



Unabhängiger Beirat  
für die Vereinbarkeit von  
Pflege und Beruf

# Second Report of the German Independent Advisory Board on Work-Care Reconciliation

June 2023



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## List of abbreviations

<b>AG</b>	Arbeitsgruppe (working group)
<b>AGF</b>	Arbeitsgemeinschaft der deutschen Familienorganisationen (Working Group of German Family Organisations)
<b>BAFzA</b>	Bundesamt für Familie und zivilgesellschaftliche Aufgaben (Federal Office of Family Affairs and Civil Society Functions)
<b>BAGSO</b>	Bundesarbeitsgemeinschaft der Senioren-Organisationen (German National Association Senior Citizens' Organisations)
<b>BDA</b>	Bundesvereinigung der Deutschen Arbeitgeberverbände (Confederation of German Employers' Associations)
<b>BEEG</b>	Bundeselterngeld- und Elternzeitgesetz (Federal Parental Allowance and Parental Leave Act)
<b>BMFSFJ</b>	Bundesministerium für Familie, Senioren, Frauen und Jugend (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)
<b>BMG</b>	Bundesministerium für Gesundheit (Federal Ministry of Health)
<b>DEAS</b>	Deutscher Alterssurvey (German Ageing Survey)
<b>DGB</b>	Deutscher Gewerkschaftsbund (German Trade Union Confederation)
<b>EstG</b>	Einkommensteuergesetz (Income Tax Act)
<b>EUTB</b>	Ergänzende unabhängige Teilhabeberatung (Complementary independent participation counselling)
<b>FPfZG</b>	Familienpflegezeitgesetz (Family Caregiver Leave Act)
<b>KJSG</b>	Kinder-Jugend-Stärkungs-Gesetz (Child and Youth Strengthening Act)
<b>SMEs</b>	Small and medium-sized enterprises
<b>KOFA</b>	Kompetenzzentrum Fachkräftesicherung (Competence Centre for Securing Skilled Labour)
<b>MD</b>	Medizinischer Dienst (Health Insurance Medical Service)
<b>PflegeZG</b>	Pflegezeitgesetz (Caregiver Leave Act)
<b>SGB</b>	Sozialgesetzbuch (Social Code)
<b>SOEP</b>	Sozio-oekonomisches Panel (Socio-Economic Panel)
<b>VRUG</b>	Vereinbarkeitsrichtlinienumsetzungsgesetz (German Act on Implementing the Work-Life Balance Directive)
<b>WfBM</b>	Werkstatt für behinderte Menschen (sheltered workshops)
<b>ZQP</b>	Zentrum für Qualität in der Pflege (Centre for Quality in Care)

# Brief summary

The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth appointed the Independent Advisory Board on Work-Care Reconciliation (Unabhängiger Beirat für die Vereinbarkeit von Pflege und Beruf) in 2015. The Advisory Board submitted its first report on work-care reconciliation in Germany on 1 June 2019.<sup>1</sup>

In its second report, the Advisory Board is putting forward a detailed model for reforming caregiver leave and family caregiver leave, and for introducing a tax-funded family caregiver allowance. The underlying concept being pursued by the Advisory Board is to gain recognition for the care of loved ones—regardless of the individual lifestyles and familial relationships involved—and, in particular, to enable those in paid work to provide this long-term care without entering financial hardship. One of the Advisory Board’s key concerns is to promote a more gender-equitable sharing of long-term care responsibilities, as women are still the primary caregivers.

Overall, the Advisory Board is aware of the approach’s limitations in the sense that it only encompasses those who provide long-term care privately and want to reconcile their care work with their professional activities. Nevertheless, it regards this approach as an important first step in

gaining recognition for the services of family carers in general, thereby homing in on its statutory mandate.

The Advisory Board wishes to emphasise that the introduction of a wage compensation benefit and the work release options will only help to solve one side of the work-care reconciliation problem. In order for the other side to be addressed, it will be necessary to put in place a professional care infrastructure that is reliable, covers the entire country and is aligned with the needs of those requiring long-term care and their family members. This calls for extensive reform, which is why the Advisory Board has grappled intensively with the cultural logic of long-term care and the social legislation surrounding such care—particularly long-term care insurance.

The majority of those requiring long-term care are getting on in years or of advanced age. Yet, care is not restricted to this group alone. Therefore, in addition to considering the care needs of this major group, the Advisory Board is also focusing on—and aiming to improve the visibility of—children or adolescents in need of care, who constitute a particularly vulnerable group. This also includes their family members. The Advisory Board considers that there is still significant need for action in relation to this group as well so that

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1 Available online at: [https://www.wege-zur-pflege.de/fileadmin/daten/Beirat/first-report-of-the-german-independent-advisory-board-on-work-care--reconciliation-data\\_1\\_.pdf](https://www.wege-zur-pflege.de/fileadmin/daten/Beirat/first-report-of-the-german-independent-advisory-board-on-work-care--reconciliation-data_1_.pdf).



growing children and adolescents can participate in life in a manner that is appropriate for them while facilitating gainful employment for their caregiving parents. A quick, easy and unbureaucratic procedure for granting assistance is particularly important within this context.

When working family members take on long-term care responsibilities, it also has a major impact on the businesses releasing them from work, especially small and medium-sized enterprises (SMEs). Consequently, any reform of family caregiver leave must take account of operational feasibility. This interplay between interests and needs within the context of work-care reconciliation, particularly at SMEs, will be covered by the Advisory Board in greater detail in the subsequent report.

The COVID-19 pandemic presented a particular challenge that mainly affected family carers who work. This revealed the fragility of Germany's long-term care system and pinpointed particular problems and challenges for the future. Although the issue of 'work-care reconciliation' falls under the remit of the Advisory Board, these problems and challenges extend far beyond it.

## Key recommendations for action (abridged)

We will start with the key points of the model proposed by the Advisory Board for the specific design of family caregiver leave and family caregiver allowance:

- It should be possible to take 36 months of family caregiver leave per person in need of long-term care. It should be possible to take six months of this allowance as full or partial release from work.
  - Tax-funded work release for family carers should involve a family caregiver allowance that works by analogy with parental allowance and covers 36 months per person in need of long-term care.
  - Family carers should be entitled to receive it. This includes caregiving family members and people with a close relationship who take on long-term care responsibilities.
  - It should be possible to take short-term absence from work multiple times for a person in need of care or in the event of death. Caregivers should be able to claim a carer's grant covering ten working days per year for each person in need of long-term care and for persons in the final phase of life.
  - Caregivers should be entitled to claim the family caregiver allowance if they are employees as defined by Section 7(1) of the Caregiver Leave Act (PflegeZG) or if they are self-employed.
- However, further elements are required to improve work-care reconciliation. These include professional care infrastructures that are reliable and aligned with the needs of those requiring long-term care and their (working) caregiving family members:
- Work-care reconciliation should be incorporated as (another) key concept of long-term care insurance.
  - Every caregiver household must have prompt and unbureaucratic access to forms of assistance and structures that are tailored to requirements, coordinated with each other and publicly available. The expansion of these across the whole country should be vigorously pursued.
  - Professional care and care by family members need to be better interlinked and it must be possible to combine them as flexibly as possible. This includes—for example—respite, short-term, day and night care services.
  - Outreach advice on home-based care must not only address the needs of those requiring long-term care but also the medium and long-term consequences for family carers (who work), as well as their health, careers and social security arrangements.

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- A legally secure foundation must be rapidly implemented for home-based care (24-hour care) that meets the needs of caregivers, those requiring long-term care and care workers.
- Low-threshold support services urgently need to be established for younger people in need of long-term care.

In addition, the legal measures need to be better tailored to particularly vulnerable groups, such as children or adolescents who require long-term care and their family members:

- Independent advice should be ensured for parents of children or adolescents who require long-term care. The structures used by existing information and advice centres should be utilised for this purpose. Specialised care services need to be offered for children and adolescents in need of long-term care.
- Improvements should be made to the expertise and capacity available for assisting and supporting children in need of long-term care within educational and/or childcare facilities. Day care and short-term care facilities, along with mobile care services, should also align themselves with the needs and interests of children and adolescents requiring long-term care.

There should be an increased focus on the problem of work-care reconciliation at SMEs because they are subject to different conditions compared to large companies. The Advisory Board will return to this issue in the next reporting period, when they will tackle it intensively.

The COVID-19 pandemic has revealed how fragile the long-term care system is in Germany and what future challenges lie ahead. On this basis, the Advisory Board has drawn up some recommendations with a view to making caring for family members more crisis-resistant:

- The measures implemented at the federal level during the pandemic should be systematically researched and evaluated. On the basis of this, crisis concepts should be developed that lay down minimum requirements under federal law.
- In future, the quality inspection criteria for residential care facilities should include a check to ensure that a successful crisis management system exists.
- Research in the area of work-care reconciliation should be strengthened in general and expanded with regard to crisis situations.

# 1

## Introduction<sup>2</sup>

In Germany, an increasing number of people are having to reconcile their care and work responsibilities. Demographic changes mean that the number of people of an advanced age is constantly growing.<sup>3</sup> Many of those who are getting on in years will become dependent on care for a period of time, with the majority then receiving assistance from family members. According to information from the Federal Ministry of Health (BMG), the number of people requiring long-term care as defined by Book Eleven of the German Social Code (SGB XI) will have reached around 6.1 million by the year 2050.<sup>4</sup> It is estimated that approximately 180,000 of these could be children and adolescents.

The members of the Baby Boomer Generation—born during the 1950s and 1960s—are the driving force behind this development simply because there are so many of them. They are officially set to enjoy a longer life expectancy than earlier

generations: men who were aged 65 in 2019 had another 17.9 years of life to look forward to on average, and women of the same age to a further 21.1 years.<sup>5</sup> Due to the close link between advanced age and the likelihood of needing long-term care,<sup>6</sup> the proportion of the total German population in need of such care is expected to increase along with the length of time for which it will be required.

As employees from the Baby Boomer Generation enter their retirement, the shortage of skilled labour is becoming more acute in all sectors. However, the Competence Centre for Securing Skilled Labour (KOFA) highlights the fact that there is a bigger skills shortage in the formal care sector than anywhere else.<sup>7</sup> For instance, this shortage of care staff is expected to peak at 288,000 vacancies (35.6 per cent) in the area of medical and health care and at 103,700 (37.3 per cent) vacancies in the area of old-age care by 2035.<sup>8</sup>

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2 This report adopts the recommendations for gender-neutral language in the federal administration according to Section 4(3) of the Federal Gender Equality Act (BGleG). This means that gender-neutral descriptions have been selected whenever possible. In cases where this was not possible, the female and male forms have been used instead. Whenever the Advisory Board writes about 'women' in this report, it means all persons who identify as or are perceived to be women; the term 'men' means all persons who identify as or are perceived to be men. When referencing studies or literature, the description used there has been carried across to this report directly.

3 See Rebaudo, Calahorrano and Hausmann 2021, page 4; see European Commission 2021, page 70 f.

4 See Bundesministerium für Gesundheit 2021c, page 19.

5 See Statistisches Bundesamt 2021b.

6 See Lampert and Hoebel 2019, page 242.

7 See Seyda, Köppen and Hickmann 2021, page 1.

8 See Burkhart 2022, page 10.

Family carers will continue to play a crucial role in this conundrum faced by society as a whole. It is only with their assistance that it will be possible to maintain a balance between the further increase in the number of people requiring long-term care and the parallel decrease in skilled workers in the professional care sector. For this, family carers will need support and a means of juggling the multiple burdens on their time, a professional assistance system that works in tandem with them and public recognition of the services they provide—including protection of their own health and life satisfaction.

Studies show that informal care within the person's own home is the preferred form of long-term care among those in need of it.<sup>9</sup> The proportion of people receiving care at home has been continuously increasing for years.<sup>10</sup> At the end of 2021, family carers alone were looking after more than half (51.7 per cent) of the 4.96 million people requiring long-term care.<sup>11</sup> Thus, family carers represent the largest 'long-term care' service in Germany. Another good fifth (21.1 per cent) of those requiring long-term care were being looked after in conjunction with/by mobile care services at the end of 2021.<sup>12</sup> According to SOEP (Socio-Economic Panel) data, 3 million women (61 per cent) and 1.9 million men (39 per cent) spent at least one hour per working day on care duties on average in 2020.<sup>13</sup> The bulk of the caregivers (46.7 per cent) are aged between 50 and 65, more than a fifth (21.3 per cent) between 30 and 49, and just under a quarter (24.6 per cent) over 65. A minority of caregivers (7.6 per cent) are aged under 30.<sup>14</sup>

When only those caregivers of working age are considered, more than 76 per cent of caregiving women and 82 per cent of caregiving men were in paid work. Of these, the caregiving women worked just under 29 hours per week on average, while the caregiving men worked an average of 39.5 hours per week. This was also reflected in their incomes: at 1,530 euros, the average net monthly income of the caregiving women was significantly lower than for the caregiving men, who earned 2,620 euros. At 44.6 per cent, the proportion of working women who spent at least ten hours per week providing care was more than double the proportion of working men at 20.6 per cent. Furthermore, caregiving women who worked were more likely to be single parents (13.2 per cent) compared to the greater number of caregiving men who were both working and partnered/married within their households.<sup>15</sup>

Work-care reconciliation is an issue for many of the family carers who work. Assuming responsibility for providing care in the home should not result in the caregiving family member having to give up their job or only being able to care for the person in need of long-term care by incurring a huge loss of income in the process. It is for this reason that good framework conditions are required for work-care reconciliation.

The legal framework is mainly governed by the Caregiver Leave Act (PflegeZG) and the Family Caregiver Leave Act (FPfZG). These statutory provisions are also what led to the creation of the Independent Advisory Board on Work-Care Reconciliation in 2015 with the aim of attending to this important subject. In its first report (1 June 2019), the Independent Advisory Board set out the

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9 See Heuchert, König and Lehnert 2017, page 1052 ff.  
10 See Rebaudo, Calahorrano and Hausmann 2021, page 6.  
11 See Statistisches Bundesamt 2022b, Table 1.1.  
12 See Statistisches Bundesamt 2022b, Table 1.1.  
13 See Herrmann, Rebaudo and Calahorrano 2022, page 14 ff.  
14 See Herrmann, Rebaudo and Calahorrano 2022, page 13.  
15 See Herrmann, Rebaudo and Calahorrano 2022, page 13.

current situation regarding work-care reconciliation in Germany, assessed experience from abroad and put forward its first fundamental recommendations for improving work-care reconciliation. It proposed the introduction of a tax-funded wage compensation benefit, including an entitlement to release from work, for people who reduce their working hours to care for loved ones, and defined the associated conditions.

The Advisory Board has now taken the recommendations from the first report and translated them into a concrete model for family caregiver leave and family caregiver allowance. In the summer of 2022, this proposed model was submitted to the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth in the form of a sub-report covering the second reporting period. As a result, this can now serve as the basis for legally defining the wage compensation benefit for care-related time off work as set out in the coalition agreement.<sup>16</sup> The majority of the Advisory Board are of the opinion that the wage compensation benefit and entitlement to release from work can only ever be a step—albeit an urgently required one—on the journey to improving work-care reconciliation. That is why this second report highlights some other important matters that affect work-care reconciliation and will help to improve the living conditions of people in need of long-term care and their family members.

Section 2 of the report explains the model proposed by the Advisory Board for the specific design of family caregiver leave and family caregiver allowance. This focuses on the following key points, among others: broadening of the term ‘close relatives/family members’, the promotion of a more gender-equitable sharing of care responsibilities, entitlement to a total of 36 months’ family

caregiver leave per person in need of long-term care, a tax-funded family caregiver allowance during this release from work and separate entitlement to paid release from work in the event of having to care for someone in the final phase of life.

Section 3 deals with the professional care infrastructures in Germany, thereby providing an overview of the support services that are available for family carers who work. It starts with an explanation of the historical background to the current state of the care network. With a specific focus on work-care reconciliation, it then assesses the existing care infrastructures and discusses the options for making changes—particularly in terms of how they could be organised in a gender-equitable manner.

The challenges of work-care reconciliation faced by families with children or adolescents in need of long-term care are addressed in Section 4. First of all, this section provides an overview of their situation based on empirical studies and first-hand statements, using case studies to explain the specific details of what they need. It then describes current care infrastructures for children or adolescents and the advisory services currently available to caregiving parents, and provides an overview of the statutory provisions and benefit entitlements.

Section 5 highlights the problems of implementing work-care reconciliation from the perspective of small and medium-sized enterprises (SMEs). Large parts of this section are based on an expert study commissioned by the Advisory Board on this subject<sup>17</sup> that brings together some key data about SMEs and available findings on work-care reconciliation from an SME viewpoint. These

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<sup>16</sup> See Bundesregierung 2021, page 81.

<sup>17</sup> See Knauthe, Joos and Hoff 2022a.

## 1 Introduction

insights are rounded off by an overview of existing guidelines for improved work-care reconciliation at SMEs and some examples of good practice. The Advisory Board will return to this issue in the next reporting period.

Section 6 considers the change in the situation of family carers as a result of the conditions prevailing during the COVID-19 pandemic. As part of this, it outlines the levels of stress they experienced, their existential fears and their

worries about family members requiring long-term care. It subsequently explores the current situation by presenting the take-up and appraisal of statutory urgent assistance linked to the pandemic ('Akuthilfen'). These are support measures offered by companies and advisory services. On this basis, the Advisory Board then offers some recommendations with a view to making caring for family members more resistant to crises.

# 2

## Family caregiver leave and family caregiver allowance

This section was submitted as a sub-report to the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and published back in August 2022.<sup>18</sup> No changes or updates have been made except for the introduction, which has been shortened.

In its first report, the Advisory Board recommended further developing the existing legal provisions, which was a majority decision. For its second report, one of the tasks that the Advisory Board set itself was to develop a concrete model for granting release from work and the wage compensation benefit to enable family carers to achieve a good balance between their long-term care and work responsibilities. The model devised by the Advisory Board will be presented and explained in this part of the report. This section is intended to set out the problems and objectives of work-care reconciliation from the perspective of the Advisory Board. First of all, the Advisory Board would like to present the problems posed by the current possibilities for achieving work-care reconciliation.

### 2.1 Problem and objective

Many working family carers report that they have problems juggling their time between their long-term care and work commitments. This problem has been highlighted by various studies and was also corroborated by the Advisory Board's first report. For the first report, studies were commissioned in which a lack of time or the problems of finding time because of work were very clearly identified as a major challenge for family carers who work.<sup>19</sup>

With the current work release options, family carers are supposed to be able to reconcile their work and long-term care responsibilities for up to 24 months without having to give up their jobs. However, the process of caring for family members does not always stop after two years. For this reason, the Advisory Board recommended extending the release period to 36 months in its first report based on available studies. The current

18 Available online at: <https://www.wege-zur-pflege.de/fileadmin/daten/Beirat/Empfehlungen-zur-familienpflegezeit-und-zum-familienpflegegeld-data.pdf>.

19 See Independent Advisory Board on Work-Care Reconciliation 2019, page 21 ff.

eligibility criteria for the work release options available under the Caregiver Leave Act (PflegeZG) and the Family Caregiver Leave Act (FPfZG) represent hurdles for family carers in terms of their desire to reconcile their long-term care and work commitments. A certain size of business is stipulated, and there has to be a familial relationship of a strictly defined nature between the person giving care and the person receiving it. A significant number of caregivers are thereby precluded from the work release options right from the start.

Work-care reconciliation creates problems for family carers in terms of both time and finances. Currently, an interest-free loan is the only option available to family carers who need to be released from work for a longer period. In the view of the Advisory Board, the lack of financial resources and huge uncertainties that long-term care creates at both a private and professional level are the main obstacles faced by family carers who are looking to reduce their working hours or take a break from work for a certain amount of time. However, it is often necessary for them to reduce their work commitments so that they can meet the demands placed on their time by their care responsibilities. In this regard, the most frequent plea heard from family carers from the perspective of work-care reconciliation is for financial support or security.<sup>20</sup>

During the first reporting period, the Advisory Board already recommended introducing a new wage compensation benefit similar to parental allowance. The main reason for this is that parental allowance provides a ready-made model that is both socially accepted and familiar. Another advantage of having a wage compensation benefit for family carers that is designed to work like parental allowance is that society would then attach the same kind of value to the long-term care of family members as to the raising of children.

The overriding focus of the Advisory Board is to offer viable solutions to employees taking on private long-term care responsibilities so that they can successfully reconcile their care and work commitments. The Advisory Board is convinced that this is the only way to ensure that as many family carers as possible can continue participating in working life. This is also in the interest of private and public employers, who should not be permanently robbed of their staff as a result of private long-term care.

When designing forms of work release and the wage compensation benefit, the Advisory Board wishes to factor in the interests of both the caregivers and businesses. However, it faces a problem of conflicting priorities here that is extremely difficult to resolve. The Advisory Board is aware that the described proposals will have a direct impact on business practice. When employees switch to temporary part-time work or take a break from work, it can create considerable challenges for businesses. The human resources capacity of the companies plays an important role in possible implementation approaches and further workplace offerings.

Providing family carers with greater protection against unemployment and poverty in old age is another particular concern of the Advisory Board. This includes both a higher level of protection against dismissal and improved security through the statutory pension insurance scheme.

A further concern of the Advisory Board is to take account of the diversity in family set-ups and relationships of responsibility. Care is not only provided by relatives but also by people who look after someone in need of long-term care within their neighbourhood or group of friends without actually being related to them. The Advisory Board deems it important for all care situations to be supported by appropriate forms of work release and a wage compensation benefit.

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<sup>20</sup> See INTERVAL 2018, page 135.



Most informal care is provided by women.<sup>21</sup> Consequently, it is primarily women that are affected by the financial, physical and mental consequences that can ensue from the long-term care of family members. The Advisory Board has already stressed this in its first report. For this reason, gender equity is one of the Advisory Board's key objectives when designing forms of work release and the wage compensation benefit for family carers. The Advisory Board wishes to develop a model that will allow both women and men to achieve a good level of work-care reconciliation.

## 2.2 Current situation regarding the existing bases for work-care reconciliation

This subsection explores the current provisions governing work-care reconciliation in detail, with the PflegeZG and the FPfZG playing a key role here. It also contains a critique of the PflegeZG and FPfZG provisions to enable further exploration of these in the next subsection. In addition, it presents some of the currently available empirical and descriptive data pertaining to the matter.

### 2.2.1 Eligible persons

Section 7(3) PflegeZG defines the term 'close relatives/family members' in respect of whose long-term care employees are entitled to make use of the options available under the PflegeZG and FPfZG. Although this term has already been expanded in the PflegeZG compared to the

previous provisions, it remains restricted to the group of close relatives/family members listed there. However, this conclusive list does not take account of the real-life circumstances of many people requiring long-term care and their loved ones.

Demographic changes are going to put long-term care even more firmly centre stage over the coming years.<sup>22</sup> Therefore, the legislature should focus on mobilising resources to ensure the provision of care and support at all levels because social changes, such as individualisation and pluralisation, effectively have the power to transform family set-ups and—in turn—care arrangements as well.<sup>23</sup> One result of postmodern lifestyles, greater (labour market) mobility and increasing numbers of working women is the erosion of traditional long-term care arrangements, whereby one family member (usually female) assumes responsibility within a joint household for caring for another family member.<sup>24</sup>

Not only are family set-ups more diverse but they have also become more transient and, in addition, now increasingly span greater geographical distances.<sup>25</sup> For this reason, it is becoming increasingly rare for the local provision of long-term care to be contingent upon direct familial relationships. Rather, this local provision is coming to reflect the diversity of modern communities of responsibility. Studies suggest that the quality of the relationship between the person giving care and the person receiving it is the most important reason why people participate in providing long-term care.<sup>26</sup>

Other European countries have already responded to these altered social realities to avoid jeopardising the provision of care. In Belgium, the caregiver merely has to be of legal age and enjoy a relationship of trust with the person in need of long-term

21 See, for example, Kantar 2019, page 96 ff.; see Rebaudo, Calahorrano and Hausmann 2021, page 12 f.

22 See Kaschowitz 2021, 7 ff.

23 See Kunstmann 2020, page 3.

24 See Bauernschmidt and Dorschner 2018.

25 See Peuckert 2019, page 2; see Wagner, Franke and Otto 2019, page 532.

26 See INTERVAL 2018, page 12.

care in order to be eligible. The care relationship is confirmed by means of a written agreement, which has to be renewed annually.<sup>27</sup> In Sweden, it is likewise the case that not just relatives but also friends and neighbours of the person in need of long-term care are eligible for the full or partial release entitlement and financial benefits available there.<sup>28</sup>

In light of the circumstances described above, the Advisory Board believes it is vital to expand the group of eligible persons and that this will be accompanied by an increase in the self-determination of those in need of long-term care. They should be able to decide with whom they want to form a care relationship that is characterised by a particular degree of intensity, responsibility and intimacy. A recommendation for expanding the group of eligible persons accordingly can be found in Section 3.1.

### 2.2.2 Eligibility criteria

Entitlement to release from work under the PflegeZG and FPfZG is subject to various criteria being met. These are briefly outlined below.

#### (1) Familial relationship

Entitlement to caregiver leave requires the beneficiary—as defined by Section 7(3) PflegeZG—to be a close family member of the person in need of long-term care. For details, see the information provided in Section 2.1.

#### (2) Employment relationship

The caregiver must be in an employment relationship. This is to be defined with reference to the term ‘employees’ within the meaning of Section 7(1) PflegeZG, which is used by both laws. This encompasses regular employees and employees

in vocational training as well as those who are to be regarded as persons similar to employees because of their economically dependent status. The provisions of the PflegeZG and FPfZG do not apply to persons with civil servant status; however, in this case, the civil service law provisions must be observed.<sup>29</sup> Self-employed persons are not included.

#### (3) Thresholds

According to Section 3(1), second sentence PflegeZG (caregiver leave), an entitlement to full or partial release from work only exists in relation to employers who usually have 16 employees or more; in the case of partial release according to Section 2(1), fourth sentence FPfZG, it only applies when there are 26 employees or more (family caregiver leave). In both laws, the number of employees is calculated based on the headcount; under the FPfZG, employees in vocational training are not included. According to this method, part-time employees and the applicant are counted in full. As regards entitlement to work release under the PflegeZG, full or partial release can be granted voluntarily at businesses with 15 employees or fewer—for this, the agreement of the employer is required. The situation is similar as far as family caregiver leave is concerned in that partial release can be granted at businesses with 25 employees or fewer if the employer agrees.<sup>30</sup> A survey of persons affected by the issue of work-care reconciliation reveals that 14.1 per cent of the respondents are employed by businesses with between 1 and 15 employees and that another 4.5 per cent by companies with a workforce size of 16 to 25. This means that almost every fifth person has no—or only a limited—legal entitlement to release from work.<sup>31</sup> In January 2022, this corresponded to just under 6.7 million people out of the more than 34.1 million employees who are subject to mandatory social insurance.<sup>32</sup>

27 See Independent Advisory Board on Work-Care Reconciliation 2019, page 31.

28 See Reinschmidt 2015, page VII.

29 See Kossens 2019, page 36 ff., for further details of care-related work release for civil servants.

30 See Kossens 2019, FPfZG Section 2, marginal numbers 18 and 24.

31 See INTERVAL 2018, page 29.

32 See Bundesagentur für Arbeit 2022.

#### (4) Notification periods

Employees must observe a notification period in relation to their employers. For caregiver leave, this is ten working days according to Section 3(3), first sentence PflegeZG; for family caregiver leave, eight weeks are stipulated according to Section 2a(1), first sentence FPfZG. For details, see the information provided in Section 2.2.5.

#### (5) Need for long-term care

In order for caregiver leave and family caregiver leave to be claimed, the close relative/family member must be in need of long-term care according to Sections 14 and 15 of SGB XI. This means that a care grade must have been assigned to the person requiring long-term care. An anticipated need for long-term care is not sufficient. Employees must prove the need for long-term care by submitting a certificate from the long-term care insurance fund or the Health Insurance Medical Service (MDK). When the person requiring long-term care has private mandatory long-term care insurance, equivalent proof must be presented.

#### (6) Home environment

As a basic principle, care must be provided in a home environment in the context of caregiver leave under Section 3(1), first sentence PflegeZG and in the context of family caregiver leave under Section 2(1), first sentence FPfZG. The term 'home environment' is not defined in any further detail in the legislation. Where those requiring long-term care are living in residential care facilities, their employed family members do not qualify for the (family) caregiver leave provisions. However, as soon as those requiring long-term care start receiving care at home at regular intervals (for example, at weekends), the provisions become applicable again even if the person mainly lives in a residential facility.<sup>33</sup>

Exceptions apply to the long-term care of underage persons until they turn 18. According to Section 3(5) PflegeZG and Section 2(5) FPfZG, the caregiver or family caregiver leave can still be claimed even if underage persons spend a prolonged period in hospital or at residential facilities. According to Section 3(5), fourth sentence PflegeZG and Section 2(5), fourth sentence FPfZG, employees can claim entitlement to family caregiver leave instead of caregiver leave. Nor does the requirement for care to be provided in a home environment apply when caring for someone in the final phase of life, which can also take place in a hospice, for example.

### 2.2.3 Duration

The provisions in the PflegeZG and FPfZG that govern the duration of the work release options are the main instrument for facilitating work-care reconciliation. The total duration of 24 months per close relative/family member in need of long-term care must not be exceeded (Section 4(1), fourth sentence PflegeZG, Section 2(2) FPfZG), making this the maximum period of leave that the caregiver can take to care for a specific person in need of long-term care.

The work release options in the PflegeZG and FPfZG differ in some respects. According to Section 4(1), first sentence PflegeZG, the maximum length of caregiver leave is six months per person in need of long-term care, with both full and partial release permitted. To enable the care of someone in the final phase of life, a three-month period of full or partial release can be taken under Section 3(6) PflegeZG. According to Section 2(1), first sentence FPfZG, a maximum period of 24 months is stipulated for family caregiver leave. During this period, family carers can go on partial release provided that the average number of hours worked per week does not fall below the minimum of 15 hours stipulated by Section 2(1),

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33 See Kossens 2019, PflegeZG Section 3, marginal numbers 23 and 24.

second sentence FPfZG. Currently, the total duration of combined caregiver and family caregiver leave granted under Section 4(1), fourth sentence PflegeZG and Section 2(2) FPfZG must not exceed 24 months per close relative/family member in need of long-term care.

However, on the basis of insurance data from BARMER, predictive modelling forecasts that a person requiring long-term care in 2019 will be reliant on it for a period of six years on average. If the group of those in need of long-term care is restricted to people entering care at the age of 60 or higher, the average duration of care drops to four years. If those in need of long-term care are differentiated by gender, it results in an average care duration of three and a half years for men and just under five years for women.<sup>34</sup> Similarly, the 2015 insurance account sample taken by the German statutory pension insurance scheme reveals that less than a quarter of all care situations (23.3 per cent) are covered by a maximum duration of six months. According to the results of this analysis, a duration of up to 24 months is only sufficient for just over half of all cases of home-based care (51.5 per cent).<sup>35</sup>

The Advisory Board recognises the discrepancy between the actual average duration of care and the maximum work release period granted for long-term care under the PflegeZG and FPfZG. It recommends aligning these periods and making them more flexible. At the same time, the Advisory Board is aware that the duration of care may deviate considerably from the average in individual cases—in particular, children in need of long-term care sometimes require it for life. A recommendation for extending the work release periods can be found in Section 3.3.

### 2.2.4 Level/calculation

In addition to release from work, the possibility of financial support also has an important role to play in work-care reconciliation.

To enable family carers to secure the necessary financial resources for the duration of their reduced working hours according to Section 2 FPfZG and Section 3 PflegeZG, applicants can apply to the Federal Office of Family Affairs and Civil Society Functions (BAFzA) for an interest-free loan under Section 3 FPfZG. These loans are paid in monthly instalments and must be paid back within 48 months of when release from work commences. The flat-rate net monthly amount is based on the employee's regular average monthly gross pay over the past twelve calendar months prior to the commencement of work release. The level of monthly loan instalments granted is half the difference between the flat-rate net monthly amounts paid before and during release from work according to (1) (Section 3(2) FPfZG).

In its draft legislation of 10 November 2014, the legislature had assumed that take-up would gradually increase. A take-up of more than 4,200 was expected by 2018.<sup>36</sup> However, the actual take-up rate is far lower than estimated.<sup>37</sup> Between 2015 and 2019, the figures for the volume of loans granted varied between 259 and 87. Since 2015, a total of just 921 people have taken out an interest-free loan. Of these, 562 loans—more than half—were paid to women.<sup>38</sup>

In addition, only 39 per cent of the respondents regard the interest-free loan as helpful; by contrast, 52 per cent deem it 'not helpful'.<sup>39</sup>

The low take-up of the loan has already been documented in the Advisory Board's first report. The latest figures from the BAFzA confirm the low efficacy of this political measure, underscoring the need for actual financial support. According to

34 See Rothgang and Müller 2021, page 96.

35 See INTERVAL 2018, page 103.

36 See Bundestag document 18/3124, page 29.

37 See Roßbach 2019.

38 See Bundestag document 19/11550, page 4.

39 See Independent Advisory Board on Work-Care Reconciliation 2019, page 45.

BAFzA data, 217 applications (from 132 women and 85 men) were received for the interest-loan in 2021 compared with (as of March) 72 applications (from 45 women and 27 men) in 2022. Of these, a total of 167 were approved in 2021 (for 101 women and 66 men) and (as of March) 52 were approved in 2022 (for 32 women and 20 men).<sup>40</sup> These figures show that well over half of the applications were submitted by women. This highlights all the more strongly the importance of ensuring fair incentives when devising any new financial support. For the reasons outlined above, the Advisory Board has already recommended—in its first report—that the loan should be abolished, calling instead for a wage compensation benefit, the concrete details of which are set out in Section 3 of this report.

### 2.2.5 Notification and application process

The PflegeZG and FPfZG lay down notification periods that must be observed by an employee so that the employer has sufficient time to make staffing and organisational adjustments while the employee is on (partial) release from work.

For short-term absences from work according to Section 2 PflegeZG, there is no notification period due to the sudden nature of the care situations involved. Nevertheless, under Section 2(2), first sentence PflegeZG, the employee is required to inform the employer without delay of their inability to work and the anticipated duration of the absence. The PflegeZG and FPfZG provide for different notification periods, which also depends on whether these run consecutively. In the case of release from work within the meaning of the PflegeZG, the employee is required under Section 3(3), first sentence PflegeZG to notify the employer in writing that they intend to make use

of it no later than ten working days before the start of the release period. Furthermore, a written declaration is required that sets out the period within which the employee is to be released from work and the extent of this release. A declaration of this kind must also be submitted when taking family caregiver leave. In contrast to caregiver leave, the notification period that must be observed for family caregiver leave according to Section 2a(1), first sentence FPfZG is eight weeks. If the employee intends to take family caregiver leave straight after caregiver leave, Section 2a(1), fifth sentence FPfZG stipulates that notification of this must be given three months before family caregiver leave commences.

