



European Network of
National Human Rights Institutions

Respect My Rights

An ENNHRI Toolkit on Applying
a Human Rights-Based Approach
to Long-term Care for Older Persons

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Foreword

All of us can recall positive moments, when someone you know defied every stereotype and continued to engage with the world as though their age really was no more than a number. Newspapers recently reported of a Missouri woman who celebrated her 70th birthday by running 7 marathons in 7 days.

But for every skydiver and poet and author and gardener, there are possibly tens, if not hundreds of other people of similar age whose lives are far from fulfilled or happy or free from loneliness or from physical pain. Increasing frailty or cognitive impairment can reduce the independence that we each crave, that we each need. The decision to accept long-term care, as well as its delivery, can also reduce autonomy.

Human rights ultimately seek to guarantee respect for our autonomy, dignity and identity. They guarantee our right to take part in decisions affecting our daily lives and our rights to get fair and equal treatment by public authorities and those acting on their behalf.

However, human rights obligations are not always easy to uphold. As research by ENNHRI has shown, providers of long-term care often face staffing and resource shortages due to factors outside of their control. At the same time, some basic knowledge of human rights, and a human rights-based approach can help care staff understand how to make decisions that respect the rights and wishes of each individual in their care.

This toolkit provides valuable guidance to care providers not just in understanding their human rights obligations, but in how to implement a human rights-based approach and introduce good practices in all areas of the care homes' work.

Congratulations to ENNHRI for the great work.

Nils Muižnieks

Commissioner for Human Rights
of the Council of Europe



List of Acronyms

CoE	Council of Europe
CRPD	UN Convention on the Rights of Persons with Disabilities
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
ENNHRI	European Network of National Human Rights Institution
EPSCO	EU Employment, Social Policy, Health and Consumer Affairs Council
FAIR	Human Rights-Based Approach to Decision-making, which involves considering the Facts, Analysing the rights at stake, Identifying the responsibilities and Reviewing actions.
GP	General Practitioner/Family Doctor
HRBA	Human Rights-Based Approach
ICESCR	UN International Covenant for Economic, Social and Cultural Rights
LTC	Long-term Care
OECD	Organisation for Economic Co-operation and Development
OPCAT	Optional Protocol to the UN Convention Against Torture
NHRI	National Human Rights Institution
NPM	National Preventive Mechanism
PANEL	Principles underpinning a HRBA: Participation; Accountability; Non-Discrimination and Equality; Empowerment and Legality.
UN	United Nations

Executive Summary

Introduction

This toolkit aims to help policy-makers and care providers throughout Europe to understand their human rights obligations to older persons seeking and in receipt of long-term care (LTC) by demystifying human rights and how to apply them in policy and practices. The toolkit draws on monitoring work of the human rights situation in the LTC sector carried out by six members of ENNHRI in 2016 by providing solutions to the most common human rights concerns.

Human-Rights Based Approach

A human rights-based approach (HRBA) to service delivery is a model that places the principles and standards of human rights at the centre of all aspects of service planning, policy and practice. A HRBA involves five key values being brought to bear on a particular issue: participation, accountability and transparency, non-discrimination and equality, empowerment of rights holders and legality, the PANEL principles. It is a useful and effective way of helping policy-makers and care providers to meet their human rights obligations and has many benefits for staff and service users alike, with the potential to save resources through better health-related outcomes, reduced staff turnover and critical incident rates.

Implementing a HRBA in Long-term Care Settings

Implementing a HRBA within a care setting has three stages: planning, implementation and continuous monitoring and improvement, all focused on ensuring that policies and practices are human rights compliant. Human rights training for care staff, formal and informal input from residents into decisions affecting their own care and the running of the care home and prioritising dignity will go a long way to implementing a HRBA.

Supporting a HRBA: European and National Policies

The adoption of a HRBA within LTC settings requires a supportive institutional and policy framework. Policies supporting a HRBA should reflect states' human rights obligations in relation to health and social care. A co-ordinated HRBA to LTC should focus on education and awareness-raising of all stakeholders within the sector, clear, practical guidelines for service providers and the empowerment of and support for service-users. States should also monitor compliance of service provision against relevant human rights indicators and put in place an independent regulatory system to ensure human rights are upheld.



Introduction

Introduction



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You don't stop laughing when you grow old, you grow old when you stop laughing.

*George Bernard Shaw,
Irish playwright*

Croatia, Germany, Hungary, Lithuania and Romania. The monitoring work was carried out in care homes over the course of 2015 – 2016 by the NHRI in each jurisdiction.

The monitoring work showed that most care workers instinctively used a person-centred approach to inform their work. However, several practices raised concerns, particularly upholding dignity, the right to privacy, autonomy, participation and access to justice. Workers in all care homes also faced daily challenges and dilemmas about how to uphold the rights of all residents, particularly how to respect the autonomy of each individual resident while protecting them from harm. The main causes were that care workers, providers and policy-makers were not always sure what their human rights obligations were towards residents, and how to put them into practice, as well as a lack of financial resources.²

This report aims to help policy-makers and care providers throughout Europe understand their human rights obligations to older persons in need of LTC by demystifying human rights and demonstrating how to apply them in LTC policies and in practice within care settings.

Section 2 explains what human rights are, while Section 3 clarifies what a human rights-based approach is and its underlying principles. Section 4 offers guidance on how to support the implementation of a HRBA in the day-to-day operations of a residential care setting. Section 5 helps policy-makers better understand how they can support a HRBA in LTC policy-planning and Section 6 provides a brief summary.

ENNHRI is the European Network of National Human Rights Institutions, comprising 41 National Human Rights Institutions (NHRIs) from wider Europe. NHRIs are state-funded institutions, independent of government, with a broad legislative mandate to promote and protect human rights. They are a key element of a strong and effective national, regional and global human rights framework. ENNHRI supports European NHRIs to be effective on the national level and to promote and protect human rights across wider Europe.

In January 2015, ENNHRI commenced a project on *The Human Rights of Older Persons and Long-term Care*, funded by the European Commission. Running until the end of 2017, the goal of the project is to improve the human rights protection of older persons in long-term care (LTC), with particular emphasis on residential care.¹

One of the key elements of the Project was the monitoring of the current human rights situation of older persons in and seeking LTC in six representative EU Member States: Belgium,

¹ See www.ennhri.org/rights4elders for more details.

² See ENNHRI, 2017, "We have the same rights:" The Human Rights of Older Persons in Long-term Care in Europe, http://ennhri.org/IMG/pdf/ennhri_hr_op_web.pdf



What are Human Rights?

2 What are Human Rights?



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2.1. What are Human Rights?

Human rights reflect the minimum standards necessary for people to live with dignity. All humans share the same rights, regardless of their nationality, place of residence, sex, national/ethnic origin, colour, religion, language, or other status.

The basic objective of human rights is to empower individuals to fulfil their potential by giving them the autonomy to change their own lives, improve their own communities and influence their own futures. At its heart, human rights legislation focuses on ensuring that all individuals have the right to choose and participate in all decisions affecting their lives.

Human rights are wide and varied, including (for example) the right to life, the right to liberty, the right to privacy, the right to freedom of thought and expression, the right to education and to an adequate standard of living.

To deny people their human rights is to challenge their very humanity.

*Nelson Mandela,
South African Politician and Philanthropist*

2.2. How are Human Rights Protected?

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, as well as through domestic human rights legislation. Regional or international mechanisms come into play mainly where the state is deliberately or consistently violating rights.

The Council of Europe's (CoE) *European Convention on Human Rights* (ECHR) is a key human rights treaty in Europe, as CoE Member States have all undertaken to protect the rights therein.

Anyone who feels that they have had their rights infringed by their own government or state can bring a case to the European Court of Human Rights (ECtHR), provided they have exhausted all domestic legal avenues.

At the international level, states have come together to draw up certain agreements on the subject of human rights. These include the nine binding United Nations (UN) human rights conventions.³ Every state that has ratified a UN human rights treaty must report to the relevant UN treaty body on the implementation of the human rights obligations contained within the relevant treaty. Some treaties also allow for individual complaints to the UN body.⁴ 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.

³ UN OHCHR, 2017, The Core International Human Rights Instruments and their monitoring bodies, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx>

⁴ In some cases, this depends on the ratification of an Optional Protocol.

The most recent UN convention, the *Convention on the Rights of Persons with Disabilities* (CRPD), is particularly important for older persons in LTC - between 60-80% of older people living in residential care settings in Europe are thought to have some form of dementia (diagnosed or undiagnosed) while approximately 80% have a form of mild to severe disability. The CRPD provides for the right for all disabled persons to receive the support they need in order to live independently in the community. In other words, all individuals have the right to refuse to live in an institution. The CRPD also firmly endorses the absolute prohibition of detention on the basis of disability.⁵ Similarly, the CRPD Committee has argued that disability alone does not justify the deprivation of legal capacity (i.e. the right to make decisions affecting their lives, including legally recognised ones). Thus, even when a person makes a decision that is considered to have negative consequences or their decision-making skills are considered to be deficient, their legal capacity must continue to be respected.

A body of “soft law” (non-binding voluntary agreements) also guides the treatment of older persons. *The UN’s Principles for Older Persons*,⁶ *the Madrid International Action Plan on Ageing*⁷ and *the Council of Europe’s Recommendation on the Promotion of Human rights of Older Persons*⁸ gives guidance to duty bearers on the rights of older persons and how to implement them.

