

BAGSO Responses to the Guiding Questions on the Focus Areas of the 9th Session of the Open-Ended Working Group on Ageing: Long-Term Care and Palliative Care

1. In your country/region, how is long-term care for older persons defined and provided for in legal and policy frameworks? What types of support and services are covered?

In Germany, ambulatory home care and residential long-term care, short-term care, interim replacement care, day care centres, and a limited amount of overnight care are available. Ambulatory care has priority over residential care. Family carers may obtain support and other forms of relief as well as short-term leaves of absence from work.

The need for care is defined in Book XI (Long-term care insurance) of the German Social Code (Sozialgesetzbuch, SGB). This makes provisions for financing material, monetary, or combined benefits (§§ 36-38) and everyday support (§§38a-45). However, the level is limited and meets only part of the overall cost. The principle is: the greater the extent of assistance a person requires in daily life, the higher the care classification and the higher the levels of aid and financial benefits. When insurance benefits, the individual's own assets, and those of their children no longer suffice, social-security benefits take effect (SGB XII). SGB Books V (Health insurance) and IX (Rehabilitation of and participation by persons with disabilities) present an additional legal framework for long-term care.

The German Charter of Rights for People in Need of Long Term Care and Assistance, which entered into force in 2005, is a significant self-imposed obligation for service providers. It serves as a framework of reference for the continued development of quality in care.

2. What are the specific challenges faced by older persons in accessing long-term care?

In Germany there is no adequate overall concept for long-term care. Depending on whether the recipients get ambulatory or residential care, varying amenities are available to them. Residential facilities only offer preventive or rehabilitating procedures very rarely, and only a restricted number of benefits that are covered by health insurance. The financing system does not yield any incentive for service providers to offer health-improvement measures, since the higher the level of care, the higher the amount of remuneration for the institution. Recipients of social-security benefits do not have free choice of residential facility. Persons who require assistance but who do not yet fall within one of the statutory classifications for care do not, in principle, have access to benefits.

The subdivisions in health and social services entail a substantial quantity of paperwork for the individuals concerned. The diverse areas of competence, types of benefit, exceptions, and opportunities for flexibility are unknown to many, and the way those interact is unclear. The difficulties begin when making the application; because of its complexity many benefits remain unused.

3. What measures have been taken/are necessary to ensure high-quality and sustainable long-term care systems for older persons, including for example:

- ***Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?***

The number of persons requiring long-term care is increasing. At present, almost everyone can be cared for by a mobile service – generally supplementing care by family members. In nursing homes there are regional differences ranging from empty beds to waiting lists. The capacities for day care are limited. During training for health-care and medical professions and unpaid volunteers, active engagement in the discussion on the human-rights conventions should be a permanent part of the curriculum, so that sensitivity to diversity needs can develop in all areas of life.

Care services were developed further through reforms. Mandatory systems of care for older persons are planned at the municipal, regional, and national levels. The “care shortage” can only be met if the care profession is made more attractive (qualification, remuneration, and working conditions).

As long as the long-term care insurance only covers the costs of assisted care up to a legal maximum, the recipients of care will be burdened with the residual costs. Fully financing long-term care must be the objective. The accessible range of services must be identical for ambulatory home care and residential long-term care.

- ***High quality of services provided?***

Nursing homes everywhere are monitored by the national home supervisory body and the Medical Service of the Health Funds (MDK). In principle, this also comprises protection against the use of force and unauthorised restrictive measures. At present the methods for quality assessment and reporting are being revised.

What is needed is a qualification campaign including new training schemes and academic qualifications.

- ***Autonomy and free, prior and informed consent of older persons in relation to their long-term care and support?***

The freedom of choice for the recipient is limited, since certain statutory prerequisites must be fulfilled for residential long-term care.

With an enduring power of attorney or an advance directive, concerned persons can state their intentions with regard to long-term care. In case of legal guardianship, the presumable will of the person must be considered.

- **Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?**

There are laws to prevent restrictive practices, which include sanctions for violations. The Werdenfels Approach indicates ways of avoiding such methods, as well as alternatives that are increasingly being implemented in practice. This is supported by ethics commissions in residential facilities and continuous further training for carers, honorary and full-time guardians, and judges.

- **Sustainable financing of long-term care and support services?**

As is the case with health insurance, long-term care must be fully funded and merged under an insurance where appropriate. The extent to which contributions should be tax-funded remains open to discussion.

- **Redress and remedy in case of abuse and violations?**

Independently of age, individuals are entitled to claim compensation and damages. Furthermore, claims can be enforced with legal and judicial assistance. However, independent and outreaching counselling and complaints bureaus in parallel with the overall legal system are not yet in general existence locally. For some time now there has been a demand for a law on the protection of adults, which would allow new forms of intervention.

4. What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

Concerned individuals should be aware of and have access to all options of ambulatory and residential services in long-term care – regardless of financing aspects. The ranking of ambulatory over residential care is predominantly finance-driven and disproportionately restricts the free will and choice of the persons affected.

5. In your country/region, how is palliative care defined in legal and policy frameworks?

At the human rights level (Art. 5 in conjunction with Art. 25) every human being is entitled to palliative care. In Germany the Charter on “care of critically ill or dying persons in Germany” (Charta zur Betreuung schwerstkranker und sterbender Menschen in Deutschland) was published in 2010. The Act for the improvement of hospice and palliative care (Hospiz- und Palliativversorgungsgesetz, HPG) came into force in 2015. Since then the nursing, medical, psychological, and spiritual care of persons in the last phase of life has improved. The aim is to achieve a dense network of hospice and palliative care at home, in hospital, in the nursing home, and in the hospice. Financing of the ambulatory and residential hospice services is accomplished through health insurance. For the recipients the benefits are free of charge; some institutions additionally depend on donations.

6. What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

Support for dying persons by hospice services varies from region to region, but is always organised independently of age. Specialised children’s hospices constitute an exception. Nursing homes enter into co-operation agreements with hospice services. In rural areas fewer options exist. An evaluation of the hospice and palliative care act is not available yet.

7. To what extent is palliative care available to all older persons on a non-discriminatory basis?

Hospice and palliative care is an element of standard care. Access to palliative services is independent of age. To date, the law has not been implemented at a locally accessible level everywhere.

8. How is palliative care provided, in relation to long-term care as described above and other support services for older persons?

In recent decades, numerous ambulatory and residential facilities for hospice and palliative care have appeared. A distinction is made between general and specialised palliative care. Individuals receive palliative care in hospitals, generally also in nursing homes as well as at home. On the whole palliative care is not yet locally accessible nationwide. For example, specialised palliative home care teams (Spezialisierte Ambulante Palliativversorgung, SAPV) or ambulatory hospices of sufficient capacity are not available everywhere.

9. Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

Multidisciplinary teams, the SAPV teams, have become established for palliative care at home. In many hospices and palliative care facilities as well as in nursing homes the culture of dying and the possibilities for dying in dignity are under discussion. Co-operative agreements with hospice services are widespread.

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