



## Germany

# FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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## Executive Summary

Governance and financing of social assistance and social care in Germany is constructed in a triangular model between the beneficiary, the state and the service provider (“*Sozialrechtliches Dreieck*”). The federal state provides for the regulation and eligibility conditions for a specific service/assistance through the Social Code Book (*Sozialgesetzbuch, SGB*) that is then implemented at the local level by individual states (*Bundesländer*). Once a person’s needs for assistance are assessed by the competent local authority, that person has a claim against the state and is entitled to receive the needed services and benefits. The state outsources social and care services to private service providers, who are usually welfare organisations (e.g. Caritas, Diakonie, etc.). The system is built to guarantee the free choice of providers for persons with disability.

There are two main systems of care and assistance related to persons with disability in Germany. Both systems are independent from each other but can be combined depending of the specific needs of the beneficiary.

★ Long-term care insurance, regulated by the Social Code Book (SGB) XI (*Pflegeversicherung*)

Traditionally, this system is meant to provide for care of persons in need of care at home and care homes. The services it offers also cover persons with disability. Long-term care insurance follows mandatory enrolment in health care insurance and is financed by employee and employer contributions. In 2019, long-term care insurance spent EUR 40.7 billion in care services.

★ Integration assistance (*Eingliederungshilfe*), regulated by the Social Code Book XII on social assistance until 2020 and thenceforth by Social Book IX on rehabilitation and inclusion of persons with disability (*Rehabilitation und Teilhabe von Menschen mit Behinderungen*).

Integration assistance is meant specifically for persons with disability and does not only relate to care but rather to the assistance and support required to maintain an independent living (e.g. it also provides employment support). This system is financed through taxes. In 2019, EUR 32.8 billion were spent on social services, including EUR 19.3 billion for integration assistance for

persons with disability. This represents an increase of 6.7% in comparison to the amount spent in 2018.

The funding and managing authorities in charge vary greatly from one state to another. While regulations are decided and harmonised at the national level, each state is responsible for their implementation. Depending on the type of disability, the occurrence and the duration of it, different funding authorities may be in charge of paying for the service. Most service providers are welfare not for profit organisations.

There are two different types of financing systems in Germany: reserved markets and personal budget. For most services, reserved markets apply, meaning that providers have to meet specific standards defined at the national level to be able to provide the service. Once a year or once every two years, depending on the local regulations, service providers negotiate (usually the umbrella organisation negotiates for its members) with the funding authority on the price of services. They reach an agreement that sets the price for the service per person benefitting from it. On the basis of this agreement, service providers receive funding from the funding authority depending on the type and number of services they provide and the actual number of beneficiaries. There is little to no competition between service providers. Stakeholders feedback suggests that quality control of service providers is not optimal and that there are great differences between various services offered in terms of quality.

Personal budget is also a financing mechanism in Germany. Both funding mechanisms cover several sectors of care and assistance and can be combined. Personal budgets were introduced in 2001 and became a legal entitlement in 2008, meaning that all applications must be approved if they meet the legal requirements. The rationale for introducing personal budget was to provide for greater opportunities for independent living and self-determination for persons with disability.

In the past years, both the long-term care and the integration assistance were reformed. The long-term care reform was completed in 2017. The Federal Participation Act (*Bundesteilhabegesetz, BTHG*) voted in 2016,

reforms the services and assistance provided for persons with disability and will be implemented until 2023. The Participation Act aims primarily at putting the beneficiary at the centre of service provision and to strengthen the self-determination of beneficiaries when it comes to care and social services.

The fact that there are significant reforms implemented in the past few years results in a difficult assessment of the situation of care for persons with disability at the time of this study in the end of 2020. The data and information provided in this factsheet is therefore to be read with caution and keeping in mind that some of the changes are still ongoing and that it is too soon to thoroughly assess the effects of the latest reforms on the management, financing and quality of service provision.

In practice, stakeholder feedback suggests that even though the care and assistance systems for persons with disability are very complex they work well in practice and interviewees have not raised any major problems.

## Introduction

Governance and financing of social assistance and social care in Germany is constructed in a triangular model between the beneficiary, the state and the service provider (*„Sozialrechtliches Dreieck“*). The federal state provides for the regulation and eligibility conditions for a specific service/assistance through the Social Code Book (*Sozialgesetzbuch, SGB*) that is then implemented at the local level by individual states (*Bundesländer*). Once a person's needs for assistance are assessed by the competent local authority, that person has a claim against the state and is entitled to receive the needed services and benefits. The state outsources social and care services to private service providers, who are usually welfare organisations (e.g. Caritas, Diakonie, etc.). The Federal Participation Act of 2016 added a new actor in this triangular system: independent counselling organisations who are meant to help persons with disability navigate the system. While this scheme is general, the funding authority, service providers and managing authority may vary depending on the type of assistance needed.