2.3. Human Rights relevant to LTC

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.⁹

This analysis identified various rights that are particularly important in the context of older persons in LTC, including:

- Access to LTC (Equal access to affordable health services for all persons; choice of LTC setting)

- Right to life
- Freedom from torture, violence and abuse
- Liberty, freedom of movement, including freedom from restraint
- Choice, autonomy, legal capacity and equal recognition before the Law
- Right to dignity
- Right to privacy and family life
- Right to participation and social inclusion
- Freedom of expression, freedom of thought, conscience: beliefs, culture and religion
- Right to highest attainable standard of physical and mental health
- Right to an adequate standard of living
- Equality and non-discrimination
- Access to justice, including the right to an effective remedy and redress¹⁰

The binding human rights conventions do not include an explicit right to LTC. However, the CRPD Committee has confirmed that persons with disabilities have a right to choose where they receive care – in a residential setting or at home.

Either way, persons with disabilities have a right to support to live independently in the community - including personal assistance.

As such, older persons with a disability should not be admitted into residential care against their will.

2.4. Human Rights Obligations

Human rights create both rights holders and duty bearers. Rights holders are all individuals who have entitlements under a particular human rights convention. They are available to all individuals, regardless of nationality or statelessness, and so they apply also to asylum seekers, refugees, migrant workers and other persons who find themselves in a state party’s territory or subject to its jurisdiction.

As states ratify human rights conventions, they are the ‘duty-bearer’ – i.e. they have primary

⁵ CRPD Committee, 2014, Guidelines on Article 14: The right to liberty and security of persons with disabilities, www.ohchr.org/Documents/HRBodies/CRPD/GC/GuidelinesArticle14.doc

⁶ UN Principles for Older Persons, 1991, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

⁷ Madrid International Plan of Action on Ageing, 2002, www.un.org/en/events/pastevents/pdfs/Madrid_plan.pdf

⁸ Council of Europe, Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons, <https://wcd.coe.int/ViewDoc.jsp?id=2162283&>

⁹ ENNHRI, 2017, Human Rights of Older Persons and LTC Project: The Application of International Human Rights Standards to Older Persons in LTC, http://ennhri.org/IMG/pdf/ennhri_application_of_human_rights_to_ltc_feb_2017.pdf.

¹⁰ Annex 1 sets out the conventions providing for each of these rights.

responsibility to uphold them. There are three types of obligations:

- respect (abstain from interfering with the enjoyment of rights)
- protect (prevent infringement by others)
- fulfill (take positive action to facilitate the enjoyment of rights through legislation, administrative measures, or budgetary allocations)

This means that the state (through the government) has a responsibility to ensure all statutory actors (local, regional/federal and national) respect, protect and fulfil human rights. In the area of LTC, this includes policy makers, care home managers, health professionals, care workers, inspectors and parliamentarians. Furthermore, it must that ensure non-state actors (including for example care providers that receive no state funding) still adhere to human rights standards. This includes any organisation, even a privately-owned one, providing LTC services for older persons.

Human rights are often divided into political and civil rights on the one hand and economic, social and cultural rights on the other hand. States have a duty to give immediate effect to civil and political rights (e.g. access to justice, freedom of expression). Some civil and political rights are absolute; the state must never interfere with the enjoyment of this right. This includes the right to protection from torture and inhuman and degrading treatment.

Other rights, qualified rights, require a balance between the rights of the individual and the needs of the wider community or state interest. As such, it is permissible under certain circumstances for duty-bearers to restrict, or allow others to restrict, these human rights, if there is a clear legal basis, provided for in the relevant article of the relevant Convention, with a legitimate aim and a proportionate restriction.¹¹ For example, the right to freedom of expression can be restricted if it incites murder or hatred. The burden of proof is on the individual to establish that there has been an interference with their rights. That burden then shifts, and it is for the State to justify the interference.

In contrast, states generally have a duty to take deliberate, concrete and targeted steps, as “expeditiously and effectively as possible”,¹² towards the full realisation of many economic,

social and cultural rights (e.g. the right to the highest attainable standard of health) according to the maximum of available resources. This is known as the principle of “progressive realisation”. States must be able to prove that they are working as fast as possible using all the resources they have available to them to progressively fulfil the human rights of all individuals in the jurisdiction. The concept of progressive realisation of rights does not justify government inaction on the grounds that a state has not reached a certain level of economic development.

However, no matter what level of resources are at their disposal, governments are obligated to make sure that people in their jurisdiction enjoy at least essential levels of protection of and access to each of their economic, social, and cultural rights. Protection from starvation, primary education, emergency healthcare, and basic housing are among the minimum requirements to live a dignified life and it is the duty of governments to ensure these at all times. Even in cases of economic downturn or other emergency, these core requirements must be guaranteed to everyone.

2.5. Policy-Makers’ and Care Providers’ Human Rights Obligations in LTC in Practice

Many rights are interpreted differently by different treaty bodies and courts, particularly around autonomy. For example, the ECtHR allows for the restriction of rights in limited circumstances, such as to protect the safety of the individual and others, whereas the UN CRPD Committee prioritises an individual’s right to make decisions others may not agree with. As such, along with an understanding of human rights obligations in practice and the human rights relevant to LTC, determining how duty-bearers are complying with their human rights obligations requires an understanding of how human rights bodies interpret binding human rights law in practice. ENNHRI’s report *The Application of International Human Rights Standards to Older Persons in Long-term Care*¹³ provides an overview of the various standards relevant to LTC and how UN treaty bodies and the courts have interpreted them.

¹¹ See Section Four of The Bingham Centre for the Rule of Law, 2012, A Training Manual on International Human Rights Law https://www.biicl.org/files/5930_building_human_rights_into_practice_-_english.pdf for guidance on restricting rights.

¹² CESCR General Comment No. 3: The Nature of States Parties’ Obligations, www.refworld.org/pdfid/4538838e10.pdf

¹³ ENNHRI, 2017, Human Rights of Older Persons and LTC Project: The Application of International Human Rights Standards to Older Persons in LTC, op cit.



What is a Human-Rights Based Approach?

3 What is a Human-Rights Based Approach?



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In each situation we confront, a rights-based approach requires us to ask: What is the content of the right? Who are the human rights-holders? Who are the corresponding duty-bearers? Are rights-holders and duty-bearers able to claim their rights and fulfil their responsibilities? And if not, how can we help them to do so?

Mary Robinson, former United Nations High Commissioner for Human Rights

3.1. A Human Rights-Based Approach

A human rights-based approach (HRBA) is a model that places the principles and standards of human rights as central to all aspects of service planning, policy and practice. The key element of a HRBA is that care becomes a right which all individuals (rights-holders) can claim.

This means that governments and care providers acting on behalf of the State meet their obligations to uphold the human rights of older persons seeking or in receipt of LTC. Implementing a HRBA also has the benefit of helping care providers

¹⁴ UK Audit Commission, 2003, Human rights: improving public service delivery. <https://www.justice.gov.uk/downloads/human-rights/acrep03.pdf>; Victorian Equal Opportunity and Human Rights Commission, 2008, From principle to practice: implementing the human rights-based approach in community organisations, <http://www.humanrightscscommission.vic.gov.au/index.php/our-resources-and-publications/toolkits/item/303-from-principle-to-practice-implementing-the-human-rights-based-approach-in-community-organisations-sept-2008>.

¹⁵ Scottish Human Rights Commission, 2009, Human Rights in a Healthcare Setting: Making It Work, An Evaluation of a human rights-based approach at The State Hospital, <http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINALVERSION.pdf>; Brownie, S. and Nancarrow, S. 2012. Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clinical Interventions in Aging*, 8, 1-10; Jenkins, R. et al, 2011, The Financial Implications of the GREEN HOUSE Model, *Seniors Housing and Care Journal*, 19(1), 3-22. Kane R, Cutler L, et al., 2007, Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program, *Journal of the American Geriatric Society*, 55(6):832-839; Kane R, Cutler L, et al. 2009, Effects of Green House® Nursing Homes on Residents' Families, *Health Care Financing Review*, 30(2):35-51; Sharkey S, Hudak S, and Horn S. 2009 Analysis of Staff Workflow in Traditional Nursing Homes & THE GREEN HOUSE® Project Sites; Afendulis, C. et al, 2016, Green House Adoption and Nursing Home Quality, *Health Service Research*, 51(1):454-74.

to improve the care service. Research suggests that organisational processes can become more consistent and efficient, in turn leading to a better organisational culture, enhanced organisational reputation, increased productivity and improvements in service delivery standards.¹⁴

Research on a HRBA in the area of LTC shows that it can help to lower some financial costs, while improving clinical outcomes (quality of life, fewer behavioural and critical incidents and a decrease in pressure sores, maintained self-care abilities longer, lower rates of depression), better relations between staff and residents as well as reduced staff turnover and absenteeism and higher job satisfaction.¹⁵

A HRBA is underpinned by the “PANEL” principles:¹⁶

- **P**articipation: older persons in receipt of care should participate in all decisions about the care and support they are receiving.
- **A**ccountability and Transparency of duty-bearers to rights-holders: Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress in order to secure human rights.
- **N**on-discrimination and equality: the most discriminated against, marginalised or excluded older persons are prioritised.
- **E**mpowerment 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.
- **L**egality – public authorities and care providers must be sure that their practices and procedures are grounded in international and national human rights law.

A HRBA essentially involves all five values being brought to bear on a particular issue. These principles are used to inform decisions, not to determine them.

All of the principles must inform each decision, but the weight given to each principle in reaching a particular conclusion will depend on the issues under consideration.

In order to put human rights laws and principles at the heart of policy making and service delivery for LTC, policy-makers, staff and older persons must all be empowered with knowledge on human rights and leadership in order to be able to understand how best to implement all human rights, paying particular attention to vulnerable individuals and groups.



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¹⁶ Scottish Human Rights Commission, 2012, Care About Rights? Human Rights and the Care of Older People Information Pack, <http://www.scottishhumanrights.com/careaboutrights>.

