



IAHPC Submission

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Human Rights Council resolution 54/6 on the centrality of care and support from a human rights perspective



The International Association for Hospice and Palliative Care (IAHPC)¹ is a global non-profit organization with members in more than 100 countries. As such this submission will not comment on legislation in any one country. It reviews selected aspects of the human rights abyss facing formal and informal caregivers and care recipients in select regions and countries of the world.

Background

- I. Applicable international human rights instruments for practices of care and support by formal (paid) and informal (unpaid, family) caregivers.
- UN Universal Declaration of Human Rights,
 - International Covenant on Economic, Social and Cultural Rights
 - Convention on the Rights of Persons with Disabilities,
 - Convention on the Rights of the Child

Human rights of unpaid and paid caregivers, and of recipients of care and support include the rights to

- work,
- social security,
- adequate housing,
- health, including preventive, curative, and palliative care.
- education,
- enjoyment of scientific advancement,
- legal capacity, equality in marriage
- independent life in the community
- rest and leisure
- rights relevant to participation.

States Parties are obliged to protect, respect and fulfill those rights through inclusive policies and regulations funded, monitored, and regularly evaluated in consultation with impacted communities.

HRC Resolution 48/3 recognized that “older persons face a number of particular challenges in the enjoyment of their human rights, including, among others [...] *access to long-term and palliative care.*” (Preamble) [...]

Encourages all States to take measures to [...] protect the human rights of older persons in [...] the provision of [...] *long-term support and palliative care services*, and to promote the development of comprehensive care systems; (OP3)²

General Comment 14 of the CESCR recognises the right to palliative care under the right to health.

¹ [www.http://www.hospicecare.com](http://www.hospicecare.com)

² <https://undocs.org/Home/Mobile?FinalSymbol=A%2FHRC%2FRES%2F48%2F3&Language=E&DeviceType=Desktop&LangRequested=False>



II. Applicable regional human rights instruments

Europe

- A. European legislation on family leave and work life balance stipulates five days of family leave per calendar year for workers.
- B. The European Charter of Fundamental Rights states that “Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.”
- C. Research by the Northern Ireland Human Rights Commission has identified the rights of informal carers and the duties of (the UK) State (government and other statutory bodies) to support them. These include:
 1. The right to a private and family life
The State has a responsibility to provide adequate support in order for families to have the right to a meaningful private life, as well as the need for a ‘fair balance’ in terms of the responsibilities of family carers – putting an onus on the State to provide supports to ensure this balance is struck.
 2. The right to an adequate standard of living
 3. The right to social security: in providing the benefits, the State is required to take into account the resources and circumstances of the child and persons having responsibility for the maintenance of the child or adult dependent.
 4. The right to work: while informal carers may experience difficulties exercising the right to work due to the absence of alternative care provision or inflexible working arrangements within the labour market, they have the right to work. States have an obligation to provide technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.
 5. The right to education: the State has an obligation to facilitate individuals to exercise the right to education. Caring responsibilities may inhibit the ability of an informal carer to engage fully in educational opportunities. The State must ensure children in compulsory education are not employed in such work as would deprive them of the full benefit of their education. The provision of caring duties is not a form of employment but can have similar detrimental implications on the ability of an individual (including a child) to engage in education.
 6. The right to health: informal carers often encounter physical or mental health problems related to their caring responsibilities. Furthermore the time commitment involved in caring can inhibit the ability of carers to access preventative treatments. States have an obligation to ensure “the provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education, particularly for the vulnerable or marginalised.”
 7. The right to participation: there are many decision making processes relating to both carers and the cared for person.

8. The rights of persons with disabilities: carers may have disabilities and with the increasing proportion of persons caring into older life it is likely that a growing proportion of carers will have acquired disabilities. The UN Convention on the Rights of Persons with Disabilities (CRPD) explicitly acknowledges the critical role played by families for the promotion of human rights and the inclusion of persons with disabilities in society. The realisation of the rights of persons with disabilities is strictly interdependent with the quality of life of their family members, and can be very much influenced by the circumstances affecting parents, partners, children and siblings living with them. Various obligations arising under the CRPD implicitly or explicitly commit public authorities to put families in the conditions of contributing to the full and equal realisation of the rights enshrined in the text. Some articles make explicit reference to measures to sustain families, while other provisions implicitly require a mainstreaming of the family dimension in order to ensure an effective implementation.
9. Children's rights: all children should grow up in a family environment, in an atmosphere of happiness, love and understanding. In circumstances where a child is required to spend a significant amount of their time performing caring duties their development may be hampered. States have a responsibility to give the necessary support to children care to ensure their well-being.

