

Open-ended Working Group on Ageing

Ninth working session

Analysis and overview of guiding questions on long-term care and palliative care received from Member States, “A” Status National Human Rights Institutions and accredited non-governmental organizations

Background

The Open-ended Working Group on Ageing, established by the General Assembly in its resolution 65/182 with the purpose of strengthening the protection of the human rights of older persons, will hold its ninth session at United Nations Headquarters from 23 to 26 July 2018. The substantive discussions will focus on two focus areas: autonomy and independence, and long-term and palliative care. To that end, the Bureau called for substantive inputs from Member States, national human rights institutions, non-governmental organizations and United Nations system agencies and bodies, following questionnaires prepared by the Secretariat on the two focus areas.

During the ninth session, the Open-ended Working Group on Ageing will consider and discuss the contributions received, based on the summary documents prepared by the Secretariat. The present document contains the analytical summary of contributions on the focus area: long-term and palliative care, following the nine guiding questions of the questionnaire.

LONG-TERM CARE

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?

It should be stated at the outset that nearly all long-term care in Member States is provided by family members – and much of it without supportive services, training or financial assistance. In addition, in some countries, any type of formal outside care assistance is viewed negatively as the social customs demand care by family members.

A number of Member States do not have legal frameworks on long-term care, although others such as Kenya, Palestine (non-member observer state), Paraguay and Peru, cite general human rights or similar legislation. Several Member States such as Argentina and Costa Rica, which have ratified the Inter-American Convention on the Protection of the Human Rights of Older Persons, refer to its Article 12 as the legal framework and definition of long-term care on which policy is based. Some countries such as the Czech Republic, Dominican Republic and Slovenia have legislation on social services, social protection and health care, but nothing specifically on long-term care. China cites Article 30 of the Law on the Protection of the Rights and Interests of Older Persons and the 13th Five Year Plan as the basis for the development of the long-term care insurance system and the wider development of the Elderly Care System. Similarly, Japan states that the Long-Term Care Insurance Act is the governing framework for policy development. Some countries such as Mauritius, which do not have broad legislation on long-term care, do have legislation on residential care homes. In the United Kingdom, England adopted a Care Act in 2014 that defines the care needs that local authorities must meet, and in Sweden, the Social Services Act governs housing and home-based care for older persons.

Most countries with formalized care systems enumerate similar overall objectives of long-term care, such as ensuring that older persons can remain independent with a high quality of life through support with activities of daily living (self-care) and instrumental activities of daily living (preparing meals, housework, etc.). Furthermore, there are wide differences among Member States in the types of support and services provided – ranging from very little, such that families rely mostly on unpaid and unsupported family care, or more organized volunteer networks that are common in South-East Asia, to formally provided home-based care services, rehabilitation and finally institutional care homes.

Service providers also vary among Government, private sector and charitable organizations, with funding sources also being diverse. In some Member States, such as the Philippines, residential care facilities of all types are available and run by the Government, the private sector and non-governmental organizations (NGOs), which are all required to be accredited by the Government, while in many developing countries there are no long-term care services beyond homes for indigent older persons run by the Government or NGOs.

There is also a great deal of overlap between medical and health care and social care – which also tends to be complicated by the involvement of different government ministries, funding and budget sources, as well as a wide variety of sometimes complicated guidelines and regulations for older persons to access entitlements. For example, formal care at home is only provided by the Government in the Czech Republic to the severely disabled and to older persons age 75 and over who are bedridden, as certified by a doctor, and in Mauritius, to those above age 90 who are bedridden or severely disabled. In other countries, care in the home is designed only for rehabilitation and is not provided for chronic or long-term care.

A growing number of Member States such as Germany, Japan and the Republic of Korea have turned to mandatory long-term care insurance schemes to both finance and organize services, and China is slowly expanding insurance coverage in this area. They are generally funded through a combination of taxation on salaries and Government budget allocation. These schemes cover all levels of care but vary in whether they provide cash benefits, benefits in kind or a combination of both. In Germany, which has one of the most extensive long-term care insurance systems, services also include ambulatory home care, residential long-term care, short-term care, interim replacement care, day care centers and some overnight care in certain cases.