3.2. A HRBA in LTC in Practice

Residential care homes for older persons have existed in many countries for over eight hundred years. Because care homes were originally modelled on acute care settings, both the physical layout and the way in which care was organised tended to follow the acute care format. Acute care settings, and thus care homes, were designed to facilitate the work practices of staff, with features such as the presence of one, central dayroom, long, sterile corridors and shared sleeping facilities designed to allow nursing staff to monitor the well-being of residents with relative ease. The impersonal feel of traditional care homes, coupled with the training of care staff (again modelled on the acute care model), meant that care homes did not meet the physical, psychological and social needs of residents.

In the 1970s and '80s, care practitioners began developing a new, more holistic model of care to replace the traditional "medical" model with one which aimed to meet the subjectively-defined needs of residents. Out of such work grew the "person-centred model" of care. This model proposes that people have six psychological needs: love; attachment; comfort; identity; occupation; and inclusion. A person-centred approach seeks to respond to all six needs by:

1. Valuing care users and those who care for them;
2. Treating people as individuals;
3. Looking at the world from the perspective of the care user;
4. A positive social environment in which the care user can experience relative wellbeing.

Being person-centred emphasises that care providers for older persons in need of care and assistance should address the changing needs of each individual in a timely and flexible manner, fully respecting their personal integrity with the aim of improving their quality of life as well as of ensuring equal opportunities in access to care.¹⁷

Care homes that offer a human rights-based approach to care focus on:

- Ensuring the setting is homely, with an open kitchen and access to the outdoors;
- Flexible schedules for residents;
- Opportunities for interaction between staff and residents, plus visits from family members (and pets);
- Opportunities for the continued growth and development of residents, who are valued as creative and resourceful individuals;
- A high staff ratio and a high level of autonomy for each staff member;
- Formal and informal opportunities for residents to input into their own care plans, daily lives and the running of the care home;
- Structured policies and procedures for dealing with grievances and complaints that are clearly communicated to all residents, staff and family members.

A person-centred approach is the embodiment of a rights-based approach, as both come from a common philosophy of protecting and promoting human rights. The key difference is that a HRBA is underpinned by an objective legal framework, reflecting the binding international human rights treaties which states have agreed to uphold.



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17 WeDo, 2012, European Quality Framework for Long-term Care Services, http://wedo.ttp.eu/system/files/24171_WeDo_brochure_A4_48p_EN_WEB.pdf



Implementing
a HRBA
in the Care Home

4 Implementing a HRBA in the Care Home



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I find that rather than seeing human rights as yet another regulatory burden, care workers on the ground are enormously excited once they start to see what it could mean. It very much resonates with the care professionals' idea of what their job is all about.

*Jean Gould,
Legal Officer, Help the Aged UK*

This section delineates the key human rights issues that emerged in ENNHRI's pilot monitoring work and offers guidance on what providers need to consider to comply with human rights standards.

4.1. Implementing a HRBA in LTC Settings: Culture Change

Implementing a HRBA within a care setting is predominantly a focus on changing the underlying culture of the care home. This process has three stages: planning; implementation; and continuous monitoring and improvement.

5 key steps to a HRBA for service providers¹⁸

1. Ensure the organisation's board understands the role of human rights and commits to a HRBA.

- Incorporate human rights into the strategic objectives of the organisation and develop a Human Rights Strategy and Action Plan so that human rights are mainstreamed within the organisation. Review current policies and procedures to ensure that they conform to human rights legislation and reflect human rights principles to help promote a human rights culture. The Traffic Light assessment tool is useful for this:

i. Red = policy/ practice is not human rights compliant

ii. Amber = policy/ practice has significant risk of non-compliance

iii. Green = policy/ practice is human rights compliant.

- Identification of policy development and training needs arising from policy assessment process. Of particular importance is looking at “blanket policies” of procedures rather than a process which took proper account of the context and individual circumstances of each individual.

2. Write action plans, with responsibility clearly designated, and monitor progress on a regular basis.

3. Develop tailored training programmes and best practice guides to engage and empower all staff (including all levels of management), helping them to act and make decisions on the basis of human rights principles and outlining the process staff should follow if faced with a situation that they believe may result in a breach of human rights, as well as an A to Z of hospital policies and practices summarising where and how human rights breaches may arise and how to prevent them from occurring.

4. Empower staff to propose changes in their own work and suggestions for the organisation to protect human rights.

5. Establish a team of staff and management to monitor compliance with human rights standards. Engage and empower service users in service improvement by giving them opportunities to voice their views and experiences and suggest solutions. Give them information about their human rights and how they can expect to be treated. Ensure there is a clear and effective complaints process, about which everyone is informed.

4.2. A HRBA to Decision-Making for Care Workers

As noted in Section 2.3, many human rights are qualified rights. This means that it is admissible for state actors to restrict these rights of older persons within certain circumstances and limits (such as the protection of national security or public safety).

Qualified rights include:

- The right to respect for private and family life, home and correspondence
- The right to freedom of thought, conscience and religion
- The right to freedom of expression
- The right to freedom of assembly and association
- The right to protection of property

¹⁸ Sources: Sources: Age Concern UK, 2008, On the Right Track, [http://www.ageuk.org.uk/documents/en-gb/for-professionals/research/on%20the%20right%20track%20\(2008\)_pro.pdf?dtrk=true](http://www.ageuk.org.uk/documents/en-gb/for-professionals/research/on%20the%20right%20track%20(2008)_pro.pdf?dtrk=true); Scottish Human Rights Commission, 2009, Human Rights in a Healthcare Setting: Making It Work, An Evaluation of a human rights-based approach at The State Hospital, op cit.

Based on the PANEL Principles, the Scottish Human Rights Commission has developed the 'FAIR' approach to help care workers consider their actions when faced with a decision as to whether (and how) to restrict the rights of an individual care recipient. The FAIR approach seeks to make sure that respecting the dignity of the individual is the goal of every decision that staff need to make about their lives and care. The basic steps of the FAIR approach are to:

- Consider the **F**acts: What is the experience of the individuals involved and what are the important facts to understand?
- **A**nalyse the rights: Develop an analysis of the human rights at stake
- **I**dentify the responsibilities: Identify what needs to be done and who is responsible for doing it
- **R**eview actions: Make recommendations for action and later recall and evaluate what has happened as a result.

When faced with a difficult decision, staff in care homes may find it useful to think about how the individual's rights will be affected by the outcome. Care workers must ensure that their planned actions are legal, legitimate and proportionate:

- **Legality** - is there a legal basis for a restriction of the individual's right?
- **Legitimacy** - is there a *legitimate* aim or justification for the restriction such as the protection of public health or the protection of other people's human rights?
- **Proportionality** - is the action *proportionate* - is it the minimum necessary restriction of the right?

When thinking about decisions that affect any of the qualified rights, it is important that the right is restricted as little as possible, only going as far as is necessary to achieve the legitimate aim.

Making Decisions Using a HRBA

Olive and Joe got married in 1940 and were a very close couple. At age 70, Joe developed Alzheimer's. As the disease progressed, Olive reluctantly agreed to put Joe in a nursing home as she no longer felt capable of caring for him on a full-time basis. Joe became very agitated and distressed when he went into the home.

He walked non-stop around the corridors, banging on the doors and demanding to be let out. He was put on medication "to calm him down" and now he mostly sits in his chair dozing, but he sometimes gets agitated and tries to get up out of the chair.

The Director of Nursing explained to Olive that this is dangerous and he could fall and injure himself badly, so Olive signed a consent form to say that the staff can use a lap belt to keep him in his chair. It seemed like the best thing to do to keep Joe safe. It breaks her heart to see him "like a zombie".

Source: *Human Rights and Older People in Ireland, 2013*¹⁹

Alternative version: a HRBA

When Joe entered the nursing home a lot of time and effort went in to developing his care plan and it is reviewed regularly in consultation with him and Olive. Joe's care plan specifies that he likes to walk a lot and that this reduces his agitation. There is a safe enclosed garden and he is able to go out himself and walk around.

There are raised beds where the residents can plant and weed with assistance from the staff. The residents regularly walk down to the local shops and park with staff members and staff make sure that Joe gets the chance to go on these outings. They have also looked at other ways of distracting him when he gets upset.

Knowing that he was a postman, they tried giving him the post to sort into piles and he enjoys this. He still gets agitated sometimes but is much calmer and more content than when he arrived. The home operates to best practice standards in relation to restraint and does not use lap belts. Staffing ratios are adequate to make sure that if a resident is distressed or wants to get out of their chair, a staff member can give them attention. Medication is not used to control behaviour.

19 <https://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/ASI-HROP-A4-Online-Report.pdf>



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4.3. Applying Human Rights Standards Relevant to Long-term Care

Dignity

Dignity refers to “respect for and protection of each individual’s physical, sexual, psychological, emotional, financial and material welfare and protection from neglect and abuse”.²⁰ Dignity is the basis of human rights. It is a founding principle

of several conventions (including the ECHR). Moreover, dignity is such a broad and cross-cutting concept that it closely relates to almost all other human rights.

The dignity of older persons can only be upheld with an adequate number of highly trained and qualified staff who are given the space to respond to each individual’s unique needs. This means that dignity needs to be a central part of staff training, with continuous leadership from the management of the care organisation.



Germany: Training for Care Workers Focusing on Dignity

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 (Müller 2015; Krohwinkel 2013), 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 a well-developed understanding of dignity, which they understood as the need to facilitate residents’ autonomy and control over their own lives.

Examples of upholding residents’ dignity and human rights in the LTC context given by interviewees included enjoying freedom of movement without restrictions the use of screens for bathing and dressing, being addressed politely, and having a free choice of activities during the day to very specific ones, like, ‘having breakfast in pyjamas’, and ‘keeping pets, smoking or having a glass of wine before going to bed’.

