial care allowance)</b> <b>2 joustava hoitoraha (flexible care allowance)</b>	/
<ul style="list-style-type: none"> <li>Prerequisite / eligibility condition</li> </ul>	For parents who give up all or part of their employment due to taking over the care of a child with disabilities under the age of 18.	<p>Re 1: All parents of a child in the 1st or 2nd grade have a legal right to part-time leave. If they work no more than 30 hours a week, they are entitled to a partial childcare allowance during this period. Parents of children with disabilities are subject to an extended compulsory schooling period of 1 year, during which the allowance can be received additionally.</p> <p>Re 2: If one parent does not work more than 30 hours per week on average and looks after a child under 3 years of age, the parents can apply for a flexible care allowance.</p>	
<ul style="list-style-type: none"> <li>Duration</li> </ul>	No time limitation	Re 1: Parents can apply for a partial childcare allowance for a maximum of 3	

		years (1st and 2nd grade plus one year).	
<ul style="list-style-type: none"> <li>Design</li> </ul>	The individual assessment and approval of compensation is carried out by the municipalities. The compensation can also be applied for only a few hours a week as well as by both parents.	<p>Re 1: The partial childcare allowance can be paid to both parents if they each reduce their working hours and take over the care of the child at different times of the day. It is only paid for one child and cannot be paid at the same time as the flexible care allowance (see 2.).</p> <p>Re 2: Both parents can receive the flexible care allowance if they both reduce their working hours and take over care of the child at different times of the day. The allowance cannot be combined with other support benefits and can only be claimed for one child per family.</p>	
<ul style="list-style-type: none"> <li>Wage compensation</li> </ul>	The compensation amounts to up to 4,200 euros per month. The amount is based on the previous gross income and is taxable.	<p>Re 1: The lump sum in 2019 was 96.89 euros per month. This amount is taxable.</p> <p>Re 2: The amount of the allowance depends on the hours worked and can be either 160.80 or 241.19 euros per month.</p>	
<b>Financial support</b>	<b><i>merudgiftsydelse (Allowance for extra costs)</i></b>	<b><i>alle 16-vuotiaan vammaistuki (disability allowance)</i></b>	<b><i>1 omvårdnadsbidrag (care allowance for children with disabilities)</i></b> <b><i>2 merkostnadsersättning (allowance to cover extra costs)</i></b>
<ul style="list-style-type: none"> <li>Prerequisite / eligibility condition</li> </ul>	The additional costs must be due to the disability or illness of a child under the age of 18 and must not yet be covered by benefits.	The disability allowance for children and youths is granted if the care and nursing of a child with long-term illnesses or disabilities results in an above-average burden and higher care	Re 1: Parents can apply for childcare allowance for children with disabilities or illness. There must be a higher amount of care and support necessary for a period of at least 6 months due to

		costs compared to a healthy child of the same age.	the disability or illness as compared to children of the same age without impairments. Re 2: This allowance can be applied with regards to additional costs incurred due to the disability or illness.
▪ Duration	/	The allowance can be granted for a fixed period or until the age of 16. There is also a disability allowance for persons aged 16 and over.	Re 1: The childcare allowance can be received from the birth of the child until the age of 18. Re 2: This allowance can be claimed for children as well as by adults with disabilities.
▪ Design	Eligible costs include additional care, medicine, special nutrition, leisure activities and transport.	/	Re 1: Both parents can receive childcare allowance for the same child. This allowance can be used for direct care needs but also for practical assistance/help in everyday life. Re 2: The additional costs must amount to at least 1,117 euros per year. Both parents can also receive this allowance for the same child.
▪ Amount	The additional costs must amount to at least 675 euros per year. The allowance is tax-free and independent of family income.	The amounts of support in 2020 are per month: 93.05 euros (basic rate), 217.13 euros (medium rate) and 421.04 euros (maximum rate). Income or assets have no influence on the level of benefits. The amounts are not taxable.	Re 1: The value of the care allowance ranges from 233 euros on level 1 to 931 euros on level 4. Re 2: The reimbursement of additional costs per child ranges from 112 to 261 euros per month.

