“We have the same rights”

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

June 2017

Co-funded by the European Union
Growing older is a process for which we hope that, after a lifelong hard work, leads to time of relaxation and enjoyment. But for some of us, it is often connected to many worries for the quality of our lives as the strength of our body declines, making us more and more dependent on the care of others – life in long term care. This report aims to influence the respect for human rights of older persons in need of such care.

ENNHRI has a vision for, and is working towards, the universal and effective enjoyment of human rights for everyone in Europe. In accordance, we believe that the best way of enabling that enjoyment of older persons in long-term care is by choosing a Human Rights Based Approach in national policies as well as in the provision of services to each individual.

Understanding the human rights situation of older persons in long-term care is the first step to improving it. I am glad to acknowledge the findings from the monitoring work carried out by six of ENNHRI’s members, in Belgium, Croatia, Germany, Hungary, Lithuania and Romania, showing that care homes throughout Europe work hard to offer their residents a good quality of life. We have indeed identified a wealth of good and innovative practices across Europe. At the same time, the monitoring work lead us to numerous practices and occasions in which older persons were denied their basic human rights.

Overall, our report shows how easily the human rights of older persons can be breached. Two key causes suggested by the findings were a lack of understanding of what human rights are (both by care workers and older persons), and resource shortages.

While acknowledging examples of tremendous work being done by policy-makers at EU and at national level, as well as by the care sector, to give older persons the best quality of life possible, ENNHRI presents this report and recommendations to underline the importance of ensuring that human rights are placed at the heart of policy development and service provision in the long-term care sector.

In particular, we urge European states to remember their positive obligation to address the factors that hinder the equal access of all individuals to health, including to prevention, treatment and care and to protect and uphold the physical integrity of all individuals and access to justice.

I wish to thank our members who participated in the project, as well as ENNHRI staff for the preparation of this report. Finally, I would like to express our gratitude to all of the care homes and individuals who participated in the study. Thanks to their involvement, our knowledge of the human rights situation of older persons in long-term care in Europe is significantly clearer.

Lora Vidović
Ombudswoman of Croatia
and Chair of ENNHRI
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>7</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>16</td>
</tr>
<tr>
<td>List of Acronyms</td>
<td>18</td>
</tr>
<tr>
<td><strong>1. Introduction</strong></td>
<td>19</td>
</tr>
<tr>
<td>1.1 The Human Rights of Older Persons and LTC Project</td>
<td>20</td>
</tr>
<tr>
<td>1.2 Methodology</td>
<td>21</td>
</tr>
<tr>
<td><strong>2. Human Rights and Older Persons’ LTC</strong></td>
<td>23</td>
</tr>
<tr>
<td>2.1 Overview of Human Rights</td>
<td>24</td>
</tr>
<tr>
<td>2.2 Identifying Human Rights Standards Relevant to LTC</td>
<td>25</td>
</tr>
<tr>
<td>2.3 NHRI Monitoring of LTC: Review of Previous Findings</td>
<td>28</td>
</tr>
<tr>
<td><strong>3. The Ageing Population of Europe and LTC</strong></td>
<td>29</td>
</tr>
<tr>
<td>3.1 The Ageing Population in Europe</td>
<td>30</td>
</tr>
<tr>
<td>3.2 Organisation of and Access to LTC in Europe</td>
<td>31</td>
</tr>
<tr>
<td>3.3 Challenges in LTC systems and EU Policy Responses</td>
<td>32</td>
</tr>
<tr>
<td><strong>4. Findings of the Monitoring NHRI in the Pilot Group</strong></td>
<td>35</td>
</tr>
<tr>
<td>4.1 The Human Rights of Older Persons Accessing LTC</td>
<td>36</td>
</tr>
<tr>
<td>4.2 The Human Rights of Older Persons in Residential LTC</td>
<td>39</td>
</tr>
<tr>
<td>4.2.1 The Right to Life</td>
<td>39</td>
</tr>
<tr>
<td>4.2.2 Prohibition of Torture, Degrading or Inhuman Treatment</td>
<td>39</td>
</tr>
<tr>
<td>4.2.3 The Right to Liberty, Freedom of Movement, and Use of Restraint</td>
<td>40</td>
</tr>
<tr>
<td>4.2.4 The Right to Choice and Autonomy</td>
<td>42</td>
</tr>
<tr>
<td>4.2.5 The Right to Dignity</td>
<td>44</td>
</tr>
<tr>
<td>4.2.6 The Right to Privacy and Family Life</td>
<td>46</td>
</tr>
<tr>
<td>4.2.7 The Right to Participation and Social Inclusion</td>
<td>48</td>
</tr>
</tbody>
</table>
4.2.8 Freedom of Expression 49
4.2.9 The Right to the Highest Attainable Standard of Health 50
4.2.10 The Right to an Adequate Standard of Living 52
4.2.11 Equality and non-discrimination 53
4.2.12 Access to Justice, and the Right to an Effective Remedy 54
4.3 Exit from Care: Voluntary Discharge and Palliative Care 55

5 Conclusions 57
5.1 Introduction 58
5.2 Overview of Findings: The Protection and Promotion of Human Rights 59
5.3 Lack of Resources for Older Persons’ LTC 61
5.4 Lack of Understanding of Human Rights of Older Persons in LTC 62
5.5 Specific Challenges for Older Persons with Dementia 63
5.6 Care Workers’ Rights and Conditions of Work 64
5.7 Gender as an Overarching Issue 66

6 Recommendations 67
6.1 A Human Rights Based Approach to LTC 68
6.2 Participation of Older Persons 70
6.3 Access to Justice and Effective Remedy 70
6.4 Investment in LTC 71
6.5 Monitoring the Human Rights of Older Persons 72
6.6 Awareness Raising and Training on Human Rights 73
6.7 Towards a Convention on the Rights of Older Persons 74

Annex 1: Membership of the Project’s Advisory Group 76
Annex 2: Methodology 77
Annex 3: Overview of LTC in the Pilot Countries 81
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!

* 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.
Executive Summary
Executive Summary

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

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

“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

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 person 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.
This report was written by Ciara O’Dwyer, Project Co-ordinator, on behalf of ENNHRI, with input from Debbie Kohner, ENNHRI Secretary General; Alicia Gomez Campos, Project Co-ordinator (Maternity Cover) and Johanna Günther, Project Assistant. The Secretariat team would like to thank the following for their input and co-operation during the pilot monitoring work.

To all the members of the pilot group involved in monitoring the human rights situation of older persons in LTC in their respective countries and in producing the national reports. A huge thank you to each of you for the fantastic work you have done in collecting comparative data on a previously hidden area.

- Davy Verhard, Rachid Bathoum, Didier Boone, Fatima Hanine and Michel Vanderkam of Unia, the Interfederal Centre for Equal Opportunities of Belgium.
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To the residents, family members, staff and management of each care home that took part in the study, thank you for your time, input, opinions, ideas and honesty. The information you provided has helped us to shed light on the challenges that all stakeholders in the sector face in respecting the human rights of older persons seeking or in receipt of long-term residential care.

To the civil servants, regional health and social care managers and staff, training providers and civil society organisations that took part in expert interviews and focus groups as part of the data collection process, thank you for giving us insights into the way in which human rights issues are taken into account in the planning and delivery of LTC services at national and regional level.

Thanks to the Project’s Advisory Group, all of whom provided invaluable advice on the design and implementation of the research and the production of this report. Thank you also for the invaluable financial support from the European Commission, DG EMPL.
## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>AGS</td>
<td>Annual Growth Survey</td>
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<tr>
<td>CAT</td>
<td>United Nations Convention Against Torture</td>
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<tr>
<td>CEE</td>
<td>Central and Eastern European countries</td>
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<tr>
<td>CESCR</td>
<td>United Nations Committee on Economic, Social and Cultural Rights</td>
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<tr>
<td>CoE</td>
<td>Council of Europe</td>
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<tr>
<td>CPT</td>
<td>Committee for the Prevention of Torture</td>
</tr>
<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<tr>
<td>CSR</td>
<td>Country Specific Recommendations</td>
</tr>
<tr>
<td>DG EMPL</td>
<td>Directorate General for Employment, Social Affairs and Inclusion of the European Commission</td>
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<tr>
<td>ECHR</td>
<td>European Convention on Human Rights</td>
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<td>ECtHR</td>
<td>European Court of Human Rights</td>
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<tr>
<td>ECSR</td>
<td>European Committee of Social Rights</td>
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<td>ENNHRI</td>
<td>European Network of National Human Rights Institutions</td>
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<td>ESC</td>
<td>European Social Charter</td>
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<td>EU</td>
<td>European Union</td>
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<td>EUCFR</td>
<td>European Union Charter of Fundamental Rights</td>
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<td>FRA</td>
<td>European Union Agency for Fundamental Rights</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>HRBA</td>
<td>Human Rights Based Approach</td>
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<td>HRC</td>
<td>UN Human Rights Council</td>
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<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>ILO</td>
<td>International Labour Organisation</td>
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<td>LTC</td>
<td>LTC</td>
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<td>MIPAA</td>
<td>Madrid International Plan of Action on Ageing</td>
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<tr>
<td>NHRI</td>
<td>National Human Rights Institution</td>
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<td>NPM</td>
<td>National Preventive Mechanism</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
</tr>
<tr>
<td>OEWG</td>
<td>United Nations Open-Ended Working Group on Ageing</td>
</tr>
<tr>
<td>OPCAT</td>
<td>Optional Protocol to the Convention Against Torture</td>
</tr>
<tr>
<td>RESC</td>
<td>Revised European Social Charter</td>
</tr>
<tr>
<td>SCU</td>
<td>Special (Dementia) Care Unit</td>
</tr>
<tr>
<td>SPC</td>
<td>Social Protection Committee</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UDHR</td>
<td>Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>UNPOP</td>
<td>United Nations Principles for Older Persons</td>
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Introduction
1.1 The Human Rights of Older Persons and LTC Project

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.

The European Commission (DG Employment, Social Affairs and Inclusion) supports ENNHRI’s project on The Human Rights of Older Persons and LTC (the Project), which runs from January 2015 to December 2017. The overarching aim of the Project is to improve the human rights of older persons in LTC, with particular emphasis on residential care.

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2 Long-term care (LTC) encompasses a broad range of services and assistance to people who are limited in their ability to function independently on a daily basis over an extended period of time, due to mental and/or physical disability. In this sense, LTC may include rehabilitation, basic medical treatment, home nursing, social care, housing and services such as transport, meals, occupational assistance and help with managing one’s daily life. The care is usually provided to individuals with physical or mental disabilities, the frail, in particular the elderly and people who need special help in managing their daily lives. Predominantly, LTC includes assistance with so-called activities of daily living (ADL), such as eating, bathing, dressing, getting in and out of bed or using the toilet. In addition, basic medical services, such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care may be included. This broad range of services entails that LTC touches upon both health and social components. Source: EU Directorate General for Employment, Social Affairs and Equal Opportunities, Unit E.4: LTC in the European Union. August 2008, p. 3. (http://ec.europa.eu/social/main.jsp?catId=792&
As part of the Project, a Pilot Group of six European NHRIs carried out intensive monitoring within their jurisdictions, based on the human rights standards and the report of monitoring methodologies of NHRIs. They each drafted national reports, setting out their findings and recommendations.3

This Report identifies key trends in the human rights situation relating to LTC in Europe, based on the six national reports. Divided in six different chapters, the report starts by providing some context on human rights and LTC in Europe. It then presents the findings of the monitoring work carried out by the six pilot group members. The findings should be read in conjunction with ENNHRI’s report The Application of International Human Rights Standards to Older Persons in Long-Term Care,4 which was used to guide the monitoring work. Those findings lead us to five different conclusions and seven recommendations which seek to ensure we translate words into key actions to improve the protection and promotion of the human rights of older persons and LTC.

1.2 Methodology

In order to learn more about the current human rights situation of older persons seeking or in receipt of LTC in Europe, six of ENNHRI’s members conducted pilot monitoring work within their jurisdictions, between July 2015 and March 2016:

- UNIA, the Interfederal Centre for Equal Opportunities, Belgium
- The Office of the Ombudswoman of the Republic of Croatia
- The German Human Rights Institute
- The Office of the Commissioner for Human Rights Hungary
- The Seimas Ombudsmen’s Office of the Republic of Lithuania
- The Romanian Institute for Human Rights

The Pilot Group carried out their monitoring work with reference to the human rights standards5 identified during the first phase of the Project.

“The European Commission (DG Employment, Social Affairs and Inclusion) supports ENNHRI’s project on The Human Rights of Older Persons and LTC (the Project), which runs from January 2015 to December 2017. The overarching aim of the Project is to improve the human rights of older persons in LTC, with particular emphasis on residential care.”

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3 Should read http://ennhri.org/-Project-Outcomes-and-Publications-
4 Should read http://ennhri.org/-Project-Outcomes-and-Publications-
It consisted of a review of legislation, policies and jurisprudence and monitoring of a minimum of four care homes selected according to the criteria of ownership (public/private/voluntary), size (small/large), location (urban/rural); and interviews with relevant stakeholders.

Methodological guidelines for the pilot monitoring work were drawn up by ENNHRI’s Secretariat team, based on approaches previously used by ENNHRI members and other human rights organisations.6 The methodology was framed using the Structure-Process-Outcomes approach,7 which ensures that the wider context is examined and understood in assessing the implementation of human rights obligations (outlined in Section 2.2). Annex 2 contains a fuller description of the Methodology. An overview of long-term care in each of the six countries can be found in Annex 3.

The small sample size and diversity in the mandates of each NHRI means that the results cannot be generalised to the LTC sector as a whole in each country.8 Instead, it seeks to give an indication of the key human rights issues that may be relevant throughout the EU. Based on these findings, this Report provides conclusions on challenges facing the respect of human rights in the LTC sector (Section Five) and makes recommendations to improve the human rights situation of older persons in LTC in Europe (Section Six).9

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8 Notably, some NHRI’s in the Pilot Group had the authority to enter residential care home without prior authorisation (Croatia, Hungary and Lithuania), as they hold the National Preventative Mechanism (NPM) mandate. NPMs, under the Optional Protocol of the Convention against Torture (OPCAT), monitor places of detention, including nursing homes. Other NHRI’s, which do not have the NPM mandate and so cannot enter care homes without permission, relied on invitations from care homes (Belgium, Germany and Romania). Only care homes from West Germany could be visited.
9 A full description of the methodology and profiles of the six countries can be found in Annex 2 and 3.
Human Rights and Older Persons’ LTC
2.1 Overview of Human Rights

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.\(^{10}\)

The human rights of individuals living in Europe are protected through a number of international and regional binding human rights treaties and other instruments adopted globally since 1945. These include the nine binding United Nations (UN) human rights conventions.\(^{11}\) Any state which has ratified a binding convention has a duty to:

- respect (abstain from interfering with the enjoyment of rights);
- protect (prevent infringement by others); and
- fulfil (take positive action to facilitate the enjoyment of rights).

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\(^{10}\) UN General Assembly: Universal Declaration of Human Rights, 10 December 1948.

\(^{11}\) UNHCR: The Core International Human Rights Instruments and their monitoring bodies. Homepage, 2016. (http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx)
Every state that has ratified a UN human rights treaty must report to UN treaty bodies on the implementation of the human rights obligations contained within the relevant treaty. Some treaties also allow for individual complaints to the UN body.\textsuperscript{12} Depending on the state, UN human rights treaties are either directly enforceable before the national courts, or might require further adoption at the national level to ensure this justiciability.

