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| Call for inputs |

HelpAge inputs to OHCHR on the right to care and support

Introduction

HelpAge International works with and through a global network of organisations who promote the right of all older people to lead dignified, healthy, and secure lives. The HelpAge Global Network is a unique worldwide alliance of over 170 members across 91 countries. Our vision is a world in which all older people can lead dignified, healthy, and secure lives. Our mission is to promote the wellbeing, rights, and inclusion of older people so we can all enjoy a future free from poverty, inequality, and discrimination.

Overview on population ageing and care and support

The world is rapidly ageing. By 2030, 1.4 billion people will be aged 60 and over, rising to 2 billion by 2050 and making up 22 per cent of the global population. The majority of older people (70 per cent) are living in low- and middle-income countries.

There is great diversity in how people age but, as people grow older, they are more likely to experience non-communicable diseases, disability and growing need for care and support. This includes the increased prevalence of conditions associated with more intensive and complex care and support needs, including, for example, dementia. Population ageing is therefore contributing to an increase in the number and proportion of people with a care and support need globally. For example, in Europe, more than one in five people are estimated to have long-term care (LTC) needs, that is, they need help with their daily activities.[[1]](#footnote-2)[[2]](#footnote-3) It is important to note that, even within Europe, the prevalence of LTC needs varies widely and is as high as 35 per cent in several countries and, on average, women, people from lower socio-economic groups, people living alone and those aged 80 and older are more likely to have care and support needs.

While need for care and support is increasing, the supply of care is insufficient and inadequate. The large majority of care and support for older people who need it is provided by women and girls of all ages and those who have fewer economic resources. It is generally unpaid or underpaid, exacerbating gender inequities and other inequalities. Inadequate investment in publicly funded, universal and rights-based care and support systems, together with shrinking family sizes, changing family structures, rising female labour force participation in some places and migration, means that reliance on unpaid care is resulting in human rights violations both for those older people who rely on care and support to meet their basic needs and for those providing care without adequate support or decent work provisions.

It is important to note that many providers of care and support for older people are older themselves. On average across OECD countries where data is available, around 13 per cent of people aged 50 and over reported providing informal care at least weekly in 2019, rising to or over 20 per cent in several countries.[[3]](#footnote-4) These figures are likely to be far higher in lower income countries where there are fewer options for formal care and support and more limited health and social protection systems.

Below we respond to the consultation questions.

1. There is no explicit standard on long-term care and support in older age in international human rights law. Article 19 of the Convention on the Rights of Persons with Disabilities (2006) establishes the right to independent living for persons with disabilities, which applies to older persons with disabilities and which includes provision of support services to enable such independent living. There is also a growing body of advisory documents by UN Treaty Bodies and Special Procedures that establish older people’s access to support services as a right. This includes recommendations by the Committee on Economic, Social and Cultural Rights in their General Comment No.14; the Committee on the Elimination of Discrimination against Women in their General Recommendation No. 27; and the Independent Expert on the enjoyment of all human rights by older persons in her 2015 thematic report that recommends states should provide care and support services to older people so that they can live independently. Also to note is the recent Human Rights Council’s Resolution 54/6 on the centrality of care and support from a human rights perspective.

Some regional human rights standards recognise care and support for independent living in older age. However, these vary and are inconsistent across regions. The Inter-American Convention on Protecting the Human Rights of Older Persons (2015) states in Article 12 that older people have the right to a comprehensive system of care that not only protects and promotes their wellbeing but also maintains their independence and autonomy. Articles 10 and 11 of the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons in Africa (2016) establish limited states’ obligations in relation to care and support in home and residential settings. Article 25 of the European Union Charter of Fundamental Rights (2000) recognises older people’s right to lead a life of dignity and independence and to participate in social and cultural life. Article 23 of the European Social Charter (1996) establishes older people’s right to social protection to enable them to remain full members of society, to choose their lifestyle freely and to lead independent lives. The Council of Europe’s Recommendation CM/Rec (2014)2 on the promotion of the human rights of older persons makes recommendations on both home and residential care settings.

These human rights standards can contribute to a better understanding of the role of the state in the on-going discussion about the respective roles of the individual, family and state in relation to long-term care and support. Central to these standards is that care and support services should enable older people to live independent and autonomous lives.

