

## Long-Term and Institutional Care: A Global Perspective and Imperative

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**Abstract:** This study provides an overview of the legal aspects of long-term care (LTC) and institutional care for the elderly. It investigates whether LTC services for seniors could be recognized as a distinct human right, possibly through a United Nations convention. The study explores the existence and core components of the right to LTC and examines the minimum standards for its investigation, implementation, and enforcement. Additionally, it analyzes the specific rights of seniors that contribute to the right to care for dependent persons while also considering the intersectionality of this right and its relationship with other human rights. The study investigates the legal frameworks for protecting the right to LTC in various countries and assesses legal solutions derived from general legal instruments and special standards, particularly those concerning individuals with disabilities. Furthermore, it discusses proposed laws aimed at preserving the dignity of seniors and preventing unnecessary examinations and abuse. The study ultimately

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evaluates whether the right to LTC is an independent right or an extension of the rights to healthcare and social security.

## 1. Introduction

In the process of codifying standards in the field of public health law, the international community cannot ignore the increasing prevalence of ageing societies and the growing demand for care services for the elderly. Collecting and placing in one document the minimum legal standards in the field of long-term and institutional care will strengthen the legal position of individuals in the public health law system, allowing them to influence the state's actions and obtain legal mechanisms for pursuing claims.<sup>1</sup> As a special group, the elderly have many unmet needs.<sup>2</sup> While it is recognized that they are vulnerable and in need of long-term and institutional medical treatment, there is no legally binding instrument addressing these critical issues. From a global perspective, long-term care (LTC) covers a wide range of services and circumstances ranging from at-home help with basic daily activities like bathing, dressing up and meals, as well as more complex healthcare services, including daycare centres and institutional care.<sup>3</sup> Due to the increasing life expectancy and the growth in the number of the elderly, the incidence of mental health diseases continues to rise,<sup>4</sup> further increasing demand for long-term care.

The international community has made clear it should be important to establish for the elderly a distinct right to dignity and autonomy in

<sup>1</sup> Allyn L. Taylor, "International Law and Public Health Policy," in *International Encyclopedia of Public Health*, 1st ed., eds. Stella R. Quah and Kristian Heggenhougen (Elsevier, 2008), 667.

<sup>2</sup> Krzysztof Orzeszyna, Michał Skwarzyński, and Robert Tabaszewski, *International Human Rights Law* (Warsaw: C.H. Beck, 2023), 50–1.

<sup>3</sup> Pamela Doty, "Long-Term Care in International Perspective," *Health Care Financing Review*, Spec No(Suppl) (1988): 145–6, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969/>; UN Ageing Group, "Report 2015," accessed May 3, 2023, <https://social.un.org/ageing-working-group>.

<sup>4</sup> Carlos A. Mendonça de Lima, "Mental Health and Mental Health Services," in *Legal, Ethical and Social Implications of Ageing: Towards an International Legal Framework to Advance the Human Rights and Health of Older Persons*, eds. Allyn Taylor and Patricia C. Kuszler (NY: Edward Elgar, 2021); Beata Ziębińska, "Uwarunkowania globalizacyjne a systemy opieki długoterminowej [Globalization and Long Term Care Systems]," *Studia Humanistyczno-Społeczne*, no. 18 (2017): 240–5.

care, including the right to long-term care, the right to palliative care and the freedom from maltreatment, unnecessary examinations, treatments, hospitalizations and admissions to intensive care.<sup>5</sup> The first international convention specifically concerning the care for older persons was the European Social Charter.<sup>6</sup> It obliges the Member States to ensure that older people living in institutions are adequately supported while respecting their privacy and participation in decisions about their living conditions in the institution. Nonetheless, a much more detailed UN regulation on this matter is necessary.<sup>7</sup> This chapter aims to provide information that may help with this task. It provides recommendations for health policy and decision-makers on how the proposed UN treaty on the human rights of older persons can be developed and improved.<sup>8</sup>

## 2. Global Context

In the 21st century, we are witnessing a process of demographic ageing, which means an increase in the share of older people (over 65) with a small share of younger people in a given society. The phenomenon of demographic ageing is forcing society to turn to older people and provide them with ongoing care when they become helpless or suffer from chronic illnesses.<sup>9</sup> This problem applies to most countries around the world. Ageing is a process that cannot be stopped or reversed, but it can be delayed. This is

<sup>5</sup> WHO Europe, “Report 2005,” accessed May 3, 2023. <http://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/healthy-ageing>; Hildegard Theobald and Kristine Kern, “The Introduction of Long-Term Care Policy Schemes: Policy Development, Policy Transfer and Policy Change,” *Policy and Politics* 39, no. 3 (2011): 338–9, <https://doi.org/10.1332/030557310X520252>.

<sup>6</sup> Council of Europe, European Social Charter, Turin, October 18, 1961, art. 23, accessed May 3, 2023, <https://rm.coe.int/168006b642>.

<sup>7</sup> UNDESA, “The Growing Need for Long-Term Care: Assumptions and Realities,” September 12, 2016, accessed May 3, 2023, [https://www.un.org/esa/socdev/ageing/documents/un-ageing\\_briefing-paper\\_Long-term-care.pdf](https://www.un.org/esa/socdev/ageing/documents/un-ageing_briefing-paper_Long-term-care.pdf).

<sup>8</sup> Israel Issi Doron and Benny Spanier, “International Convention on Rights of Older Persons: Where We Were, Where We Are, and Where Are We Going?,” *IFA Global Ageing* 8, no. 1 (2012): 7–15.

