**Input on the recognition and protection of human rights of persons with care needs and their formal and informal carers in Germany**

Re: Call for inputs for an expert workshop and a comprehensive thematic study on the human rights dimension of care and support

*Authored by the Federal Ministry of Health, the Federal Ministry of Labour and Social Affairs and the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth*

# 1. Recognition and protection of human rights of persons with care needs and their formal/informal carers

In Germany, the rights of persons in need of long-term care and of their informal and formal carers are based on a number of laws, in particular the Basic Law for the Federal Republic of Germany (“Grundgesetz”) and the German Social Code (“Sozialgesetzbücher”). The catalog of fundamental rights laid down in the Basic Law contains a series of general human rights - i.e. rights that everyone can invoke, regardless of age, origin or other factors. These fundamental rights thus correspond to the human rights protected at international level and in some cases also go beyond the internationally specified human rights. The fundamental rights are binding on state authorities in all its forms and activities: For example, the legislative bodies must observe them when enacting laws, the executive authorities must follow them when applying laws and the courts are obliged to observe them when interpreting laws.

These fundamental rights are reflected in the specific regulations and provisions of the legal framework for persons in need of long-term care and for their informal and formal caregivers. These regulations will be presented in the following, with a particular focus on Germany‘s long-term care insurance law as laid down in the Eleventh Book of Germany’s Social Code. Germany‘s long-term care insurance was introduced as a compulsory insurance in 1995. The aim of introducing this fifth independent pillar of the German social insurance system (in addition to health insurance, accident insurance, pension insurance, unemployment insurance) was to mitigate the financial and social impact of the risk of being in need of long-term care, to sustainably improve the situation of persons in need of care and their relatives and to create essential incentives to expand long-term care provision in Germany. The principle of self-determination is a central tenet of long-term care insurance law. The long-term care insurance benefits are intended to help care-dependent persons live a life as dignified, independent and self-determined as possible. The care, assistance and support services provided through long-term care insurance benefits should be geared towards regaining or maintaining the physical, mental and emotional resilience of those in need of care, including in the form of activating care.

Long-term care insurance gives those in need of long-term care the opportunity to decide for themselves how and by whom they are cared for. For example, they can choose whether they want to receive help from professional carers or receive cash-benefits, which are often given to family members or other informal carers as a financial recognition for their care. Persons in need of care can also choose between different care institutions and services offered by various providers. Individual counselling, also for relatives, is offered timely and on a regular basis. To ensure that those in need of care can continue to live at home and stay in their familiar surroundings for as long as possible, there is a fundamental priority for care at home. Therefore, long-term care insurance benefits are primarily intended to support the provision of home care and the willingness of family members, friends and neighbours to provide care.

In line with this, family members who care for close relatives as informal carers have specific rights to support their role in caring for persons in need of long-term care. They are entitled to take (partial) leave from work for up to 24 months to care for persons in need, enabling them to adjust their working hours accordingly (so-called “Pflegezeit” and “Familienpflegezeit”). Additionally, informal caregivers have access to financial support through interest-free loans provided by the state.

The social law regulations for persons with disabilities and persons at risk of disability are set down in the Ninth Book of the Social Code. The aim of the law is to promote self-determination and equal participation in society, to avoid disadvantages and to counteract them.

Other important legal sources that are intended to protect the rights of persons in need of care in Germany can be found in the laws and sublegal regulations of the 16 federal states (“Laender”) as well as in the Housing and Care Contract Act, which regulates civil law contracts at federal level between persons of legal age and companies that offer housing in connection with care or nursing services. In addition, there exists a so-called “Care Charter” (“Pflege-Charta”) which summarizes how the human rights should be reflected and respected in the everyday lives of persons with long-term care needs. The Charter was first published in 2006 and has been reissued several times since then. It was drawn up jointly by representatives from all areas of care and self-help. The aim of this charter is to strengthen the position as well as the legal status of persons with long-term care needs. To this end, eight articles summarize and explain the basic rights of persons in need of assistance and care, directly addressing the affected persons throughout the charter. At the same time, the charter highlights quality features of good care for persons with long-term care needs. In this regard, it also serves as a guideline for all those who assume responsibility for care, support and treatment. The charter appeals to all those who are professionally or privately committed to the well-being of persons in need of help and care.