In wider Europe, the Council of Europe’s (CoE) European Convention on Human Rights (ECHR)\textsuperscript{13} is a key human rights treaty, as Member States must undertake to protect the rights defined in ECHR. This means that any organisation acting on behalf of the state, including those providing LTC services for older persons, must exercise all their powers and duties in a way that is compatible with the ECHR. Individuals can lodge an application with the European Court of Human Rights if they consider that they have personally and directly been the victim of a violation of the rights and guarantees set out in ECHR or its Protocols, committed by one of the States bound by the Convention, and have previously exhausted all the domestic remedies for redress in the State.\textsuperscript{14}

The EU Charter of Fundamental Rights gained the force of the EU Treaties in 2009. As a result, it has direct effect in all EU Member States and is justiciable in their national courts, as well as the Court of Justice of the European Union – but only when they are in the scope of EU law. The Charter recognises the rights to human dignity to integrity and to access to health care. Article 25 sets out principles relating to the protection of older persons and Article 34 of the Charter of Fundamental rights sets out rights in relation to social protection. According to the EU Treaty, long-term care provision is a Member State’s responsibility as a strand of social protection, and so is not in itself covered under EU law.

\textbf{2.2 Identifying Human Rights Standards Relevant to LTC}

\textit{Legally binding standards}

While all existing human rights conventions apply to older persons, there is currently no specific international convention protecting the rights of older persons. Instead, standards that protect older persons’ human rights are dispersed throughout the existing international and regional conventions. As a result, it takes time and expertise to identify all of the human rights standards relevant to older persons in or seeking LTC. This runs the risk that both older persons (the ‘rights holders’) and the providers of care (state actors and their agents; the ‘duty bearers’) are generally unaware of the minimum standards that must be respected. Furthermore, aspects of the lives of older persons are not addressed adequately by existing human rights law. For example, as outlined in Section 4.1, it is unclear whether the right to equal access to healthcare services includes access to LTC services. The most recent UN convention, the Convention on the Rights of Persons with Disabilities\textsuperscript{15} (CRPD) is important for older persons in LTC. About 60% of Europeans aged 75 years and over reported limitations in daily activities due to a health problem\textsuperscript{16} and between 60-80% of older people living in

\textsuperscript{12} In some cases, this depends on the ratification of an Optional Protocol.
\textsuperscript{14} http://www.echr.coe.int/Documents/Questions_Answers_ENG.pdf
\textsuperscript{15} Ratified by 45 out of the 47 countries in the CoE (only Ireland and the Netherlands have not ratified the CRPD).
residential care settings in Europe are thought to have some form of dementia (diagnosed or undiagnosed), while approximately 80% have a form of disability.\textsuperscript{17}

The circumstances of older persons with a disability are recognised explicitly in the text of the CRPD in relation to the right to health and the right to an adequate standard of living.\textsuperscript{18} In addition, the European Union itself has become a party to the CRPD, making it a high priority within the EU and its institutions. Article 19 CRPD also provides for individuals with disabilities to choose where they want to live, and to have access to a range of services to enable them to live independently in the community if they so wish. As such, older persons with disabilities in need of LTC should have the choice to live in a residential care setting, or an alternative model of LTC such as home or community care.\textsuperscript{19}

LTC services are often not defined as disability services by the policy makers or service providers, even though many older persons in receipt of LTC have a disability. This may result in the CRPD not being applied to older persons in LTC in practice, which in turn could impact on the design and delivery of services, as well as the reporting on the state’s implementation of the obligations set out in CRPD.

Under the ECHR, the right to respect for private and family life\textsuperscript{20} (Article 8) has been interpreted by the European Court of Human Rights (ECtHR) to include the right to respect for personal dignity, and the right to respect for personal autonomy, such as being involved in decisions about one’s own life, controlling one’s own body and participating in society.\textsuperscript{21}

In summary, the various binding human rights instruments contain many rights that are applicable to older persons seeking or accessing LTC. However, in practice, tailored measures may be needed to guarantee older persons full enjoyment of their rights.

Non-binding standards

A body of “soft law” developed by the UN, the CoE and civil society also guides the treatment of older persons. These ‘soft-law’ instruments provide guidance on older persons’ human rights but are not legally binding and so are more difficult to enforce. The Madrid International Action Plan on Ageing (MIPAA)\textsuperscript{22} is the only international instrument exclusively dedicated to older persons. It was adopted by 159 UN Member States in 2002. Building on the UN’s Principles for Older Persons (UNPOP),\textsuperscript{23}

\begin{figure}[h]
\centering
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\caption{An image related to the text.}
\end{figure}
it requires action in three areas: older persons and development; advancing health and well-being into old age; and ensuring enabling and supportive environments. MIPAA aspires to include participation of older persons in the planning and decision-making of the care they receive.

However, the UN Independent Expert on the Enjoyment of All Human Rights by Older Persons has argued that the MIPAA was not designed as a human rights instrument and therefore is not an adequate framework to guarantee the full enjoyment of their human rights by older persons. Recent research by AGE Platform Europe has found that MIPAA is largely disconnected from the national policy agenda across almost all EU Member States, and has done little to involve older persons directly in the policy planning process. Both the Independent Expert and Age Platform Europe call for a new legal instrument to be put in place.

Indeed, since 2010, the UN has a dedicated Open-Ended Working Group (OEWG) to consider the existing international framework of human rights of older persons and identify possible gaps and how to best address them. It has acknowledged that the human rights of older persons have not been adequately addressed to date.

The CoE’s Recommendation on the Promotion of Human rights of Older Persons gives guidance to duty bearers on the rights of older persons and how to implement them and it also emphasises the importance of autonomy and independence for persons with disabilities.

Overview

In 2015, ENNHRI carried out a text-based analysis of the binding and non-binding international and European conventions in order to identify the human rights standards relevant to the organisation and delivery of LTC.

This analysis 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 equal access to affordable health care services
- Right to an adequate standard of living
- Non-discrimination and equality
- Access to justice, including the right to an effective remedy

Although the binding human rights conventions do not include a specific right to LTC, nor the right to have a choice of LTC service, the 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.

Our analysis of the various binding human rights conventions and their usage concluded that these rights may not be adequately protected in practice for two reasons:

- there is a lack of clarity as to the standards’ applicability in relation to LTC, particularly as to whether or not it is considered a healthcare service;
- the lack of a dedicated treaty on the human rights of older persons results in a lack of awareness among government officials about the need to respect the human rights of older persons seeking and in receipt of LTC.

As such, ensuring that the human rights of older persons in LTC in Europe are respected is challenging, given the diversity and demands facing the sector.

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2.3 NHRI Monitoring of LTC: Review of Previous Findings

To date, there has been little research carried out assessing the extent to which the human rights of older persons in receipt of LTC are adequately protected, both in Europe and globally. European NHris constitute one of the most informative sources of evidence in this area. NHris each have a mandate to promote and protect the full range of human rights within their national jurisdictions. They monitor and investigate the human rights situation on the ground, including complaints handling, and use this to publish research, recommendations and opinions. They report to monitoring bodies such as the UN and Council of Europe, and they advise decision-makers to address core human rights concerns. NHris also raise public awareness and offer training on human rights challenges. Through this, NHris support individuals, address structural concerns to help ensure national laws and practices comply with international human rights norms and promote a culture of rights.

In addition, some NHris have a specific mandate to monitor the implementation of CRPD and report to the UN Committee on the Rights of Persons with Disabilities. As noted above, CRPD has much relevance to older persons in LTC. In addition, some NHris have a specific mandate to monitor places of detention and report to the UN Sub-Committee on the Prevention of Torture. This mandate, known as a National Preventative Mechanism, empowers NHris to access and monitor residential centres for LTC without prior warning or authorisation.

As state-mandated bodies, independent of government, NHris sit between the state and civil society. Their independence, pluralism, and accountability is tested by reference to the UN Paris Principles. All NHris must also cooperate with a variety of actors, including state bodies, other national bodies working on human rights, international mechanisms and civil society.

Over the last five years, 11 European NHris have written special reports in the area of LTC for older persons, based on detailed monitoring investigations. Overall, the care settings visited as part of each investigation had a relatively high standard of care, and most had an open and positive atmosphere. Moreover, the majority of caregivers placed a high priority on valuing older care users as individuals; respecting their dignity and independence and understanding the value of social interaction. However, all 11 NHris reported concerns in relation to the protection of the human rights of older persons in receipt of LTC, particularly in relation to choice and autonomy, participation, privacy and dignity.

The most serious issues included older persons not being fed or being left without access to food and water, or in soiled clothes/sheets. Other concerns appeared at first to be less severe, such as a resident in a care home being left unable to reach their glasses, hearing aid or false teeth. However, as noted by a number of the monitoring NHris, they could potentially be judged a breach of the right to respect for private life under the ECHR (Article 8). Such acts may even reach the threshold for a violation of Article 3 of the ECHR (prohibition on inhuman or degrading treatment), depending on the severity and frequency of neglect.

Another key outcome emerging from the review of the 11 reports is the lack of clarity as to which human rights standards and instruments are relevant for the protection of the rights of older persons in and seeking LTC, which stands in contrast with other groups, such as children and persons with disabilities.

References:
- Article 33(2) CRPD.
- See Optional Protocol of the UN Convention Against Torture.
- The Austrian Ombudsmen Board; the Federal Migration Centre of Belgium; The Institution of Human Rights Ombudsmen/Ombudsmen of Bosnia & Herzegovina; the Equality and Human Rights Commission of Great Britain; the Office of the Commissioner for Fundamental Rights of Hungary; the Commission Consultative des Droits de l’Homme of Luxembourg; the Netherlands Institute for Human Rights; the Northern Ireland Human Rights Commission; the Norwegian Centre for Human Rights; the Protector of Citizens of the Republic of Serbia; and the Office of the Ukrainian Parliament Commissioner for Human Rights. Report available at http://ennhri.org/-Project-Outcomes-and-Publications-
The Ageing Population of Europe and LTC
3.1 The Ageing Population in Europe

Across the EU, 95m persons are aged 65 and over, equating to 18.5% of the total population. The population structure of Europe has changed radically since 1950 (see Figure 3.1). Estimates show that approximately 45% of individuals aged 65+ have a disability, and between 60% of Europeans aged 75 years and over reported limitations in daily activities due to a health problem. Over a quarter of the total older population are aged 80+, and around half of all LTC users are aged 80 and over. In light of the rapid population ageing, LTC policies have undergone significant reform in most countries over the last two decades.

Figure 3.1: Age distribution of Europe, 1950-2014

3.2 Organisation of and Access to LTC in Europe

Until the late 1990s, Northern and Western European countries were largely characterised by high levels of state support and public provision for older persons in need of care, while Southern, Central and Eastern countries were characterised by extremely limited state provision and funding, with a heavy reliance on informal care from families.

Over the last ten years or so, many countries have increased expenditure and coverage on LTC services, and in particular Mediterranean and Central and Eastern European states, where formal LTC services were previously under-developed. In contrast, others (Czech Republic, Germany, Ireland, Switzerland, Sweden and the UK) have slowed or even cut back on spending and coverage in response to the rising costs of care.

In spite of this overall trend, formal LTC services in Southern and Eastern Europe developed from such a low base that the relative increase in service provision was too small to have bridged the gap with countries with a higher initial investment. This has led to a three-tier Europe, characterised by high levels of public expenditure and coverage by Northern European countries, medium expenditure and coverage by many Western countries and low expenditure and coverage by Mediterranean, Central and Eastern European countries and Ireland (see figure 3.2).

The coverage rate of formal LTC services ranges from 0.1% (Romania) to almost 30% (Netherlands) of the population across the OECD area (see Figure 3.3). Although formal LTC services developed in Eastern Europe later than elsewhere in the continent, residential care dominated over home-care services. As such, home- and community-care services in Eastern Europe, and in some Western European countries including Ireland, Italy and Portugal, remain under-developed relative to residential care.

Population ageing and the consequent increased demand for formal LTC services means that the universal model (i.e. access without consideration of financial means) that has operated in many Northern and Western countries has developed into a form of “restricted universalism”, whereby services are now largely targeted towards those with the highest levels of caring needs, limited by financial constraints, longer waiting times and budget ceilings, and with a greater reliance on informal care from family members and non-statutory providers.

Projections predict that further population ageing are likely to place further demand on LTC services throughout the EU, which in turn will create huge pressure on European governments and public finances to increase the supply of affordable, high quality LTC services. This requires innovative and creative policy responses that not only save on costs, but take into account the respect to human rights.

Figure 3.3: Coverage Rates of formal LTC, 65+, OECD, 2009


Figure 3.2: Public Expenditure on LTC as a % of GDP in 2010, all ages

3.3 Challenges in LTC systems and EU Policy Responses

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. These priorities are currently guiding the policy response to the many challenges faced by European countries in expanding the coverage of LTC services for older persons, particularly given labour market shortages. Indeed, the development of formal LTC services can also help free informal care workers to participate in paid employment.

Throughout Europe, and globally, LTC is not typically seen as an attractive sector for workers. Difficult working conditions and low pay often generate high turnover, contribute to a negative image of LTC, and create difficulties in attracting highly motivated, highly qualified care staff. Overall, labour intensity in the LTC sector varies widely throughout Europe. Sweden and Germany have the highest ratio of formal workers against service users (1.1 and 1.0 respectively), compared with 0.19 and 0.15 in Estonia and the Czech Republic, where formal LTC is still relatively under-developed. Moreover, qualification levels tend to be lower than in the healthcare sector overall, and the ratio of nurses to care workers is also low.

Many countries are developing policies to support family carers (e.g. carers’ leave, financial support, respite services) to solve the problem of access. On average, around 70 to 90% of those who provide care are family carers. For Europe, it has recently been calculated that the economic contribution of (unpaid) family work ranges – depending on the method used – between 20.1 and 36.8% of European GDP. In many Northern and Western European countries, support for informal carers (particularly the complementarity between formal and informal care services) is developing to allow them to reconcile their caring responsibilities with a professional career, and thus retain their salary and independence. In contrast, family members in Southern and Eastern countries have more intense caring responsibilities, which can limit them from having a viable career. At the same time, cash benefits for informal carers in these regions tend to be lower, which largely coincides with a legal obligation on family members to care for an older relative.

“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 are to try to reduce demand for LTC through prevention initiatives, rehabilitation and the use of technology; and to 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.44

Although responsibility for long-term care policy and provision lies with EU Member States rather than the EU, all EU Members have agreed under ‘soft law’ (Open Method of Coordination) to guarantee access to affordable, sustainable and quality care.45 The European Commission has also encouraged all countries to plan for ageing population by sharing good practices, reforming LTC policies and encouraging members to address basic human rights requirements by providing adequate access to affordable quality care.46 The 2016 Skills Agenda also recognises that the EU workforce is ageing and shrinking, leading to skills shortages in some cases, requiring better and more targeted career guidance and skills training, through co-ordinated action from the EU, national, regional and local governments.47

Both the New Start initiative, also known as the work-life balance initiative48 and the European Pillar of Social Rights49 tackle carers’ rights and LTC. The New Start initiative seeks to identify avenues for EU legislative action to effectively address women’s underrepresentation in the labour market. The European Pillar of Social Rights proposes to set out principles to improve social protection mechanisms and fair labour markets, and set out in greater detail possible ways to operationalise them. In the area of adequate and sustainable social protection, the European Commission proposes to provide for the right to access quality, affordable long-term care services, including home-based care, provided by adequately qualified professionals. It also emphasises that the financing of long-term care services shall be strengthened and improved to access adequate care in a financially sustainable way.

Although the Pillar of Social Rights will not have any legal powers, it is proposed that it should become a reference framework to screen the employment and social performance of participating Member States, to drive reforms at national level and, more specifically, to serve as a compass for renewed convergence within the euro area. However, the inclusion of these provisions, which set out standards for a domain in which the European Union is not yet active, though is a welcome development, and will bring European Commission actions in line with the provisions of Article 25 of the Charter of Fundamental Rights of the European Union, enshrining the right of older persons to live in dignity and independence.
The European Semester, the main policy tool to address recommendations to Member States within the objectives of Europe 2020, has issued concrete recommendations on LTC in 2016. Both the Annual Growth Survey and the Country Specific Recommendations (CSRs) point out that reforms need to continue to make long-term accessible and cost-effective while maintaining a high quality of service.

In 2016, nineteen Member States’ national reports cited LTC challenges. Eleven focused on scarce provision and coverage, making the link to insufficient female labour participation and sustainability issues. In spite of the large number of countries to report challenges in the area of LTC, the European Commission only made recommendations on the sector to Spain and Slovenia, largely as a result of the current policy of focusing on a small number of major priorities. Although there is a stated commitment to fundamental rights, this does not often translate into attention in practice from the EU to human rights in LTC. While listed as a priority on the EU agenda, human rights could have a clearer, dedicated action in practice from the European Institutions.

Although the availability of data has improved and life expectancy across the EU have risen, 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. At the same time, many countries are expanding service provision through market mechanisms – contracting out state services to non-statutory (for- and non-profit providers).

This highlights the complexities in developing the LTC sector and shows the need to ensure Member States’ human rights obligations remain high on the policy agenda.

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52 Malgorzata, K: EU Action in the area of LTC and Elder Abuse, World Elder Abuse Awareness Day, Brussels, June 2016.
53 Malgorzata, K: 2016, op cit.; recommendations focused on: implementing cost-efficiencies in the sector and increasing the supply of formal LTC services in order to increase female labour force participation respectively.
56 Deuss, B., Pace, C. And Antonieta, A. 2016, “Facing the Challenges in the Development of Long-Term Care for Older People in Europe in the Context of an Economic Crisis”, Journal of Social Service Research, 42(2), 144-150.
Findings of the Monitoring NHRIs in the Pilot Group
The Human Rights of Older Persons Accessing LTC

There is no explicit right to LTC articulated in any binding human rights convention. However, various conventions contain references to the right to equal access to healthcare services, the right to independent living, the right to social security (affordability of health care) and the requirement for consent to residential care. As such, these important aspects of older persons’ access to LTC were reviewed in the pilot countries by the monitoring NHRIs.

As can be seen in Table 4.1 below, expenditure on the sector has a significant impact on the availability of LTC, both in residential settings and in their own home/community. Waiting lists exist in all countries, with research suggesting that they can be open to abuse, e.g. individuals jumping up the list after contacting the “right” person or providing false declarations. Monitoring NHRIs in all six countries found residents that had not been part of the decision-making process to enter the care setting, indicating some shortcomings in implementing Article 19 of the CRPD (ratified by all six countries), which provides for the right for persons with disabilities to live independently in the community.
Belgium is the only country in the pilot group to exceed the EU average public expenditure on the sector (though private spending in Germany brings the total spend above average). The availability of LTC is relatively high in both countries, as is the bed capacity within the residential care sector. Both countries provide a range of home- and community-based services, which ensures older persons have a choice of where to receive care and access to other medical and healthcare services on an equal basis.

However, co-payments in both countries are significant; older persons in residential care in Belgium are expected to pay for “hotel” costs (which can be up to €1,500 a month). Individuals with a lower income can receive a subsidy towards these costs, though this is subject to a means test. Furthermore, care managers reported that fees are likely to increase in order to maintain the level and quality of care provided. With the average pension in Belgium reaching between €1,000 and €1,500 month, there is a bracket of individuals above the ceiling of the income threshold who may struggle to pay the full cost.

Previous research has found that most CEE countries are investing in the LTC sector, though rapid population ageing may hamper the capacity to keep pace of rising demand. Both Hungary and Lithuania have put significant emphasis on the development of LTC services since 1990, though largely in residential care. Formal home care services cater for approximately 5% of the 65+ population in Hungary, though they are largely privatised. As such, access to residential care may be relatively straightforward, though the choice of remaining at home may not be possible for many older persons. This highlights the potential for further development of home- and community based services for older persons. Costs of LTC are generally funded by the state, though local authorities may charge user fees, calculated by official algorithms which take the user’s personal income into account. Formal homecare services in Lithuania are provided by the municipality, who often lack the capacity to provide them, though new programmes are underway since 2015 to facilitate this process. Both countries continue to rely often on families for informal care, but they also offer some (limited) cash or compensation benefits for carers. In some care homes, older persons may have to rent or sell parts of their property before accessing financial support.

<table>
<thead>
<tr>
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<th>% GDP on LTC</th>
<th>% 65+ in receipt of LTC</th>
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</tr>
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<td>2.9</td>
<td>841</td>
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</tr>
<tr>
<td>Lithuania</td>
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<td>-</td>
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<td>-</td>
</tr>
<tr>
<td>Romania</td>
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<td>0.9</td>
<td>136</td>
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</tr>
<tr>
<td>EU/OECD Average</td>
<td>1.8</td>
<td>4</td>
<td>490</td>
<td>-</td>
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</table>

61 Private spending on LTC in Germany is one of the highest in Europe at 31% of the total LTC budget.
Individuals in Croatia are also subject to means testing, and so those exceeding a threshold are obliged to cover/pay costs of institutional long term care. The monitoring team found some individuals being subject to additional (unspecified) charges, which can create stress for care recipients, who were not always sure that their pension can support the total cost of their care. The Croatian NHRI intervened in the case of one woman whose continuous opposition to long-term institutional care and wish to return home was ignored. They found that relatives had signed the admission forms on behalf of the resident, even when they were not her allocated legal guardian, in contravention of national legislation. As a result of their intervention, the individual was placed in accommodation of their choice. The NHRI also highlighted that, even when the legal guardianship system was appropriately applied, it could be found to be in contravention of Article 12 of the CRPD, which calls for supported, as opposed to substituted, decision making.

In Romania, statutory social assistance for older persons is of a subsidiary nature, whereby the family has the obligation to support and care for older relatives. Public support is only provided in the case of individuals in need of support who have no family, or whose family are partly or totally incapable of providing them with support and care; in such cases, assistance is provided based on the individual’s needs. The general undersupply of services for older persons in need of care has left something of a care vacuum which has only been filled to some extent with the introduction of cash payments to allow for the employment of informal carers.

In summary, there is a considerable coverage gap regarding the estimated number of dependent people and those who have actually received some type of state-supported care, as there are shortages of formal residential services in all six countries. As well as long waiting lists, there appears to be something of a care vacuum, with a large number of older persons living alone with unmet needs. The absence of formal support, and the principle of subsidiarity, means the responsibility can fall on families. At the same time, some countries do not operate a system to pay individuals for taking time off work to care for a family member, and there are limited opportunities for unpaid leave.

Monitoring NHRI in all six countries found residents that had not been part of the decision-making process to enter the care setting. States have a positive obligation to address factors that hinder the equal access of all individuals to prevention, treatment and care and to protect and uphold the physical integrity of all individuals. As such, the below average investment into the sector may be cause for concern for the UN Committee on Economic, Social and Cultural Rights (CESCR), which has already expressed concern about the shortage of healthcare services in two pilot countries.
4.2 The Human Rights of Older Persons in Residential LTC

4.2.1 The Right to Life

The right to life comprises both the duty not to take away anyone’s life nor neglect their needs, and also a positive obligation on the state to take reasonable steps to protect life. Article 2 of the ECHR places an obligation on the state and its public authorities “to take appropriate steps to safeguard the lives of those within its jurisdiction”. This includes an obligation on managers of care homes acting on behalf of the state to ensure that the physical environment is safe and does not pose a risk to residents’ safety. Furthermore, the state has a duty to ensure third parties do not compromise the enjoyment of human rights and to investigate any potential violation.

“I am coming to life here. At home, I was becoming numb, I was turning into a vegetable. Now that is all over.”

Resident, Belgium

The right to life is strongly protected in national legislation in all six pilot countries, and there was no evidence of any clear breach of this right in any of the six countries. Legislation provides for euthanasia in Belgium and Germany in certain cases. Death as a result of neglect (or a failure to act) can also be seen as a breach of the right to life under Article 2 of the ECHR, as well as in national legislation in all six countries. In general, the physical environ-

ment and standard of care did not pose a direct risk to residents’ right to life. Indeed, some care homes had introduced some innovative practices to protect residents, such as using alarm mats and providing residents with arm bracelets, wheeled walkers, and protection trousers together with educational programmes. While investment is required to provide such materials, there is evidence that they can prove cost-effective in the long run.

However, some of the monitoring NHRIs witnessed unsafe environments, which may pose a threat to the lives of residents. The Croatian and Lithuanian NHRIs also reported that staff shortages could lead to residents being left unsupervised, which in turn could lead to falls. As fulfilling the obligation of states to safeguard the lives of its citizens includes a positive obligation to facilitate the enjoyment of human rights, insufficient steps to protect their safety has the potential to be interpreted as a failure to fully comply with this provision.

4.2.2 Prohibition of Torture, Degrading or Inhuman Treatment

The broad definition of torture in the Convention of Torture (CAT) includes any intentional act which causes pain or suffering to an older person living in a publicly-funded residential care setting. Treatment is degrading if it: “[…] is such as to arouse in the victims feelings of fear, anguish or inferiority capable of humiliating and debasing [an individual]”. There is no requirement that humiliation or debasement is intended, thus neglect which results in humiliation can equally violate the right not to be subjected to degrading treatment. However, neglect on its own does not amount to torture, which has been defined as the deliberate infliction “of inhuman treatment causing very serious and cruel suffering.”

70 For example, long corridors without grab rails, unlocked doors (with no staff nearby to manage the movement of residents), leading to an outdoor space with uneven paving and onto a large, unfenced, drop.
States are under a duty to prevent and investigate any act of alleged torture.72 UN Treaty Bodies have highlighted the vulnerability of older persons in institutional and LTC to inhuman or degrading treatment73 and the need for states parties to ensure an adequate number of staff, train nursing care personnel, and conduct more thorough inspections of care homes, in order to improve the situation of older persons in nursing homes and improve inhuman conditions.74

None of the monitoring NHRIs in any of the six countries witnessed any evidence of torture or violence directly. However, some staff and residents made reference to incidents of aggressive behaviour, often enacted by other residents with cognitive impairment, which can be a result of a challenge in communicating their needs, or the outcome of an unmet need. However, for the most part, the care homes visited had strong systems for follow up and intervention. For example, the Romanian NHRI reported periodic staff meetings take place in all of the care homes visited, focusing on issues such as adequate behaviour towards residents and how to engage on periodical dialogues with them.75

Three of the monitoring NHRIs, Belgium, Germany and Romania also cited secondary research which found that violence, neglect and degrading behaviour, often enacted by other residents with cognitive impairment, which can be a result of a challenge in communicating their needs, or the outcome of an unmet need. However, for the most part, the care homes visited had strong systems for follow up and intervention. For example, the Romanian NHRI reported periodic staff meetings take place in all of the care homes visited, focusing on issues such as adequate behaviour towards residents and how to engage on periodical dialogues with them.

Care homes can also offer respite for individuals who had been abused by family members. Care home staff furthermore admitted to rare incidents of verbal aggression towards patients. Residents interviewed by one NHRI complained about occasionally being treated in an aggressive or brusque manner.

In summary, older persons are highly vulnerable to inhuman or degrading treatment in care homes. An adequate number of care staff, together with training of care nurses, and inspections, help avoid inhuman or degrading treatment from happening in residential care homes. Although the six NHRIs did not report cases of violence or abuse in their studies, neglect or degrading treatment still occurs in care homes. The monitoring NHRIs reported good control mechanisms, such as regular staff meetings, were in place in the care homes visited.

4.2.3 The Right to Liberty, Freedom of Movement, and Use of Restraint

Care homes can also offer respite for individuals who had been abused by family members. Care home staff furthermore admitted to rare incidents of verbal aggression towards patients. Residents interviewed by one NHRI complained about occasionally being treated in an aggressive or brusque manner.

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4.2.3 The Right to Liberty, Freedom of Movement, and Use of Restraint

According to the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, restraint can include: shadowing (when a staff member is constantly at the side of a patient and intervenes in their activities when necessary), manual control, mechanical restraints such as straps, straitjackets or enclosed beds, chemical restraint (medicating a patient against his/her will for the purpose of controlling behaviour) and seclusion (involuntary placement of a patient alone in a locked room).77

Under Article 15 of the CRPD, practices involving restraints and seclusion may be considered torture or another form of ill-treatment.78 The CRPD Committee has requested state parties to refrain from subjecting persons with disabilities to non-consensual treatment. While Article 5 of the ECHR permits the deprivation of liberty, including restraint, for individuals when they may be a danger to public safety, the CRPD does not allow for such deprivation.
safety and also when their own interests may necessitate their detention, the CRPD is having an impact on how the ECtHR interprets the right to liberty and freedom of movement. Various forms of restraint were witnessed in all care homes in all six countries and included both unconscious or accidental actions resulting in unintentional restraint (e.g. forgetting to remove a tray from in front of someone’s chair after they have finished eating) and well-meaning attempts by staff to protect residents’ safety while they were occupied with other staff.

Wheelchair belts and guard rails were deliberately used to prevent residents from rolling out of bed, and doors were locked in order to prevent residents from wandering into unsafe areas. In many instances, these efforts were recorded, monitored and steps were taken to compensate for them in order to ensure their autonomy while protecting their safety. In a small number of care homes, the physical environment also served to constrain residents’ freedom, such as steps leading down into a garden, an absence of a lift, grab rails along corridors, and bars located on windows.

In Hungary, Lithuania and Romania, monitoring NHRI’s witnessed residents in some care homes experiencing chronic restraint and deprivation of liberty, caused by extremely low numbers of staff, and a lack of knowledge about human rights, as well as non-barrier-free environments. In these care homes, some residents were completely bed bound, with extremely limited opportunities to exercise, engage in meaningful activities or have their independence and autonomy facilitated. This had an impact on their physical, mental and emotional well-being. The Croatian NHRI reported freedom of movement was guaranteed for residents in all care homes visited, even those with significant limitations, though the main doors could be locked for security at times.

“In a care home, patients with dementia are able to go out with the company of the care staff who will make sure the resident feels comfortable and not forced to supervision.”

Croatian National Report

80 It is possible that at least some of the stark differences between the six countries in terms of freedom of movement as an issue is due to the different strategies used to recruit care homes for monitoring, as outlined in the Methodology section above.
The Lithuanian NHRI observed that one care home locked some room doors from the outside. Several monitoring NHRIs also documented reports, from individual residents, family members and staff, that residents were given tranquilisers in order to prevent challenging behaviour, and questioning whether they were medically necessary. Even if some actions were well-meaning, their consistent and repeated use has the potential to be seen as a form of ill-treatment.81

Overall, the biggest contributing factor to residents not having freedom of movement was a lack of staff available to facilitate the movement of residents, as well as a lack of understanding by staff of this human right and its implications on residents’ well-being. Although this was an issue common to care homes in all six countries, the level of severity varied from care home to care home and from country to country. These findings suggest that a higher staff ratio as well as training for staff on human rights and how to implement them in practice can help European states meet their obligations towards older persons in care. While several care homes reported that restraints could reduce the risk of falls, creative ways of enhancing individual safety were also reported as an alternative including electronical devices that allow residents to be more independent while not applying methods of physical restraints.

“Rather than restricting residents in their mobility, German care homes used various creative ways of enhancing individual safety, such as alarm mats, alarm bracelets, wheeled walkers, protection trousers and other devices – solutions that the Head of Management at one care home called ‘freedom-enhancing’, in contrast to ‘freedom-restraining.’”

German National Report

The Lithuanian NHRI observed that one care home locked some room doors from the outside. Several monitoring NHRIs also documented reports, from individual residents, family members and staff, that residents were given tranquilisers in order to prevent challenging behaviour, and questioning whether they were medically necessary. Even if some actions were well-meaning, their consistent and repeated use has the potential to be seen as a form of ill-treatment.81

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“I have encountered cases in which the night-time medication was given during the day that is a little disturbing.”