The NGO AARP notes that in the United States of America there is no legal right to long-term care and to Medicaid benefits, which can cover the costs of long-term care and which are means tested and aimed at low-income older persons. On the other hand, in countries such as the United Kingdom, long-term care entitlements differ in the four nations of England, Northern Ireland, Scotland and Wales, where the funding, entitlements and regulations governing the long-term care system vary. In England, the configuration of services even varies among local authorities with local National Health Services arranging services to suit their populations. In Scotland, for instance, free personal care is available for all over age 65 who are assessed by the local government as needing care, regardless of income, as is free nursing care. In Wales, the Social Services and Well-being (Wales) Act of 2014 provides equivalent rights and entitlements for adults and children to long-term care. In England, the Care Act of 2014 sets out a legal duty to meet adults’ “eligible needs” and requires a financial

needs assessment of an individual in cases where a local authority chooses to charge for care and support.

The NGO Vietnam Association of the Elderly points to an additional alternative long-term care approach in some countries of South-East Asia, which is provided through civil society organizations of volunteers who form self-help groups. Viet Nam has some 1,300 groups which offer help with activities of daily living for older persons who live alone. However, it is noted that sustainability is an issue, with little or no financial support or ongoing training.

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

Nearly all Member States, both developed and developing, cited the issue of affordability of care for older persons and their families as a problem, in addition to the cost of expanding services that are covered by the government budget. Service availability also remains a challenge. The Red Cross of Serbia and the Commissioner for Protection of Equality in Serbia and the Government of Argentina note that in rural areas and small towns and villages, there is often a lack – or inadequate range – of services required.

The Ombudsman of Croatia reports that older persons face extremely long waiting times to access State-run long-term care facilities (up to 10 years). The Office of the Public Defender of Georgia also reports similar issues as well as waiting lists for in-home services.

A severe lack of trained personnel and age-specific services is common in most African countries as reported by Burkina Faso and the Nigerian National Human Rights Commission. Kenya also notes that there is a basic lack of information about and understanding of what long-term care means beyond institutionalization among the general population. This is true for most countries in the region which recognize the changing family structures and dynamics that make the provision of quality care by family members more challenging, but lack a national long-term care concept or framework.

Bahrain and the Russian Federation cited a lack of coordination of services and support to families as an issue. Malaysia echoes the same concerns and notes that the care industry is still in its infancy and as a result, trained care givers are in high demand and short supply. China also notes that demand outstrips the supply of quality services and trained personnel. Mexico's National Human Rights Institution states that long-term care must be recognized by law as outlined in the Political Constitution and the Inter-American Convention on Protecting the Human Rights of Older Persons, which would then trigger a budget allocation.

The Russian Federation also states that it lacks a system for knowing who needs care and relies on older persons specifically requesting assistance, and that there is a lack of uniform standards at the regional level. Furthermore, in many other countries, such as Slovenia, there is a disconnect between those providing social care and medical care services as well as inequity in access to care due to different points of entry, needs assessments and benefits and in-home help that is patchy in geographic coverage or non-existent.

NGOs in the United States and England note that affordability and access to long-term care are a problem for most middle-income families, as they have too many assets to receive free care. The Japan Support Centre for Activity and Research for Older People noted the problem of rising out of pocket costs for care within the long-term care insurance scheme (from 20 to 30 per cent), which the Government states is aimed at ensuring sustainability of

the system and maintaining equality among generations. Both Age Platform Europe and HelpAge International address the problems of lack of choice and control over the support that older persons require, even where it is available. Human Rights Watch cites widespread inappropriate use of antipsychotic drugs in nursing homes to “control” behavior in a study they conducted in the United States, particularly among older persons with dementia. This is also cited by Alzheimer’s Disease International along with the use of physical restraints. The German NGO BAGSO points to the complexities of the long-term care insurance benefits system which has a complex paperwork requirement. This was also mentioned by the Red Cross of Serbia. NGOs in India point to the multi-faceted problem of changing family situations that makes it difficult to provide the traditional care culturally expected of them, as well as a lack of supportive infrastructure and systems to do so. At the same time, the social stigma around organized long-term care, and in particular, long-term care centers, is a continued obstacle to their development.