# 2. Concrete policy or programmatic measures taken to promote and ensure the rights of caregivers and recipients of care and support in national care and support systems, mentioned under Question 1 above. If possible, please indicate the impacts of such measures.

## a) Comprehensiveness of long-term care insurance benefits

In principle, all insured persons can use various forms or facilities of care and support. Which option is chosen by those affected and their relatives depends on the severity of the need for care on the one hand, but also on the specific individual circumstances? Long-term care insurance benefits include:

* benefits in kind for services provided by outpatient or home care service providers,
* a care allowance for home care (a cash benefit that is mostly as a recognition for informal carers providing home care),
* combinations of cash benefits (mainly used for informal carers) and benefits in kind (used for professional home care services),
* additional cash benefits for persons residing in outpatient assisted living groups, for care aids and for measures to improve the living environment (for example, to make places of residence barrier-free),
* respite care at home as well as short-term care in fully residential facilities (to receive professional care if an informal caregiver is temporarily unable to attend),
* semi-residential care (day and night care),
* inpatient care in rehabilitation facilities when an informal caregiver makes use of preventive or rehabilitation services in the same facility,
* fully residential long-term care,
* social security benefits for informal caregivers (e.g. under certain conditions, compulsory insurance in the statutory pension system with simultaneous payment of the corresponding pension contributions) and a relief amount (to relieve the burden on informal caregivers),
* digital care applications,
* care counselling as well as care courses for family members and volunteer caregivers, and
* additional cash benefits in case of a short-term absence from work (for up to ten working days per calendar year per person in need of care).
* Long-term care also includes end-of-life care.

## b) Accessibility of long-term care services

Long-term care insurance is a mandatory insurance. Insured persons can receive long-term care insurance benefits upon application. Long-term care insurance benefits are granted from the date of application, but no earlier than the date on which the conditions for the entitlement to benefits are met. Entitlement to benefits exists if the insured person was insured as a member or had family insurance for at least two years in the ten years preceding the application. Periods of continued insurance are taken into account when determining the required period of prior insurance. For insured children, the pre-insurance period is deemed to have been fulfilled if one parent fulfils it.

To assess the individual care needs, the Medical Service of the Health Insurance (“Medizinischer Dienst”) visits the applicant at home and assesses his/her need of care. Based on this assessment, the MDK then recommends a respective grade of care. In 2017 a new definition of needing long-term care has been introduced with assessment categories that are more strongly oriented towards the needs of each individual person, their individual life situation and their individual impairments and abilities. On this basis, all persons in need of long-term care receive equal access to the benefits of long-term care insurance, regardless of whether they are affected by physical, mental or psychological impairments. The new definition of the need for long-term care now covers persons whose independence or abilities are limited due to health impairments and who consequently need support for an estimated period of at least 6 months.

## c) Quality of long-term care

The German Social Code (Eleventh Book) determines the legal framework for maintaining and improving the quality of the long-term care services to be provided by inpatient long-term care facilities and outpatient long-term care providers, strengthening quality knowledge and internal quality management and creating greater transparency of results for all those involved.

Long-term care insurance funds (as the cost bearers of the system) and the care service providers have jointly agreed on standards and principles to ensure and further develop the quality of care. According to these principles, all long-term care facilities are obliged to provide care services that are tailored to the individual needs of the care recipients. Thus, care and support services should help persons in need of care to lead a life as independent and self-determined as possible while maintaining their privacy and intimacy. The religious and spiritual needs of persons in need of care must also be taken into consideration and, where possible, the needs for culturally sensitive and gender-sensitive care must be taken into account. In addition, those in need of care also have a say in the organization of everyday life and care. These standards and principles thus make a significant contribution to ensuring the quality of life and human dignity of persons with care needs.