<sup>9</sup> Åke Blomqvist and Colin Busby, “Long-Term Care for the Elderly: Challenges and Policy Options,” *C.D. Howe Institute Commentary*, no. 367 (2012): 2–32, accessed May 3, 2023, [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2182774](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2182774).

possible thanks to the comprehensive actions taken by national authorities, which include ensuring that every older person has access to long-term care and medical institutions. Yet, the efforts of national authorities should be complemented by international organizations. These play a substantial role due to the competencies vested in them by states; they exert a notable influence on the substance and structure of medical law regulations and some, like the European Union, even establish regulations directly applicable to states.<sup>10</sup> From a formal and legal standpoint, the most comprehensive protection for elderly individuals outside the European human rights systems is provided by the Organization of American States.<sup>11</sup>

It is important to pay attention to the needs of the older population because, from a global perspective, national systems of geriatric healthcare and support aimed at older people are ineffective and unprepared for rapid demographic changes and an increased number of the oldest citizens. Actions taken by individual countries in this area remain insufficient, inconsistent and ineffective.<sup>12</sup> Some pressing problems of national healthcare systems include an insufficient number of geriatric specialists, geriatric wards and new geriatric clinics, the lack of new methods of diagnosing dementia, as well as the lack of an appropriate funding system and support instruments for carers of the elderly. Moreover, existing international law instruments are incapable of meeting new challenges related to coordinated, holistic and long-term medical care for older people.<sup>13</sup>

According to the OECD, “long-term and institutional care” should be construed not only as services but also as long-term financial benefits for people aged 65 and up who need help with basic day-to-day activities or complex living activities. LTC services should be distinguished from

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<sup>10</sup> Agata Wnukiewicz-Kozłowska, “Spory medyczne,” in *Spory medyczne przed sądami międzynarodowymi*, ed. Agata Wnukiewicz-Kozłowska (Wrocław: Uniwersytet Wrocławski, 2021), 147.

<sup>11</sup> Barbara Mikołajczyk, “Older Persons’ Right to Health – A Challenge to International Law,” *Ageing and Society* 39, no. 8 (2018): 18, <https://doi.org/10.1017/S0144686X18000156>.

<sup>12</sup> Geeta Anand, “How Not to Grow Old in America,” *New York Times*, August 29, 2019, accessed May 3, 2023, <https://www.nytimes.com/2019/08/29/opinion/sunday/dementia-assisted-living.html>.

<sup>13</sup> UN Ageing Group, “Report 2015,” accessed May 3, 2023, <https://social.un.org/ageing-working-group>.

long-term support, which is a broader concept that obliges national authorities to conduct an intersectional state policy favouring independence and activity while respecting the autonomy and dignity of seniors.<sup>14</sup> According to WHO classification, long-term and institutional care includes two categories of actions: activities of daily living (ADL) and instrumental activities of daily living (IADL).<sup>15</sup> The first category includes basic medical care, nursing care, preventive care and physical therapy provided to older people. In contrast, IADL consists in providing at-home help or assisting the elderly with handling administrative matters.<sup>16</sup> A special type of right included in the range of services offered to older people is the right to palliative care.<sup>17</sup> Such care aims to improve the quality of life and is supposed to prevent or relieve pain and other somatic symptoms, as well as to alleviate mental, spiritual and social suffering at the end of life.<sup>18</sup>

### 3. Older Persons and Human Rights in LTC

The human right to long-term care has not been formulated yet and access to long-term care services for the elderly is not directly addressed in any treaty – so far, it is only declaratory. Article 25 of UDHR proclaims the right of everyone to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of

<sup>14</sup> Barbara Mikołajczyk, “International Law and Ageism,” *Polish Yearbook of International Law* 34, (2014): 90, accessed May 3, 2023, <https://ssrn.com/abstract=2811745>.

<sup>15</sup> Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 243; Tomasz Sroka, “Opieka długoterminowa,” in *System Prawa Medycznego*, vol. 2, eds. by Leszek Bosek and Agata Wnukiewicz-Kozłowska (Warsaw: C.H. Beck), 972.

<sup>16</sup> WHO Europe, “Report 2005,” accessed May 3, 2023, <http://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/healthy-ageing>.

<sup>17</sup> Anand, “How Not to Grow Old in America,” *New York Times*, August 29, 2019, accessed May 3, 2023, <https://www.nytimes.com/2019/08/29/opinion/sunday/dementia-assisted-living.html>.

<sup>18</sup> Patricia Kuszler, “End of Life and Access to Pain Medicine,” in *Legal, Ethical and Social Implications of Ageing: Towards an International Legal Framework to Advance the Human Rights and Health of Older Persons*, eds. Allyn Taylor and Patricia C. Kuszler (NY: Edward Elgar, 2021).

livelihood in circumstances beyond his control.<sup>19</sup> This provision imposes on UN member states numerous positive obligations aimed at older people. It means that the elderly are first and foremost entitled to any necessary medical measures used to maintain their quality of life or at least to maintain their current state of health without deterioration, if possible.

The right to use LTC includes access to medical services and access to nursing care, which can also be provided outside a medical facility<sup>20</sup>. This category of benefits also includes services provided by licensed or certified nurses and therapists specializing in physical, speech, or occupational therapy. Other health-related services like bathing, dressing, eating, toileting, mobility, day or night sitting services can be provided in a medical facility, at the patient's home or in any other place where older people are residing.<sup>21</sup> Nurses help bedridden and chronically ill patients for as long as is required, depending on a given person's health.