### Main findings:

- ★ The integration assistance is meant for persons with disability and aims to foster participation of persons with disability in society. The long-term care insurance covers the whole population and only persons with disability who need long-term care can receive benefits through this system.
- ★ In both systems, providers are financed through reserved markets.
- ★ Personal budget also exist in Germany but are said to be resource consuming for their beneficiaries.
- ★ The recent reforms in Germany, especially the implementation of the Federal Participation Act is still on-going and it is difficult to assess the effect of these reforms on the social services and care services systems at the moment this Factsheet was written.

There are two main systems of care and assistance related to persons with disability in Germany:

- ★ Long-term care insurance, regulated by the Social Code Book (SGB) XI (*Pflegeversicherung*)

Traditionally, this system is meant to provide for care of persons in need of care at home and care homes. The services it offers also cover persons with disability. Long-term care insurance follows mandatory enrolment in health care insurance and is financed by employee and employer contributions.

- ★ Integration assistance (*Eingliederungshilfe*), regulated by the Social Code Book XII on social assistance until 2020 and thenceforth by Social Book IX on rehabilitation and inclusion of persons with disability (*Rehabilitation und Teilhabe von Menschen mit Behinderungen*).

Integration assistance is meant specifically for persons with disability and does not only relate to care but rather to the assistance and support required to maintain an independent living (e.g. it also provides employment support). This system is financed through taxes.

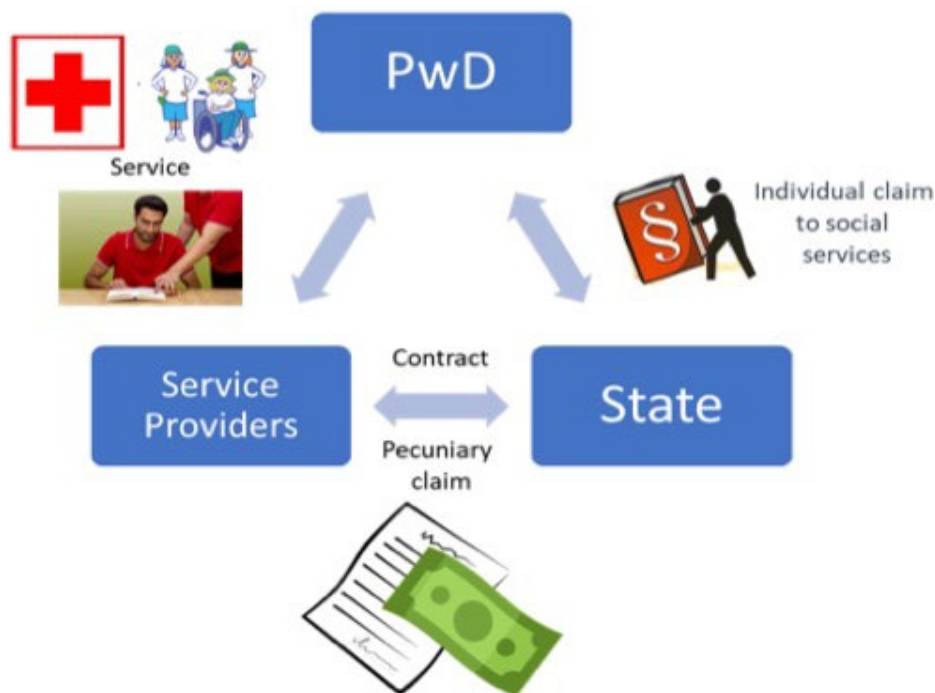
The two systems are separate and independent from each other, even though persons with disability can receive assistance and care from both. They have different management mechanisms as well as different classification systems to assess the needs for services.

In addition to these two systems, social assistance regulated by the Social Code Book XII (*Sozialhilfe*) provides for assistance to the whole population having no income. This assistance is financed through taxes and covers people living in poverty, which may be the case of persons with disability. It can provide financial assistance and cover the costs of care in case a person is not covered by the long-term care insurance via the care assistance (*Hilfe zur Pflege*). The social assistance funding authority calculates the amount of financial aid that can be provided on the basis of the income of the person with disability. Until 2020, the assessment also took into account the

income of their relatives to determine the amount of aid to be received. In 2020 the thresholds of income also became higher<sup>1</sup>, meaning that there are less chances that persons with disability will have to pay for services themselves.<sup>2</sup>