Different notification periods may be sensible and necessary to accommodate the various situations of family carers; in many cases, it is possible to plan things further ahead, making a longer notification period satisfactory. However, having two laws for work-care reconciliation—the PflegeZG and the FPfZG—with different associated notification periods makes the provisions confusing.<sup>41</sup> It is desirable for the notification periods to be standardised.

This is an important concern of the Advisory Board, which is why it also proposes simplifying the notification periods in Section 2.3 by merging the PflegeZG and the FPfZG.

### 2.2.6 Social insurance

Partial or full release from work leads to lower pension insurance contributions and, in turn, to reduced pension entitlements. The current provisions covering the legal pension arrangements for family carers do not sufficiently compensate for the lower pension entitlements in the event of their having to reduce their work com-

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40 Federal Office of Family Affairs and Civil Society Functions (BAFzA) 2022 (internal statistics).

41 See INTERVAL 2018, page 114.

mitments in order to provide long-term care. Neither the PflegeZG nor the FPfZG create a legal framework to counter this detrimental position.

When people take on the long-term care of close relatives/family members, the long-term care insurance fund or the private insurance company providing private mandatory long-term care insurance credits the caregiver's pension account with a payment to compensate for reduced working under the following conditions: the person or persons in need of long-term care must have been assigned a care grade of at least 2 and must be receiving voluntary care for at least ten hours a week within a home environment, usually delivered on at least two days of the week (Section 44 (1), second sentence SGB XI). In addition to the care provided, the caregiver's paid work must not exceed 30 hours per week or may only exceed this time limit temporarily (Section 44 (1), first sentence SGB XI). The level of the contributions paid by the long-term care insurance fund or insurance company ultimately depends on the care grade and the type of benefit received by the person in need of long-term care (Section 166(2) of Book Six of the Social Code [SGB VI]). Based on the care grade and type of benefit received, a contribution is paid as a set percentage of the reference amount. Currently, this reference amount still varies between the old and new federal states but is to be standardised by no later than 1 July 2024.<sup>42</sup>

For example, as of June 2022, family carers receive a pension benefit of 9.37 euros (West) or 9.15 euros (East) per month if the person in need of long-term care has been assigned care grade 2 and is receiving care allowance. To cover this, the long-term care insurance fund or insurance company pays contributions in the amount of 165.22 euros (West) or 158.19 euros (East) per month. With a care grade of 5, the pension benefit

for this scenario—as of June 2022—is 34.70 euros (West) or 33.89 euros (East). To cover this, the long-term care insurance fund or insurance company pays contributions in the amount of 611.94 euros (West) or 585.90 euros (East) per month. By comparison, average earners receive approximately 34 euros per pension point (as of June 2022). However, more than 7,200 euros in contributions will actually need to be paid to cover this in 2022.<sup>43</sup> Moreover, only a small number of family carers appear to benefit from these pension insurance contributions: there is a large discrepancy between the number of care receivers being cared for by family members and the number of family carers who are insured as caregivers within the pension insurance scheme.<sup>44</sup> For this reason, it is often the case that many family carers do not receive any compensatory pension entitlements while taking caregiver leave.

The Advisory Board has found that the current provisions put caregiving employees at a disadvantage compared to non-caregiving employees from the perspective of their legal pension arrangements. A substantial proportion of family carers appear not to be covered by the pension insurance scheme and those that are do not receive full compensation compared to non-caregiving employees. The Advisory Board deems it important to improve this situation for caregivers.

### 2.2.7 Protection against dismissal

The PflegeZG contains provisions that protect the employee from being dismissed by their employer as a result of taking caregiver leave. These provisions also apply to release from work under the FPfZG (Section 2 III FPfZG).

42 See Deutsche Rentenversicherung Bund 2021a, page 25 f.

43 See Knauthe and Deindl 2019, page 56; see Bundesministerium für Gesundheit (internal statistics).

44 See Deutsche Rentenversicherung Bund 2021b, page 59.



Special protection against dismissal applies to both caregiver leave and family caregiver leave. For instance, Section 5(1) PflegeZG stipulates that the employer is not allowed to terminate the employment relationship from the time of notification—subject to this being no more than twelve weeks before the announced start date—up until the end of the short-term absence from work according to Section 2 PflegeZG or up until the end of release from work according to Section 3 PflegeZG. Permitted exceptions in special cases are governed by Section 5(2) PflegeZG. According to Section 2(3) FPfZG, this protection against dismissal as set out in Section 5 PflegeZG applies mutatis mutandis to release from work under the FPfZG. Extensive protection against dismissal is the key to empowering employees to assert their rights while signalling to the employer that dismissal is not permitted until the end of release from work under the PflegeZG and FPfZG.

The employment security of caregivers is a crucial priority for the Advisory Board. Even though the vast majority of caregiving employees can count on their job being secure, a survey by Prognos AG indicates that eight per cent of men and seven per cent of women are affected by dismissal for care-related reasons. Having said that, only 504 caregivers were surveyed.<sup>45</sup> However, the results of surveys among caregivers and parents (to be) tend to point in the same direction. For this reason, the Advisory Board argues that protection against dismissal should be improved for both groups of employees in one fell swoop.

Particularly in the case of longer notification periods, immediate protection against dismissal is required to prevent dismissal.

## 2.2.8 Care for someone in the final phase of life

Full or partial release from work under the PflegeZG can be taken to care for a close relative/family member in the final phase of life.

This form of release lasts up to three months and is legally governed by Section 3(6) PflegeZG. According to these provisions, the close relative/family member who is dying must be suffering from an illness which is progressive and has already reached a very advanced stage in which a cure can be ruled out and palliative medical care is necessary and can only be expected to provide limited a life expectancy of weeks or months. Employees must provide their employer with proof of the situation by means of a doctor's note. Care of a close dying relative can also take place outside the home without this being subject to a need for long-term care. The small business clause applies in this case, along with a notification period of ten working days.

In a representative survey of the population, more than 80 per cent of those surveyed rated the legal entitlement to time off work to care for a close dying relative/family member as very or rather positive.<sup>46</sup> Despite this favourable assessment, only just under 20 per cent were aware that a corresponding legal provision actually exists.<sup>47</sup> In 2018, the average period of release from work to care for someone in the final phase of life lasted 74 days.<sup>48</sup>

Release from work to care for someone in the final phase of life counts as part of the total leave duration of 24 months but does not have to follow the previous period of leave directly.

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45 See Prognos AG 2021, page 99.  
46 See INTERVAL 2018, page 44.  
47 See INTERVAL 2018, page 50.  
48 See INTERVAL 2018, page 54.

### 2.2.9 Short-term absence from work

Care situations often occur unexpectedly, making them difficult to plan for. If the need for care arises without warning, it presents huge challenges for those affected. In this kind of scenario, it is vital to have legal provisions in place that enable employees to respond quickly and appropriately to sudden care situations involving a close relative/family member.

Short-term absence from work according to Section 2(1) PflegeZG entitles employees who are faced with a sudden care situation to stay off work for up to ten working days as needed so they can arrange tailored nursing care for a close relative/family member in need of long-term care or can ensure the provision of care and support during that time. According to Section 2(2) PflegeZG, the employer must be informed of the inability to work without delay. In addition, a doctor's note verifying the need for long-term care and the necessity of the measures must be submitted to the employer on request. The anticipated need for long-term care is not sufficient.

If the caregiver is not entitled to claim continued payment of wages from their employer during the short-term absence from work, the caregiver can receive one carer's grant per person in need of long-term care as a wage compensation benefit for a total of up to ten working days in accordance with Section 2(3), second sentence PflegeZG in conjunction with Section 44a (3) SGB XI.<sup>49</sup> During the COVID-19 pandemic, the carer's grant can be claimed for up to 20 working days; the same applies in the case of the short-term absence from work.<sup>50</sup>

There are no official figures on the extent to which short-term absence from work is taken because this is not subject to any reporting requirements.

However, it can be shown empirically that the number of people taking a short-term absence from work is around twice as high as the number of those who have applied for the carer's grant.<sup>51</sup> According to the Deutsches Ärzteblatt medical journal, the Federal Ministry of Health (BMG) revealed—in response to a request for information by the publisher Funke Mediengruppe—that around 9,000 people applied to the long-term care insurance funds for a carer's grant in 2019.<sup>52</sup> Thus, roughly 18,000 people are estimated to have taken a short-term absence from work.

Quite rightly, the taking of a short-term absence from work is not limited to a one-off absence of up to ten working days for the same person in need of long-term care. An unexpected deterioration in the care situation can occur multiple times, or the existing care arrangements can suddenly become unworkable. Accordingly, family carers are able to take a short-term absence from work multiple times to look after a person in need of long-term care. It should also be noted that the current version of the PflegeZG does not allow for sudden death. Although care of a close dying relative/family member is possible according to Section 3(6) PflegeZG (see Section 2.2.8), it might not be possible to observe the associated notification period of ten working days in individual cases.

### 2.2.10 Carer's grant

Employees have been receiving direct financial support for short-term absence from work (Section 2 PflegeZG) since 1 January 2015. Employees can stay off work for up to ten working days in order to respond to a sudden care situation involving a close relative/family member (see Section 2.2.9) and are entitled to the payment of a carer's grant in accordance with Section 44a(3)

49 See Bundestag document 18/3449 2014, page 13.

50 See Section 9(1) in conjunction with Section 2(1) PflegeZG, Section 9(2) and Section 2(3), second sentence PflegeZG in conjunction with Section 150(5d), first sentence SGB XI.

51 See INTERVAL 2018, page 41.

52 See Deutsches Ärzteblatt 2020.



SGB XI. Special legal provisions to support family carers during the pandemic apply temporarily until 31 December 2022, allowing caregivers to claim the carer's grant for up to 20 working days; the same applies regarding short-term absence from work.<sup>53</sup> The carer's grant is provided by the long-term care insurance fund or the insurance company of the close relative/family member in need of long-term care. It is set at 90 per cent of the lost net pay in a similar way to the level of sickness benefit awarded in the case of a sick child (Section 45(2), third to fifth sentences, Book Five of the Social Code [SGB V]). The grant is funded by the long-term care insurance of the family member in need of long-term care as a means of partially compensating the caregiver for their lost pay.<sup>54</sup>

According to Section 44a(3) SGB XI, employees are entitled to the carer's grant under the following circumstances: if they are faced with a sudden care situation involving a close relative/family member who has already been categorised as in need of long-term care or as likely to need long-term care, continued payment of wages by the employer is not possible and the application for the carer's grant is submitted without delay to the long-term care insurance fund together with a doctor's note verifying the care situation.<sup>55</sup>

In principle, the level of the carer's grant is set at 90 per cent of the net pay but, at the same time, it is limited to 70 per cent of the health insurance contribution assessment ceiling according to Section 233(3) SGB V. Compulsory and voluntary

membership of a health insurance scheme is maintained throughout the entire period when the caregiver is claiming the carer's grant. The carer's grant is provided subject to the payment of health insurance contributions (Section 249c SGB V) and to compulsory enrolment in the pension insurance scheme (Section 3, first sentence, no. 3 SGB VI) and the unemployment insurance scheme. Within this context, the contributions have to be calculated on 80 per cent of the lost gross pay, up to the limit imposed by the contribution assessment ceiling of the unemployment insurance scheme.<sup>56</sup>

In 2019, around 5.59 million euros from statutory long-term care insurance funds flowed into financing the carer's grant under the provisions of Section 44a of SGB XI.<sup>57</sup> At the same time, 9,000 applications for carer's grant were received by the long-term care insurance funds compared to the 20,000 applications per year anticipated by the Federal Government.<sup>58</sup> Originally, the legislature had estimated a take-up of less than 200,000 cases per year.<sup>59</sup>

Interest associations attribute the lower take-up to the high level of bureaucracy involved in the application process and a lack of awareness of the benefit.<sup>60</sup> In addition, the carer's grant is not extensive enough and does not cover the caregivers real needs because a total of ten working days is not sufficient to put the framework conditions in place for a care situation that is constantly evolving.<sup>61</sup>

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53 According to Section 150b SGB XI, working days for which a COVID-related carer's grant was claimed do not count towards the number of working days for which a carer's grant was claimed under Section 44a(3). For details of the special provisions covering the period of the COVID-19 pandemic, see Section 9(1) in conjunction with Section 2(1) PflegeZG, Section 9(2) and Section 2(3), second sentence PflegeZG in conjunction with Section 150(5d), first sentence SGB XI.

54 See Kossens 2019, PflegeZG Section 2, marginal number 62.

55 See Kossens 2019, PflegeZG Section 2, marginal numbers 60 and 61.

56 See Kossens 2019, PflegeZG Section 2, marginal number 63.

57 See Bundesministerium für Gesundheit 2021a, page 153. Since then, the figure has increased. In 2021, the amount spent was 10.6 million euros, which corresponds to a recipient count of just under 15,000, (unpublished) financial statistics of the statutory long-term care insurance scheme.

58 See Deutsches Ärzteblatt 2020.

59 See Bundestag document 18/3124, page 3.

60 See Deutsches Ärzteblatt 2020.

61 For details of the carer's grant, see also the response published by wir pflegen e.V. 2019.

## 2.3 Recommended actions for designing family caregiver leave and a family caregiver allowance

The key provisions governing work-care reconciliation and their implementation have been explored in detail in the previous section. The Advisory Board has deliberated on the resulting implications and drawn up some recommendations for further development. These recommendations are described and presented in this section. Details of minority votes dissenting from the recommendations can be found in the Annex. A key aspect of the Advisory Board's recommendation is that the two laws that have been in force to date (the PflegeZG and FPfZG) should be merged into one piece of legislation. Following the same principle as the one used for the parental allowance and parental leave provisions, this single law should be subdivided into provisions covering release from work (family caregiver leave) and provisions covering a wage compensation benefit (family caregiver allowance). The loan as a form of financial support should cease to exist accordingly. In the recommendation, the term 'family members' has also been broadly revised. In the context of the provisions referred to below, the expanded definition always applies to both family caregiver leave and family caregiver allowance whenever the term 'family members' appears below. As well as including caregiving family members, this now also encompasses those with a similarly close relationship to the person in need of long-term care. The aim of the recommendations is to improve work-care reconciliation for all those affected.

### 2.3.1 Eligible persons

Given the shortcomings of the current legal framework outlined in Section 2.1, the Advisory Board recommends expanding the group of eligible persons. In its first report, the Advisory Board has already recommended investigating an expansion of this kind. For the purpose of the second report, the Advisory Board has discussed and fleshed out this expansion.

One of the major issues from the Advisory Board's perspective is that the existing definition of eligible persons is formally restrictive and no longer reflects the modern-day, real-life circumstances of many people in need of long-term care and those capable of providing it. Families often no longer reside in one place, which can make it difficult, or even impossible, for family members to actively provide care beyond the level of mere organisation. People form new close relationships with others locally to whom they are not necessarily related. Therefore, expanding the group of eligible persons would seem sensible.

The Advisory Board has discussed the possible expansion of the group of eligible persons. The majority of its members are convinced that the overall result does not have to be an increase in entitlement to full or partial release from work to the detriment of businesses. Firstly, providing long-term care is always a challenge and can also quickly become a form of mental stress. Therefore, we need not fear that a larger number of people will actually take on this kind of responsibility for someone who is not a relative. Secondly, the Advisory Board presumes that the primary result of expanding the group of eligible persons will be that the care responsibilities of one caregiver (close relative/family member) will be shifted onto another caregiver (close person), but that this will not raise the number of caregivers claiming entitlement to release from work. At the same time, a provision of this kind would also increase the chance of businesses seeing their employees

return to their old jobs following their full or partial release from work and thus remaining at the business; in view of the skilled labour shortage, this would be another advantage.

### **The Advisory Board makes the following recommendations for family caregiver leave and family caregiver allowance:**

- Family carers should be entitled to receive it. This is to include both caregiving family members and those with a similarly close relationship to the person in need of long-term care.

The Advisory Board defines family carers as people who are either a relative within the meaning of the existing definition of a close relative/family member under the PflegeZG<sup>62</sup> or people who provide substantial elements of long-term care because of a special relationship they have with the person in need of it. Only the person in need of long-term care or their legal representative(s) must be able to determine who constitutes a close person in the eyes of the person requiring care or to determine who they want to care for them. Within this context, the expansion of the group of eligible persons applies to both family caregiver leave and family caregiver allowance. Nevertheless, to ensure that a commitment also exists formally, family members and those with a similarly close relationship must be formally confirmed by the person in need of long-term care. A particular concern of the Advisory Board is that the application process should be made as non-bureaucratic as possible.

### **The Advisory Board makes the following recommendations for family caregiver leave and family caregiver allowance:**

- Each person in need of long-term care must officially confirm their own family carers via a non-bureaucratic process. If this is not possible (because they are children or people living with dementia), authorised third parties (such as parents or those with power of attorney) should be able to do it on their behalf.

This confirmation could be based on a binding declaration by the person in need of long-term care that is submitted to the competent institution. A similar procedure relying on the principle of self-determination by the person in need of long-term care was first used in some federal states for the purpose of prioritising vaccinations as part of the COVID-19 vaccination strategy, and proved successful within this context. To the best of the Advisory Board's knowledge, there were no signs of people seriously abusing this system of self-determined prioritisation and so the fears around this were unfounded. Consequently, the Advisory Board assumes that this tool is appropriate.

### **2.3.2 Eligibility criteria**

The provisions relating to family caregiver leave should enable employees to care for family members in need of long-term care (see Section 3.1). To be able to take advantage of the new family caregiver leave and family caregiver allowance, several eligibility criteria would have to be met. These are described below.

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62 Including expansion of the list to encompass the persons stipulated in the first report, see Independent Advisory Board on Work-Care Reconciliation 2019, page 48 f.

### (1) Need for long-term care

A need for long-term care according to Section 14 SGB XI and a minimum care grade of 1 would still have to be ascertained by the competent long-term care insurance fund or the private insurance company providing private mandatory long-term care insurance. This is the same condition that already has to be met for the currently applicable provision on caregiver leave.

By contrast, entitlement to family caregiver allowance would be conditional upon a minimum care grade of 2.

#### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The person in need of long-term care must have been assigned a care grade of at least 1.

#### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- The person in need of long-term care must have been assigned a care grade of at least 2.

### (2) Home environment

Entitlement to family caregiver leave and family caregiver allowance would be conditional upon the care essentially being provided in a home environment. This does not mean that the person in need of long-term care and the eligible person would have to be from the same household. The person in need of long-term care would not have to receive care in their own home; rather, they could also be cared for in the home of the eligible person. The following exceptions would apply concerning the requirement for a home environment: the care of an underage family member in need of long-term care or care for someone in the final phase of life.<sup>63</sup> This is similar to the exception stipulated in the currently applicable PflegeZG and FPfZG. Thus, the currently applicable conditions are to be carried across from there.

#### **The Advisory Board makes the following recommendations for family caregiver leave and family caregiver allowance:**

- Care must be provided in a home environment. The persons involved do not have to be from the same household. In the case of under-age family members in need of long-term care, care can also be provided outside the home.

### (3) Employment relationship

Entitlement to family caregiver leave and family caregiver allowance would be conditional upon the family carer being in an employment relationship according to Section 7(1) PflegeZG. Therefore, this is to include regular employees, employees in vocational training and persons who are to be regarded as persons similar to employees because of their economically dependent status; this also encompasses those who work from home or have an equivalent employment status. The existing provision should be retained because it has proven to be workable.

Up until now, the self-employed have not been covered by the PflegeZG and FPfZG. A benefit similar to the tax-funded wage compensation benefit should be made available to them in order to enable—or make it easier for them—to care for a family member in need of long-term care. The period for claiming this tax-funded benefit should be the same as the one for employees. The level of entitlement could be based on the average monthly income as recorded in the previous year's notice of income tax assessment. Alternatively, a flat-rate monthly amount could be defined for payment to the self-employed person as a tax-funded benefit. If the wage compensation benefit for employees were to be limited to a maximum amount, then an equivalent limit would also have to be imposed for the tax-funded benefit for the self-employed.

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63 For details of care for someone in the final phase of life, see also Section 2.3.8 and the associated decisions concerning care outside the home.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The recipient must be employed as defined by Section 7(1) PflegeZG.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- The recipient must be employed as defined by Section 7(1) PflegeZG or must be self-employed.

#### **(4) Working hours**

The Advisory Board has discussed whether the maximum number of weekly working hours should be stipulated in the case of partial release from work. No such limit is imposed by the currently applicable provisions of the PflegeZG and FPfZG.

The argument in favour of limiting the number of working hours is that the freed-up time would benefit both the caregiver and the person in need of long-term care. Firstly, it would ensure that the caregiver had enough time left to actually take care of the person in need of long-term care. Secondly, this limit would help protect the eligible person from becoming overburdened so that they would still have time for themselves and their own needs alongside their care and work commitments.

However, as regards the new entitlement to family caregiver allowance, the Advisory Board advocates limiting the number of weekly working hours to a maximum of 32 in the case of partial release from work. The justification for this provision, which differs from the one covering family caregiver leave, is that the majority of Advisory Board members have expressed the opinion that the family caregiver allowance should emulate the provisions covering parental allowance. These stipulate that the eligible person should not be doing more than 32 hours of paid work per week on a regular basis.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- In the case of partial release from work, the caregiver should be required to reduce their working hours compared to before. It is important to note that a family caregiver allowance is only to be paid in the event of the number of working hours being reduced to a maximum of 32.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- In the case of partial release from work, the maximum number of working hours should be 32.

#### **(5) Thresholds**

The members of the Advisory Board shared their opinions on business thresholds at length. Two opposing points of views emerged in the course of this.

Some of the Advisory Board members were in favour of abolishing thresholds altogether. In their view, all taxpayers should have equal access to a tax-funded wage compensation benefit without disadvantaging employees who work for smaller businesses. This argument was not accepted by the Advisory Board as a whole.

Major objections to the complete abolition of thresholds, even in the case of partial release from work, primarily come from the employers' side. One of the arguments against abolishing them completely in the context of partial release for family caregiver leave is that this could have certain consequences specifically for smaller businesses.

The introduction of thresholds could lead to another problem on the labour market that the Advisory Board would like to draw attention to. Many family carers work for small businesses.

## 2 Family caregiver leave and family caregiver allowance

If these caregivers are not entitled to family caregiver leave in the context of partial release from work and, in turn, have no entitlement to family caregiver allowance either, it could lead to these family carers either reducing their working hours (without receiving a wage compensation benefit) or possibly leaving their job completely to provide the long-term care.

These conflicting factors are almost impossible to resolve satisfactorily in light of demographic development and the associated shortage of skilled labour.

As a compromise, it was agreed that the thresholds should be standardised at the lower level of the PflegeZG. For this reason, it is proposed that caregivers should not be automatically entitled to family caregiver leave in the context of partial release if their employer generally has 15 employees or fewer. Nevertheless, the possibility of taking family caregiver leave and receiving family caregiver allowance even in the context of partial release from work should still exist for employees at businesses with 15 employees or fewer. Therefore, it was decided that in cases where smaller businesses voluntarily allow their employees to take family caregiver leave in accordance with the provisions of the new Family Caregiver Leave Act, then these employees should likewise be entitled to family caregiver allowance.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- Entitlement to partial release from work should not apply in the case of employers that generally have 15 employees or fewer. However, businesses of this size should have the option of implementing family caregiver leave in consultation with their employees. Incentives need to be created for this.<sup>64</sup>

- Entitlement to full release from work should exist regardless of the size of business.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- Entitlement to the allowance should not apply during partial release from work in the case of employers that generally have 15 employees or fewer. If small businesses voluntarily exercise the option of granting release following family caregiver leave, those involved should not be disadvantaged compared to businesses with more than 15 employees.<sup>65</sup>
- Entitlement to family caregiver allowance should exist throughout any period of full release from work regardless of the size of business.

### **(6) Income of the eligible persons**

The Advisory Board is of the view that those with low and medium incomes are the people most in need of support, as this group is exposed to a high risk of poverty during the period of long-term care and will, therefore, particularly benefit from the family caregiver allowance. High earners are able to provide care out of their own resources for the period of family caregiver leave even without receiving family caregiver allowance. In light of this, entitlement to family caregiver allowance should cease to apply if the beneficiary has demonstrated a taxable income according to Section 2(5) Income Tax Act (EStG) that amounts to more than 250,000 euros per year—in keeping with Section 1(8) Federal Parental Allowance and Parental Leave Act (BEEG), the Advisory Board advocates linking entitlement to the capital income of beneficiaries.

64 The cabinet decision of 8 June 2022 concerning the Act on Implementing the Work-Life Balance Directive (VRUG) states the following: under the Federal Parental Allowance and Parental Leave Act (BEEG), PflegeZG and FPfZG, employers at businesses with fewer employees than the respective thresholds will only be permitted to reject applications for release from work in the future if they provide justification; see Bundesministerium für Familie, Senioren, Frauen und Jugend 2022. A legal situation of this kind is likely to have an impact on the take-up of care-related time off work at businesses with 15 employees or fewer.

65 Ibid.



### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- There should be no entitlement if the beneficiary has a taxable income of more than 250,000 euros per year.
- The income of the person in need of long-term care is irrelevant.

### **(7) Number of eligible persons**

Many caregivers are exhausted or even completely overburdened by the work that their care responsibilities involve. This particularly affects care scenarios where most of the work is done by one person.

An important priority for the Advisory Board is creating the possibility for the care responsibilities to be shared to a greater extent, thereby relieving the burden—where possible—on one primary caregiver. Enabling the family caregiver allowance and family caregiver leave to be shared between several caregivers is intended to create an incentive that will also allow this responsibility to be taken on by people who would not otherwise be able to for financial or time-related reasons.

Within this context, the Advisory Board is not specifying a maximum number of eligible persons per person in need of long-term care, because the individual circumstances and options of family carers differ so much. The Advisory Board is convinced that it would be best for the caregivers to determine themselves how the responsibilities should be shared.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- Several family members should be able to share the entitlement between them. There should be no maximum number of eligible persons per person in need of long-term care.

### **2.3.3 Duration**

In its first report, the Advisory Board has already explained why it is appropriate to extend the work release period from the current 24 months to 36 months. This recommendation is being revisited here in relation to both family caregiver leave and the payment period for family caregiver allowance. The intention is to ensure that the statutory forms of release come as close as possible to covering the actual average duration of long-term care, thereby accommodating real-life circumstances as best as possible. This average duration is approximately 36 months. The Advisory Board is aware that some people require care for a substantially longer period—which is particularly true of children in need of long-term care.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- Each family carer should be entitled to a maximum of 36 months of family caregiver leave per person in need of long-term care.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- It should be possible for a tax-funded wage compensation benefit (family caregiver allowance) to be paid per person in need of long-term care for a maximum of 36 months on a one-time basis.

With regard to how the leave should be broken down into full and partial release from work, the Advisory Board proposes carrying the provisions across from the PflegeZG and FPfZG to the new Family Caregiver Leave Act. This means that the family carers would be able to take full release from work for up to six months out of the maximum of 36 months available for each person in need of long-term care—although this time could also be taken as partial leave from work (working fewer than 15 hours would also be possible in this context).

When taking partial release for the remaining months, they would not be allowed to work for less than a minimum of 15 hours per week on average.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- Out of the total duration of the family caregiver leave, it should be possible to take a maximum of six months as full release or partial release from work (working fewer than 15 hours would also be possible in this context). In the case of partial release from work, the caregiver should be required to reduce their working hours compared to before.
- It should be possible to take the remaining months as partial release provided that the caregiver works a minimum of 15 hours per week.

It should be up to the eligible persons to decide the order in which these (paid) absences from work are taken. If an eligible person should end up caring for more than just one person throughout their working life, they should be able to claim family caregiver leave and family caregiver allowance more than once as well.

The Advisory Board wishes to stress the importance of long-term care responsibilities being shared between several people and people of different genders, and would encourage caregivers to share the responsibilities jointly. For this reason, options should be created for sharing family caregiver leave and family caregiver allowance between several people. In addition, it should be possible for caregivers to claim—under their own responsibility—family caregiver leave and family caregiver allowance consecutively or simultaneously so that the individual care situation can be accommodated as best as possible.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The individual eligible persons should be able to take family caregiver leave consecutively or simultaneously.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- Family carers should be able to claim family caregiver allowance consecutively or simultaneously.

The Advisory Board likewise recognises the potential dynamics of a care situation that would require the total duration to be split into individual blocks of time. The Advisory Board realises that, from the perspective of operational implementation, the process of dividing up entitlements to full and partial work release could put pressure on staffing arrangements and, in individual cases, might also create additional pressure for other employees within the business temporarily. This is because it is extremely difficult to temporarily fill posts that are often only offered on a part-time basis, a situation that is further exacerbated by the shortage of skilled labour. However, the focus of the Advisory Board has to be on protecting caregivers and their needs, a group whose care responsibilities depend so heavily on the condition of the person in need of long-term care. This can deteriorate or improve, often without warning. To enable the caregivers to respond, what they essentially need is sufficient flexibility when taking full or partial release without any minimum duration.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- It should be possible for the family caregiver leave per eligible person to be divided up into a maximum of three time blocks. With the agreement of the employer, further time blocks should also be possible.
- There should be no minimum duration for the family caregiver leave.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- The minimum duration for family caregiver allowance should be one month.



### 2.3.4 Level/calculation

The level of any future wage compensation benefit is the most sensitive element of the design process. The degree of practicability, social fairness, social acceptance and potential for greater gender equity all very much depend on what level is set.

The need for political action is justified because there is a considerable gap between the earnings of caregiving and non-caregiving employees. While non-caregiving employees have an average gross income of approximately 2,900 euros per month, caregiving employees only earn 2,350 euros on average.<sup>66</sup>

According to the preliminary proposal in the first report by the Advisory Board, the tax-funded wage compensation benefit is to be structured in a similar way to parental allowance.

#### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- The tax-funded family caregiver allowance should be income-dependent.
- The level of and calculation method for family caregiver allowance should be based on the provisions governing parental allowance. The amounts should be dynamically indexed.
- In the case of partial release from work, the difference in income between the time before and after the caregiver began providing care should be used to calculate the family caregiver allowance.

The analogy with parental allowance (in terms of the principle) will make it easier to understand and apply the family caregiver allowance. However, the process of calculating and applying for financial compensation in the case of concurrent part-time work—which is the crucial factor from

the perspective of the Independent Advisory Board on Work-Care Reconciliation—should be designed to be as user-friendly as possible.

The Advisory Board briefly discussed the alternative of having a flat-rate wage compensation benefit not linked to the caregiver's income. However, this would not have been compatible with the decisions taken in the Advisory Board's first report and the majority of members were of the opinion that its standardised level would have brought more disadvantages than advantages.

The discussion initially focused on the level at which the family caregiver allowance should be set because the current incarnation of parental allowance is no longer in keeping with the times. The Advisory Board believes that the assessment percentages and upper limit of 1,800 euros need to be increased considerably but that this change should be implemented for parental allowance and family caregiver allowance alike, and then dynamically indexed to the rising cost of living.

A broad discussion took place about the particularly problematic situation facing family carers taking full release from work that consists of the substantial difference compared to their previous earnings. This is a problem because they have often reached a higher age and, in many cases, also a higher income level or because there is now an even bigger gender pay gap than before. However, the Advisory Board backed away from attempting to define another percentage-driven calculation basis or upper limit, as it wanted to retain the analogy with parental allowance. At the same time, the Advisory Board wishes to point out that a fresh decision should be taken concerning the adequacy and dynamic indexing of the parental allowance amounts and that these provisions should then apply to family caregiver allowance as well. This calls for a set of clearly justified design criteria because a wage compensation benefit has to be assessed from all kinds of different angles.

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66 See Budnick 2021, page 6.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- Note: the legislature should take a fresh decision concerning the adequacy of the parental allowance amounts. The family caregiver allowance is then to be adjusted accordingly.

By analogy with parental allowance, the calculation basis should be the caregiver's average net income for the last twelve calendar months prior to providing notification of family caregiver leave. If the caregiver is self-employed, the average monthly income from the previous year should be used.

There were differences of opinion as to whether the concept should involve a rigid upper limit of 36 months (six months' full release plus 30 months' partial release) or whether this should be made more flexible by having a system for navigating between full and partial work release. For instance, one month of full work release could be deemed equivalent to two months of partial work release.

However, the analogy with parental allowance broke down at several points. Unfortunately, it is not possible to devise a provision comparable to the partner bonus that is available with parental allowance because there is no predefined second person when taking on care responsibilities like there usually is when claiming parental allowance.

In particular, the Advisory Board rejected the idea of establishing a bonus based on the BEEG partnership bonus to cover cases where people of different genders share the long-term care on the grounds that this would be discriminatory. Consequently, the effectiveness from the perspective of equality policy is to stem solely from the establishment of the wage compensation benefit and the associated value that society will come to attach to long-term care provision.

Nor can the multiple birth bonus be carried across easily to the new context. Although the long-term care of additional persons should be recognised by paying a twofold and multi-carer bonus, the fact

that each instance of long-term care has a different start date and duration makes drafting a workable provision extremely demanding.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- By analogy with the multiple birth bonus that is available as part of parental allowance, there should be a separate amount for each additional person receiving long-term care.

When devising a separate amount to be paid per additional person (simultaneously) receiving care, it is important to consider that if the application for family caregiver allowance is only submitted in relation to one person in need of long-term care, then the family caregiver allowance will stop automatically if there is no longer a reason for providing the care (for example, if a person in need of long-term care should pass away). In this regard, a non-bureaucratic mechanism must be created whereby the person who was being cared for in parallel can be rapidly promoted to the status of the primary person in need of long-term care, at least for the period of time that has already been approved, so that their ongoing care can be ensured and the family caregiver allowance can continue being paid to the caregiver.

However, multi-carers would also be able to apply for family caregiver allowance consecutively for the respective persons in need of long-term care.

### **2.3.5 Notification and application process**

The length of notification periods is an important regulatory aspect from the perspective of employees and employers alike. It is in the interest of the caregiver for the notification period to be standardised, transparent and as short as possible. Given that it is often impossible to predict or plan how a care situation will develop, having the shortest possible notice period is user-friendly. This allows caregivers to respond appropriately to changing circumstances and, where applicable, to take on

care commitments themselves. In certain situations, employees may be reliant on a short notice period if they want to change their working hours to tie in with their care responsibilities.

On the other hand, having a sufficiently long notification period is an absolute necessity from the company's perspective so that they can adjust to an employee's absence or a reduction in their working hours. It is generally more difficult to fill a temporary post, particularly when the part-time work involved is tied to set times and is not flexible (such as in retail shops). If caregiver leave is preceded by a short-term absence from work, it effectively constitutes release from work without notice from the perspective of the employer. In any event, in cases where provision of long-term care can be planned, for example because someone is taking on the care responsibilities from somebody else in the context of a pre-existing care situation, a longer notification period is desirable from the company's vantage point. In this case, the longer notification period would automatically need to be accompanied by a correspondingly longer period of protection against dismissal (see Section 2.3.7).

As regards the duration of the notification periods, the Advisory Board is in favour of periods that are appropriate for the circumstances. Within this context, there should be no deterioration of the situation for family carers and people in need of long-term care compared to now. Equally, operational feasibility should be ensured.

