

ANSWERS OF THE GERMAN INSTITUTE FOR HUMAN RIGHTS TO THE GUIDING QUESTIONS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING:

Autonomy and Independence

NATIONAL LEGAL FRAMEWORK

1. What are the legal provisions in your country that recognizes the right to autonomy and independence? Do they have a constitutional, legislative or executive foundation?

The German legislator tried to achieve a paradigm shift through legislative changes in the Social Code XI¹: Older persons have to be recognized as right-holders, not as the objects of regulation. This is an attempt to counter-act ageism.

Moreover, standards to ensure autonomy and independence are enhanced by an improved training and education of the nursing staff, which is regulated by the Geriatric Care Act².

In addition, adult guardianship is another instrument that could enable older persons to maintain their autonomy and, within their abilities, lead a life in line with their wishes. The adult guardianship has to be limited to matters which the person affected cannot manage on his/her own. Nevertheless, the way adult guardianship is designed in Germany, it does not enable autonomous decisions, rather it overtakes them and deprives persons an independent and self-sufficient life.

The non-binding charter for the rights of persons in need of care³ was an attempt by the government, in cooperation with various other state and civil actors, to make human rights applicable. The Charta's articles were partly legally established through various acts⁴.

Moreover the UN Convention on the Rights of Persons with Disabilities (UN-CRPD) has been in force since ratification in Germany in 2009 as national law. It contains autonomy and independence not as a human right but rather as a human rights principle, which has to be used to interpret all human rights enshrined in the treaty⁵. Article 9 and 12 UN-CRPD in particular illustrate that autonomy is indivisibly intertwined with human dignity and the rule of equality. However, only persons with disabilities can assert their rights under the UN-CRPD.

¹ Sozialgesetzbuch XI (SGB XI).

² Altenpflegegesetz, AltPflG, BGBl. I S. 1690.

Art. 3 states that the training in care for the older person should impart knowledge, skills and abilities necessary for self-reliant and self-dependent care, including advising, accompanying and caring for older persons in their personal and social affairs. It also includes help to maintain and activate independent living, including the promotion and maintenance of social contacts.

³ Pflege-Charta , <https://www.pflege-charta.de/de/die-pflege-charta/acht-artikel.html>.

⁴ Nursing Care Development Act (Pflege-Weiterentwicklungsgesetz), Nursing Care Realignment Act (Pflege-Neuausrichtungsgesetz), Nursing Care Strengthening Acts (Pflegestärkungsgesetze), Prevention Act (Präventionsgesetz).

⁵ Art. 3 UN-CRPD.

The constitutional principle of equality⁶ does not refer to the age of a person. The sub-constitutional General Equal Treatment Act prohibits age discrimination.⁷ This prohibition, however, is limited to certain areas.⁸

NORMATIVE ELEMENTS

2. What are the key normative elements of the rights to autonomy and independence? Please provide references to existing laws and standards where applicable.

Autonomy and independence for older persons should be framed as a principle and a right.

The principle shall be:

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

Key elements on the right

Older persons have the right to enjoy legal capacity, to make decisions, to determine life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. This includes the right to have those decisions respected.

The right to autonomy and independence for older persons include personal, economic and financial and procedural aspects.⁹

3. How should *autonomy* and *independence* be legally defined?

Older persons have the right to personal autonomy and independence over all aspects of their lives in line with their will and preferences and on an equal basis with others.

IMPLEMENTATION

4. What are the policies and programmes adopted by your country to guarantee older person's enjoyment of their right to autonomy and independence?

The German legislator adapted the definition of persons in need of care by the 2nd Long-Term Care Strengthening Act¹⁰ in 2015 to improve the rights of older persons and broadening the group of beneficiaries to include persons who suffer from dementia. Therefore more persons in need of care, can access insurance benefits and enable/ enhance an autonomous lifestyle.

⁶ Art. 3 National Constitution (GG).

⁷ § 1 General Equal Treatment Act (AGG).

⁸ § 2 General Equal Treatment Act (AGG).

⁹ For further information see the joint submission with the Polish Commissioner for Human Rights.

¹⁰ BGBl. I S. 2233, 2239.