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

Bulgaria cites a new Plan of Action for the period 2018-2020 for the implementation of a National Strategy on Long-Term Care, with a first stage that focuses on deinstitutionalization of care for older persons and persons with disabilities and transfer of services to in-home care and the provision of services in the community. In China, a pilot programme has been launched for long-term care insurance with the aim to building a long-term care system according to Chinese culture, underpinned by a strong focus on the promotion of healthy ageing and other preventive measures.

The European Commission is working with the OECD on researching long-term care costs and the long-term care workforce. In Germany, new regulations have increased benefits for all care services since 2015, particularly for out-patient care, additional nursing staff for care facilities, and the improved coordination of care and support services. Germany has also approved higher benefits for persons with the most need, particularly those with dementia.

The Kenyan Government has started a baseline survey to identify existing care homes, surveyed the care services being provided and plans to construct a Government-owned model for future care institutions. The Government also plans to develop a national long-term care strategy in collaboration with the Ministry of Health. In the same vein, Lesotho reports having started drafting a legal instrument to protect the rights of older persons that will include guidelines on long-term care and address violence and abuse issues.

Slovenia has a draft long-term care Act which is currently being updated based on public comments and which aims to establish a comprehensive, integrated long-term care system for all. Sweden has produced a web-based Elderly Guide to improve information access. The Commission on Human Rights of the Philippines reports that legislation is before the Congress for an Act establishing and institutionalizing long-term care for senior citizens. The Bill would mandate the State to provide long-term care services for older persons.

The Republic of Korea adopted the 2nd Basic Plan for Long-term Care 2018-2022 which expands care services and reduces co-payments and strengthens care in the community while focusing on long-term sustainability, and in Portugal there is a Development Plan of National Networks for Continued Integrated Care 2016-2019.

The European Union cites the European Pillar of Social Rights which includes the principle of the right to affordable long-term care services of good quality, in particular, home care and community-based services.¹

A growing number of Member States is now citing quality oversight of long-term care institutions as a new initiative. Malaysia notes the Private Aged Healthcare Facilities and Services Bill of 2017, albeit it that it is pending implementation by development of a Regulation; Malta also introduced Minimum Standards for Care Homes for Older Persons in 2015, and Paraguay's Ministry of Public Health and Social Welfare adopted a resolution establishing a system of registration, accreditation and inspection of care homes. Enforcement, however, is a challenge, with the Ombudsman of Croatia pointing out that although long-term care facilities are inspected by the Government, there are not enough inspectors to cover the number of facilities. Similarly, the Human Rights Attorney of Guatemala notes that although a Regulation exists covering accreditation, minimum standards and supervision of care facilities, the State is not fully in compliance and there is a lack of quality in service provision.

Examples of customer satisfaction and complaint mechanisms are cited, such as that of Northern Ireland, which has the Regulation and Quality Improvement Authority, an independent body responsible for monitoring and inspecting the availability and quality of health and social care services. Scotland has adopted National Care Standards through legislation, and from April 2018, Health and Social Care Standards. The Red Cross of Serbia and the Commissioner for Protection of Equality notes that with the adoption of a Law on Social Protection in 2011, the process of licensing service providers in social care has started. The Law requires training of providers to work with older persons and covers services in institutions and at home, albeit monitoring of services is currently lacking.

Member States such as Sweden are also putting efforts and resources into increasing care staffing levels and qualifications, both to improve the quality of safety of services as well as to enhance professionalization and pay levels to attract more care workers. The Human Rights Commission of New Zealand references a recent pay equity settlement which resulted in significantly higher wages for care workers, and thereafter increased the value of care work as a career.