At national level, various studies provide an overview of the limited legislation and policy on care and support for older people in low- and middle-income countries.[[4]](#footnote-5) However, of the 125 governments that responded to the Decade of Healthy Ageing progress report survey in 2023, 95 (76 per cent) self-reported that they had long-term care legislation or policy,[[5]](#footnote-6) though only 34% (45/133) reported having adequate resources available for action on long-term care and support. This aligns with what older people we work with tell us about the availability of formal care and support. We include more on this below.

2. Some low- and middle-income countries are increasingly recognising and responding to the increasing need for care and support. In recent years, several countries have been investing in developing long-term care and support strategies and integrated care pilots, for example, Indonesia, Mongolia, Sri Lanka, Tonga, Vietnam and the Maldives, with support from the Asian Development Bank[[6]](#footnote-7); Turkey including with support from the EU; and other countries such as Qatar, Singapore, Brazil, China and the like. The extent to which this is participatory, consultative and engages older people and their caregivers varies but should be considered a necessary part of policy and system formation. Good practice is also taking place in the Dominican Republic to design an age sensitive, disability inclusive and gender responsive national care systems that meet the needs and uphold the rights of those providing and receiving care across the lifecourse.[[7]](#footnote-8) Such approaches which are engaging older people providing and receiving care and their communities can help ensure that their voices, needs and preferences are placed at the centre of care and support systems. HelpAge and partners have been an active participant in a number of these processes at national level.

In Thailand, LTC is being integrated into broader Universal Health Coverage schemes. A pilot program established in 2016 and managed by the National Health Security Office and local authorities operates through a care-management system and provides at least two to eight hours of home-based care support a week, depending on need. The caregivers, who each receive 70 hours of training, are supervised by a care manager. Social services such as assistance with housework, activities of daily living, and obtaining assistive devices are provided to older persons who meet the eligibility criteria. Medical services, including preventive services and physiotherapy, are also available through the programme and the Thailand universal health coverage package.[[8]](#footnote-9)

Some countries provide supplementary disability benefits for older people, in addition to social pensions, recognising the increased costs related with disability, including need for care and support. This is the case, for example, in Vietnam, South Africa, Mauritius, Thailand and Georgia. [[9]](#footnote-10) However, it is important to note the limited coverage and adequacy of these benefits and social pensions in general for older people in low- and middle-income countries.

Various reviews of long-term care and support systems for older people globally have identified various good practices and priorities for system and service development. These include, inter alia: supporting ageing in place, including through deinstitutionalisation and the provision of community- and home-based care and support services; the delivery of person-centred care based on older people’s needs, values and preferences; comprehensive and integrated services delivered by multidisciplinary teams covering health and social care and based upon personalised care plans; supporting innovation; investing in a well-trained, well-paid and well-supported formal care workforce; supporting informal caregivers; ensuring strong governance and leadership arrangements; developing strong information systems; sustainable finances; and recognising the place of LTC within the broader context of age-friendly communities, housing, transport, social protection, and healthy ageing programmes.[[10]](#footnote-11)

Supporting and developing the capacity of those providing care is critical to ensuring the delivery of rights-based support. In 2017, the European Network of National Human Rights Institutions (ENNHRI) developed a Toolkit for Care Providers on Applying a Human Rights-Based Approach to Long-term Care for Older Persons. This report aims to help care providers throughout Europe to understand their human rights obligations to older persons in need of long-term care and how to apply them in care settings. It draws on monitoring work of the human rights situation in the long-term care sector carried out by members of ENNHRI in six European states to highlight how a human rights-based approach to long-term care can help care providers to meet their human rights obligations. Research from ENNHRI has found that care homes had the most difficulty upholding the right to dignity, the prevention of abuse, the right to autonomy, participation, privacy, the highest attainable standard of health and access to justice. However, a range of good practices were also found, which often resulted from HRBA training for care staff and formal and informal input from residents into decisions affecting their own care and the running of the care home. Many HelpAge International partners are engaged in the delivery of care and support either through the provision of formal services or through training and supporting the delivery of informal care to older people in the community and at home through volunteer schemes. This is the case, for example, in Vietnam, Sri Lanka, Uganda, Ukraine and more. The volunteer model is often based on necessity, given the availability, affordability, accessibility and acceptability barriers to accessing quality formal services in most of the countries where our partners work. However, in general, it is important to note and consider the risks associated with volunteer models, including how relying on unpaid, largely female volunteer caregivers (older women dedicate an average of[4.3 hours per day](https://www.ageinternational.org.uk/globalassets/documents/reports/2021/age-international-older-women-report-v11-final-spreads.pdf) to unpaid care and domestic work) who often lack professional training may impact on the rights of both those providing and receiving care; how volunteer models may perpetuate inequalities in the provision and receipt of care and support, including those related to gender and socio-economic inequalities; and, ultimately, how volunteer models may contribute to a failure of State as the duty bearer to invest in publicly funded, universal and rights based care and support systems.