Currently, applications for release from work have to be submitted in writing. When establishing the new benefit of family caregiver leave in the context of merging the PflegeZG and FPfZG, the legal provisions should be standardised and simplified. Accordingly, the application process should likewise be made as straightforward as possible. In light of today's technology and the customary use of digital methods of communication, the Advisory Board is in favour of allowing applications for family caregiver leave to be submitted in 'text form', i.e. digitally. This will lighten the bureaucratic burden for employees and employers alike. The same should apply to applications for family caregiver allowance.

Once again, a rapid and straightforward application process must be ensured.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The procedure for notifying the employer should be straightforward with a notification period appropriate to the circumstances. Within this context, there should be no deterioration of the situation for family carers and people in need of long-term care compared to now.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- The application process should be fast and straightforward, and allow submissions in digital and analogue form.

The application form for family caregiver leave/family caregiver allowance should be available in both analogue and digital form and be supported by suitable advice infrastructures (if possible: multilingual ones). Low-threshold access should be supported by independent advice centres. The necessary infrastructure already exists nationally because of the entitlement to advice under Section 7a SGB XI. Empirical evidence suggests that a wage compensation benefit is likely to be accompanied by a high level of demand for advice. For this reason, further advisory services should also be involved, such as the national care advice hotline, which offers expert information concerning all benefit entitlements and the support provisions available in the context of long-term care. The care hotline should provide guidance while facilitating access to local advisory services. The care hotline has close links with the citizen service provided by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. As a result, people will have quick access to its wealth of experience in providing differentiated advice about wage compensation benefits.

In this regard, attention should be drawn to the need to staff the advisory services appropriately and in good time.

### 2.3.6 Social insurance

In accordance with Section 44 SGB XI, the statutory long-term care insurance scheme only pays pension insurance contributions for caregivers as defined by Section 19 SGB XI if the caregiver does not regularly work more than 30 hours per week in their paid job. In its first report, the Advisory Board has already identified a need for action in relation to the legal pension arrangements for family carers. It is now considering whether a limit of this kind should also be imposed in respect of family caregiver leave and family caregiver allowance in cases where the caregiver takes partial release from work. The argument against doing this is that it would restrict entitlement to partial release in the context of family caregiver leave compared to the existing provision.

Improving the legal pension arrangements for family carers does, of course, mean higher costs, which would have to be financed by the general public. However, ensuring that long-term care is provided to those who need it is a societal responsibility. Family carers make a very important contribution in this regard. Some family carers have to reduce their working hours because of their care commitments or leave their job altogether. To compensate for lower or missed pension contributions, it is important—and only right—that family carers should be able to acquire pension entitlements in the statutory pension insurance scheme by virtue of the care they provide. The pension contribution payments are currently funded by the statutory long-term care insurance of those in need of long-term care. However, the coalition agreement raises the prospect of a tax-funded approach.<sup>67</sup>

#### **The Advisory Board makes the following recommendations for family caregiver leave:**

- It is unacceptable for family members to be disadvantaged in the area of old-age provision because they take care-related partial or full release from work. The legal pension arrangements for family carers need to be revised in relation to this. Family carers and parents should not be disadvantaged compared to the current legal provisions on pension arrangements.
- The pension contributions should be funded by tax.

To prevent employees from becoming overburdened while ensuring they have sufficient time for their care commitments, the Advisory Board said it was in favour of funding the family caregiver allowance up to a maximum of 32 working hours per week—once again by analogy with parental allowance. To avoid a situation whereby caregiving employees who work at or close to this upper limit are disadvantaged in terms of credits towards their pension, the Advisory Board recommends synchronising the maximum number of weekly working hours and the legal mechanism for awarding pension credits.

#### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The legal pension arrangements for family carers should be conditional upon their working no more than 32 hours per week.

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67 See Bundesregierung 2021, page 66, 73 ff.

### 2.3.7 Protection against dismissal

To create a stable situation for caregiving employees, the employment relationship should—as best as possible—be safeguarded by a high level of protection against dismissal.

**The Advisory Board makes the following recommendations for family caregiver leave:**

- Protection against dismissal should be governed in a similar way to Section 5 PflegeZG.

As soon as the employee gives notification of family caregiver leave within the legally defined periods, special protection against dismissal should commence. This should also include preparations for dismissal as laid down by the European Work-Life Balance Directive and as already enshrined in Section 17(1), third sentence, Maternity Protection Act (MuSchG).<sup>68</sup> This will prevent dismissal immediately following notification and, among other things, will also make it impossible for the job of a caregiving employee to be re-advertised while the extended protection against dismissal is in effect.

In the coalition agreement, it has been agreed to extend protection against dismissal by three months following the return to work in the case of parental leave. The Advisory Board advocates granting this protection to caregiving employees as well, with the aim of better ensuring the resumption of their original working hours.

The objective here is to allow employees to re-establish themselves within their old employment pattern at the end of the care-related time off work or reduction in working hours. These measures will create greater obstacles to dismissal for care-related reasons and put comprehensive safeguards in place to ensure that legal entitlements around care can be asserted. Unlike an appeals mechanism, protection against dismissal should act as a preventative measure here.

**The Advisory Board makes the following recommendations for family caregiver leave:**

- In the event of changes to the notification periods, protection against dismissal must be adjusted accordingly. The extension of protection against dismissal by three months following the (full) return to work—as agreed in the coalition agreement—should be adopted by analogy with the BEEG.

### 2.3.8 Care for someone in the final phase of life

Within the confines of the maximum duration of caregiver or family caregiver leave, the currently applicable legislation allows caregivers to take full or partial release from work for up to three months to care for a close relative/family in the final phase of life. This right is also to be retained in the context of the extended duration for family caregiver leave of up to 36 months that is being recommended by the Advisory Board. In the future, entitlement to this should (unlike family caregiver leave itself) also be possible without a care grade having to be ascertained. Similarly, it should remain the case that care for someone in the final phase of life does not have to be provided in a home environment.

In light of the particular situation and psychological stress faced by the parties involved, the Advisory Board is of the view that care for someone in the final phase of life should be enabled for everyone who has a limited life expectancy of only weeks or months. To accommodate this, the caregiver should be entitled to partial or full release from work.

Employees who take partial or full release from work to care for someone in the final phase of life should be entitled to family caregiver allowance. Their situation deserves a level of protection

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68 See EU Work-Life Balance Directive 2019/1158; see also Treichel 2021.

comparable to that of individuals taking leave for long-term care. If release from work to care for someone in the final phase of life is preceded by family caregiver leave with receipt of family caregiver allowance, the latter should be limited to the overall payment period set for family caregiver allowance, which is 36 months per person in need of care. An exception should apply limiting receipt of family caregiver allowance to a maximum of six months in the case of full release from work. Care for someone in the final phase of life should be possible in addition to this; in this case, it should be possible to draw family caregiver allowance (in the event of full release from work) for up to nine months.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- It should—under certain conditions—be possible to take a maximum of three months out of the total duration of family caregiver leave as partial or full release from work to care for someone in the final phase of life.
- The maximum of three months should be grantable in addition to the six-month period of full release from work.
- This should not be conditional upon a care grade.
- It should not be necessary for the end-of-life care to be provided in a home environment.

### **The Advisory Board makes the following recommendations for family caregiver allowance:**

- It should be possible for a tax-funded family caregiver allowance to be paid per person in the final phase of life for a maximum of three months on a one-time basis, including in the event of full release from work.

### 2.3.9 Short-term absence from work

Care situations are often unforeseeable, arising unexpectedly. Employees must be able and entitled to respond quickly and appropriately to sudden care situations as well. It is absolutely vital to have

legal provisions in place that appropriately support those affected even if the sudden need for long-term care and support occurs repeatedly. For this reason, the possibility of claiming benefits multiple times in respect of the same person in need of long-term care must be expressly clarified in the legislation. Clear provisions that reflect reality should be in place specifically for the purpose of accommodating a crisis situation where the person in need of long-term care suddenly requires support.

### **The Advisory Board makes the following recommendations for family caregiver leave:**

- The provisions on short-term absence from work (Section 2 PflegeZG) should be extended.
- It should be possible for family carers to make multiple use of the short-term absence from work provision to care for a person in need of long-term care, provided that the legal requirements are met.
- It should be possible to take a short-term absence from work in the event of sudden death as well as in relation to a sudden care situation.

### 2.3.10 Carer's grant

Furthermore, limiting entitlement to carer's grant to a total maximum of ten working days—as currently stipulated in the PflegeZG—does not allow scope for addressing the care needs and possible sudden situations. During the COVID-19 pandemic, this was extended to 20 days. In the future, when family carers make multiple use of the short-term absence from work provision, this should be accompanied by an annual allowance of up to ten working days of carer's grant.

### **The Advisory Board makes the following recommendations for carer's grant:**

- Caregivers should be able to claim a carer's grant covering ten working days per year for each person in need of long-term care and for persons in the final phase of life.



## 2.4 Tabular overview of the model for family caregiver leave and family caregiver allowance

The Advisory Board's recommendations for a new family caregiver leave and family caregiver allowance have been described and presented in detail in the previous section. This section revisits the recommendations by bringing them together in the form of a clear table.

The main focus of the concept is on long-term care and work commitments operating in parallel. When designing the measures, care was taken not to fall short of the time opportunities afforded by the current PflegeZG and FPfZG and not to exceed the financial constraints of the BEEG.

Details of the matters to be covered by the provisions:

Family caregiver leave	Family caregiver allowance
<b>Eligible persons</b>	<b>1. Eligible persons</b>
<ul style="list-style-type: none"> <li>Family carers should be entitled to receive it. This is to include both caregiving family members and those with a similarly close relationship to the person in need of long-term care.</li> <li>Each person in need of long-term care must officially confirm their own family carers via a non-bureaucratic process. If this is not possible (because they are children or people living with dementia), authorised third parties (such as parents or those with power of attorney) should be able to do it on their behalf.</li> </ul>	<ul style="list-style-type: none"> <li>Family carers should be entitled to receive it. This is to include both caregiving family members and those with a similarly close relationship to the person in need of long-term care.</li> <li>Each person in need of long-term care must officially confirm their own family carers via a non-bureaucratic process. If this is not possible (because they are children or people living with dementia), authorised third parties (such as parents or those with power of attorney) should be able to do it on their behalf.</li> </ul>
<b>2. Eligibility criteria</b>	<b>2. Eligibility criteria</b>
<ul style="list-style-type: none"> <li>The person in need of long-term care must have been assigned a care grade of at least 1.</li> <li>Care must be provided in a home environment. The persons involved do not have to be from the same household. In the case of underage family members in need of long-term care, care can also be provided outside the home.</li> <li>The recipient must be employed as defined by Section 7(1) PflegeZG.</li> <li>In the case of partial release from work, the caregiver should be required to reduce their working hours compared to before. It is important to note that a family caregiver allowance is only to be paid in the event of the number of working hours being reduced to a maximum of 32.</li> <li>Entitlement to partial release from work should not apply in the case of employers that generally have 15 employees or fewer. However, businesses of this size should have the option of implementing family caregiver leave in consultation with their employees. Incentives need to be created for this.</li> <li>Entitlement to full release from work should exist regardless of the size of business.</li> </ul>	<ul style="list-style-type: none"> <li>The person in need of long-term care must have been assigned a care grade of at least 2.</li> <li>Care must be provided in a home environment. The persons involved do not have to be from the same household. In the case of underage family members in need of long-term care, care can also be provided outside the home.</li> <li>The recipient must be employed as defined by Section 7(1) PflegeZG or must be self-employed.</li> <li>In the case of partial release from work, the maximum number of working hours should be 32.</li> <li>Entitlement to the allowance should not apply during partial release from work in the case of employers that generally have 15 employees or fewer. If small businesses voluntarily exercise the option of granting release following family caregiver leave, those involved should not be disadvantaged compared to businesses with more than 15 employees.</li> <li>Entitlement to the allowance should exist throughout any period of full release from work regardless of the size of business.</li> <li>There should be no entitlement if the beneficiary has a taxable income of more than 250,000 euros per year.</li> <li>The income of the person in need of long-term care is irrelevant.</li> <li>Several family members should be able to share the entitlement between them. There should be no maximum number of eligible persons per person in need of long-term care.</li> </ul>

## 2 Family caregiver leave and family caregiver allowance

Family caregiver leave	Family caregiver allowance
<p><b>3. Duration</b></p> <ul style="list-style-type: none"> <li>Each family carer should be entitled to a maximum of 36 months of family caregiver leave per person in need of long-term care.</li> <li>Out of the total duration of the family caregiver leave, it should be possible to take a maximum of six months as full release or partial release from work (working fewer than 15 hours would also be possible in this context). In the case of partial release from work, the caregiver should be required to reduce their working hours compared to before.</li> <li>It should be possible to take the remaining months as partial release provided that the caregiver works a minimum of 15 hours per week.</li> <li>The individual eligible persons should be able to take family caregiver leave consecutively or simultaneously.</li> <li>It should be possible for the family caregiver leave per eligible person to be divided up into a maximum of three time blocks. With the agreement of the employer, further time blocks should also be possible.</li> <li>There should be no minimum duration for the family caregiver leave.</li> </ul>	<p><b>3. Duration</b></p> <ul style="list-style-type: none"> <li>It should be possible for a tax-funded wage compensation benefit (family caregiver allowance) to be paid per person in need of long-term care for a maximum of 36 months on a one-time basis.</li> <li>Family carers should be able to claim family caregiver allowance consecutively or simultaneously.</li> <li>The minimum duration for family caregiver allowance should be one month.</li> </ul>
	<p><b>4. Level/calculation</b></p> <ul style="list-style-type: none"> <li>The tax-funded family caregiver allowance should be income-dependent.</li> <li>The level of and calculation method for family caregiver allowance should be based on the provisions governing parental allowance. The amounts should be dynamically indexed.</li> <li>Note: the legislature should take a fresh decision concerning the adequacy of the parental allowance amounts. The family caregiver allowance is then to be adjusted accordingly.</li> <li>In the case of partial release from work, the difference in income between the time before and after the caregiver began providing care should be used to calculate the family caregiver allowance.</li> <li>By analogy with the multiple birth bonus that is available as part of parental allowance, there should be a separate amount for each additional person receiving long-term care.</li> </ul>
<p><b>5. Notification</b></p> <ul style="list-style-type: none"> <li>The procedure for notifying the employer should be uncomplicated with a notification period appropriate to the circumstances. Within this context, there should be no deterioration of the situation for family carers and people in need of long-term care compared to now.</li> </ul>	<p><b>5. Application process</b></p> <ul style="list-style-type: none"> <li>The application process should be fast and straightforward, and allow submissions in digital and analogue form.</li> </ul>



Family caregiver leave	Family caregiver allowance
<b>6. Social insurance</b>	
<ul style="list-style-type: none"> <li>It is unacceptable for family members to be disadvantaged in the area of old-age provision because they take care-related partial or full release from work. The legal pension arrangements for family carers need to be revised in relation to this. Family carers and parents should not be disadvantaged compared to the current legal provisions on pension arrangements.</li> </ul>	
<ul style="list-style-type: none"> <li>The legal pension arrangements for family carers should be conditional upon their working no more than 32 hours per week.</li> </ul>	
<ul style="list-style-type: none"> <li>The pension contributions should be funded by tax.</li> </ul>	
<b>7. Protection against dismissal</b>	
<ul style="list-style-type: none"> <li>Protection against dismissal should be governed in a similar way to Section 5 PflegeZG.</li> </ul>	
<ul style="list-style-type: none"> <li>In the event of changes to the notification periods, protection against dismissal must be adjusted accordingly. The extension of protection against dismissal by three months following the (full) return to work—as agreed in the coalition agreement—should be adopted by analogy with the BEEG.</li> </ul>	
<ul style="list-style-type: none"> <li>Care for someone in the final phase of life</li> </ul>	<ul style="list-style-type: none"> <li>Care for someone in the final phase of life</li> </ul>
<ul style="list-style-type: none"> <li>It should—under certain conditions—be possible to take a maximum of three months out of the total duration of family caregiver leave as partial or full release from work to care for someone in the final phase of life.</li> </ul>	<ul style="list-style-type: none"> <li>It should be possible for a tax-funded family caregiver allowance to be paid per person in the final phase of life for a maximum of three months on a one-time basis, including in the event of full release from work.</li> </ul>
<ul style="list-style-type: none"> <li>The maximum of three months should be grantable in addition to the six-month period of full release from work.</li> </ul>	
<ul style="list-style-type: none"> <li>This should not be conditional upon a care grade.</li> </ul>	
<ul style="list-style-type: none"> <li>It should not be necessary for the end-of-life care to be provided in a home environment.</li> </ul>	
<b>Short-term absence from work</b>	
<ul style="list-style-type: none"> <li>The provisions on short-term absence from work (Section 2 PflegeZG) should be extended.</li> </ul>	<b>Carer's grant</b>
<ul style="list-style-type: none"> <li>It should be possible for family carers to make multiple use of the short-term absence from work provision to care for a person in need of long-term care, provided that the legal requirements are met.</li> </ul>	<ul style="list-style-type: none"> <li>Caregivers should be able to claim a carer's grant covering ten working days per year for each person in need of long-term care and for persons in the final phase of life.</li> </ul>
<ul style="list-style-type: none"> <li>It should be possible to take a short-term absence from work in the event of sudden death as well as in relation to a sudden care situation.</li> </ul>	

# 3

## The cultural and legal logic of long-term care—consequences and options for change

This report assumes that work-care reconciliation can only be improved by considering the supporting infrastructure in addition to the framework conditions for informal care within private households. The design of this infrastructure affects—in all kinds of ways—the conditions under which people seek solutions to the problem of work-care reconciliation. The wage compensation benefit and entitlement to release from work are a long-overdue solution—but are not sufficient on their own. The recommendations in this section deal with the further development of care models and infrastructures that will enable options such as mobile and semi-residential forms of support. They pay particular attention to the group that is responsible for providing the vast majority of home-based care: women.

The Advisory Board is aware of the fact that some of the care reform proposals discussed here involve taking account of many different aspects that go well beyond its remit of work-care reconciliation. Nevertheless, it wishes to provide a major impetus for profound reform of the entire long-term care system. This has to start with the interests of those in need of long-term care and

the family members who care for them, although the Advisory Board has not taken account of the financial impact of these measures. The Advisory Board wishes to stress that a long-term care system capable of meeting the challenges of the future can only be developed in the context of the interplay between informal and professional care and the associated support services.

The only way to understand the current long-term care infrastructures is in light of the cultural logic that underpins them and their historical development. Evaluating them from the perspective of work-care reconciliation and identifying options for changes, including—in particular—for the purpose of making them gender-equitable, is very important to the Advisory Board (Section 3.1.1). This framework firmly incorporates a reflection on freedom of choice and self-determination in the provision and use of long-term care services (Section 3.1.2). On the basis of this, the Advisory Board then provides an overview of support services for family carers who work (Section 3.2). Finally, there is an exploration of the importance of enabling mixed care arrangements for work-care reconciliation (Section 3.3).

### 3.1 Outline of the problem: the cultural logic behind German long-term care policy and its gender-specific implications

The specific manner in which labour is divided between the social stakeholders involved in the provision of long-term care—namely the government, providers of independent social welfare services, the family, individuals and market players—can vary widely. In Germany, it is the family that bears the primary responsibility; in Sweden, by contrast it is the government, while in the UK each individual is responsible for themselves.

The underlying cultural logic has evolved over centuries, becoming institutionalised within the German welfare state when the first welfare state mechanisms were created at the end of the 19<sup>th</sup> century and within the German social state following the Second World War. The question now arises as to whether this cultural legacy and social division of labour originating from the 19<sup>th</sup> and 20<sup>th</sup> centuries are still appropriate for the 21<sup>st</sup> century.

Thirty years ago, Gosta Esping-Andersen—the author of the most influential classification system for socio-political systems or welfare state

regimes—<sup>69</sup> categorised the German welfare state/social state as a ‘conservative-corporatist welfare state regime’. It was labelled ‘conservative’ due to the dominance of conservative moral values in the (gender-specific) division of paid work and unpaid care work, and ‘corporatist’ because of the strong social position of collective bargaining partners.<sup>70</sup> European countries are now classified as various ‘care regimes’ based on how care work is delivered. For instance, in 1996, Anttonen and Sipilä<sup>71</sup> categorised Germany as a ‘social care regime’ that relies on informal care work but provides at least partial compensation for this from government resources. The long-term care insurance scheme, which had only just been introduced at the time, slots seamlessly into this category.

These care regimes are strongly shaped by the country-specific cultural values and traditions associated with care work. For instance, the birth of governmental social policy in Germany at the end of the 19<sup>th</sup> and start of the 20<sup>th</sup> century was primarily politically motivated, firstly with the aim of putting effective protection in place against the risks of losing income in an industrialised society (age, disability, illness—with unemployment and the need for long-term care coming later) and secondly to deter the working class from any ideas about starting a revolution by instead integrating them effectively into society.<sup>72</sup> The German care regime was strongly shaped by Catholic social doctrine and the traditional model of the ‘male breadwinner’<sup>73</sup>—the man traditionally having primary responsibility for earning an income, while the woman was primarily responsible for caring for the family.<sup>74</sup>

69 See Esping-Andersen 1990, page 24 f.

70 The subjects of care work and ‘gender-specific division of labour’ were not even mentioned in this publication but the normality it describes is based on the ‘male breadwinner model’. Following criticism in relation to this—for example, from Lewis 1992, page 160 ff.; Sainsbury 1994; and Pfau-Effinger 1999, page 147 ff.—more recent publications by Esping-Andersen expressly include these aspects (see Esping-Andersen 1999, Esping-Andersen 2002, and Esping-Andersen and Sarasa 2002, page 9 ff.).

71 See Anttonen and Sipilä 1996, page 97.

72 See Alber 1987, page 24 ff.; for information about the development of governmental social policy, see Lampert and Althammer 2014.

73 See, for example, Knauthe, Brandt and Hoff 2021.

74 For details of the sea change in gender relations, see Leitner, Ostner and Schratzenstaller 2004; see Ciccia and Verloo 2012, page 510 ff.

Catholic social doctrine is based on the principle of subsidiarity, whereby tasks are divided between the individual, family and state in such a way that responsibility starts with the individual, the family and other smaller social groups. After that, it is the duty of the state to help individuals or families to help themselves—and also to take on the task if the smaller unit is unable to cope. According to this principle, the state has an obligation to provide active support<sup>75</sup>. It is precisely this role that the long-term care insurance scheme is supposed to perform. However, in the course of legislative consultations, it has had to take on board other factors, as a result of which the primary responsibility has increasingly been shifted back onto the family. As a consequence, the traditional care regime has become fixed.<sup>76</sup>

Even though sections of contemporary society base their actions strongly on rational criteria,<sup>77</sup> the traditional model continues to be reflected in social mechanisms and legislation that subtly reinforce this division of labour in everyday life. This begins with the way that men earn more than women on average: women's average gross hourly earnings are 18 lower than men's (the gender pay gap).<sup>78</sup> The effect of this mechanism is that a family is economically better off if women take responsibility for the care work. By taking on the lion's share of informal care, women<sup>79</sup> become even more financially disadvantaged over the course of their lives<sup>80</sup> and they remain financially dependent on their partners<sup>81</sup>—right into ad-

vanced age due to their lower retirement pensions. The pension gap between women and men (known as the 'gender pension gap') stands at 49 per cent, meaning that the pension entitlements that women have in their own right are 49 per cent lower on average.<sup>82</sup> Thus, long periods of caregiver leave can become a risk factor for women suffering poverty in old age.<sup>83</sup>

German income tax law provides another disincentive for the gender-neutral division of care labour. The tax splitting mechanism for married couples, which was introduced in the 1950s, rewards them with a large difference in income between the two partners,<sup>84</sup> which—in effect—encourages men to work full-time while women work part-time. Even though the roles could be reversed (at least in theory), what actually happens within our society in practice clearly works to the disadvantage of women.

The rise in the number of working women is supported by a labour market and social policy that has been based on the 'adult worker model'<sup>85</sup> since the 2000s. According to this model, all adults of working age—including both women and men—are supposed to be able to earn their own living. The reform of spousal maintenance law (2008) also fitted in with this model by expecting women to earn their own living after a separation or divorce. For this to succeed, companies also have an obligation to facilitate a proper balance between family and work commitments.

75 For information about Catholic social doctrine, see Nell-Breuning 1980.

76 See Dammert 2009, for example; see Zängl 2015.

77 See Bell 1994.

78 See Statistisches Bundesamt 2021a.

79 See, for example, Herrmann, Rebaudo and Calahorrano 2022, pages 15 and 4 f.: 'According to SOEP 2020, around 3 million of the 4.9 million caregivers are women, which corresponds to 61.3 per cent of all caregivers. (...) A more detailed analysis of caregivers that differentiates by gender reveals that female caregivers spend more time on care duties on average and are less likely to be in paid employment.'

80 See Knauthe, Brandt and Hoff 2021.

81 See Lewis and Ostner 1994, page 18 ff.; see Trappe, Pollmann-Schult and Schmitt 2015, page 239.

82 See Hobler, Pfahl and Schubert 2021, page 2.

83 See Knauthe and Deindl 2019, page 84 ff.

84 See Dingeldey 2001, page 656 ff.; see Ochmann 2013, page 1.

85 See, for example, Daly 2011, page 2 ff.; see Lewis and Giuliani 2005, page 77 ff.

In the seven decades since the Federal Republic of Germany was founded, the concept and lived reality of marriage and family have changed dramatically. Since 1970, the divorce rates have more than doubled to 35 per cent.<sup>86</sup> More than a third (35 per cent) of today's children are born outside of marriage.<sup>87</sup> 41 per cent of all households are single-person households and another 34 per cent are two-person households.<sup>88</sup>

The innovations introduced under family and long-term care policy in the 1980s and 1990s—such as child-raising allowance and child-raising leave in 1986 and long-term care insurance offering 'partial cover' in 1995/1996—continued to follow the logic of the subsidiarity principle. The manner in which the social insurance systems are organised is also essentially based on the principle of subsidiarity. These rely on the concept of self-administration, meaning that the representatives of the insured persons and the employer—as the payer of the contributions—decide for themselves how the funds are to be allocated. The family policy reforms of the 2000s/2010s (parental leave/parental allowance and parental leave plus/parental allowance plus) are more closely aligned with the real lives and wishes of parents for whom fairness within the relationship is important but without truly breaking away from the traditional German care regime. The 'dual breadwinner model'<sup>89</sup> is now a reality—provided that no children are born and no family members need long-term care. Assuming that equality is the reality before the start of any caregiving commit-

ments, the logical consequence is that men should bear equal responsibility for the care of underage children and elderly family members in the same way that women are increasingly engaging in paid employment on an equal footing with men.

Accordingly, the Second Gender Equality Report by the Federal Government published in 2017 advocated for a new guiding principle allowing all people to give care privately alongside their paid work commitments according to the demands placed on them over the course of their lives. It should also be possible for care to be provided informally in parallel with paid work at any time (earner-carer model).<sup>90</sup> However, in reality, achieving work-care reconciliation has become significantly more challenging in recent decades due to the increased demand for employees to be flexible in terms of their work locations and schedules.

In light of this, the problem of work-care reconciliation affects the genders to different extents. If it becomes necessary to care for underage children or family members in need of long-term care, then it is still the women who end up reducing their working hours. Although half of all German couples constitute double-income households, more than half of women are employed on a part-time basis because of family commitments<sup>91</sup> (with 72.6 per cent working part-time and 27.4 per cent working full-time<sup>92</sup>)—compared to 9 per cent of men<sup>93</sup>.

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86 See Statistisches Bundesamt 2018, page 58.

87 See Statistisches Bundesamt 2016a, page 38.

88 See Statistisches Bundesamt 2016b, page 24.

89 See Pfau-Effinger 1999.

90 See Sachverständigenkommission zum Zweiten Gleichstellungsbericht der Bundesregierung (Expert Commission for the Third Gender Equality Report) 2017, page 45.

91 An analysis produced by the Federal Institute for Population Research (BiB) (2018, page 2 ff.) showed that there are still differences between eastern and western Germany in the area of part-time employment. According to this data, a higher proportion of male employees work part-time in eastern Germany than in western Germany across all age groups. As regards female employees from eastern Germany, the proportion working part-time is lower than for female employees from western Germany. The difference in the proportion of part-time workers between eastern and western Germany is much more pronounced among female employees than male employees.

92 See Statistisches Bundesamt 2022c.

93 See Crößmann, Mischke and Hoffman 2016, page 48.

Despite numerous care reforms,<sup>94</sup> the cultural logic has changed very little within the context of long-term care policy. The Federal Government's Seventh Report on Ageing published in 2016 summed the situation up as follows: 'Despite all the changes that have taken place in the world of paid work, a reorganisation of care has so far been neglected.'<sup>95</sup> Within this context, an ageing society is no longer a medium-term future prospect but has long since become an everyday reality.

However, the cultural values of our society have changed. In addition to the normalisation of educational and employment opportunities for all genders, another aspect is that the older generations today place great emphasis on maintaining an independent lifestyle well into their later years. There is less of an expectation for support to be provided by the family than in the past—but this means that spouses/partners and friends play a bigger role in the provision of long-term care and assistance.

In the future, an ever decreasing number of younger and middle-aged people will have to care for an ever increasing number of very elderly people—often over large geographical distances. This reduced potential for providing long-term care will affect families and the professional care sector alike.

As already described, new directions for long-term care must be deliberated and discussed. Given the increasing participation in paid work by both genders, a more diverse mix of long-term care is required.<sup>96</sup> The aim should be to support working family carers—in a way that takes account of their preferences, resources, and limitations—by giving

them equal access to a rich juxtaposition of options that are geared towards their needs and draw on individuals, families, society, businesses and the government. This will enable true freedom of choice for both family carers and those in need of long-term care.

#### 3.1.1 Freedom of choice

One of the key aims of the long-term care insurance scheme is to help those in need of long-term care to lead a life that is as independent and self-determined as possible in spite of their need for assistance.<sup>97</sup> The long-term care arrangements used to achieve this depend on the individual case concerned. Here, it is necessary to consider the interests and needs of the person in need of long-term care and everyone involved in delivering it. Within this context, freedom of choice also means allowing those in need of long-term care and their family members to decide against informal care, and ensuring they are supported in this decision.<sup>98</sup>

The long-term care insurance scheme is silent on the matter of the family carers' right of self-determination. In its first report, the Independent Advisory Board on Work-Care Reconciliation explicitly recommended that decisions not to provide informal long-term care should be respected and that those affected should be supported in this.<sup>99</sup>

The long-term care insurance scheme maintains a catalogue of benefits/services, the design of which has a major impact on the degree of flexibility available to family carers who work. For this

94 See—inter alia—the Act on Quality Assurance in Long-Term Care (PQsG) 2001, Supplementary Act on Long-Term Care Services (PflEG) 2002, Long-term Care Further Development Act (PfwG) 2008, Caregiver Leave Act (PflegeZG) 2008, Family Caregiver Leave Act (FPfZG) 2011, Long-Term Care Realignment Act (PNG) 2012, First Act to Strengthen Long-term Care (PSG I) 2014, Act for a Better Reconciliation of Family, Care and Work 2014, Second Act to Strengthen Long-term Care (PSG II) 2015, Third Act to Strengthen Long-term Care (PSG III) 2016, Act to Improve Health Care and Long-Term Care (GPVG) 2020, Healthcare Development Act (GVWG) 2021.

95 See Bundesministerium für Familie, Senioren, Frauen und Jugend 2016, page 210.

96 By this, we mean family and voluntary caregivers as well as formal (professional) carers; see also Görres, Seibert and Stiefler 2016.

97 Section 2 SGB XI—Self-determination: (1) The benefits/services of the long-term care insurance scheme shall help those in need of long-term care to lead a life that is as independent and self-determined as possible in keeping with human dignity in spite of their need for assistance.

98 For further information on this subject, see also Ludwig and Daldrup 2022, page 259, and Bohnet-Joschko, Korte and Kreyenschulte 2022, page 262.

99 See Independent Advisory Board on Work-Care Reconciliation 2019, page 5.

reason, the process of reforming it must not just take account of the needs of those requiring long-term care but also the interests of family carers, many of whom are in paid work.

#### 3.1.2 Social space orientation and caring communities

‘Social space orientation’ is the literal translation of ‘Sozialraumorientierung’, a German term from the field of social work. The concept became established in the 1990s. It encompasses approaches that are associated with empowering and encouraging those potentially in need of assistance to take advantage of community support services at an early stage, thereby taking preventative action to counter social exclusion and deprivation. The approach is not without controversy but—regardless of this—is increasingly being factored into long-term care. In fact, social space orientation is an important driver of reform in the further development of the care infrastructure in Germany.<sup>100</sup>

When concepts based on social space orientation are implemented, it disrupts the juxtaposition between professional care services (on the one hand) and the informal provision of care by family members (on the other). Assistance structures present within the immediate living environment are actively incorporated into long-term care processes by way of caring communities<sup>101</sup>. Those actually in need of long-term care and their family members are involved in planning the processes. Alignment with the principle of social space orientation does not solve all the problems of long-term care—but it does offer an opportunity for family members to play an active part in a diverse array of care settings in accordance with their capabilities and their own values and ideas.

The Advisory Board is of the view that professional long-term care settings need to be more closely aligned with the social space to enable better work-care reconciliation.

#### 3.1.3 Non-residential first, residential second—the legal framework for home-based care and its gender-specific consequences

According to the Social Code, ‘attending to the long-term care needs of the population (...) is a societal responsibility’ (Section 8(1) SGB XI). However, its implementation follows the principle of subsidiarity. In addition, Section 3 SGB XI states the following: ‘Via its benefits/services, the long-term care insurance scheme shall primarily support home-based care and the willingness of family members and neighbours to provide long-term care so that those in need of it can remain in their home environment for as long as possible. Semi-residential care and short-term care services take priority over fully residential care services.’

As already detailed in the introduction to the cultural logic involved, long-term family-based care in Germany is organised according to widespread gender role norms. The Social Code has expressly incorporated family-based care since the introduction of the long-term care insurance scheme. This binding legal norm establishes a duty to safeguard home-based care as the first priority. The freedom to choose between caregiving and paid work is often demanded. However, for both men and women, the ability to exercise this ‘freedom of choice’ is effectively heavily restricted by economic pressures—often with the result that women become financially dependent. Out of those who provide informal long-term care, 42 per cent are women and 26 per cent are men of working age ranging from 17 to 64 years old.

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100 For more information on the subject of social space planning, see Klie 2022, page 81.

101 See Klie 2016, page 22.



Another 18 per cent are women and 14 percent are men aged 65 and above.<sup>102</sup> The employment rate among caregiving women has increased significantly over recent decades and now stands at 71 per cent. However, the degree of employment also plays an important role in securing a livelihood. Caregiving women work fewer hours than women without any long-term care commitments; they are much less likely to be employed full-time (just 27.4 per cent<sup>103</sup> of them).<sup>104</sup> A contrasting situation has always applied in relation to men, with no significant difference observable between those who provide long-term care and those who do not. The gender-specific differences in the weekly amount of work have remained constant over time. Thus, the average monthly earnings of caregiving women are lower, with the average monthly gross pay gap having consistently remained at a substantial 1,000 euros in the period from 2001 to 2017.<sup>105</sup>

If caregivers are considered as a whole—by including those who are no longer of working age—then two thirds of the members of this group are women.<sup>106</sup> Children in need of long-term care are primarily cared for by their mothers.<sup>107</sup>

The above data and findings on the gender-specific assumption of care duties and reduction in employment indicate that, in spite of being drafted in a gender-neutral way, the legislation covering long-term care insurance still has a gender-specific impact. Therefore, it is not just the application of this legislation that needs to be challenged but also the very manner in which it has been drafted. This is because law making involves various assumptions about reality that shape the resulting legislation.<sup>108</sup> In this case, the primary focus is on the family, meaning that women are the ones mainly affected.

Simply demoting informal care within the context of long-term care insurance would not, in and of itself, be sufficient to challenge the notion that the family is responsible for providing long-term care. Rather, it would involve allowing caregivers and care receivers to decide for themselves how long-term care within the home environment should be organised. Legislation not only has the potential to reflect society but also to change it.

To facilitate the gender-equitable organisation of long-term care, the redistribution of care duties between all genders should be encouraged. The wage compensation benefit recommended by the Advisory Board for caregiver leave offers a tool for achieving this—other measures are also required, such as the expansion of mobile professional care and assistance services, or household-related services.

As well as ensuring that the long-term care insurance scheme was aligned with the legally stipulated preference for home-based care, another key aim when introducing it was to limit the costs of this new class of insurance. The partial benefits principle—a concept that had hitherto been alien to the German social insurance system—was introduced for this purpose and the principle of meeting needs replaced by the budget principle. According to this approach, a standardised financial limit was imposed in respect of the individual entitlement regardless of the actual extent of the need for assistance. This is another instance of how the long-term care insurance scheme creates obligations for the families of people in need of long-term care, this time by limiting the benefits provided.

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102 See Ehrlich 2020, page 173.

103 See Statistisches Bundesamt 2022c.

104 See also Herrmann, Rebaudo and Calahorrano 2022, page 15 ff.

105 See Ehrlich 2020, page 174.

106 See Ehrlich 2020, page 174.

107 See Budnick 2021, page 72. See also Section 4 of this report.

108 For information about the shaping of gender roles by legislation, see Schmidt 2012; for information about the concept of indirect discrimination, see Wrase and Klose 2012.



We are not attempting to challenge the priority status of home-based care, as set out in Section 3 SGB XI. Nevertheless, family members must not be legally or morally coerced into taking responsibility for long-term care. This has direct consequences for the practical implementation—and, in turn, also the reconciliation—of work and care. In light of this, the function and effect of the supplementary phrase ‘and the willingness of family members and neighbours to provide long-term care’ in Section 3 SGB XI should be reviewed.

In order for care work and, in turn, long-term care responsibilities to be divided evenly between women and men, long-term care policy must be formulated from an equality policy perspective—with the specific aim of ensuring that equality policy is consistent across all policy areas without any contradictions, for example, between the guiding principles of long-term care insurance and those of labour market policy.

## 3.2 Support services for working family carers who provide family members with home-based long-term care

The ability to reconcile care and work commitments does not just depend on financial incentives (as described in Section 2) but also on whether—and in what form—support and assistance services are available and accessible within the region.<sup>109</sup>

A good level of reconciliation also depends on the quality and stability of home-based care, which—in turn—is influenced by healthcare services. For instance, family carers are reliant on support from (specialist) doctors and timely diagnosis. It is also important that doctors can be contacted in the event of suddenly occurring health problems.

Another prerequisite for the use of assistance services is that family carers and those in need of long-term care must be aware of what services are available, that these must be appropriate to their own life circumstances and the needs of those in need of long-term care, and that these must be flexible and accessible in a non-bureaucratic way.<sup>110</sup> If someone is given information about an advice service as part of a doctor’s appointment, they are much more likely to use the service.<sup>111</sup>

This report also addresses work-care reconciliation for parents whose children require long-term care (see Section 4). There is a group of people who have been almost completely ignored and this is still the case today. These are the people aged below 65 who start needing long-term care at the mid-stage of life and are no longer able to pursue their education or career.<sup>112</sup> This situation also has a severe impact on family carers because the loss of family income ‘forces’ them to work more rather than less. At the same time, those who are sick and in need of long-term care are increasingly reliant on support. They need stimulation and structure from a source outside of themselves—usually in the form of family members. This can lead to family members having to decide whether they should work more to safeguard the family’s income or whether they need to be present for the person in need of long-term care in order to provide everyday assistance. As regards work-care reconciliation, these families are generally left to

109 See Haumann 2022, page 54 and 62: At any rate, in a representative survey that was conducted on behalf of the DAK-Gesundheit insurance company by the Allensbach Institute, 38 per cent of respondents with experience of long-term care said that an increase in the care allowance was more important to them than having more support services available locally for caregivers. The survey also revealed that the wage compensation benefit remains a key element alongside this because three quarters (75 per cent) of the entire population is in favour of introducing a government wage compensation benefit that works in a similar manner to parental allowance. The percentage was equally high for both non-working and working family carers.

110 See Büscher et al. 2022, page 7.

111 See Grossfeld-Schmitz et al. 2010, page 4 f. The results relate to a survey undertaken as part of the project ‘IDA—Initiative Demenzversorgung in der Allgemeinmedizin’ (the Dementia Care Initiative in Primary Practice) (Holle et al. 2009).

112 In Germany, for example, there are 102,800 people below the age of 65 who are living with dementia. Of these, 47,300 are younger than 60. See information sheet 1 ‘Häufigkeit von Demenzerkrankungen’ (Frequency of Dementia Illnesses), which is available online at: [www.deutsche-alzheimer.de/Publikationen/Informationsblätter](http://www.deutsche-alzheimer.de/Publikationen/Informationsblätter).

their own devices because the available support services are mainly aimed at elderly people (see also Section 4 for information about children and adolescents). Currently, there are no services for younger people within this group, such as day hospitals for the mentally unwell or sheltered workshops for people with disabilities.

#### 3.2.1 Description of support and assistance services

This subsection explores the existing support and assistance services (which are partly funded by the benefits of long-term care insurance) in terms of the opportunities inherent within them for optimising the conditions associated with the long-term care of family members.

##### 3.2.1.1 Information and advice

In its first report, the Advisory Board has already stressed the importance of information and advice for enabling successful work-care reconciliation and for tailoring long-term care arrangements to individual needs. Section 4 of that report states: ‘Family members who face the decision on whether and how they will care for another person or whether and how they can combine work and care are reliant on the availability of information and advice. Ultimately, “caring” for a person can involve a number of very different challenges.’<sup>113</sup>

Within the context of individually tailored advice that also covers the resources and limitations of the persons concerned, family members should be able to decide whether to provide long-term care and to what extent (freedom of choice). The first report also says: ‘If family members reach a joint decision with the person in need of long-term care to care for them in their home, they require a variety of support services in order to do so. But only where the different legal options and support provisions are known can they be used as needed.’<sup>114</sup>

These pleas for family carers to receive early advice and information and for this to be neutral and transparent are just as valid now as they were before.<sup>115</sup> This includes important advisory services for working family carers to explain which legal provisions are applicable to them, particularly those of the PflegeZG and FPfZG.<sup>116</sup> This advice can be (and actually is) used by employers of family carers, which can have a positive impact on the internal dissemination of information on this subject within the company.<sup>117</sup>

##### 3.2.1.2 Support services for day-to-day tasks

All those who require long-term care and live in their own home have been entitled to a support allowance of up to 125 euros per month since the introduction of the Second Act to Strengthen Long-term Care (PSG II). Among other things, this can be used to fund support for day-to-day tasks where these services are recognised under federal state law.

113 See Independent Advisory Board on Work-Care Reconciliation 2019, page 50.

114 See Independent Advisory Board on Work-Care Reconciliation 2019, page 50.

115 To find out more about the importance of information on support services in the context of long-term care, see Haumann 2022, Section 2.2. Among other things, the survey revealed that 67 per cent of respondents with experience of long-term care were not aware of some of the support services mentioned in the survey (page 42). Nonetheless, when asked about each of the support services that they did use, a large percentage said these were helpful (page 43). Moreover, 71 per cent of people with experience of long-term care said that long-term care worked either well or very well when accompanied by support (page 44).

116 See Rennert, Richter and Kliner, page 86 f. for information about the extent to which work-care reconciliation measures exist at the employee’s workplace and the level of awareness concerning these.

117 In this regard, the first advisory services consist primarily of the care hotline provided by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the website [www.wege-zur-pflege.de](http://www.wege-zur-pflege.de), which is to offer special advisory services/information for employers in the future. In addition, family carers are entitled to receive long-term care advice in their own right. Further information on this topic can be found at: [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-pflege/pflegeberatung.html](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-pflege/pflegeberatung.html).

There is a vast array of different providers in the area of support services for day-to-day tasks. For instance, there are professional commercial providers, services delivered by the independent social welfare sector and—in particular—self-help organisations, such as the regional Alzheimer’s associations. In addition to these, some regions also have help groups or individual helpers available, who provide support for day-to-day tasks in the context of neighbourhood assistance schemes, for example. Voluntary helpers might, for instance, look after and entertain those in need of long-term care by the hour. As part of this, they help to create structure for the day and prevent social isolation. Support for day-to-day tasks also includes the provision of care within a group in addition to individual services that are delivered in the home of the person requiring long-term care, with the latter likewise incorporating aspects of instruction and training. These are supplemented by advisory services and long-term care courses for family carers. These services provide respite for family carers who work. Within the federal states, a variety of different structures undergird the support services for day-to-day tasks, such as specialist and coordination centres, regional offices, care contact points (called ‘Kontaktstellen Pflegeengagement’) or service points.

The widespread take-up of the support allowance shows the significant impact on family caregivers and long-term care recipients that can come from having such a flexible budget while keeping the

bureaucratic burden relatively small.<sup>118</sup> The support services for day-to-day tasks that are recognised under federal state law always stem from a commitment to long-term care at the local level. Unfortunately, this means that the family carers who could potentially make use of the budget cannot access it to the same extent everywhere.<sup>119</sup>

#### 3.2.1.3 Mobile care and support services

As of December 2021 there were 15,376 mobile care and support services in Germany, representing an increase of around 4.7 per cent compared to 2019.<sup>120</sup> The newly defined concept of the ‘need for long-term care’ took effect in 2017. Since then, the range of authorised mobile care facilities has been reorganised and expanded to include long-term care measures such as assistance with orientation, structuring of the person’s daily routine and the maintenance of social contacts. Alongside physical care measures (such as nutrition, mobility promotion and personal hygiene) and home-based nursing care according to Section 37 SGB V (such as drug administration, the changing of dressings and injections), these are now part of the professional long-term care infrastructure.<sup>121</sup> By taking charge of these activities, mobile care facilities are making an important contribution to work-care reconciliation. It takes the burden off working family carers and ensures that the needs of those requiring long-term care are met while their caregiver is at work.

118 See Matzke et al. 2021, page 244.

119 See Bundesministerium für Gesundheit 2021a, page 102 f.

120 See Statistisches Bundesamt 2022b, Table 2.1.

121 See Bundesministerium für Gesundheit 2021a, page 51 ff.

Nevertheless, the total take-up figures show that only 25 per cent of those receiving long-term care at home are actually making use of an authorised mobile care and support service.<sup>122</sup> This suggests that, in practice, these services are having a relatively small effect on work-care reconciliation. So far, no reliable studies have been conducted into the reasons for this low take-up.<sup>123</sup> When calling the national Alzheimer’s hotline provided by Deutsche Alzheimer Gesellschaft (the German Alzheimer’s Association), family carers cite the following reasons, among others: to enable work-care reconciliation, the service has to be ‘accepted’ by those receiving the care. However, the frequent changes in staff (lack of relationship-based care) make it difficult to establish a relationship of trust and those in need of long-term care refuse to accept care from a ‘stranger’. The tight schedule is another exacerbating factor—in particular, this leads to people with dementia feeling ‘left behind’ and unable to fully exercise their right of self-determination.

At a fundamental level, there is a major problem in that care and support services across the whole of Germany are affected by a huge shortage of skilled staff. This is set to become even more acute over the coming years, which will have a direct impact on the quality of care. As long ago as 2019, there were 16,000 vacancies in this sector and this led to more and more requests for care being rejected or terminated even though the services themselves were theoretically available across the whole of Germany.<sup>124</sup>

#### 3.2.1.4 Self-help groups for family carers

According to estimates, 3.5 million people in Germany are involved in self-help groups with the aim of ‘tackling psychological problems and conflicts, and the concomitant effects of (chronic) physical illnesses and disabilities’.<sup>125</sup> By working with others who are affected in the same or a similar way, they hope to change their personal circumstances while also influencing the social and political sphere.

Open personal discussion and mutual assistance lie at the heart of the self-help groups. ‘Through an atmosphere of acceptance and mutual understanding’<sup>126</sup> family carers learn, for example, that they are not alone with their fears, feelings of guilt and the unbearable pressure that causes so many of them to give up work. Family carers can share with each other about the importance of attending to their own needs, accepting support and setting limits. This gives them more room for manoeuvre, on the basis of which they are able to make a more assertive decision concerning whether or not they feel it is right, for example, to take on long-term care commitments or seek to reconcile work and care responsibilities.

Being part of a collective—whether in the form of groups or self-help organisations—also makes it easier to identify gaps in the care infrastructure and to create and make public ideas for support services, or for the group/organisation to develop its own support services. In this way, self-help organisations are making a major contribution towards continuously improving quality of life for family carers and care recipients and, in turn, to work-care reconciliation.

122 See Statistisches Bundesamt 2022b, Table: Eckdaten der Pflegestatistik (key statistics for long-term care).

123 See Haumann 2022, page 46. The question is framed in relation to the person’s experience: ‘based on everything you have personally experienced or heard’. Two thirds (64 per cent) of those surveyed (= population) say that—based on what they have personally experienced—it tends to be difficult or very difficult to find a long-term care service for a family member within their locality. No significant differences could be identified for the purpose of differentiating between eastern and western Germany (single-choice question).

124 See Zentrum für Qualität in der Pflege (ZQP) 2019, page 14.

125 Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen (NAKOS) 2009.

126 Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen (NAKOS) 2009.

To be able to participate in a group, family carers need access to support services so that the care recipients are properly looked after while they are busy with the group.

During the lockdown imposed as part of the COVID-19 pandemic, groups and training became available in a new online format. These online options enable caregivers to remain informed and in contact with others if they live in rural regions or find it difficult to leave the house due to the care situation.

#### **3.2.1.5 Voluntary assistance provided by friends and neighbours**

Many citizens voluntarily assist and support people in their neighbourhood who require help—generally without being paid. They do the shopping, spend time visiting, drop off meals and provide lifts to the doctor and official appointments. This additional low-threshold support supplements the professional care system. Furthermore, these fellow citizens are usually a highly flexible and reliable source of assistance, providing a basis for others, including working family carers, to build on.

#### **3.2.1.6 Day/night care**

Semi-residential care is an important pillar of support for family carers who work. It ensures that the person requiring long-term care gets occasionally looked after during the day at a care facility designed for this purpose. It is clear that this service is particularly important for working family carers because caregivers who work during the day are the ones who make the greatest use of it.<sup>127</sup>

With a view to strengthening day and night care provision, this service was separated from the mobile services under the First Act to Strengthen Long-term Care in 2015 to prevent it from being deducted from the entitlement to a long-term care service or the care allowance. In particular, this has led to the establishment of new semi-residential facilities.<sup>128</sup> The number of approved day and/or night care places grew from 82,899<sup>129</sup> in 2019 to 96,494 in 2021,<sup>130</sup> an increase of 16 per cent. Within this context, night care is virtually negligible with just 269 places available in 2021.<sup>131</sup>

The increase in day care places and associated take-up rate clearly show that these services have constantly been growing in importance over recent years and that they are helping to further facilitate the work lives of family carers. By encouraging the social participation of those receiving care and creating ways for them to maintain and strengthen their self-determination and independence, they make a substantial contribution towards providing stability for home-based care scenarios.

#### **3.2.1.7 Short-term care**

The aim of short-term care is to enable people to remain in home-based care in the longer term by covering temporary periods when this is not possible, not yet possible or not possible to the necessary extent. This applies, for example, to transitional periods after the person in need of long-term care has been in hospital or in the event of other crisis situations, for example if the caregiver cannot provide care for a temporary period because they are ill. Fully residential short-term care is also a possibility in other

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<sup>127</sup> See Bundesministerium für Gesundheit 2021b.

<sup>128</sup> See Lötzerich 2019.

<sup>129</sup> See Statistisches Bundesamt 2020, page 35.

<sup>130</sup> See Statistisches Bundesamt 2022b, Table 3.3.

<sup>131</sup> See Statistisches Bundesamt 2022b, Table 3.3.

situations where home-based or semi-residential care is not possible or sufficient for a temporary period, such as when the caregiver goes on holiday. The aim is to provide respite for family carers and give stability to home-based care arrangements. However, the potential scope of the service could be widened far beyond this by focusing more intensively on the preventative and rehabilitative measures that could be implemented during the stay at the short-term care facility.<sup>132</sup> This might make it possible to delay or prevent the person from entering fully residential care permanently.<sup>133</sup>

#### 3.2.1.8 Live-in care (24-hour care)<sup>134</sup>

24-hour care is not offered as a standard service under the long-term care insurance scheme. However, when those in need of long-term care want to stay in their own home despite their growing need for support, family carers often say ‘that there are no appropriate options available for comprehensive and fundable care that meets their needs’.<sup>135</sup> In such situations, many people in need of long-term care and their family members feel that ‘the only chance of maintaining the desired way of life it to have an Eastern European carer living in the household to attend to the person’s basic and everyday care needs’.<sup>136</sup> This is financed by private means and/or through payment of the care allowance.

This 24-hour care, which is mainly provided by women,<sup>137</sup> is controversial. In many cases, it breaches the provisions of employment law. To keep the costs as low as possible, the carers often do not get paid the statutory minimum wage.<sup>138</sup> Even when family members do endeavour to ensure that the employment is legal (or as legal as possible), agencies are increasingly offering the self-employed model. However, in the majority of cases, this is actually ‘false self-employment’. The employment of what are mainly Eastern European care workers also raises ethical concerns, among other reasons, because the process of taking them away from their home countries can lead to gaps in care provision there (known as the ‘care drain’).<sup>139</sup>

The Bundesverband für häusliche Betreuung und Pflege (Federal Association for Home Care and Nursing) estimates that there are around 300,000 households receiving care from Eastern European care workers.<sup>140</sup> Given that the average staff turnaround time is six to twelve weeks, the total number of care workers involved is believed to be in the region of 700,000.<sup>141</sup> Without Eastern European care workers, home-based care would collapse in many households. In such an event, demand for mobile care and support services, as well as residential facilities, would increase by around a third. As things currently stand, it would not be possible to meet this demand.<sup>142</sup> Therefore, there is an urgent need for action here.

132 In a survey, 77 per cent of participants said they needed more help with short-term care (see Büscher et al. 2022, page 7 and Sozialverband VdK 2022).

133 See Kutzner and Bäker 2021, page 132; for more detailed information, see Grabfelder et al. 2022, page 91 ff.

134 The Advisory Board deliberately avoids using the term ‘24-hour care’. The duties of carers are varied and encompass household tasks as well as care. They include preparing meals and helping the person to eat them, as well as assistance with personal hygiene, getting dressed and undressed, going to the toilet and getting up and going to bed. By contrast, medical care is only allowed to be provided by appropriately trained staff and must not form part of these kinds of home-based care duties.

135 See Herweck and Weg 2022, page 399.

136 See Herweck and Weg 2022, page 399.

137 See Horn et al. 2019.

138 See Oblacewicz and Petö 2022, page 2 ff., for details of the home-based care conditions, employment conditions and the ruling by the Federal Labour Court.

139 For information about 24-hour care, see also Städtler-Mach and Ignatzi 2020.

140 The DAK care report from 2022 also contains further estimates of the number of ‘24-hour care workers’. For instance, there are thought to be more than 100,000 people working in 24-hour care. In 2018, the Hans Böckler Foundation estimated the number to be between 300,000 and 500,000 (see Klie 2022, page 88). According to another source, there are an estimated 850,000 ‘24-hour care workers’ from Eastern Europe (see Haumann 2022, page 88 f.).

141 See Bundesverband für häusliche Betreuung und Pflege e. V. (VHBP) 2022.

142 See Herweck and Weg 2022, page 400.



In 2021, the Federal Labour Court made a landmark ruling that on-call periods must also be paid according to the German minimum wage. This effectively spells the end for conventional practice. Therefore, one of the top political priorities is finding a solution to the situation faced by those in need of long-term care who are affected, along with their family members and those employed in 24-hour care.

#### 3.2.1.9 Assisted living group homes

Over recent years, a plethora of ‘new’ living and care options have developed for people in need of long-term care that offer a halfway house between a ‘care home and living at home’. This expansion has been strategically promoted by legislation on long-term care and care homes, and by corresponding funding (such as the group home allowance). In 2016, there were believed to be just over 3,100 assisted living group homes.<sup>143</sup> This is an upward trend.<sup>144</sup>

The innovative part is that these care approaches combine community living with care services that are mainly provided directly in the home. While allowing for maximum diversity, they are intended to provide as much autonomy and individuality as possible in conjunction with the highest levels of security and social integration for users. In light of this combination, they effectively resemble mini care homes and their establishment must be decided on a case-by-case basis in accordance with the provisions on care homes that apply at the federal state level. In any event,

the underlying contractual agreements between companies and users must conform to the consumer protection provisions of the Accommodation and Care Contract Act if the living space is provided in conjunction with the delivery of care or support services.

According to a survey among users of these living options and their family members, the latter feel as though the new living options ease the burden of caring for their relatives who are in need of long-term care.<sup>145</sup> Within this context, the family members said that the burden was lighter in terms of providing care and support and having to be available around the clock. At the same time, family members stated that they could envisage greater leeway for their own personal involvement and engagement due to the design of and legal arrangements covering the assisted living group homes. Providers and users of assisted living group homes need to be well informed so that they know what options are available—both legally and in practice—for jointly organising the communal living arrangements and so that they understand the limits of ensuring appropriate care in this kind of setting. By allowing those in need of long-term care to be looked after in an assisted living group, expertly managed assisted living group homes that receive input from committed relatives can offer a viable form of care for the future. High-quality assisted living group homes that are integrated within the local neighbourhood also have the potential to be an effective means of supporting family carers.

143 See Klie et al. 2017, page 95.

Due to the lack of official statistics, the number of assisted living group homes can only be estimated. However, it can be assumed that the current number is substantially higher, as a positive trend in favour of them seems to be developing. For instance, based on its analysis of DAK policyholders with long-term care needs, the DAK care report from 2022 states that the number living in assisted living group homes increased from 240 in 2017 to 2270 in 2020 (see Klie 2022, page 85).

144 See Rothgang, Müller and Preuß 2020; and Klie 2022, page 85. See also Klie et al. 2017, page 95.

145 See Kremer-Preiß, Maetzel and Huschik 2021, page 124.



#### 3.2.1.10 Hospice and palliative care

The end-of-life stage often constitutes a crisis situation for the seriously ill and dying, and their family members and loved ones. Clarity concerning the available care options plays a significant role in work-care reconciliation. The process of treating, caring for and supporting people with limited life expectancy due to an incurable and extremely advanced illness is called palliative care. Palliative and hospice care and support are aimed at ‘increasing the quality of the remaining life with the aid of medical treatment, care and psychosocial measures—in whatever environment the people concerned want’<sup>146</sup>—not only for those who are ill but also for their family members. It involves relieving pain and symptoms as well as avoiding burdensome medical treatment and unnecessary hospital stays during the end-of-life stage. There are different forms of palliative care depending on requirements:

- General outpatient palliative care (AAPV): in the case of AAPV, the palliative patients receive care from general practitioners, specialist doctors and mobile care services with appropriately qualified staff.
- Specialised outpatient palliative care (SAPV): SAPV may be provided at home, in a care home, at housing provided by the social integration support service or at a residential hospice if a complex set of symptoms arises in the patient.

- Mobile hospice services: these give advice to dying people and their family members and arrange for trained volunteers to deliver end-of-life care at home, at a care home, at housing provided by the social integration support service or at a hospital, thereby relieving the burden on family members.<sup>147</sup>
- Residential hospices: if at-home care can no longer be ensured but hospital treatment is not necessary or desired, people who are dying can spend the last part of their life in a residential hospice (Section 39a SGB V). In Germany, there are approximately 250 hospices for adults and 19 for children and adolescents.<sup>148</sup>
- Palliative care in hospitals/palliative care units

In Germany, entitlement to hospice and palliative care—both mobile and residential—is enshrined in law.<sup>149</sup> This means that everyone is entitled to these services regardless of whether they are living at home, in a care facility or in housing provided by the social integration support service.<sup>150</sup>

#### 3.2.1.11 Supplementary support from municipalities

To ensure the stability of home-based care situations, it is vital that the long-term care of family members can be combined with support services within their locality and social environment that meet their needs. In addition to the

146 See also—for example—the information on palliative medicine from the German Association for Palliative Medicine, which is available online at: <https://www.dgpalliativmedizin.de/> or the guide published by Deutsche Alzheimer Gesellschaft e.V.: Fortgeschrittene Demenz und Lebensende – Ein Ratgeber für Angehörige über die Ziele und Möglichkeiten der Palliativ- und Hospizversorgung (Advanced dementia and end of life—A guide for family members explaining the aims and possibilities of palliative and hospice care); the German Hospice and Palliative Care Association ([www.dhpv.de](http://www.dhpv.de)); the Charter for the Care of the Critically Ill and the Dying in Germany (<https://www.charta-zur-betreuung-sterbender.de/>).

147 A list of addresses can be found at: [www.wegweiser-hospiz-palliativmedizin.de](http://www.wegweiser-hospiz-palliativmedizin.de).

148 Attention should be drawn to the fact that children’s hospices serve a different function from adult hospices. Children and adolescents with a life-shortening illness are entitled to receive care in a children’s hospice from the point of diagnosis. Further information is available on the website of the Deutscher Kinderhospizverein (<https://www.deutscher-kinderhospizverein.de/>) or the Bundesverband Kinderhospiz e.V. (<https://www.bundesverband-kinderhospiz.de/>), both of which are associations for children’s hospices.

149 According to Sections 39a, 27, 37, 37b and 87(1b) SGB V.

150 See also the Charter for the Care of the Critically Ill and the Dying in Germany, Koordinierungsstelle für Hospiz- und Palliativversorgung in Deutschland (Centre for the coordination of hospice and palliative care in Germany).

various services provided by the long-term care insurance scheme, municipal public services may be suitable, particularly assistance for the elderly. It is the task of the municipalities to organise the public services and implement an old-age policy that is in keeping with the times.<sup>151</sup> Assistance for the elderly according to Section 71 of Book Twelve of the Social Code (SGB XII) is aimed at enabling older people to participate in society.

In light of this, proper assistance for the elderly takes account of the risks of isolation and poverty in old age even before the potential need for long-term care arises. Assistance for the elderly from municipalities encompasses everything from advice infrastructures, meeting places, mobility aids and housing options tailored to the needs of the elderly right through to barrier-free access in public spaces.

The municipalities have a coordinating and managing role to play within this context.<sup>152</sup> Plazek and Schnitger (2016) identify four areas in this regard: establishing and supporting effective networking bodies, actively making use of the organisational possibilities of the municipal administration, advice for investors and providers from municipalities, and the expansion of assistance services for family carers.<sup>153</sup>

Integrated social planning by municipalities that relies on the participation of all groups and stakeholders moves away from compartmentalised thinking and action, emphasising instead the links between departments and sectors. It helps

people identify more strongly with their locality and boosts the development and fostering of 'caring communities'. This, in turn, is crucial for the participation and integration of people with and without long-term care needs. Solid municipal advice and support infrastructures that are interlinked within the community are not necessarily directly related to care. However, they are vital to tackling this area and enabling successful work-care reconciliation.

## 3.3 Recommended actions for the further development of care models and infrastructures

This closing subsection presents some recommended actions for the further development of care models and infrastructures. The primary concerns are, firstly, the issue of mixed care arrangements (Section 3.3.1) for enabling better work-care reconciliation and, secondly, the development of municipal infrastructure (Section 3.3.2). This will be followed by a summary of the specific recommended actions for improving the support infrastructure for family carers who work (Section 3.3.3 to Section 3.3.5).

151 See Bundesministerium für Familie, Senioren, Frauen und Jugend 2016, page 21.

152 However, according to Hellermann (2022), the districts (including both the urban and the rural districts as the providers of assistance for the elderly)—at the very least—are responsible for ensuring a minimum level of services according to Section 71 SGB XII. They can either make these available themselves or can provide them in collaboration with other public or private stakeholders. This goes beyond the functions of coordination and management.

153 See Plazek and Schnitger 2016, page 9 f.

### 3.3.1 The significance of mixed care arrangements for work-care reconciliation

The increasing employment rate of both genders calls for a more diverse mix of long-term care. This depends on expansion of the range of professional care services and, within this context, particularly on the ability to combine respite, short-term, day and night care services in as flexible a way as possible. The aim should be to support working family carers—in a way that takes account of their preferences, resources and limitations—by giving them equal access to a rich juxtaposition of options that are geared towards their needs and draw on individuals, families, society, businesses and the government. This will enable true freedom of choice for both family carers and those in need of long-term care.

Expanding the care infrastructure and encouraging people to actually make use of it will also increase the quality of long-term care.<sup>154</sup> If women are to be financially independent throughout their lives and it is to be made easier for men to take on care responsibilities, people of all genders will need sufficient time to earn a living, even in the context of the care situation. Although there is an urgent need to improve the financial security of family carers, this alone will not be sufficient to meet the increasing demand for long-term care. Rather, this can only be achieved by expanding the professional care infrastructure in parallel.

#### The Advisory Board recommends:

- Every caregiver household must have prompt and unbureaucratic access to forms of assistance and structures that are tailored to requirements, coordinated with each other and publicly available. The expansion of these across the whole country should be vigorously pursued. For working family carers, mixed care arrangements must be possible throughout the entire duration of care; only then can the reconciliation of work and care be ensured.

### 3.3.2 Flexible organisation of mixed care arrangements

Many actions are required to enable those in need of long-term care to lead a life that is as independent and self-determined as possible in spite of their need for assistance. If the burden is to be eased for family carers, a differentiated view of care must be adopted because assisting with personal hygiene, nutrition and mobility calls for a different skill set and manner compared to general support, supervision or facilitating social interaction or to the process of organising long-term care or the meeting of household needs.<sup>155</sup>

If individually tailored, low-threshold services geared towards people's needs could be organised promptly in a non-bureaucratic way while ensuring that people actually took advantage of them, it would make it easier for family carers to retain the long-term care responsibility for those in their care.

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<sup>154</sup> See Scheele 2017, page 52.

<sup>155</sup> When the amount of time spent by the primary caregiver is broken down according to type of activity, it becomes clear that general support (16.5 hours per week) and housekeeping (13 hours per week) are extremely time-consuming. Assistance with personal hygiene (7.7 hours per week), mobility (5.6 hours per week) and nutrition (5.2 hours per week) take up considerably less time. Organising care (2.0 hours per week) and doctor's appointments (1.4 hours per week) require the least amount of time and—in contrast to the other activities—this does not increase as the care grade gets higher (see Hielscher, Kirchen-Peters and Nock 2017, page 56).

In addition to making the process of using the services more flexible, the flexibility of care infrastructures will also have to be increased. Possible combinations involving day and night care, for example, should be investigated to accommodate the needs of those requiring long-term care and their family members, particularly in terms of the challenges of reconciling care with the specifics of everyday working life (such as shift and weekend work and business trips). The opportunities for interlinking the various services should also be exploited.

**The Advisory Board recommends:**

- Work-care reconciliation should be incorporated as (another) key concept of long-term care insurance.
- Professional and family care need to be better interlinked, and it must be possible to combine them as flexibly as possible. This includes—for example—respite, short-term, day and night care services.

#### 3.3.3 Proactive outreach advice

Alongside their work and long-term care commitments, family carers only have limited time available. For this reason, they repeatedly say they would like ‘advice from a single source’. They need a permanent local contact person with the necessary expertise, who knows what services are regionally available and can continuously provide them with tailored support throughout the long-term care process—as and when necessary and in the event of changes in the framework conditions.

**The Advisory Board recommends:**

- Case managers must be on hand—where necessary—to actively reach out and offer neutral advice in parallel with the long-term care process. While taking account of the respective needs, they should provide information and advice about appropriate support services and moderate the long-term care process. Family carers and those in need of long-term care should be informed in good time of the available services as soon as the need for long-term care arises.
- Outreach advice on home-based care must not only address the needs of those requiring long-term care but also the medium and long-term consequences for family carers (who work), as well as their health, careers and social security arrangements. Only then can those involved take informed decisions on the use of cash and non-cash benefits.

#### 3.3.4 Live-in care

Many people in need of long-term care want to be cared for at home and working family members frequently decide to accommodate these wishes. A large number of Eastern European care workers are currently playing a key role in ensuring that this can happen. This leads to major challenges for all the parties involved—family members, those in need of long-term care and care workers. In many cases, this employment also breaches the provisions of employment law.

**The Advisory Board recommends:**

- A legally secure foundation must be rapidly implemented for home-based care that meets the needs of caregivers, those requiring long-term care and care workers.

### 3.3.5 Family members of younger people in need of long-term care

Germany is home to a large number of people under the age of 65 who need long-term care. Accidents and illnesses (such as dementia or the possible effects of a COVID-19 infection) do not just affect older people but also those who are in the middle of their career. This has far-reaching consequences for those directly affected along with the entire family.

As a result, working family members of this particular group are exposed to extreme stress and, in turn, major health risks. In most cases, they do not have the time and space to attend to other family members, such as children of school age, or even to their own needs.

#### **The Advisory Board recommends:**

- Low-threshold services are urgently required for younger sick people. Assistance services—similar to those for people with disabilities—could enable them to participate actively in life in accordance with their capabilities. Services that give the day structure are another possibility, such as setting up a support group for younger people in need of long-term care.

# 4

## Children and adolescents in need of long-term care

This part of the report is dedicated to the particular situation faced by family members who care for children, adolescents and young adults in need of long-term care. There are approximately 161,000 of these within the ‘15 and under’ age bracket alone. They often get overlooked because there are relatively few of them compared to the number of families with older or elderly members receiving care (see Section 1). As this group starts receiving care within the structure of the family while they are still in their childhood, we will refer to them below as ‘children in need of long-term care’ regardless of their actual age.

### 4.1 Problem and objective

Children are usually born at a stage of life when the parents are either already working or are in vocational training. This stage is a particularly vulnerable one from the perspective of reconciling family-based care with work responsibilities. Parents are rarely prepared for the arrival of a child that will constantly need their care, assis-

tance and support—often for their whole life. If organ malformations or the visible effects of genetic mutations become apparent before or (immediately) after birth or if the child develops a serious illness or has an accident, the parents’ entire plan for a certain lifestyle is shattered as of that point. These kinds of circumstances are usually accompanied by an extensive need for support on the part of the affected child.