National Human Rights Institutions and NGOs, particularly in developing countries, highlight the need for policy development and legislative action. Both the National Human Rights Commission of India and a national NGO mention that there is an urgent need for long-term care facilities and institutions, particularly for older persons living in poverty, to be established. The Philippine Commission on Human Rights notes that Congress should debate the proposed Act on Establishing and Institutionalizing Long-term Care for Senior Citizens as soon as possible. This would mandate the State to provide long-term care and services for older persons. The Commissioner of Human Rights in Poland also notes that it is necessary to implement a comprehensive policy for older persons, ensure adequate funding and shift from institutional care to care in the home and community. The South Africa Human Rights Commission notes that a draft Special Housing Needs Policy and Programme from 2015, which would provide capital funding for people unable to live independently and who require

¹ https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights_en.

State-assisted housing, needs to be urgently acted upon. This would also include institutional care. Other African National Human Rights Institutions such as that of Tanzania note that the establishment of a long-term care system for older persons is a priority. The NGO Alzheimer's Disease International emphasizes that policymakers need to pay much more attention to dementia as the root cause of the increasing need for long-term care services, and particularly institutional care.

HelpAge International, AGE Platform Europe, the National Association of Community and Legal Centres Australia, and The Law in the Service of the Elderly all state that explicit, legally-binding international human rights standards are needed on the right of older persons to affordable, appropriate, integrated, quality, timely, holistic care and support services adapted to individual needs to protect well-being and maintain autonomy, dignity and independence. Further, this right should be independent of incomes of family members.

Most responding Member States report the existence of a system of informed consent by an older person before admittance to a residential institution and in relation to the type of care provided. Some such as Bahrain cite articles of law, with Germany referring to a Consumer Protection Act and a Residence and Care Contract Act. The German Institute for Human Rights further notes that the German legislature has worked to achieve a paradigm shift through legislative changes that recognize older persons as rights holders and not as objects of regulation. Member States such as Japan and England and Scotland of the United Kingdom cite acts that require older persons to be involved in the development of care plans and agree with the content of the plan. A number of NGOs including Alzheimer's Disease International and BAGSO of Germany note the importance of promoting advance legal directives by older persons to clarify their wishes for care and medical treatment. However, several human rights institutions point to either a lack of legislation on informed consent, such as in Guatemala, or to the common practice of families deciding to have older relatives admitted to institutions, even if against their will, as in the case of the Philippines, which notes this despite the existence of guidelines and standards on the matter.

The Dominican Republic notes that there are large gaps in the elimination of restrictive practices, which the Government is currently creating protocols to address. Both the German Government and a national NGO refer to laws against restrictive practices which include sanctions for violations. Much effort has been put into implementing alternative approaches to these practices in care settings, with the results of a project of the Germany Ministry of Health, "Non-violent Nursing: Prevention of violence against older persons in long-term care," to be published soon. Some Member States such as Poland, Qatar and Spain refer to restrictive practices being "regulated" under mental health or similar legislation and protocols, based on the orders of certified physicians and under close supervision and monitoring. The national human rights institutions of Guatemala, Latvia and Serbia, as well as Alzheimer's Disease International and Human Rights Watch, refer to issues around the excessive use of psychotic medications and restraints. The Croatian Ombudsman states that while liberty-depriving restrictive practices are prescribed for psychiatric facilities, they are used in long-term care settings with no legal basis.

Generally, it appears that redress for abuse of older persons in long-term care facilities falls under general legal provisions on violence and abuse rather than being targeted to care situations (Argentina, Bahrain, China, Malaysia, Mexico, Philippines, Qatar). The German

NGO BAGSO notes that there has been demand for a law on the protection of older adults since accessing the legal system to claim compensation is complex for older persons. Both the Polish and the Hungarian national human rights institutions mention a Commissioner for Patients' Rights and an Integrated Legal Protection Service. A common theme, even with protection systems that are already in place, is chronic underfunding or understaffing (AARP, Red Cross Serbia). Further, the Croatian Ombudsman notes that complaints are handled informally by long-term care facilities themselves, with no defined protocol.

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?

The majority of respondents refer to the rights to information, autonomy and independence, choice of treatment and living arrangements (which should not be financially driven by Government), participation in society and access to health care and rehabilitation services. Many also cite the right of dementia patients to plan their care and treatment through advance directives; the right to be free from restrictive practices (whether physical or chemical); and the right to receive care from institutions that is compatible with cultural and personal life choices and identities.