In 2019, EUR 32.8 billion were spent on social services, including EUR 19.3 billion for integration assistance for persons with disability. This represents an increase of 6.7% in comparison to the amount spent in 2018. Other social assistance (*Sozialhilfe, SGB XII*) services account for the rest of the amount spent on social services but they do not target specifically persons with disability, even though they can benefit from this assistance too.<sup>3</sup> In 2019, long-term care insurance spent EUR 40.7 billion in care services. These services cover the whole population that benefits from long-term care insurance, not only persons with disability.<sup>4</sup>

FIGURE 1 | The social triangle in Germany<sup>5</sup>



1 From 2020 the income of partner will no longer be considered and the income threshold is now around EUR 50,000

2 Bundesministerium für Arbeit und Soziales (2016) Weiteres Vorgehen – Inkrafttreten [https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Infografiken/reformstufen-des-bundesteilhabegesetzes.pdf;jsessionid=63555CD4B2A35B59A29BAD90446838B4?\\_\\_blob=publicationFile&v=5](https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Infografiken/reformstufen-des-bundesteilhabegesetzes.pdf;jsessionid=63555CD4B2A35B59A29BAD90446838B4?__blob=publicationFile&v=5) [accessed 26/08/2020]

3 Destatis Statistisches Bundesamt (2020) Sozialhilfeausgaben im Jahr 2019 um 5.8% gestiegen, [https://www.destatis.de/DE/Presse/Pressemitteilungen/2020/08/PD20\\_314\\_221.html;jsessionid=2BAA9019F1356E66C54A40A62BD1943D.internet8732](https://www.destatis.de/DE/Presse/Pressemitteilungen/2020/08/PD20_314_221.html;jsessionid=2BAA9019F1356E66C54A40A62BD1943D.internet8732) [accessed 27/08/2020]

4 Bundesministerium für Gesundheit (2020), Zahlen und Fakten zur Pflegeversicherung [https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3\\_Downloads/Statistiken/Pflegeversicherung/Zahlen\\_und\\_Fakten/Zahlen\\_und\\_Fakten\\_der\\_SPV\\_17.Februar\\_2020\\_barr.pdf](https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen_und_Fakten_der_SPV_17.Februar_2020_barr.pdf) [accessed 26/08/2020]

5 Figure provided by stakeholders.

The funding and managing authorities in charge vary greatly from one state to another. While regulations are decided and harmonised at the national level, each state is responsible for their implementation. Depending on the type of disability, the occurrence and the duration of it, different funding authorities may be in charge of paying for the service. The service providers likewise vary depending on the service provided. Most service providers are welfare not for profit organisations. For long-term care insurance, providers can also be private for-profit organisations. Integration assistance until 2020 was provided by the same providers as social assistance. Since 2020 integration assistance has become a standalone system and federal states can now decide whether to allow other providers to provide the services. In practice, stakeholder feedback<sup>6</sup> suggests that the type of providers has not really changed and that there are generally very few new providers entering the market since the change. The diversity of providers is important in Germany and there are usually more than one provider in each sector, especially in bigger cities. The system is based on the idea that persons in need of care and assistance should be able to choose the providers for services.

Wages for the care and social assistance workers are usually relatively low in comparison to the average wages in Germany. Working conditions can vary greatly from one facility/service to another.<sup>7</sup>

Both the long-term care and integration assistance systems have been reformed in the past five years. The long-term care reform has been completed since 2017.<sup>8</sup> The Federal Participation Act (*Bundesteilhabegesetz, BTHG*), voted into law in 2016, foresees significant reforms to integration assistance and the changes are to be implemented progressively until 2023.<sup>9</sup> In 2023, access to integration assistance benefits will be redesigned. The current conditions apply until 2023.<sup>10</sup> The

rationale for the respective reforms is to ensure adequate finances for the services and assistance, as well as to guarantee accessibility for persons in need of care and assistance. The Participation Act aims primarily at putting the beneficiary at the centre of service provision and to strengthen the self-determination of beneficiaries when it comes to care and social services. The fact that there are significant reforms implemented in the past few years results in a difficult assessment of the situation of care for persons with disability at the time of this study in the end of 2020. The data and information provided in this factsheet is therefore to be read with caution and keeping in mind that some of the changes are still ongoing.

In practice, stakeholder feedback suggests that even though the care and assistance systems for persons with disability are very complex they work well in practice and interviewees have not raised any major problems.

## Funding mechanisms across care services for PwDs

As mentioned in the introduction, the financing and management of social and care services for persons with disability follow a triangular model. There are two different types of financing systems in Germany: reserved markets and personal budget. For most services, reserved markets apply, meaning that providers have to meet specific standards defined at the national level to be able to provide the service. There is little to no competition between service providers and any organisation that meets the requirements can become a service provider. Stakeholders feedback suggests that quality control of service providers is not optimal and that there are great differences between various services offered in terms of quality. Personal budget is also a financing mechanism in Germany. Both funding mechanisms cover several sectors of care and assistance and can be combined.

