

BAGSO Responses to the Guiding Questions on the Focus Areas of the 9th Session of the Open-Ended Working Group on Ageing: Autonomy and Independence

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

Independence and autonomy are enshrined in the Basic Law or constitution of Germany (Grundgesetz, GG): “Every person shall have the right to free development of his personality insofar as he does not violate the rights of others or offend against the constitutional order or the moral law” (Art. 2 GG). This legal claim on the state covers all persons whatever their age.

2. 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?

In addition to the binding rights that derive from the **UN Conventions on Human Rights** without restriction for all older persons also, Germany committed itself to the UN International Plan of Action on Ageing in 2002. The legal framework is specifically based not on age but on the amount of assistance needed. For older persons with disabilities, the **UN Convention on the Rights of Persons with Disabilities (UNCRPD)** applies, which was ratified by Germany in 2009 and which defines individual autonomy as a principle of human rights. Also, both Art. 3 GG as well as the German **General Act on Equal Treatment (Allgemeines Gleichbehandlungsgesetz, AGG)** prohibit unequal treatment due to ethnic origin, gender, religion or ideology, disability, age, or sexual identity. Furthermore, to prevent any form of discrimination against women, the CEDAW human rights convention (Convention on the Elimination of All Forms of Discrimination Against Women) applies.

For older persons requiring long-term care, the guiding framework (soft law) since 2005 has been the German **Charter of Rights for People in Need of Long Term Care and Assistance**. When an individual is not fully able to take decisions, they may transfer decision-making rights to a trusted person of their choice through an **enduring power of attorney** or **advance directive**. Subsidiarily, the **law on guardianship (Betreuungsrecht)** applies. The type and scope of guardianship are laid down by the court that monitors the guardianship and re-examines the need for it in regular intervals.

In **Book XI of the Social Code (Sozialgesetzbuch, SGB)** self-determination is an important element. However, the legislation contains the proviso that insured beneficiaries are eligible only for “wishes concerning plans for assistance (...) within the limits of their benefits” (§2 (2)). The priority of ambulatory home care is also laid down therein.

The **hospice and palliative care act** of 2015 regulates the provision of palliative care at home or in residential facilities. Care providers are required e.g. to work together with residential hospice services so that dying with dignity and maintaining the greatest possible autonomy until the end are possible. 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.

3. What are the key issues and challenges facing older persons in your country/region regarding autonomy and independence? What studies and data are available?

Implementation of the legal framework is not happening to the full extent. In many cases older persons are still not being viewed as actors, as legal subjects who represent themselves, but as objects of charity. In this regard primarily older women from all segments of the population, members of minorities, and other particularly vulnerable groups are more likely to be affected by disadvantages. Implementation of the UNCRPD by the individual federal states is in its early stages: uneven and disparate specifically with respect to women and girls with disabilities or special needs as well as refugee women, immigrants, and minorities. Inside the **health and care system** there are numerous barriers to autonomous, independent living:

- The inadequate number of nursing staff and physicians with specialised geriatric training means that access to either ambulatory or residential care is not assured at the statutory level everywhere. This affects urban as well as rural regions – the latter in particular – and restricts statutory freedom of choice with regard to one’s practitioner (family or general) and the nursing care service.
- Prevention and rehabilitation as prerequisites for autonomy and independence are financed to only a limited degree by German long-term care insurance due to the way the latter is constructed.
- Depending on whether persons are covered by social security or by private insurance, regulations diverge. Subsidies (co-payments) for visual or hearing aids, for example, vary from one group to the other.
- At the **municipal and regional levels** there is a dearth of independent and qualified information and counselling centres that can advise affected parties about their rights on maintaining or recovering their autonomy and independence, and can provide support in asserting those rights.
- Poverty among older persons restricts their financial autonomy. Old-age poverty caused by the gender-specific wage and pension gap primarily affects women.
- Housing shortages, rising rents, and gentrification in cities, as well as new regulations on modernisation and renovation measures, all considerably restrict free choice of domicile, financial autonomy, and participation in society. The situation is compounded by the lack of barrier-free housing.
- The same is true for obstacles in public areas. Older persons frequently encounter restrictions to their mobility. In transport planning the requirements of older persons are not sufficiently taken into consideration. In many rural areas the public transportation network is thin. Often buses and trains are not barrier-free. Seating is likewise scarce in public areas.
- Local amenities are scanty especially in rural zones and the urban fringe.