German Institute for Human Rights, Human Rights of Older Persons in Long-Term Care: National Report

²⁰ http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf

Safety v Liberty and Autonomy

All older persons have the right to make choices which others may not agree with, even when there are questions over their capacity to make these decisions. Human rights law suggests that such individuals are entitled to support to help them make legal decisions affecting their lives and care.

It is perhaps no surprise that organisations providing LTC experience challenges in balancing residents' right to choice and autonomy with ensuring their safety.²¹ Directors of care are largely acutely aware of the 'backlash' they may face if an individual's life

is put at risk, even when the individual themselves was aware of the consequences. However, a HRBA requires providers to focus on the individual's needs rather than those of the organisation.

The FAIR approach to a HRBA is key to respecting the autonomy of each individual and finding solutions that respect the wishes of residents. In addition, ensuring that the daily schedule of the care home is flexible enough to allow residents to live according to their own routine and preferences is also a way to provide autonomy. Creative solutions and technology can also help to respect autonomy.



Belgium: Facilitating Residents' Right to Autonomy

In Belgium, many care homes sought to maximise each resident's autonomy by taking an account of their life story (see above). This was used as the basis for the Personal Care Plan of each individual, which helped to plan activities, food and personal preferences, notes the preferred mode of address etc.

This is reviewed after six weeks and any necessary adjustments are made. In turn, the Personal Care Plan for all residents are used to review the

daily schedule of the care home and change the activities available. Many care workers commented that it helps them to see the care user as a person, to understand their behaviour and to change the way that they delivered care.

Residents can further contribute to the management of the care home through the Residents' Committee, which can make recommendations about the general functioning of the care setting.

Residents are given the opportunity to choose what they would like to eat – the menu is sent a week in advance with three choices. While there are often set mealtimes, anyone who does not want to eat at that time is accommodated. Their meal is kept warm or prepared at an earlier/later time.

Source: Unia, Human Rights of Older Persons and Long-Term Care: Monitoring Report on The Human Rights situation of Older Persons in Belgian Residential Care Settings.

Participation

Access to information is key to ensuring residents' participation in all aspects of decision-making in their own lives and care, the life of the care setting and in the wider community. Information provided in accessible formats and offering the possibility of choice is in line with a HRBA. As such, it is important

to understand how residents wish to participate and spend their time in the care setting. While some may prefer physical activities, others may prefer intellectual stimulation. There is a large body of evidence to show that older persons wish to feel valued and contribute to the running of the care home.

²¹ In its Guide on Article 5, the ECtHR states that the Convention allows individuals to be deprived of their liberty if they may be a danger to public safety and/or if their own interests may necessitate their detention. In contrast, the UN's CRPD is based upon the principle of "individual autonomy, including the freedom to make one's own choices" and so includes the obligation on states parties to take appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion (Article 21).



Croatia: *Feeling Valued through Everyday Participation in Residential Care*

While care home residents in several European countries tend to be among the oldest old, with physical disabilities, communication problems and/or dementia/cognitive impairments, residents in care homes in some countries are often younger, or remain physically active.

This means that care home providers must ensure that their residents have the opportunity to participate in care home activities and in the life of the wider community.

As well as drawing up an individual care plan with each resident upon admission, residents are informed about the activities taking place in the home, which are also advertised each week.

Along with group exercises and birthday parties, most care homes also organise other joint activities for the residents: choirs, dancing, board games. In some homes there are additional facilities such as bowling or bocce courts. There is also a practice of organising theatrical performances and other cultural events on the premises,

typically in collaboration with amateur troupes or schoolchildren.

Some homes also organise music concerts for all residents, dancing, drama groups and various other activities.

Some homes that are not located in the vicinity of public transport provide their residents with a shuttle service to town in the morning, with buses departing from and returning to the care home at set times. At other times, resident travel to town on their own.

Residents are free to go on trips or visit their families for several days. Such goings are announced to the staff in advance.

Residents can exercise their voting rights in all care homes, with polling stations typically set up on the premises. All care homes are urged to register residents' change of address to facilitate this process.

Residents also have an opportunity to participate in the management of the care home. Regular meetings take place between the care home manager and staff and residents and residents also have representatives in each care home governing council.

Source: Office of the Ombudswoman of Croatia, Human Rights of Older Persons and Long-Term Care: Monitoring Report on The Human Rights Situation of Older Persons in Croatian Residential Care Settings.

Privacy

The right to privacy has been broadly interpreted to include the right to respect for one's dignity and personal autonomy, and the right to respect for social relationships. The right to privacy can be accommodated within care homes not only through the physical environment (use of screens, single rooms, dedicated spaces for medical checks etc) but in ensuring that each individual's right individual identity and privacy is respected, particularly during the provision of personal care. It is also important that each individual is given enough support to maintain contact with family members whilst in care.



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Lithuania: the Use of EU Structural and Investment Funds to protect privacy

In Lithuania, one care home renovated in 2000 with the help of EU Structural and Investment Funds was based on the design of Swedish and Norwegian care homes.²² The new design allowed residents to have their own private rooms, equipped with call bells. Private rooms were also

provided for medical examinations and space to allow each resident receive visitors without being disturbed.

In other care homes, where space is more limited and residents share bedrooms, care staff use screens to protect residents' privacy while being washed and dressed. Residents at the end of their lives are moved to a single room where possible in order to maintain their privacy and dignity, and so that the privacy and dignity of other residents will also be protected.

Source: The Seimas Ombudsmen's Office, Report on the Situation of Human Rights of Older Persons in Residential Care in Lithuania.

The Right to the Highest Attainable Standard of Health

Ensuring access to ancillary health services can be somewhat challenging for LTC providers, who often rely on availability at national/regional level. However, providers can take some steps to ensure

older persons enjoy this right. Ensuring an adequate number of staff is key in monitoring and providing healthcare services, particularly prevention and rehabilitation. Regularly reviewing medication and involving each resident in decisions affecting their care (including their right to refuse treatment) is important in implementing a HRBA.



© Moyan Brenn A couple having a rest in Jardin du Luxembourg, Paris, 2010

²² It is important to note that the EU's ratification of the CRPD means that it has an obligation to allow persons with disabilities to be cared for in the community and so not to build new institutions. As a result, the Lithuanian government has developed policies to develop home- and community-based services for older persons.



Romania: *Protecting the Right to the Highest Attainable Standard of Health with Limited Resources*

Under Romanian legislation, the right to the protection of health is guaranteed and individuals are entitled to medical care of the highest quality that society can provide, in conformity with its human, financial and material resources. Older persons living in residential care should have access to medical services and therapies and should be either enrolled with a General Practitioner (GP) or have access to one facilitated by the direction of the care home. Given that a relatively small proportion of staff in care homes in Romania tend to have qualifications, access to GPs is particularly important.

However, within Romania, there is a shortage of GPs and medical specialists, particularly in rural areas. As a result, many care homes monitored had difficulties ensuring that their residents had access to the medical care necessary to attain the highest standard of health.

Several care homes had made efforts to meet their

obligation to their residents in different ways. Two of the five centres in rural areas had established half time medical services agreements with local GPs, whereby the doctor would work in the care home either every morning or afternoon. Other care homes sought to call GPs or geriatrician as required. If necessary, they used the Centre's or Director's car to go there. Another collaborated with a GP who already had a large workload and was based at some distance from the home over the phone in order to receive medical advice. This allowed the GP to remain updated on any changes in her patients and offer advice when necessary.

Care homes in general sought to focus on preventing the deterioration of medical conditions and on rehabilitation where possible, although access to physical and other therapists was also challenging. They also indicated that they sought to facilitate residents' right to choose their GP and refuse treatment.

As in Lithuania, some care homes in Romania had benefitted from EU Structural and Investment Funds (European Regional Development Funds) to buy basic medical equipment (computer, blood pressure monitors, echoscope, blood glucose metre) and to provide rehabilitation surgery.

Source: Romanian Human Rights Institute, Human Rights of Older Persons and Long-Term Care: Monitoring Report on The Human Rights Situation of Older Persons in Romanian Residential Care Settings.

Access to Justice

Access to justice and the right to an effective remedy broadly refers 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.

It is a challenging right for care homes to fulfil, given that many older persons may be reluctant to complain for various reasons, including a fear of reprisal. Suggestions for complying with this right include:

- Providing 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.
- Providing effective avenues for complaint that allow individuals to report breaches of their human rights or well-being without fear of reprisal.
- Responding to complaints within a reasonable timeframe.
- Providing residents with access to independent advocacy services.



Hungary: the Use of External Advocates

Patient rights in Hungary date back to 1997, with the passing of a new Health Care Act, which proclaimed the patients' rights for self-determination and related rights. This led to trained patient advocates starting work in acute hospitals and later psychiatric institutions through an NGO.

In 2000, the institution of advocating patients' rights was officially launched in July, 2000, when 54 advocates started to work under the control of ÁNTSZ (National Service of Medical Officers).

Each care home is visited once every three months by a Patient Rights Representative, who informs individuals of their rights and explores any complaints and concerns residents have about

their lives in the care home. They help individuals to make official complaints when necessary as well as officially record the complaints and their resolutions. The data collected are subsequently used to determine if there is a need for more investigation of abuse within a particular care home.

Moreover, the Office of the Commissioner for Fundamental Rights also has a mandate to receive complaints and monitor residential care settings for older persons. Within the care homes monitored by the Office of the Commissioner for Fundamental Rights, other mechanisms were used to receive and investigate complaints, such as structured meetings between the care home manager and residents, the use of complaints boxes for anonymous suggestions and the use of volunteers as intermediaries between residents and staff when necessary.