The guardianship law¹¹ is anchored in the German Civil Law Codex¹² and is continuously developed (downside see National Framework). Due to the 3rd Guardianship Amending Act¹³ the living will is part of the Civil Code since 2009.

The German law provides further opportunities for strengthening and maintaining self-determination, e.g. by issuing an enduring power of attorney.¹⁴

A multitude of publicly funded self-help groups, organizations, and contact points exists throughout Germany and pilot projects (e.g. shared housing) are funded.

However, the various programs are fragmented, difficult to overlook and of very limited capacity. The standards are also not inspected in these new, alternative accommodation models. A nationwide information system does not exist. Assistance and support services are urgently needed to enforce autonomy and independence.

EQUALITY AND NON-DISCRIMINATION

6. Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to autonomy and independence, paying special attention to groups in vulnerable situation?

Maintaining the autonomy and independence of older persons in rural areas is a particular challenge,¹⁵ especially as mobility in old age decreases significantly and infrastructure in these areas is not fully developed. That means neither enough support nor enough options are available to have an actual choice. Therefore in all areas support services have to be developed and improved.

With increasing age, independent living and social life of someone are endangered and depend to a high degree of support by the family or the community. It is important to note, that autonomy must not be influenced by an externally induced a-priori limitation (e.g. "older person's well-being"). Autonomy necessarily requires options and the information of the individual. The will of the individual is always decisive if it was decided with a full informed consent. That will has to be determined thoroughly and then be respected.

Access to health care and fostering is often limited due to shortage of skilled caretakers. Also those affected often lose some independence and autonomy because nursing staff has enough time to only help them doing everyday activities. Rather they undertake these actions for the older person.

¹¹ Betreuungsrecht.

¹² Bürgerliches Gesetzbuch, BGB.

¹³ Dritte Gesetz zur Änderung des Betreuungsrecht, BGBl. I S. 2286; cf. § 1901a, b Civil Codex (Bürgerliches Gesetzbuch, BGB).

¹⁴ SelbstBestimmt im Alter! - Vorsorgeunterstützung im Team; <https://www.bmfsfj.de/bmfsfj/themen/aeltere-menschen/hilfe-und-pflege/selbstbestimmung-im-alter>. For instance, since 2017, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth has been funding a pilot project called 'Self & Determined in Old Age! – Prevention and Support within a team at 15 locations throughout Germany.

¹⁵ Data can be taken from the German Reports on the Elderly by the German Government. Already in the report of 2001, and again in the last report (2016), health promotion, prevention and rehabilitation are recognized as goals of great importance concerning the preservation of independence, autonomy and participation in old age. All of these areas are very important for the development of the potential of old persons in social networks and thus for the preservation of existing or new care structures. Besides these governmental reports the German Centre for Gerontology regularly publishes the German "Alterssurvey".

Eventually, those affected may also face financial obstacles. As the level of care and the duration of care increases, the risk of financial dependence increases as well. Especially living in a residential care home can exceed financial resources rather quickly.

PARTICIPATION

7. The design and implementation of normative and political framework related to autonomy and independence included an effective and meaningful participation of older persons?

To ensure an effective participation of older persons maintaining social structures in the domestic and residential environment is crucial. Therefore in the nursing care insurance system, domestic and outpatient care is prior to inpatient care. Different mechanisms have been established to further implement this system, e.g. the expansion of nursing services and the financial support of shared housing of old persons or persons with dementia¹⁶.

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 autonomy and independence?

Every administrative act has to contain instructions on how to file an appeal. In addition, legal actions do not have to be in writing, but can also be presented to an employee of the court, who writes down the action.¹⁷

Individual rights and entitlements concerning social security are legally enforceable. The jurisdiction lies with the Social Court, where legal acts are free of charge and the principle of official investigation applies, which is why the court investigates facts on its own initiative. In case of more complicated legal cases, the costs of a lawyer are borne by the state.

Ordinary civil court proceedings are also open to everyone (e.g. the civil law constitutes the contractual liability of a nursing home inclusive damages). However, older persons are often discouraged from taking legal actions due to the cost of a lawsuit before the civil court and the amount of bureaucracy.

¹⁶ § 45 e, 45f Social Code XI (Sozialgesetzbuch XI, SGB XI).

¹⁷ § 90 Social Court Act (SGG).