Family member of a resident, Belgian Care Home

4.2.4 The Right to Choice and Autonomy

Human rights law in the area of choice and autonomy (incorporating legal capacity and equality before the law) is complex. While the UN’s Human Rights Council (HRC) and the CoE have traditionally suggested that the right to liberty is not absolute, the CRPD Committee considers that perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity under Article 12.82 As such, persons with disabilities have the right to supported, as opposed to substituted, decision-making.

Monitoring NHRIs in Hungary and Lithuania found that residents often had little opportunity to input into their care plan or were not aware of its existence. Opportunities for self-furnishing rooms vary between care homes and countries. While the Hungarian NHRI reported that most care homes gave few opportunities to residents for furnishing their rooms, in Croatia and Germany, residents are allow to furnish their rooms as per their wishes.

81 CPT 2015: 61
“During the inspections a majority of residents pointed out that after they moved to the care home, they were not asked whom they would prefer to live and about the preferences as their roommate.”

Lithuanian National Report

Monitoring NHRI’s also documented incidents where residents were required to sign their full pension over to the care home and then receive “pocket money” from what is left over, once all charges had been paid.

In some of the care homes visited, the daily routine was flexible, and residents have the opportunity to organise their own schedule. In others, the schedule was pre-determined, leaving residents with limited opportunity to organise their own daily routine. For instance, they did not have the possibility to prepare their own food, wash their clothes or organise activities themselves. Residents also highlighted that they lacked information about the way life in the home was organised, and had little opportunity to feed into decision-making processes, both about their own lives and the running of the care home itself.

In Belgium, various studies have shown mixed levels of satisfaction with respect for choice and autonomy. The Belgian NHRI found that residents were able to freely enter and exit the facilities with the exception of some residents with limited mobility such as residents with dementia or having other exceptional pathologies. Those residents were reliant on staff to help them perform certain activities. Given the lack of availability of staff at certain times due to their heavy workload, on occasions this restricted how and when residents were given the assistance they required. However, other residents suggested that the care home staff made a significant effort to discuss all relevant and important issues with individual residents.

The (self-selected) care homes visited in Germany placed a strong emphasis on promoting each resident’s autonomy, seeking to empower each individual and to provide them with stable day-to-day structures in which they can function with the greatest degree of independence. In some of the care homes visited, residents were encouraged to carry out simple daily chores, such as helping with the preparation of the meals they ate, tending to plants in the kitchen garden and sort out laundry. One care manager said that residents preferred to be engaged in activities that made a practical impact in the home, rather than those provided simply to pass the time (such as bingo or watching movies). In one care home, additional staff were available at night-time, due to residents’ high level of activity. Reflecting national legislation, an individual care plan is drawn up when residents move into the care setting. This starts with the development of a “biological narrative”, from conversations with the resident and/ or relatives, and is complemented with observation by staff of each resident’s behaviour and preferences.

In summary, although the right to autonomy comprehends certain complexity, all NHRI’s could envisage certain limitations to the autonomy of residents in care homes, especially with regard to inputting into their care plan or choosing their routine. However, innovative practices reported by some of the monitoring NHRI’s showed different possibilities to go around those issues.

“Pasvalys Centre establishes an activity plan for each month, there is a schedule of activities, they are versatile (including stoneware, handicrafts, billiard, tennis table, tea meetings,...) there is a room for table games, a computer room with internet connection. In addition, there are growing efforts to involve preventive programs into arranged activities such as lectures about correct oral hygiene, alcoholism and the damage caused by it.”

Lithuanian National Report

4.2.5 The Right to Dignity

The right to dignity is the basis of many human rights treaties. It is rarely listed as a stand-alone right, with the EU Charter a notable exception - including the right to dignity as its first article, and it also sets out “the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”. The ECtHR has clarified the scope of Article 8 of the ECHR to include the right to respect for personal dignity and personal autonomy.

Findings on the right to dignity varied widely amongst the six countries. Due to the sampling approach used in Belgium and Germany, most of the care homes monitored had made considerable effort to develop a reputation as care homes that placed residents’ right to dignity at the centre of everyday practice, even within the context of national/regional regulatory systems underpinned by a focus on dignity and human rights.

In Germany, most residential care settings organise their work on the basis of the so-called Supportive Processual Care (Fördernde Prozesspflege) developed by the German nurse and gerontologist Monika Krohwinkel, of which the fundamental principle is respect for personal dignity, achieved through an understanding of each person's unique needs and by empowering them to retain their autonomy. As such, managers and care workers interviewed had some understanding of dignity, which they conceptualised as the need to facilitate residents' autonomy and control over their own lives, providing them with respect and individuality.

Even with this clear insight, problems emerged. Reports were made to the NHRIs about staff being rude to residents, refusing to change incontinence pads and empty urine bags. An oft-cited reason was the pressure facing care teams due to staff shortages:

84  Such as ECHR, CRPD and ICESCR.
85  Article 25 EU Charter of Fundamental Rights.
86  Pretty v. UK (2002), Application no. 2346/02
“When I am under stress, I, too, can do things which I disapprove of. For example, a resident comes to me to talk, and I put her in front of the TV instead. Me, the Head of this Home! (laughs) I do precisely the thing I find terrible because I have no time for anything else. I try to find a nurse who could take care of the resident, but they, too, have no time. There is absolute deficit of workforce here, and this alone is a strong pre-condition for violence and neglect of human rights in nursing care. Everything that we do, we do with our best intentions, but there are limits for everything…”

German Care Home Manager

The Belgian NHRI also found that staff and management placed significant emphasis on dignity and facilitating residents’ autonomy, which was corroborated by secondary research on LTC in Belgium, suggesting that residents are satisfied that they are treated with respect.88 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.

However, there was some evidence of individual instances of residents’ privacy not being maintained, or being treated in a patronising manner, though these appeared to be individual instances and were largely an exception to the overwhelming focus on protecting and respecting residents’ right to dignity.

Although statutory LTC has gone through substantial reforms in recent decades in Croatia, Hungary, Lithuania and Romania, and elsewhere in Central and Eastern Europe, the sector is still under-developed, with below EU-average investment, supply and oversight.89 It is possible that this underinvestment has led to considerable variation in the quality of care witnessed by the monitoring teams. While the quality of care varied, threats to dignity were reported in everyday practice in at least five care homes. This included insufficient attention to the privacy and dignity of residents, such as personal care tasks being carried out with doors wide open or not using curtains/ screens; transporting residents in a state of undress; inappropriate clothing; bathing several residents at the same time; providing meals of an inadequate temperature, quantity and quality; and an inadequate physical environment, resulting in areas being blocked off from residents or in undignified forms of transport.

Such instances may fall short of the right to respect for personal privacy and dignity required by Article 8 of the ECHR. The overall lack of respect for privacy seems to stem from workers or their managers not thinking about the older person as an individual who needs to be accorded dignity and respect for their personal privacy, and may indicate a wider cultural attitude which fails to focus on dignity and human rights. Regardless, it is important to note that the definition of elder abuse adopted by the WHO does not differentiate between intentional and unintentional acts or lack of action.90 As such, training for all staff appears to be urgently needed on how to deliver a human rights-based approach as well as higher staff ratios.

90 Elder abuse can be defined as “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person”, http://www.who.int/ageing/projects/elder_abuse/en/
4.2.6 The Right to Privacy and Family Life

The right to respect for privacy and family life is enshrined in ECHR (Article 8), Universal Declaration of Human Rights (UDHR) (Article 12), ICCPR (Article 17), and CRPD (Article 22). It largely relates to respect for residents’ right to individual identity and private space, including modesty when dressing or bathing, and privacy when one’s personal circumstances are discussed by others. As outlined in other sections, Article 8 of the ECHR has been interpreted more broadly by the ECtHR to include the right to respect for one’s dignity and personal autonomy, and the right to respect for social relationships.

Care homes in all six countries had a high proportion of residents living in shared rooms, ranging from 40% in Germany, to close to 100% in Croatia, Hungary, Lithuania and Romania (approx. 90%). The lack of individual private rooms (and bathrooms) hindered residents’ right to privacy in several ways. Not only did it compromise residents’ modesty when carrying out personal care tasks, it also prevented them from personalising their bedroom (e.g. bringing their own furniture), protecting their personal belongings to a greater extent, offering a constant space to speak privately, including with visitors, and informing a culture of respect for privacy amongst staff. For residents in need of higher surveillance there were rooms with up to six beds with no curtains or means of privacy between beds and residents’ private space. Care managers reported efforts made to achieve better privacy conditions for residents with disabilities and or in need of supervision.

NHRIs noted how shared spaces created an atmosphere in which residents’ privacy was not respected. For Hungary and Croatia, this sometimes meant that a higher number of residents than allowed for in national regulations shared a room or that a room was only accessible through another one. One Hungarian care home pinned the residents’ individual care plans to the door of their rooms in order to make it easier for staff and family to check on the health status of the residents. However, this practice was an infringement of privacy rights. As noted earlier, some residents were witnessed being transported in a state of undress. Both in Hungary and Lithuania, examples were found of staff failing to knock before entering rooms, and residents could not lock their rooms or securely lock away their private belongings.
“It’s good, my only objection is that it is a room for two people. By no means a room for three people (the third bed was unoccupied). For two people it is exquisite, three people are already too many. The toilet is shared with another room but this is not a problem. Of course, if it was possible to have one toilet for every room it would be better.”

Resident, Romanian Care Home

In Belgium and Germany, a high proportion of single rooms nationally meant that even care homes with shared rooms place a great deal of emphasis on privacy, using screens and ensuring staff knock before entering, though problems still arose. For example, a woman interviewed for the study in Germany spoke about how sharing a room with a dying resident had had a huge, negative psychological impact on her wellbeing. In addition, strict regulations on the number of residents per room in Germany limited a more creative way of caring for older persons with dementia. Several Pflege-Oasen (Care Oases) have existed for several years in Germany. Offering round the clock care by highly trained care staff, a Pflege-Oase consists of 5-7 residents living in the same room, with a social area, sleeping area, quiet area, a kitchen and hygienic facilities. However, this model is now under threat in spite of evidence on the positive effect such living arrangements had on residents’ well-being.

Living autonomously and having respect for private lives also entails the possibility of sexual or intimate relations. As the monitoring NHRIs indicate, care home staff often had not received any specific training on this issue. In Romania, couples that either formed during the stay at the centre (married or unmarried), or that came and were admitted together at the centre had their own room.

In Belgium, care home staff indicated that they try to give as much privacy as possible to residents and their spouses, and also where a resident shows signs of sexual arousal during care. In Lithuania and Hungary, couples may live together if they wish.

As previously suggested, some of these findings could suggest that care homes may be in breach of Article 8 of the ECHR and again highlight the need for training and awareness raising of current and future staff on human rights and a HRBA. In particular, our findings have demonstrated the need for residential care settings to find ways of carrying out personal care tasks, health checks and to facilitate private meetings with family and friends in a way that respects each individual’s right to privacy. As outlined in Section 4.2.10, shortcomings in the physical environment are a significant cause of the problem, which may in turn be due to inadequate funding available from the state. States need to demonstrate that they are putting maximum available resources into developing LTC services in line with the principle of progressive realisation.
4.2.7 The Right to Participation and Social Inclusion

The right to participation and social inclusion includes both the right to take part in the conduct of public affairs and to vote (Article 25 of the ICCPR), and also participation in the community, including the community within the residential care setting (CRPD Article 4). This places an obligation on care providers to facilitate residents’ participation in decisions affecting their daily lives and care, as well as access to recreational activities.

Homes in each of the six countries varied widely in terms of how they met their obligations in relation to this right. Care homes in all countries sought to allow residents to access community-based services, both recreational and medical, where necessary, although many residents complained that there were no tours and outings organised. They also sought to invite residents from the local community to engage with residents within the facility, such as through volunteering initiatives.

Many provided their residents with several activities, such as health and rehabilitation services (motor skills development, reminiscence therapy, and pet therapy), art and crafts, bingo, choir, dancing, drama and theatre performances, a literary circle, sport, and gardening. Nonetheless, dependent residents have little opportunity to engage in activities in some care homes monitored. Others had a relatively limited range of activities, which tended to be only offered during office hours.

Furthermore, in almost all care homes monitored, the activities on offer were largely chosen by staff rather than residents, with the notable exception of Germany as outlined above. In Belgium, Croatia and Germany, care providers were heavily reliant on volunteers to deliver many activities and support the participation of their residents in various events. Several care managers reported that they worked hard to maintain a stream of volunteers to support this work.

Participation is also a particularly important right for older persons with dementia, other cognitive impairments and/ or communication problems. As noted in Section 4.2.4, several care homes in all six countries sought to ensure that the wishes and needs of persons with dementia and communication problems were taken into account in developing their individual care plan and they were encouraged to participate in the daily life of the home.

Elsewhere, monitoring NHRI’s saw little evidence of how the views of such individuals were taken into account. Indeed, residents in several care homes were often left bed bound all day with little emphasis on their individual needs. This highlights not only the need for higher staff ratios, but also the need for greater specialist training for care staff in understanding and managing with persons with dementia, and in communicating their care needs and preferences for daily living.

Care homes in Belgium, Croatia, Germany, Lithuania and Romania all established ways of ensuring residents’ collective representation in decision-making within the home such as establishing residents’ councils or advisory boards. According to the monitoring NHRI’s, these bodies only partly fulfilled their functions: for instance, the German NHRI observed that the residents’ representatives were not always able to engage in dialogue with other residents or make complaints to the management due to challenges such as their physical or mental situation. All care homes monitored sought to ensure the right to vote in general elections for their residents. Training in a HRBA to LTC may be useful in guiding care homes to ensure older persons’ meaningful

“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

participation in decisions affecting their own lives and the management of the care home itself; participation is fundamental to the delivery of a HRBA.

### 4.2.8 Freedom of Expression

The right to freedom of expression, freedom of thought and conscience, is upheld in various international human rights treaties. The right to freedom of expression also includes the right to receive and impart information, and the CRPD further stipulates that this information should be available in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost (Article 21). The Human Rights Committee also urges states parties “to ensure, in particular, the right of all persons to worship or assemble in connection with a religion or belief and to establish and maintain places for these purposes [...]”.

None of the six countries reported any issues in relation to the right to freedom of expression. Indeed, efforts were made in care homes in all countries for residents to continue to vote, and to practice their religion, either through attending services in a local church or chapel within the care home, or through services made available through the public address system installed in their rooms.

In general, residents with a migrant or ethnic minority background are well catered for, with food being prepared in an appropriate way. A care home in Belgium also facilitated a special request by a care worker to have a uniform that accorded with her wishes, though the NHRI also recommended greater research to identify the specific needs of migrants and ethnic minorities in order to ensure that their needs are taken into account in policy planning and service delivery.

The six monitoring NHRIs reported that the right to freedom of expression was respected on the care homes visited, especially when it came to freedom of religion and access to information.

“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 a traditional Arabic outfit 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.”

Lithuanian National Report

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92 UDHR (Articles 18, 19), ICCPR (Articles 18,19), ECHR (Articles 9,19), CRPD (Articles 21, 29); EUCFR (Articles 10,11)
4.2.9 The Right to the Highest Attainable Standard of Health

The international human rights framework provides for the right to the highest attainable standard of physical and mental health, requiring health facilities, goods and services to be made available, accessible, affordable, acceptable, and be of good quality for older persons without discrimination. The CESCR highlights the importance of an integrated model of care, combining elements of timely preventative, curative and rehabilitative health treatment. The CESCR has also drawn attention both to the need for a national strategy on the health of older persons, and to states parties’ obligations to ensure availability, accessibility, acceptability and quality of health care.

Access to high quality healthcare services is a priority to care providers in all six countries, though is challenging everywhere; staff shortages in care homes can have implications for ensuring personal care tasks are carried out. This in turn can have implications for overall hygiene and health. For example, in Lithuania, two care homes monitored failed to provide regular baths and did not disinfect mattresses before giving them to new residents.