- Because of digitalisation many older persons are cut off from important matters.

By way of the official care statistics of the German Federal Statistical Office, the Medical Service of the Health Funds, and the care reports of individual health funds, data are published regularly. Additional publications:

- German Institute of Applied Nursing Research (DIP) "Pflege-Thermometer 2018" ("Care Thermometer," in preparation)
- Federal government Reports on Older People (during every parliament's term of office)
- Federal government Reports on Poverty and Wealth (during every parliament's term of office)

Comprehensive evaluation studies are lacking to date. There is still a disparity between needs and the actual extent to which especially individuals with particularly restricting life experiences avail themselves of welfare facilities for older persons. This concerns, for example, persons who have experienced flight or displacement, members of sexual or gender-related minorities, and persons with HIV.

4. What steps have been taken to ensure older persons' enjoyment of their right to autonomy and independence?

The guiding principle of inclusion as defined in the UNCRPD has led to many measures for inclusion and social participation – independently of age. Age and disability are not sharply divided: age is perceived as a part of the life cycle that often comes with impairments.

The right to autonomy and independence is a component of social law, nursing home legislation (= housing and participation laws), the **agreements** between health funds and service providers, the contracts with beneficiaries of care, and training of qualified nursing staff.

In Part 2 of the **law to support long-term care (Pflegestärkungsgesetz II)** the concept of requiring care was linked closely to independence: "Individuals requiring care under the terms of the present Law are defined as persons who present health-related impairments to independence or ability and thus are in need of assistance by others" (§13 SGB XI).

Independence and autonomy have also acquired greater importance in assisted living and **new forms of communal living**. In SGB XI (§38a, assisted-living subsidies) the promotion of autonomy is granted explicit importance and more options for autonomy and self-determination are given.

Throughout Germany there are **self-help groups** of older persons, funded in the long-term care domain under §45d SGB XI: "Formation and expansion of self-help groups, organisations, and contact points."

In connection with the **law on guardianship**, the question of which new regulations and amendments are needed to promote autonomy is currently under debate.

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

Under the terms of general law, individuals have legal claims to compensation and damages upon culpable violation of a statutory right. Nevertheless, proving culpability is almost impossible. What is more, claims need to be asserted and possibly enforced. Within the health funds there are so-called arbitration boards. These do not operate independently and are not impartial, however. For quite some time now, Germany has seen demands for a law on the protection of adults. It is supposed to make new forms of intervention possible.

Overall, an autonomous lifestyle must become a matter of course in the presence of physical and mental impairments too. This goes further than the establishing of new legal instruments.

6. What are the responsibilities of other, non-state, actors in respecting and protecting the rights to autonomy and independence of older persons?

Actors in civil society have a responsibility to create awareness for the needs of older persons and represent their interests. In conjunction with counselling and complaints offices, care support centres, Alzheimer's associations, professional providers of advice or care, health-care funds, and senior-citizens' organisations, civil society places the topic in the public eye and pools information. In the process those actors are helpful in alerting politics and society to deficiencies in the transfer of theory into practice and in calling for assessments whether – and to what degree – the legal framework is being transposed into legal practice. As a rule, they act from the perspective of those concerned (bottom-up mode); while in the top-down approach, older persons are habitually viewed as objects of charity ("coercive care") and are treated accordingly.

BAGSO, as a representative of the interests of older persons in civil society, is committed to the existence of local advice centres for older persons, and it advocates outreach counselling and support. Organised by civil societies, such a comprehensive network of counselling, support, and monitoring demands adequate financial backing and clearly-defined responsibilities. Local communities must be reinforced as places of co-existence and diversity. In practice, work at every level should pursue a human-rights based approach, guaranteeing empowerment and access for all.