Virtually all children in need of long-term care receive this care exclusively in the home, usually from their mothers.<sup>156</sup> Given the changes that are taking place in Germany with regard to childcare and the fact that more men are now willing to provide care within the family,<sup>157</sup> the care of sick children and children with chronic illnesses, children in need of long-term care and children with disabilities is also an equality issue—particularly from the perspective of work-care reconciliation. Firstly, this is a question of ensuring that the amount of working time and caregiving time is split equally between the parents and, secondly, that they are better able to reconcile their work commitments with the demands of the care situation.

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<sup>156</sup> See Kofahl and Lüdecke 2014, pages 8 and 18; the proportion of men surveyed was significantly smaller than the proportion of women (mothers n=1183, fathers n=257).

<sup>157</sup> See Bundesministerium für Familie, Senioren, Frauen und Jugend 2020, page 25.

A child's development is a dynamic process that is not predictable in every respect. There is no blueprint for individual development or for knowing how much support and associated assistance the child will need. For this reason, parents of children requiring long-term care are exposed to major uncertainties and worries about the future. Challenges already exist for families whose children do not need long-term care and these are exacerbated for families with children who do. This is particularly the case when multiple challenges are encountered at once. For example, single parents and parents with more than three children already face particular challenges when it comes to reconciling work and family life regardless of the extent to which their family members are in need of long-term care. Overall, the care situation often leads to career gaps or to parents giving up work long-term and it is not uncommon for this to result in poverty in old age, particularly among women. In addition, families with children in need of long-term care are at a much higher risk of poverty than the average family.<sup>158</sup> For fathers, particularly those in conventional family set-ups (whereby the fathers undertake paid work to a greater extent than the mothers), their 'breadwinner role' quite often becomes set in stone in order to cover the additional costs incurred due to the need for long-term care (rent, living space modifications, vehicle conversions, and so on). Having to work overtime on a regular basis and the need to focus on their career alienate them from the child requiring long-term care and from other family members, as well as the everyday reality of care, placing the partnership under strain and sometimes even leading to separation.<sup>159</sup>

Overall, looking after children who need long-term care—often for life—creates a particular challenge in terms of work-care reconciliation.

Families who provide long-term care to children or adolescents live in very different situations from one another. As a result, the stresses placed on them and their calls for advice, assistance and support are equally diverse. The one thing they do have in common is that any stress suffered by the parents also affects the child's well-being at the same time. Enabling the participation of both parts of the family—the child in need of long-term care and the other members—is one of the most important objectives of all supportive measures. This also includes work-care reconciliation. This should be realised in such a way that children can be cared for equally by their fathers and mothers whatever the nature of the relationships involved and that solidarity can be found in the context of caring family units (where these exist). At the same time, it must be ensured that the families do not end up worrying about their livelihood if paid employment is not possible (either at all or for certain periods). This includes being able to resume careers that have been put on hold, ensuring sufficient financial security to cover care periods and having supplementary measures in place to lessen the risk of poverty in old age.

However, when implementing the measures, employers also need the relevant support so that they can respond appropriately to the flexibility requirements of employees with children or adolescents who need long-term care.

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158 See Kofahl and Lüdecke 2014, page 10.

159 See Latteck et al. 2020.



## 4.2 Current situation: the caregivers and their children or adolescents requiring long-term care

This section takes a closer look at children or adolescents in need of long-term care and their caregivers. Descriptive and empirical data concerning the matter will be presented to provide an overview of their situation and their needs.

### 4.2.1 Caregivers: facts and figures

Virtually all children with a need for long-term care receive that care at home.<sup>160</sup> It is usually provided by mothers (80 per cent), with 17 per cent sharing the care responsibilities with their partners.<sup>161</sup> Just under 14 per cent are single parents or do not have a long-term partner.<sup>162</sup> Parents remain the primary caregivers right into mid-adolescence and adulthood (30 years old).<sup>163</sup> When the children reach legal age, other care arrangements (such as services providing support for general everyday tasks) become more important. In the case of those who do not specify the primary caregiver, the care is provided in various types of accommodation for people with disabilities.<sup>164</sup>

Data from the Federal Statistical Office also highlights the central caregiving role of parents; according to this data, 99.83 per cent of children

and adolescents in need of care receive this care at home up until the age of 15. Only a small proportion of the affected children and adolescents (225 or 0.17 per cent) receive care in a fully residential setting provided by the social integration support service.<sup>165</sup> The care infrastructure as a whole and the facilities, in particular, are not very well suited to the needs and interests of young people requiring long-term care.<sup>166</sup> For instance, the care staff (regardless of whether the care setting is non-residential or residential) are not sufficiently specialised in the professional care of young people, with the care frequently being delivered by hospital or elderly care nurses.<sup>167</sup> This makes it much more difficult for families to find and make use of institutional respite care services. Up until the age of 19, it is almost exclusively other loved ones and family members that step in to cover any periods when the parents have to take a break from providing care.<sup>168</sup> As a result of taking on long-term care responsibilities, many people—particularly women—reduce their work commitments or give up their job altogether. For instance, 26.2 per cent of women (around one in four) report that they stopped working following the birth of a child in need of long-term care (compared to 9 per cent of the men surveyed) so that they could provide this care. One in two women with a child requiring long-term care (50.6 per cent) have significantly reduced the extent of their work (compared to 21.8 per cent of men)—while 62.7 per cent of the men surveyed said they had made no change at all.<sup>169</sup> Furthermore, mothers of children in need of long-term care often do jobs for which they are overqualified and that are poorly paid.<sup>170</sup>

160 See Kofahl et al. 2017, page 26; Engstler 2018, page 8; Statistisches Bundesamt 2020, page 21.

161 See Kofahl and Lüdecke 2014, page 18 f. To date, no robust empirical findings have been produced to show how caregiving labour is divided in relationships where there are two mothers or two fathers.

162 See Kofahl and Nickel 2022, page 8.

163 See Rothgang et al. 2017, page 214.

164 See Rothgang et al. 2017, page 214.

165 See Statistisches Bundesamt 2020, page 21.

166 See Engstler 2018, page 8.

167 See Rothgang et al., page 169; Kofahl et al. 2017, page 32. It remains to be seen whether and how the practical experience of staff will change with the implementation of the Care Professions Reform Act (PfBRefG).

168 See Rothgang et al. 2017, page 214.

169 See Kofahl and Lüdecke 2014, page 19; the proportion of men surveyed was significantly smaller than the proportion of women (mothers n=1,183, fathers n=257).

170 See Meier-Gräwe, Buck and Kriege-Steffen 2014, page 20.

A recent online survey that was conducted nationally by the University Medical Center Hamburg-Eppendorf sheds light on the situation faced by caregiving parents with a child in need of long-term care who want to reconcile their work and care commitments.<sup>171</sup> In the survey, the majority of caregiving parents (65.2 per cent) say that they sometimes experience problems in their everyday work life that make their care responsibilities more difficult. A good 14 per cent report having such problems all of the time. Specific work-related stresses that impede care include: a high workload (50.6 per cent say they agree), overtime (25.9 per cent say they agree), a long commute to work (21.8 per cent say they agree), no opportunity to plan a holiday at short notice (21 per cent say they agree), inflexible working time arrangements (20.4 per cent say they agree) and frequent evening and weekend scheduling (14.3 per cent say they agree).

The following support services are perceived as being (very) helpful: short-term absence from work (Section 2 PflegeZG) with the option of applying for carer's grant (Section 44a(3) SGB XI), release from work under the PflegeZG and FPfZG, respite and short-term care (Sections 39 and 42 SGB XI), care allowance or non-cash care benefits (Sections 37 and 36 SGB XI) and the support allowance for home-based care (Section 45b SGB XI).<sup>172</sup>

The caregiving parents were also asked about their everyday worries. Approximately 60 per cent of the parents worry about their own economic situation and their professional careers. More than 40 per cent worry about their jobs. The biggest worry expressed by more than 90 per cent of parents concerned their own health and ensuring that the care needs of their child were met. As regards their own pension provision, 81.4 per cent

of the parents surveyed report being somewhat or very worried.

### 4.2.2 Those in need of long-term care: epidemiology, states of health and needs

As at the end of 2019, there were a total of 160,953 children and adolescents below the age of 15 in need of long-term care.<sup>173</sup> Thus, children and adolescents below the age of 15 in need of long-term care represent approximately 3.9 per cent of the 4.1 million people in Germany who require long-term care according to SGB XI.<sup>174</sup>

In a study from the year 2016, the young people requiring long-term care were broken down into different age brackets. This breakdown reveals that around 15,000 children required long-term care from birth until the age of four. In the five-to-nine age bracket, the number rises significantly to almost 40,000 children. The number of children requiring long-term care between the ages of ten and 14 stood at more than 40,000. Boys are much more often dependent on long-term care than girls.<sup>175</sup> The proportion of boys requiring long-term care is 58 per cent compared to 42 per cent of girls.<sup>176</sup>

Of the children who had been assigned a care grade, just under half had received a grade of 2 or 3, while 49 per cent had been allocated a grade of 4 or 5. 87 per cent of the (studied) children had a recognised disability according to Book Nine of the Social Code (SGB IX). Where the affected children are entitled to benefits within the meaning of SGB XI, these are taken as cash benefits in 78 per cent of cases. Only 3 per cent relied on non-cash benefits exclusively and 19 per

171 See Kofahl and Nickel 2022, page 4 ff.

172 See Kofahl and Nickel 2022, page 20 ff. This national online survey was conducted during the period from 23 August to 6 October 2021. It was aimed at parents who look after a child with long-term care needs within their household. A total of n=1,070 people completed the survey.

173 See Statistisches Bundesamt 2020, page 21.

174 See Statistisches Bundesamt 2020, page 21, in-house calculation.

175 See Engstler 2018, page 9; Rothgang et al. 2017, page 171 f.

176 See Kofahl and Nickel 2022, page 9.

cent on a combination of non-cash and cash benefits.<sup>177</sup>

In the majority of cases, the need for long-term care arises in early childhood (between the ages of zero and four or between the ages of five and nine).<sup>178</sup> The result is that the children and adolescents in need of long-term care generally have to be cared for and supported for their whole life.

#### 4.2.2.1 Reasons behind the need for long-term care: What are the health problems and conditions that affect children and adolescents requiring long-term care?

The need for long-term care does not always exist from birth. Cerebral impairments—which include mental impairments, disorders of the motor system and sensory impairments (such as reduced perceptual sensitivity, hearing or vision; learning disabilities and attention deficit disorders)—and many genetic mutations and rare illnesses often only appear or are only recognised during the child’s development. Furthermore, accidents can cause permanent damage, and mental changes may become increasingly relevant in everyday life. In addition to this, advanced illnesses that are often incurable, such as cancer and hereditary diseases, can necessitate challenging care measures that require a lot of time, energy, money and expertise. The causes of the most common illnesses in children and adolescents with long-term care needs are congenital neurological diseases and malformations, multiple disabilities, metabolic disorders, carcinoma formation, chromosome aberrations and mental disorders. Within this context, children and adolescents with behavioural and mental developmental disorders make up the majority of those assigned a care grade of 1.<sup>179</sup> Congenital malformations, deformities and the increasing number of cancers account for a significant proportion of those in the care

grade 2 bracket. In the care grade 3 bracket, cancers—along with nervous system disorders—make up the bulk of the problems. During late adolescence, there is a considerably higher rate of developmental disorders and intellectual disabilities.<sup>180</sup>

#### 4.2.2.2 The needs of children or adolescents

Families commit considerable amounts of time, physical and mental energy, and financial resources to the long-term care of their children.<sup>181</sup> Among other things, parents assist their children with personal hygiene, nutrition and mobility.<sup>182</sup> In addition to these aspects, other time-consuming measures are required to facilitate social participation and recreational activities, along with medically required tasks such as the administration of drugs and monitoring of vital signs. As far as young adults are concerned, another element is assistance with housekeeping.<sup>183</sup>

It is often impossible or extremely difficult for the affected children or adolescents to form social relationships and build friendships with their peers because of the stresses and strains associated with their illness. The illness itself or the forms of treatment required tear children away from their social relationships, sometimes even before friendships have had a chance to form.<sup>184</sup> For this reason, leisure activities, hobbies and school excursions often rely on parents, who wish to compensate for the lack of social interaction that children and adolescents typically enjoy. The first effect of this is that the children form a particularly strong emotional bond with their parents. Secondly, there are consequences for the parents in terms of their careers because it means, for example, that they have very little time for professional development activities or business trips. In this regard, the care situation can contribute to career discrimination, even if only indirectly.

177 See Kofahl and Nickel 2022, page 10.

178 See Rothgang et al. 2017, page 180 f.

179 See Rothgang et al. 2017, page 185.

180 See Engstler 2018, page 11.

181 See Kofahl et al. 2017, page 32.

182 See Rothgang et al. 2017, page 194.

183 See Kofahl et al. 2017, pages 28–32.

184 See Kofahl et al. 2017, page 31.

##### **Case study interview: child diagnosed with 'Down's syndrome and intestinal malformation'**

By the time her son is born in 2008, the mother—a university graduate in her early 40s—has progressed to a middle management position and also does some freelance work. In addition, she volunteers as the manager of an association, has achieved professional recognition and has very good connections. Her life—with a job that provided money and security and was also a vocation—changes dramatically following the diagnosis of Down's syndrome and intestinal malformation.

The first few years are dominated by hospital stays lasting several months at a time because of the organ malformation. She soon also becomes a single parent. And instead of constantly progressing in her career, she loses her livelihood. As a result of the hospital stays, she can no longer pursue her freelance projects, and a work contract linked to a specific project comes to an end; she gradually has to step down from the volunteer roles that are so important for her career. She then has to claim Unemployment Benefit I and, after that, is forced to live off her savings and the money she has set aside for retirement because these resources prevent her from claiming Unemployment Benefit II and because—despite a lot of effort—she cannot get any more contracts or other work. Everyone in her professional circle is aware of the repeated absences she had to take due to her child's illness, and because of this no one will entrust her with management responsibilities any more.

However, she also recognises the risks of hiring an employee with permanent care commitments, particularly for smaller employers, and is urging the government to take action, for example by introducing a benefit to cover the full wage of caregiving parents who are unable to work or a grant to compensate businesses for the reorganisation costs they incur.

The situation becomes particularly precarious when the child—who has been assigned a care grade of 4—has to return to hospital for a prolonged period because even the care allowance the mother is receiving gets taken away without anything to replace it. The mother's health is also detrimentally affected for several years as a result of having to provide long-term care (night care; personal hygiene care with an increased risk of infection), which puts further strain on her career. In this regard, improving medical care for family carers would help with work-care reconciliation.

To enable her professional reintegration, she downgrades her job by working as an administrator/project manager for a former colleague—but only for a significantly reduced number of working hours, because otherwise, the long-term care would not count towards her pension entitlement. The financial situation is extremely stressful. And despite the pension points earned through long-term care, her pension statements show that she is heading directly for poverty in old age. She criticises the way that it has become so difficult for her to earn a living. Yet this is exactly what is needed to ensure her professional stability and allow her to increase the number of hours she works per week (her employment is still project-based). In her view, the system does not take sufficient account of the fact that she is not providing care temporarily but constantly and that this is going to be the case for decades to come. Nor is she able to access the kinds of mutual support networks that other working parents are often able to establish. For a variety of reasons, this is simply not feasible for someone whose child has a mental disability and is heavily dependent on long-term care.

Her everyday life imposes too many burdens on her time. Due to the intestinal malformation she also has to provide care several times during the night. On top of looking after her child with his numerous doctor's and hospital appointments while also working, another burden is the constant bureaucracy, mainly involving the Youth Welfare Office and the long-term care insurance fund. Psychosocial stress represents a further burden: on the one hand, family carers need to be self-assured at work, but, on the

other, they are exposed to structurally determined situations that are often personally humiliating for them. Several of the mother's acquaintances are forced to give up work as a result of having to reconcile these two roles and, in her case, it takes a tremendous amount of effort.

Due to the lack of an institutional inclusion and care policy, she cannot see the concerns of caregiving parents being reasonably represented anywhere. For the purpose of dealing with the bureaucracy and all the unforeseen events, she would find it helpful to have a tax-funded day off once a month. Up until now, she has never claimed the support allowance of 125 euros to cover things like household-related tasks because of the lack of available services and the excessive bureaucracy involved. Payment of this would be helpful for making private support arrangements—such as assistance with the above-average number of household chores created by the care situation—both from the perspective of relieving the burden on her personally and reconciling work and care. The excessive time demands also make it difficult for her to attend her own doctor's appointments, which again has an impact on her professional performance.

The COVID-19 pandemic is both a challenge and an opportunity for her. It is a challenge in the sense that her son requires special protection as a member of a high-risk group, as a result of which she has to isolate with him for more than a year until the vaccine becomes available. But it is also an opportunity because the introduction of work from home improves her participation in professional life in spite of her need to provide home schooling and home therapies simultaneously. The flexible working hours and saved journey time are the main benefits for her. For example, she does a lot of work in the early hours of the morning while her son is still sleeping.

By this point, her son has become a teenager. At the age of one and a half he was able to attend an inclusive nursery—despite frequent bouts of illness—and this worked well. He did not go to his catchment school but they were able to find a primary school close to home with an inclusive approach. Nevertheless, overseeing her son's school career demanded a great deal from her. She explains that it took five to twelve months before her application for 'individual case assistance' was approved and that the shortage of skilled labour is making it increasingly difficult to find someone to provide this kind of assistance. Currently, she is campaigning against the reduction in teaching assistant hours. The child's mental and physical disabilities are severe but he has relatively good speaking abilities and integrates well socially when helped to do so. They were also able to find an inclusive school up until the tenth year of school.

But some tough times lie ahead for the mother. She cannot currently see the next step or any vocational training prospects for her son because of the lack of local opportunities and institutions, even though the son has considerable potential for contributing to society in the context of a social job. Essentially, she feels that the concept of inclusion is barely ever implemented in the working world and that the potential of people with disabilities is curtailed rather than being unlocked. As the child gets older and when the mother eventually dies, the child will have to manage on his own, and the mother is very worried about whether he will be able to lead an independent life because there are simply not enough places within disabled housing.

She never used to hide her private situation from her colleagues (because 'the private sphere is political!') but she is now less open about it because of bad experiences she has had in the past. To begin with, she campaigned strongly on behalf of parents with children in need of long-term care. And she also gave interviews. However, these usually ended with 'expressions of dismay' without any concrete concerns actually being addressed. Since then, strength and commitment have given way to extreme tiredness. And in her eyes, we are not living in a 'meritocracy' because her professional capabilities are not being tapped into and her caregiving work is not truly recognised.

### 4.2.3 The situations faced by affected parents and families

To gain a direct insight into the current needs of families with children in need of long-term care, the Advisory Board organised a hearing with experts on 5 November 2020, during which the people affected and representatives from self-help organisations described their situations. The hearing emphatically confirmed what was already known: parents with children in need of long-term care are under enormous stress due to the pressures of work-care reconciliation.

The problems exist on several levels:

- Fundamentally, society is insufficiently geared towards the inclusion of children with special needs (to cite one of the experts interviewed: ‘behaviourally unique’ children). When the UN Convention on the Rights of Persons with Disabilities was ratified in 2009, it enshrined in law the paradigm shift towards inclusion, but this is still a long way from being fully realised. As a result, many parents feel abandoned and isolated in their situation and often do not receive sufficient support at an institutional level either.
- Before an application can be made for assistance, such as social integration support (according to Section 99 SGB IX or Section 35a SGB VIII), the existence of a specific need must always be proven based on the identification of supposed deficits in the child. This pathologises them by way of a diagnosis, which—in turn—creates a double burden, particularly for children requiring mild forms of support and

their families: it takes up a large amount of time while also creating a high level of mental stress due to the often lengthy diagnostic process and the constant emphasis on deficits. These high levels of stress also have negative consequences for the employment or earning capacity of the parents and, in turn, their ability to reconcile work and care.<sup>185</sup>

- In practice, nurseries and schools, along with sport, leisure and youth work services, are often insufficiently geared towards the specific needs of the affected children and their families.
- Similarly, families encounter complex, formalised structures within various other institutions and services whose procedures are shaped by bureaucracy rather than with the child or family in mind, meaning that they fail to address the diverse forms of requirements.
- Up until now, any necessary assistance—whether staffing-related or of a technical, medical (medicinal) or an educational nature—has not been conceived of as the automatic right of all children. Instead, it is predicated upon deficits existing in children and has to be applied for as an additional special measure. Approval is usually based on a necessary diagnosis and the identification of deviations from what is supposedly normal. In cases where no disorder or aberration can be identified according to the stipulated standards, no (additional) assistance is provided.
- Inclusive structures for children requiring long-term care need to be expanded in such a way as to enable parents to achieve work-care reconciliation.

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185 See Rohrmann and Weinbach 2017, pages 10 and 21.



- Parents of children in need of long-term care usually also find it more difficult to fulfil their duty of care towards the sick child’s siblings, who are generally healthy. Not only do these siblings end up having to take a back seat to the child in need of long-term care but, in many cases, they themselves are among the family members who assist with the care. As a result, they suffer gaps and deficits in their own schooling, career development and recreational activities.<sup>186</sup>

Families with children in need of long-term care are often forced to make fundamental decisions at an early stage: due to pragmatic considerations, they often have to steer things in ways that have a far-reaching impact on how they and their children live. As a result, many families find themselves in a dilemma because they are forced to choose the only possible course of action, which is frequently out of step with what they actually want. For instance, early on in their children’s lives, they often have to choose between special services plus special institutions (‘abnormalisation’) and integration into standard structures (‘normalisation’).<sup>187</sup>

As regards work-care reconciliation, many parents find themselves back in the conventional mould when it comes to dividing the care and paid work between them, with the father acting as the principal earner and the mother as the primary caregiver. This applies regardless of whatever arrangements they may have had before. It has nothing to do with their original ideas about caregiving and paid work, and often leads to a situation where it is not possible for both parents to earn a living equally—including making adequate provision for old age. Instead, additional financial pressure frequently ensues, creating huge pressure to go out and earn, usually for fathers.

Only 15.2 per cent of the primary caregivers surveyed—mainly women—are in full-time employment, while just under 60 per cent are employed on a part-time basis. A quarter are marginally employed or not employed at all.<sup>188</sup> Moreover, the process of dividing up the care duties increases the amount of organisation and level of communication required. The experts thereby confirmed the data presented above by stressing that the equal sharing of care and work commitments seemed virtually impossible to them and that, in their view, the more unlikely this becomes as the severity of the children’s need for care increases. In addition, there is also a concern that fathers, who likewise often have to miss work because of the numerous appointments and obligations connected with their children’s care situations, will suffer from poor career prospects.

In addition to weighing up the individual circumstances of the respective family, the following factors must also be considered to enable successful work-care reconciliation and a decision as to whether—and to what extent—both parents are able to be involved in providing care:

1. **Division of working hours:** Are both parents in paid work and to what extent? The answer to this question determines who will opt to take on the lion’s share of the care duties.
2. **Division of income:** Who earns what within the family? Within partnerships, care-related demands on time (such as regular treatment or diagnostic appointments) are assessed on the basis of any associated loss of income that comes from dropping down to part-time hours or taking a career break, and decisions about how to divide up the work are taken accordingly.

186 See Metzging 2022, page 190 ff.

187 For information about this, see the contribution to the discussion made by Rensinghoff 2009, page 132 ff., and—more fundamentally—also Buchner, Pfahl and Traue 2015.

188 See Kofahl and Nickel 2022, page 14. Within the surveyed sample, the vast majority of respondents (93 per cent) identified as women.



- 3. Journey to and from work:** For the families concerned, there is also the issue of who regularly has to travel to and from the workplace and how long the journey takes. For this reason, a well developed local public transport system at the infrastructural level is extremely relevant to the matter of work-care reconciliation in the context of home-based care.
- 4. Urban-rural disparity:** Sometimes, there are very considerable differences between rural and urban regions in terms of the infrastructure and transport routes. These need to be counteracted by implementing appropriate and individually adaptable measures.
- 5. Working conditions:** Is work from home/ remote work/telework possible? Are flexible working hours possible for employees? Does the parent's workplace have good stand-in arrangements? Can the parent take the child to work—at least by way of an exception?

In addition, issues arise in relation to the sharing of responsibilities. This becomes particularly relevant, for example, if parents are divorced and other family members are to be involved in looking after the child in need of long-term care. If the child's need for long-term care leads to the parents separating, the challenges of organising the separated parents' daily care routine become extraordinarily complex, including with regard to work-care reconciliation. An equal division of tasks between the parents following separation and divorce—as practised in the joint custody

model, for example—seems to be virtually impossible under the currently prevailing conditions in the event of a child needing long-term care. In this context, the higher the number of (underage) children needing to be looked after, the lower the chance of tasks being distributed approximately equally.

As things currently stand, the scope for making use of legally enshrined forms of support is usually not flexible enough to involve close relatives in the long-term care. In this regard, the report (Section 2.3) makes suggestions for improvement with its recommended model for family caregiver leave and family caregiver allowance, which are also intended to have a positive impact on the particular situation faced by families with children in need of long-term care. Nevertheless, the Advisory Board is aware that the 36-month time limit for these recommendations can only ever provide temporary relief for this group specifically.

Last but not least, the availability of institutions with inclusive child day care and inclusive schools (with or without full-day care) must also be considered in order to estimate the chances of the affected parents being able to reconcile care and work (see Section 3). Although progress has been made over recent years as regards efforts to ensure the inclusion of children of nursery and primary school age, there is a lack of inclusive secondary school options for adolescents and young adults in need of long-term care that would continue to allow the parents to remain in their jobs.

**Case report: young child with a brain tumour**

We live in Berlin. The two of us were in our mid-thirties, not married and were looking forward to the arrival of our second child. Our 'eldest' had started wearing glasses at the age of two and a half because of his slight 'squint'. He then developed balance problems, often held onto us while walking, and started complaining about headaches and wanting to be carried a lot. Given that his sibling had just come into the world, we initially interpreted his symptoms as 'big brotheritis'. However, it did seem strange to us when he started throwing up at nursery and had to be regularly picked up after breakfast. The paediatrician arranged for his intraocular pressure to be measured. The result triggered an immediate series of actions, with an emergency MRI scan finally providing the diagnosis. It was a medulloblastoma, which is a malignant tumour of the cerebellum. This type of cancer tends to occur in early childhood and is slightly more prevalent in boys. The tumour, roughly the size of a ping-pong ball, was the cause of the pain, nausea and balance problems he had been experiencing over the previous six months. Dad and child 1 were taken by emergency ambulance to the hospital for an immediate emergency operation. Mum and baby were merely informed via a brief telephone call.

As of that moment, our life was turned completely upside down. The post-natal exercise course and other parent-child activities that had taken place with child 1 had to be cancelled. These were replaced by operations, hospital stays and chemotherapy that involved alternating between periods at home and stays at the children's oncology ward. The treatment was expected to last for twelve months. All our plans for parental leave went out the window. Being at home meant attending regular appointments at the day unit—taxi there and back—and then staying at home for the rest of the time and avoiding contact with others as much as possible because chemo weakens the immune system considerably. That is also the reason why some interim stays at the paediatric clinic proved necessary—because some infection or another had caused a fever. The hospital phases meant mum and baby spending all day at the ward from 8:00 am until 4:30 pm; dad then took over after work and stayed overnight from 4:30 pm until 8:00 am to provide the majority of the necessary care. Rooming-in often involved the two children and one of us parents camping out in a twin room surrounded by beeping drip equipment and instruments, where we slept on extra beds (which the hospital staff called 'maternity beds').

As soon as our baby turned one, we were no longer allowed to take him along to the oncology ward. The risk of infection would have been too high for the patients. In parallel with this, it was now time for mum to return to work after ten months of parental leave and, on top of that, we had to get child 2 acclimatised to day care/nursery.

We have no idea how we would have coped with everything if it had not been for the help of grandpa and grandma and the regular shopping trips made by our friends... The assistance we received from a care service was helpful—but also burdensome—during the outpatient phases; they arranged some home help for us. Without the parental leave and dad's part-time post, as well as the flexible working time granted by his employer, it would have been impossible to do the rooming-in and be present for the necessary measures during the inpatient phases (operations, treatments). The expert advice and psychological support we received directly on the ward (including the communal cooking and meals organised by volunteers) were also a great help, not least when applying for all kinds of assistance.

One thing is for sure: our relationship as a couple suffered. The parent-child bond with child 2 was significantly affected. Work-care reconciliation only proved possible because our parental leave happened to coincide.

## 4.3 Advice and care infrastructures and benefit entitlements

This subsection describes the current advisory services available to caregiving parents and the care infrastructures, as presented to us by the persons affected and experts invited to the hearing held on 5 November 2020. Based on the current state of the advice and care infrastructures, challenges are identified and illustrated by means of case studies. Furthermore, an overview is provided of the statutory provisions and the benefit entitlements for caregiving parents and their children in need of long-term care.

### 4.3.1 The role of advice

Solid advice infrastructures that are individually tailored to the needs of the families involved in long-term care can make the everyday lives of the families much easier.

The services presented in the box can have an inherently positive impact on work-care reconciliation. However, advice dedicated solely to work-care reconciliation is not usually offered.

#### **Examples of services:**

The long-term care advice centres (long-term care advice according to Section 7a SGB XI) regard themselves as a source of support for family carers who are seeking relief. As such, they also act as a point of contact for families with children in need of long-term care, even though they generally focus on old-age care. They can provide information about the costs of long-term care and the services/benefits offered by the long-term care insurance scheme. They assist with benefit applications, communication with the Health Insurance Medical Service (MD) and, where applicable, help to find a suitable care service.

Telephone advice is available nationally for family carers via the care hotline of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

Even before their children with long-term care needs are born, the parents can access support via expert or—in the majority of cases—self-help portals, such as the Kindernetzwerk (children's network), Bundesverband für körper- und mehrfachbehinderte Menschen (Federal Association for People with Physical and Multiple Disabilities—bvkm), the Bundesvereinigung Lebenshilfe (a self-help organisation for people with intellectual disabilities) and pregnancy counselling agencies. In light of this, many of the self-help groups have now also put psychosocial support for the siblings of children with long-term care needs on their agendas.

During early childhood, the following serve as important points of contact: social paediatric centres, early intervention centres, special education day care centres, autism outpatient clinics, the family supporting service (FuD) and the community-based support organisations known as the 'Offene Hilfen'. Advice can always be found there as well.

For parents, the following are good places to go for help with all kinds of problems: the long-term care advice centres; psychological advice centres for parents, children and adolescents; and the marriage, family and life counselling centres. Courses focussing on preventative approaches, such as 'KESS erziehen—Kinder mit Handicap', and special holiday services that provide rest and respite for parents can also be found at various locations in Germany.

In addition to long-term care advice, there is a special service called 'complementary independent participation counselling' (EUTB). With the introduction of the Federal Participation Act (BTHG), this service became enshrined in SGB IX on 1 January 2018. The EUTB advice centres are financed by federal funds and are independent of the funding bodies and service providers. The advisory service is provided free of charge and encompasses information and advice on rehabilitation and participation services according to SGB IX. Details of the EUTB advice centres can be found on the website [www.teilhabeberatung.de](http://www.teilhabeberatung.de).

There are now some separate services available for the siblings of children in need of long-term care because they often get 'sidelined' by parents and support agencies. However, these are not available nationwide.

In the course of the hearing with the affected persons and experts, it became clear that even though a wide range of advisory services exist, when families try to gain an overview of the different services that fit their individual situation, they are all too often forced to rely on themselves.

The aforementioned advice centres usually focus on individual areas, such as self-help, social integration support, participation counselling, long-term care advice, healthcare, education, early intervention, and so on. Although they are certainly experts within their own field, they are not usually able to provide solid advice and support spanning the different areas. And yet it is precisely because of the diverse range of applicable legal norms and laws that families of children in need of long-term care require continuous interdisciplinary case management if they are to have any chance of reconciling work and care.

In the absence of the central case coordination that ought to be triggered as soon as the child's need for long-term care arises, the plethora of norms, laws and (segmented) advice services robs parents of their time, causes confusion and is, ultimately, frustrating. This heavily impedes work-care reconciliation. This applies all the more if the affected families suffer from linguistic barriers that make it even more difficult for them to understand the complex issues involved.

Continuous interdisciplinary support is the only way to ensure that families can make necessary adjustments or navigate their way through the steps required and receive the expert help they need to complete all the essential formalities whenever new circumstances arise (such as when the child starts nursery, school or vocational training). Another factor is that many of these services rely on the commitment of other affected parents, who provide them voluntarily. As welcome as this commitment is, it turns out to be

inadequate in various respects: firstly, from the perspective of the medium to long-term reliability but especially from the viewpoint of the level of assertiveness required to deal with a vast array of authorities, government agencies and other institutions. However, reliability is important, particularly for parents of children in need of care because they are likely to need this care for a very long time.

Advice—in general—and shoulder-to-shoulder care support services for families—in particular—require a long-term professional commitment and the establishment of personal connections. To enable reliable reconciliation of care and work when children are in need of long-term care, it is necessary to relieve the burden on families and the above factors appear to be the only way of achieving this.

### **School as an illustration of the system's fragility**

The problems became particularly clear during the COVID-19 pandemic when many of the structures supported by volunteers collapsed. At the same time, the example of learning support assistants and teaching assistants highlights the fragility of the entire system: if the support person/assistant is absent, schools often refuse to ensure the care and education of the affected children, leaving parents with no choice but to keep their child at home. In addition, there are questions surrounding the legal safeguards for the institutions. Without the additional specialist staff (learning support and teaching assistants), they often feel overwhelmed by the responsibility of providing emergency aid or the right medication, for example. Another exacerbating factor is that—according to multiple reports from the affected persons during the hearing organised by the Advisory Board—the employment terms of learning support and teaching assistants are often precarious, with the result that these posts often remain vacant. Overall, the school system is patchy. Particularly when it comes to holiday supervision, children with special needs frequently fall through the cracks, meaning that their parents have to organise this supervision themselves, which also creates associated problems for them in terms of work-care reconciliation.

### 4.3.2 Care infrastructures throughout the stages of life

Enabling reliable participation in working life for parents of children in need of long-term care depends on having a consistently stable care and assistance infrastructure that can be flexibly adjusted to meet the individual needs of the children. Moreover, many of the children remain dependent on support and assistance in adulthood, with the result that the protection provided by this infrastructure is not restricted to the spheres of child/youth welfare and school but goes beyond these.<sup>189</sup>

The process of enabling work-care reconciliation for parents with nursery age children starts with the implementation of the Child and Youth Strengthening Act (KJSG). Schools offer supervised afternoon and holiday activities that many families with school age children take as read nowadays, but these are not available to children with long-term care needs to the same extent. Therefore, many parents often find it impossible to cover the roughly 62 days of school holidays each year.

In the case of adolescents, the transition to the world of work is also a major challenge because there are very few appropriate training positions and jobs. This often means that these adolescents end up living with their parents for longer than their peers. In turn, this hampers the transition to independence for these young adults. Even if they do manage to find a training position or job, these are often only low-qualification roles. Due to their low income, many of them are dependent on social welfare and other government benefits.