In some countries, care providers struggle to ensure that their residents have access to a general practitioner, nurse or specialist provider when necessary, within the scope of what is available in terms of practitioners’ schedules and the centres’ budgets. At least one monitoring NHRI found that access to some specialist services, such as dentistry, psychotherapy or gynaecology was more limited. Although most residents are given a choice of general practitioner in theory, some in practice are encouraged to accept the services of the one affiliated with the care home.

As mentioned in Section 4.2.2, problems with administering medication also proved an issue in some of the countries, with evidence of inadequate prescription and polypharmacy, as well as poor practices for storing and maintaining medical records. Care home staff and family members interviewed by the Belgian and German NHRI indicated

“There is a pervasive lack of staff in public care homes, which renders residents hesitant to request help, even when it is necessary. The nurse on night duty in one care home takes care of seventy-five residents located in the infirmary unit, while also performing the tasks of the aides. During the day, one nurse takes care of fifty residents during the day. A total of forty-two carers work in that home in daily shifts, each caring for fourteen residents.”

Croatian National Report

95 CESCR: Concluding Observations on the Kingdom of the Netherlands (E/C.12/NDL/CO/4-5), November 2010.
96 Polypharmacy is the concurrent use of multiple medications. It can be associated with the prescription and use of too many unnecessary medicines at dosages and frequencies higher than therapeutically essential. Polypharmacy is most common in the elderly. It refers to use of four or more medication by a patient generally adults over 65 years.
that sometimes medication was provided inappropriately, for instance staff confused daytime and night medication.

Other common problems identified by all care teams which may compromise the right to the highest attainable standard of health was that short staffing, a shortage of health care professionals and funding shortages may limit the availability of therapy and assistance, with some residents consequently reluctant to ask for help when required. Indeed, a strong emphasis on rehabilitation was seen only in a few care homes with residents of some monitored countries discontent with the lack of available room for such services and specialists. In Hungary, a change in legislation in 2008 meant that only care homes with relevant authorisation can or have the opportunity to provide specialist nursing and medical services to older persons in need of such therapy, without the care home receiving additional funding to provide them. Providing specialist nursing is not obligatory for care homes, though they are compelled to provide it if they want to function. This makes the operation of residential care extremely challenging for social service providers, who have been placed in a position of having the responsibility of upholding the rights of care recipients without adequate resources from the state. This in turn may serve to compromise the rights of residents. In Romania, access to a geriatrician was reported as practically not possible in all the care homes visited. However, private settings appeared to have a more careful evaluation of residents. This has been noted in Concluding Observations to Hungary and Romania, with recommendations to increase the supply.  

“The option to choose a certain GP only exists in urban areas where several medical service providers are available and where the residents coming from nearby can keep their GP with whom they have already established a relationship.”

Romanian National Report

4.2.10 The Right to an Adequate Standard of Living

Article 11 of the UN International Covenant on Economic and Social Rights (ICESCR) and Article 28 CRPD recognise the right to an adequate standard of living, which includes adequate food and housing. Furthermore, the state has a responsibility for progressive realisation and to ensure against retrogression (worsening) within the resources available. The CESCR has highlighted the need for states parties to ensure an adequate number of staff, training nursing care personnel according to the recently adopted standards of training and conduct more thorough inspections of care homes in order to improve the situation of older persons in nursing homes.98

Overall, there was a high diversity, both between and within countries in the living conditions in the care homes monitored. For example, in Croatia, statutory services tended to be less well-equipped than private ones, due to the limited availability of public funding. However, in Lithuania, some public homes had a relatively high quality physical environment, due to investment from the European Union.

There was clear evidence that several care homes are failing to consider their positive obligations to facilitate the better enjoyment of residents’ right to an adequate standard of living, or are prevented from doing so because of the inadequate funding available from the state. For example, the Croatian NHRI reported that the heating had been turned off in several care homes to save money. In one home, the temperature measured was 19°C, below the set lower limit, in spite of cold temperatures outside. Some violations, including an inadequate physical environment and overcrowding, appeared to be an outcome of the organisation of LTC at the national or regional level.

Some care homes tended to be well-designed and suited to the needs of residents, with non-slip floors, escalators and a home-like environment personalised with residents’ own possessions. Many had unique spaces designed with residents’ needs in mind, such as small kitchens where residents can cook, or an outdoor space with a special feature, such as a pond, flower or vegetable plot. In contrast, other care homes tended to be less well-designed and equipped, have older furniture, a more hospital-like feel, shared bedrooms and bathrooms between many offering limited privacy, and a lack of secure storage space for residents’ possessions and clothing. Some facilities were clean and tidy, others were dirty with poor ventilation, and lacking in natural light and access to outdoor spaces. A small number lacked alarm bells for residents to alert staff when required. In Romania, some of the centres were not equipped with elevators, which caused difficulties for mobility dependent residents sometimes located in upper floors hence incapable of taking part in the centre’s activities.

While none of the NHRI included a dietitian on their monitoring team, reports from two pilot countries showed some care homes did not have all types of dietary menus available for their residents with special diet requirements (for residents with cardiovascular disease, diabetes, coeliac, dysphagia (difficulty swallowing)).

In summary, the right to an adequate standard of living proved challenging in some of the monitoring care homes due to insufficient funding, making it impossible for some care settings to provide inhabitants with enough private space. Also adequately safe environment conditions and dietary menus were not always provided.

4.2.11 Equality and non-discrimination

Neither the ICCPR nor the ICESCR explicitly mention discrimination on the basis of age. Nevertheless, article 26 of the ICCPR has been interpreted to mean State parties have a general obligation not to enact legislation with a discriminatory content, nor to apply laws in a discriminatory way.\(^9\) In addition, the UN Human Rights Committee has stated that “a distinction related to age which is not based on reasonable and objective criteria may amount to discrimination on the ground of other status.”\(^100\)

The ECHR also contains references to discrimination on the ground of “other status”. However, under Article 14 of the ECHR, there is no free-standing right to non-discrimination. The EU Charter, Article 21, includes non-discrimination clauses relating to age. The Revised European Social Charter provides an explicit basis for combating age-related discrimination. Given the diversity amongst older persons in LTC, it is important to note that anti-discrimination legislation also covers the grounds of race and ethnic origin, religion, disability, sexual orientation and gender. Indirect discrimination occurs when a policy has a disproportionate negative impact on a specific group, which is relevant in the case of women and older persons with disabilities, who make up a large majority of older persons in residential LTC.\(^101\)

The pilot group reported instances of discrimination either age-based or otherwise. In particular, an older person can be placed in LTC based solely on another person’s request, which is not the case with certain other societal groups.\(^102\) In some countries, it is permissible for the contract with the care home to be signed by a member of the immediate family (particularly if they had agreed to pay the care home’s costs) on behalf of the potential beneficiary, without legal intervention. Applications submitted in this way are inserted into the beneficiaries’ files. Such beneficiaries, despite having been in a good psycho-physical state at the time of their admission, did not express their free and informed consent to being placed in the institution.

Rising out of pocket payments can have severe consequences for older persons and their families, even leading to financial ruin in some cases. Recent research by the International Labour Organisation (ILO) has concluded that wide gaps of social protection coverage in LTC and infrastructure and unequal treatment of older persons in need of LTC compared to younger persons with similar needs, such as health care, constitute a form of age-based discrimination. Pensions being automatically taken from care centres’ residents who were only given the remaining pocket money is a related form of systemic age-based discrimination,\(^103\) reported in several countries. This practice puts residents at a disadvantage in comparison to those living in their own homes, as the former are not able to use their financial resources by using debit cards or purchasing goods in instalments.

The Belgian NHRI also witnessed age-based discrimination in regard to volunteers who could not be above 75 years at one care home. Upon receiving complaints about this issue the care home management withdrew this age limit. The Belgian NHRI also raised concerns about the situation of LGBTI people indicating that there were no data available in terms of equal access to LTC and non-discrimination. In this regard, the Belgian NHRI emphasised special attention should be paid to the possible risk of multiple or intersectional discrimination when accessing residential care.

The six NHRIs highlighted a clear gender imbalance in terms of the caregiving workforce, whereby the proportion of care workers who are predominantly women in the (long-term) care sector, is noticeably higher than in other professional occupations. All six countries reported a majority of women among the residents. In addition, existing gaps in pensions between men and women, and the requirement in some countries that pensions be transferred to pay the care home expenses, could lead to discrimination in terms of access to care. This issue is discussed in greater detail in Section 5.5.

\(^9\) HRC, General Comment 18, 69/GEN/1/Rev.9 (Vol 1) 195, para. 12.


\(^103\) Scheil-Adlung, X, 2015, op cit.
4.2.12 Access to Justice, and the Right to an Effective Remedy

Access to justice and the right to an effective remedy broadly refer to the right to be treated fairly according to the law, placing an obligation on states to provide individuals whose rights have been breached with a remedy and reparation, as well as equal protection of the law. Access to justice is strongly protected in international and regional human rights conventions and means more than individuals having access to the court/justice system, but having access to an organised and formal complaints mechanism when accessing statutory care services, including:

- the provision of information in an accessible format to residents on their rights, as well as about their care, charges and services, facility rules and regulations, complaints procedures;
- deterring conduct that would infringe human rights;
- effective avenues for complaint that allow individuals to report breaches of their human rights/well-being without fear of reprisal; and
- potentially providing residents with access to independent third party advocacy services.

All six members of the pilot group noted that access to justice was one of the most challenging rights to fulfil, given that many older persons living in residential care may be reluctant to complain for various reasons, including a fear of reprisal. They suggested that care homes would therefore need to have a highly-developed complaints system that takes these issues into account.

Most care homes in all six countries reported that they had a formal complaints system in operation. In Belgium, Croatia, Lithuania and Germany the complaints system consisted of various steps on the ladder, starting with informal oral complaints to care workers or the care home manager, coupled with anonymous suggestion boxes. Some care homes also had a residents’ council which worked well, albeit with some limitations. In several care homes in Croatia, Hungary and Romania, the complaints system frequently consisted of residents being able to make complaints orally to the care

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104 Article 3 of the ICCPR, Article 13 of the CRPD, Articles 6 and 13 of the ECHR and Article 47 of the EUCFR.
106 It is important to reiterate that homes monitored in Belgium and Germany were self-selected and do not constitute a representative sample of the care home landscape in these countries.
home manager (with a complaints box system in operation in some care homes), but there was often no clear evidence either of how residents were informed of this system or of how complaints were addressed. In Hungary, and in one care home in Germany, residents had access to an external advocate who visited the care home to assess the quality and organisation of care and to ensure all residents were happy with all aspects of their care and make complaints/enquiries on their behalf when necessary. Both the German NHRI and the Hungarian NHRI stated that this external oversight mechanism worked well. The German NHRI further made the point that the fact that the independence of external advocates independence was helped by the fact that they operated on a voluntary basis, rather than being paid by the care homes.

Our findings showed that care homes that used diverse approaches had better success in receiving (and responding to) complaints. This is because each approach has challenges. First, providing residents with accessible information about the procedures and bodies that investigate complaints. Secondly, residents can face challenges making complaints (fear of reciprocity, negotiating the formal complaint system etc.). Thirdly, complaints systems in some countries, such as Germany, are extremely fragmented, with various actors – including non-governmental organisation focussing on LTC – involved, which sets limitations to the effectiveness of complaint-handling.

It is also important to remember that staff need to have options for redress, as human rights can sometimes take place due to the challenging working conditions under which care staff work on the sector.

4.3 Exit from Care: Voluntary Discharge and Palliative Care

The principle of consent to residential care, set out in CRPD for persons with disabilities, also refers to exit from care: individuals have the right to discharge themselves at any time and to be discharged without restriction. Articles 2 and 8 of the ECHR also provide for the right to appropriate care arrangements to be in place upon discharge. It is important to note that the lack of community-based services, which could ensure such individuals remain living independently at home, also plays a role in enabling their institutionalisation.

The protection of end-of-life and palliative care rights are seldom articulated in international or regional binding conventions. The ICESCR states that, with regard to the realisation of the right to health of older persons, “attention and care for chronically and terminally ill persons [is important], sparing them avoidable pain and enabling them to die with dignity” and Article 23 of the European Revised Social Charter (RESC) requires the provision of adequate palliative care services.

“I live for today, not tomorrow. I have the impression that people now are more occupied with their death than with their life.”

Resident, Belgian Care Home

107 At article 19.
108 http://www.echr.coe.int/Documents/FS_Elderly_ENG.pdf
Only the Belgium NHRI had contact with a family member of a deceased resident. The rest of the monitoring NRHIs did not witness the full extent of palliative care in the care homes visited. Overall, NRHIs observed that the lack of availability of private (single) bedrooms hindered the ability of care providers to ensure privacy for an individual close to death in all six countries. Monitoring NRHIs also relied on the statements of residents and care workers to evaluate the protection of residents’ right to palliative care.

In some countries, care homes focus on learning the wishes of each resident in advance of their death and ensuring privacy and dignity as they die. In Germany for example, rituals such as a paper star on the door of a dying resident sought to ensure that anyone passing the door would remember to keep their voices down to ensure peace and tranquility to the dying resident and those in attendance. Even with this strong focus on respecting the right to dignity for the dying, problems still arose, largely related to the legal status of an individual’s dying wishes. It was found that the voice of an individual in relation to their wishes for death was not necessarily prioritised over those of others, even the next-of-kin, which serves to highlight the importance for older persons in receipt of LTC of determining their choices for death and dying as early as possible and using recognised legal channels (such as an Advanced Care Directive).

Elsewhere, care teams were guided by national legislation, which to a large extent focuses on the aftermath of death, including notifying relatives, drawing up an inventory of the individual’s possessions, and making a tribute to the memory of the deceased. This may be interpreted as a failure to fully comply with states’ obligations to ensure individuals are enabled to die with dignity and free of pain.

In Lithuania, the NHRI found that a dying person is usually separated from other persons living in the room by a screen. If possible, the dying person is transferred to a separate room. Furthermore, relatives or other persons specified by the dying person in the resident questionnaire are immediately notified. Moreover, if the person requests so, a religious leader or a psychologist are invited.

In summary, NRHIs reported a strong emphasis on providing residents with the best services possible during their last days. However, privacy in relation to death and dying proved challenging in some care homes, which may amount to a breach of Article 8 of the ECHR – the right to respect for private life.

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“Head of Care at Home 1 spoke of a resident whose greatest fear was to be intubated against her will and be unable to decide about when and how to die. Although this woman has expressed her wishes to the Home personnel many times, she has never signed an Advance Health Care Directive – and once she had 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 to her daughter’.”

German National Report

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109 No deaths occurred, and only the Belgium monitoring team had contact with family members whose relative had died while living in the care setting.
Conclusions
5.1 Introduction

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 only likely to grow in the future. However, the long-term care sector is a driver of employment and of the economy in Europe. Long-term care is a major source of employment in many European countries, particularly for women. In the Netherlands, one in every seven working women is employed in the care and welfare sector. It offers opportunities for part-time work, allowing women to reconcile work and family responsibilities. Rising employment in the sector increases consumer spending. As a result, the health and social services sector contributes about 5 percent of Europe’s total economic performance. Looking at the extent to which long-term care services meet their human rights obligations is thus an ideal way to improve the quality of the sector, in turn increasing opportunities for private investment and the expansion of the sector, attracting qualified and motivated staff as well as fulfilling the EU’s social obligation of supporting older persons and their families.

“We don’t have a demographic problem, we have a policy problem.”

Colm McCarthy, Irish Economist
Although our self-selected monitoring teams were largely based in EU Member States with comparatively low levels of public expenditure and coverage, our findings offer useful learning points for policy-makers and care providers in all Member States. Our findings highlight the common challenges faced by care home providers in all six countries, even where human rights are already integral to the LTC system. Indeed, the current momentum internationally and within Europe on clarifying and strengthening the human rights of older persons means that it is timely for all European countries to consider the extent to which their LTC sector is compliant with human rights standards.