Many refer to principles of non-discrimination and equal treatment in accessing long-term care. The Government of Argentina cites the rights to privacy, participation, freedom of expression, beliefs and values, which is also echoed by Bahrain. The right to receive care when self-care is failing is cited as a basic right under the right to health by China. The right to autonomy and informed consent, and the right to sexuality/intimacy is noted by Costa Rica, and the right to a dignified life with physical, economic and social security is emphasized by the Dominican Republic. The European Union cites the European Charter for the rights and responsibilities of older people in need of care, which outlines nine rights and one article on responsibilities as a guiding framework. The right to redress and to lodge complaints through a legal and or complaints framework is noted by the United Kingdom. Several African countries mention rights associated with the preservation of ownership of property.

PALLIATIVE CARE

5) In your country/region, how is palliative care defined in legal and policy frameworks? 8) How is palliative care provided, in relation to long-term care as described above and other support services for older persons? 9) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

A large number of Member States has either no definition of and/or legal framework for palliative care and, by implication, limited or no palliative care services. This is reflected in the fact that according to the International Association for Hospice and Palliative Care, only 14 per cent of people who need palliative care on a worldwide basis actually receive it. Costa Rica refers to Article 2 of the Inter-American Convention of the Human Rights of Older Persons as a basis for its definition of palliative care. Malaysia notes that there is no policy on or definition of end-of-life care but that services are available in select government and private hospitals. The Nigerian National Human Rights Commission and the Government of Lesotho report no definitions of or frameworks on palliative care and limited or no

availability of services. Zimbabwe, however has a 2014 National Palliative Care Policy and a definition of such care. While many Member States with policy and legal frameworks in place refer to similar definitions of palliative care, some define it as applicable only to those with a terminal disease, and others to those with a serious and/or incurable disease.

Palliative care is being more widely recognized as an area of treatment, with new frameworks being put into place over the last five years. For example, a Russian NGO notes that the Federal Law on healthcare of 2011 identified palliative care as an area for development, and that in 2012 the Ministry of Health ordered the creation of a palliative care service. The Government of Colombia also notes that development of its service started in 2014 with a new law, and Albania additionally introduced a new law in the same year. In India, palliative care is not defined in legal or political frameworks but is referenced in the 2011 National Policy on Senior Citizens. In Argentina, the right to receive comprehensive palliative care is enshrined under the Law on Patient's Rights in caring for a disease or ailment. Hungary provides for palliative care within the Healthcare Act, as do the Philippines, Poland and Ukraine. However, the Philippines Commission of Human Rights notes that the existence of the law does not necessarily mean availability due to a lack of resources, and the Polish Commissioner of Human Rights notes that palliative and hospice care is only available to those diagnosed with certain diseases.

Interestingly, in several countries such as Japan, the legal basis for palliative care provision is embedded within cancer care (Article 15 of the Cancer Control Act). In this case, it covers "other disease." In Kenya, however, palliative care is targeted towards terminally ill patients such as those with AIDS and cancer, but not age-related diseases. The Dominican Republic, Guatemala and Mauritius also point to this issue. In the latter country, while palliative care for cancer patients is in place with referral criteria, for non-cancer care it would be provided by treating doctors and is therefore quite uncoordinated. In each of the United Kingdom's four nations there is a strategic framework, vision, programme and plan to improve palliative and end-of-life care.

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

It is evident that even where there is a palliative care programme or legal framework in place that lays out the right to palliative care, availability and access, particularly beyond urban areas, are a challenge in many countries. This is mentioned by Colombia, Costa Rica and the Human Rights Commissions of Croatia, Georgia, Hungary, India, New Zealand, the Philippines and South Africa. Further, a lack of financing, trained personnel and institutions offering palliative care services is cited by national human rights bodies in Croatia, the Russian Federation, Ukraine and Zimbabwe. The Governments of France and Germany also mention a lack of comprehensive information available to older persons and their families as a challenge to ensuring timely access to palliative care.

The Centre for Gerontological Studies of India notes that while there are two WHO Collaborating Centres in the country, which include palliative care training and support, availability, accessibility and affordability of palliative care is "grossly inadequate," noting that only around 1 per cent of patients who require it receive palliative care.