UDHR also includes other long-term and institutional care services which the state is obliged to provide.<sup>22</sup> Even though these services are not directly related to healthcare, the WHO considers them necessary to ensure an adequate quality of life for the elderly. It includes sheltered living arrangements (i.e. small-group shared housing for the elderly, foster care); subsidized housing for the disabled elderly; delivering food and preparing meals (shopping, cooking, meals delivered to the elderly person's home);

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<sup>19</sup> Universal Declaration of Human Rights (UDHR) (adopted 10 December 1948), G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948).

<sup>20</sup> Doty, "Long-Term Care in International Perspective," *Health Care Financing Review*, Spec No(Suppl) (1988): 150–1, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969>; UN Ageing Group, "Report 2015," accessed May 3, 2023, <https://social.un.org/ageing-working-group>; Ziębińska, "Uwarunkowania globalizacyjne a systemy opieki długoterminowej," 235–7; Charlene M. Kampfe, *Counseling Older People Opportunities and Challenges* (Alexandria: Wiley, 2015), 225–47.

<sup>21</sup> Doty, "Long-Term Care in International Perspective," *Health Care Financing Review*, Spec No(Suppl) (1988): 145–7, 150–1, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969>; Natalie D. Pope and Jane E. Riley, "Keep Dignity Intact: Exploring Desires for Quality Long-Term Care Among Midlife Women," *Journal of Gerontological Social Work* 56, no. 8 (2013): 694–5, <https://doi.org/10.1080/01634372.2013.840351>.

<sup>22</sup> Universal Declaration of Human Rights (UDHR) (adopted 10 December 1948), G.A. Res. 217A (III), U.N. Doc. A/810 at 71 (1948); WHO Europe, "Report 2005," accessed May 3, 2023, <http://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/healthy-ageing>.

homemaker or chore services (i.e. help with cleaning, laundry, errands and chores at home). Support in this regard can be provided by professional caregivers or family members.<sup>23</sup>

#### 4. The Use of Long-Term Care Service Systems by the Elderly

The WHO classification distinguishes several types of long-term and institutional care systems: Scandinavian, Continental, British, Mediterranean, traditional, and mixed.<sup>24</sup> In many European countries and the Americas, the responsibility for organising the basics of long-term care rests with local and regional authorities; however, in developing countries, a model of dispersed responsibility prevails. The Scandinavian system, used in Denmark, Finland, Norway, and Sweden, is considered to provide the most comprehensive care. It is based on public, caregiving and universal services, which are usually provided by local authorities, with lower participation of non-governmental organizations and private sector entities.<sup>25</sup> In these countries, state participation in long-term and institutional care services is over two times higher than in other developed countries. In developing economies, LTC is a priority for families and local communities, not for central governments, and in post-communist countries, relatives are legally obliged to care for elderly family members (maintenance obligation). For this reason, the latter countries are better prepared to provide informal long-term care than high-income countries.<sup>26</sup>

<sup>23</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review*, Spec No(Suppl) (1988): 151, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969/>; Pamela Doty, Korbin Liu, and Joshua Wiener, “An Overview of Long-Term Care,” *Health Care Financing Review* 6, no. 1 (1985): 69–78, accessed May 3, 2023, <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/Health-CareFinancingReview/Downloads/CMS1191904dl.pdf>; WHO Europe, “Report 2005”; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–7.

<sup>24</sup> Ibid.

<sup>25</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review*, Spec No(Suppl) (1988): 147–150, 152–3, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969/>; Doty, Liu, and Wiener, “An Overview of Long-Term Care,” 69–78; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–7; WHO Europe, “Report 2005.”

<sup>26</sup> Robert Tabaszewski, “The Role of Local and Regional Authorities in Prevention and Control of NCDs: The Case of Poland,” *BMC International Health and Human Rights* 20,

Other healthcare systems also guarantee access to long-term and institutional care services, but the range of these services is more limited than in the Scandinavian model. In the continental model, LTC is funded by the state but the direct service suppliers are non-governmental organizations. Still other mechanisms are at work in the British model, which is based on private caregiving services. In the Mediterranean system, LTC services are provided to older people mainly by their family members, friends, or other private individuals, with support from non-governmental and church organizations. In post-communist countries, which adopted a mix of the Mediterranean and continental systems, older people rarely obtain institutionalized care and rely on the help and care provided by their family members<sup>27</sup>. In less- and medium-developed countries, “responsibility for LTC often falls between different line ministries or is delegated to local government, thus reducing its profile and policy priority.” Local authorities base their policies on the traditional multi-generational family model and the intergenerational solidarity principle. In developing countries, families increasingly use informal paid caregivers who often lack specialist training and are therefore not recognized and paid by the government.<sup>28</sup>

An analysis of LTC system models shows that they are much more varied than classic social care systems, educational systems, and pension schemes. In most countries around the world, LTC services are provided by the public sector, non-governmental sector, and informal sector.<sup>29</sup> Due to the profound demographic changes currently underway in many developed countries, national authorities are increasingly striving to establish a deinstitutionalized care model, develop a preventive care system that would address the risk of prematurely losing one’s independence, and

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no. 17 (2020): 1–9, <https://doi.org/10.1186/s12914-020-00238-8>; Peter Lloyd-Sherlock, “Beyond Neglect: Long-Term Care Research in Low and Middle Income Countries,” *International Journal of Gerontology* 8, no. 2 (2014): 66–9.

<sup>27</sup> Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–7.

<sup>28</sup> Lloyd-Sherlock, “Beyond Neglect,” 4.

