314-1081/000\*21 - Q 4 30.01.2019

The Federal Republic of Germany - Answer to the

**GUIDING QUESTIONS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING:**

**Long-term and Palliative Care**

**Preliminary remark:**

With regard to the results of the 9th Session of the OEWGA of July 2018, the elements intended to strengthen the rights of older people presented by Germany as part of the session are forwarded as follows.

With these, Germany would like to make a further constructive contribution to moving the substantial public debate on strengthening the rights of older people in the above general areas further forward. Germany does not wish to give the impression of striving for a binding, normative ruling at UN level. **On the contrary, the elements listed below describe the parameters within which the substantial debate should be held, in Germany's view.[[1]](#footnote-1)**

**National legal framework**

1. What are the legal provisions in your country that recognise the right to long-term and palliative care? Do they have a constitutional, legislative or executive basis?

*Answer:*

*The law of the social long-term care insurance has been codified in the Social Code Book XI[[2]](#footnote-2), and palliative care in the Social Code[[3]](#footnote-3).*

**Normative elements**

2. What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.

*Answer:*

*Long-term care:*

* *The social long-term care insurance covers over 50 per cent of the cost of long-term care-related expenditure. A need extending beyond that, in case of financial need, will be met by care assistance within the framework of social assistance and social compensation law.*
* *The benefits provided by the social long-term care insurance are to help those in need of long-term care, despite a need for assistance, to lead a life as independent and as self-determined as possible, in line with human dignity. Assistance should be geared towards restoring or preserving the physical, mental and emotional capacities of those in need of long-term care also by using activating care.*
* *The following principle applies: outpatient is preferable to inpatient; but there is freedom of choice when it comes to the type of service for outpatient and inpatient care.*
* *Social long-term care insurance benefits are granted upon application. In need of long-term care within the sense of the law are persons who suffer from health-related impairments of their autonomy or their capacities and who are therefore in need of assistance by others. It has to be people who cannot compensate for or cope with physical, cognitive or mental impairments or health-related strain or requirements themselves. The need for long-term care has to be permanent, expected to last for at least six months, and with a statutorily defined severity – graduated in five grades of care.*
* *All long-term care services have to respect human dignity and ensure a quality management. All nursing homes and nursing-care services are checked with regard to that and also with regard to a multitude of other quality aspects by the Health Insurance Medical Service (MDK) every year.*
* *The right to comprehensive information and education on entitlements and support services and benefits; the right to the reconciliation of care responsibilities and work for family caregivers.*

*Palliative care:*

* *Palliative care is defined within the legal framework of the Social Code Book V – and is particularly strengthened by the Hospice and Palliative Care Act of 2015[[4]](#footnote-4). Palliative care has explicitly been made part of standard care of the statutory health insurance. All insured persons are entitled to and have access to palliative care.*
* *Definition: comprehensive medical, nursing, psychosocial and, if need be, also spiritual care and support for the critically ill and the dying with the objective of a dignified and self-determined life during the last phase of life.[[5]](#footnote-5)*
* *Care can be provided on an outpatient basis at home, on an inpatient basis or in a nursing care facility.*
* *Insured persons are entitled to individual counselling and assistance by the statutory health insurance funds when choosing and claiming benefits and services of palliative and hospice care.*

3. How should *long-term care* and *palliative care* be legally defined?

*Answer:*

*In Germany such definitions exist; see answer to question no. 2.*

**Implementation**

4. What are the policies and programmes adopted by your country to guarantee older person’s enjoyment of their right to long-term and palliative care?

*Answer:*

*The law on social long-term care insurance (SGB XI) as well as the law on statutory health insurance (SGB V) are continuously being developed further in order to ensure high quality nursing and medical care and to expand them further.*

*This way, Germany also supports the implementation of the Charter of Rights for People in Need of Long-Term Care and Assistance (currently undergoing a revision process) which was published for the first time in 2006, as well as the “Charter for the Care of the Critically Ill and the Dying in Germany” and its recommendations for action drafted by the stakeholders of hospice and palliative care. Measures and programmes accordingly comprise, for instance, the promotion of people-oriented care by promoting the expert debate on the nursing tasks according to the definition of the need for long-term care, the promotion of the quality of care by better staff training, recruitment and organisation (concerted action on long-term care - KAP), the promotion of the reconciliation of care responsibilities, family and work, the improvement of the outpatient hospice work for instance by recruiting volunteers for terminal care and grieving and the qualification of the volunteers.*

5. What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

*Answer:*

*The adoption and implementation of normative frameworks is ensured by the democratically legitimised legislative process.*

*Health care provision in Germany is not exclusively ensured by government or the state directly or by the legislator. In Germany, the principle of self-administration applies (health insurance and long-term care insurance funds, service providers as well as their institutions); there the normative framework is shaped further.*

**Equality and non-discrimination**

6. Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situations?

*Answer:*

*A comprehensive obligation to take out insurance applies: everyone having statutory health insurance coverage is automatically insured under the social long-term care insurance scheme and everybody with private health insurance coverage has to take out compulsory long-term care insurance. No differentiation is made regarding age or sex either in long-term care insurance or in palliative care. Reasonable requests for instance to be cared for by a nurse of the same sex or that the patient’s religious needs are taken into account when being cared for are to be accommodated.*

**Participation**

7. Does the design and implementation of a normative and political framework related to long-term and palliative care include an effective and meaningful participation of older persons?

*Answer:*

*Yes; e.g.:*

* *Participation (hearing) in legislative procedures;*
* *Participation in decisions relating to rules/regulations to ensure the quality of service provision;*
* *Entitlement to counselling and support when selecting services/benefits of the long-term care insurance according to their needs and preferences/desires (including those of the dependents).*

**Accountability**

8. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to long-term and palliative care?

*Answer:*

*Appeals procedures and legal action guaranteed by law:*

*The right to objection or review (by the competent supervisory authority) with regard to decisions taken by the long-term care insurance fund. The possibility of taking legal action – free of charge – in the Social Court.*

*Other than that, there are a number of disclosure and reporting requirements for health and long-term care insurance funds as well as systems for quality reporting.*

1. *Quite a few of the elements listed in the following are taken from the existing human rights treaties which are binding in international law for the contracting states;*  [↑](#footnote-ref-1)
2. *Eleventh Book of the Social Code* *(SGB XI) ‒ Social long-term care insurance‒*  [↑](#footnote-ref-2)
3. *Fifth Book of the Social Code (SGB V) ‒ Statutory health insurance ‒* [↑](#footnote-ref-3)
4. *Act to Improve Hospice and Palliative Care in Germany (Hospice and Palliative Care Act ‒ HPG) of 1st December 2015.* [↑](#footnote-ref-4)
5. *See* *“Charter for the Care of the Critically Ill and the Dying in Germany (2010)“,* [↑](#footnote-ref-5)