To support families and other informal caregivers to provide support to older people in low- and middle-income countries, and to address gaps in available manuals for caregivers with regards to 1) low resource settings and 2) mainstreaming of dementia care across other domains of care and support, HelpAge has developed a [Caregiver Manual - HelpAge International](https://www.helpage.org/resource/caregiver-manual/). This was based on review of a wide range of tools and resources from the HelpAge network and wider stakeholders working on care and support for older people. The guide places human rights at the centre and aims to promote person-centred care that upholds the autonomy, independence and dignity of those receiving and providing support.

1. The failure to clearly articulate how human rights apply in older age in international human rights law leads to violations of older people’s rights at all levels. An international legally binding instrument (a new UN Convention on the rights of older persons) is urgently needed to provide a comprehensive framework to promote and safeguard the rights of older people, including their right to provide and receive care and support. This would also serve as a powerful tool in combating ageism, discrimination, abuse and neglect, all of which are central barriers to fulfilling older people’s rights in general and their right to receive and provide care.

Where legislation and policy on care and support exist at national level, they often fail to adopt a rights-based approach and to promote the choice, independence and autonomy of older people receiving and providing care.

Few countries have invested in the development of universal, publicly funded and community-based care and support systems that meet the needs and uphold the rights of older people receiving and providing care or the rights of those providing it.[[11]](#footnote-12) This is especially true in low- and middle-income countries where the majority of older people live.

What limited formal care and support mechanisms do exist are often underfunded, fragmented and lack strong governance, regulatory and quality assurance mechanisms to uphold older people’s fundamental human rights. There are also significant workforce challenges, with all countries globally facing significant workforce gaps and with those who are working care and support often facing poor pay, poor working conditions and limited training and support.[[12]](#footnote-13)

A large number of older people we consulted on care and support in 2017/8 said there were no long-term care and support services available in their community other than the support provided by family members or other informal caregivers.[[13]](#footnote-14)

“There are no support services available to older people in my community. Only family members are taken as or believed to provide assistance with daily activities. But this does not happen for all.” Nepal, 71-year-old woman

“The truth is these services are scarce and cannot meet the demand.” Zambia, 72-year-old man

“[I have access to] homecare and treatment, but this only covers a tiny proportion of my needs.” Serbia, man in his seventies

Even where some services are available, participants described barriers to accessing them. Services were too costly, insufficient or it was difficult to find information about them. Other barriers to access were failing eligibility criteria, bureaucracy, having to travel long distances and a lack of government policy. Family members’ shame at being seen as inadequate carers was also identified as a barrier.

“[A barrier to accessing care and support is] family members not having enough income to hire a paid carer or to send their parents to a care centre.” Myanmar, group discussion

“[A barrier to accessing care and support is] bureaucracy. To receive disability benefits you must annually confirm your status as a disabled person. It turns out you need to go to the hospital and get a paper that [confirms] for the year you have not grown a new leg or kidney. It would be funny if it weren’t so humiliating.” Kyrgyzstan, woman in group discussion

 “Some people say they cannot leave their parents in a care centre since people will gossip and say they have been defeated in caring for their parents.” Sudan, group discussion

Across all contexts, intersecting discrimination and inequalities related to age, gender, disability, socio-economic and other factors lead to multiple and often compounded barriers to older people accessing good quality care and support services in line with their needs, preferences and rights.

These barriers leave many older people dependent on care provided by family members or other community members to meet their basic needs, with little choice or autonomy over the support they receive. Of the older people we consulted, the majority reported having no say in the management of their care and support.

“We do not have any say since it is a favour.” Kenya, group discussion

“Usually an old person has to put up with the way they are cared for.” Russian Federation, 65-year-old woman

Not only does having to rely on informal care and support provided by family affect older people’s choice and autonomy, but it can also put them at greater risk of emotional, financial and physical abuse or neglect, especially where they have high physical, mental and/or cognitive care and support needs, including dementia.

