April 2024

Response by BAGSO to the call for inputs to the study on care and support, pursuant to HRC resolution 54/6

As German National Association of Older Persons’ Organisations, we focus our response to this call for input by the Office of the High Commissioner of Human Rights (OHCHR) on older persons as caregivers and recipients of care and support. Further, we primarily focus on the federal perspective and on laying out current challenges and gaps in relation to support and care in Germany. We do not claim for this response to be comprehensive, acknowledging that there are areas, such as protection against violence, coercion and legal guardianship, that the following input fails to address.

Basis of our response are previously established position papers developed in our expert group on health and care and approved by BAGSO’s board. The expert group is composed of representatives of our 120+ member organisations.

Recognition and protection of human rights

The rights of people in need of care are set out in a number of laws, such as the German Basic Law and the German Social Code. The rights are mentioned in international and European legal instruments, in particular, the United Nations’ Convention on the Rights of Persons with Disabilities (UN-CRPD), the European Social Charter and the Charter of Rights of the European Union. They relate, among others, to self-determination, freedom, security, privacy, participation, respect and professional care that is tailored to individual needs.

These rights are summarised and further explained in the Care Charter (Charter of the Rights of People in Need of Assistance and Care[[1]](#footnote-1)), a catalogue of rights for people in need of care. It was developed by representatives from the federal government, federal states, local authorities, associations, practitioners as well as academia and published by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the Federal Ministry of Health (BMG).

The Care Charter provides knowledge about the rights of people in need of care and explains in concrete terms how these rights should be reflected in everyday life. It contributes to strengthening these rights and is intended to encourage improvements in the situation of people in need of care by setting the standard for dignified care and strengthen their position in the healthcare system. To promote the implementation of the Charter, the Centre for Quality in Care (ZQP) provides educational offers around its content.[[2]](#footnote-2)

Despite these legal provisions, BAGSO is concerned about the human rights of unpaid and paid caregivers as well as recipients of care and support. In BAGSO’s view, a fundamental redesign of care and nursing structures is essential to address existing system deficiencies. Care is at its limits, with a high level of dependency on social welfare among those in need of care, a high risk of poverty among family caregivers and a dependency on irregular forms of employment and professional nursing on temporary employees. These deficiencies lead to a lack of availability and choice among care recipients as well as caregivers. Instead of being able to ask questions about the quality of an offer, the bare availability of a nursing care place or any kind of support is key for many of those affected and their families. The desired forms of accommodation and care are often not available or available to the required extent in the local area and those affected have few options when it comes to supervision, care and nursing services. This has serious consequences for both the human rights of caregivers as well as recipients of care and support.

In relation to other rights mentioned in the Annex of the Call for Inputs, such as the rights to social security, adequate housing, independent life in the community, please refer to BAGSO’s contributions to the discussions of the Open-Ended Working Group on Ageing (OEWG-A)[[3]](#footnote-3) in which it lays out normative and implementation gaps related to older persons, including those in need of care and support. We could like to particularly point out the challenges related to the right to social inclusion and the right to health available on the website of the OEWG-A[[4]](#footnote-4),[[5]](#footnote-5).

Policy and programmatic measures

We refrain from giving a comprehensive overview of policy and programmatic measures taken by the Federal Government, state governments or municipalities, and rather refer to a few nationwide civil society initiatives supporting care recipients and caregivers by offering services and advocating for their rights, many of which are funded by the government.

The **German Federal Representation of Interests for the Older People and Persons in Need of Care (BIVA-Pflegeschutzbund)** provides legal advice on issues relating to care and support in older age. The organisation offers, for instance, contract review of outpatient and in-patient care contracts and provides advice when problems with care institutions arise. The legal advice is financed through an annual membership fee. BIVA also does advocacy and capacity building work.

The **Federal Association we care (Bundesverband wir pflegen e.V.)** is an advocacy and self-help organisation for unpaid, informal carers. It supports caregivers in providing recognition, contact and information as well as a voice in politics and society – as equal partners in care. It develops peer support initiatives – nationwide, locally and digitally – in order to pool and share diverse experiences and extensive expertise of those affected. The Association is active at federal level, has five state associations[[6]](#footnote-6).

Through the **Alliance for good care (Bündnis für gute Pflege)** more than 20 nationwide active civil society organisations (trade unions, social and welfare organisations, professional associations and self-help organisations) demand better care for the care of older persons in Germany. As part of the campaign the Alliance demands better services and support for those in need of care and their caregivers, better pay and working conditions for formal caregivers and the introduction of a citizens’ insurance to finance care based on the principle of solidarity.[[7]](#footnote-7)

Together with six other associations – **BAG Selbsthilfe, Sozialverband vdk, SoVD, Verbraucherzentrale Bundesverband, Interessenvertretung Selbstbestimmt Leben** – BAGSO has the legal mandate to represent the rights of people in need of care and their relatives at federal level. As a representative of those affected, it is represented on the Care Quality Committee and in various working groups and advisory boards.

BAGSO formulates requirements for good care provision and takes a stand on important changes in care. It also provides materials to support caregivers, such as the brochure on “Respite for the soul – a guide for caregiving relatives”[[8]](#footnote-8).

For **persons with dementia and their caregivers**, there are specific offers, including counselling via phone and e-mail (reaching between 5.000 and 6.000 persons/year) offered by the **German Alzheimer Society** and local offers by so-called “Local Alliances for People with Dementia”, which focus on developing and expanding networked aid structures as a measure of the National Dementia Strategy[[9]](#footnote-9). These local networks are supported by a Network Office that acts at federal level, which focuses on the exchange of experience and transfer of know-how.[[10]](#footnote-10) In terms of intersectionality, there is for instance a project specifically addressing the intersection between dementia and disability (Down syndrome)[[11]](#footnote-11) or a project aimed at people with dementia and migrant backgrounds.[[12]](#footnote-12)

BAGSO and other civil society organisations are represented on the **Independent Advisory Board for the reconciliation of care and work** which was created in 2015 by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth. The Board “addresses matters relating to work-life balance, accompanies the implementation of relevant regulations and discusses their effects.“[[13]](#footnote-13) It provides recommendations to the Federal Ministry.

Challenges at national level

In the face of current demographic developments, providing for people who are reliant on care and support is a major social challenge in Germany. Data from 2021 shows that almost 5 million people were recorded as being dependent on care within the meaning of the German Social Security Code XI. Of these, 84% are cared for at home, most of them exclusively by family members (61%). A smaller proportion is cared for by family members with assistance by third parties. 790.000 care-dependent persons (16%) live in in-patient facilities.[[14]](#footnote-14)

BAGSO criticises the existing system of care and nursing as being at its limits, with a high level of dependency on social welfare among those in need of care and a high risk of poverty among family caregivers. Those dependent on nursing are increasingly not receiving adequate and good care.

To date, those in need of care have mainly been cared for by their children, the baby boomer generation. With the ageing of these large cohorts, however, an increased need for care is becoming apparent, while at the same time the number of potential caregivers in the following generations is decreasing. In the future, it will be crucial to ensure that those in need of care can live a self-determined life in dignity, despite their increasing numbers, declining family resources and the shortage of skilled workforce.

Even though the right to care was anchored in the German Basic Law in 1995, persons in need of care often cannot access care and support services due to limited offers. There is a lack of adequate care and nursing services geared towards the various needs. Regular services pertaining to household assistance and household-related services are also lacking. This is mainly due to a shortfall in staff, but a dearth of or insufficient refinancing options via nursing care insurance also impacts the services on offer.

Consequently, the desired forms of accommodation and care are often not available or available to the required extent in the local area and those affected have few options when it comes to supervision, care and nursing services. They cannot make decisions based on quality, but on availability.

There are, indeed, huge shortages in the provision of care and support in Germany. For instance, only three percent of persons in need of care are able to access day care due to a lack of places, as reported by BAGSO’s member organisation “Wir pflegen”. The organisation representing the interests of informal caregivers further reports that people with high care needs are often not able to access institutionalised care and home care is often either completely lacking or only providing insufficient care. Of those in need of care and cared for at home, 75 percent rely solely on the support of relatives.[[15]](#footnote-15) The organisation is further reporting that homecare services increasingly deny to offer services to persons with high care needs and demands to stop this growing practice of “care triage”.[[16]](#footnote-16) In a study by another BAGSO member organisation, VdK, more than a third of all family carers surveyed stated that they were only able to cope with caring with difficulty or not at all. 63% had daily physical complaints and 59% stated that they neglected their own health due to caring. According to the study, people’s entitlements to support and respite services are often not utilised: on the one hand, because there is a lack of respite service availability such as outpatient services, day care places and short-term/preventive care services, or because family carers are hardly able to look for available capacities due to time constraints and overload, and on the other hand, because the use of these services requires high co-payments, which are usually not affordable.[[17]](#footnote-17), [[18]](#footnote-18)

Another issue of concern in Germany is the application of physical and chemical restraints in older persons living in care institutions and coercion and involuntary treatment of older persons in residential care facilities, as expressed by the UN Committee for the Rights of Persons with Disabilities in 2015.[[19]](#footnote-19) For persons with dementia, the nationwide implementation of dementia-friendly concepts is of utmost importance.

