

Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Aging: Long-term care and palliative care

Input from the German Institute for Human Rights

- 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 2016 17.5 million people in Germany have reached the age of 65. 2,878,300 are currently in need of care. The majority of older persons requiring care (2.08 million) are treated on an outpatient basis (73 %) and 783,000 are hospitalized (23%).

There are some legal provisions concerning care, at federal and state level. The federal Social Code XI (Sozialgesetzbuch XI¹, SGB XI) regulates the social insurance. The state provides benefits in kind for care (§ 36 SGB XI), care allowance (§ 37 SGB XI), other care aids and measures that improve the home (§ 40 SGB XI). Also benefits for caregivers are included (§§ 44 ff. SGB XI). Inpatient measures are subsidiary to outpatient assistance. The benefits to be granted to a person depend on the degree of care and the need of care. However, this is not a cost-covering social insurance. Parts of the measures have to be payed by the individual (partial coverage principle). Due to that one can apply for financial support granted by the Social Code XII (SGB XII²).

In addition, consumer protection standards were improved through the Living and Support Contracting Act (Wohn- und BetreuungsvertragsG, WBVG³). Entrepreneurs who offer the provision of housing combined with the provision of care services have obligations to extensive inform and to adjust existing contracts.

The non-binding charter for the rights of persons in need of care (Pflege-Charta⁴) was an attempt by the government, in cooperation with various other state actors and civil actors, to make human rights applicable.

The legislative competence for regulatory provisions of home law lies with the Länder. They all have issued statutory ordinances. These concern e.g. authorizing the operation of homes for older persons or care-dependent persons, the staffing or structural equipment of the institutions and sanctions for the non-compliance of legal regulations.

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

First, there are problems in informing older persons about their rights and entitlements. In this respect, a distinction must be made between older persons in rural areas and those living in cities and between care given by family, outpatient care and inpatient care. It is essential that the information is easy to be understood. A nationwide information system does not exist, despite the introduction of so called "Pflegestützpunkte".

The procedure is too bureaucratic. Therefore a lot of possible measures are not being applied for by older persons in need. Furthermore, those affected often face financial challenges, as benefits under the SGB XI only partly cover the financial burden of a long-term care. In these cases, social assistance is little claimed, since many elders reject social assistance.

¹ https://www.gesetze-im-internet.de/sgb_11/

² https://www.gesetze-im-internet.de/sgb_12/

³ <http://www.gesetze-im-internet.de/wbvg/index.html>

⁴ <https://www.pflege-charta.de/de/die-pflege-charta/acht-artikel.html>

Finally, there is a shortage of qualified nursing staff and supportive infrastructures such as counseling and nursing care facilities. This leads to considerable waiting times and affected have to move away from their usual social environment.

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

More attention has to be paid to the privacy and habits of those affected, if care measures are taken. The acceptance of accommodation in a care facility by an older person can be increased by involving him or her in the process of creating a new everyday life. It helps, if the changes compared to the life lived before are small. In this regard it is necessary to respect the rights of older people to autonomy, independence and to establish effective nursing structures that make it possible to ensure these rights.

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

Everyone is entitled to the benefits of the SGB XI. But one has to bear in mind, that the social insurance is only a partial insurance (see above no. 2). Also the accessibility needs to be improved, for example through targeted and area-wide information and the reduction of bureaucracy (see above no. 2).

- *High quality of services provided?*

Recently, nursing laws ("Pflegerstärkungsgesetze"⁵) and the prevention law (Präventionsgesetz⁶) were passed. Since the quality criteria (so called „Pflegernoten“) have proved to be unsuitable, the development of new criteria are on the political agenda. These criteria should be aligned with human rights requirements. Furthermore, not only older persons in care have to be protected and supported, but the caregivers as well.

The "Altenpflegeberufsgesetz" (AltpfIG)⁷ serves the qualified training of nursing staff. This training has to provide knowledge and skills required for self-reliant and responsible care, including counseling, support and care of older people. This also includes topics such as the preservation and restoration of individual abilities. In this context one need to know something about geriatric and gerontopsychiatric rehabilitation concepts, health care including nutritional counseling and the accompaniment of a dying person.