<sup>29</sup> Council of Europe, “Recommendation CM/Rec(2014)2 of the Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons,” February 19, 2014, accessed May 3, 2023, <https://www.coe.int/en/web/commissioner/-/the-right-of-older-persons-to-dignity-and-autonomy-in-care>; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–7.

combine funding from multiple sources.<sup>30</sup> All this makes it harder to develop one global model of guaranteed benefits for older people. Due to disparities in economic growth and limited national budgetary resources that can be allocated to LTC, more and more countries are opting to use mixed solutions.<sup>31</sup> Yet, LTC is provided by informal caregivers, often migrants, even in the most developed countries. In contrast, developing countries struggle with the grey economy and assistance there is typically provided by the youngest family members who do not receive any support on this account.

In the European Union, the need to establish a new social welfare mix model is coming up more and more. Such a system would make it possible to ensure a common minimum standard of services for older people.<sup>32</sup> The basic rules on caring for the elderly were developed by regional human rights organizations, including the Council of Europe, which devised such things as the European Social Charter (revised) and the 2014 Recommendation by the Committee of Ministers on the promotion of human rights of older persons.<sup>33</sup> The issue of accessibility of LTC services for older people was also addressed by the European Convention on Human Rights and the Commissioner for Human Rights. These authorities consider such services to be a part of the right to a decent life. This results directly from Article 11(1) of The International Covenant on Economic, Social and Cultural Rights (ICESCR) and is dictated by the need to ensure the protection of the life and health of the elderly. However, it may be problematic to monitor medical services in nursing homes.<sup>34</sup> Hence, it is also necessary to introduce institutional and legal frameworks laying down minimum standards for the protection of the elderly at a universal level.

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<sup>30</sup> WHO Europe, “Report 2005”; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 236.

<sup>31</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review*, Spec No(Suppl) (1988): 148–9, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969/>; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 245.

<sup>32</sup> *Ibid.*, 240–2.

<sup>33</sup> H.S. Aasen, “The Right to Health Protection for the Elderly: Key Elements and State Obligations,” in *Health and Human Rights in Europe*, eds. Brigit Toebes et al. (Cambridge: Intersentia, 2012), 292–6.

<sup>34</sup> Theobald and Kern, “The Introduction of Long-Term Care Policy Schemes,” 336–8.

Another aspect of the right to long-term care (LTC) is the degree to which national governments participate in funding the services in nursing homes for the elderly. Significant financial resources should be allocated to long-term care for the elderly and their family members if their needs cannot be met. This is also because, in most cases, running a nursing home is not a non-profit activity.<sup>35</sup> Running 24-hour care facilities entails addressing the social assistance needs of the elderly and implementing the human right to health on the one hand, while also purposefully and rationally assessing the costs and expenses on the other.<sup>36</sup> Therefore, due to the increasing costs that the elderly will have to bear, as well as the growing number of economically inactive people, developed countries should consider introducing the Japanese model of elderly care.<sup>37</sup> It involves the introduction of a universal long-term care insurance system. In Japan, nursing home stays are co-financed by employers and employees from individual premiums paid by each insured person over 40. The remainder is paid by the state. Similarly, state subsidies cover assisted living and daycare for the elderly.<sup>38</sup> In the future, however, institutionalized care will still prevail in many countries, hence it seems reasonable to consider a model based on the system of universal social insurance.

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<sup>35</sup> Council of Europe, “Recommendation CM/Rec(2014)2 of the Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons,” February 19, 2014, accessed May 3, 2023, <https://www.coe.int/en/web/commissioner/-/the-right-of-older-persons-to-dignity-and-autonomy-in-care>.

<sup>36</sup> Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–43.

<sup>37</sup> Anand, “How Not to Grow Old in America,” *New York Times*, August 29, 2019, accessed May 3, 2023, <https://www.nytimes.com/2019/08/29/opinion/sunday/dementia-assisted-living.html>; John C. Campbell, “Japan’s Long-Term Care Insurance System,” in *Eldercare Policies in Japan and Scandinavia*, eds. John C. Campbell et al. (NY: Palgrave Macmillan, 2014), 9–30, [https://doi.org/10.1057/9781137402639\\_2](https://doi.org/10.1057/9781137402639_2); Theobald and Kern, “The Introduction of Long-Term Care Policy Schemes,” 333–4.

<sup>38</sup> Anand, “How Not to Grow Old in America,” *New York Times*, August 29, 2019, accessed May 3, 2023, <https://www.nytimes.com/2019/08/29/opinion/sunday/dementia-assisted-living.html>; Campbell, “Japan’s Long-Term Care Insurance System,” 9–30; Ziębińska, “Uwarunkowania globalizacyjne a systemy opieki długoterminowej,” 235–7.

## 5. The Right of Older Persons to Dignity and Autonomy in Long-Term Care

Long-term care may be provided by various entities that render health services directly or indirectly. Such services need to be carried out with respect for the senior's will and dignity.<sup>39</sup> The first group of entities that support the elderly includes medically-oriented residential facilities: chronic-care hospitals, geriatric wings of acute care hospitals, nursing homes, and rehabilitation hospitals. The second group includes nonmedical residential facilities, such as homes for the aged, frail ambulant homes, personal care homes, and board and care homes. In this group, one can distinguish the so-called institutionalized care, which includes facilities run by state entities – fully financed by or subordinate to national authorities (e.g. residential care homes) – and private facilities.<sup>40</sup> The range of services included in long-term and institutional care is determined not only by varying cultural traditions and models of interpersonal relations but mostly by the affluence of a given society and the national budgetary resources of a given country.