Source: Office of the Commissioner for Fundamental Rights Hungary, Summarising Study on the (on-site) investigations of the commissioner for fundamental rights concerning the operation of old people's homes.

Palliative Care

Although the right to palliative care is not explicitly mentioned in many binding human rights conventions, it is noted by treaty bodies as an important element of the right to the highest attainable standard of health for all individuals. The right to be spared pain and to die with dignity can be met if service-users' preferences around

their death are taken into account well in advance. Within a residential care setting, moving residents to a private room or respecting their privacy in other ways, accommodating family and friends to visit (in line with the wishes of the individual) and establishing rituals such as a paper star on the door of a dying resident to ensure that everyone remembers to keep their voices down and retain an atmosphere of peace and tranquillity.

Think Ahead Initiative

The Alzheimer Society of Ireland and the Irish Hospice Foundation produced a booklet as part of their joint initiative, Think Ahead, in order to help them plan for the future and ensure that

their wishes were respected. The booklet sets out guidance for individuals with dementia to plan financial and legal affairs, how they wish to be cared for (and where) and resources on planning for their future.

[https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers_PlanForFuture-Brochure_web1-\(1\).pdf](https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers_PlanForFuture-Brochure_web1-(1).pdf)



Supporting a HRBA in Long-term Care Policy-Planning and Service Provision

5 Supporting a HRBA in Long-term Care Policy-Planning and Service Provision



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We don't have a demographic problem, we have a policy problem.

*Colm McCarthy,
Irish Economist*

5.2 Developing a human rights-based approach to the design and delivery of LTC

As with the integration of human rights and a HRBA within the care home, ensuring that LTC policies take States' obligations into account requires an understanding of those obligations, a review of existing policies and a plan for reform.

5.1 Introduction

Although care providers assume many of the State's responsibilities for protecting and promoting the rights of older persons in receipt of LTC, the adoption of a HRBA within LTC settings requires a supportive policy framework to function properly. Indeed, putting this framework in place represents an opportunity for states to demonstrate their commitment to protecting and promoting the human rights of older persons in care. As outlined below, the national/regional's government's responsibilities lie primarily with facilitating equal access to LTC, supporting care providers to meet their obligations and addressing the causes of human rights concerns in the LTC sector.

1. Identification of human rights obligations and duty-bearers

LTC policies and practices can only be viable and effective when they are based on a firm foundation of legal norms and operate under the rule of law. Most measures needed to protect the rights of older persons and care workers can be found in the framework of international human rights and standards. ENNHRI's publication *The Application of International Human Rights Standards to Older Persons in Long-term Care* (February 2017) contains an analysis of the relevant rights and outlines states' obligations. This process also includes clarifying the various duty-bearers and their corresponding

obligations (e.g. care providers, the government, acting on behalf of the state). As noted in Section 2.3, this can be challenging, given that there may be existing grey areas in the obligations of care providers and whether there is a clear delineation of their responsibilities to help the state meet its own human rights obligations.

2. Assessment of Existing Policies

In consultation with a human rights expert, an analysis of all policies relating to the provision and support of LTC services for older persons can be carried out to ascertain their compliance with international human rights standards. The Traffic Light Assessment Tool, Outlined in Section 4.1, can be useful for this process.

3. Updating/Reform of National/Regional Long-term Care Policies

An LTC policy relates to many areas of national policy and service-planning – in healthcare, social protection and pensions, employment, quality monitoring, public expenditure and enterprise and entrepreneurship. It is important to have policy coherence and recognize the legal and human rights requirements in other areas (e.g. staff working hours).

A useful starting point for updating or reforming LTC policies is the development of a national/regional Positive Ageing Strategy, incorporating a plan for the development of LTC services. It is particularly useful as it incorporates all the elements of the PANEL principles (see Section 3.1), key to a HRBA.

Developing a National Positive Ageing Strategy

Many European states have now developed national or regional positive/healthy ageing strategies –i.a. Denmark, Netherlands, Flanders, Ireland, Lithuania, Scotland, several regions in Spain and Wales. Several European countries have also developed a specific LTC strategy, or dementia strategy. Most were developed according to a similar methodology:

- 1.** Establishment of a Working Group made up of all relevant stakeholders, including older persons and their national/regional advocacy groups
- 2.** Public Consultation Process
- 3.** Review of human rights obligations, Positive Ageing Strategies from elsewhere, relevant national policy developments in related fields and demographic projections
- 4.** Consider the needs of most discriminated against, marginalised or excluded older persons.
- 5.** Development of a Draft Positive Ageing Strategy
- 6.** Second Public Consultation Process

- 7.** Publication of the National Positive Ageing Strategy:
 - a.** Vision Statement
 - b.** Mission Statement
 - c.** Operating Principles
 - d.** National Goals and Objectives
- 8.** Development of an Implementation Strategy (with ring-fenced funding), detailing which actors are responsible for which activities.
- 9.** Development of evaluation indicators and a monitoring framework and strategy

Developing a National Positive Ageing Strategy in consultation with key stakeholders helps the government to be accountable in meeting its obligation of ensuring the participation of older persons in service planning and delivery. Consultation processes can also help to ensure other human rights obligations, e.g. the right to dignity and privacy, are met, as these tend to be key concerns of older persons themselves.

5.3 Supporting a HRBA to LTC Policy-Making and Service Delivery

As noted earlier, the national/regional's government's human rights obligations in the area of LTC lie broadly in facilitating equal access to LTC, supporting care providers to meet their obligations and addressing the causes of human rights concerns in the sector.

Leadership from the Government on Human Rights Compliance

Leadership from the government on human rights compliance and positive attitudes towards ageing

and older persons can help to ensure other actors put renewed focus on human rights in the area of LTC. This can include:

- Making commitments to older persons that their rights will be protected and promoted
- Highlighting how policies and legislation in the area of LTC take human rights obligations and values into account
- Supporting, facilitating and promoting HRBA approaches adopted by care providers
- promote better understanding of positive human rights obligations, and consider options for codifying these within legislation



Scotland: Charter on Human Rights and People living with Dementia

In Scotland, it was recognised that people living with dementia are entitled to the same human rights as everyone else. Nevertheless people living with dementia were still often being denied their rights due to social and cultural barriers. These barriers included a lack of understanding within the population, and a lack of training for care staff

in how to respect and protect the human rights of people living with dementia. Therefore in 2009 the Scottish Parliament adopted *The Charter of Rights for People with Dementia and their Carers in Scotland*. The aim was to uphold the human rights of people living with dementia both in the community and in care facilities in Scotland.

Cross-Party Group in the Scottish Parliament on Alzheimer's, 2009, Charter of Rights of People with Dementia and their Carers in Scotland. Edinburgh: Alzheimer Scotland.

Financial Investment into the Sector

As noted in Section 2.3, the principle of progressive realisation means that states must be able to prove that they are working as fast as possible using all the resources they have available to them to progressively fulfil the human rights of all individuals in the jurisdiction.

The principle of progressive realisation means that, regardless of whether State funding is above or below average (vis-à-vis other European states) on LTC, states should continue to financially invest in the sector in line with available resources. While

balancing the need to ringfence funding for LTC services with other social needs, a wealth of evidence suggests that higher public expenditure is associated with a higher quality of care. Furthermore, investment in care to improve care outcomes leads to cost-savings, given lower rates of critical incidents such as falls.

Additional financial resources will not only help to ensure an adequate supply of affordable LTC services, but to promote older persons' right to dignity, autonomy and freedom of movement by increasing staffing levels and the provision of training for current and future care workers.

Provision of an Adequate Supply of Affordable, High Quality Long-term Care Services

As noted earlier, there is no explicit right to LTC articulated in any binding human rights convention, though several international human rights organisations have proposed recognising LTC as a right.²³ However, state parties to the UN's International Covenant on Economic, Social and Cultural Rights (ICESCR) have an obligation to put the maximum available resources into protections of 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 provision of an adequate supply of LTC is one possible way for states to meet this obligation.²⁴

States also have an obligation to provide individuals with equal access to healthcare services (whereby no individual should have greater opportunity of access than any other),²⁵ providing for the specific needs of groups that generally face particular health challenges, such as higher mortality rates or vulnerability to specific diseases. States parties to the CRPD also have an obligation to enable persons with disabilities to live independently in the community, with the choice of where and with whom to live, and the support to allow them to do so.

Suggestions for states to ensure equal access to affordable LTC services and the right to a choice of LTC services include:

- Accessible and reliable information on accessing LTC;
- Transparent waiting lists;
- Provision of an adequate number of LTC care services;

- Developing community and home-care services for older persons to allow older persons a choice of where to receive care;
- Developing services and supports to facilitate family/friends to take on caring duties (respite, financial support, accessible and reliable information, measures that enable working carers to combine their care and work responsibilities, measures to ensure that carers do not lose their financial and social security rights as a result of their caring responsibilities);
- Reduction of co-payments and out of pocket costs for accessing LTC.

States that have ratified the CRPD have an obligation to provide older persons with a choice of where to receive LTC services. This includes access to services that allow older persons to live independently within the community, including home help, meals on wheels, day centres and related services. There is growing evidence that community-based models of care are not inherently more costly than institutions, once a comparison is made on the basis of comparable needs of residents and comparable quality of care.

