“We have the same rights”

The Human Rights of Older Persons in Long-term Care in Europe

Executive Summary

June 2017
The book (rights and obligations)

Book, how big you are, book, and how thick.
Why do you hide your wealth of laws and rights?
So good of you to store them for people.
It’s good to read what you have to offer:
Freedom, goodness and love, self-determination?
and old or even very old .......
as we are or remain, we are still citizens and have the same rights.
A Bible of human obligations and hopes, a beacon of light for the old.
You have given a form to all of this,
the way that we are covered, through our obligations.
A well-balanced scale to measure the values and needs of mankind.
After all, the elderly aren’t yet dead, don’t forget us!

Het boek (Rechten en plichten)*

Boek, wat bent gij groot, boek, wat bent gij dik.
Waarom verberg je toch die schat aan recht en wet?
Wat goed dat u bergt voor de mensen staat.
‘t Is goed te lezen wat U ons hebt te geven:
Vrijheid, goedheid en liefde, zelfbeschikking?
    al zijn we oud zelfs heel oud .......
bleven of zijn, wij zijn nog steeds burgers en hebben ook dezelfde rechten.
Een bijbel van mensenplicht en wensen, een baken van licht voor oude mensen.
Gij hebt dat alles in vorm gegoten,
hoe ze ons dekken, door onze plichten.
    Een weegschaal met gelijk gewicht om de waarden en noden, van de mens te meten.
    Bejaarden zijn noch niet dood, ook niet te vergeten!

* This poem was composed and sent to the Belgian monitoring team via email by a 93-year-old resident after he took part in an interview for the project.
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Introduction

The increased number of older persons in Europe goes hand in hand with an increased demand for long-term care (LTC). Policy-makers in all European countries face significant challenges in ensuring that the supply and quality of LTC will remain adequate in the face of population ageing. Despite the growing numbers of LTC services, older persons in and seeking LTC across Europe face their own challenges accessing and using these services. Moreover, in spite of commitments to various human rights conventions, the human rights standards and situation of older persons are not well known or understood.

In 2015, the European Network of National Human Rights Institutions (ENNHRI) started a project funded by the European Commission to increase awareness of the human rights of older persons living in or seeking access to long-term care in Europe, as well as to develop the capacity of NHRIs to monitor and support human rights-based policies in this area. As part of the Project, six members of ENNHRI (NHRIs in Belgium, Croatia, Germany, Hungary, Lithuania and Romania) carried out intensive monitoring within their jurisdictions, based on the ENNHRI reports on human rights standards for older persons LTC and monitoring methodologies of NHRIs. They each drafted national reports, setting out their findings and recommendations. This Report uses the six national reports to identify key trends in the human rights situation relating to LTC in Europe.

“We don’t have a demographic problem, we have a policy problem.”
Colm McCarthy, Irish Economist

1 All six national reports are available at http://ennhri.org/Project-Outcomes-and-Publications.
Human Rights and Older Persons’ LTC

Human rights are objective minimum standards required for all individuals to live with dignity. Human rights are universal and indivisible – all human rights apply to all persons. The human rights of individuals living in Europe are protected through a number of international and regional binding human rights treaties and other instruments from the United Nations (UN), Council of Europe (CoE) and the European Union (EU).

“Doesn’t matter what skin colour or religion, a person has to be respected for who they are... You’ve got to treat each person like you would treat yourself.”

German Care Home Manager

A text-based analysis of the binding conventions identified various rights that are particularly important in the context of older persons in LTC, including:

- Right to life
- Freedom from torture, degrading or inhuman treatment
- Freedom of movement, including freedom from restraint
- Right to autonomy
- Freedom of expression, freedom of thought, conscience
- Right to dignity
- Right to privacy and family life
- Right to participation and social inclusion
- Right to highest attainable standard of physical and mental health
- Right to an adequate standard of living
- Non-discrimination and equality
- Access to justice, including the right to an effective remedy

The analysis also highlighted that older persons accessing LTC have the right to equal access to affordable health care services (including long-term residential care), and assurances that care services be affordable, through the provision of social protection if necessary. In addition, while the various human rights conventions do not include a specific right to LTC, nor the right to have a choice of LTC service, the United Nations’ Committee on the Rights of Persons with Disabilities has confirmed that persons with disabilities have a right to choose the type of care, including residential, home or community care, and so older persons with a disability should not be admitted into residential care against their will.
“A majority of residents pointed out that, after they moved to the care home, they were not asked with whom they would prefer to live and with whom they would like to share a room.”

Lithuanian National Report

However, these rights may not be adequately protected, and older persons’ human rights are scattered throughout various human rights treaties, leaving a risk that they could be neglected in implementation, monitoring and reporting, and interpreted differently depending on the human rights mechanism and context.