Today, organizations dealing with the protection of the elderly increasingly support the idea of moving away from institutionalized care and transitioning to well-coordinated home care, which guarantees dignity and

<sup>39</sup> UNDESA, “The Growing Need for Long-Term Care: Assumptions and Realities,” 2, September 12, 2016, accessed May 3, 2023, [https://www.un.org/esa/socdev/ageing/documents/un-ageing\\_briefing-paper\\_Long-term-care.pdf](https://www.un.org/esa/socdev/ageing/documents/un-ageing_briefing-paper_Long-term-care.pdf); Lise-Lotte Franklin, Britt-Marie Ternstedt, and Lennart Nordenfelt, “Views on Dignity of Elderly Nursing Home Residents,” *Nursing Ethics* 13, no. 2 (2006): 137–41, accessed May 3, 2023, <https://journals.sagepub.com/doi/10.1191/0969733006ne8510a>; Ann Gallagher et al., “Dignity in the Care of Older People - A Review of the Theoretical and Empirical Literature,” *BMC Nurs* 7, no. 11 (2008): 2, accessed May 3, 2023, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2483981>; Robert Tabaszewski, “Health as a Value in the Integration Policies of European and East Asian Countries. A Historical and Legal Perspective,” *Journal of European Integration* 25, no. 1 (2019): 105, <https://doi.org/10.5771/0947-9511-2019-1-99>.

<sup>40</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review, Spec No(Suppl)* (1988): 145–6, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969>; Franklin, Britt-Marie Ternstedt, and Lennart Nordenfelt, “Views on Dignity of Elderly Nursing Home Residents,” 130–1, 139–41; Gallagher et al., “Dignity in the Care of Older People,” 7–9.

respects the privacy of older people.<sup>41</sup> The most important features of this model are informality and turning to family care, as well as maintaining a common family budget. Supporters of this model also emphasize that it gives more opportunities to protect the traditional family, with a patriarchal division of roles, which is identified as the source of an individual's prosperity. Family care is also seen as a way to relieve the burden on the public sector to fund, organize, and manage long-term and institutional care services. For a deinstitutionalized care system to function properly, all involved entities providing long-term and institutional care services must agree to this type of care; this applies not only to older people but also to other household members and entities which provide funding.

Some problems highlighted by human rights advocates in developing countries include the underdeveloped network of long-term and institutional care facilities, long waiting times for admission to such facilities, the poor quality of services provided in both public and private facilities, as well as instances of human rights violations (i.e. maltreatment, inhuman and degrading treatment), especially in long-term and institutional care facilities operating in less developed countries<sup>42</sup>. Fees in state-run care homes have led to an increased interest in private care homes, which are more affordable. It is therefore necessary to develop a uniform funding model based on the principle of non-discrimination to combat ageism and stigma.<sup>43</sup> Due to human rights obligations, national authorities must provide special social and medical care to people who are unable to function independently due to their age and cannot receive help from their relatives. It is

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<sup>41</sup> UNDESA, "The Growing Need for Long-Term Care: Assumptions and Realities," 2, September 12, 2016, accessed May 3, 2023, [https://www.un.org/esa/socdev/ageing/documents/un-ageing\\_briefing-paper\\_Long-term-care.pdf](https://www.un.org/esa/socdev/ageing/documents/un-ageing_briefing-paper_Long-term-care.pdf); Gallagher et al., "Dignity in the Care of Older People," 7–10; Jennifer Kane and Kay de Vries, "Dignity in Long-Term Care: An Application of Nordenfelt's Work," *Nursing Ethics* 24, no. 6 (2017): 3–4, <https://doi.org/10.1177/0969733015624487>.

<sup>42</sup> Manfred Nowak, "Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Interim Report of the Special Rapporteur of the Human Rights Council on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment," July 28, 2008, accessed May 3, 2023, <https://www.refworld.org/docid/48db99e82.html>; Adrian O'Dowd, "Basic Human Rights of Older People Are Abused in Home Care," *BMJ*, no. 343 (2011), <https://doi.org/10.1136/bmj.d7678>.

<sup>43</sup> Mikołajczyk, "International Law and Ageism," 102–3.

the responsibility of each state to provide long-term and institutional care, whether at the request of the elderly person or upon notification from their friends, local communities or social organizations.

However, branches and representatives of the state government cannot provide long-term and institutional care in isolation from the principle of respect for the autonomy and will of the elderly.<sup>44</sup> This means that the basis for providing care to the elderly is their informed and voluntary consent, which should, as a rule, be given in writing or through a care provider. The obligation to respect the will of the elderly should be implemented at all stages of long-term and institutional care and should apply to things like assistance in daily matters and delivering medical and care services, and should commence at the stage of admission to a nursing home<sup>45</sup>. During long-term and institutional care, public authorities should ensure that older people have the right to manage their own lives and that their freedom and independence are respected.

The most frequently cited problems in the doctrine of international human rights law in the area of exercising the rights of the elderly are related to the alignment of the needs of seniors with those of their families and household members, as well as relationships in nursing homes, and especially those between elderly people, their carers, healthcare personnel and other nursing home residents.<sup>46</sup> In particular, the requirement to respect autonomy somewhat correlates with the duty to satisfy the needs of older people, especially those who are dependent, impaired, or disabled. Special responsibilities should be incumbent on medical staff, volunteers and social workers who are obliged to always bear in mind the free will and independence of the elderly when providing services. The attitude of

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<sup>44</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review*, Spec No(Suppl) (1988): 150–4, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969>.

<sup>45</sup> Kane and de Vries, “Dignity in Long-Term Care Aasen,” 3–4, 11; “The Right to Health Protection for the Elderly,” 283.