For example, the 'life-long living programme' in Fredericia (Denmark) seeks to support older people to live in their own homes as independently as possible. The project has saved the community around EUR 10 million over five years compared to the previous care model.²⁶

In addition, as States are obliged to provide all individuals with the highest attainable standard of physical and mental health, it is important that LTC is well-coordinated with acute health services to ensure a consistent continuum of care for older persons. This can be achieved by ensuring that

- Older persons have (safe physical) access to a general medical practitioner and other allied health professionals (physiotherapists, occupational

²³ Article 23 of the CoE's Revised European Social Charter does provide older persons with the right to housing suited to their needs and their state of health and the health care and services necessitated by their state, though only twelve states that have ratified the RESC have bound themselves under Article 23; Scheil-Adlung, X., 2015, Long-term care protection for older persons: A review of coverage deficits in 46 countries, http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---soc_sec/documents/publication/wcms_407620.pdf; WHO, 2015, World Report on Ageing and Health 2015, http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1

²⁴ Grover, A. 2011. Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover. http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37_en.pdf

²⁵ CESRC, 2000, General Comment No. 14, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2f2000%2f4&Lang=en

²⁶ Social Platform, 2017, Investing in Services for People's Well-Being, http://www.socialplatform.org/wp-content/uploads/2017/03/investing_in_services_for_peoples_well_being_final_230317.pdf

therapists, dietitians, social workers, chiropractors etc) on a non-discriminatory basis and that meet their needs and preferences;

- Ensuring that residential care services are located within communities with established networks of health and social services and with acute hospitals;
- Putting in place measures to expand the provision of community-based healthcare as necessary, even if the State's resources are limited;²⁷
- Putting mechanisms in place to guarantee health

professionals and medical consultants will attend patients living in residential care settings as required;

- Monitor the quality of healthcare services;
- Ensure the cost of ancillary healthcare services is acceptable. Provide means-tested support as necessary.

A focus on coordination should be extended to the various entities involved in quality improvement initiatives.



Sweden: Facilitating Access to LTC

Sweden is one of the biggest providers of LTC services in Europe per capita, with over 4% of the population using either home care or residential services (compared with an OECD average of 2.3%). It also has the highest public expenditure on LTC in Europe, spending 3.8% of GDP on the sector, compared to an OECD average of 1.7%.

The responsibility for the welfare of older persons is divided among three governmental levels. At the national level, the parliament and the government

have set out policy aims and directives by means of legislation and economic steering measures. At the regional level, county councils or regions are responsible for the provision of health and medical care. And at the local level, the 290 municipalities are legally obliged to meet the social service and housing needs of older persons. Services provided by doctors are not included in the care for which municipalities are responsible. Some municipalities have contracted out their care services to private providers and in certain areas, older persons are allowed to choose whether they want help at home or in special housing managed by public or private operators.

Sources: OECD, 2011, *Help Wanted? Providing and Paying for LTC*. OECD, Paris. EU Commission Expert Group on Gender Equality and Social Inclusion, 2009, *Access to healthcare and Long-term Care: Equal for women and men?*

Legal Capacity

States that have ratified the CRPD have an obligation to ensure that all individuals, particularly persons with dementia are able to enjoy legal capacity on an equal basis with others and have the right to supported, as opposed to substituted, decision-making.



© Photo by Tiago Muraro on Unsplash

²⁷ OHCHR, 2008, The Right to Health, Factsheet No. 31, <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

²⁸ <http://wedo.ttp.eu/quality-care-training-package>

²⁹ Respectful of human rights and dignity; person-centred; preventive and rehabilitative; available; accessible; affordable; comprehensive; continuous; outcome oriented and evidence based; transparent; gender and culture sensitive, http://wedo.ttp.eu/system/files/24171_WeDo_brochure_A4_48p_EN_WEB.pdf



Norway: Shared Decision Making related to health and daily care

A Norwegian study was conducted to understand how people with dementia participate in decision making, and the role that their caregivers and health professionals play in the decision making process. It was found that people with moderate dementia were involved in decision making to different extents for example, some people with dementia delegated decision making to a

caregiver or health professional, whilst others made decisions autonomously. The study also showed that the best approach to involve people living with dementia in decision making was to: Recognize that the person living with dementia was capable of making decisions, ensuring that he or she understood the decision to be made, and if necessary structuring and simplifying the environment to support decision making, providing cues to prompt memory, narrowing the range of available choices and clearly stating alternatives if the person did not understand.

Source: Smebye, K. L., Kirkevold, M., Engedal, K. How do people with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research*. 2012; 12:241:1-12.

Training Initiatives

Implementing a HRBA requires ensuring that all those involved in service provision understand how it potentially changes their role and tasks.

Training bodies and professional regulators (doctors, nurses, care workers) thus play a role in promoting human rights by reflecting the obligations of human rights legislation in professional standards and in their requirements for undergraduate training.

This includes:

- training on care providers' and care workers' own human rights obligations;
- the provision of a HRBA approach to care and decision-making;

- the right to dignity (particularly in the provision of personal care);
- alternatives to restraint, including chemical restraint;
- including each residents in decisions affecting their lives and care;
- creative solutions for protecting residents' well-being while respecting their autonomy;
- facilitating participation in decisions affecting daily lives and care;
- specialist training on dementia care;
- communication with older persons, particularly those with communication difficulties.

In addition, training should be provided to public officials at all levels to know their legal obligations under human rights legislation.

WeDO2: Training Initiative on Improving the Quality of Long-term Care

Funded by the European Commission, the WeDO2 partnership seeks to develop new educational tools (an online train the trainer toolkit, learning areas where trainings will be tested), using a participatory approach to improve the quality of LTC in Europe.

Over a two-year period, WeDO2 developed an interactive, train the trainer toolkit²⁸ adapted for different groups (older people, informal carers

and service providers). The toolkit provides an overview of the rights of older people in Europe, the principles of quality care²⁹ and modules on elder abuse and a participatory approach to LTC, as well as exploratory discussions for training recipients to consider how they can improve their current practices/experiences in order to improve the quality of care for older persons.

Older people themselves were involved in developing the training modules as well as in undertaking the training to better understand their rights and how to access them.

Source: <http://www.wedo-partnership.eu/wedo2>

Human Rights Protection in LTC: Monitoring and Oversight

As well as helping care providers and workers to understand their rights through training and education initiatives, States can ensure that human rights obligations are upheld by monitoring compliance against minimum standards, such as in the areas of:

- Admission procedures (legal capacity of the resident)
- The care home's physical environment (safety, privacy)
- Staffing levels and qualifications to ensure that older persons enjoy the full range of human rights to which they are entitled
- Personal care and interaction with residents (dignity, autonomy, freedom from restraint, privacy, abuse prevention)
- Provision of healthcare (legal capacity)
- Complaints procedures

Research suggests that optimal human rights monitoring of LTC services is carried out by a well-resourced, independent body, measuring compliance against a small number of broad standards, as opposed to a large number of detailed standards. In several countries, the monitoring

of LTC services is carried out by an independent quality inspectorate, which collaborates with the National Human Rights Institution.³⁰ In other countries, human rights monitoring is carried out by the "National Preventive Mechanism" (NPM), the national component of the preventive system established by the Optional Protocol to the United Nations Convention Against Torture (OPCAT).

NPMs are mandated to conduct regular visits to all types of places where persons are deprived of liberty and make broad recommendations on the protection of dignity, privacy, etc, rather than simply on torture prevention. In recent years, NPMs have been expanding their work outside of monitoring "traditional" institutions, such as prisons and police stations, to psychiatric settings and LTC settings for older persons.



© Simon Nowicki Nursing Home, used with permission



Netherlands: Monitoring LTC

LTC in the Netherlands has comprehensive coverage, the possibility to choose services in cash, and a high availability of home care services. This comprehensive system is under stress to demonstrate high quality and value for money from high levels of spending. The Netherlands spends 3.7% of GDP on LTC, the highest of the OECD countries (Table 1). The growth in public expenditure on LTC has been above 10% in real terms during 2000-10. Projections suggest that expenditure may at least double by 2050.

A major reform in LTC is currently taking place in the Netherlands. An important objective of the reform is to reign in expenditure growth to safeguard the fiscal sustainability of LTC. Other objectives are to improve the quality of LTC by making it more client-tailored. The reform consists of four interrelated pillars: a normative reorientation, a shift from residential to non-residential care, decentralization of non-residential care and expenditure cuts.

In practice, reform has been controversial, with several aspects rolled back due to a lack of support from providers (including measures to reduce expenditure on the sector), with fears of mass layoffs and inferior employment conditions debated in the media. Although the success of the reform will strongly depend on how coordination

³⁰ Such as England and Wales: <https://www.equalityhumanrights.com/en/care-and-support/guidance-care-quality-commission-inspectors>

problems will be solved and cost-shifting from one regime to another will be avoided, it is anticipated that LTC care will remain a largely publicly funded provision, with a statutory health insurance scheme to cover residential care.

As part of the reform process, new standards were set by the Netherlands Care Institute, which are monitored by the Dutch Health and Youth Inspectorate (IGJ) to check the safety and quality of care in nursing homes.

The primary aim is not only to make sure that care is safe and of a high quality, but that it is person-centred. As such, the regulations state that must

provide a good mix of staff with the right training and experience and sufficient attention for the people and that there is always someone who really knows each resident. Regulations also focus on training requirements of staff and the presence of a personalised care and life plan. Inspectors also look for a safe working environment, the culture of the setting and care of individuals with dementia.

The Inspectorate has 35 inspectors to monitor care. Homes are selected for inspection on the basis of risk-controlled supervision, based on data collected from the care home, other healthcare providers, past visit findings and notifications.