6 Interviews conducted in the summer and early fall of 2020

7 Stakeholder feedback

8 European Commission DG Employment, Social Affairs and Inclusion (2017) Peer Review on "Germany's latest reforms of the long-term care system" Host Country Discussion Paper – Germany <https://ec.europa.eu/social/main.jsp?langId=en&catId=1024&newsId=9008&furtherNews=yes> [accessed 26/08/2020]

9 Bundesministerium für Arbeit und Soziales (2016) Weiteres Vorgehen – Inkrafttreten [https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Infografiken/reformstufen-des-bundesteilhabegesetzes.pdf;jsessionid=63555CD4B2A35B59A29BAD90446838B4?\\_\\_blob=publicationFile&v=5](https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Infografiken/reformstufen-des-bundesteilhabegesetzes.pdf;jsessionid=63555CD4B2A35B59A29BAD90446838B4?__blob=publicationFile&v=5) [accessed 26/08/2020]

10 Persönliche Assistenz – Das Infoportal (n.d.) Die wichtigsten Informationen zum Bundesteilhabegesetz <https://www.persoelliche-assistenz-berlin.de/informationen-bundesteilhabegesetz/#toggle-id-30> [accessed 27/08/2020]

The way service providers are financed for both the long-term care insurance and integration assistance follows a similar structure (reserved market). Service providers assess the costs of the provision of one service. Once a year or once every two years, depending on the local regulations, they negotiate (usually the umbrella organisation negotiates for its members) with the funding authority on the price of services. They reach an agreement that sets the price for the service per person benefitting from it. On the basis of this agreement, service providers receive funding from the funding authority depending on the type and number of services they provide and the actual number of beneficiaries.

Benefits in kind are the classic type of social benefits for persons with disability. A personal budget is a different financing mechanism that exists in Germany and it does not follow the triangular model. Personal budgets were introduced in 2001 and became a legal entitlement in 2008, meaning that all applications must be approved if they meet the legal requirements. The rationale for introducing personal budget was to provide for greater opportunities for independent living and self-determination for persons with disability. Multiple service providers can be involved in service provision for a person having a personal budget: the health insurance fund, the federal employment agency, the accident insurance carrier, the pension insurance funds, youth welfare organisations, social services organisations, the long-term insurance carrier and the local integration office. Benefits may be provided by several providers but the person with the personal budget only has one contact point and source for the benefits (the primary provider). The personal budget beneficiary can also decide to use the budget to pay for services that are not provided by traditional service providers. Some service providers expressed some resistance regarding personal budget because it can be used to pay for services that do not necessarily have to

meet the same quality standards that they are bound to meet. It also changes the relations between the providers and the person with disability. They do not deal with a beneficiary of integration assistance but rather with a client and they might have to adjust their offer to meet the client's demands.<sup>11</sup> The personal budget is reassessed every two years and can be adjusted if needed.<sup>12</sup>

Benefits in kind and the personal budget can be combined for different types of services. For example, a person receives an in-kind contribution for day-care or a sheltered workshop and has an additional personal budget for supported living or to pay for care services. However, the beneficiary cannot receive in-kind services if they are supposed to be covered by the personal budget at the same time.<sup>13</sup> The personal budget amount is assessed on a case by case basis by the local authority. The smaller budget is EUR 36 and the highest EUR 12,683. The majority of the budgets amounts to between EUR 200 and 800 per month.<sup>14</sup>

In theory, personal budget beneficiaries can be all persons with disability regardless of the type and severity of their disability. In practice, however, personal budgets are not easy to manage and require a lot of energy from the person with disability. Stakeholder feedback suggests that this funding mechanism works very well but is not meant for all persons with disability. Only a small proportion (less than 5%) of persons with disability use the personal budget scheme because of the associated administrative burden. Few persons with severe mental or psychological disabilities use the personal budget option.

In the sectors examined in this factsheet, there are no such things as call for tenders or public procurement procedures. However, this exists in other sectors such as employment and training.