Moreover, our findings highlight the usefulness of a human rights-based approach to LTC, in which opportunities are created for each individual to make decisions as to how (and where) their own needs and wishes can best be met. ENNHRI is currently in the process of developing toolkits for policy-makers and care providers to help them implement a HRBA to LTC.

5.2 Overview of Findings: The Protection and Promotion of Human Rights

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. The monitoring teams also reported a wealth of good and innovative practices across Europe. However, 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 any signs of torture or deliberate abuse or ill treatment, several rights proved challenging for care providers in all six countries, particularly upholding dignity, the right to privacy, choice and autonomy, participation and access to justice. Others were challenging in specific locations 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, the right to an adequate standard of living. These findings strongly reflected those of previous investigations of the LTC sector carried out in the last five years by other ENNHRI members (in Austria, Bosnia and Herzegovina, Belgium, Hungary, Luxembourg, Netherlands, Northern Ireland, Norway, Serbia, the UK and the Ukraine). 110

The evidence suggested that the majority of human rights relevant to long-term care were at risk, if not breached, in all six countries, while two of the other four were at risk in at least one country (see Table 5.1).

**Table 5.1: Summary of Rights at Risk**

<table>
<thead>
<tr>
<th>Rights at risk in all 6 countries</th>
<th>Rights at risk in specific countries</th>
<th>Rights Rarely At Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal access to health services for all persons</td>
<td>Right to Life (Romania)</td>
<td>Freedom of Expression, Freedom of Thought and Conscience</td>
</tr>
<tr>
<td>Affordability of healthcare services</td>
<td>Freedom from Torture, violence and abuse (Belgium, Croatia, Germany)</td>
<td>Equality and Non-Discrimination</td>
</tr>
<tr>
<td>Choice of Long-Term Care Service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dignity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choice and Autonomy</td>
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<td></td>
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<tr>
<td>Freedom of movement and restraint</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation and social inclusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privacy and Family Life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right to highest attainable standard of physical and mental health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>An adequate standard of living</td>
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<td></td>
</tr>
<tr>
<td>Access to Justice, effective remedy, redress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff Rights</td>
<td></td>
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</tbody>
</table>

“These findings strongly reflected those of previous investigations of the LTC sector carried out in the last five years by other ENNHRI members.”

5.3 Lack of Resources for Older Persons’ LTC

As noted in Section 3, expenditure on formal LTC provision varies considerably throughout Europe. All EU Member States are facing significant population ageing, which is leading to unparalleled spending projections to 2060 and beyond. The supply of formal long-term care services in many European countries and statutory investment into the sector is low, with heavy reliance on informal care by family members.

The findings from this study indicate that limited funding and the inadequate coverage of LTC needs has an impact on the human rights protection of older persons in LTC. Waiting lists are growing and care home managers and family members have no choice but to provide informal care services to their older dependent relatives because there are no formal services available. Staff in residential care settings in all six pilot countries reported that they operated on a very tight budget, relied on considerable additional fees paid by residents, and expected to have to increase co-payments in the future due to reductions in public funding. Limited resources bear consequences at various levels, and may lead to facilities becoming inadequately equipped, putting residents at risk. Indeed, several monitoring NHRRIs reported overcrowding in shared rooms and a lack of private meeting rooms for visitors and medical examinations. The under-development of social protection for LTC also impacted on the ability of older persons to access the care services they require – both residential and home-based services. Furthermore, vulnerable older persons in need of intense care, such as persons with dementia or multiple disabilities, could find themselves at risk.

This creates undue pressure on families to fill the care vacuum, and may also be considered a violation of human rights, given states’ obligation to provide for the right to the highest attainable standard of health. States have a positive obligation to address factors that hinder the equal access of all individuals to prevention, treatment and care and to protect and uphold the physical integrity of all individuals. Limited resources cannot justify inaction or indefinite postponement of measures to implement these rights. As such, European states have an obligation to provide for access to affordable, quality health facilities for all older persons, particularly when they are chronically or terminally ill. This highlights the need for greater development of LTC services throughout Europe, including community-based services, which correspond with many older persons’ own wishes. This is also in line with the European Commission’s and Social Protection Committee’s recommendations to Member States, as well as Article 19 of the CRPD.

The European Structural and Investment Funds are one way in which the EU can contribute in a meaningful way to the development of LTC services for older persons, particularly in CEE states, where the sector is often relatively new and under development. However, our monitoring work found in some cases that ESIF were used to build new institutional settings, in contravention of Article 19 of the CRPD, an issue which has been raised by civil society organisations and the CRPD Committee itself. It is also important to remember that the current policy direction advocated by the European Commission and the SPC is to reduce demand for LTC by taking steps to protect older persons from dependency in their own old age.

111 European Commission (ECFIN), 2015, op cit.
113 Colombo et al. 2011, op cit.
5.4 Lack of Understanding of Human Rights of Older Persons in LTC

Financial resources alone were not responsible for rights concerns. A lack of understanding among care staff, providers and policy-makers of their human rights obligations also contributed to rights concerns in care homes in all six countries, regardless of statutory investment into the LTC sector. As noted throughout the findings, most care workers interviewed in all countries could identify at least some human rights standards. However, various actions witnessed by the monitoring teams suggested that they experienced challenges in translating these rights into practice within the residential care setting. As noted in Section 4, staff inadvertently and repeatedly restrained residents by placing them in deep armchairs, putting a table or tray in front of their seat or leaving their wheelchair belt on without a clear recognition that they may impinge on the freedom of movement of individual residents (e.g. documenting a justification for the action).

However, other findings, such as residents being spoken to aggressively or being transported in a state of undress, suggest a lack of awareness of the fundamentality of dignity and privacy to human rights. As noted throughout Section 4, these concerns may each amount to breaches of the right to respect for private life under Article 8 of the ECHR. 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.

Although a lack of resources (particularly staffing) appeared to at least partially explain some of these concerning practices, the wider policy context also appeared to play a role. Duty bearers (municipal, regional and/or national governments as well as private care providers acting on behalf of the State) have positive obligations to promote and protect human rights, including a duty to respond to human rights breaches and to develop and implement legislative and administrative framework to deter conduct that would infringe human rights. As outlined further in Section 6, this highlights the need for a culture shift in national LTC policies towards a HRBA, where policy-makers understand their human rights obligations and the need for new and existing policies to be checked for human rights compliance, as well as the provision of training for care workers.


5.5 Specific Challenges for Older Persons with Dementia

In 2015, an estimated 10.5 million persons were reported to live with dementia in Europe. With prevalence steadily increasing in recent years, it has become the second cause of disability for people over 70 in Western Europe. Prevalence, and related costs, are likely to grow by almost 50% by 2030. Research suggests that between 60-80% of older persons living in residential care have some form of dementia or cognitive impairment. As such, it is important to take particular account of the needs and wishes of these individuals.

Since 1997, the European Commission has taken different actions to develop and implement measures aiming to improve the care situation for persons suffering from Alzheimer’s disease and other forms of dementia. However, specialist formal care services for persons with dementia are in short supply throughout the EU, with a strong reliance on informal care. Indeed, informal carers, who are usually female, need support in order to provide a sufficient level of care, and also to participate in the economy and society. Home care is also in keeping with the approach towards deinstitutionalisation for persons with disabilities, as reflected in Article 19 of the CRPD.

The most prevailing problem raised by care home staff and management alike was the lack of qualified care workers and the low staff-residents ratio, in particular during night shifts. As the German NHRI indicated referring to a report published in 2015, during night shifts one nurse may have to care for as many as 50 residents, 20 of whom may be affected by dementia. Care workers indicated that caring for persons with dementia proved physically and psychologically challenging, due to the aggressive or agitated behaviour of residents, and of a lack of time or knowledge on the part of the care workers to adequately respond to the needs of these individuals. This points to the need for specialist human rights training for staff, which can help staff learn innovative ways of overcoming these challenges.

Another major issue which particularly affected individuals with dementia was the issue of legal capacity and consent. States parties to the CRPD are required to put in place systems of supported, rather than substituted, decision-making. However, some individuals requiring support to manage their financial and legal affairs did not have an individual allocated to support them with their legal decisions. Instead, care managers took over some of their responsibilities without obtaining official permission. Similarly, residents who became agitated or exhibited challenging behaviour were often physically or chemically restrained without care home managers and staff ascertaining that their actions were medically necessary, legitimate and proportionate. This occurred even in care homes which have a strong focus on human rights within LTC.

These worrying practices, which may be interpreted as human rights breaches, again appear to be related to a lack of understanding of human rights obligations and a lack of resources. Given the vulnerability of persons with dementia, they arguably highlight the need, not just for greater training of care staff and more resources, but for a culture change and a human rights-based approach (HRBA) to LTC. ENNHRI is currently developing toolkits for policy-makers and care providers on this topic.

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117 http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Cost-of-dementia/Prognosis-to-2030
118 http://ec.europa.eu/health/major_chronic_diseases/disease/dementia/index_en.html#fragment2; http://www.alcove-project.eu/
121 It is important to note again the different interpretation of Article 15 of the CRPD and Article 5 of the ECHR, as noted in Section 4.2.3.
The findings in our study point to the centrality of a highly qualified, motivated staff, in adequate numbers, to ensure the full enjoyment by older persons in care of their human rights. Indeed, the monitoring NHRIs found that the majority of care staff in all care settings across all pilot countries work hard, in often difficult conditions, to fulfil residents’ expectations and quality care. The monitoring NHRIs also reported the same challenges in all six countries: salaries tend to be low, often at or marginally above the minimum wage; and working conditions can be challenging – physically demanding and emotionally testing, with long or split shifts covering anti-social hours, corroborating previous research by the OECD.  

5.6 Care Workers’ Rights and Conditions of Work

Although part-time work can be beneficial as a way of reconciling work and family responsibilities, care workers raised the issue of “forced part-timing” due to shift work and a higher demand for care workers during day shifts, in particular during meal times. Low wages and irregular working patterns contribute to a high turnover of staff. A high turnover of

“There is little respect for residential care centre employees in our society. We are seen a little bit as failed hospital staff. But that image is wrong.”

Staff Member, Belgian Care Home

staff can interfere with the development and maintenance of a team spirit, and also create additional burdens on staff to support and acquaint new staff with their duties. NHRI s in all six pilot countries reported – although to varying extent – that staff-residents ratios were very low particularly during night shifts.

As noted by the OECD, a lack of resources may also cause an inadequate staff complement, and an unattractive working environment for staff members. Monitoring NHRI s noted that inadequate levels of staffing, and a lack of staff training, had an impact on whether residents were treated with dignity, and with respect for their freedom of movement, autonomy and privacy. Furthermore, wages were found to be considerably lower than in other parts of the health sector. In Germany and Belgium staff also reported that their profession did not receive adequate societal recognition.

The sector is heavily staffed with women close to retirement age, due to challenges in attracting career-starters into the sector. There is also a high proportion of migrant workers and individuals from ethnic minorities in the sector, with some reports of discrimination and even exploitation. Finally, it was reported that staff found it difficult to access necessary or relevant training. Altogether, this can lead to burnout and high dropout rates and does not allow for a healthy work-life balance.

These working conditions can lead to discontent among care workers, and there was some evidence that it was a contributing factor to some infringements of older persons’ human rights. This reinforces suggestions that most infringements of human rights in LTC settings occur due to inadequate working conditions and lack of skilled personnel in care homes. Staff working excessive hours under poor conditions may lack an attention to detail required to ensure mistakes and oversights do not occur. Furthermore, a lapse in professionalism may result in staff venting their frustrations upon LTC residents.123 It is important that staff with concerns regarding their working conditions are able to raise these issues and seek redress.

The challenges facing the LTC sector in terms of staffing and upskilling are not unique to the LTC sector and efforts are underway to streamline policies for a new Skills Agenda.124 Our findings point to the need not just for qualifications in LTC (such as provided through the Vocational Education and Training sector) but specifically for human rights education and training for staff and students alike. This would improve the professionalisation of the sector and provide workers with full awareness of the rights of older persons. This in turn will help make the sector more attractive for potential workers. Indeed, evidence suggests that retention rates are higher in countries where LTC has been largely professionalised.125

124 European Commission: A New Skills Agenda for Europe, op cit.
LTC affects women and men differently. In all six pilot countries, as indeed, throughout the EU, women make up the vast majority of both residents (due to higher life expectancy) and care workers. This in turn contributes to systemic gender bias reported elsewhere, 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 full time labour market obstructed by their caring duties thus affecting their pensions. In turn, rising co-payments may reduce their access to formal LTC services in their old age.

Moreover, as professional care workers are largely under-paid with limited control over their working hours, and often forced to part-time shifts, their own pensions and private lives are likely to suffer. This shows clear evidence of the underrated importance of care work within the labour force which leads to precarious conditions in the sector. Access to LTC services is thus important to promote work-life balance for family members with dependent relatives, to make sure the caring sector responds to equality policies of non-discrimination. Furthermore, as noted above, policies are 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.

127 European Commission: New start to address the challenges of work-life balance faced by working families. Roadmap, Brussels 2015.
Recommendations
6 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.

6.1 A Human Rights Based Approach to LTC

Policy-makers and service providers should integrate a human rights-based approach to the design and delivery of LTC.

Implementing a human rights-based approach (HRBA) requires a move to a situation where human rights were acknowledged in policy development and in day-to-day practice. A HRBA places the principles and standards of human rights at the centre of all aspects of service planning, policy and practice. It aims to support policy-makers and care workers so that they put the rights of each individual older person at the centre of how they organise and deliver care. As such, it is a way of adapting the LTC model that can improve quality outcomes through integrating recognised, objective human rights standards, which can be applied to different care settings across a diverse Europe. A HRBA has already been shown to positively affect the extent to which staff interact with patients, and hence increased work-related satisfaction, in care settings, without necessarily imposing additional costs on either the individual care institution or the sector as a whole.128
A HRBA is underpinned by five key human rights principles:129

Participation: older persons in receipt of care should be able to participate in all decisions about the care they are receiving, including through supported participation, if required.

Accountability and Transparency of duty-bearers to rights-holders: those involved in the provision, commissioning and policy-making of LTC have a responsibility to ensure that the standards of accountability are clear and accessible providing effective remedies when breaches do occur.

Non-discrimination and equality: older persons have different identities based on their gender, ethnicity, religion and many other grounds. Each of these identities should be respected when receiving care and support services. Gender was identified as requiring particular attention in LTC policies, given the high representation of women among both residents and care workers.

Empowerment of rights holders: all older persons in receipt of care should understand what their rights are and how they can claim these rights. Achieving this may require the provision of appropriate advocacy or other communication support. Facility for older persons to organise collectively can provide an important mechanism for empowerment.

Legality – public authorities and care providers must be sure that their practices and procedures are grounded in human rights law and must not breach the human rights of anyone. If breaches do occur these should be addressed through legal means.

A HRBA to LTC means all existing and new policies and legislation needs to be checked for human rights compliance. ENNHRI advocates compliance with Article 12 of the CRPD, namely, replacing substituted decision-making arrangements with supported decision-making where relevant. We also encourage all European governments to develop a National Positive Ageing Strategy, underpinned by a HRBA. ENNHRI is currently developing a toolkit for policy-makers and for care-providers to help them move to a HRBA to LTC.
6.2 Participation of Older Persons

Policy makers and service providers should take steps to ensure the participation of older persons in the design and delivery of LTC

Including the voice of older persons in the design of LTC policies is essential in order to understand their needs and expectations, and ensure the individual right to choice and autonomy. Older persons’ participation will also help avoid the wasting of resources, as investment in the sector will respond directly to the needs of the end user. This approach also ensures that the voice of an important group in our society is valued.