Sources:

Dutch Health and Youth Inspectorate, <https://www.rijksoverheid.nl/onderwerpen/verpleeghuizen-en-zorginstellingen/zorg-ouderen-verpleeghuizen-verbeteren>, <https://www.igj.nl/zorgsectoren/verpleeghuiszorg/inspecteur-bezoek>;

Maaerse, J. and Jeurissen, P., 2016, The policy and politics of the 2015 long-term care reform in the Netherlands, Health Policy, 120, 3, 241-245, <http://www.sciencedirect.com/science/article/pii/S0168851016000282>; OECD, 2013, The Netherlands, Highlights from A Good Life in Old Age? <https://www.oecd.org/els/health-systems/Netherlands-OECD-EC-Good-Time-in-Old-Age.pdf>

Assuring the Quality of Long-term Care: A Voluntary European Quality Framework For Long-term Care

In 2012, AGE Platform Europe and their partners published the European Quality Framework for long-term care services—a set of 11 quality principles (outcome standards) and 7 areas of action, recommendations for policy makers and a methodology on how to implement them with a human rights approach. The Framework suggested that LTC care services should be

- Respectful of human rights and dignity
- Person-centred
- Preventive and rehabilitative
- Available
- Accessible
- Affordable

- Comprehensive
- Continuous
- Outcome oriented and evidence based
- Transparent
- Gender and culture sensitive

It provides policy and practice examples from various EU countries to show how these standards can be met. The Framework was inspired by WeDO's "European Charter of the rights and responsibilities of older people in need of care and assistance" launched in 2010 and the Voluntary European Quality Framework for Social Services, guidance on how to set, monitor and evaluate quality standards for social services, which was developed by the EU's Social Protection Committee, the EU advisory policy committee for Employment and Social Affairs Ministers in the Employment and Social Affairs Council (EPSCO).

Source: https://www.age-platform.eu/sites/default/files/24171_WeDo_brochure_A4_48p_EN_WEB.pdf, <http://ec.europa.eu/social/BlobServlet?docId=6140&langId=en>



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Commissioning and Contracting Out

To a greater extent, LTC services in Europe are being contracted out to private (for-profit, and to a less extent, not-for-profit) providers. Research conducted as part of the *Close to Home*, a study conducted by the Equality and Human Rights Commission in the UK, found that many commissioners of care (often municipalities) fail to understand their obligations in protecting and promoting the human rights of older persons and so do not make this a key criterion in procuring care providers and in monitoring compliance with the contract.

Often, value for money is the key factor in determining which care company will win a contract, which often leads human rights issues becoming sidelined, as care workers are pressurised to carry out as many caring tasks as possible in a given time

period. This often leads to too little time to consider their human rights obligations. The study found a number of good practices for municipalities to commission oversee care operated by statutory providers:

- ensuring commissioning/service plans incorporate a HRBA;
- adopting a realistic attitude towards the cost of high-quality care;
- using service specifications that require practices and outcomes aimed explicitly at promoting and protecting human rights;
- involving older service users in the commissioning/service planning process;
- proactively monitoring contracts to see that human rights are respected; and
- taking action when they are not.

Commissioning Long-term Care

Halton Borough Council employs a Dignity in Care Co-ordinator, whose role is to integrate a 'whole system' human rights based approach across all health and social care services including home care. All partner organisations and care providers work to embed dignity via a Dignity Champions' Network, having signed up to Halton's Dignity Charter and

appointed Dignity Champions. Providers report back regularly on the practical steps they are taking to promote the human rights of people using their services.

A senior local authority manager highlighted the benefit of having a dedicated co-ordinator:

'It (dignity) becomes the norm really for [us] ... It becomes the norm to recognise that within contracts and ... in the provision of services as well.'

Source: Equality and Human Rights Commission, 2011, Close to Home.

Participation and Empowerment of Older Persons

Facilitating older persons to participate in policy-making and service planning for LTC services not only helps the State to meet its human rights obligations, but can ensure that policies are targeted at meeting users' needs.

The direct participation of older persons in receipt of LTC requires innovative measures, given that such a high proportion can have late-stage dementia or other cognitive impairments, communication problems, physical impairments, frailty and multiple co-morbidities. As such, a multi-pronged approach is required.

Proposed options for supporting older persons to participate in policy-planning include:

- ensuring older persons both seeking and in receipt of LTC are part of any official Working Group tasked with drafting policy proposals or background preparation, as well as representatives from advocacy organisations for older persons
- a selection of older persons living in care are consulted about their wishes
- support from advocacy services or residents' councils may help older persons to give their views on the services they receive.

It is also important for older persons themselves to be given support to understand and assert their rights. This includes the provision of information widely available in accessible formats on how to access LTC and to understand their rights while in care and information on resources (NGOs, NHRIs, national advocacy services) that can help them understand and assert their rights. This means supporting organisations in a position to empower and support older persons. The Scottish Human Rights Commission's *Care About Rights* course includes a module to enable older persons and their families on their human rights and on steps towards resolving breaches of their rights.

Empowerment also means a continuous cooperation between advocacy programmes and care service providers, so older persons receiving care and assistance are supported in improving their understanding of their human rights in residential care homes as well as in the situation of home care services.

Access to Justice: Complaints Mechanisms and Support Systems for Older Persons in Care

Closely related to the empowerment of older persons is the issue of states' obligations to ensure that older persons in receipt of care have effective remedies if their rights are breached. It is important to provide service users with access to legal aid if required and to ensure that care home owners:

- deter conduct that would infringe human rights;
- provide care users with 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;
- provide care staff with training on their human rights obligations, including the specific measures to be taken if the older person needs adapted communication;
- provide effective avenues for complaint that allow individuals to report breaches of their human rights or well-being without fear of reprisal, including a formal complaints mechanism within the care setting and support for making a complaint through statutory or legal channels if and when required;
- provide residents with access to independent third party advocacy services;
- protect whistle-blowers, whether they are an older person receiving care, a family carer or care staff.



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Ireland: National Advocacy Service for Older Persons

In Ireland, a non-profit organisation, Third Age, was given funding to establish and operate an independent advocacy service, Sage, for older persons in Ireland. In conjunction with a national university, the service has provided training to

over 70 volunteers over the course of one year. Using a rights-based approach, these volunteers are responsible for care homes for older persons throughout the country in order to raise awareness of the service and offer support to any individual who requires it, raising their capacity to move towards non-instructed advocacy when possible. The advocates also seek to collaborate with the owners and staff of the care homes to raise issues and seek co-operation to change practices when required.

Source: <http://www.thirdageireland.ie/sage>

It is also important that EU Member States implement the European Victims' Directive, which can play a role in improving the protection of older persons who have suffered abuse, violence and maltreatment. The Directive requires EU Member States to offer access to information, specialist victim support services, special protection measures and information about a decision not to prosecute.



Rights of Care Workers

According to the OECD, LTC is an unattractive sector for care staff, given the poor working conditions, low wages and high labour-intensity of the work. This leads to high turnover and burnout rates, as well as challenges attracting career-starters.³¹ To resolve these problems, the OECD recommends:

- improving recruitment efforts, including through the migration of care workers, in some OECD countries (while remaining mindful of the need to avoid “poaching” care workers needed in their own countries, and the extension of recruitment pools of workers;
- increasing the retention of successfully recruited LTC workers, by improving the pay and working conditions of the workforce; and
- seeking options to increase the productivity of care workers.³²

Moreover, it is important that staff who feel that their rights have been breached also have access to justice, both in the form of a clear formal complaints system as well as to the courts. Staff should be relied upon to compensate for inadequate staffing levels. Relevant publications from the International Labour Organisation (ILO) also delineate the rights of care workers in Europe, both in residential and domestic settings.³³

³¹ Colombo, F. et al. (2011), Help Wanted? Providing and Paying for Long-Term Care, OECD Health Policy Studies, OECD Publishing.

³² Colombo, F. et al. (2011), Help Wanted? Providing and Paying for Long-Term Care, OECD Health Policy Studies, OECD Publishing.

³³ http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/documents/genericdocument/wcms_208561.pdf;
http://www.ilo.org/wcmsp5/groups/public/---ed_dialogue/---actrav/documents/publication/wcms_218133.pdf,



Summary

6 Summary



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At its heart, human rights legislation focuses on ensuring that all individuals have the right to choose and participate in all decisions affecting their lives. States and any organisation providing services on behalf of the state, including a residential care setting providing LTC services for older persons, have a responsibility to protect and promote human rights.

Research from ENNHRI has found that care homes had the most difficulty upholding the right to dignity, the prevention of abuse, the right to autonomy, participation, privacy, the highest attainable standard of health and access to justice. However, a range of good practices were also found, which often led from HRBA training for care staff and formal and informal input from residents into decisions affecting their own care and the running of the care home.

A HRBA is a useful and effective way of helping care providers to meet their human rights obligations. It has many benefits for staff and service users and has the potential to save resources through

Give to every human being every right that you claim for yourself.

*Robert G. Ingersoll,
American Lawyer and Political Leader*

better health outcomes, reduced staff turnover and incident rates.

A HRBA involves five key values being brought to bear on a particular issue: participation, accountability and transparency, non-discrimination and equality, empowerment of rights holders and legality. To put human rights laws and principles at the heart of policy making and service delivery for LTC, staff and residents must be empowered with knowledge on human rights and leadership in order to be able to understand how best to implement all human rights, paying particular attention to vulnerable individuals and groups. Support for a HRBA from the state, ideally with legislation to require service providers to adopt a HRBA, is more likely to generate lasting success.