## 6 European initiatives

There are various initiatives at EU level to improve the reconciliation of care and work and the situation of children in need of care and their families in the Member States.

In 2017 the **European Pillar of Social Rights** was signed by the European Parliament, the Council of the EU and the European Commission (EU COM 2017). It contains 20 social policy principles in the areas of equal opportunities and access to the labour market, fair working conditions, social protection as well as social inclusion, and is intended to bring about social reforms in the EU Member States as a minimum standard.<sup>54</sup>

Principle 9 deals with the right to reconcile work and private life. It grants parents and people with care or custody responsibilities the right to appropriate leave times and flexible working arrangements as well as access to care and support services. It also emphasises the promotion of a partnership-based sharing of care responsibilities between women and men: access to special leave for care responsibilities should be equal, and women and men should be encouraged to use it in a balanced way.

The implementation of the European Pillar of Social Rights includes monitoring through a social scoreboard<sup>55</sup> consisting of indicators on different areas of the corresponding principles. However, none of the indicators on the scoreboard reflects leave, flexible working arrangements, access to care or support services in accordance with Principle 9.<sup>56</sup>

The European Pillar of Social Rights is designed as a Recommendation to the European Commission and is therefore not legally binding. Concrete initiatives are therefore needed to implement the principles. One of these initiatives is Directive 2019/1158/EU of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and caregivers (*Directive on work-life balance*).<sup>57</sup>

This **Work-life balance Directive** aims to provide and develop leave and flexible working arrangements for families and caregivers. In addition, for the first time it has been possible to legally establish a more partnership-based division of unpaid care work between women and men throughout the EU (see also Gärtner et. al. 2020: 27). The EU Member States are now called upon to adopt the necessary laws, regulations and administrative provisions to implement the Directive within three years (i.e. by 2 August 2022).

The Work-life balance Directive sets the following standards for Member States' reconciliation policy:

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<sup>54</sup> [https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles\\_en](https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en)

<sup>55</sup> <https://ec.europa.eu/eurostat/web/european-pillar-of-social-rights/overview>

<sup>56</sup> <https://ec.europa.eu/eurostat/web/european-pillar-of-social-rights/indicators>

<sup>57</sup> <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32019L1158>

- **Paternity leave:** Ten days paid leave for the second parent around the birth of the child. Wage compensation must be guaranteed at least equal to the amount of sick benefits.
- **Parental leave:** Four months parental leave for each parent, two months of which are paid and not transferable to the other parent. The level of their remuneration is to be determined by the Member States. Parents also have the right to take leave flexibly (e.g. part-time or with breaks).
- **Leave for family caregivers:** Five days of care per year. There are no regulations on wage compensation for the caregiver.
- **Leave due to force majeure:** Right to leave from work for urgent family reasons, in case of illness or accident in the family. There are no regulations on wage compensation for the caregiver.
- **Schemes for flexible working hours:** Right to apply for flexible working arrangements (part-time, flexitime and teleworking) for parents of children up to 12 years of age as well as for family caregivers.
- **Protection against discrimination and dismissal** when exercising the above rights.