Another immense challenge for care and support in Germany are unattractive work conditions and a growing shortfall in nursing staff. In 2022, an average of 37,000 vacancies in the care profession were reported across Germany.[[20]](#footnote-20)

A lack of accessible housing contributes to the institutionalisation of persons in need of care. Already now, there is a deficit of at least 2.5 million accessible or mostly accessible homes. Not only do the homes need to be equipped for older persons and persons with disabilities, but their location also needs to attend the needs and living arrangements of older persons. An alliance of 13 civil society organisations positioned itself demanding reforms to ensure more affordable housing, including more accessible housing options.[[21]](#footnote-21)

To create robust and resilient care and support systems with full respect for human rights it is necessary to establish easily accessible offers and sustainable long-term structures in the area of health promotion, prevention and rehabilitation. So far, such structures are not widely available, in particular in rural areas. For people with limited mobility the situation is further exacerbated.

While the legislators have recognised the importance of services at municipal level for older persons by making provisions in Section 71 of the Social Security Code XII, setting out participatory services for older adults, in practice these provisions are inadequately implemented. This is in BAGSO’s view fatal, jeopardizing the health and quality of life of older people and the support for family caregivers.

Every care-dependent person and their family carers or other persons are entitled to individual care advice. However, these services are not transparent and their quality varies greatly. They do not meet the diverse needs of those dependent on care and their families. They do not provide concrete help and support services in the sense of case management, do not consider the limited availability of services or the required waiting times.

Due to demographic and social change processes the sustainability of care within the family is called into question. The limitations both in terms of family and professional care leads thousands of households to switch to primarily irregular forms of employment of caregivers (24-hour live-in care and household assistance).

In Germany, long-term care insurance was conceived as a “partial performance insurance”, resulting in increasingly high co-payments. As a consequence, dependence on care is often associated with the risk of poverty, not only for the person in need of care and support, but also for family caregivers who do not receive adequate financial support.

In order to address these challenges, in its 2023 position paper “Assistance and long-term care: new structures in municipal responsibility”, BAGSO lays out detailed recommendations.[[22]](#footnote-22)

Data and information

In relation to data and information, the Statistical Office of Germany provides relevant data, including estimations of the number of persons in need of care in the future[[23]](#footnote-23). For instance, it is expected that the number of those in need of care will rise to just under 6 million by 2030. By then, 28% of the population will aged 65 and over, compared to 22% in 2021. The number of people aged 85 or older is projected to be more than three million.

In the years leading up to 2045 – when the baby-boomer generation will be between 75 and 90 years old – the care system will face even greater challenges. To be mentioned here, in particular, are older people with disabilities, parent carers of children with disabilities, care-dependent people with migration backgrounds, care-dependent people with different gender identities and sexual orientations and those with technology-intensive care requirements.

The Statistical Office of Germany also provides estimates of the number of formal caregivers needed in the future and looks, for instance, at the age structure of formal caregivers.[[24]](#footnote-24) However, because the term “family caregiver” is not clearly defined and their number is not definitely recorded, there are no official figures on the number of informal caregivers. Estimates on how many relatives bear the responsibility of care range from around four to just under 10 million people, mostly women.[[25]](#footnote-25)

**In conclusion**

In relation to care and support, BAGSO calls for a redesign of the care and nursing structures in Germany. At global level, it advocates for a UN Convention on the Rights of Older Persons as comprehensive legally binding instrument which would contribute to raising the awareness of the human rights of older persons, both as caregivers and care recipients. It would provide Member States with guidance on how to better protect the human rights of persons in need of care and those providing care and support. In BAGSO’s view, a Convention would also empower older persons as caregivers and care recipients to assert their rights and seek justice when their rights are violated. It would contribute to a paradigm shift away from a charity-based approach to a human-rights based approach.



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BAGSO – The voice of older people

BAGSO, the German National Association of Senior Citizens’ Organisations, represents the interests of older generations in Germany. It stands up for active, healthy and self-determined ageing in social security. BAGSO is an umbrella organisation of more than 120 civil society organisations that are run

by or work for older people.

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