The UK Example

The Human Rights Act (HRA)1998 (Came into force in 2000) and the [Equality Act 2010](#). The "Human Rights Guide for Carers"³ a government publication, details these rights, provides examples of violations, case studies, and instructions about how to report and seek protection. Examples from the HRA include:

- Article 8: The right to respect for private and family life, home, and correspondence. (concrete action: public authorities should guarantee adequate respite care)
- Article 3: The right to freedom from inhuman and degrading treatment
 - Article 14: The right to be free from discrimination - also protected by the Human Rights Act (Article 14)
 - Article 2: In extreme circumstances, right to life.

The *Human Rights Guide for Caregivers* states that care recipients are most at risk of having their human rights abused. Carers have a key role to play in protecting the human rights of the person they care for. These rights include:

- respect for private and family life, home and correspondence (Article 8)
- freedom from inhuman and degrading treatment (Article 3)
- life (Article 2) and liberty (Article 5)
- from discrimination (Article 14)

Americas

The Inter-American Convention on the Rights of Older Persons⁴ is an exemplary instrument recognizing the right of older persons to receive care, including palliative care, under

1. Article 6 of the 'Right to Life and Dignity in Old Age'.

³ https://www.cogsclub.org.uk/carers/files/BIHR%20Pocket%20Guide%20for%20Carers_1.pdf

⁴ https://www.oas.org/en/sla/dil/docs/inter_american_treaties_A-70_human_rights_older_persons.pdf



2. Article 9 stipulates the right to safety and a life free of violence of any kind, including in care institutions and at home, and to this end, calls on states Parties to
 - Train and sensitize government officials, social workers, and health care personnel responsible for attending to and caring for older persons in long-term care facilities or at home about the different forms of violence, in order that they are treated with dignity and to prevent negligence, violence, and mistreatment.
 - Develop training programs for family members and persons providing home care services, in order to reduce violence in the home or household unit.
3. Article 12, Rights of older persons receiving long-term care stipulates the state obligation to
 - [...] design assistance measures for families and caregivers through the introduction of services for those providing care to older persons, taking into account the needs of all families and other forms of care
4. Article 19, the Right to Health, Article 19 commits states Parties to
 - Promote the development of specialized integrated social and health care services for older persons with diseases that generate dependency, including chronic degenerative diseases, dementia, and Alzheimer's disease.

Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Mexico, Peru, Suriname, and Uruguay, have all either signed or ratified the Convention.

Exemplary national implementation of the OAS Convention:

Uruguay

Uruguay was one of the earliest adopters along with Argentina, in 2015. Both countries now have national palliative care laws, and Uruguay has developed an exemplary long term care system for older persons and their carers based on the concept of universal rights and the concept of dependency.⁵

According to UN Women, "Uruguay's Care Act has changed the concept of "care". Under the new law, all children, persons with disabilities and elderly persons, have the right to care. The state not only provides care services, but also guarantees their quality by providing training and regulations."⁶

See this report on Long Term Care in the Americas (PAHO)⁷

III. National best practices examples of paid caregiver leave policies.

Costa Rica is one example of a country that has a law explicitly allowing caregivers to take time off work and receive a stipend while caring for a sick family member. A national care policy was developed to progressively implement a care system to support people in a situation of dependency. The policy targeted older adults, people

⁵ Decree 427/017 Art. 16 Catálogo y definiciones del Sistema de Cuidados. Establishes the catalog of services that constitute the system of care, rights, and obligations of users and definitions of dependency and the instrument for mediation. See The Long-Term Care System in Uruguay. Social Policy Country Briefs, 6. University of Bremen. https://www.researchgate.net/publication/351283109_The_Long-Term_Care_System_in_Uruguay_Social_Policy_Country_Briefs_6_University_of_Bremen

⁶ <https://www.unwomen.org/en/news/stories/2017/2/feature-uruguay-care-law#:~:text=Uruguay's%20Care%20Act%20has%20changed,by%20providing%20training%20and%20regulations.>

⁷ https://iris.paho.org/bitstream/handle/10665.2/57688/9789275127155_eng.pdf?sequence=1



living with disabilities and people living with chronic conditions, offering services such as remote support, domestic support, day centres, long-stay residential services, and a care network for older adults and their families.⁸

Other national jurisdictions with policies allowing caregivers to leave paid employment to care for sick or disabled family members include the **Czech Republic, Belgium, Australia, Germany, and the United Kingdom (UK)**.⁹ Challenges cited for these policies include the fact that paid leave is not available to all workers in Germany, such as those employed by small firms. Eligibility requirements for direct payments in Australia and the UK such as limits on hours worked or earnings can make it difficult for someone to work outside their caregiving role. Experts in all countries cite the fact that caregivers, many of whom may be undocumented, illiterate in the host country's language, or working under constraint, may be unaware of available supports. Some states in the USA provide support for caregivers under Medicaid, but this varies by jurisdiction.