It is a legal requirement that all inpatient long-term care facilities and all outpatient long-term care service providers are subject to an external quality inspection which needs to conducted once a year by the Medical Service or by the Auditing Service of the Private Health Insurance companies. Fully residential long-term care facilities that have achieved a high level of quality may be audited every two years further on. In addition to the regular audits, additional audits can be carried out on an ad hoc basis - for example, if there are valid indications of quality deficiencies or other irregularities. The quality inspections are carried out on the basis of the guidelines of the National Association of Statutory Long-term care/Health Insurance Funds for quality inspections in care facilities, which are binding for all inspections.

Since 2018 the introduction of a new quality system in fully residential long-term care facilities (nursing homes) is under way. The legal mandate requires that outcome quality plays a far greater role in the new quality system. Twice a year, nursing homes have to collect quality-related data based on a total of ten quality indicators. These indicators relate to different aspects of care quality such as fall prevention or the (mis)use of custodial measures (restraints; bed rails). Results of indicators and inspection visits are published; this serves the aim of creating transparency about quality in long-term care.

The newly-designed external quality audits conducted by the Medical Service or the Auditing Service of the Private Health Insurance build on these quality-related data that indicate existing potentials for quality improvements in a facility. Audits will no longer use nursing documentation files as the main source of information. Instead, the professional dialogue between the auditors and the care staff will play a far more important role. Both the results of the indicator-based data collection and the external quality audits are published. The new system significantly advances in-house quality assurance, external quality assessments and quality reporting. A new quality system for non-residential care is being developed and will be introduced in 2025.

## d) Integration Assistance

With the reform of the Federal Participation Act, integration assistance was realigned in order to strengthen persons with significant disabilities in leading a self-determined life. Integration assistance is now set down as a separate benefit and participation law in Part 2 of the Ninth Book of the German Social Code. According to the person-centred approach integration assistance services are consistently geared towards the individual needs of persons with disabilities and no longer towards a specific form of housing.

The planning procedure (“Gesamtplanverfahren”) is one of the most important elements for ensuring full participation in life in society. It provides the basis for achieving a needs-based provision of services and is an essential prerequisite for structuring the services in such a way that full, effective and equal participation in life in the community is possible in individual cases. Recipients of support must be involved in all steps of the process and can express their wishes, which should be taken into account.

# 3. Main challenges faced at the national level in creating robust, resilient and gender-responsive, disability-inclusive and age-sensitive care and support systems with full respect for human rights.

Germany is in the midst of demographic change with permanently low birth rates and increasing life expectancies. Against this backdrop, the number of persons in need of long-term care in Germany has been growing for years - even though the average number of expected healthy life years has also increased. With the implementation of the new definition of the need for long-term care in 2017, the number of persons entitled to long-term care insurance benefits was significantly expanded, giving a large number of persons access to long-term care insurance benefits for the first time. These developments led to increasing expenses for the long-term care insurance funds. In order to cover the rising costs, the contribution rate for long-term care insurance was raised in several stages to its current level of 3.4 % of the insured person‘s gross income (insured persons without children have to pay a contribution surcharge of an additional 0,6 %, while members with more than one child are relieved with reduced contribution rates). By the end of May 2024, the federal government will draw up recommendations for the sustainable long-term financing of long-term care insurance.

Besides, good quality care can only be achieved with sufficient and well-qualified staff and adequate staffing levels. In Germany, despite a steady increase in the number of persons employed in the care sector, the effects of demographic change are also noticeable in regard to care workers, therefore intensifying the shortage of skilled workers in the sector. Against this backdrop, one political focus in recent years has been on recruiting staff and increasing the attractiveness of the nursing profession. As part of the so-called Concerted Action for Nursing, the federal and state governments and all relevant stakeholders in the nursing care sector have jointly agreed on binding targets and concrete measures to noticeably improve the day-to-day work and working conditions of professional careers, relieve the burden on them and strengthen training in the nursing care sector. Building on this, in recent years numerous measures have been implemented to reform training programmes and to improve working and renumeration conditions in the care sector. In addition, the federal government is currently planning further measures to secure the supply of skilled workers in the health and care sector in the long term.