The Government of Morocco notes that it needs to develop a palliative care strategy and to extend the care network. Slovenia mentions that palliative care is mostly provided to patients with cancer because of a lack of clear criteria for inclusion and a lack of qualified staff.

Inputs received on data regarding end-of-life care are scarce. According to the International Association for Hospice and Palliative Care, the need for palliative care for older persons is increasing due to both population ageing and non-communicable diseases. Non-communicable diseases kill 40 million people each year—25 million of whom are persons over the age of 69. Data reported mainly focus on place of death, number of hospices or palliative care units, as well as number of older people in receipt or need of palliative care. In parallel, studies reported on palliative care largely address perceptions about and experiences of palliative care, its accessibility and quality, the need for such care, and adapting it to the national context.

In the United Kingdom, for example, England conducted a national audit of end-of-life care in hospital. In France, there are nearly 225,000 deaths each year under conditions requiring palliative care, and not all patients are able to access such care. Moreover, while 80 per cent of people in that country say that they want to spend the last moments of their lives at home, surrounded by relatives, the proportion of home deaths has decreased from 28.5 to 24.5 per cent between 1990 and 2010. The Republic of Korea similarly highlights an increase in the number of deaths of older persons in hospitals. That country's National Human Rights Commission references a 2014 Survey on Older Persons, in which the number of older people living alone or suffering from chronic diseases is increasing, and 88.9 per cent of respondents oppose life-sustaining treatment.

In Japan, specialized palliative care services are provided by hospital palliative care teams and out-patient clinics at 401 designated cancer hospitals and 36 local cancer centers. In the Russian Federation, the number of older persons who received palliative care in 2017 amounted to 140,000 people. Colombia estimates that there are approximately 80,000 people per year under palliative care, a number that is considered an under-estimation. The South African Human Rights Commission refers to a study conducted with 1,443 hospital inpatients in the Cape Town Metropole, which found that 16.6 per cent of the patients had an active life-limiting disease, the greatest burden of which was in the general medical wards, to which an overall 54.8 per cent who met the requirements for palliative care were admitted.

Data and studies reported show that significant efforts are needed to enable older persons to receive palliative care and to be accompanied at home near the end of their lives. Studies cited in the inputs are available at the following link < <https://social.un.org/ageing-working-group/lcstudiesninthsession.shtml>>.

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

While no direct discrimination against older persons is reported in any Member State, discrimination by omission is common due to resource constraints, lack of information, training and knowledge, place of residence and care setting, and overly-restrictive drug regulations, in particular for morphine.

The International Association for Hospice and Palliative Care notes that more than 80 per cent of persons experiencing serious health-related suffering die in low-resource countries with severely limited access to palliative care and oral morphine for pain relief.

NGOs note that some regional human rights frameworks recognize the right to palliative care, but that they vary and are inconsistent. NGOs find it important to establish the right in all care settings, not just medical institutions.

Several Member States and NGOs mention the importance of advance directives and/or support to enable individuals to exercise legal capacity or benefit from assisted decision-making based on instructions and preferences for treatment. Alzheimer's Disease International points to the particular importance of understanding the untreated pain symptoms of older persons with dementia and the danger of exclusion of dementia patients from treatment.

Alzheimer's Disease International notes that a national medicines policy is required that ensures the availability of essential medicines for pain. For example, Argentina cites its National Programme on Palliative Care which promotes the public production and free distribution of morphine and methadone in accordance with strict requirements for controlled substances to ensure timely access to palliative medication.

ECLAC notes that although Article 19 of the Inter-American Convention establishes State obligations regarding palliative care, most countries in the region do not meet the demand for it and fail to recognize it as a discipline or to include it in public or private health care systems. Since few have legislated for palliative care, funding and continuity have been negatively affected. This has led to some initiatives by private centres to provide end-of-life care, but at high financial cost and even with lax oversight.

New Zealand's Human Rights Commission notes that, since most palliative care is provided through hospices and by palliative care nurses, there needs to be greater integration of palliative care into long-term care residential facilities.