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11 Interview feedback

12 Bundesministerium für Arbeit und Soziales (n.d.) Fragen und Antworten zum Persönlichen Budget <https://www.bmas.de/DE/Themen/Teilhabe-Inklusion/Personliches-Budget/Fragen-und-Antworten/faq-personliches-budget.html#:~:text=Wie%20hoch%20ist%20das%20Pers%C3%B6nliche,und%20800%20Euro%20im%20Monat.> [accessed 27/08/2020]

13 Bundesministerium für Arbeit und Soziales (n.d.) The Multi-Provider Personal Budget [https://www.bmas.de/SharedDocs/Downloads/EN/PDF-Publikationen/a730-personal-budget-flyer.pdf?\\_\\_blob=publicationFile&v=1](https://www.bmas.de/SharedDocs/Downloads/EN/PDF-Publikationen/a730-personal-budget-flyer.pdf?__blob=publicationFile&v=1) [accessed 27/08/2020]

14 Bundesministerium für Arbeit und Soziales (n.d.) Fragen und Antworten zum Persönlichen Budget <https://www.bmas.de/DE/Themen/Teilhabe-Inklusion/Personliches-Budget/Fragen-und-Antworten/faq-personliches-budget.html#:~:text=Wie%20hoch%20ist%20das%20Pers%C3%B6nliche,und%20800%20Euro%20im%20Monat.> [accessed 27/08/2020]



Following the outbreak of Covid-19 in Germany and the lockdown measures decided by the Federal government and the states, emergency funding mechanisms were put in place. At the federal level, the law on the deployment of social service providers (*Sozialdienstleister-Einsatzgesetz, SodEG*) was voted.<sup>15</sup> It provides for subsidies for most service providers of the Social Code Book. Service providers of the long-term care insurance (SGB XI) are not covered by this measure. The amount of the subsidy is based on the monthly average that was paid to service providers in the past 12 months. The law states that the subsidy shall not exceed 75% of the monthly average and can be granted after an application by the service provider. This law was meant to last until 30 September 2020 and can be prolonged until December 2020 but not further. At the point of this research, it was unclear whether the law was to apply beyond 30 September 2020. Just as for normal financing procedures, implementation takes place at the state level and some states may decide to go beyond the scope of this law. Some states, such as Baden-Württemberg continued to pay 100% of the costs of the benefits during lockdown.<sup>16</sup>

The specific sector sections below describe the challenges in terms of accessibility, quality and provide sector-specific funding data when available.

## Day Care

In the SGB IX<sup>17</sup>, day care (*Tagesförderstätte*) is defined as a service for persons with severe disability to enable them to acquire and maintain practical skills as well as participate in community life. Day-care encompasses training and support groups to carry out practical life activities, including domestic tasks and to prepare clients for working and independent life. The services provided fall under the services and benefits for social participation provided by integration assistance.

In relation to day care, the changes introduced by the Federal Participation Act (BTHG) are not as significant as in the area of supported living.

Regulations for social services for persons with disability are federal but they are implemented at the local level. In principle, every day-care facility should meet the same requirements nationwide and the local authorities (*Bundesländer*) decide on how to implement them. As a result, the structure for implementation, the managing authority and funding authority may vary from one Land to another.

Day care services are in principle responsibility of the state. However, there are no state services and the state outsources service provision. Day-care services are mostly run by welfare organisations. About half of the day care services have a direct proximity or are run jointly with sheltered workshops. Services provided are then different.<sup>18</sup> Day care services provided with proximity to a sheltered workshop provide services usually meant to help the person with a disability to later integrate in the sheltered workshop. Other day care services are likely to provide different kinds of activities.

The funding follows the negotiated procedure described in the section on 'Funding mechanisms across services'. Municipalities subsidise 'investment costs' covering the rent of the facilities for example. Day care facilities apply directly to the relevant municipality for these subsidies.

In 2018, EUR 914 million were spent in the provision of day-care services and 36,656 adult persons with disability benefitted from these services. On average, EUR 24,940 were spent per adult in a day-care facility.<sup>19</sup> These numbers describe the situation before the Federal Participation Act's full implementation.

15 Bundesministerium der Justiz und für Verbraucherschutz (2020) Gesetz über den Einsatz der Einrichtungen und sozialen Dienste zur Bekämpfung der Coronavirus SARS-CoV-2 Krise in Verbindung mit einem Sicherstellungsauftrag, <http://www.gesetze-im-internet.de/sodeg/> [accessed 28/09/2020]

16 Stakeholder feedback

17 Paragraph 81 SGB IX – Rehabilitation and participation of people with disabilities

18 Interview feedback

19 BAGüS (2020) Kennzahlvergleich Eingliederungshilfe 2020, Berichtjahr 2018, [https://www.lwl.org/spur-download/bag/Endbericht%202018\\_final.pdf](https://www.lwl.org/spur-download/bag/Endbericht%202018_final.pdf) [accessed 25/08/2020]

For sheltered workshops, the number of adult beneficiaries was 276,452 and EUR 17,091 were spent per person participating in a sheltered workshop in 2018. About half of the people working in a sheltered workshop live without inclusion support (integration assistance). In total, EUR 4,725 billion were spent on sheltered workshop services in 2018.<sup>20</sup> These numbers describe the situation before the Federal Participation Act's full implementation.