Adult children with a need for long-term care or a disability are also often affected by a lack of suitable housing, which prevents them from moving out of the parental home. Parents count themselves lucky if they are able to find any place for them in housing at all. The transition from adolescent living to adult living is extremely difficult. People sometimes forget that when someone requires long-term care or has a disability, nothing changes from a care perspective just because they grow up and switch to an adult setting due to their age. Support staff are often unable to give residents the individual support or time that they would like to devote to them. Caregiving parents get older: in many of the families that have children in need of long-term care, these children will outlive their parents. The question of where the children should go when the parents age and pass away is a very pressing one for many families. Parents worry whether an appropriate quality of living and life can be sustained without their help or the assistance of the family. Ultimately, parents do not want a stopgap solution but good and appropriate housing. Various institutions help families to create a way for grown-up children with a need for long-term care or a disability to make the transition out of their original family. However, there are currently nowhere near enough facilities (including assistance and support services) or assisted living group homes for young adults with major long-term care needs. Therefore, it is extraordinarily difficult for families to find a suitable facility and they sometimes have to wait an extremely long time for a place, with the result that 'flying the nest' becomes more and more difficult for both the parents and the children. Alternatively, parents are forced to take the initiative and establish suitable forms of living as a means of helping themselves. Many of them do not have the time and energy for this.

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189 The subsequent statements mainly originate from the hearing with affected persons and experts that was held on 5 November 2020.

Nationwide, there is also a blatant lack of short-term care spaces for children, adolescents and young adults with a need for long-term care.<sup>190</sup> A particularly acute problem in this and similar areas is the lack of infrastructure for parents of children with major or very specific support needs—that was the unanimous view expressed by the affected persons and experts at the hearing. To provide the care and support that these children need, special expertise is often required that goes beyond care skills and also encompasses pedagogical expertise in the care of such children. However, professional care services to support families are not available to a sufficient extent. This lack of availability has a particularly serious impact in the area of what is known as out-of-hospital intensive care. Due to the shortage of qualified nurses that applies in many cases, parents whose children require constant artificial respiration—for example—are often forced to provide some of this highly qualified medical care themselves. Furthermore, providing hospital care to children and adolescents with a long-term need for care is a problem in some places. A critical eye should be kept on whether the new generalist nursing training brings improvements in this regard.

The availability of inclusive crèches, nurseries and schools, along with child/youth leisure services and holiday programmes, would significantly improve the foundation for enabling parents with children in need of long-term care to participate fully in the labour market. Furthermore, it is crucial to significantly expand forms of assisted living for children and adolescents transitioning into adulthood. Firstly, this will strengthen their independence and equal participation. Secondly, it will improve opportunities for parents to pursue a career of their own.

### 4.3.3 Statutory provisions and benefit entitlements

Provisions that can potentially enable parents of children in need of long-term care to reconcile care and work are to be found in various pieces of legislation (SGB VIII, SGB IX, SGB XI, SGB V).<sup>191</sup> Essentially, the first statutory provisions worthy of mention are those of social law, which are directly aimed at improving work-care reconciliation. These include the following:

#### The Caregiver Leave Act

Short-term absence from work allows an employee to stay off work for up to ten working days if a sudden care situation arises so that they can provide or organise the care; this option exists regardless of the size of business. Carer's grant can be claimed for this period. Entitlement to caregiver leave involves partial or full release from work for up to six months to enable the care of a close relative/family member in a home environment. This entitlement only applies when the employer has more than 15 employees. In addition, the employee is entitled to release for the same period of time in order to care for close relatives/family members in need of long-term care outside the home as well as at home. To enable the care of someone in the final phase of life, full or partial release can similarly be taken for up to three months.

#### The Family Caregiver Leave Act

Under the FPfZG, employees are entitled to reduce their working hours to a minimum of 15 hours a week for a maximum of 24 months in order to care for a close relative/family member in a home environment. This entitlement only exists when the employer has more than 25 employees.

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190 According to Section 42(3), first sentence SGB XI, people with long-term care needs who are cared for at home are entitled—in justified individual cases—to also receive short-term care at suitable facilities for people with disabilities and other suitable facilities if it is not possible or does not seem reasonable for the care to be provided at one of the care facilities approved for short-term care by the long-term care insurance funds. Thus, the SGB XI has extended the entitlement to short-term care from approved care facilities to these facilities as well.

191 See the overview in Bundesverband für körper- und mehrfachbehinderte Menschen 2023 (Federal Association for People with Physical and Multiple Disabilities—bvkm): 'Mein Kind ist behindert—diese Hilfen gibt es' (My child is disabled—these are the available forms of assistance).



Entitlement to release also exists so that underage close relatives/family members in need of long-term care can be cared for outside the home as well as at home.

Family carers can apply for an interest-free loan for the release period according to the PflegeZG and FPfZG. This report recommends merging the statutory provisions of the two laws while making relevant adjustments.

Due to the COVID-19 pandemic, urgent assistance for family carers (known as 'Akuthilfen') was introduced in May 2020. Accordingly, a short-term absence from work can be taken for up to 20 working days; the same applies to carer's grant. In addition, greater flexibility has been built into the PflegeZG and FPfZG. On the last occasion, these measures were extended until the end of April 2023. On request, months when there was a drop in income due to the pandemic can be ignored when determining the loan amount.

### **Sickness benefit in the case of a sick child according to Section 45 SGB V**

According to Sections 45(1) and (2) SGB V, employees are entitled to release from work in the case of a sick child for ten working days per child and per year. A sickness benefit amounting to 90 per cent of the lost net pay is paid during this time. The child must be below the age of twelve or have a disability and be dependent on assistance. During the COVID-19 pandemic, the entitlement period was extended.<sup>192</sup> In addition, Section 45(4) SGB V provides for a period of entitlement with no time restriction that can be granted in several very limited exceptional cases. These exceptional cases include when a child is suffering from a serious and incurable illness, has a limited life expectancy of weeks or months, or when palliative treatment is necessary or requested by a parent.

### **Further provisions**

In addition, there are some other provisions that are at least conducive to work-care reconciliation, as the parents can only pursue a career if the children or adolescents in need of long-term care are being properly looked after and cared for. These include the following benefits, which are enshrined in SGB IX (Rehabilitation and participation of people with disabilities) and—in the case of children and adolescents with a mental disability—in Book Eight of the Social Code (SGB VIII) (Child and youth welfare):

- Benefit for participation in education (such as school assistance according to Section 112 SGB IX; since 2020, this has also been available in the context of afternoon care at what are known as open all-day schools)
- Benefit for participation in working life (such as attending a sheltered workshop [WfbM] according to Section 111 SGB IX)
- Benefit for social participation (such as assistance during leisure time according to Section 113 SGB IX)

Some provisions support parents of children or adolescents in need of long-term care in particular. These include, in particular, short-term care (Section 42 SGB XI), respite care (Section 39 SGB XI) and support allowance (Section 45b SGB XI). Provisions can also be found in employment law. These include the Maternity Protection Act, the Act on Part-time Work and Fixed-Term Employment (TzBfG)<sup>193</sup> and a right to work from home/remote work that is partly based on company and collective bargaining agreements.

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<sup>192</sup> Last extended to 30 days for the year 2022 by the Act to Amend the Infection Protection Act and other Acts in Response to the Repeal of the State of an Epidemic of National Significance of 22 November 2021.

<sup>193</sup> Thanks to the changes introduced in the TzBfG—in the form of the new 'bridge' period—it is possible for parents to work part-time for a temporary period of one to five years before returning to their previous working hours. These provisions came into force on 1 January 2019.



The BEEG provides for financial compensation if the parents' income drops after the birth of their child because of reduced working hours. Parental allowance is also available to parents who had no income at all prior to the birth. Furthermore, the BEEG grants a career break to parents who look after and bring up their children themselves. Release from work can be taken for up to three years before the child's third birthday—a portion of which can also be taken in the period between the child's third and eighth birthdays.

However, the statutory provisions that are specifically intended to facilitate work-care reconciliation are not adequately designed for parents of children with a need for long-term care. This primarily applies to the FPfZG and PflegeZG. These fail to meet the long-term need that working parents have when their child is permanently reliant on care and support.

Social integration support services are likewise only suitable for enabling paid work to an extent. As regards social integration support according to SGB IX, the legal situation has improved since 2020 as a result of the Federal Participation Act (BTHG). However, for parents of underage children with a physical or mental disability, there are still additional assistance costs associated with supervised afternoon and holiday activities. Support services are available under the statutory long-term care insurance scheme according to SGB XI to enable parents of children with disabilities to take a break from care but—once again—these are inadequately designed. For instance, respite care—essentially the most flexible and, thus, most important relief service for parents of children in need of long-term care—may only be increased by half the amount of short-term care rather than by the full amount. From the perspective of the families, there is an urgent need for the greater flexibility that would come from having a single budget for all benefits. Moreover, the budget

for short-term and respite care is set without drawing any distinction in terms of the care grade. Therefore, the budgets get used up more quickly in the case of children that need a high level of support (those allocated a care grade of 4 and 5), as more specialised care services are usually required, making them more expensive. As a result, the parents concerned get less time off from their care commitments than parents whose children need a lower level of support (care grades 2 and 3) even though they are placed under greater psychological and physical stress.

Legal entitlements often also go to waste because the necessary infrastructure is lacking (see Section 3.3.2).

### Consequences

The consequences of the deficits in the law and infrastructure are shaping the current situation: on account of these deficits, one parent usually gives up work completely or reduces their work commitments considerably to ensure that a child requiring long-term care receives the care and support they need. This shrinks the family income substantially for many years. The same applies to the family's retirement income even though the long-term care insurance scheme covers the costs of the legal pension arrangements for caregivers. In addition, financial burdens arise from specific home equipment needs, the necessity for disability-friendly vehicles and the costs of support services that are not reimbursed. Often, these expenses cannot be offset by entitlements to financial grants under Section 40(4) SGB XI, such as those for improving the individual living environment of the child in need of long-term care. Parents that act as the sole earner are under enormous pressure to keep their jobs. They often attempt to cushion the loss of their partner's income by working overtime or taking on special duties. The situation faced by single parents is particularly precarious.

## 4.4 Summary and recommendations for action

To enable parents and family members of children or adolescents in need of long-term care to stay in their jobs, it is necessary to establish a social climate and workplaces where men and women can share the caregiving responsibilities equally, as well as a care landscape in which the children and adolescents experience appropriate inclusion, nurture and care at an institutional level.

At the same time, it is essential to remember that the premises and basic parameters on which families base their care arrangements are extremely varied and complex. For instance, in addition to coping with the demands that stem from the needs and care of the child, on the one hand, and from the professional context, on the other, parents of children requiring long-term care often have to navigate competing obligations and a lack of support structures. Other influencing factors, which may be specific to the individual case (such as the health situation of the parents), shape the decisions taken within the family, determining them afresh whenever a change occurs. Therefore, all the recommendations of the Advisory Board are to be understood from the perspective that, in the case of many families, they will only be able to solve some of the problems associated with the long-term care of a child or adolescent and the simultaneous need for both parents to be working.

The above analysis of the situation facing families with children or adolescents in constant need of care describes a specific set of problems that differ from those encountered in long-term care of the elderly. It also reveals that the affected families—of which there are well over 160,000—are each subjected to different circumstances. In response to these findings, the Advisory Board would like to make the following general recommendation to all those responsible for designing support

services: this state of affairs should be borne in mind and, wherever possible, a high degree of flexibility enabled so that young people in need of long-term care and their families can find solutions better tailored to their requirements. The Independent Advisory Board recommends improving work-care reconciliation for the affected family carers by adopting the target group-specific measures described below, thereby fostering their right to participation.

### 4.4.1 Advice and support

For the purpose of providing assistance throughout life, there is currently no independent information and advisory body at a higher level that possesses comprehensive expertise spanning the diverse array of statutory provisions and the resulting breadth of support options for families of children in need of long-term care. Parents still spend a large proportion of their time and energy gathering all the information about support services that is of relevance to them.

#### The Advisory Board recommends:

- Independent advice should be ensured for parents of children or adolescents in need of long-term care. The structures associated with existing information and advice centres should be used for this purpose. At the federal level, a competence centre should be established and developed that will provide guidance and have particular expertise in the needs of families with children or adolescents in need of long-term care.

Explanation: despite the extensive benefit entitlements of affected family carers, a one-stop shop for advice is currently lacking to address the specific problems faced by children and adolescents in need of long-term care. This should be institutionalised at the federal level (by expanding the central care hotline, for example) and linked to the network of existing local advice infrastructures.

#### 4.4.2 Inclusive education and/or childcare facilities

It is a major step, both for children or adolescents in need of long-term care and for their parents, when the children start attending an educational and/or childcare facility. It can also be the moment when the parents are able to resume careers that have been put on hold or increase their working hours.

##### The Advisory Board recommends:

- Improvements should be made to the expertise and capacity available for assisting and supporting children in need of long-term care within educational and/or childcare facilities.

Explanation: all too often, those working in the various educational and/or childcare facilities lack the expertise and capacity required to give appropriate support to children or adolescents in need of long-term care and their family members. This also applies in relation to inclusive leisure activities in the afternoon and to the supervision of children with long-term care needs during the school holidays. To bring about a significant improvement in the situation, teachers and childcare workers should receive enhanced training and professional development focusing on an inclusive approach. In addition, school social work should be expanded, in particular. School/nursery nurses and assistants at the institutions are another potential source of meaningful supplementary support.

#### 4.4.3 Care within care infrastructures

It is seldom possible for children or adolescents with long-term care needs to be looked after by care facilities while their parent or parents go to work because of the lack of differentiated provision.

##### The Advisory Board recommends:

- Day care and short-term care facilities, along with mobile care services, should specialise in the needs and interests of children and adolescents requiring long-term care as well as other groups.

Explanation: for many children and adolescents in need of long-term care and their caregiving families, the legal entitlement to short-term care (Section 42(3) SGB XI) goes to waste because there are virtually no short-term places available at facilities for the disabled. The majority of day care services are geared towards older and elderly people and not to the needs of young people. It is a similar picture for non-residential care. This is another area where there has so far been a lack of services with specialist knowledge in relation to children and adolescents in need of long-term care.

#### 4.4.4 Area: Caregiver Leave Act, Family Caregiver Leave Act and other statutory provisions

Via its recommendations, the overall call of the Advisory Board is for legal framework conditions to be put in place that will empower caregivers to stay in their jobs in accordance with their own wishes. The Advisory Board is advocating for legal provisions that will encompass as many as possible of the situations faced by families of children with a need for long-term care. The following two recommendations could prove particularly significant in relation to parents of children or adolescents with a need for long-term care.

### The Advisory Board recommends:

- For working parents with a child or an adolescent in need of long-term care, there should be a permanent increase in the number of working days for which parents are entitled to sickness benefit in the case of a sick child—in line with the provisions in force during the COVID-19 pandemic.

Explanation: children with a need for long-term care usually get sick more frequently than children without long-term care needs. Due to their illnesses, they often also have to spend long periods in hospital. The legislature now takes account of these special needs of parents with children in need of long-term care via Section 44b SGB V. However, at the same time, it should also be stipulated by law that the child's place at a day care facility must remain guaranteed in the case of long hospital stays.<sup>194</sup>

### The Advisory Board recommends:

- It should be possible for child sickness benefit to be transferred to caregiving family members and those with a similarly close relationship to the child (see model proposed by the Advisory Board).

Explanation: up until now, there has been no facility for transferring the child sickness benefit to third parties, such as grandparents, as they are often not part of the household. To allow for different family set-ups, it should be possible to transfer it.

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<sup>194</sup> Entitlement to sickness benefit is dependent on the child having an illness. However, parents of children with disabilities often miss work because they have to take their children to appointments with a doctor or therapist or to consultations at a medical supply store. In such cases, Section 45 SGB V does not apply. Therefore, in addition to extending the period of entitlement to sickness benefit, the bvkm also believes it would be sensible for caregiving parents to be granted ten days of special leave a year for the purpose of attending such appointments/consultations. See also the current petition at: [https://epetitionen.bundestag.de/content/petitionen/\\_2022/\\_09/\\_28/Petition\\_139520.html](https://epetitionen.bundestag.de/content/petitionen/_2022/_09/_28/Petition_139520.html).

# 5

## Caregivers at small and medium-sized enterprises (SMEs)

In scientific research and in public discussions, work-care reconciliation is often considered primarily from the perspective of those within the world of work who provide care informally. A far less common perspective is the idea of companies being active contributors to the issue of work-care reconciliation. As a general rule, the smaller the size of company, the less the amount of information available. Accordingly, only a small number of studies exist in relation to microenterprises (companies with up to nine employees). The state of research is slightly better for companies with up to 25 employees. SMEs have only very limited personnel resources, including at the management and administration levels. In the case of small companies, the management/administration often consists solely of the business owner, who may (or may not) be assisted by a secretary. In light of this, SMEs are exempt from implementing statutory provisions on work-care reconciliation up to a certain number of employees. The aim of this is to avoid imposing additional administrative burdens on them. For example, these exemptions include caregiver leave, which only applies to companies with more than 15 employees, and family caregiver leave, which only comes into play for companies with more than 25 employees.

To grapple with the particularly challenging problem of work-care reconciliation at SMEs, the Independent Advisory Board appointed a working group for work-care reconciliation in April 2021, which met regularly until June 2022. During this period, the working group produced the following key results:

- Differences in the definition of (or threshold values for) SMEs lead to classification difficulties, including when dealing with the self-employed/solo self-employed.
- Gaps in knowledge exist as regards the current key data on SMEs, such as a breakdown of the data by sector and details of the gender distribution.
- Although individual scientific studies and grey literature can be found on the subject of work-care reconciliation at SMEs, there is no systematic synthesis of the available evidence and, overall, the data is scant.
- There are very few practical examples of SMEs with effective solutions or initiatives that offer specific measures for improved work-care reconciliation at SMEs.

After establishing that substantial gaps in knowledge exist concerning the subject, the working group decided to commission a study that would first produce an assessment report so that the working group would then be able to draw up some recommendations for action based on this. By resolution of the Advisory Board on 21 June 2022, the work of the working group has been temporarily suspended until the Advisory Board submits its second report.<sup>195</sup> It is to be resumed as a matter of priority in the next (third) reporting period.

This section provides an overview of work-care reconciliation at SMEs. Large parts of it are based on an expert study commissioned by the Advisory Board on this subject<sup>196</sup> and it follows the same structure as this study. It starts by presenting the key data on SMEs and available data on work-care reconciliation at SMEs. It then explores some existing guidelines for better work-care reconciliation at SMEs and some examples of good practice.

## 5.1 The significance of SMEs within the German economy

SMEs are an essential part of the German corporate landscape and a major driver of economic output. Not only are they the biggest employers in Germany but they are also represented in virtually every sector. Below is a rough overview of the primary key data from this vast field.

### 5.1.1 SMEs as a proportion of all the companies in Germany

According to public perception, large companies are the main focus of attention. In actual fact, just 0.6 per cent of companies in Germany are classed as large because they have 250 or more employees—with the remaining 99.4 per cent classed as small and medium-sized enterprises (SMEs). Within the category of SMEs, medium-sized enterprises (50 to 249 employees) make up the smallest proportion numerically at 2.5 per cent (of all companies), followed by small enterprises (10 to 49 employees) at 14 per cent and microenterprises (fewer than ten employees) at 82.9 per cent.<sup>197</sup>

### 5.1.2 Economic output of SMEs

SMEs account for 42.3 per cent of the gross value added. This is less than the 57.7 per cent that the financially stronger large enterprises contribute to the economic output achieved by all companies in Germany.<sup>198</sup> In terms of annual turnover, SMEs generate more than two trillion euros (or two thousand billion euros)—corresponding to 30.3 per cent of the total turnover achieved by companies in Germany (2021). Of this, 856 billion euros (12.8 per cent) is attributable to medium-sized enterprises, 738 billion euros (11 per cent) to small enterprises and 438 billion euros (6.5 per cent) to microenterprises.<sup>199</sup>

To enable European comparisons, a system of enterprise size classification is used at the EU level. This relies on a combination of the employee

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<sup>195</sup> The primary reason for temporarily suspending the work of the working group was that the outsourcing of a study on the subject did not adequately coincide with the deadlines for submitting the Advisory Board's second report. For this reason, the planned expert hearing has also been cancelled/postponed until the next reporting period.

<sup>196</sup> Knauthe, Joos and Hoff 2022.

<sup>197</sup> See Statistisches Bundesamt 2022a. The solo self-employed are not taken into account in this text. The Advisory Board is aware of the specific situation facing the solo self-employed in relation to work-care reconciliation and will therefore include this in a subsequent analysis.

<sup>198</sup> See Statistisches Bundesamt 2022a.

<sup>199</sup> See Statistisches Bundesamt 2022a.

count and the amount of turnover. According to this system, medium-sized enterprises have fewer than 250 employees and an annual turnover of no more than 50 million euros, small enterprises have fewer than 50 employees and an annual turnover of up to ten million euros, and microenterprises have fewer than ten employees and an annual turnover of up to two million euros.<sup>200</sup>

### 5.1.3 Number of persons employed by SMEs

SMEs are responsible for employing more than half (55 per cent, or a total of 16.2 million people) of all those who work for companies within Germany. This equates to seven employees per SME on average. That is almost twice the EU average, which is 3.7 employees per SME.<sup>201</sup> Out of all the SMEs, small enterprises are the biggest employers with 6 million employees (20.5 per cent of all people working for companies), followed by microenterprises with 5.4 million employees (18.3 per cent) and medium-sized enterprises with 4.8 million employees (16.3 per cent).<sup>202</sup>

### 5.1.4 Employment at SMEs according to gender

The societal shift towards a service economy correlates directly with the employment rate of women, which increased from 45.9 per cent in 1970 (old federal states) to 72.1 per cent in 2021, although a high proportion of them work part-time. Within the same period, the employment

rate for men decreased from 87.7 per cent (1970) to 79.4 per cent (2021).<sup>203</sup> In this context, notably high employment figures for women are evident in the service sector, while men continue to be overrepresented in the manufacturing and processing industries.<sup>204</sup> Most SMEs are to be found in the service sector. As a result, women are strongly represented at SMEs—at microenterprises with fewer than five full-time equivalent posts, they constitute the majority of the employees (60 per cent).<sup>205</sup>

Companies with fewer than 50 employees are the ones with the most part-time employees. The percentage of part-time employment is particularly high in retail. It is also very apparent that the proportion of women who work part-time is considerably higher in western Germany than in eastern Germany (48.6 per cent compared to 34.7 per cent).<sup>206</sup> The proportion of women at SMEs does not just depend on the sector but also correlates with other contextual factors. When SMEs are managed by women, a higher proportion of the workforce consists of women (61 per cent) compared to SMEs that are managed by men (53 per cent). Work-care reconciliation is also an important criterion for women when choosing an employer. If measures are already in place to improve work-care reconciliation, it results in a nine per cent increase in the proportion of women employed.<sup>207</sup>

200 See EU Commission 2003/361/EC, page 39.

201 See Institut für Mittelstandsforschung Bonn 2021.

202 Statistisches Bundesamt 2022a.

203 See Knauth, Joos and Hoff 2022a, page 23.

204 Bundeszentrale für politische Bildung 2020.

205 See KfW 2019, page 2.

206 See WSI 2020, page 28.

207 See KfW 2019, page 3.



## 5.2 Current state of research into work-care reconciliation at SMEs

Only the research literature on work-care reconciliation at SMEs that has been published since 2015 has been taken into account when drafting this section.<sup>208</sup> The reason for restricting it to this period is that the First Act to Strengthen Long-term Care and the Act for a Better Reconciliation of Family, Care and Work took effect in 2015, thereby dramatically changing the legal framework for the whole issue of work-care reconciliation. The section does not take account of publications that dealt exclusively with childcare and work or those that were not (or were no longer) accessible.

It was specifically in the publications from the years 2015–2017 that an attempt was made to explain the legal changes and the resulting rights and opportunities for informal caregivers. In publications that approached work-care reconciliation from the perspective of those affected, there was a focus on the needs of working family carers at SMEs and any shortcomings that existed. When the subject was approached from an employer perspective, the publications discussed topics such as the need for employer branding, staff retention, human resources development and raising awareness about long-term care at the management level. The increasing shortage of skilled labour was a key theme that arose in this context.<sup>209</sup> Other topics were also investigated in individual cases, such as the activities of entrepreneurial women who engage in work and simultaneously bear responsibility for informal long-term care, gender equity and measures for adapting businesses to an ageing workforce.

### 5.2.1 Company measures at SMEs to improve work-care reconciliation

In terms of the recommended measures, there were certain parallels between the publications that focussed on informal caregivers and those that concentrated on the concerns of businesses. When presenting the measures below, a distinction will be drawn between (a) measures that have long been known and are already established to some degree and (b) new and innovative measures that are not yet widely used at SMEs (or are only used in exceptional cases).

#### **Conventional measures: flexible work location and working hours**

The most widespread measures for work-care reconciliation at SMEs are the ones that were introduced as part of flexible working. These are measures that provide greater flexibility in terms of the work location—such as remote work or telework—or working hours.

In the case of remote work, employees are free to choose their own work location. Companies do not have to set up a workstation but must take care of all the technical aspects required to enable the work. In the case of telework, the employee often works from a home office set up by the employer. In this case, the employee does not have a workstation at the company as well, unless it has been agreed that they can alternate between working from home and working at the company's premises. Flexible working hours either consist of abolishing core working time or offering various part-time possibilities. In addition, employees can be released from work for a limited period, particularly in the case of an emergency.

208 For further information on this subject, see also Eggert et al. 2016 and Eggert et al. 2018; Schumann and Kather Skibbe 2016; Rothgang and Müller 2018; Waldenberger et al. 2022; Reichert 2022; Deindl and Knauthe 2019; Völz and Schneck 2021; Ruppert, Heitmann-Möller and Hasseler 2016.

209 See Knauthe, Joos and Hoff 2022b, page 3.

Moreover, there is the individual discussion between company management and employees who provide long-term care informally. Clearly, many companies still regard this as the preferred channel for communicating internally with employees.

#### **Innovative measures**

The innovative measures proposed in the publications go further, providing the caregivers with support that is more closely tailored to their individual needs.<sup>210</sup> A distinction is drawn here between work place-related measures, advisory services, forms of care support, health and preventative health courses, and measures for raising the awareness of company management teams. Not all of these measures are suitable for every size of company. Particularly at small enterprises and microenterprises, the available resources are often insufficient.

#### **Work-place related measures**

Four measures are mentioned in this category: (a) a re-employment guarantee, (b) trust-based working hour arrangements, (c) job sharing and (d) financial support. In the first case, the company commits to re-employing informal caregivers at the end of the care period or, if they went down to part-time hours because of their care commitments, to increase their working hours to the original level. Trust-based working hour arrangements are where the company only monitors the work results—the actual number of hours worked is not recorded. Job sharing was mentioned as a means of sharing the work and the workstation between several people. Finally, companies have the option of providing informal caregivers with financial support in the form of vouchers (from partner companies, for example) or grants for specific purchases.

#### **Advisory services**

Once again, this category encompasses four measures: (a) referral to competence centres, (b) internal care advisers, (c) advice on technical resources and (d) digital advice. In the first case, affected employees are referred for advice to advisory bodies that specialise in long-term care—some of these also reach out proactively. Some companies also train internal employees to become care advisers. As technical care resources become increasingly available, the knock-on effect is a greater need for advice. Some companies offer their employees support in this area by referring them to advice centres that specialise in assistive technologies (cooperation agreements). Recently, there has also been an increase in digital advisory services, allowing companies to enter into partnerships for the purpose of advising affected employees.

#### **Care support**

Three possible measures were mentioned within this category: (a) care support provided by the company itself, (b) cooperation with institutionalised care services and (c) the establishment of a volunteer pool. In the first case, the company runs its own day care facility that is similar to a workplace nursery. Another possibility consists of cooperation with long-term care providers, day care facilities, short-term care providers, and so on, thereby giving company employees priority access to long-term care services for their family members. Finally, some companies report that they have their own network of volunteers within the business to support family carers. These volunteers do not necessarily just have to be recruited from the company's own ranks.

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210 The innovative measures were identified through a systematic literature review of 112 academic publications on work-care reconciliation at SMEs from 2015 to 2022 (see Knauth, Joos and Hoff 2022a, page 33 ff.).

### Health and preventative health courses

Once again, three options were mentioned within this category: (a) training in long-term care, (b) personal health courses and (c) self-help courses. In the case of health and long-term care courses, companies cooperate with course providers so that relevant training can be offered to the company's own workforce. Sometimes, this may also involve partnerships with the statutory health insurance funds. By contrast, self-help courses are aimed directly at employees within the company who provide informal long-term care. These courses encourage them to establish an in-house self-help group so that they can support each other.<sup>211</sup> Meanwhile, the company provides assistance with the logistical aspects.

### Raising the awareness of companies

Two measures come into play here: (a) training for company managers and (b) certification of the company itself as a family-friendly or care-friendly business. These measures consist of targeted training on the subject of the 'long-term care of family members' for company management and (where applicable) middle management, and the company's participation in certification processes to demonstrate that it is family/care-friendly.

Implementation of the aforementioned measures was defined as a means of winning the loyalty of staff and preventing them from contemplating a change of employer. The costs that would inevitably result from the employee changing jobs would ultimately amount to more than implementing work-care reconciliation measures.

## 5.2.2 Obstacles to implementing work-care reconciliation measures at SMEs

It is not presumed that the majority of SMEs are already implementing the measures referred to under 5.2.1. There are often obstacles that hamper or completely prevent their implementation, such as the limited personnel resources at the management or administrative levels. The following points of criticism have been taken directly from the research literature.<sup>212</sup> They exclusively apply to those companies where the specified factors are relevant. No assessment can be made concerning the extent to which they are representative of SMEs as a whole. They indicate the dominance of a highly performance-oriented and/or traditional company culture.

1. A highly performance-oriented company culture
2. Success of the company is more important than the needs of employees
3. Traditional company management
4. Lack of trust in the workforce

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<sup>211</sup> Within this context, the Advisory Board also wishes to draw attention to the Act to Strengthen Health Promotion and Prevention (Prevention Act—PrävG).

<sup>212</sup> See Knauth, Joos and Hoff 2022a, page 36.

When a company culture is strongly geared towards performance, it often results in exclusion mechanisms in the workplace. In other words, family carers are sometimes left out of internal team communications (because they were unable to attend important meetings and were not kept in the loop, for example) or they are disadvantaged in terms of their career and which tasks they are assigned. The financial success of a company is, of course, vital for its survival. What is meant here is a form of internal communication that leads to a company culture in which family carers do not tell senior management about the burdens placed on them by long-term care. One consequence of a traditional approach to company management is that the senior management barely comes into contact with the issue of work-care reconciliation. Therefore, the burdens resulting from long-term care are frequently underestimated or incorrectly assessed and the potential overburdening of affected employees goes unnoticed. In this kind of business context, family carers often face extreme time pressure, whether it be externally imposed or self-inflicted.

Many SME management teams resist the formalisation and legislation of measures for improved work-care reconciliation. Instead, they continue to prefer individual discussions between company management and employees who are informal caregivers (the advantage of this approach is that it allows flexible and individual solutions to be found). The problem with this is that these conversations often fail to take place because the long-term care of family members remains a taboo subject within companies.<sup>213</sup> Although the need for a work-life balance because of children is now recognised by many businesses and is no longer taboo, this is not always true when it comes to balancing long-term care and a career.<sup>214</sup>

### 5.2.3 Consequential costs of unsuccessful work-care reconciliation at SMEs

In the long term, it is estimated that companies will incur consequential costs of 19 billion euros as a result of unsuccessful work-care reconciliation.<sup>215</sup> The investment costs required to solve the problem of work-care reconciliation are highly likely to be lower than the consequential costs, although this is yet to be verified.

The information below deals with business-related consequential costs that result from the behaviour of affected employees who experience difficulties with work-care reconciliation.

#### Consequential costs for companies

The inability to reconcile work and care commitments can lead to employees resigning or, in the case of older caregivers, taking early retirement.<sup>216</sup> Thus, companies lose skilled employees, who cannot be (adequately) replaced in the current climate. In addition, the resulting employee turnover at the company can often damage its public image and increase the workload of the remaining employees.

#### Consequential costs for family carers

Family carers do not merely lose their earned income and, in turn, their pension entitlements by giving up their jobs or reducing their working hours but also an activity that provides a sense of purpose and the opportunity to interact with colleagues. Because caregiving tasks are not distributed equally between women and men, these consequential costs affect women more frequently.<sup>217</sup>

213 See Knauthe, Joos and Hoff 2022b, page 4.

214 See Mohr et al. 2021, page 45.

215 See Ruppert et al. 2016.

216 See Knauthe, Joos and Hoff 2022b, page 4.

217 See Knauthe, Joos and Hoff 2022a, page 37.

## 5.2.4 Discussion

### Little attention paid to SMEs

The underlying systematic review of the literature has revealed that the issue of ‘work-care reconciliation’ at SMEs is still only receiving minimal attention. Companies are usually considered without reference to their size and what possibilities and resources are available as a result. Furthermore, the fields of action and adjustments identified have barely changed throughout the entire period under consideration. Conventional measures involving flexible working hours and a flexible work location are usually top of the list. After these, advisory and support services were described as helpful measures for work-care reconciliation.

### Greater work flexibility and an awareness of long-term care

The conventional measures (see Section 3.1) for work-care reconciliation are often exactly the adjustments that informal caregivers say they want. However, another priority for caregivers was for companies to show a greater understanding of their specific situation. This brings us to another aspect systematically highlighted in the studied publications: the plea for a care-aware company culture that is also visible to the outside world. This mainly relates to having a trusting atmosphere where informal caregivers can approach the company’s management with their requests for adjustments without fearing that they will suffer disadvantages as a result.

### A change of thinking by companies

One final point that many publications had in common was the need for companies to change their thinking urgently. The first reason for this is demographic change and the second is to achieve a higher level of staff retention. However, it is also clear that SME management teams need to be made more aware of employees’ care responsibilities than they have been to date. Further research is required into this topic, along with innovative proposals for action.

## 5.3 Guidelines for better work-care reconciliation at SMEs<sup>218</sup>

In addition to having concrete projects for improving work-care reconciliation, various institutions produce guidelines that are aimed specifically at companies.<sup>219</sup> Given that these guidelines contain many practicable approaches, they will be briefly summarised below. The aim of the guidelines is to provide companies with skills, tips, examples and experiential reports so that they can review the work-care reconciliation strategies at their own business. Another objective is to motivate companies to take a (more) proactive approach and offer employees greater options for work-care reconciliation as part of a care-aware human resources policy. Once again, we have only considered tools that have been published since 2015. The analysis is based on nine

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218 For the purpose of addressing care shortfalls caused by COVID-19, various special provisions were introduced in the long-term care insurance legislation (SGB XI) right at the beginning of the coronavirus pandemic. In order to support people receiving long-term care at home and their family members, an entitlement to COVID-19-related carer’s grant was introduced under Section 150(5d) SGB XI. Alongside this, other notable examples of such support include the provisions covering the reimbursement of the costs of mobile care non-cash benefits under Section 150(5) SGB XI, the flexible use of the support allowance in the case of a care grade of 1 under Section 150(5b) SGB XI, the higher flat-rate care equipment allowance under Section 40(2), first sentence, second half sentence SGB XI, and the special provisions covering advice for those who are solely recipients of care allowance under Section 148 SGB XI.