<sup>46</sup> Anand, “How Not to Grow Old in America,” *New York Times*, August 29, 2019, accessed May 3, 2023, <https://www.nytimes.com/2019/08/29/opinion/sunday/dementia-assisted-living.html>; Council of Europe, “Recommendation CM/Rec(2014)2 of the Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons,” February 19, 2014, accessed May 3, 2023, <https://www.coe.int/en/web/commissioner/-/the-right-of-older-persons-to-dignity-and-autonomy-in-care>; Blomqvist and Busby, “Long-Term Care for the Elderly.”

care home staff is crucial since they sometimes undermine the credibility of older people who strongly protest against violations of their dignity and autonomy. In many cases, carers of the elderly deserve to be called human rights advocates, because they are the first link in the chain of contact between elderly people and public institutions who are obliged to protect and fulfil the right to long-term and institutional care.<sup>47</sup>

## 6. LTC and Human Rights Perspective

Apart from these obligations concerning institutional care, it is also worth discussing the potential tensions and synergies in the public health approach to long-term care. The most sensitive issues at the juncture of human rights and the need to implement long-term and institutional care for the elderly as human beings are as follows: freedom from torture, inhuman and degrading treatment and punishment; the right to liberty and security; the freedom of movement; privacy rights; and freedom from discrimination.<sup>48</sup> Some issues of contention include the amount of state resources that should be allocated to the elderly; the degree to which the elderly are free to decide about their affairs in the event of danger to life and limb in a nursing home; the issue of relieving pain and suffering, of euthanasia on request, and a model of monitoring the degree of implementation of seniors' rights, including the appointment of impartial and independent inspectors in places where the elderly are staying.

Ill-treatment, i.e. a practice that is at odds with basic human rights standards, including Article 7 of the ICCPR and Article 3 of the ECHR, may occur in some places where long-term and institutional care is provided. Any treatment intended to make the elderly feel inferior, fearful and humiliated should be deemed inappropriate.<sup>49</sup> In nursing homes, corporal

<sup>47</sup> UNDESA, "The Growing Need for Long-Term Care: Assumptions and Realities," 2–7, September 12, 2016, accessed May 3, 2023, [https://www.un.org/esa/socdev/ageing/documents/un-ageing\\_briefing-paper\\_Long-term-care.pdf](https://www.un.org/esa/socdev/ageing/documents/un-ageing_briefing-paper_Long-term-care.pdf).

<sup>48</sup> Kane and Kay de Vries, "Dignity in Long-Term Care," 2, 4, 7, 11; Kerry Brydon, "The Rights of Older People? Reflections on One Institutional Response to Ageing," *Reflective Practice* 15, no. 2 (2014): 122–8, <https://doi.org/10.1080/14623943.2013.868791>; O'Dowd, "Basic Human Rights of Older People Are Abused in Home Care."

<sup>49</sup> Aasen, "The Right to Health Protection for the Elderly," 281–2; ECtHR Judgment of January 17, 2012, *Stanev v. Bulgaria*, application no. 36760/06, hudoc.int.

punishment, cold baths, starvation, excessive use of disciplinary measures, unjustified administration of sedative and psychotropic drugs, covert administration of medicines hidden in food, or with the help of a security guard, should be deemed inhumane treatment. Ill-treatment of the elderly also includes raising one's voice, verbal aggression, pushing, performing procedures in the presence of other people, or lack of privacy during hygiene care. The reasons for ill-treatment may range from the absence of empathy for older people to acceptance of incidents of repeated violence to disregard for the will and autonomy of seniors when providing them with medical services.<sup>50</sup>

The freedom of movement of long-term and institutional care recipients can be infringed in various ways: by prolonged isolation at home or in a specific room; by overcrowding in the nursing home; by insufficient equipment and number of carers to allow free movement; and by depriving the elderly person of pharmaceuticals to support physical capacity. Most often, however, it is infringed by additional physical barriers, as was the case in *Stanve v. Bulgaria* in 2012.<sup>51</sup> In the case in question, the care home was housed in three separate buildings enclosed by a high metal fence, its residents had limited ability to communicate with each other, and toilets were located in the garden outside the building. Other issues like restrictions on the freedom of contact with family, relatives and medical staff, confining the elderly to their rooms, prohibiting them from gathering in rooms, restricting access to traditional means of communication like phones and post, and modern forms of communication such as e-mail or mobile phones, also represent serious violations of the human rights of an elderly person living in a nursing home.<sup>52</sup>

Ensuring the privacy of older people while they receive care and medical treatment is another area that requires protection by human

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<sup>50</sup> Nowak, "Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment"; Silvia Perel-Levin, "Elder Abuse and Violence Against Older Persons," in *Legal, Ethical and Social Implications of Ageing: Towards an International Legal Framework to Advance the Human Rights and Health of Older Persons*, eds. Allyn Taylor and Patricia C. Kuszler (NY: Edward Elgar, 2021).

<sup>51</sup> ECtHR Judgment of January 17, 2012, *Stanev v. Bulgaria*, application no. 36760/06, hudoc.int.