Policy Context: The Ageing Population of Europe and LTC

In light of rapid population ageing across Europe, LTC policies have undergone significant reform in most countries over the last two decades. Although the quality, quantity and oversight of LTC throughout the EU varies considerably, a new trend has emerged whereby population ageing and the consequent increased demand for formal LTC services has led to public services being restricted towards those with the highest levels of caring needs in almost all countries. This has implications for access to services, waiting times and increasing co-payments.

Respect for fundamental rights is a central priority for the current College of Commissioners of the European Commission, as is creating jobs in growing sectors, including care for older persons. Proposals by the European Commission to Member States (MS) are to try to reduce demand for LTC through prevention initiatives, rehabilitation and the use of technology; and create incentives for informal carers to reduce the pressure on formal care services, alongside boosting efficient, cost-effective (formal) care provision at home and in residential care settings. The European Commission seeks to support EU Member States to improve LTC policies through the Open Method of Co-ordination and the proposed New Start Initiative and European Pillar of Social Rights both seek to tackle carers’ rights.

However, analyses of recent national policy reforms indicate that many Member States are not adequately planning for the future, but are instead “muddling through”, relying on informal care workers and/ or limited cash support for care recipients, which increases illegal migrant care.

“I don’t want to ask for a cup of coffee as I am not sure if it is included or if it costs extra, and I don’t know if I can afford it.”

Resident, Care Home, Croatia
Findings

Overall, the majority of caregivers in all care homes visited instinctively used a person-centred approach to inform their work, valuing older care users as individuals; respecting their dignity and independence, and understanding the value of social interaction. A wealth of good and innovative practices across Europe addressed to the care of older persons were reported.

However, there is significant variety in the extent to which each is respected in the countries and care homes visited, and several practices identified in relation to the full protection of the human rights of older persons in care homes raised concerns. Although there were no clear signs of torture or deliberate abuse or ill treatment, several practices witnessed in all six countries raised concerns, particularly in upholding dignity, the right to privacy, autonomy, participation, and access to justice.

Others were specific to specific countries or care homes and appeared to be related to limited funding within the sector overall, including access to LTC, the right to the highest attainable standard of health and the right to an adequate standard of living.

“One Care Manager spoke of a resident whose greatest fear was to be intubated against her will. Although this woman has expressed her wishes to the Home many times, she never signed an Advance Health Care Directive. When she suffered a stroke and her children decided for artificial respiration, the Home had no instruments to protect the resident's autonomy and her will. She died, as Head of Care says, with her face to the wall, refusing eye contact with her daughter”

German National Report
<table>
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<tr>
<th>Rights</th>
<th>Examples of concerning practices</th>
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| Access to Care (see 4.1 and 4.2.9)                                    | Entry to residential LTC without consent  
Prohibitive or hidden costs for LTC                                                                |
| The Right to Life (see 4.2.1)                                        | Unsafe environments, such as staircases being too steep and narrow                                 |
| Freedom from Torture, Inhuman and Degrading Treatment (see 4.2.2)    | Verbal or physical aggression                                                                     |
| The Right to Choice and Autonomy (see 4.2.4)                         | Lack of possibility for older persons to input to their care plan                                  |
| Freedom of Movement and Restraint (see 4.2.3)                        | Residents given tranquilisers in order to prevent challenging behaviour  
Locking doors from the outside  
Putting brakes on wheelchairs  
Leaving traytops on armchairs                                   |
| The Right to Dignity (see 4.2.5)                                     | Transporting residents in a state of undress  
Bathing several residents at the same time                                                          |
| The Right to Privacy and Family Life (see 4.2.6)                     | Leaving a dying person in the same room with other residents  
Residents' individual care plans pinned to the door of their rooms                                  |
| The Right to Participation (see 4.2.7)                               | Activities on offer largely chosen by staff rather than residents                                  |
| Freedom of Expression, Freedom of Conscience (see 4.2.8)             |                                                                                                  |
| Right to Highest Attainable Standard Health (see 4.2.9)              | Lack of medical support, such as dental care  
Inadequate/overuse of medication  
Lack of rehabilitation                                                  |
| The Right to an Adequate Standard of Living (see 4.2.10)             | Heating turned off to save money  
Dirty facilities with poor ventilation and overcrowded rooms  
Insufficient daily meals                                                |
| Access to Justice, Right to Effective Remedy (see 4.2.12)            | Residents not being made aware of complaint procedures  
Limitations to the effectiveness of complaint-handling  
Operational limitations of complaint-handling mechanisms (resident's councils) |

The Rights are listed in the leftmost column, and their corresponding examples of concerning practices are provided in the rightmost column. Each right is described with a brief explanation of the type of practice that concerns it.
Examples of innovative or good practices