In Italy, which has the largest population over 65 in Europe, the Budget Act 2021 established a new Economic Fund for the recognition of the social and economic value of the non-professional care activity carried out by the family caregiver. The IC assisting disabled persons - pursuant to Law 104/92 - can apply to the National Social Insurance Agency to try to obtain an economic bonus to support their activity. The financial compensation is however symbolic and far from appropriately rewarding the complex activity carried out by family caregivers. The fund can satisfy a very limited number of applicants across Italy, selected on the basis of income and level of severity of the assisted person's disability.¹⁰

In Italy, as in many countries that retain traditional practices, the family plays an important role in providing care to its older parents but many children still have to work so that they can survive financially and as a result many caregivers are migrant workers.

These migrant workers come in search of work from many parts of the world such as Moldavia, the Philippines, and Peru; however, the largest population of immigrant workers come from Ukraine. Many of the caregivers work long hours and weeks, and also leave their own families behind and send them the money they make.^[9]

Czech Republic: The Parliament passed an amendment to Act No. 187/2006 Coll. in September 2017, introducing a new direct cash benefit called "long-term caregiver's allowance" (dlouhodobé ošetrovné). Since 1 June 2018, the carer, whether employed or self-employed, is compensated for the loss of income from work due to caring

7. Inter-American Development Bank and International Labour Organization, Política Nacional de Cuidados 2021-2031, 2023, <https://www.imas.go.cr/sites/default/files/custom/Sistematizaci%C3%B3n%20de%20avances%20en%20herramientas%20de%20georreferenciaci%C3%B3n%20y%20pasos%20siguientes.pdf>.

⁹ Source: GAO review of government documents and interviews with foreign government officials and experts. | GAO-20-62. <https://www.gao.gov/assets/gao-20-623.pdf>

¹⁰ Gazzetta Ufficiale della Repubblica Italiana. Decreto 28 dicembre 2021. Presidenza del consiglio dei ministri, ufficio per le politiche in favore delle persone con disabilità. Criteria and modalities for the use of the Fund's resources to support the care and assistance role of the family caregiver for the year 2021. (22A02351) Available to: <https://www.gazzettaufficiale.it/eli/id/2022/04/14/22A02351/sg>. Cited in Cioffi A, Cecannecchia C, Baldari B, Karaboue MAA. Informal caregivers in Italy: the 'phantom zone' of welfare. Acta Biomed. 2023 Feb 13;94(1):e2023018. doi: 10.23750/abm.v94i1.13660. PMID: 36786259; PMCID: PMC9987501.



responsibilities, at the same rate as in the case of short-term care, during the period when he/she provides care for a family member discharged from the hospital after at least a 7-day hospitalisation and requiring at least 30 days of further care (maximum 90 days). The entitlement is subject to the approval of the responsible physician.¹¹

According to the OECD¹², **Belgium** provides the longest publicly *paid* leave, for a maximum of 12 months, which employers may refuse only on serious business grounds. In **Japan**, paid leave is also fairly long, since carers can take leaves up to 93 days with 40% of wage paid through the employment insurance if the company does not compensate during the leave. In terms of remuneration, Scandinavian countries tend to pay the most. In Norway and Sweden paid leave is equivalent to 100% and 80% of the wage respectively. In **Denmark**, in exchange for employers continuing to pay full wages during care leave, municipalities reimburse a minimum equivalent to 82% of the sick benefit ceiling.

Belgium, France, Spain and Ireland provide long *unpaid* leaves of one or more years. Unpaid leave is not a statutory right for workers in **Ireland and Spain** and may be refused by employers on business grounds. In **France**, employers may not oppose the leave but eligibility criteria remain strict: only to care for a relative with 80% autonomy loss. . English-speaking countries and **the Netherlands** provide relatively short leave of up to three months, **Austria** and **Germany** provide six months leave, with Austria limiting unpaid leave to the care of terminally ill relatives.