<sup>52</sup> Ibid.

rights standards.<sup>53</sup> Treatment without the consent of the elderly, and under coercion from household members and families, should be restricted to life-threatening situations. Emphasis should be placed on increasing the number of qualified long-term and institutional care service workers, which should be done through better training, instruction, and the improvement of pay and working conditions in care homes. When it comes to private facilities, it is necessary to establish minimum standards of medical service delivery to protect seniors.<sup>54</sup> Older people should have additional guarantees regarding the right to own and dispose of their belongings, including financial resources, the right to own and care for small animals, and the right to access non-life-threatening tobacco and alcohol products.<sup>55</sup>

Any cases of intimidation of older people and irregularities related to long-term and institutional care for them should be reported to the appropriate authorities. Nevertheless, practice shows that due to few complaints about abuse in care facilities for the elderly, detecting irregularities is much more difficult. Continuous monitoring of long-term and institutional care by state authorities is thus recommended; however, it is hampered when traditional measures are used that do not fully adapt to the specificities of older people's rights. When it comes to elderly care, discrimination and related human rights violations may well be disguised as actions for their benefit or the good of the general elderly population.<sup>56</sup>

In the case of the elderly population, the violations are not obvious: they most often involve a failure to respect the wishes of the elderly when providing a particular service. It is also difficult to prove abuse based on the subjective beliefs of older people, some of whom suffer from dementia-related disorders, rather than direct reports of victims or credible, evidence-based third-party accounts.<sup>57</sup> Often, there are also no witnesses or people whose testimony would be trustworthy and verifiable; this is due to

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<sup>53</sup> O'Dowd, "Basic Human Rights of Older People Are Abused in Home Care."

<sup>54</sup> Doty, "Long-Term Care in International Perspective," *Health Care Financing Review*, Spec No(Suppl) (1988): 151, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969>.

<sup>55</sup> O'Dowd, "Basic Human Rights of Older People Are Abused in Home Care."

<sup>56</sup> Blomqvist and Busby, "Long-Term Care for the Elderly."

<sup>57</sup> Ziębińska, "Uwarunkowania globalizacyjne a systemy opieki długoterminowej," 242.

age, health condition, possible cognitive impairment, as well as the actual dependence of older people on long-term and institutional care staff.<sup>58</sup>

## 7. Long-Term and Institutional Care For Older Persons and a New International Legal Instrument

Given the importance of the rights of older people, there is an urgent need for a legally binding document cataloguing the rights and freedoms of older people, together with a separate right of access to long-term and institutional care. The catalogue of already existing rights and freedoms of seniors should be presented in a new context that takes into account the global demographic changes, the stakes and benefits of seniors themselves, their family members, local communities, and entire societies affected by ageing. The new document, which would be legally binding, should comprise both social and health welfare rights guaranteeing access to coordinated care at home or institutionalized state care that would respect the dignity and privacy of older people, as well as rights ensuring freedoms and privileges related to physical integrity based on respect for autonomy, physical integrity and personal, mental and sexual security.

The draft document should list the basic obligations of the state which ensure access to care services and long-term care. These include 1) respect for the autonomy and the will of older people making independent decisions on at-home or long-term care; 2) supporting seniors and their families in the implementation of at-home care using financial and non-financial support; 3) providing long-term care if at-home care and daycare are insufficient; 4) providing palliative care.<sup>59</sup> In terms of welfare, this means guaranteeing a minimum standard of care services for the elderly, as well as providing specific financial and other support to their families.<sup>60</sup> Access to services and care facilities for the elderly should be guaranteed, including access to nursing and geriatric care in terms of availability, accessibility, affordability, and quality.

<sup>58</sup> Doty, “Long-Term Care in International Perspective,” *Health Care Financing Review*, Spec No(Suppl) (1988): 145–54, accessed May 3, 2023, <https://pubmed.ncbi.nlm.nih.gov/10312969/>; Doty, Korbin Liu, and Joshua Wiener, “An Overview of Long-Term Care,” 69–78.

<sup>59</sup> Kuszler, “End of Life and Access to Pain Medicine.”

<sup>60</sup> Xenia Scheil-Adlung, “Long-Term Care Protection: A Review of Coverage Deficits in 46 Countries,” *ESS Paper Series (ILO)*, no. 50 (2015): 16, 31–9.

The second chapter of the new convention should enumerate the state's basic legislative, educational, administrative, and judicial obligations regarding the fullest implementation of elderly care. The convention should draw from the experiences of the Inter-American Convention on Protecting the Human Rights of Older Persons, which came into force on January 11, 2017, and to a lesser extent from the more general provisions included in the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa, adopted at the African Union forum on January 31, 2016.<sup>61</sup> Legal requirements include legal safeguards for care to enable an improved quality of life, together with the prevention and alleviation of pain and other somatic symptoms and the mitigation of physical, mental, spiritual, pastoral, and social suffering.<sup>62</sup> In educational terms, training medical and social assistance staff, as well as educating the elderly, is a duty. Administrative responsibilities include ensuring supervision over institutional care and monitoring the long-term and institutional care system. Judicial obligations pertain to the possibility of judicial redress for counteracting discrimination in private long-term and institutional care and the introduction of a legal procedure to file complaints and claims about any system irregularities.

The third chapter of the convention should establish a control mechanism in the form of an elderly rights committee. It would be a body supervising the implementation of obligations regarding the exercise of the right to long-term and institutional care by seniors. The committee could receive complaints from older people, as well as their families, carers, friends, and acquaintances, as well as NGOs. The committee would enable effective redress and prevent secondary victimization of seniors deprived of family and institutional care. Victimized seniors would be allowed to file complaints if state measures were insufficient. It is also vital for the committee to have the right to issue periodic guidelines and general comments on the exercise of the rights of older people, regardless of whether they are in nursing homes or seek at-home care.

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<sup>61</sup> Mikołajczyk, "Older Persons' Right to Health," 18–9.

<sup>62</sup> Robert Tabaszewski, "Právo pacienta na pastorační péči ve světle předpisů mezinárodního práva [Patients' Right to Pastoral Care in Light of International Law]," *Revue Cirkevního Práva [Church Law Review]* 69, no. 4 (2017): 45–56.