There are waiting lists for day care services while there is none for sheltered workshops, mainly because sheltered workshops are highly regulated and the law provides for an obligation to accept and integrate in the sheltered workshop all people who meet the requirements.

## Supporting / Independent Living

Supported and Independent living is the area where the Federal Participation Act has the most impact. Since 2020, it is regulated by the Social Code Book 9 (SGB IX) and covers services and benefits for social participation. The effects of this reform on the right to live independently according to UNCRPD can only be measured in a couple years from the time of this study in late 2020, because the law is being implemented progressively until 2023. However, the German Institute for Human Rights notes that "the law does not sufficiently reflect an individual's opportunity to choose".<sup>21</sup>

For supported and independent living, the social triangle described in the introduction applies and the funding mechanisms are based on the negotiation procedure between the service providers and the funding authority described in the section 'Funding mechanisms across services'. Funding for supported and independent living can come from either the long-term care insurance or integration assistance depending on the individual situation of the person with disability.

In the case of supported and independent living, the PwD can decide to receive services and benefits in different ways:

- ★ In-kind services (*Sachleistungen*): the person never sees the price of the services but receives the services from its chosen provider (e.g. 3 hours of home cleaning per week).
- ★ Cash benefits (*Geldleistungen*): the PwD is provided with money to pay for the services. The expenses need to be justified to the funding authority.

Both options can be combined. The amount of services and benefits received depend on the assessment of the disability made by the local authority in charge. While that authority may differ from one federal state to another, the assessment grid is based on WHO's International Classification of Functioning (ICF) in addition to a medical assessment and is the same nation-wide for the integration assistance scheme. For long-term care assistance, each beneficiary is assigned a care grade (from 1 to 5 – high care needs) and the benefits the person is entitled to depend on the assigned care grade.

In 2018, 207,794 adults with disability lived in supported living arrangements (in their own apartment or group homes – *ambulant betreutes Wohnen*). EUR 2.1 billion were spent on these arrangements. Of these adults with disability, 25.6% have a mental disability, 70.2% have a psychological disability and 4.2% a physical disability. On average, supported living arrangements cost EUR 10,079 per adult with disability in 2018. The numbers describe the situation before the Federal Participation Act's full implementation.<sup>22</sup> Only around 50% of persons with cognitive disability live in supported living arrangements. The rest lives with their relatives who are providing support.<sup>23</sup>

20 BAGüS (2020) Kennzahlvergleich Eingliederungshilfe 2020, Berichtsjahr 2018, [https://www.lwl.org/spur-download/bag/Endbericht%202018\\_final.pdf](https://www.lwl.org/spur-download/bag/Endbericht%202018_final.pdf) [accessed 25/08/2020]

21 German Institute for Human Rights (2018) National CRPD Monitoring mechanism – Pre-list of Issues on Germany [https://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Sonstiges/MSt\\_2018\\_Pre\\_LoL\\_English\\_bf.pdf](https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Sonstiges/MSt_2018_Pre_LoL_English_bf.pdf) [accessed 25/08/2020]

22 BAGüS (2020) Kennzahlvergleich Eingliederungshilfe 2020, Berichtsjahr 2018, [https://www.lwl.org/spur-download/bag/Endbericht%202018\\_final.pdf](https://www.lwl.org/spur-download/bag/Endbericht%202018_final.pdf) [accessed 25/08/2020]

23 Stakeholder feedback

Access to accommodation is assessed as problematic according to the German Institute for Human Rights. Even though the institute notes that no data is available on accessibility, a lack of accessible accommodation must be assumed for several reasons, including inappropriate provisions for the building regulations in the federal states, the rising cost of rent and the decreasing number of rent-controlled flats.<sup>24</sup> There are waiting lists for supported living in Germany but there are differences between federal states and within the federal states. It might take from six months to a couple years to find a place in an accommodation.<sup>25</sup> Persons who need more support are likely to have to wait longer. Some service providers also provide emergency housing options, for example in case of death of the supporting relatives. Persons with disability can stay in emergency housing options until a long-term solution is found. The waiting list can also be anticipated by the relatives of the person with disability by registering early with one of the welfare organisations providing supported living options.

Generally in Germany, the needed assistance devices for independent living are financed through the insurance system (health insurance, long-term care insurance or accident insurance). When the insurance does not pay, assistance can be asked to the social assistance. In cases where the costs exceed the amount covered by the care insurance, persons with disability must bear the cost themselves. The amount covered by the insurance depends on the assessment of the severity of the disability (5 levels of care needs and ICF to assess disability).