Such risks are exacerbated by a lack of financial or other support for the provision of care by informal caregivers, especially where care provision results in high levels of caregiver strain. Even in OECD countries, only two-thirds provide cash benefits to family caregivers; cash-for-care allowances for recipients, which can be used to pay informal caregivers; or periods of paid leave for informal carers.[[14]](#footnote-15) Only some countries (such as Australia, Germany and Luxembourg) also provide counselling/training services, many rely heavily on the voluntary sector. Such financial or other support is even less common in lower income countries but examples include Mongolia’s carers allowance (increasing to about 85-90 USD/month in 2024)[[15]](#footnote-16).

A 2016 mapping of ageing policy in Asia by HelpAge found legislation mandating the care of older people by family members in China, India, Nepal, Sri Lanka, Viet Nam, DPR Korea, Pakistan and the Philippines.[[16]](#footnote-17) Such legislation undermines the choice, autonomy and independence of older people receiving and providing care, and shifts responsibility away from the State as the duty bearer.

Older people we consulted in 2017/8 informed us that day centres and residential facilities were available in some communities.[[17]](#footnote-18) These were run by the state, the private sector or faith-based organisations. However, as with formal care in the community, challenges facing care in residential settings include weak and fragmented funding; inadequate workforce training, pay and support; and limited regulation, quality assurance and governance mechanisms all of which contribute to high risk of human rights violations for people receiving care and support in these settings. This has been brutally highlighted during the COVID-19 pandemic where, despite being one of the groups most at risk of severe disease and death, people living in institutional settings experienced multiple rights violations, including violations of their right to health and to life.[[18]](#footnote-19) In general, COVID-19 exposed the lack of protection of older people’s rights in relation to care and support services in all settings, and multiple barriers to the availability and accessibility of support during emergencies. In doing so, it highlighted the considerable need to build preparedness and resilience for emergency response into care and support systems in all settings to ensure the right of those most at risk are upheld during pandemics, natural disasters, climate crisis or wider humanitarian emergencies.[[19]](#footnote-20)

The absence of data to understand the needs and preferences of those providing and receiving care and their current access to support to inform system and service design and delivery is another key barrier. For example, only 37 per cent of 131 countries reported having cross-sectional, nationally representative data on older people and their health and care needs in a recent WHO survey.[[20]](#footnote-21)

More broadly, limited access to health services, health insurance coverage and social protection coverage in low- and middle-income countries has a profound impact on older people with care and support needs being able to enjoy their human rights and meet their basic needs. Limited integration between the health, social care and broader social protection systems that do exist creates additional challenges.[[21]](#footnote-22) There is urgent need to prioritise the funding, design and delivery of integrated care and support as part of universal health coverage (UHC) and social protection to ensure the delivery of holistic, person-centred and joined-up care that effectively supports healthy ageing and upholds older people’s rights.

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2. It is important to note that, even within Europe, the prevalence of LTC needs varies widely from more than 35 per cent in Portugal, Hungary, and Lithuania, but less than 15% in Malta and Ireland. [↑](#footnote-ref-3)
3. OECD Health at a glance: 2021, Informal caregivers. Accessed 01.04.2024. [Informal carers | Health at a Glance 2021 : OECD Indicators | OECD iLibrary (oecd-ilibrary.org)](https://www.oecd-ilibrary.org/sites/0ebfc7c0-en/index.html?itemId=/content/component/0ebfc7c0-en) [↑](#footnote-ref-4)
4. See for example: World Bank (2023) Silver Opportunity: building integrated services for older adults around primary health care, <https://openknowledge.worldbank.org/handle/10986/39422>; OECD (2023) [Access to long-term care | Health at a Glance 2023 : OECD Indicators | OECD iLibrary (oecd-ilibrary.org)](https://www.oecd-ilibrary.org/sites/70bff492-en/index.html?itemId=/content/component/70bff492-en#:~:text=More%20than%2020%25%20of%20people,States%2C%20Poland%20and%20Latvia).); UNFPA East and Southern Africa Region (2022) Rapid Review of Healthy Ageing and Long-term Care Systems in East and Southern Africa; Asia Development Bank (2022) The Road to Better Long-Term Care in Asia and the Pacific: Building Systems of Care and Support for Older Persons. [↑](#footnote-ref-5)
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7. [Crafting a National Care System: 5 things you should know about the development of a Communities of Care pilot in the Dominican Republic | Joint SDG Fund](https://jointsdgfund.org/article/crafting-national-care-system-5-things-you-should-know-about-development-communities-care#:~:text=The%20development%20of%20a%20Local,management%20to%20offer%20families%20an) [↑](#footnote-ref-8)
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