219 See Knauthe, Joos and Hoff 2022a, page 40 ff.

sets of guidelines. Typically, guidelines of this kind are issued by higher-level project units and apply to multiple rural districts at once.<sup>220</sup>

The guidelines essentially concentrate on having a care-aware company culture or human resources policy. They encourage companies to scrutinise the extent to which work-care reconciliation is already being taken into account by comparing what happens with the needs identified. Four similarly worded fundamental questions recur in all the guidelines:

1. Do you know how many employees at the company are providing long-term care to family members?
2. Are measures already in place or could options that have so far been primarily offered to parents be extended to family carers?
3. Are managers and employees being made aware of the problem situation?
4. Is information available, and are information events held on this topic?

#### Practical tips for creating a care-aware human resources policy

The key focus of most guidelines is the introduction and implementation of a care-aware human resources policy. Concrete instructions or options are always included to enable manageable implementation. The guidelines are extremely detailed in this respect and provide step-by-step instructions for rapid implementation so that the companies do not have to go through the time-consuming process of collating information in advance. In summary, the sub-steps are as follows:

- **Gather information.** This step is intended to help companies immerse themselves in the topic and cultivate their own awareness. It includes gaining an overview of the facts, which are described in detail in the guidelines. The process of gathering information also involves ascertaining the situation at the company. For this purpose, surveys or interviews should be conducted. Almost all guidelines offer appropriate interview guidelines or questionnaires for use by human resources managers. It can also be helpful to exchange information with other companies to gain an impression of what problems exist and any measures (that may be in place) in the region.
- **Analyse the current situation.** This involves, firstly, identifying the needs of employees within the company and, secondly, considering what measures are already in place. It may be possible to take agreements that have mainly been available to parents and extend them to family carers.
- **Identify needs.** This follows on directly from the analysis of the current situation. However, in this case, it is more about the precise suitability of the measures that are to be offered. This also involves analysing the employee surveys in order to identify problems of both a collective and an individual nature. On the basis of the results, investments should ideally be made in improving work-care reconciliation.

One of the most frequently cited aspects is greater flexibility with regard to working hours. It is recommended to limit the duration of agreements (such as trial part-time arrangements) to test their precise suitability for meeting the needs of employees and the company. The next step is

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<sup>220</sup> A good example is Competentia NRW, the Competence Centre for Women & Work, which issues virtually identical guidelines to the rural districts of Bonn/Rhein-Sieg, Siegen-Wittgenstein, Mettmann and Westfälisches Ruhrgebiet. A similar approach is adopted by the German Chamber of Commerce and Industry (DIHK), which uses the same guidelines in several regions, sometimes in cooperation with the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the 'Erfolgsfaktor Familie' (Success Factor Family) corporate network. The most recent example consists of the practical guidelines entitled 'Pflegerische Beschäftigte brauchen Unterstützung. Leitfaden für eine gute Vereinbarkeit von Beruf und Pflege' (Caregiving employees need support. Guidelines for good work-care reconciliation), which were published in 2020. See Knauth, Joos and Hoff 2022a, page 40 ff.



work organisation. For this purpose, the options offered by the company and organisational arrangements should be set out in writing in a company agreement to ensure clear procedures and planning certainty for everyone. This could include arrangements for an internal work release scheme or flexible breaks or advisory services for caregivers. The discussion around the work location is another theme found in all the guidelines. This concerns the distances between the work location, the employee's home and the place where the long-term care is provided. All these locations should be as close to each other as possible to minimise commuting times. Proposed solutions range from alternating between working from home and on site through to renting a local satellite office close to the employee's home.

Alongside the points outlined above, other services/benefits are addressed in the guidelines. These consist of further benefits for family carers that the company could offer by way of special support. Towering above all these measures for improving work-care reconciliation is the issue of human resources development. One of the crucial factors identified is the need to hold regular discussions (human resources development interviews) with employees about their professional and private situation. These discussions can be used to highlight the various ways in which the company can provide support. This is just as important as gaining an understanding of the care situation and the associated stress factors. Managers should receive further training in relation to this.

Conversely, the guidelines also advocate training for family carers so that they can manage their time more effectively, for example. Another aspect of human resources development involves remaining in contact with employees who take a temporary break from work due to care commitments. They should be offered the opportunity to

participate in professional development, general staff meetings and occasional small job assignments. This then paves the way for a successful return at the end of the care phase.

All these measures can only succeed and be implemented if they are communicated and people are aware of them. Managers are repeatedly identified as key figures within the company with the ability to open up the taboo subject of long-term care by making targeted measures available. This is more likely to succeed when participation in training and professional development is ensured (digital services make it easier to access this). External consulting is also a possibility here. In addition to raising the awareness of managers, there are also calls for designated contact persons at companies.

### 5.4 Side note on examples of best practice at SMEs

The study only considered examples that either existed or were initiated after 2015 and could be found through their respective websites. Projects specifically geared towards SMEs were few and far between. The projects 'Work & Care in der Region Ostwestfalen-Lippe (OWL)' (Work and care in the region of Ostwestfalen-Lippe) and 'Arbeiten-Pflegen-Leben im Ennepe-Ruhr-Kreis' (Working, caring, living in the district of Ennepe-Ruhr) were selected to serve as substitutes because of their similar content. Both projects rely on an interconnected structure comprising companies, public bodies and educational establishments. In this context, the realms of work and personal life are envisioned as networks within which caregivers and companies can be supported through social



and technical innovations.<sup>221</sup> They each make advisory services available to companies. To do this, they make use of information materials that have been developed into a ‘corporate care kit’ and a web-based version of the tool. With a view to enabling practical support, employees from the participating companies are trained free of charge so that they can subsequently act as care advisers. In addition, the projects involve raising awareness of the support provisions in the respective regions. This is achieved through websites, digital address lists and a specially designed app that brings all the services together in one place. As part of the Work & Care project, a digital case manager was designed that can match the needs of working family carers to the available services, thereby putting together a tailored support package. Finally, the programmes offer their own certification processes or employer branding systems to make the company’s efforts and offerings visible to the outside world. Both projects currently have an average of 30 participating companies, which—considering the size of each region—represents a solid average value.

#### **Specific offerings at the state and federal levels**

A range of projects are under way within the various federal states. We were able to find several projects that focus on work-care reconciliation. Most of these were located in the federal state of North Rhine-Westphalia. Various federal state ministries, rural districts, municipalities and health insurance funds are actively engaged in financing and publicising the projects. Thanks to the involvement of these higher-level organisational units, many projects are permanently established or, in the case of specialist departments, come under the jurisdiction of the town/city or rural district administration. This makes them more enduring than projects that only run for a brief period in the context of research. All these projects arose in cooperation with companies.

Efforts are under way to make specific offerings from the projects available for SMEs. Primarily, these consist of a large number of free services, such as the ability to access combined information materials via web portals and digital and analogue ‘corporate care kits’. In addition, care advisers can be trained in partnership with health insurance funds, a service which is free of charge for the participating companies. As well as focussing on the introduction or expansion of a care-aware human resources policy, along with relevant key personnel, the projects also involve further services for family carers. These include the aggregation of long-term care services—such as care support centres, long-term care insurance funds, mobile services, and so on—and app-based systems that bring together household-related services within the respective region.

In addition, many projects offer employer branding, which is a way of making the company’s efforts in the area of work-care reconciliation visible. This is intended to improve the company’s attractiveness as an employer, which is particularly relevant to SMEs because they face greater challenges in securing the next generation of specialists compared to large enterprises. As a strategy, certification has now become firmly established in Germany. The *berufundfamilie* (workandfamily) audit is a powerful example of employer branding that is known and recognised throughout Germany. It is available for companies of all sizes, with the list of companies that have already undergone certification revealing that approximately one third of participating companies are SMEs and two thirds are large enterprises.

It should be stated that companies that commit themselves to a family-conscious human resources policy are not automatically care-aware. Nor is this apparent based on general certification programmes (*berufundfamilie*) or corporate networks (*Erfolgsfaktor Familie*). Determining

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221 See Völz and Schneck 2021, page 4 ff.; Beermann 2018, page 1 ff.

whether they are care-aware would require an in-depth review but, considering that there are approximately 10,000 companies, this would not be possible or worthwhile from a capacity perspective. Instead, we can explore some examples based on the size of company that open up trailblazing and/or innovative approaches for employees. Nevertheless, it should be noted that large enterprises are significantly overrepresented here.

### 5.5 Summary of caregivers at SMEs

SMEs are responsible for more than 40 per cent of German economic output, and they employ more than half of Germany's working population. To avoid imposing additional administrative burdens on them, SMEs are exempt from implementing statutory provisions on work-care reconciliation up to a certain number of employees. For example, these exemptions include caregiver leave, which only applies to companies with more than 15 employees, and family caregiver leave, which only comes into play for companies with more than 25 employees. Due to their contribution to the economy as a whole and high proportion of women employees (particularly at microenterprises with fewer than five full-time equivalent posts), SMEs face particular challenges in relation to work-care reconciliation compared to large enterprises.

As regards work-care reconciliation in the context of SMEs since the introduction of the First Act to Strengthen Long-term Care in 2015, the data is relatively scarce. Nevertheless, tried-and-tested measures (such as greater flexibility in terms of the

work location and working hours) and innovative measures (such as advisory services and support programmes for caregivers) can be found in SMEs with the potential to relieve the burden on family carers who are trying to balance long-term care with work. Even though there are all sorts of reasons why these measures are not being sufficiently implemented by some SMEs, it is in their economic interest to foster a family-conscious and care-aware company culture.

Various institutions publish guidelines for creating a culture of this kind and these can reveal possible courses of action to SMEs that they will find helpful. Furthermore, regular personnel interviews and training for everyone involved can empower people to address the issue of work-care reconciliation without treating it as a taboo subject. Where applicable, certification programmes can help SMEs to signal to the outside world that they have a care-aware human resources policy in place.

Even though many good approaches are highlighted in the measures presented here, the Advisory Board is not making any recommendations for action in this section. The reason for this is that the Independent Advisory Board wishes to intensify the work that has already begun on this subject. It intends to continue this work in the next (third) reporting period and clarify some important matters, such as how many SMEs are actually taking measures to improve work-care reconciliation, and what these measures are. To ensure a thorough exploration of the issue of work-care reconciliation in the context of SMEs, not only is a further literature review urgently needed but also—among other things—an expert hearing that can be used as a basis for drawing up some recommended actions for improving work-care reconciliation at SMEs.

# 6

## Work-care reconciliation under the conditions prevailing during the COVID-19 pandemic

Working family carers already faced major challenges before COVID-19 but these were exacerbated by the pandemic, prompting the Federal Government, employers and many other stakeholders to adapt their family-oriented support measures for a better work-life balance to the new circumstances. On the basis of numerous studies, this section sheds light on how the situation changed for family carers who work.

### 6.1 Problem: increase in stress

The COVID-19 pandemic had an impact on the levels of stress experienced by family carers. All the studies analysed reveal a significant increase in stress or deterioration in the care situation.<sup>222</sup> This stress led to a greater sense of being overwhelmed, causing some of the family carers to question the feasibility of continuing home-based care altogether.<sup>223</sup>

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222 The results of the studies differ with regard to the number of persons affected and the degree of stress. Depending on the study design, an increase in stress was recorded for 32 to 95 per cent of respondents. Firstly, the studies relied on different designs and populations and, secondly, the periods of investigation were slightly out of step with each other. The results also depended on the operationalisation of 'stress'. In the case of Eggert et al. (2020), 32 per cent of respondents said that their personal care situation had deteriorated over the past four to eight weeks (ibid., page 7), while as many as 45 per cent affirmed that 'long-term care is always difficult but it has become even more difficult in the current situation' (ibid., page 18). In the study by Horn and Schwappe (2020), 52 per cent felt that long-term care had become more stressful compared to before the COVID-19 pandemic (ibid., page 7). By contrast, in the case of Rothgang et al. (2020), 71 per cent had 'more problems' in relation to the issue of work-care reconciliation (ibid., page 38). When asked 'How would you rate your care-related stress during the COVID-19 pandemic compared to the period before it?' (Fischer Münnich et al. 2020), 95 per cent reported a deterioration, with 33 per cent of these saying it was 'slightly' worse and 62 per cent that it was 'much' worse (ibid., page 11). Here is an overview of the sources, broken down according to the period of investigation, method and sample: Fischer Münnich et al. 2020 | 11/20 | Document analysis (n=20) with data from the SOEP, German Ageing Survey (DEAS), long-term care statistics from the Federal Statistical Office; qualitative interviews with facilitators from advice centres and interest groups representing family carers (n=12), online questionnaires (n=202); Rothgang et al. 2020 | Online survey (n=1000); Horn and Schwappe 2020 | 06/20 | Online survey (n=330); Eggert et al. 2020 | 04/10-05/10 | Online survey (n=330).

223 'In the case of Eggert et al. (2020), a quarter feel overwhelmed by the current care situation; in the case of Horn and Schwappe (2020), it is actually slightly higher at 38 per cent. Just under a quarter of family carers are worried that they can no longer cope with providing home-based care (Eggert et al. 2020)'—quote taken from Fischer Münnich et al. 2020, page 14.

The altered circumstances impinge on the mental and physical health of the caregivers themselves while also affecting the relationship between the caregiver and the person in need of long-term care.

‘There is no longer any such thing as down time for family carers. The stress has increased to such an extent that it has led to existential problems.’<sup>224</sup> Various impacts were identified within this context. ‘The proportion of caregivers with depressive symptoms increased between 2017 (6 per cent) and 2020 (15 per cent).’<sup>225</sup> The additional physical strain is also highlighted.<sup>226</sup> In the study by Rothgang et al. (2020), 52 per cent of respondents reported a deterioration in the health of family carers and a reduction in their quality of life in their own eyes. A clear deterioration in psychosocial health can be observed among family carers compared to the time before the COVID-19 pandemic.<sup>227</sup> Those affected reported an increase in feelings of helplessness (29 per cent), stressful conflicts (24 per cent), feelings of despair (22 per cent) and anger (20 per cent) in the context of the care situation.<sup>228</sup>

When the person in need of long-term care has dementia, it makes the situation even more stressful for caregivers. Within this group, 35 per cent felt there was a risk of not being able to continue the care, which was much higher than for the group where the person in need of long-term care did not have dementia.<sup>229</sup>

The causes of the sometimes substantial deterioration in care arrangements are as varied as the context-specific mental and physical consequenc-

es that result from it. The reasons for the changes in stress levels due to the COVID-19 pandemic are covered in detail in the literature and will be presented below.

### 6.1.1 Absence of support

The factor cited as the main cause of increased stress for family carers, particularly during the first phase of the pandemic, was the support that they perceived to be inadequate at various levels.<sup>230</sup>

In the context of residential long-term care, mobile care and informal home-based care, the pandemic led to a dramatic collapse in services. The most drastic effects resulted from the closure of day and short-term care facilities and sheltered workshops for people with disabilities. Around a third of those affected stopped receiving support from their family doctor and 20 per cent experienced a reduction in assistance from mobile care services.<sup>231</sup> Furthermore, the border closures at the beginning of the pandemic prevented the return of assistants and care workers who had gone back to their home countries.<sup>232</sup> Another aspect relates to the conditions and negative experiences associated with residential care facilities.<sup>233</sup> Family carers increasingly showed a preference for the home-based care of family members in need of long-term care rather than entrusting them to residential care facilities.<sup>234</sup> For 57 per cent of family carers, the loss of support structures resulted in long-term care taking up more of their time.<sup>235</sup> In the case of some caregivers, this coincided directly with an increase in financial pressures and job-related worries. For many of

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224 RMC 2020, interviews with facilitators, quote taken from Fischer Münnich et al. 2020, page 11.

225 Klaus and Ehrlich 2021, page 3.

226 See Kuhlmeier and Rode 2020, page 10.

227 See Kuhlmeier and Rode 2020, page 9 f.

228 See Eggert et al. 2020, page 9.

229 See Eggert et al. 2020, page 12.

230 Fischer Münnich et al. 2020, page 11 f.

231 See Eggert et al. 2020, page 14.

232 See Fischer and Geyer 2020, page 3.

233 In addition to the negative experiences with residential care facilities and the conditions inside them, temporary pauses in admissions to these facilities were another factor that inevitably resulted in people making less use of them. According to a study by the ZQP, a total of 62 per cent of the residential care facility managers who were surveyed reported at least a temporary pause in admissions at their facility as a result of the COVID-19 pandemic; see Eggert and Teubner 2021, page 22.

234 See Kuhlmeier and Rode 2020, page 5 f.

235 See Fischer Münnich et al. 2020, page 10.

those affected, their number one choice for countering the increased stress was to take holiday and take time off in lieu for overtime. Accordingly, the majority tended to reduce their working hours, sometimes substantially and without pay.<sup>236</sup> This problem was more acute among those who did not do their work digitally or who were self-employed.

Additional strain was also placed on family carers who had children living in their own household due to the closure of schools, day care facilities and the openly accessible services of family centres, for example. For parents of children with disabilities, home schooling increased the need for additional supervision, as these children found learning in digital classes more challenging than in traditional classrooms.<sup>237</sup> Support from volunteers and neighbours 'ceased completely' in 20 per cent of cases and 'dropped' in 23 per cent.<sup>238</sup>

Overall, the collapse of the support services had a massive impact on family carers. It resulted in their care commitments taking up more of their time, leading in turn to increased stress.

### 6.1.2 Existential fears

Existential worries are being expressed by family carers. A survey conducted from April to early June 2020 found that 9.6 per cent of family caregivers are fearful about their financial security.<sup>239</sup>

In the case of groups that already had a chronic shortage of finances before the COVID-19 pandemic (such as single parents, people in marginal

employment), the deterioration in the situation translated into existential fears. 13 per cent are extremely worried about their professional future.<sup>240</sup> When those affected are broken down according to their monthly net household income, significant differences emerge: within the group with an income of less than 2,000 euros, 44 per cent said they were very worried to slightly worried, whereas this was only true of 21 per cent of those in the group with an income of 4,000 euros or above.<sup>241</sup>

That caregivers have existential worries is also evident from electronic messages received by the secretariat of the Independent Advisory Board on Work-Care Reconciliation. This was particularly reported by self-employed family carers.<sup>242</sup>

### 6.1.3 Worries about family members in need of long-term care

In addition to the loss of support, family carers mainly cite two further reasons for their increased stress levels. Firstly, many felt even more marginalised as a result of social distancing. Secondly, the disappearance of leisure activities and opportunities for family relaxation meant that an important balance was lacking.

As a result of the pandemic, the proportion of family carers who said they felt lonely increased from 33 to 51 per cent.<sup>243</sup> Another factor leading to increased stress was the worry that the majority of all those surveyed (54 per cent) had about bringing the virus home from work and infecting the

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236 See Kuhlmeier and Rode 2020, page 6.

237 See Kuhlmeier and Rode 2020, page 4.

238 See Eggert et al. 2020, page 13.

239 See Theurer et al. 2022, page 138.

240 See Eggert et al. 2020, page 17.

241 See Eggert et al. 2020, page 17.

242 See Kuhlmeier and Rode, page 8.

243 See Rothgang et al. 2020, page 43.

person in need of long-term care.<sup>244</sup> Even though caregivers and those in need of long-term care often both belong to a risk group, family carers were more worried about infecting the person in need of care than getting sick themselves—this particularly affected family carers working in sectors where there was a very high risk of exposure (such as hospital nursing staff).<sup>245</sup>

Moreover, managers banned visits and imposed restrictions at the vast majority (98 per cent) of residential care homes for the elderly during the first wave of infection.<sup>246</sup> As a result, family members had worries about the care and condition of their loved ones at the homes. Family members expressed their fears and worries to the care staff to such an extent that—depending on the specifics of the study—40 to 55 per cent of care staff experienced this as a considerable source of stress.<sup>247</sup> The question of whether these worries were justified and to what extent has not yet been answered.

## 6.2 Objective: ensuring work-care reconciliation in times of crisis as well

The COVID-19 pandemic had a sometimes drastic impact on those in need of long-term care and family carers. As members of groups that were already vulnerable, they were more severely affected—depending on the initial situation—by the pandemic’s negative material and psychosocial consequences and sometimes even suffered existential crises.

A wide range of data is now available on the social impact of the crisis, firmly revealing how work-care reconciliation can better be ensured under the exceptional circumstances of a pandemic. Conclusions should be drawn from this on various levels to prepare for future crises.

Firstly, urgent assistance from the Federal Government must be carefully crafted so that it truly provides relief and ensures a certain amount of security and planning ability in an unclear and confusing situation. Secondly, work urgently needs to be undertaken to make support structures fit for a crisis so that those in need of long-term care are guaranteed to receive care and support and have their other needs met under the circumstances of a pandemic as well as during normal times. Another priority is to assist employers in creating working conditions that are appropriate for the high levels of stress during a pandemic.

## 6.3 Current situation

Measures exist to support the long-term care of family members. Some of these address long-term care directly, while others are intended to reduce the conflicting priorities of work and care. In addition to federal laws, the forms of relief that can be granted by employers also play a key role in work-care reconciliation. Furthermore, support structures provided by civil society—such as information portals, care advice services, self-help groups, volunteers and day care services—are of fundamental importance in relieving the burden on family carers.

244 See Fischer Münnich et al. 2020, page 12.

245 See Kuhlmeier and Rode, page 2 f.

246 See Hering et al. 2021a, page 2.

247 See Hering et al. 2021b, page 3, and Hower et al. 2020, page 19.

The COVID-19 pandemic brought about structural changes on all these levels. Some services and forms of assistance initially disappeared (in some cases without anything to replace them) and were subsequently adapted to the circumstances. The legislature decided to extend its range of measures and employers expanded what they could offer in accordance with the options available to them in each case.

### 6.3.1 Urgent assistance

The Second Act to Protect the Population During an Epidemic Situation of National Significance was passed in May 2020, thereby putting urgent assistance for supporting family carers into effect in the PflegeZG, FPfZG and SGB XI. These special statutory provisions were last extended until 30 April 2023 with the introduction of the Act to Strengthen the Protection of the Population and Particularly Vulnerable Groups Against COVID-19 on 16 September 2022.

The urgent assistance is intended to support family carers in the event of care shortfalls. In particular, the special provisions allow employees to stay off work for up to 20 working days if a sudden care situation arises (see Section 9(1) PflegeZG, previously: ten working days). According to Section 150(5d), first sentence SGB XI, a carer's grant is likewise granted for 20 working days.<sup>248</sup> Furthermore, the provisions offer greater flexibility in terms of organising caregiver leave and family caregiver leave. For example, it is now possible to provide notification in 'text form' (such as via email) instead of in writing (i.e. via a letter with a handwritten signature) (see Section 9(3) PflegeZG and Section 16(2) FPfZG) and to provide notification of family caregiver leave by giving ten working days' notice (see Section 16(2) FPfZG). In addition, any unused months of a work release period can now be taken up to the respective maximum or total duration (see Section 4a PflegeZG; Section 9(4),(5) PflegeZG and Section 2b FPfZG; Section 16(3),(4) FPfZG). On request, months when there was a drop in income due to the pandemic can be ignored when determining the loan amount (see Section 3 FPfZG).

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248 To prevent care shortfalls in the context of home-based care, long-term care insurance funds can, at their own discretion, approve the reimbursement of the costs of mobile care non-cash benefits according to Section 36 SGB XI for those allocated a care grade of 2 to 5 following the submission of an application (Section 150(5) SGB XI). This is conditional upon other measures not being sufficient to ensure the provision of care. Cost reimbursement approvals of this kind must be limited to a maximum of three months. The National Association of Statutory Health Insurance Funds has set out the details in its recommendations. This provision is intended to provide a flexible way of better compensating for COVID-19-related shortfalls in home-based care. As part of this, the long-term care insurance funds are being given greater room for manoeuvre. When taking advantage of this, they are supposed to be able to adopt a graduated approach: the greater the care problems, the less bureaucratic the process of solving them should be. First and foremost, the solution should rely on service providers managed by qualified nurses. After that, it should rely on other service providers (such as services that provide support for general everyday tasks), other medical service providers and, finally, on neighbours.

This provision was introduced as part of the COVID-19 Hospital Relief Act of 27 March 2020 and originally applied until 30 September 2020. It has been extended several times—on the last occasion until 30 April 2023 via the COVID-19 Protection Act.



There is a high level of awareness of urgent assistance among family carers. In June 2020, almost half of family carers agreed with the statement that they were well informed about the ‘COVID-19 assistance package’;<sup>249</sup> just five months later, the figure had risen to 64 per cent.<sup>250</sup>

In the same month, 43 per cent of the managing directors and human resources managers surveyed in a study by Kienbaum Consultants said that they were familiar with the new legal provisions.<sup>251</sup> Distinctions can also be made with regard to respondents’ knowledge of the individual measures: 36 per cent rated their knowledge as high or quite high as far as the ability to make flexible use of family caregiver leave was concerned.<sup>252</sup> The least well-known measure was the one allowing pandemic-related losses of income to be ignored when determining the loan amount for caregiver and family caregiver leave.<sup>253</sup> This reveals that these legal options receive far less attention, at least on a company level.<sup>254</sup>

### 6.3.1.1 Take-up of urgent assistance

The literature posits an urgent assistance take-up rate of six<sup>255</sup> to twelve per cent<sup>256</sup> among those affected. The most frequently used form of assistance was family caregiver leave (partial release from work for up to 24 months) or caregiver leave (partial or full release from work for a total of up to six months), particularly the ability

to take a short-term absence from work (full release from work for up to 20 working days<sup>257</sup>) in the event of a sudden care situation. This option was used by more than half (58 per cent) of those taking advantage of the assistance. The interest-free loan was used less often.<sup>258</sup>

A telephone survey conducted as part of the German Ageing Survey (DEAS) in the period from November 2020 to March 2021 even revealed that 98 per cent of respondents had not made use of any legal measures.<sup>259</sup> The percentage taking advantage of the provisions on short-term absence from work and on caregiver leave was one per cent in both cases; none of the respondents made use of family caregiver leave or release from work to care for someone in the final phase of life (partial or full release from work for a maximum of three months).<sup>260</sup>

Demand for the urgent assistance legislated for in the context of the COVID-19 pandemic also differed according to the size of company: at 21 per cent, the proportion of those making use of it was higher among respondents from companies with more than 250 employees; meanwhile, at small companies with fewer than 50 employees, virtually no use was made of statutory urgent assistance (with only three per cent saying that they did).<sup>261</sup>

249 See Fischer Münnich et al. 2020, page 20.

250 See Fischer Münnich et al. 2020, page 22.

251 See Kienbaum Consultants 2020, page 8.

252 See Kienbaum Consultants 2020, page 8.

253 See Kienbaum Consultants 2020, page 8.

254 See Kienbaum Consultants 2020, page 8.

255 See Horn and Schweppe 2020, page 9.

256 See Kienbaum Consultants 2020, page 9.

257 It was normal for short-term absence from work to be taken as full release from work for up to ten working days. To make work-care reconciliation easier during the pandemic, the legislature increased full release from work to a maximum of 20 working days.

258 See Kienbaum Consultants 2020, page 9.

259 See Ehrlich et al. 2022, page 15.

260 The authors state that the number of take-ups may have been underestimated due to the methods used to determine the period when care and support were provided; see Ehrlich et al. 2022, page 15, footnote 6.

261 See Kienbaum Consultants 2020, page 9.

Fischer Münnich et al. (2020) are cautious in making statements about the characteristics of users, as the small sample size makes it impossible for these to be validated. Family caregiver leave/ caregiver leave and short-term absence from work tend to be used slightly more often by the surveyed family carers who look after someone aged 65 or over.<sup>262</sup> As regards the gender of the users, it is evident that family caregiver leave or caregiver leave, carer's grant and short-term absence from work are predominantly used by women.<sup>263</sup>

In light of the above, it can be asserted that the proportion of family carers who made use of the statutory urgent assistance was quite low. The reasons for this are varied: some family carers simply do not meet the application criteria, as they are marginally employed, are (frequently) self-employed or do not meet the definition of close relatives/family members because the person they are looking after is their uncle or aunt, for example.<sup>264</sup> For another group, the application process involves too much bureaucracy and, given that they cannot be sufficiently certain whether the application will succeed, they cannot afford to take the risk. The urgent assistance measures are still not meeting specific needs in some cases. Examples include no prospect of being able to pay back the loan, and the increased allowance of 20 days being regarded as a sticking-plaster solution to a problem that was severe even before the COVID-19 pandemic. Business-related reasons are also cited: sometimes, employers do not show

sufficient respect and recognition for caregiving duties, causing caregivers to fear losing their job if they were to take advantage of the assistance measures.<sup>265</sup>

Regardless of the take-up rate for urgent assistance, the microcensus (an annual survey of German households) is used to estimate the take-up of full or partial release from work under the PflegeZG or FPfZG. According to a special evaluation of the microcensus, 186,000 people said in 2020 that they had jobs and were taking full or partial release from work under the PflegeZG or FPfZG. In 2021, the number stood at 251,000 people. In 2020, approximately 60 per cent of the people taking advantage of the option were women and approximately 40 per cent were men but, in 2021, the ratio changed to around 50 per cent women and 50 per cent men. The microcensus does not contain any information about the extent and duration of the caregiving duties.<sup>266</sup>

### 6.3.1.2 Appraisal

There are major differences between employers and employees in terms of how they appraise the effects of the urgent assistance. From the perspective of reducing the levels of stress experienced, 45 per cent of family carers feel that the urgent assistance is not helpful, another 39 per cent are unsure and only 17 per cent find it helpful.<sup>267</sup> By contrast, 72 per cent of employers and human resources managers appraise the urgent assistance as helpful.<sup>268</sup>

262 See Fischer Münnich et al. 2020, page 28.

263 See Fische, Münnich et al. 2020, page 29

264 For the purpose of addressing care shortfalls caused by COVID-19, various special provisions were introduced in the long-term care insurance legislation (SGB XI) right at the beginning of the coronavirus pandemic. In order to support people receiving long-term care at home and their family members, an entitlement to COVID-19-related carer's grant was introduced under Section 150(5d) SGB XI. Alongside this, other notable examples of such support include the provisions covering the reimbursement of the costs of mobile care non-cash benefits under Section 150(5) SGB XI, the flexible use of support allowance in the case of a care grade of 1 under Section 150(5b) SGB XI, the higher flat-rate care equipment allowance under Section 40(2), first sentence, second half sentence SGB XI, and the special provisions covering advice for those who are solely recipients of care allowance under Section 148 SGB XI.

265 See Fischer Münnich et al. 2020, page 33.

266 See Statistisches Bundesamt 2022e.

267 See Fischer Münnich et al. 2020, page 15.

268 See Kienbaum Consultants 2020, page 9.

Criticism of the measures by family carers follows the same logic as the aforementioned reasons for not taking advantage of the urgent assistance. In particular, there is a clearly held view in relation to the loan: in light of the obligation to repay it, the loan is of little use and is only of benefit to people who are financially secure. In addition, family carers stress the amount of bureaucracy involved, which represents an additional burden in crisis situations.<sup>269</sup>

### 6.3.2 Support provided by businesses

Not much data is available on the take-up and appraisal of support provided by businesses during the crisis. For this reason, this subsection is mainly based on surveys of the employers themselves.

According to Kienbaum Consultants (2020),<sup>270</sup> 65 per cent of the surveyed employers offered support measures in the context of the COVID-19 pandemic (primarily in the form of home working) and 62 per cent of them expanded the options they were already offering. These included flexible working hours, an increase in short-time working allowance, paid release from work, more holiday or days off, and childcare facilities within the company. Furthermore, 44 per cent of the companies offer advice and information on better work-care reconciliation and 19 per cent offer specific networking opportunities.<sup>271</sup>

#### 6.3.2.1 Take-up

At the surveyed companies, the measures—where available—were used by a high proportion of employees. Almost 90 per cent of caregiving employees took advantage of flexible working arrangements with regard to work location and working hours, and short-time working.<sup>272</sup> Aside from the measures specified by the employers, employees primarily made use of individual business strategies, such as taking time off in lieu for overtime (23 per cent), accruing negative hours by working undertime or taking unpaid leave (11 per cent).<sup>273</sup>

#### 6.3.2.2 Appraisal

78 per cent of employers rated the support measures provided by businesses as adequate.<sup>274</sup>

Meanwhile, a study by the Centre for Quality in Care (ZQP) dating from 2020 reveals that 64 per cent of employees are satisfied with their employers and that they regard specific models—such as working time agreements that are flexible with regard to working hours and location—as key elements for making work-care reconciliation easier.<sup>275</sup> Working from home at the beginning of the pandemic essentially enabled family members to compensate—at least in part—for lost sources of assistance by becoming personally involved in the long-term care and flexibly adjusting their working hours. The extent to which this had a generally positive effect on the stress levels experienced cannot be unambiguously stated on the basis of the currently available studies. Messages

269 See Fischer Münnich et al. 2020, page 28.

270 In their analysis, Kienbaum Consultants (2020) evaluated three existing studies. This was supplemented by conducting 253 telephone surveys with human resources managers at SMEs from an extremely wide range of sectors and regions, and ten interviews with employers who were considered role models for a care-friendly working environment (mainly winners of/nominees for the Otto Heinemann Prize for work-care reconciliation). The following studies were analysed: ZQP and Charité (June 2020): *Pflegende Angehörige in der COVID-19-Krise: Ergebnisse einer bundesweiten Befragung* (Family carers during the COVID-19 crisis: results of a national survey); Johannes Gutenberg University Mainz (July 2020): *Häusliche Altenpflege in Zeiten von Corona: Erste Studienergebnisse* (Home-based old-age care in the times of the coronavirus); University of Bremen in cooperation with DAK-Gesundheit and wir pflegen e.V. (2020): *Zur Situation der häuslichen Pflege in Deutschland während der COVID-19-Pandemie: Ergebnisse einer Online-Befragung von informellen Pflegepersonen im erwerbsfähigen Alter* (Concerning the situation of home-based care in Germany during the COVID-19 pandemic: results of an online survey among informal caregivers of working age).

271 See Kienbaum Consultants 2020, page 17.

272 See Kienbaum Consultants 2020, page 18.

273 Rothgang and Wolf-Ostermann 2020, page 39: *Online-Befragung (n=1.000) von informellen Pflegepersonen im erwerbsfähigen Alter* (Online survey (n=1,000) among informal caregivers of working age).

274 See Kienbaum Consultants 2020, page 9.

275 See Eggert et al. 2020, page 18.

received by the Independent Advisory Board on Work-Care Reconciliation show, for example, that work from home was perceived as a challenge that did not reduce the stress associated with providing care at home.