In concrete terms, ensuring the participation of older persons means ensuring their input into service planning at all levels in a meaningful way – national and regional policies, in the care home and in their daily lives. Beyond, integrating coherent and easily accessible complaint and redress mechanisms into policies is crucial to address and process problematic practices and systematic or institutional flaws. It is also important to consider the specific needs of older persons with disabilities, such as dementia, so that they also have a voice. The NHRI monitoring teams used some innovative techniques to interview residents with dementia, some of which have been documented by ENNHRI.130

6.3 Access to Justice and Effective Remedy

Older persons in LTC must be provided with the means to access justice and effective remedy.

Access to justice is a key human right often not realised due to a lack of information on and support in accessing existent mechanisms and their functioning. It is often understood as having a case heard expeditiously in a court of law, and in practice largely refers to access to free legal aid and to a fair trial, but can also be achieved or supported more broadly through mechanisms such as National Human Rights Institutions, Equality Bodies and Ombudsman institutions, as well as the European Ombudsman at EU level. At a more practical level, care providers have obligations to provide their residents with an organised and formal complaints mechanism, as outlined in Section 4.2.12.

As we found evidence of structural problems in accessing and functioning of complaint mechanisms, we wish to highlight that available mechanisms need to be accessible to older persons who should feel comfortable and supported when needing to bring a complaint, being provided with assistance and/or peer-to-peer support services to help tackling underreported abuses.

130 ENNHRI, forthcoming, op cit.
European states should invest in LTC, as an investment in our society and in Europe’s future

Financial pressures notwithstanding, European states should invest in LTC in order to meet their human rights obligations towards older persons. In addition, we recommend that EU funding continue to be used in particular to support Central and Eastern European countries, bearing in mind the implications of the EU’s ratification of the CRPD. In the light of today’s demographic patterns, establishing sustainable LTC systems of high quality involves investing in a fast growing sector with huge potential for development in terms of demand, accessibility, employment opportunities, entertainment branches and health care programmes.

Greater financial investment in the sector is especially needed to ensure the availability of LTC, where a low staff ratio could place older persons’ human rights at risk. As noted earlier, the European Commission’s proposal for a Carers Directive may need to be complemented with a push for greater resources into the LTC sector in order to ensure that the systemic gender bias is not exacerbated. Indeed, a coherent investment strategy, combining financial and social investment, can help to create a healthier and more sustainable working environment for care workers including better wages, which in turn can attract more young professionals into the sector. Investment in the LTC sector could ultimately serve the objective of enhancing labour opportunities across Europe.131

Beyond, investing in high quality care which is firmly grounded in human rights helps to (re)build trust in the care system and 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 fulfil its obligation in relation to de-institutionalisation, by supporting sustainable alternatives to residential LTC.

6.5 Monitoring the Human Rights of Older Persons

European states should facilitate the ongoing monitoring of the human rights situation of older persons in LTC

As long-term care has become more pervasive, ensuring its quality has become an ever-pressing issue for local, regional, and national policy-makers. In conjunction, recent reports of poor conditions, neglect and abuse, and medical errors in long-term care facilities, particularly nursing homes, have captured national and EU-level attention. In order to ensure compliance with human rights standards, it is essential to monitor residential and home care services on a continuous basis. Monitoring on an ongoing basis can contribute to identifying factors that constitute a risk that inhuman treatment may occur and which require action. Currently, few EU Member States have continuous quality monitoring systems by independent regulators, particularly in which human rights are taken into account.

Preventive monitoring

Within the EU, LTC provision is a Member State’s responsibility as a strand of social protection. As such, the European Commission has no mandate to introduce legally binding minimum quality standards in the LTC sector. Instead, under the OMC, the European Commission operates a framework to promote the sharing of experience and best practice, thus supporting Member States in their efforts to reform health care and long-term care. However, the European Commission does have the capacity to set objectives, or minimum standards, to ensure the availability of high quality, affordable long-term care services. Much preparatory work and good practice already exists in this area. For example, the European Quality Framework for Long-term Care Services,132 based on the European Quality Framework for Social Services,133 set out principles and guidelines for the wellbeing and dignity of older people in need of care and assistance.

The traffic light system devised by the Scottish Human Rights Commission within a HRBA to LTC also offers a user-friendly way of assessing policies and practices according to their compliance with human rights standards. Many independent health and social care service regulatory bodies throughout Europe, including the Care Quality Commission in the UK and the Health Information and Quality Authority in Ireland inspect long-term care services against standards underpinned by a human rights framework. NHRIs can also monitor the situation on the ground, through visits to care homes, interviews, focus groups and other means. Some NHRIs have a mandate to enter nursing homes without prior authorisation or permission in order to monitor the human rights situation, including under OP CAT.

Traffic Light assessment Tool:

- **Red**
  - policy/ practice is not human rights compliant
- **Amber**
  - policy/ practice has significant risk of non-compliance
- **Green**
  - policy/ practice is human rights compliant

Responding to incidents

NHRIs with a complaint handling function review patterns in complaints received and may be able to recommend redress. Elsewhere, NHRIs cooperate with the independent health and social care services regulator to ensure a human rights-based approach to the regulatory system.

Monitoring provides input for policy assessment

Further, NHRIs review compliance of national and local laws, policies and practice with human rights standards.

Monitoring can also help promote older persons’ human rights, through proving an evidence base to raise awareness among the public and policymakers. Through a more detailed understanding of the situation of older persons in LTC, policy makers can also provide more creative, relevant and impactful solutions to challenges faced. Regular monitoring, involving a baseline and indicators, enables states to gauge the impacts of its policies and measure improvements over time.

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Monitoring provides input for training and awareness-raising

NHRIs also use the information collected through their monitoring activities to inform their awareness-raising and training activities, in order to promote a culture of rights and understanding among a wide variety of actors of the human rights situation.

6.6 Awareness Raising and Training on Human Rights

Regional mechanisms, European states and local authorities should provide awareness raising and training on the human rights of older persons in LTC

Training on human rights for policy-makers, care workers and managers is an essential component of an effective protection of human rights of older persons. Increasing awareness of human rights obligations and practices compliant with human rights standards enables policy-makers and care workers to take human rights into account throughout the design, organisation and delivery of care on a daily basis. In particular, we recommend training for policy-makers and care workers on Article 8 of the ECHR (the right to respect for private and family life, home and correspondence), which our findings showed to have been at issue in many instances, given its wide scope in protecting the right to respect for one's dignity and personal autonomy, and the right to respect for social relationships.

The pilot group found much evidence of a lack of understanding of the human rights of older persons in LTC. It is difficult to ensure the respect of older persons' human rights without understanding what they are, how they are applied in a LTC context, and where to find further information and support.

Older persons and their families should also be aware of their rights so that they can speak out in case of abuse. Finally, the public as a whole should be aware of the human rights situation and perspectives of older persons across European societies. Shining a light on the lived experience of this important and growing section of our society will help us to understand the challenges and to take responsibility for ensuring that older persons in LTC in Europe can live in dignity.

Sharing good practices across European states can support capacity building initiatives, as can working in partnerships with actors who have expertise in the human rights of older persons in LTC, such as NHRIs, civil society organisations or international human rights organisations.
6.7 Towards a Convention on the Rights of Older Persons

European states and the EU are encouraged to support a stronger protection framework for the rights of older persons, including implementation of existing standards and a convention on the rights of older persons to address the gaps and fragmentation in current texts.

As this study has shown, a wide variety of actors have insufficient understanding of the human rights of older persons in LTC. Indeed, older persons’ human rights are scattered throughout a number of human rights conventions, and are not collated into one binding instrument. Although the rights of many older persons in need of LTC are addressed through the CRPD, there are significant gaps including the right to LTC, age discrimination, neglect, breach of autonomy and the application of human rights to end-of-life and palliative care. Moreover, the CRPD does not adequately address the unique situation of older persons with LTC needs.

Therefore, this research supports need for a specific binding instrument to address the particular human rights challenges older persons face, as recommended by the UN’s Independent Expert on the enjoyment of all human rights by older persons. A convention on the rights of older persons would enumerate all relevant rights in one place, which would boost accessibility and understanding, as the CRPD did for persons with disabilities. Further, it would raise visibility and accountability of older persons’ human rights. Indeed, reporting on the implementation of such a convention would assist states in understanding the extent to which they are complying with human rights standards and which actions might be required to improve implementation.

Such a convention would also provide guidelines for care workers and policy-makers who design and deliver LTC policies. Fundamentally, it would provide older persons with a clearer route for redress where they believe their human rights have been violated. A convention enshrining the rights of older persons would therefore serve as a powerful instrument to clearly define and protect older persons’ human rights.

With or without a Convention on the Rights of Older Persons, all actors should act to ensure the implementation of human rights standards and work towards the fulfilment of human rights for older persons in or seeking LTC throughout Europe.

Annexes
# Annex 1

## Membership of the Project’s Advisory Group

<table>
<thead>
<tr>
<th>Organization</th>
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<tbody>
<tr>
<td>AGE Platform Europe</td>
</tr>
<tr>
<td>(Unia) Belgian Interfederal Centre for Equal Opportunities</td>
</tr>
<tr>
<td>Commissioner for Human Rights Ukraine</td>
</tr>
<tr>
<td>Council of Europe</td>
</tr>
<tr>
<td>ENNHRI Secretariat</td>
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<tr>
<td>Equality and Human Rights Commission UK</td>
</tr>
<tr>
<td>European Commission, DG EMPL</td>
</tr>
<tr>
<td>European Commission, DG JUST</td>
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<tr>
<td>European Union Agency for Fundamental Rights (FRA)</td>
</tr>
<tr>
<td>Finnish NHRI: Human Rights Centre</td>
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<tr>
<td>German Institute for Human Rights</td>
</tr>
<tr>
<td>Greek National Commission for Human Rights</td>
</tr>
<tr>
<td>Human Rights Defender Institution of the Republic of Armenia</td>
</tr>
<tr>
<td>Institution of Human Rights Ombudsmen of Bosnia &amp; Herzegovina</td>
</tr>
<tr>
<td>Irish Human Rights and Equality Commission</td>
</tr>
<tr>
<td>National Human Rights Institution of Norway</td>
</tr>
<tr>
<td>Netherlands Institute for Human Rights</td>
</tr>
<tr>
<td>Northern Ireland Human Rights Commission</td>
</tr>
<tr>
<td>Office for the Commissioner of Fundamental Rights Hungary</td>
</tr>
<tr>
<td>Office of Public Defender (Ombudsman) of Georgia</td>
</tr>
<tr>
<td>OHCHR</td>
</tr>
<tr>
<td>Ombudsman of the Republic of Croatia</td>
</tr>
<tr>
<td>Protector of Citizens - Ombudsman of Serbia</td>
</tr>
<tr>
<td>Romanian Institute for Human Rights</td>
</tr>
<tr>
<td>Scottish Human Rights Commission</td>
</tr>
<tr>
<td>Slovak National Centre for Human Rights</td>
</tr>
<tr>
<td>The Seimas Ombudsmen’s Office of the Republic of Lithuania</td>
</tr>
<tr>
<td>National Preventive Mechanism</td>
</tr>
<tr>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>United Nations Open-Ended Working Group on Ageing</td>
</tr>
<tr>
<td>Optional Protocol to the Convention Against Torture</td>
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<tr>
<td>Revised European Social Charter</td>
</tr>
<tr>
<td>Special (Dementia) Care Unit</td>
</tr>
<tr>
<td>Social Protection Committee</td>
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<tr>
<td>United Nations</td>
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<tr>
<td>Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>United Nations Principles for Older Persons</td>
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</tbody>
</table>
Annex 2
Methodology

The first stage in the process was the selection of the pilot group conducting the monitoring work. The following criteria were used to make the final selection of the pilot group (see Table A2.1).

- LTC system in Europe:
  - Regional diversity
  - NHRI Characteristics:
    - Type of institution – Commissions / Institutes and Ombuds.
    - Accreditation status and independence
    - Functional effectiveness
    - Expertise and need for capacity building (some of each)
  - Mandate: NPM/ non-NPM

Applying these criteria, the six members that volunteered to take part in the pilot group were selected, namely: the NHRI of Belgium, Croatia, Germany, Hungary, Lithuania and Romania.

Methodological guidelines for the pilot monitoring work were drawn up by ENNHRI’s Secretariat, based on approaches previously used by ENNHRI members and other human rights organisations, and with input from the Advisory Group. The methodology for the current study was framed using the Structure-Process-Outcomes approach, which ensures that the wider context is examined and understood in assessing the implementation of human rights obligations.

Table A2.1: Pilot Group Characteristics

<table>
<thead>
<tr>
<th>Type of Institution</th>
<th>Accreditation Status</th>
<th>Mandate</th>
<th>Previous expertise in LTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belgium Centre</td>
<td>B (previous)</td>
<td>Non-NPM</td>
<td>Research, awareness raising and training</td>
</tr>
<tr>
<td>Croatia Ombuds</td>
<td>A*</td>
<td>NPM</td>
<td>Complaints handling</td>
</tr>
<tr>
<td>Germany Institute</td>
<td>A*</td>
<td>Non-NPM</td>
<td>Research</td>
</tr>
<tr>
<td>Hungary Commission</td>
<td>A*</td>
<td>NPM</td>
<td>Complaints handling</td>
</tr>
<tr>
<td>Lithuania Ombuds</td>
<td>A*</td>
<td>NPM</td>
<td>Complaints handling</td>
</tr>
<tr>
<td>Romania Institute</td>
<td>Seeking accreditation</td>
<td>Non-NPM</td>
<td>Research, awareness raising and training</td>
</tr>
</tbody>
</table>

* Granted A status in April 2017
This approach involved examining the following aspects of the LTC sector:

- Structures: Macro-level policies (formal and informal) and legislation deemed necessary for facilitating realisation of a human right, as well as staffing ratios, qualifications of staff and type of ownership (micro level).
- Processes: The budget available for LTC, as well as programmes and regulations governing the sector. At the micro-level, process measures broadly consist of all of the activities carried out by care staff to deliver services that have an impact on human rights outcomes.
- Outcomes: Outcome indicators capture attainments, individual and collective, that reflect the status of realisation of human rights in a given context. At the macro-level, this would include any findings measuring the level of satisfaction of older persons living in care that their rights are protected, the number of reported cases of abuse or rights violations within the LTC sector and the length of waiting lists to access care. At the micro-level, it involves capturing residents’ level of satisfaction that their rights are adequately protected.

In line with this approach, each NHRI was asked to complete three main activities in order to gain insights into the extent to which human rights are taken into account in policy formation (macro level) and service delivery (at the micro level) of LTC:

1. A review of legislation, policies, jurisprudence, recommendations and complaints received (where applicable);
2. Monitoring visits of a minimum of four residential care homes, selected according to the criteria of ownership (public/private/voluntary), size (small, large), location (urban and rural homes);
3. Interviews with relevant target groups (residents, family members) and stakeholders.

The pilot NHRI were also asked to include the voice of older persons and were given suggestions on how to do this. NHRI were also asked to adhere to the code of conduct set out by the UN in carrying out their monitoring work and to consider the ethical considerations of the monitoring work, including in particular obtaining consent from study participants, including in particular older persons themselves and for accessing any documents related to their care.

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139 See table A2.3
Selection of Care Homes

Three NHRIs conducting the pilot monitoring work (NHRIs of Croatia, Hungary and Lithuania) hold the mandate of National Preventive Mechanism (NPM), the national component of the preventive system established under the UN’s Option Protocol of the Convention against Torture (CAT). NPMs are mandated to conduct regular visits to all institutions, statutory and non-statutory, where persons may be deprived of their liberty. This includes psychiatric institutions and care settings for children, persons with disabilities and older persons in receipt of LTC, where individuals may be placed without their consent, or have their liberty deprived in other ways. The purpose of the visits is to strengthen the protection of these persons against torture and other cruel, inhuman or degrading treatment or punishment.\(^{142}\)

NPMs do not need to obtain permission or give prior notice to these institutions prior to the visit. Care homes monitored in Croatia were selected at random. In Lithuania, all care homes in a specific region were first asked to complete a questionnaire, giving the NHRI some prior information. Care homes were then selected at random. In just one case in Hungary, the NHRI selected a care home after an individual had registered a complaint about the operation of the institutions. Although the NPM mandate allows any care home to be visited, the lack of opportunity for warning also limited the NHRIs’ access to potential respondents, particularly family members, who may have made an effort to be present if given advance notice.