The German government commissioned a research institution to carry out a study on the participation of persons with disability. This study will be completed in

2021.<sup>26</sup> This study will also examine the perception of the quality of services by persons with disability.

## Long-term Institutional Care

The Federal Participation Act (BTHG) from 2016 promotes independent living. However, some regulations can still force persons with disabilities into residential homes if the costs to maintain an independent living are 'disproportionately higher' than the costs of being in a care home. This is due to the 'higher cost reserve' (*Mehrkostenvorbehalt*). How the costs are assessed to be 'disproportionately high' is not defined in the law and leaves the responsible local authority in charge of making the decision.<sup>27</sup>

Long-term care for persons with disability can be paid for by the long-term care insurance, social assistance and inclusion assistance or all three. If the person with disability has reached retirement age and is eligible to long-term care benefits (i.e. depending on the assessment of the care grade), then long-term care insurance covers the costs of the benefits according to the assessment of the care needs (care grade). If the person with disability has not reached retirement age but could nevertheless be entitled to the benefits of long-term care insurance, then long-term care insurance covers 15% of the costs if the person with disability has a care grade of 2 to 5, but the amount provided cannot exceed EUR 266 per calendar month.<sup>28</sup> For 2020, the rule of thumb of the budget of long-term care insurance is to spend EUR 32 million in facilities for persons with disability per 10,000 service beneficiaries.<sup>29</sup>

24 German Institute for Human Rights (2018) National CRPD Monitoring mechanism – Pre-list of Issues on Germany [https://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Sonstiges/MSt\\_2018\\_Pre\\_LoL\\_English\\_bf.pdf](https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Sonstiges/MSt_2018_Pre_LoL_English_bf.pdf) [accessed 25/08/2020]

25 Stakeholder feedback

26 German Institute for Human Rights (2018) National CRPD Monitoring mechanism – Pre-list of Issues on Germany [https://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Sonstiges/MSt\\_2018\\_Pre\\_LoL\\_English\\_bf.pdf](https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Sonstiges/MSt_2018_Pre_LoL_English_bf.pdf) [accessed 25/08/2020]

27 DOTCOM: The Disability Online Tool of the Commission (2019) Germany [https://www.disability-europe.net/dotcom?!%5B%5D=16&t%5B%5D=17&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&t%5B%5D=43&t%5B%5D=44&t%5B%5D=45&t%5B%5D=46&view\\_type=list](https://www.disability-europe.net/dotcom?!%5B%5D=16&t%5B%5D=17&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&t%5B%5D=43&t%5B%5D=44&t%5B%5D=45&t%5B%5D=46&view_type=list) [accessed 26/08/2020]

28 Social Code Book (SGB) paragraph 43a, book XI.

29 Bundesministerium für Gesundheit (2020), Zahlen und Fakten zur Pflegeversicherung [https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3\\_Downloads/Statistiken/Pflegeversicherung/Zahlen\\_und\\_Fakten/Zahlen\\_und\\_Fakten\\_der\\_SPV\\_17.Februar\\_2020\\_barr.pdf](https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen_und_Fakten_der_SPV_17.Februar_2020_barr.pdf) [accessed 26/08/2020]

In 2017, there were about 14,500 residential care homes covered by long-term care insurance, of which 53% were managed by not for profit private organisations (e.g. welfare organisations). As explained in the first section of this factsheet, social care insurance is not primarily meant for persons with disabilities, rather to provide care and support to the whole population, and especially to the aging population. Therefore, a clear majority of care homes are meant for people of advanced age who need care, while only 2% of care home are predominantly used by persons with disabilities.<sup>30</sup>

As mentioned before, care for persons with disability is also part of integration assistance. In this framework, in 2018, 199,745 adults with disability lived in a care home (*stationäre Einrichtung*), which cost EUR 9.4 billion (this figure covers the price of accommodation price plus basic living expenses such as food and livelihood support). The cost per adult with a disability is EUR 47,097 in 2018. Some 63.1 % of the adults in such facilities have an intellectual disability, 30.4% a mental disability and 6.5% have a physical disability.<sup>31</sup> These numbers describe the situation before the full implementation of the Federal Participation Act (BTHG).

The latest reforms changed the way care homes are financed. They used to receive a lump sum to cover the costs for care and assistance per person in a care home. Now, the costs are assessed on an individual basis and depending on the needs of each person living in the care home.<sup>32</sup>

The latest reform of long-term care insurance implemented in 2017 introduced changes in the working conditions of workers in care homes. The number of

support staff increased from 28,000 in 2013 to 60,000 in 2017. This contributes to improving the quality of life in residential care facilities.<sup>33</sup> There is also an incentive for adequate salaries in long-term care facilities. The statutory minimum wage per hour in the long-term care sector varies between EUR 10.05 (Eastern states) and 10.55 (Western states) across Germany since 2018.<sup>34</sup> It is unclear whether these provisions also apply to the facilities financed through integration assistance.