The creation and promotion of alternative forms of living (such as shared housing of old persons or persons with dementia, housing of more generations together) is necessary. At the same time it is important to ensure the privacy of those affected. Double bedrooms for example should be assigned only on explicit demand.

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

The German legislator tried to archive a paradigm shift through legislative changes: Older persons have to be recognized expressly as right-holders, not as the objects of regulation. It has yet to be determined if it has been successful or not. Furthermore, the benefits of the Social Code XI were extended. They now include support for caregivers (especially relatives).

⁵ PSG I, BundesGBI. Nr. 61 vom 23.12.2014 ; PSG II, BundesGBI. Nr. 54 vom 28.12.2015; PSG III, BundesGBI. Nr. 65 vom 31.12.2016.

⁶ BundesGBI. Nr. 31 vom 24.07.2015.

⁷ <http://www.gesetze-im-internet.de/altpfllg/index.html>

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

The number of mechanically restrain measures has decreased. However, it has been reported in practice that medicamentous coercive measures are increasing. Especially dementia patients are affected by this. It is very urgent to improve the patients nurse ratio. Findings about long-term care at home (e.g. by family members or private care services) are scarce due to lack of research.

- *Sustainable financing of long-term care and support services?*
- *Redress and remedy in case of abuse and violations?*

In principle, in case of abuse and violations legal recourse to the courts is open to everyone. In fact, this is hardly used by older persons, as a timely compensation cannot be expected and costs and bureaucracy are caused. Low-threshold complaint mechanisms or contact persons are missing. In addition, a large portion of the victims affected, do not take action due to shame.

Furthermore, the protection of whistleblowers is also inadequate. Also in this regard, the expansion of low-threshold and independent complaint mechanisms in the care sector is indicated.

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?*

Autonomy and independence are essential. Also the following rights are to emphasize: right to health, the right to access to justice and the right to privacy.

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

The palliative care is expressly part of the standard care of the statutory health insurance and legally defined in § 37b (1) SGB V.

In 2015, the law on the improvement of hospice and palliative care⁸ was adopted. Also, the Charter for the care of seriously ill and dying persons⁹ has decisively shaped and promoted national political processes. However, this charter still faces practical barriers as it lacks in-depth training in palliative care. Furthermore since November 2017, the Home Nursing Directive¹⁰ has included palliative care, but this lacks a quality control mechanism.

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

One challenge is the timely diagnosis of the palliative need. This concerns in particular communication-limited persons.

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

⁸ BundesGBl. Nr. 48 vom 07.12.2015.

⁹ http://www.charta-zur-betreuung-sterbender.de/die-charta_leitsaetze.html

¹⁰ <https://www.g-ba.de/informationen/richtlinien/11/>

Everyone is legally entitled to palliative care. In fact, timely access to palliative care of sufficient quality is not guaranteed due to the lack of trained staff and facilities. Palliative care structures exist more prevalent in cities than in rural areas.

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

A nationwide palliative care supply does not exist. This is currently being developed in form of pilot projects. In this area too, the problem of a shortage of skilled workers is evident.

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

Human rights are little known among those affected and the nursing staff. The German criteria for quality of care are not aligned with human rights. The Care Charter, which provides a practical guide to apply human rights in the care sector, is not binding and is therefore applied sparsely. Due to that the charter is also not part of the training to become a care person. Experience has shown that a combination of care concepts, employee training and a palliative care person in one institution can increase quality of long-term care and palliative care.

The recommendations of the Council of Europe¹¹ were not communicated well by the German government. This could have promoted a nationwide discussion on this topic.

Article 12 ICESCR guarantees the right to the enjoyment of the highest attainable standard of physical and mental health. This also includes palliative care. 2016 the GIHR published an analysis on „Human Rights in the Nursing Practise“, which presents some practical barriers.

¹¹ Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons.