

## Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Aging: Autonomy and independence

Input from the German Institute for Human Rights

*In your country/ region, how is the right to autonomy and independence of older persons defined in legal and policy frameworks?*

The German legislator tried to achieve a paradigm shift through legislative changes in the Social Code XI: Older persons have to be recognized expressly as right-holders, not as the objects of regulation. This is an attempt to counteract ageism. The future will show whether or not this will be successful.

The law on care of the elderly (Altenpflegegesetz, AltPflG) in paragraph 3, it states that the training in care for the elderly 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 (see § 3 Abs. 1 S. 2 Nr. 8, 9 AltPflG).

The UN Convention on the Rights of Persons with Disabilities (UN-CRPD) contains legal standards for the definition of autonomy. Article 3 UN-CRPD lays this term down in the context of the General Principles of that treaty. This illustrates that autonomy does not describe a human right as such. It is rather a human rights principle, which has to be used to interpret all human rights contained in the treaty. Article 9 and 12 UN-CRPD in particular illustrate that autonomy is indivisibly intertwined with human dignity and the rule of equality. But only older persons with disabilities can assert their rights under the UN-CRPD.

Article 1 of the non-binding German Charter of Rights for People in need of long-term Care and Assistance (so called Care-Charta) states: "Every person in need of help and care has the right to help to self-help and assistance in order to lead a self-determined and independent life."

- 1) *What other rights are essential for the enjoyment of the right to autonomy and independence by older persons, or affected by the non-enjoyment of this right?*

Essentially for the enjoyment of the right to autonomy and independence is precisely the possibility to exercise all rights that everyone – regardless of age – is entitled to. First of all, this requires comprehensive information (see question no. 5) as well as further assistance services and support. This is the only way an older person can be enabled to participate in social life. They fear a loss of autonomy as soon as they are deprived of everyday life. In this regard, the necessary protection against discrimination is to emphasize (see e.g. the General Equal Treatment Act (Allgemeines Gleichbehandlungsgesetz, AGG)). The aim of the AGG is to eliminate and to prevent discrimination, especially for reasons of age but with a limited scope. Measures are needed that empower the group of older persons to exercise their rights (meaning: motivation, active determination of will, a "culture of empowerment" and a low-threshold complaint mechanism).

Furthermore, a mere promotion of the so called "productive aging" should be avoided, as this leads to a negative stigmatization of older persons outside the labor market.

- 2) *What are the key issues and challenges facing older persons in your country/ region regarding autonomy and independence? What studies and data are available?*

Maintaining the autonomy and independence of older persons in rural areas is a particular challenge, especially as mobility in old age decreases significantly and infrastructure in these areas is not fully

developed. Which means there are not enough support or options available to have a real choice. For example, it is difficult for an older person to independently and autonomously access stores, infrastructure facilities, other services and cultural events, if these are not in the immediate living environment. In cities, such facilities often exist nearby, however older persons encounter other barriers (such as e.g. high old buildings without an elevator, overcrowded medical practices). 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 on 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 such as dressing, making coffee, preparing food. Instead they simply undertake these things for the elderly. Furthermore, accessibility is often limited. In many cases difficulties arise in determining the will of the person concerned. This significantly endangers the autonomy.

Eventually, those affected may also face financial hurdles. As the level of care and the duration of care increase, also the risk of lack of financial independence increases. Especially living in a residential care home can exceed the financial resources.

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".

*3) What steps have been taken to ensure older persons' enjoyment of their right to autonomy and independence?*

The German legislator changed the term used for people in need of care. This had strengthened the rights of older people.

The law of care for adults ("Betreuungsrecht") is anchored in the main German Civil Law Codex (Bürgerliches Gesetzbuch, BGB). This law is continuously developed. For example, due to the mental capacity act the patient's provision is now part of the Civil Codex (see §§ 1901 a, b BGB).

Furthermore, an attempt was made to strengthen the information for older persons. But a nationwide information system does not exist. Assistance and support services are urgently needed to enforce autonomy and independence. This should happen at the regional or local level.

*4) What mechanisms are necessary, or already in place, for older persons to seek redress for the denial of autonomy and independence?*

Basically, the ordinary court proceedings are open to anyone (e.g. the civil law constitutes the contractual liability of a nursing home inclusive damages). However, there are many barriers that older persons affected can't handle (e.g. the costs of a lawsuit and the bureaucracy). Also the courts are overloaded with work and therefore not effective for older persons to seek redress.

Complaint possibilities can be found at the Medical Service of the Health Insurance (Medizinischer Dienst der Krankenversicherung, MDK) and at the state agencies of every federal state that determines whether a care home fulfills the legal requirements of the German Home Act (Heimgesetz, HeimG). Also many care institutions already established an internal complaints system. However, there are still no nationwide low-threshold complaint options.

It is necessary to reflect on de-institutionalization and creating of services based on human rights in order to better anchor the autonomy and independence of older persons socially and legally. The autonomy of those affected is especially at risk due to structural barriers (e.g. in nursing care). This precarious human rights situation can be improved by state actors through political reforms.

After all, the state of Germany has an educational mandate. It requires an awareness raising and educational process to empower its population to use its own autonomy. The need for information is closely linked to the decision-making of an independent and self-determined decision. It is important to ensure that the older persons can actually capture the information content.

*5) What are the responsibilities of other, non-State, actors in respecting and protecting the right to autonomy and independence of older persons?*

Responsible non-State actors are the relatives, nurses and carriers of nursing institutions as well as service providers and legally appointed guardians. The working environment (including voluntary associations) also has a responsibility, as it creates structural barriers to the independence of a person, for example by no longer trusting in the ability of an older person to fulfill the tasks as in earlier times. This situation can be remedied by prevention.

The inclusion of the social environment is crucial. Likewise, the involvement of volunteers and the further development of the work of non-profit associations are worthy of development.

Finally, the communities and cities have to be involved. These can implement concrete measures to enable older persons to participate in social community life. An ombudsman could be an effective way to connect different social levels.