With regard to children in need of care, the Directive also calls on the Member States to examine whether the conditions and modalities of access and the rules should be adapted or made more generous, inter alia for parents of children with disabilities or chronic illnesses as well as for other vulnerable groups.<sup>58</sup>

Eurocarers, the European informal caregivers' association, welcomes the EU's initiative, but continues to see room for interpretation by the Member States (Eurocarers 2019). Eurocarers notes:

- The relatively narrow definition of family caregivers merely includes children, parents, partners and members of the same household – and does not include grandparents, for example. It is also up to the Member States to determine when there is a need of care, i.e. “serious medical reasons” within the meaning of the Directive.
- Although Member States are asked to pay for leave for family caregivers, they are not obliged to do so.
- The right to apply for flexible working arrangements for parents and family caregivers may be refused by the employer on presentation of reasons. In order to ensure equal treatment for all caregivers, due attention should be paid to ensuring that flexible working arrangements are also available to those caregivers whose working environment makes such measures more difficult (for example, working in small businesses). Attention should also be paid to ensuring that the arrangements match the needs of caregivers, for example in terms of duration, as the granting of flexible working arrangements may be limited in time.

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<sup>58</sup> For instance, single parents, adopting parents, parents with disabilities, parents in exceptional life situation such as after multiple birth or a premature birth.

The Work-life balance Directive does not specifically focus on the situation of parents of children in need of care, but only calls on the Member States to make the rules more generous for certain groups, if necessary – and thus also for parents of children in need of care. However, the **Proposal for a Council Recommendation Establishing a European Child Guarantee**<sup>59</sup> is directed to vulnerable children<sup>60</sup>. Member States should identify the specific disadvantages of children with disabilities, in addition to the factors of poverty, migrant background and precarious family situations, and use the Child Guarantee to support them.

The aim is to prevent and combat social exclusion by ensuring that children in need have access to a range of essential services. Specifically, Member States are requested to guarantee children in need effective and free access to early childhood care, education, educational and school-related activities, at least one healthy meal per school day and health care, as well as effective access to healthy nutrition and adequate housing. The proposal for a Council Recommendation was preceded by a comprehensive preparatory action at European level to discuss design and implementation options to address child poverty and social exclusion more effectively across Europe.<sup>61</sup>

Like the Directive on work-life balance, the Child Guarantee is intended to promote the implementation of the European Pillar of Social Rights, in particular principle 11, i.e. the right of every child to protection against poverty, to education and care, and to the promotion of equal opportunities.

It also aims in particular to complement and reinforce Commission Recommendation 2013/112/EU "Investing in children: breaking the cycle of disadvantage" of 20 February 2013<sup>62</sup>.

A report on children with disabilities was also published as part of the preparatory action. This report also highlights that families with children with disabilities are on average more affected by poverty, have poorer access to high-quality services, have less opportunities to build social networks, and parents have lower chances of finding secure employment with regard to reconciliation (Hunt 2019: 7). A further problem is that in most EU Member States, policies for child participation as well as the needs of children with disabilities (and their families) are not sufficiently taken into account (ibid.). This is why the study calls for, on the one hand, the needs of children with disabilities to be mainstreamed into all policies. On the other hand, the study's authors point to the fact that children with disabilities and their parents may need additional arrangements and support schemes to be able to exercise their rights (ibid.).

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<sup>59</sup> <https://ec.europa.eu/social/BlobServlet?docId=23788&langId=en>

<sup>60</sup> This refers firstly to persons under the age of 18 who are at risk of poverty or social exclusion, secondly to children with a migrant background, and thirdly to children in precarious family circumstances (for example, in single-parent households or in households where one parent lives with disabilities or a long-term illness). In addition, Member States should also identify for themselves which other children are in need and, within this group, take into account specific forms of disadvantage experienced by, among others, children with disabilities.

<sup>61</sup> All published studies on the feasibility study for a European Child Guarantee can be found on the associated [website](#) of the European Commission.

For an overview of the Child Guarantee, see also the Observatory's Newsletter on [Prospects for an EU-wide Child Guarantee to combat child poverty in Europe](#).

<sup>62</sup> <https://eur-lex.europa.eu/legal-content/DE/ALL/?uri=CELEX:32013H0112>

Better access for children with disabilities in the areas covered by the Child Guarantee (particularly in the area of care and education) would relieve the burden on parents and relatives and could thus also contribute to a better reconciliation of care and work.