### 6.3.3 Advice

The long-term care of family members sometimes places heavy cognitive and emotional demands on those affected. Therefore, advice and access to information can be crucial for relieving the burden on them and maintaining the provision of high-quality care.<sup>276</sup> In 2017, a study by Schneekloth et al. showed that virtually all those in need of long-term care or family carers (96 per cent) had sought advice in connection with the care situation on at least one occasion. However, this mainly concerned care advice in the narrower sense rather than issues around work-care reconciliation, in respect of which there were significant information gaps.<sup>277</sup>

At the beginning of the COVID-19 pandemic, numerous advisory services initially disappeared without anything to replace them. This not only involved the local offices of the advisory institutions but also proactive outreach advice provided in the home, as well as support groups and information events.<sup>278</sup> Below, we examine the subsequent structural changes to the advisory landscape, the main subjects of advice and the level of demand.

#### 6.3.3.1 Take-up of information and advice

In Eggert et al. (2020), 18 per cent said that they had already sought information about COVID-19 and home-based care, and four per cent said that they had taken professional advice specifically on the subject.<sup>279</sup>

Following an initial period of reduced contact between advice centres and family carers—which, among other things, was due to technical obstacles and a lack of contactability, virtually all the facilitators interviewed by Fischer Münnich et al. (2020) reported on the establishment of telephone-based advisory services during the first lockdown from March to May 2020.<sup>280</sup> Within this context, increasing demand for numerous services was recorded. Crisis calls to the care hotline and email enquiries from those seeking advice in crisis situations quadrupled in 2020 compared to the previous year. There was also an increase in the average length of each consultation.<sup>281</sup> In addition, not only was there greater demand for existing digital services, such as the website [www.wege-zur-pflege.de](http://www.wege-zur-pflege.de), but new ones were also established, such as online self-help groups and other family carer networks.<sup>282</sup> In contrast to this, when an analysis was made of the volume and duration of care advice provided in-person by mobile care services in Bavaria, it revealed an 80 per cent drop in the number of consultations from the end of March to mid-April 2020 compared to February 2020.<sup>283</sup> This slump in the advice figures can be explained by people's worries about getting infected with SARS-CoV-2.<sup>284</sup>

276 The legislature responded to the need for advice by making advice services more flexible under Section 148 SGB XI as part of the special COVID-19 provisions.

277 Schneekloth et al. (2017) stress that a large proportion of family carers were unaware of many work-care reconciliation support services even before the COVID-19 pandemic: '[...] 64 per cent of those surveyed were unaware of the entitlement to a short-term absence from work due to care commitments, only a third were aware of the existence of carer's grant as a wage compensation benefit, 40 per cent were unaware of the possibility of taking caregiver leave, just under half (49 per cent) were aware of the ability to take family caregiver leave with partial release from work for up to 24 months, and only a fifth of the working respondents also knew about being able to apply for an interest-free loan in addition to taking six months of caregiver leave or family caregiver leave' (ibid., quote taken from Fischer Münnich et al. 2020, page 16).

278 See Fischer Münnich et al. 2020, page 17 f.

279 See Eggert et al. 2020, page 15.

280 See Fischer Münnich et al. 2020, page 18.

281 See Fischer Münnich et al. 2020, page 19.

282 See Fischer Münnich et al. 2020, page 18.

283 See Hallensleben and Wöhler 2021, page 84.

284 See Hallensleben and Wöhler 2021, page 85.

The two subjects that dominated consultations during the COVID-19 pandemic were urgent assistance and the feeling of being ‘overwhelmed’ that came from worrying about the person in need of long-term care, although the latter was by far the most commonly addressed topic.<sup>285</sup> 19 per cent of users enquired about urgent assistance, with the advisers reporting that the most frequently enquired about option was time off in the form of a short-term absence from work, whereas the new provisions on family caregiver leave and caregiver leave were seldom broached and the types of relief afforded by the loan and provisions of SGB XI were virtually never mentioned at all.<sup>286</sup> Enquiries from employers about urgent assistance were extremely rare. Instead, it tended to be more a question of receiving complaints from family carers whose employers had refused to grant them release from work.<sup>287</sup> A study from 2021 suggests that those in need of long-term care and their family members needed advice (very) frequently when the vaccinations against infectious COVID-19 started, both in relation to the vaccine itself (50 per cent) and the issuing of appointments (44.1 per cent).<sup>288</sup>

In addition to COVID-19-specific concerns, many questions about unresolved matters were submitted directly to the Independent Advisory Board on Work-Care Reconciliation. These included: improvements for family carers commuting to and from work, the impact of short-time working on family caregiver leave, the ability of family members to take on care duties while being confident of financial security and receiving associated contributions towards their pension entitlement, general forms of financial support and the Advisory Board’s future strategy in relation to self-employed family carers.<sup>289</sup>

### 6.3.3.2 Appraisal

For the purpose of appraising the wide range of advisory services, very few quantifiable statements are to be found in the publications on work-care reconciliation under the conditions prevailing during the pandemic. However, just under a fifth of respondents (19 per cent) in the business survey felt that there were gaps in services, consisting predominantly of a lack of information and advice channels for family carers at a business level. This figure was slightly higher among surveyed companies with more than 250 employees, where it stood at 27 per cent. Meanwhile, it was found to be particularly low (less than eleven per cent) among respondents from companies with fewer than 50 employees.<sup>290</sup> This is consistent with the statement made by the majority of employers, who said that they only share information on request.<sup>291</sup>

A clear thread running through the survey by Fischer Münnich et al. (2020) was that the affected persons were not lacking advice and information—for instance, 87 per cent felt that they were well-informed about COVID-19 in general<sup>292</sup>—but that there was no standardised communication infrastructure in place.<sup>293</sup>

### 6.3.4 Number of caregivers and people in need of long-term care

When multiple waves of the DEAS survey were analysed, it revealed that the proportion of family members in need of long-term care barely changed in the course of the COVID-19 pandemic. The figure for parents (and parents-in-law) stood at 49.2 per cent in 2017, at 54.5 per cent in the summer of 2020 and at 54.2 per cent in the winter

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285 See Fischer Münnich et al. 2020, page 19.  
286 See Fischer Münnich et al. 2020, page 21.  
287 See Fischer Münnich et al. 2020, page 21.  
288 See Strube-Lahmann et al. 2021.  
289 See Kuhlmeier and Rode 2020, page 10.  
290 See Kienbaum Consultants 2020, page 26.  
291 See Kienbaum Consultants 2020, page 8.  
292 See Eggert et al. 2020, page 15.  
293 See Fischer Münnich 2020, page 18.

of 2020/2021. Prior to the COVID-19 pandemic, the proportion of partners in need of long-term care was 17.0 per cent, compared to 14.9 per cent at the beginning of the pandemic and 20.7 per cent in the winter of 2020/2021. The proportion of unrelated neighbours and friends requiring long-term care increased from 20.9 per cent in 2017 to 24.5 per cent in the summer of 2020 before subsequently dropping to 17.9 per cent in the winter of 2020/2021. The authors conclude that the frequency of care for parents (and parents-in-law) and partners during the COVID-19 pandemic was similar to the period before the outbreak. Support for neighbours and friends increased only temporarily during the first wave of the pandemic.<sup>294</sup>

However, some initial special evaluations based on the SOEP-CoV data<sup>295</sup> indicate that substantially more people engaged in the provision of care in 2020. The number of people who said—in the context of a survey conducted during the first COVID-19 lockdown—that they were regularly providing care on working days increased from 4.1 million in 2019 to 6.4 million in 2020, a rise of around 56 per cent.<sup>296</sup>

### 6.3.5 The health of family carers

We already know from electronic messages received by the secretariat of the Independent Advisory Board on Work-Care Reconciliation between January and October 2020 that family carers felt overwhelmed by their physically strenuous care responsibilities during the first wave of the pandemic.<sup>297</sup> Similarly, an analysis of depressive symptoms in the context of the DEAS survey suggests that these symptoms were more prevalent among people with support and care

duties in the first wave of the COVID-19 pandemic (14.8 per cent) than before it (6.3 per cent). This difference was particularly apparent among female caregivers (7.2 per cent versus 16.2 per cent). During the second wave of the COVID-19 pandemic in the winter of 2020/2021, the prevalence of depressive symptoms decreased to pre-pandemic levels both within the general population and within the female partial sample (6.4 per cent and 7.3 per cent respectively). However, this sample's subjective perception of their own health did not change over the course of the pandemic.<sup>298</sup>

### 6.3.6 Summary

In an area of conflicting priorities that is as complex as work-care reconciliation under pandemic conditions, family carers are reliant on support measures that are geared towards their needs and available on multiple levels. In a survey by the University of Bremen, family carers were asked to rate potential measures from various areas in descending order on a scale from 'good' to 'bad' according to whether they regarded them as suitable for reducing stress:<sup>299</sup>

- Flexible use of the support allowance (according to Section 45b SGB XI, the long-term care insurance funds or private insurance companies can pay 125 euros per month to people in need of care who have been allocated a care grade of 1 or above but it must be used for a specific purpose)
- Periods of release from work with continued pay
- Provision of protective materials/equipment<sup>300</sup>

294 See Ehrlich and Kelle 2022, page 4 f.

295 See Calahorrano, Herrmann, Rebaudo 2022, page 15.

296 See Calahorrano, Herrmann, Rebaudo 2022, page 15.

297 See Kuhlmeier and Rode 2020, page 9.

298 See Ehrlich and Kelle 2022, page 6 ff.

299 See Rothgang and Wolf-Ostermann 2020, page 46. They were not asked which existing services were helping but which services would help those affected. Thus, the result is more like a 'wish list'.

300 With regard to this point, we should explain that the increase in the flat-rate care equipment allowance (Section 40 SGB XI) from 40 to 60 euros applied until 31 December 2021.



- Expansion of COVID-19 tests
- Work from home
- Freely available budget to cover the costs of day care and short-term care
- Flexible working hours
- Telephone-based advisory services
- Reduction in working hours
- Other support
- Expansion of digital support and advisory services
- Unpaid release from work in emergency situations
- Special shopping times and priority treatment for delivery services
- Day care at the workplace for those in need of long-term care
- Online self-help groups

An examination of this list quickly reveals which measures are better for countering the causes of increased stress for family carers and which ones are less well suited. The top half of the list clearly consists of various forms of assistance that provide those affected with more time and financial resources while simultaneously better supplying them with healthcare items. Release from work with continued pay and flexible use of the support allowance are the primary factors that would result in long-term care duties being labelled a ‘worthwhile task’.<sup>301</sup>

The low take-up rate for statutory urgent assistance and the fact that family carers themselves are critical of it clearly reveal that—even though it is viewed as a sign of recognition by younger caregivers in particular—the measures fail to reach large swathes of those affected and should be better tailored to their needs. In addition to the aforementioned strategies, other measures that caregivers use to combat stress primarily include sick notes from doctors, holiday, teleworking and other support services, such as day and respite care, meals on wheels and assistance from their own family.

The data shows that—in this situation—caregivers mainly made use of the relief options available within the context of their employment. Here, the effect of their supervisor’s/line manager’s attitude must not be underestimated. Support from businesses was prioritised over statutory urgent assistance, partly due to the fact that this support can be implemented more quickly and with less bureaucracy. However, the long-term or medium-term impact of this support has not yet been adequately researched. Firstly, sick notes are finite and holiday entitlements eventually get used up; secondly, the permanent effects of teleworking on long-term care settings have not been sufficiently quantified.

It is obvious that time and money are no substitute for advisory services. However, despite being grouped together towards the bottom middle of the above ranking, the importance of advisory services must not be overlooked. This is because they are closely linked to the other support services. Firstly, they are the starting point for applying for these services and, secondly, crisis calls—for example—can provide significant relief in care situations that arise suddenly.

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301 See Rothgang and Wolf-Ostermann 2020, page 48 f.



## 6.4 Recommendations for action

Due to their responsibilities and limited time resources—especially in times of crisis—family members who provide home-based care are reliant on framework conditions that are transparent, comprehensible and reliable. Particularly at the beginning of the COVID-19 pandemic, this was not always the case. Therefore, it is absolutely essential to draw on the experience that has been gained to create concepts for action, support and communication that meet these requirements. Some concrete guiding principles for consideration in the future have emerged as a result of analysing the situation of family carers who had to reconcile work and care under the sometimes very difficult conditions of the COVID-19 pandemic. Overall, the COVID-19 pandemic has once again highlighted the existing deficiencies of long-term care provision in Germany and has emphasised the need for the system to undergo fundamental reform. It has become apparent that both home-based and residential long-term care are not adequately prepared for crisis situations and that there is an urgent need to improve crisis preparedness and crisis management.

With regard to possible future crisis situations, it is not enough simply to draw up emergency plans. What truly matters is for precautionary measures to be laid down by law. Among other things, this includes creating medical and pharmacological capacity, ensuring that protective equipment and other materials are available not only to care homes and mobile care services but also to family carers, and planning additional staffing resources in sensitive areas. This kind of crisis preparedness planning must take place at the national, regional and municipal levels.

### The Advisory Board recommends:

- The measures implemented at the federal level during the pandemic should be systematically researched and evaluated. On the basis of this, crisis concepts should be promptly developed, for which minimum requirements should be laid down in federal law that will apply in all

federal states. Implementation of these provisions must be monitored, with responsibilities to be agreed locally among the stakeholders.

### 6.4.1 Making support networks crisis-proof

The proper functioning of support structures is always absolutely vital for work-care reconciliation—but all the more so during a crisis. This not only applies to the maintenance of care services but also those services (such as advice) that benefit the mental health of family carers. As well as addressing the deficits in care provision (including, among other things, the shortage of staff, the problem of care staff overload and the regional differences in the availability of care provision) that were already generally known and simply became more apparent as a result of the pandemic, work should also be done to make the services more resilient to crises by drawing on the experience gained from the years of the pandemic. Services to relieve the burden on caregivers, such as mobile services or short-term care, need to function properly in times of crisis as well as the rest of the time. Among other things, this calls for standardised hygiene concepts, obligatory further training in this area for all employees and reliable access to testing capacity and hygiene equipment/materials. In addition to strengthening mobile care in this way, similar measures are also required in relation to residential retirement homes and care homes for the elderly.

### The Advisory Board recommends:

- All institutions that look after people in need of long-term care should be developed to ensure that they can continue functioning properly if any new crisis and pandemic situations should arise. In future, the quality inspection criteria for care facilities should include a check to ensure that a successful crisis management system exists. Among other things, this means having modern hygiene concepts in place, documenting the further training of staff in this area and keeping a stock of protective equipment.

### 6.4.2 Synchronising the advice topics covered and ensuring low-threshold distribution

The studies on the pandemic have revealed that advice and information are key elements for supporting family carers. Particularly in times of crisis, the Federal Government, federal states and municipalities should coordinate the advice topics covered to ensure consistency while ensuring low-threshold access to the advice. Given the high level of psychosocial stress exerted on family carers, all municipalities need to have advisory and support services that are thoroughly interconnected and can spring into action immediately, including in emergencies (in the form of ‘immediate aid teams’, for example). Especially in times of crisis, these should also refer caregiver households to household-related services that are available free of charge, such as shopping assistance services.

**The Advisory Board recommends:**

- Information about sources of assistance, support networks and advice services in times of crisis should be produced centrally and made available to everyone able to distribute it in their capacity as a facilitator. Both formal and informal structures should be involved in this.

### 6.4.3 Strengthening the position of family carers through publicity and research

Greater public recognition is important to family carers. A majority of family carers would like the issue of ‘care and work’ to enjoy a higher public profile and would like to be shown greater appreciation for the dual role that they perform.<sup>302</sup>

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302 See Kienbaum Consultants 2020, page 10.

**The Advisory Board recommends:**

- The topic of work-care reconciliation, including in crisis situations, should be addressed in a more public manner.

To strengthen public recognition of family carers who work, their situation needs to be researched further with more conclusive results. For instance, although sociodemographic and economic categories do feature in the studies on stress levels and support measures, the influences of age, gender and income have barely been quantified so far. Other variables, such as place of residence and type of employment relationship, are covered to an even lesser extent. However, one particular area that has not yet been sufficiently studied is how the individual care situations affect the ability to overcome crises. In-depth analysis could provide detailed findings on the impact of various stress or relief factors and associated means of overcoming crises.

**The Advisory Board recommends:**

- Research in the area of work-care reconciliation should be expanded in general and also in relation to crisis situations. Further findings should be obtained on how measures (in crises) can be better tailored to the needs of the target group and how support structures should be made more effective (in crises).

# 7

## Minority votes regarding family caregiver leave and family caregiver allowance

### 7.1 Minority vote by the BDA regarding the decisions of the Independent Advisory Board on Work-Care Reconciliation: practical approaches to work-care reconciliation are important to businesses

Long-term care is an important issue for the whole of society. This is becoming increasingly apparent in everyday business life. That is why many companies ensure that it is possible to reconcile family commitments with the demands of work so that they can support, motivate and retain employees while also attracting new ones on the German labour market. The numerous solutions that have been found at a local level consider the interests of employees and the needs of businesses equally. As the umbrella organisation representing the sociopolitical and politico-economic interests of a million businesses with around 20 million employees, the Confederation of German Employers' Associations (BDA) advocates for a business-friendly, family-conscious human resources policy via initiatives and activities such as those associated with the 'Frauenförderung im Unternehmen' (Promotion of Women in Business) and 'Erfolgsfaktor Familie' (Success Factor Family) programmes.

According to the 'Unternehmensmonitor Familienfreundlichkeit' (Monitor of Corporate Family Friendliness) (commissioned by the Federal

Ministry for Family Affairs, Senior Citizens, Women and Youth), more than half of employees say that, in general, they are able to reconcile their working hours with their family and social commitments outside of work 'well', with a third of all employees even going as far as to say that they can do this 'very well'. Only 1.5 per cent can see absolutely no possibility of reconciling the two aspects. Over recent years, there has been a constant increase in the options offered by businesses in the event of employees having to provide family members with home-based care. According to the working time report by the Federal Institute for Occupational Safety and Health (BAuA), these include partial and full release from work—sometimes even beyond the scope of the statutory provisions—and associated financial support. Well over half of employees have also benefited from the flexibility offered by working time accounts, which are an indispensable component of a family-friendly human resources policy.

The decisive factors for what is offered in each individual case are the level of resilience and the operational feasibility of measures, particularly in light of the company's size. However, operational feasibility imposes limits as far as the employer is concerned, as confirmed by the 'Unternehmensmonitor Familienfreundlichkeit' (Monitor of Corporate Family Friendliness) survey. From the perspective of companies, the Advisory Board's recommendations go too far by proposing an extension of the statutory entitlements to release from work and part-time hours, and the introduction of a wage compensation benefit in the form of family caregiver allowance. Further voluntary solutions should be promoted while increasing the necessary room for manoeuvre with a view to identifying solutions that are sensible and sustainable for both parties and will be accepted accordingly.

### On specific recommendations

#### **Expanding the group of eligible persons would be counterproductive**

The BDA is critical of the recommendation to expand the group of eligible persons to include those with especially close ties to the person in need of long-term care. This is expected to result in additional requests for release from work or part-time hours beyond what businesses have—in practice—so far been required to implement based on the various legal entitlements. Skilled and replacement staff of the requisite quality are already almost impossible to find when businesses need them. Nor are there any criteria for determining what constitutes a 'person with a similarly close relationship'. Official confirmation by the caregiver is not sufficiently reliable on its own for granting such an extensive entitlement to release from work or a reduction in working hours in conjunction with special protection against dismissal and financial support. Having a clear set of criteria to justify use of the benefits is also essential from the perspective of preventing abuse.

The eligible group of relatives is already large and, according to the recommendations of the Advisory Board, is to be further expanded. As a result, an

appropriate range of people will be covered—in other words, only those who are related to the person requiring long-term care. By contrast, there is no justification for expanding the group in an indiscriminate manner.

#### **Decision concerning care grade 2 upheld**

During its previous term of office, the Advisory Board decided that a care grade of 2 should be the key criterion for granting entitlement to (partial) release from work and to the financial support. This is appropriate. The process of implementing release from work places a considerable burden on businesses from the perspective of personnel planning and entitlement to this should only be triggered as of a certain degree of need for long-term care. In a new decision, the Advisory Board has changed its recommendation by unnecessarily reducing the requirements for care-related release from work; from now on, a care grade of 1 should suffice. This cannot be explained or justified on the grounds that the care levels have been changed to care grades since the Caregiver Leave Act came into force. The previous care level of 1 was much broader, encompassing what is now care grade 2 under today's much more strongly differentiated system of care grades. From the perspective of what the different care grades cover, release from work can only be justified from a care grade of 2.

#### **Thresholds for full release from work are essential**

Thresholds are a generally recognised instrument under labour law to protect small and medium-sized enterprises (in particular) from excessive burdens that could ultimately jeopardise their existence to the detriment of employees. The greater the volume of temporary part-time entitlements to be implemented by a company, the greater the effort involved in searching for the necessary personnel or in reorganising the core business on which it relies to generate profit and maintain jobs. In addition, such positions increasingly remain vacant in spite of making every effort to fill them. They are not attractive due to the limited number of hours and their temporary nature, with the result that the remaining colleagues are left to shoulder the workload.

Therefore, from the perspective of companies, thresholds for protecting small businesses need to be retained—including in the case of full release from work. The ‘Unternehmensmonitor Familienfreundlichkeit’ (Monitor of Corporate Family Friendliness) survey has identified certain limits of feasibility for supportive measures, particularly in the case of SMEs. The human resources capacity of the companies was found to play an important role in workplace offerings. Smaller companies and businesses lack the necessary leeway to arrange cover for an absent employee by redistributing tasks. Furthermore, no comparison can be made with the Federal Parental Allowance and Parental Leave Act (BEEG), which does not stipulate any threshold for full release from work. In contrast to elderly persons in need of long-term care, newborns cannot normally be placed in the care of others.

The Advisory Board is currently exploring the specific issue of work-care reconciliation at SMEs in the context of a further working group. In our view, the results of the working group should be fed into the political discussion about a possible change to the applicable thresholds. They should not be left out of considerations just because a request has been made for the first part of the report to be submitted early to the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

### **Loan solution should be retained**

The BDA is in favour of retaining the existing loan. The specific reasons for the loan’s extremely low take-up rate are unknown. A wage compensation benefit that would be set in a similar way to parental allowance and would be granted for up to 36 months per person in need of long-term care would be a heavy financial burden on the state at the current time. In addition, an increase in benefits of this kind could provide incentives to claim considerably more time away from work. This would lead to a significant additional burden on businesses. The greater the number of employees being released from work, the greater the company’s need for personnel planning, and the more costly and hopeless the chances of finding

replacement staff. A family caregiver allowance in the form of a ‘lost grant’ would ultimately burden employers twice: financially via tax co-financing and operationally via the organisational implementation of the periods of work release (which would be likely to increase).

### **Extending and splitting up family caregiver leave would place a substantial burden on businesses**

There are already various entitlements allowing employees to change their working hours or to be released from work for a limited period, sometimes without there having to be an objective reason for temporarily deviating from the contractually agreed working time. At the same time as the bridge period, an entitlement to a discussion was introduced in 2019 should the employee request a change to the duration or scheduling of their working time. In addition, there are numerous collective bargaining agreements covering further working time-related entitlements. But irrespective of this, the contracting parties can—in practice—choose from a wide range of solutions for needs-based reconciliation of work and care. In light of the current labour market situation, it would be a mistake to extend the duration of family caregiver leave.

In particular, the plan to divide up the entitlements to work release is mistaken. The recommended split into three time blocks would impose major organisational and bureaucratic challenges on businesses because an employee would then be able to take the same family caregiver leave three times. On each individual occasion, the available personnel would have to be reorganised or replacement staff would have to be sought. If the company were not able to redistribute the work internally, new employees would have to be hired to cover the temporary partial reduction in the released employee’s working hours. In the case of many sectors and jobs, it is almost impossible to find suitably qualified replacement staff for a limited period and for positions that are only part-time. Placing an additional burden on the remaining employees, for example in the form of overtime, can rarely be avoided.

**Setting notification periods that are appropriate for both parties**

Having a sufficiently long notification period is an absolute necessity from the company's perspective so that they can adjust to an employee's absence or a reduction in their working hours. Sufficient time must be allowed to enable the reorganisation of business processes or to find and induct appropriately qualified replacement staff. It is generally more difficult to fill a post that is only temporary, particularly when the part-time position involved is tied to set times and is not flexible (such as working afternoons in a retail shop).

As regards the length of the notification periods, the Advisory Board argues for periods that are appropriate to the circumstances and stresses that there should be no deterioration of the situation compared to now. However, when determining *appropriate* periods, the interests of employees and employers vis-à-vis the respective entitlement must be considered and weighed up. Currently, a notification period of only ten days applies for caregiver leave. If caregiver leave is preceded by a short-term absence from work, it effectively constitutes release from work without notice from the perspective of the employer. This prevents the employer from being able to prepare at all. Given

that the Advisory Board has also decided that operational feasibility needs to be ensured, periods such as these should be critically reviewed. In any event, in cases where provision of long-term care can be planned, for example because someone is taking on the care responsibilities from somebody else in the context of a pre-existing care situation, a longer notification period is required from the company's vantage point.

**Special protection against dismissal is adequate**

Plans to extend special protection against dismissal by three months following a return to work after parental leave should not be carried across too hastily to family caregiver leave. The coalition agreement is expressly limited to parental leave.

**Contact:**

BDA | DIE ARBEITGEBER  
Bundesvereinigung der Deutschen  
Arbeitgeberverbände  
(Confederation of German Employers'  
Associations)  
Department of labour law and collective  
bargaining policy  
Telephone: +49 30 2033-1203  
Email: [arbeitsrecht@arbeitgeber.de](mailto:arbeitsrecht@arbeitgeber.de)

## 7.2 Minority vote by the Federal Association of Municipal Employers' Associations and the Association of Municipal Employers' Associations

The municipal employers are aware of the responsibility they have towards their employees, including in light of the increasing significance of long-term care for family members. For this reason, they support many aspects of the recommendation for action. However, the municipal employers have long been offering flexible models and advisory support for family carers. Therefore, the Federal Association of Municipal Employers' Associations and the Association of Municipal Employers' Associations reject any further expansion of legal entitlements to release from work

and part-time hours. This stance is partly aimed at maintaining the voluntary commitment shown by employers in providing tailored and individual offerings and options for employees. Consequently, the Federal Association of Municipal Employers' Associations and the Association of Municipal Employers' Associations support the minority vote by the Confederation of German Employers' Associations (BDA) regarding the decisions of the Independent Advisory Board on Work-Care Reconciliation.



## 7.3 Minority vote by the AGF on the level and calculation of family caregiver allowance

The AGF emphasises the high level of importance that it attaches to designing family caregiver allowance in a socially equitable manner. Making a direct analogy with the wage compensation benefit of parental allowance is not conducive to achieving this objective. For this reason, it is advocating for a lump-sum benefit set at an appropriate level but, as a minimum, for a design that takes greater account of social criteria than in the case of parental allowance. If the extent of family caregiver allowance is to be determined on the basis of the employee's previous wage, this might mean—for example—using a calculation for low-income groups that incorporates a higher percentage of the previously earned income than when calculating parental allowance or, alternatively, raising the income limit up to which a full wage compensation benefit will be paid.

The AGF recognises the need for more gender-equitable distribution of care work and supports measures that pursue this objective. However, the design of family caregiver allowance should also allow for social factors since long-term care services that are not covered by long-term care insurance represent an excessively high financial burden, particularly for low-income families, with the result that these families (are compelled to) take on the care duties themselves.

From the perspective of achieving the gender equity aimed for, the AGF has doubts about the planned family caregiver allowance. It is not sure whether the same effects in the sphere of gender

policy can be expected as those that have—fortunately—been witnessed in connection with parental allowance. In the realm of long-term care for family members, we are less concerned with the kinds of male-female dyads that apply in the context of childcare for most parents, who freely decide (or decide based on economic incentives) which parent is going to take responsibility for which share of the care work.

Therefore, the AGF questions whether the use of resources is efficient in the case of family caregiver allowance from the perspective of achieving the equality policy aim. At the same time, it fears that calculating family caregiver allowance in exactly the same way as parental allowance could result in a socio-politically unjust distribution of resources to the detriment of those with low incomes. After weighing up these points, the AGF believes that the impact of a lump-sum family caregiver allowance that is set at an appropriately high level, is conducive to social balancing and involves exactly the same total tax outlay would be more compelling and efficient for achieving the desired objective compared to the equality policy-related impact of the planned benefit that is the preferred option of the majority of the Advisory Board members and would be largely equivalent to the employee's wage. The AGF fears that this approach is not capable of achieving an equality-policy related impact of a similar level to parental allowance and, therefore, that the associated 'bottom to top' redistribution is not justified.



# 8

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# 9

## Annexes

### 9.1 Mandate and framework

The Independent Advisory Board on Work-Care Reconciliation was appointed by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth in 2015. In accordance with its remit under Section 14(2) FPfZG, the Advisory Board deals with issues concerning work-care reconciliation and monitors implementation of the relevant statutory provisions, particularly the Caregiver Leave Act (PflegeZG) and Family Caregiver Leave Act (FPfZG). Every four years, the Advisory Board submits a report to the ministry in accordance with Section 14(3) FPfZG. The Advisory Board's first report was submitted on 1 June 2019. There, the Advisory Board took comprehensive stock of the current situation regarding work-care reconciliation, presented the statutory provisions and thoroughly considered the support services for family carers (who work). Numerous recommended actions were proposed for each of the individual issues. However, the key

recommendation focussed on reforming the statutory provisions—by merging the Caregiver Leave Act and Family Caregiver Leave Act into a single law, adapting the provisions in line with actual needs and introducing a wage compensation benefit for family carers who work. The Independent Advisory Board carried on with this work in its second report, which presents a specific model for reforming the Family Caregiver Leave Act. The work was carried out within the context of several working groups, conferences and Board meetings. Decisions concerning the report and recommended actions are taken at the Board meetings according to Section 8 of the Advisory Board's Rules of Procedure. These require the consent of two thirds of the 21 Advisory Board members. The Advisory Board is supported by a secretariat, which is located at the Federal Office of Family Affairs and Civil Society Functions (BAFzA) in Berlin.

## 9.2 Working groups

Work on the second report was carried out within five working groups, each of which had a specific focus. The contributions and recommendations from each working group were discussed and developed further at the Board meetings. The focal areas of the working groups were:

**Working group 1:** Models for wage compensation benefits and forms of release from work for working carers

**Working group 2:** Further development of care infrastructures to support work-care reconciliation

**Working group 3:** Work-care reconciliation in the case of children who require long-term care

**Working group 4:** Work-care reconciliation at small and medium-sized enterprises (SMEs)

**Working group 5:** Work-care reconciliation under the conditions prevailing during the COVID-19 pandemic

## 9.3 Board members

The gender-balanced Advisory Board consists of 21 members appointed by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. Prof. Dr. phil. Adelheid Kuhlmei, a medical sociologist and gerontologist, has been Chair of the Board since 1 January 2020. Prof. Dr. Andreas Hoff, Professor of Social Gerontology, is currently serving as the Deputy Chair. The composition of the Independent Advisory Board on Work-Care Reconciliation is governed by Section 14 of the Family Caregiver Leave Act. The period of tenure is five years. The members serve on the Board in a voluntarily capacity. The currently appointed members are:

1. **Chair:** Prof. Dr. Adelheid Kuhlmei (Charité—University Hospital)
2. **Deputy Chair:** Prof. Dr. Andreas Hoff (Zittau/Görlitz University of Applied Sciences)
3. Antje Asmus/Juliane Zinke (Deputy) (Deutscher Frauenrat/National Council of German Women's Organizations)
4. Dr. Uda Bastians/Dr. Kay Ruge (Deputy) (Bundesvereinigung der kommunalen Spitzenverbände/Federal Association of Municipal Employers' Associations)
5. Andreas Besche/Anne-Kristina Vieweg (Deputy) (Verband der Privaten Krankenversicherung e.V./Association of Private Health Insurers)
6. Brigitte Bührlen/Dr. Eckart Bührlen (Deputy) (Wir! Stiftung pflegender Angehöriger)
7. Benjamin Fehrecke-Harpke/Lisa-Marcella Schmidt (Deputy) (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege/Federal Association of Non-statutory Welfare—BAGFW)
8. Ulrike Gebelein/Jana Teske (Deputy) (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege/Federal Association of Non-statutory Welfare—BAGFW)
9. Dr. Regina Görner/Anna Brückner (Deputy) (Bundesarbeitsgemeinschaft der Senioren-Organisationen e.V./German National Association Senior Citizens' Organisations—BAGSO)
10. Ullrich Hoffmann/Sven Iversen (Deputy) (Arbeitsgemeinschaft der deutschen Familienorganisationen e.V./Working Group of German Family Organisations—AGF)

11. Donald Ilte/Cornelia Lange (Deputy)  
(Arbeits- und Sozialministerkonferenz/  
Conference of Ministers for Labour and  
Social Affairs of the Länder—ASMK)
12. Monika Kaus/Helga Schneider-Schelte (Deputy)  
(Deutsche Alzheimer Gesellschaft e.V./German  
Alzheimer's Association)
13. Gernot Kiefer/Sonja Heitmann (Deputy)  
(GKV-Spitzenverband/National Association of  
Statutory Health Insurance Funds)
14. Kerstin Plack/Astrid Pape (Deputy)  
(Bundesvereinigung der Deutschen Arbeit-  
geberverbände/Federal Association of  
Municipal Employers' Associations—BDA)
15. Heike Schmalhofer (Jugend- und Familien-  
ministerkonferenz/Conference of Ministers  
for Youth and Family Affairs)
16. Dr. Anja Schneider (Deutscher Hospiz- und  
PalliativVerband e.V./Association of German  
Hospice and Palliative Care Organisations)
17. Dr. Dag Schölper/Klaus Schwerma (Deputy)  
(Bundesforum Männer e.V./Federal Forum  
Men—Interest Association for Boys, Men and  
Fathers)
18. Frank Schumann/Dr. Sigrun Fuchs (Deputy)  
(wir pflegen e.V./Bundesarbeitsgemeinschaft  
der Senioren-Organisationen e.V./German  
National Association Senior Citizens'  
Organisations—BAGSO)
19. Ulrich Silberbach/Jan Oliver Krzywanek  
(Deputy) (dbb Beamtenbund und Tarifunion/  
German Civil Service Federation)
20. Dr. Wolfgang Spree/Katja Roland (Deputy)  
(Vereinigung der kommunalen Arbeitgeber-  
verbände/Association of Municipal Employers'  
Associations—VKA)
21. Anja Weusthoff/Heike Lehmann (Deputy)  
(Deutscher Gewerkschaftsbund/German Trade  
Union Confederation—DGB)

## **Imprint**

### **Author:**

Independent Advisory Board on  
Work-Care Reconciliation

### **Contact:**

Bundesamt für Familie  
und zivilgesellschaftliche Aufgaben  
Geschäftsstelle des unabhängigen Beirats  
für die Vereinbarkeit von Pflege und Beruf  
Auguste-Viktoria-Straße 118  
14193 Berlin, Germany

Telephone: +49 30 69 80 77-245

Email: [gst-pflege-beruf@bafza.bund.de](mailto:gst-pflege-beruf@bafza.bund.de)

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