## Respite Care

There are at least two different options for respite care that are covered by long-term care insurance. It is unclear to what extent those apply specifically to persons with disability as long-term care insurance is not primarily meant for persons with disabilities. It remains unclear whether there are services specific to persons with disabilities in this sector. Integration assistance is meant to provide assistance for independent living. Thus, it does not clearly foresee a respite care system.

For up to six weeks per year, a relative of a person in need of care can use the “*Verhinderungspflege*” that can only be applied to persons with disability with a care grade 2 to 5. Long-term care insurance covers the cost of care at home while the private/informal caregiver is on leave. When care is privately organised, it must be paid by the person in need of care and it can then be reimbursed by the care insurance. This type of care can also be provided in an in-patient facility and in this case, only care-related expenses are paid for. The amount paid depends on the care grade assigned to the beneficiary (from EUR 474 to 1,351.5).<sup>35</sup>

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30 Destatis (2017) Pflegestatistik, Pflege im Rahmen der Pflegeversicherung Deutschland Ergebnisse [https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/Publikationen/Downloads-Pflege/pflege-deutschlandergebnis-se-5224001179004.pdf?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/Publikationen/Downloads-Pflege/pflege-deutschlandergebnis-se-5224001179004.pdf?__blob=publicationFile) [accessed 26/08/2020]

31 BAGüS (2020) Kennzahlvergleich Eingliederungshilfe 2020, Berichtjahr 2018, [https://www.lwl.org/spur-download/bag/Endbericht%202018\\_final.pdf](https://www.lwl.org/spur-download/bag/Endbericht%202018_final.pdf) [accessed 25/08/2020]

32 Interview feedback

33 European Commission DG Employment, Social Affairs and Inclusion (2017) Peer Review on “Germany’s latest reforms of the long-term care system” Host Country Discussion Paper – Germany <https://ec.europa.eu/social/main.jsp?langId=en&catId=1024&newsId=9008&furtherNews=yes> [accessed 26/08/2020]

34 Ibid.

35 Bundesministerium für Gesundheit (2020), Zahlen und Fakten zur Pflegeversicherung [https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3\\_Downloads/Statistiken/Pflegeversicherung/Zahlen\\_und\\_Fakten/Zahlen\\_und\\_Fakten\\_der\\_SPV\\_17.Februar\\_2020\\_barr.pdf](https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen_und_Fakten_der_SPV_17.Februar_2020_barr.pdf) [accessed 26/08/2020]

Short-term care facilities can also be used for respite care even though this is not their main purpose. If the person in need of care has a care grade between 2 and 5, the person can apply for short-term care facilities with the long-term care insurance. There is a maximum threshold that the insurance will pay for and it can be used for a maximum of 8 weeks per year.

In case a care grade has not been assigned, short-term care can be used for a transition period of maximum 56 days (after a hospital stay or provided that nursing care does not meet the needs of the person in need of care). A financial threshold also applies in this case and if the costs are higher, the patient must pay out of pocket.<sup>36</sup>

The service providers are those providing long-term care insurance services and the same working conditions, quality and accessibility standards apply.

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36 Pflegestützpunkte Berlin (n.d.) Factsheet No 8 Respite Care – Short-term care <https://www.pflegestuetzpunkteberlin.de/en/topic/respite-care-short-term-care/> [accessed 26/08/2020]

## Interviews

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- ★ Katharina Bast, European consultant - Federal Association of Workshops for the Disabled People e. V., Umbrella organisation, Interview on 24<sup>th</sup> of August, 2020
- ★ Heinz Becker, Expert (day-care), Interview on 27<sup>th</sup> of August, 2020
- ★ Christine Blankenfeld, Ministry for Social Affairs and Integration Baden-Württemberg, Regulator, Interview on 3<sup>rd</sup> of September, 2020
- ★ Ulrich Nielhoff, *Lebenshilfe* care home for the elderly and disabled, Service provider, Interview on 4<sup>th</sup> of September, 2020
- ★ Prof. Dr. Grundun, Wansing Humboldt University, Berlin Institute for Rehabilitation Sciences – Rehabilitation sociology, Expert, Interview on 4<sup>th</sup> of September, 2020
- ★ Anonymous caregiver of two relatives (1 with 100% disability) and the other being blind and needing care, service user, Interview on 20<sup>th</sup> of August, 2020

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