- Providing a range of residential, home and community-based care options
- Training for staff on safe handling and movement of residents
  Using wheeled walkers, protection trousers and non-slip floors
- Staff training, in particular with regard to caring for persons with dementia
- Strengthening support for home and family carers
- Using alarm mats/arm bracelets that send alerts when they move outside of safe areas
  Training on alternatives to restraint and awareness of unintended restraint
- Supportive Processual Care, taking account of each resident’s unique needs
  Personal Care Plans
- Private rooms for family visits
  Waiting a few seconds after knocking on the resident’s bedroom door before entering
  Establishing rituals such as a paper star on the door of a dying resident to ensure that anyone passing the door remembers to keep their voices down to ensure peace and tranquillity to the dying resident and those in attendance
- Residents from local community invited to engage with residents, such as through volunteering initiatives
- Food being prepared with respect for resident’s (religious) needs and wishes
  Provision of prayer rooms
- National Ageing Strategies including an integrated approach to health
- Personalised living space
  Use of kitchen or vegetable garden
- Information on complaints process in accessible formats
  Suggestion boxes
  Access to an external advocate (e.g. a volunteer) who visits the care home to
Conclusions

The LTC sector in Europe, formal and informal, provides support for older persons with significant and complex caring needs, often towards the end of their lives. This costs significant sums of money, which, we are continually reminded, is only likely to grow in the future. However, the long-term care sector is a driver of employment and of the economy in Europe. The health and social services sector contributes about five percent of Europe’s total economic performance.

Investing in high quality care, which is firmly grounded in human rights, helps to (re)build trust in the care system. This in turn may enable informal carers, otherwise engaged in caring work, to join the labour force and to better reconcile work and family life, a key goal of the EU. Investments could be also be aimed at capacity building, particularly in regard to staff training. Investment can also help the EU to fulfil its obligations in relation to de-institutionalisation, by supporting sustainable alternatives to residential LTC.

In spite of the wealth of good practices identified in care homes in all six countries, human rights concerns were widespread. These appeared to be due to a lack of resources, namely limited funding and the inadequate coverage of LTC in the context of population ageing. This has an impact on the human rights protection of older persons in LTC. Investment in the LTC sector could ultimately serve the objective of enhancing labour opportunities across Europe. In particular, we advocate for use of the European Social Fund (ESF) to support quality training and mutual exchange in the long-term care sector in CEE countries where state investment has traditionally been low and availability is consequently scarce.

However, financial resources alone were not responsible for rights concerns. A lack of understanding of the human rights of older persons in LTC, both by care providers and older persons themselves, was also a significant cause. Although most care workers interviewed in all countries could identify at least some human rights standards, they experienced challenges in translating these rights into practice within the residential care setting.

“Although the number of employees at night met the Standards for Working Time Costs, the residents pointed out that such a number of employees could not satisfy their needs at night and on weekends.”

Lithuanian National Report
“The fact that the right to freedom of religion also applies for the staff is demonstrated by the negotiated solution that Unia facilitated in a residential care centre: a female employee in the washing room of a residential care centre asked her employer if she could wear an outfit compliant with her religious views instead of the relatively formfitting work uniform with logo. A compromise was reached: the same work uniform, but then several sizes larger so that it would meet the requirements of her religion.”

Belgian National Report

This is unsurprising, given that older persons’ human rights are scattered throughout various human rights treaties. As such, their specific application to older persons in or accessing LTC is often not included in reports to international human rights treaty bodies. Several care home managers spoke of a “slippery slope”, whereby allowing minor questionable practices to go unchallenged led to them becoming commonplace, which in turn allowed other, more serious issues to emerge.

While human rights challenges affected all residents, the monitoring NHRI s in all pilot countries also found specific challenges in relation to the organisation of LTC for persons suffering from dementia. It is also important that the rights of care workers be fully respected. The monitoring NHRI s found that the majority of care staff in all care settings across all pilot countries work hard to fulfil residents’ expectations and quality care, in spite of difficult conditions.

Care workers and residents appear to be affected by a systemic gender bias evident in the sector, whereby older women in need of care are often cared for by female family members at home, who in turn see their access to the labour market obstructed by their caring duties thus affecting their pensions. Lower pensions can exclude women from accessing formal LTC services, given the rising out-of-pocket user contributions required. Policies are also needed to reduce demand for LTC by supporting informal carers should take steps to protect carers from dependency in their own old age, particularly in light of the proposed Carers’ Directive.

Recommendations

The findings from this study lead to a number of recommendations for ensuring that the rights of older persons seeking and in receipt of LTC are fully respected, as well as those who care for them.

1. Policy-makers and service providers should integrate a human rights-based approach to the design and delivery of LTC.
2. Policy-makers and service providers should take steps to ensure the participation of older persons in the design and delivery of LTC.
3. Older persons in LTC must be provided with the means to access justice and effective remedy.
4. European states should invest in LTC, as an investment in our society and in Europe’s future.
5. European states should facilitate the ongoing monitoring of the human rights situation of older persons in LTC.
6. Regional mechanisms, European states and local authorities should provide awareness raising and training on human rights of older persons in LTC.
7. European states and the EU are encouraged to support a stronger protection framework for older persons in LTC, including the implementation of existing human rights standards, and a convention on the rights of older persons to address the gaps and fragmentation in current texts.