The Caregivers Welfare Act in **the Philippines** (Republic Act 11965) guarantees caregivers overtime and night shift pay in line with regional minimum wages. The law also mandates their coverage under the Social Security System, Philippine Health Insurance Corp., and Home Development Mutual Fund. Caregivers said the law empowers them to negotiate salaries higher than the minimum wage based on the difficulty of caring for assigned clients. The law covers caregivers in private homes, nursing or care facilities, and other residential settings, including those hired through Public Employment Services Offices or Private Employment Agencies.¹³

The report of the International Alliance of Carer Organizations provides detailed analysis of policies and best practices in many countries, including challenges and opportunities for improvement.¹⁴

Gender imbalance The Commonwealth Fund's 2023 International Health Policy Survey find that across 10 high-income countries, women were more likely to act as caregivers to a family member compared with men. In most countries, women reported providing informal care or assistance to family members was stressful.¹⁵ Gender is a predictor of caregiver burden resulting in ill health, depression, and poverty in most countries studied.¹⁶

¹¹ IVAN MALÝ - EUROPEAN SOCIAL POLICY NETWORK MAY 2018.

https://www.google.com/url?sa=t&source=web&rct=j&opi=89978449&url=https://ec.europa.eu/social/BlobServlet%3FdocId%3D19644%26langId%3Den%23::~:~:text=%3DSince%25201%2520June%25202018%2520the,at%2520least%2520a%25207%2520day&ved=2ahUKewjX04uZ1LeFAxXqSKQEHQsaB_UQFnoECBUQAw&u=g=AOvVaw1WDwaGkNdzQUX-To1E-2F6

¹² Policies to Support Family Carers, OECD <https://www.oecd.org/els/health-systems/47884889.pdf>

¹³ <https://www.bworldonline.com/the-nation/2023/12/03/561192/caregivers-welfare-law-lauded/>

¹⁴ <https://internationalcarers.org/wp-content/uploads/2021/07/IACO-Global-State-of-Caring-July-13.pdf>

¹⁵ <https://www.commonwealthfund.org/blog/2024/unequal-weight-caregiving-women-shoulder-responsibility-10-countries>

¹⁶ <https://diposit.ub.edu/dspace/bitstream/2445/138177/1/659104.pdf>



Racial imbalance In **Brazil**, the majority of caregivers are women of African or indigenous descent, who experience intersectional discrimination thus double or triple caregiver burden.¹⁷ In the US, the majority of unpaid family caregivers and the direct care workforce, are female, Black, indigenous and people of color.¹⁸

- IV. Main challenges faced at the national level in creating robust, resilient and gender-responsive, disability-inclusive and age-sensitive care and support systems with full respect for human rights.
1. Invisibility and often poverty of the caregiving and care recipient population
 2. Migrant caregivers' often irregular status, functional illiteracy in host country language, and often hidden/enclaved residential situation, discourages official identification of caregivers for census purposes, agency toward collective mobilization to claim rights, public organization for presentation of complaints, etc.
 3. Severely reduced public sector budgets for data collection, policy drafting and monitoring, resulting from outsourcing and privatization of public service functions, lack of tax revenue, weak policy frameworks preventing encroachments of global corporations capitalizing on ageing populations and need for care.
 4. High foreign debt burden of many lower- and lower-middle-income countries resulting in reduced capacity of the public sector and civil service to deliver rights respecting policies and practices.
 5. Paucity of disaggregated data, particularly of older adults over 65.
 6. Lack of functional and implemented palliative care policies and trained workforces in countries where palliative care and dependency needs are estimated to be high.
 7. Unavailability of internationally controlled essential medicines for clinical disciplines such as mental health, palliative care, surgery, maternal-child health, and treatment of substance use disorder as a result of unduly national restrictive regulations and lack of an appropriately trained health and care workforce. This unavailability and lack of workforce capacity increases the dependency burden and stress on both informal and professional caregivers, including those in nursing homes and institutions.

Persons deprived of liberty. General Comment 14 stipulates prisoners' right to palliative care. Yet palliative care is largely unavailable to prison populations worldwide. A model program is the Humane Prison Hospice Project, which trains inmates as caregivers, at San Quentin in California USA.¹⁹

¹⁷ http://www.scielo.edu.uy/pdf/ech/v12n2/en_2393-6606-ech-12-02-e3131.pdf; see also https://www.researchgate.net/publication/348291248_Access_to_Health_Services_and_Assistance_Offered_to_the_Afro-Descendant_Communities_in_Northern_Brazil_A_Qualitative_Study

¹⁸ <https://ncrc.org/the-bipoc-caregiver/>

¹⁹ <https://humanepriisonhospiceproject.org>