## 7 Conclusion

There are a number of policies and laws that affect the reconciliation of work and private life for workers across Europe. These relate in particular to maternity leave arrangements, parental benefits and parental leave, flexible working hours, care leave and childcare. Parents of children with disabilities usually need to be particularly flexible in their work situation in order to be able to address the additional needs of the child in their everyday life, reconciling work and private life (Equinet 2018).

Leave for parents of children with disabilities are offered in different forms in all EU Member States (except for Slovakia) (Bouget et al. 2017: 167). While reconciliation appears easier to be realised in continental and Nordic countries, it seems to be more difficult in Eastern and Southern Europe. These discrepancies can be explained, among other things, by the different development of welfare state regulations and rules on working time flexibility (Eurofound 2017: 46f). Based on the assumption that the Nordic countries have best practice models in place, this working paper presented existing leave and flexibility schemes as well as financial benefits to support the reconciliation of care and work when it comes to children in need of care in Denmark, Finland and Sweden.

In all three countries studied, there are schemes for parents with children in need of care to take leave or to make work more flexible as well as to receive financial support.<sup>63</sup> In general, parents of children in need of care in Denmark are entitled to compensation for loss of income for an indefinite period of time if they give up entirely or reduce their employment to care for the child. The compensation benefit can be claimed by both parents in order to share the care work for the child in partnership. There is a subsidy in Denmark for any additional costs incurred. In Finland, compensation for loss of income is available in the form of a so-called special care allowance if one parent is unable to pursue their own employment because they have to take care of the child. This can be claimed for up to 60 working days per year. The flexibility model in Finland is linked to the legal entitlement of all parents of a child up to the second grade (one year longer for parents with children in need of care) to part-time leave. The parents can receive a partial care allowance or a flexible care allowance (for children under three years of age) for their reduction to part-time work. Financial support is available in the form of a disability allowance. In Sweden, parents and children with disabilities can take advantage of different models: there are two leave schemes – contact days and temporary parental benefit – and two financial support schemes – the care allowance for children with disabilities and the allowance to cover extra costs. The description of these Swedish schemes explicitly refers to the fact that both parents can receive the compensation for the contact days for the same child and the same period of time, and both parents can each receive care allowance for the same child with disabilities and/or the allowance to cover extra costs. This can also serve to promote the fair distribution of care work, for example, when the parents do not live in the same household but nevertheless share responsibility and care for the child.

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<sup>63</sup> The schemes were covered descriptively in this working paper. The aspect of the effectiveness of the schemes was not considered. According to Prof. Yeandle, however, there is often a lack of knowledge about effectiveness and uptake of services/schemes/benefits (Reinschmidt 2018: 12). Whether this holds true for the schemes described here could not be ascertained.

Comparable schemes for leave and flexibilisation in the provision of care in Germany are the Family Caregiver Leave Act and the Caregiver Leave Act. Under the Family Caregiver Leave Act, employees (at companies with more than 25 employees) are entitled to reduce their working hours flexibly to a minimum of 15 hours a week for a maximum of 24 months in order to care for a close relative at home. In order to compensate for the loss of income, an interest-free loan can be applied for, but must be repaid at the end of the family care period. Another possibility for short-term leave in order to care for a close relative is the Caregiver Leave Act: Within this framework, a so-called “short-term incapacity to work” can be claimed for up to ten working days.

Regarding the models of compensation for loss of income (DK), compensation for loss of income in the form of a special allowance (FI) and the temporary parental allowance (SE), it should be emphasised that all three are provided with financial benefits which – in contrast to the German model – do not have to be repaid. There is no time limit for receiving compensation for loss of income. Compensation for loss of income in the form of an allowance can be claimed for 60 days per year, plus a further 30 days on medical grounds.

The temporary parental allowance can be compared with the sickness benefit paid in Germany when a child is ill. However, the entitlement in Germany only exists for a maximum of ten working days per year and is therefore considerably lower than the entitlement of up to 120 days per year in Sweden (Wissenschaftliche Dienste des Deutschen Bundestages 2019: 18).