Monitoring NHRIs in Belgium, Germany and Romania do not have the NPM mandate.\(^ {143}\) This meant that care homes in each jurisdiction could refuse to take part in the study. Each NHRI used a similar (non-purposive) strategy to access care homes, making contact with care providers’ associations and asking them to notify their members about the study; making contact with care homes directly through established databases and networking through established contacts. This led to the recruitment of care homes that were, on the whole, interested in the area of human rights, sought to provide high quality care using a human rights-based approach and wanted opportunities to develop good practices to a greater extent. Directors of several of the care homes monitored made efforts to facilitate the monitoring NHRIs to conduct interviews and focus groups with staff and residents in private.

Moreover, the voluntary nature of their involvement, and willingness to learn from the outcomes of the monitoring work, helped to establish an atmosphere of collegiality and cooperation with the monitoring NHRI. However, the low response rate (approximately 16%) means that the findings from these visits should not be taken as representative of the standard of care or of human rights protection within the LTC sector within the three jurisdictions. Indeed, findings from the project would suggest that the vast majority of care homes monitored in Belgium and Germany pay more attention to human rights protection than the average care home in their jurisdictions.

Each monitoring NHRI was asked to carry out monitoring visits to a minimum of four care homes, though some visited more than this, in order to ensure variation in the care homes visited. The smallest home visited accommodated 36 residents, while the largest catered for more than 400. Homes visited were located in cities, towns and remote, rural areas and varied in ownership (see Table A2.2 below).

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142 Office of the UN High Commissioner for Human Rights: Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or punishment. New York, December 2002. (http://www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx)

143 Belgium has yet to ratify the OPCAT, while the NPM function rests with a different body in Germany - The Federal Agency for the Prevention of Torture and the Join Commission of the Lander; and the People’s Advocate respectively.
Almost all NHRIs preceded the visits to the care homes with focus groups or interviews with policy-makers or experts in order to further develop their understanding of the sector (see Table A2.3). Monitoring NHRIs teams in all six countries were small, ranging approximately from two to five people within each NHRI. In some instances, just one staff member completed a monitoring visit alone. Visits lasted two days on average.

Table A2.2: Selection Criteria for Site Visits

<table>
<thead>
<tr>
<th></th>
<th>Public</th>
<th>Private (for profit)</th>
<th>Private (not for profit)</th>
<th>Total</th>
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<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Germany</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Hungary</td>
<td>2</td>
<td></td>
<td>2</td>
<td>4</td>
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<tr>
<td>Lithuania</td>
<td>5</td>
<td></td>
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<td>8</td>
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<td>Romania</td>
<td>6</td>
<td></td>
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<tr>
<td>Total</td>
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<td>2</td>
<td>11</td>
<td>39</td>
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Table A2.3: Target groups, right holders and stakeholders consulted

<table>
<thead>
<tr>
<th></th>
<th>Residents</th>
<th>Family members</th>
<th>Staff/Management</th>
<th>Policy Makers</th>
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<tbody>
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<td>19</td>
<td>69</td>
<td></td>
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<td>20</td>
<td>2</td>
<td>40</td>
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<tr>
<td>Germany</td>
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<td>3</td>
<td>27</td>
<td>3</td>
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<td>Romania</td>
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<td>1</td>
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<tr>
<td>Total</td>
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<td>31</td>
<td>193</td>
<td>23</td>
<td>603</td>
</tr>
</tbody>
</table>

*In Lithuania, all care homes in a specific region completed a questionnaire providing beforehand information to the NHRI.*
Belgium

The origins of the Belgian health insurance system can be traced to the late 19th century, when workers created mutual benefit societies to protect affiliated members against the risk of disease, unemployment and incapacity for work. At the beginning of the 20th century, the sickness funds were then grouped into national associations according to their political or ideological bent (religious, socialist, liberal, etc.). The Belgian health insurance system has gradually evolved towards universal coverage.

While formal LTC has been available in Belgium for over 200 years, thanks to religious groups, LTC services still operate on the principle of subsidiarity, with the family having primary responsibility to care for their older relatives. It is estimated that almost 10% of persons aged 15 or over provide informal care. However, formal LTC services comprise home care and community services, short-term and long-term residential care and hospital care, with high levels of coverage. The focus of formal services is to retain the independence and autonomy of individuals to the best of their ability. Access to all services is determined on the basis of need. In recent years, there has been a concerted effort to replace residential care with home-based services. A national strategy was adopted to assist the shift.

In recent years, responsibility for LTC has transferred from the federal government to the regions, which has emphasised some differences in care outcomes. Thus, while Belgians express satisfaction with the organisation of LTC generally, the overall adequacy of service provision masks some regional imbalances, including rather substantial waiting times in Walloon residential care homes.

In 2014, the CRPD Committee expressed concerns over the high rate of referral to institutional care for persons with disabilities in Belgium and the lack of de-institutionalisation plans.


Ibid.
Croatia's social health insurance system is based on the principles of solidarity and reciprocity, by which citizens are expected to contribute according to their ability to pay and receive basic health care services according to their needs. In Croatia, although there was a general shift towards privatization in the early 1990s, the state increased its control of the health sector during that time.

The Croatian Health Insurance Fund (CHIF) was established in 1993 to facilitate this goal, providing universal health insurance coverage to the whole population, with varying rates of co-payment for services. However, access to funding for LTC services was not possible through the CHIF. Instead, LTC was, and continues to be, organised on the principle of subsidiarity, with families providing much of the care on an informal basis, with little support in place for the care they provided. The 2013 Social Care Act includes provisions on generational solidarity, the objectives of which are to keep the elderly in their own homes and with their family; promote their social inclusion; and improve their quality of life by developing and expanding non-institutional services and volunteering.147

Formal LTC for those with intensive, LTC needs is provided largely through residential care, which developed in Croatia largely after 2000. The price of statutory residential services is determined by the Minister for Social Welfare, while private providers can set their own prices. Co-payments for residential care are generally high. However, financial support is available from the State in the event that they cannot bear the costs. Extra-institutional forms of accommodation for older people are also available within family-type homes and foster families.

A social care home or other service provider has to meet minimum requirements for provision of social services, i.e. it has to be licensed. Minimum requirements are set in the Rulebook on Minimum Requirements for Provision of Social Services that sets minimum requirements in terms of space and equipment for service provision; minimum scope and nature of a structure and duration of direct interaction with beneficiaries; structure and duration of other activities; and requirements and minimum number of professional and other staff for a given service. However, care homes are not inspected for assessing their compliance with the regulations.

There is a considerable coverage gap regarding the estimated number of dependent people and those who have actually received some type of care and the shortages of formal services in institutionalized context. Waiting lists for county nursing homes are long, while private providers are financially unaffordable for many. This will likely increase the demand for institutionalized types of care and may also increase the burden borne by family carers.148 However, the evidence is clear that LTC services for the disabled and the elderly are beginning to be de-institutionalised.

In 2015, the CRPD Committee commended Croatia on several National Plans, including a Plan for Deinstitutionalization and Transformation of Social Welfare Homes [...] and legal measures to abolish legal guardianship, though it encouraged Croatia to work more rapidly towards its goal of de-institutionalisation.149

147 Živković, I, and Vajagić, M: LTC – the problem of sustainable financing. LTC in Croatia. Peer Review in Social Protection and Social Inclusion programme coordinated by ÖSB Consulting, the Institute for Employment Studies (IES) and Applica, Ljubljana, November 2014. (ec.europa.eu/social/BlobServlet?docId=13217&langId=en)
Germany

The German state has a long history of providing welfare services to its citizens. In the 1840s, Germany’s then Chancellor Otto von Bismarck introduced an old-age pension, and mandatory health insurance (for approximately 10% of the population) in order to prevent unrest and secure political support. Over the course of a century, this system evolved to provide universal health coverage.150

Yet until 1994, LTC in Germany was predominately the task of the family. In 1995, the German long term care insurance system (LTCI) was introduced as the fifth pillar of the social security system to make financial provision for the risk of care a necessity. Financed through salary deductions of the working population, the LTCI system covers almost the entire population, contributing to the costs of home/residential care. The amount of the fee is based on the contribution rate and the assessable income of the members.151

In 2008, the system was reformed to provide tangible and concrete improvements for individuals requiring LTC. This included strengthening and developing home-based care, by providing additional support services to family caregivers; improve the quality of services; and extend services for individuals with dementia.

Overall, the system is world famous as one of only four countries with a dedicated insurance system for LTC. The spreading of the “risk” of needing care through the entire population has ensured a well-developed system with high coverage and a wide range of high quality services. However, the LTC scheme does not cover all costs; co-payments can be substantial, up to 30% of expenditure. There are concerns that the system may not be sustainable in the long term; at the moment, the system works well because the size of the labour force favours well compared with current users. However, as the population aged 65+ begins to outstrip the working age population, the ratio of recipients to non-recipients will rise, putting more pressure on the system.

In 2007, the German government funded a grassroots initiative to develop a Charter of Rights for People in Need of LTC and Assistance. In 2011, a demography strategy was launched to develop inter alia a long-term strategic approach for older persons to self-determined ageing.

At the same time, challenges remain.152 In 2011, the CESCR noted “with deep concern that the State party has not taken sufficient measures to improve the situation of older persons in nursing homes who reportedly live in inhuman conditions and continue to receive inappropriate care due to a shortage of qualified personnel and inadequate application of standards of care (art. 12)”.153 This perhaps highlights the challenges facing States in realising human rights, even with well-developed policies and the investment of significant financial resources.

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151 The membership rate for the long term care was raised on 1 July 2008 by 0.25% so the care rate rose from 1.7% to 1.95%. For people without children, the nursing care rate rise up to 2.2% of gross salary. The higher care premiums should be sufficient to 2014. After that, the maintenance care rates should adjust for price increases every 3 years.
Hungary

Hungary has a long-standing tradition of health services dating back to the infirmaries established and run by monasteries beginning in the eleventh century. A landmark in the development of mandatory social health insurance (SHI) was Act XIV of 1891, which made such insurance compulsory for industrial workers and provided for guaranteed benefits-in-kind and cash benefits. This Act was the third of its kind in Europe, following similar legislation in Germany in 1883 and in Austria in 1887, though provision was often complex and challenging. However, the emphasis on statutory welfare in Hungary contrasts with the principle of subsidiarity and the responsibility placed on families to provide care in many other CEE countries.

After more than 40 years within the sphere of influence of the USSR (since 1949), Hungary regained its full sovereignty and declared itself an independent republic on 23 October 1989. LTC was provided to older persons in Hungary prior to independence, largely in residential settings, but were limited to individuals who had no family members to care for them. Yet, at the same time, Hungary had a higher than (CEE) average availability of home care, servicing up to 4% of the 65+ population.

Following independence in 1989, a mixed welfare system was adopted, which included universal social health care and a contributory pension system. The Social Welfare Act of 1993 made it mandatory for local authorities to provide home care (for a maximum of 4 hours a day) and meals for persons over 60 in a normative-based financing system, though small towns and disadvantaged regions were unable to meet the requirements and provide basic services.154 Economic challenges throughout the 1990s led to retrenchment in the healthcare system, with cost-saving measures and high co-payments for healthcare services.155 Since 2000, more emphasis has been put on healthcare planning, with an expansion of privatised services.

Austerity measures in 2008 tightened the conditions for older persons to access residential care and reduced the coverage of community-based care services. By 2012 the formal care system was struggling with serious problems of quantity and quality. The Fundamental Law (Constitution) of 2011 further exacerbated the trend of shifting the burden of care to the families by enjoining the duty of caregiving on them. In 2015, the threshold score in the system of rating the state of physical and mental health was raised, thereby pushing home care in the direction of nursing without providing the necessary resources, and simply leaving families to shoulder a new care task.156 As a result, Hungary has shifted over the last few years to the position of many other CEE states, with a high burden on family members to care for older relatives.

Data on the quality of LTC services in Hungary are limited, though some indicators suggest that the average quality of the infrastructure in residential homes is rather low: 75% of rooms serve three or more clients and have no separate bathroom.157

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156 Ibid.
Lithuania

Between 1918 and 1940, a health system based on the Bismarck model started to develop in Lithuania. During the country’s incorporation into the USSR, health care was organized according to the Semashko system. The system was hierarchical, centrally funded and planned. Following the restoration of independence in 1990, efforts were made to decentralise health services, and a limited health insurance scheme was introduced, eventually expanded to the entire population in 1997. In the late 2000s, the economic crisis and the need to reduce the public deficit affected public spending, including on health care, leading to a reduction in health service provision and higher co-payments.

Until 1990, LTC services for older persons was mainly undertaken by family members, with a limited availability of residential care services. The focus on residential care continued after independence (in 1990). After 1996, many small rural hospitals were transformed into nursing facilities. The development of LTC is a huge challenge resulting from demographic changes and the ageing tendencies of the population. Nowadays, the capacity of LTC homes in both the health and social care sectors is estimated at 2.5 places per 10,000 persons, which is far less than the growing need and far below the average of the EU-15.²⁵⁸

According to the Social Report 2007-2008 (Ministry of Social Security and Labour, 2009), the orientation in LTC provision is shifting from institutional care towards home-based care. The aim of the reform of 2002 was to reorganize social services in such a way as to establish the legal, administrative and financial premises to enable social service provision in a community.¹⁵⁹ However, LTC in Lithuania still operates on the principle of subsidiarity, though home care services have recently been prioritised for development. LTC services have been regulated by Social Care Standards since 2008, with inspections overseen by central government.

In 2016, the CRPD Committee expressed concerns over the deprivation of liberty of persons with disabilities and at the lack of sufficient choice and range of adequate support mechanisms, including independent living schemes, to ensure that persons with disabilities regardless of sex, age or impairment can access accommodation within their local community.

²⁵⁹ Ibid.
Romania

Romania has had a long tradition of organised health care. Between the First and the Second World Wars, there was a social insurance system based on the Bismarckian sick-fund model. Workers from industrial enterprises, merchants, employers and their families, and the self-employed, were insured; an income-related premium was paid in equal proportions by employers and employees. However, at the time, the insured represented only 5% of the population.

The Semashko health care system in pre-1989 Romania was limited to an institutionalized aid for older persons, persons with disabilities, chronically or psychically ill persons, and children in special situations, which failed to provide a decent living standard. It left little or no choice to the user but seeking to achieve a high level of equity. The legacy of Semashko system has been reflected in the relatively small proportion of GDP dedicated to health care, poor coverage, and poor quality of healthcare services.

Prior to 1990, residential care services for older persons existed but were fragmented, with family members primarily taking responsibility for the LTC of older persons. It was only in 2000 that care for older persons was explicitly addressed in social assistance reform, seeking to move from a medical model of care to a social care approach. Cash benefits are available for informal carers, but are limited.160

Currently, Romania has a major shortage of residential care services. Policies seek to promote home-based care services, the most commonly used care option for dependent elderly people because of the comfort the family provides and the reduced (direct) costs as compared to institutionalised care. Provision by NGOs has risen in recent years, though, due to limited accessibility and financial resources, there are inequalities in geographical distribution and in the number of LTC services, leading to long waiting lists. Much of the cost of residential care is borne by the public purse, though every person in receipt of care in an elderly home must contribute a monthly amount of up to 60% of their monthly income, without exceeding the monthly maintenance costs set for every nursing home. If there is a gap between the amount requested and the amount paid by the beneficiary, that difference must be covered by the family or the legal guardian of the family if their monthly income is above 150 euro/month/family member (600 RON).161

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