## 8. Draft Articles of the New Treaty

The new instrument should be workable and should comprise a preamble and a legally binding part. The operative part should include both general principles establishing a minimum level of obligations to ensure that older people can live reasonably independent lives, as well as LTC provisions supporting the traditional family model of care, assuming a holistic state policy towards care recipients and carers. The provisions on the right to LTC should be compatible with existing treaty obligations, in particular with the Convention on the Rights of Persons with Disabilities. In this light, we propose new provisions for the Convention, emphasizing the need for a comprehensive and workable framework that caters to the diverse needs of our senior citizens.

### Preamble

The States Parties to the present Convention:

- a. Having in mind the principles proclaimed in the Charter of the UN which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice, and peace in the world;
- b. Recognizing that the United Nations, in the UDHR and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind;
- c. Recognizing also that discrimination against any older person is a violation of the inherent dignity and worth of the human person;
- d. Recognizing further the diversity of older persons and their special needs, including long-term care and palliative care;
- e. Recognizing the need to promote and protect the human rights of all older persons, including those who require more intensive support until the end of their lives;
- f. Recognizing the importance for older persons of their autonomy and independence, including the freedom to make their own choices [...].

### **General principle: (1) Non-discrimination**

1. Older persons shall be entitled to their human rights and freedoms, including the right to long-term care without any discrimination on any grounds.
2. States Parties shall take appropriate measures to ensure that:
  - a. long-term care services shall be available for older persons without any discrimination;
  - b. long-term care programmes shall be affordable for older persons;
  - c. long-term care services shall be in place to assist older persons with covering their costs, whether in full or in part, with no discrimination;
  - d. palliative care shall be served without undue delay, including at home and in long-term care settings.

### **General principle: (2) Protecting dignity**

1. Older persons shall have the right to respect for their inherent dignity.
2. States Parties undertake to adopt immediate, effective, and appropriate measures:
  - a. to foster respect for the rights and dignity of older persons in long-term care;
  - b. to raise awareness throughout society, including at the family level and among medical personnel, regarding older persons;
  - c. to guarantee the protection of the inherent dignity in palliative care in all circumstances, including mental disorders, disability, disease, and end-of-life situations;
  - d. to protect older persons from maltreatment and inhuman and degrading treatment in long-term and palliative care.

### **General principle: (3) Protecting autonomy**

1. Older persons shall have the right to lead their lives independently, in a self-determined and autonomous manner.
2. States Parties shall take appropriate measures to ensure:
  - a. that older persons shall only be placed in residential or institutional care upon their free and informed consent;
  - b. that individual constraints for an older person may only be implemented with the free and informed consent of that person;
  - c. sufficient and adequate residential services for those older persons who are no longer able or do not wish to reside in their own homes;

- d. freedom from any maltreatment, unnecessary examinations, treatments, long-term care hospitalizations and admissions to intensive care;
- e. the right to freedom of movement for older persons in institutional care, including life-sustaining treatment.

### **Substantive regulations**

#### **Right to health care**

- 1. States Parties recognize that older persons shall have the right to enjoy the highest attainable standard of health [...] including the right to access long-term care services [...].

#### **General – Right to long-term care**

- 1. Every older person shall have the right to receive assistance in everyday personal, administrative, medical and home activities. To assess and fulfil the needs of older persons, States Parties shall:
  - a. provide food, domestic help, basic health care, mediation in exercising rights and educational, sports, cultural, and entertainment activities;
  - b. ensure that home care, daycare, residential care, nursing homes, and palliative and institutional care long-term care services are available and affordable for all older persons;
  - c. ensure that long-term care programmes are in place to assist older persons, where necessary, by reimbursing care costs in full or in part;
  - d. ensure sufficient training and support for long-term care providers;
  - e. ensure monitoring of the long-term and institutional care system.

## **9. Conclusions**

The proposed draft provides for the right to LTC to be set forth in separate regulations. The right to LTC is different from the right to healthcare, and it should not be equated with the right to social welfare and charity. Perhaps the convention's provisions should be supplemented with additional mechanisms for the protection of elderly people and their caregivers in a pandemic. In 2020, in fear of contracting the virus, many seniors across the world consciously gave up their LTC rights, staying at home and relying solely on the help of their families, friends and neighbours. All this also contributed to the financial crisis and the bankruptcy of many LTC

providers. One prospective solution involves establishing a legal framework for the increased use of robots, telemedicine, e-commerce, and services tailored to elderly individuals, potentially serving as alternatives to human caregivers. Further considerations include privacy and data protection, as well as reinforcing local monitoring and reporting systems. Given the growing prevalence of Alzheimer's and dementia, there is an urgent requirement for a distinct convention that leverages existing legal precedents to institute comprehensive guidelines safeguarding the autonomy of those impacted by such conditions.

The COVID-19 crisis has directly affected seniors, their families, caregivers and LTC care providers, undermining their right to personal safety. In the spring of 2020, news broke around the world of a huge number of COVID-19 deaths in long-term care facilities, including in the Italian province of Bergamo. In the spring and autumn of 2020, access to caregivers, nurses, gerontologists and elderly carers decreased sharply. Many seniors were deprived of opportunities to socialize, participate in community life, and in many cases, even to carry out daily activities. When establishing the minimum obligations for the convention's signatories, it should also be taken into account that the staff and financial shortages faced by many countries even before 2020 are still prevalent in care and treatment institutions, social welfare homes, and at-home care under the pandemic restrictions. In shaping the gerontological policy, it is crucial to find the right balance between the legitimate needs and rights of elderly people, the duties and rights of caregivers, and the state's financial resources.

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