In all three countries, parents with children in need of care are explicitly supported via schemes for the reconciliation of care and work. They offer the possibility to reduce employment, to interrupt it for a long or short period of time, to apply for wage replacement or allowances for lost income. There are differences in the eligibility conditions, duration, form and amount of wage compensation. Financial support in the form of subsidies for additional costs, allowances and childcare allowance can help to ease the financial situation of families and thus provide greater scope for finding a personal balance between employment and childcare.

Not only target-group-specific measures that are available exclusively for parents of children with disabilities are relevant for the reconciliation efforts for these parents: They can also benefit from the general regulations which apply to all parents or to all employees.

All three countries have a – in European comparison – very high female employment rate, generous parental leave or flexible parental leave arrangements and a legal guarantee to a childcare placement (in Denmark already for children from six months). Among the general measures to promote partnership-based work sharing between men and women, the following are particularly noteworthy: In Sweden, 90 days of the 240 days per parent of paid parental leave are not transferable. In Finland, reforms of parental benefits will be implemented from 2021 onwards, inter alia with the aim of introducing a gender-neutral entitlement to parental benefits. Finnish fathers are entitled to nine weeks (54 working days) of paid paternity leave. In Denmark, fathers are entitled to two weeks of paid paternity leave after childbirth. In Sweden again, all parents with children under the age of eight have the right to reduce their normal working hours by up to 25%, which also benefits parents with children in need of care.

The situation of parents of children in need of care at European level, which was presented in [Chapter 6](#) is not specifically addressed in the Work-life balance Directive. The Member States

are merely called upon to make the regulations more generous, if necessary, for certain groups – and thus also for parents of children in need of care. The initiative of a European Child Guarantee, on the other hand, focuses particularly on children in vulnerable situations and thus also takes children with disabilities (and their families) and needs into account. Better access for children with disabilities in the areas covered by the Child Guarantee (particularly in the area of care and education) would relieve the burden on parents and relatives and could thus also contribute to a better reconciliation of care and work.

The time spent caring for dependent people is often split towards three groups of people in need: children with disabilities, adults with disabilities, and elderly people in need of care. The focus in societal debate and in the scientific literature, but also within associations for care-giving relatives, is clearly directed towards the care of elderly persons by their relatives. This focus can probably be explained by the significantly higher prevalence of care dependency among older people. The “caregiving relatives” of children in need of care are seen first and foremost as parents, and their special needs are hardly noticed. This is despite the fact that the need for care of a child is often much more complex than the need for care of an elderly person, and therefore cannot be compared. For instance, care and nursing of a child also includes education and the promotion of development as central components. Added to this is the fact that the parents are mostly of working age and thus pursue employment alongside the care and support of their own child (Kofahl et al. 2017: 26).

For the long-term care of children with disabilities there are, in addition to parental leave – as presented in this working paper – possibilities for leave and flexibilisation aimed to improve reconciliation of care and employment. However, these measures also become less frequent and pronounced as the child grows older, while responsibility for a child in need of care usually only ends at a higher age and thus much later.

The poor visibility of children with disabilities in the statistics makes it even more difficult to react and adopt measures and schemes aimed at this target group. Often, people with disabilities are not included in the data until they are 16 or 18 years old.

In addition to the schemes and support measures and the design of legal and financial framework conditions examined in this working paper, which are central to the reconciliation of care and work, parents of children in need of care also need good service provision, time relief, psychosocial support, information, counselling and guidance via the care systems. This requires networking and cooperation between the various service providers and actors, but also the embedding of the challenges faced by these parents in social and health policy discourses. This has become particularly apparent in the context of the current coronavirus pandemic, during which the public debate has often failed to consider the effects of the pandemic on children with disabilities and the double burden on their parents.

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