Annex 1

RIGHT		SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: GOVERNMENT	SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: CARE PROVIDERS
ACCESS TO LONG-TERM CARE	ICESCR (Articles 9, 12) CRPD (Article 14, 19, 25) ECHR (Article 2) ESC (Articles 11, 12, 13) RESC (Articles 11, 12, 13, 15, 23)	<ul style="list-style-type: none"> • Transparent waiting lists. • Development of home- and community-based services. • Positive Ageing/Long-term Care National Strategy, developed in consultation with care providers, older persons and advocacy organisations. • Clear guidance for care providers on older persons' right to consent to care. 	<ul style="list-style-type: none"> • Transparent waiting lists. • Residential services can provide community-based services at home.
RIGHT TO LIFE	UDHR (Article 1) ICCPR (Article 6) ECHR (Article 2)	<ul style="list-style-type: none"> • Develop legal minimum physical environment standards for care homes. • Develop minimum care standards for safe handling and patient transfer. 	<ul style="list-style-type: none"> • Ensure the safety of residents through the physical layout of the care setting and put in place arrangements to prevent falls (grab rails and adequate number of trained staff). • Personal care should ensure safe handling of residents.
FREEDOM FROM TORTURE, DEGRADING OR INHUMAN TREATMENT; VIOLENCE AND ABUSE (INCORPORATES THE RIGHT TO AN EFFECTIVE REMEDY)	UDHR (Article 5) CAT (Article 2) ICCPR (Articles 2, 3a, 7) ECHR (Articles 3, 13)	<ul style="list-style-type: none"> • Develop minimum standards on the provision of personal care and interaction with care users that raises awareness of the potential for violence and/or abuse of older persons in receipt of care and advises them on which measures to take if they suspect that abuse has taken place and in particular to encourage them to report abuses to competent authorities. • Programme of inspection of care homes by an independent statutory authority; human rights training for inspectors. • Ensure care homes provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner. 	<ul style="list-style-type: none"> • Provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner. • Put oversight mechanisms in place to monitor the situation of older persons in nursing homes and manage risks that may arise. • Train staff on the quality of care to prevent abuse and advise them on which measures to take if they suspect that abuse has taken place. • Encourage staff to report abuses to competent authorities.
LIBERTY, FREEDOM OF MOVEMENT AND RESTRAINT	ICCPR (Articles 7, 9, 10, 12) CRPD (Article 14, 15, 18) ECHR (Articles 3, 5)	<ul style="list-style-type: none"> • Make alternative community-based services available in order to provide less restrictive alternatives to confinement. • Programme of inspection of care homes by an independent statutory authority; human rights training for inspectors. • Ensure care homes provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner without the need for restraint. • Ensure training courses for care workers include modules on restraint. 	<ul style="list-style-type: none"> • Provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner in order to avoid having to restrain them. • Train staff to understand what constitutes restraint (e.g. placing an individual into a chair which they cannot get out of without assistance and then leaving them to carry out other duties) and how to use alternative approaches to restraint to ensure each individual's well-being.

Relevant Human Rights Standards Protections Related to LTC and Suggestions for Demonstrating Compliance

RIGHT		SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: GOVERNMENT	SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: CARE PROVIDERS
CHOICE, AUTONOMY, LEGAL CAPACITY AND EQUAL RECOGNITION BEFORE THE LAW	ICCPR (Articles 14, 16, 17, 18) CRPD (Article 12, 13, 17, 19) ECHR (Article 6, 8) RESC (Articles 15, 23)	<ul style="list-style-type: none"> • Develop legislation, policies and practices to facilitate supported decision-making, rather than substituted decision-making. • Provide individuals with access to support to protect against any abuse of the right of individuals to exercise legal capacity. • Clear guidance for care providers on older persons' right to consent to care. 	<ul style="list-style-type: none"> • Care providers must recognise that each resident has legal capacity on an equal basis with others in all aspects of life, and that disability alone does not justify the deprivation of legal capacity. Thus, even when a person makes a decision that is considered to have negative consequences or their decision-making skills are considered to be deficient, their legal capacity must continue to be respected. • Develop policies and practices to facilitate supported decision-making, rather than substituted decision-making. • Facilitate individuals' involvement in decisions affecting their life and healthcare.
DIGNITY	UDHR (Article 1) ICCPR (Articles 7, 10) ICESCR (Principles) CRPD (Article 3) ECHR (Article 8)	<ul style="list-style-type: none"> • Develop minimum standards for care workers on personal care and interaction with care users. • Programme of inspection of care homes by an independent statutory authority; human rights training for inspectors. • Ensure care homes provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner without the need for restraint. • Ensure training courses for care workers include modules on dignity. 	<ul style="list-style-type: none"> • A critical mass of staff with post-second level training in long-term care. • On-going training for staff in human rights and dignity. • An adequate staff complement. • Leadership from management (e.g. highlighting questionable practices they are not willing to permit). • Ensure each resident's potential is met and fulfilled. • No unnecessary restraint. • No incontinence pads when the individual can access the toilet with support.
PRIVACY AND FAMILY LIFE	UDHR (Article 12) ICCPR (Articles 17, 23) CRPD (Article 22, 23) ECHR (Article 8) ESC, Article 16 RESC (Articles 16, 23)	<ul style="list-style-type: none"> • Provision of an adequate supply of LTC services, at home and in residential settings. • Minimum standards regarding residents sharing rooms and other measures to protect privacy and on the provision of contact with family members and friends. • Guidance for care providers on the circumstances in which it is permissible to provide personal care or medical treatment without an individual's consent. • Ensure training courses for care workers include modules on respect for privacy. 	<ul style="list-style-type: none"> • Respect each resident's right to individual identity and private space, including modesty when dressing/bathing and privacy when one's personal circumstances are discussed by others. • Respect each individual's personal choice as to their preferred mode of dress and address. • Take reasonable steps to help each individual maintain contact with family members and accommodate spouses or same sex couples who wish to live together and continue their relationship in the home. • Ensure privacy of correspondence, data and discussions about care are also protected. • Provide each individual with information about their human rights if it is clear that their rights are at risk. • Care homes may restrict an individual's right where they can show that its action is lawful, necessary and proportionate in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Annex 1 (cont'd)

RIGHT		SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: GOVERNMENT	SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: CARE PROVIDERS
PARTICIPATION AND SOCIAL INCLUSION	ICCPR (Article 25, 26) ICESCR (Article 15) CRPD (Articles 3, 19, 26, 29) RESC (Articles 15, 30)	<ul style="list-style-type: none"> • Education, employment, health care, social service systems, transportation, technology and society should be adapted to ensure they are accessible and appropriate. • Systems should be in place to support older persons and persons with disabilities to vote. • States should closely consult with and actively involve older persons (with disabilities...) through their representative organisations in the development and implementation of legislation and policies to implement processes concerning policies and other issues relating to persons with disabilities. 	<ul style="list-style-type: none"> • Facilitate the right to take part in the conduct of public affairs and to vote. • Provide or facilitate access to a range of educational programmes, recreational activities and events. • Facilitate individuals' involvement in decisions affecting life and healthcare. • Care homes may restrict an individual's right where they can show that its action is lawful, necessary and proportionate in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.
FREEDOM OF EXPRESSION, FREEDOM OF THOUGHT, CONSCIENCE: BELIEFS, CULTURE AND RELIGION	UDHR (Articles 18, 19) ICCPR (Articles 18, 19) ICESCR (Articles 6, 7, 13) ECHR (Articles 2, 9,10) CRPD (Articles 21, 29)	<ul style="list-style-type: none"> • Ensure older persons in receipt of LTC have access to education, medical care, employment and information. 	<ul style="list-style-type: none"> • Provide each resident with information about the care setting and issues affecting their daily lives and healthcare in accessible formats and technologies as required, in a timely manner and without additional cost. • Facilitate the right to worship or assemble in connection with a religion or belief and to establish and maintain places for these purposes. • Provide reasonable access to the foodstuff in accordance with dietary requirements of a religious faith. • Have regard to the fair balance that has to be struck between the general interest of the community and the competing private interests of the individual, or individuals, concerned.
HIGHEST ATTAINABLE STANDARD OF PHYSICAL AND MENTAL HEALTH	ICESCR (Article 12) CRDP (Article 25) ESC (Article 11) RESC (Article 11, 23)	<ul style="list-style-type: none"> • Use the State's available resources to provide timely and appropriate health care. • Provide access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions and access to health-related education and information, including on sexual and reproductive health. • Ensure the participation of each individual in all health-related decision-making. • Ensure care providers respect each individual's right to refuse treatment. • Make health facilities, goods and services available, accessible, affordable, acceptable insofar as possible. 	<ul style="list-style-type: none"> • Ensure the participation of each individual in all health-related decision-making. • Respect each individual's right to refuse treatment. • Make health facilities, goods and services available, accessible, affordable, acceptable (and tailored) insofar as possible. • The provision of an integrated model of care, combining elements of preventative, curative and rehabilitative health treatment. • Regularly review each individual's medication, including a review of the appropriateness of continuing with dementia or anti-psychotic drugs. For residents who have decision-making capacity, a process of review can ensure that they are aware of the risks and benefits of a particular medication, so that their consent to continue or refuse treatment is properly informed. • Provide mental health programmes, adequate palliative care services and measures designed to promote health, for instance, prevention and awareness-raising.

Relevant Human Rights Standards Protections Related to LTC and Suggestions for Demonstrating Compliance

RIGHT		SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: GOVERNMENT	SUGGESTIONS FOR DEMONSTRATING COMPLIANCE: CARE PROVIDERS
ADEQUATE STANDARD OF LIVING	ICESCR (Article 11) CRPD (Article 28)	<ul style="list-style-type: none"> • Ensure care homes are adequately funded to meet the State's obligation to provide residents with an adequate standard of living. • Provide an adequate number of trained staff to ensure adequate living conditions. 	<ul style="list-style-type: none"> • Provide adequate food and nutrition, clothing, housing and the necessary conditions of care (when required) and the obligation to take immediate steps to achieve progressively the full realisation of the right to the highest adequate standard of living.
EQUALITY AND NON-DISCRIMINATION	ICCPR (Article 4) ICESCR (Article 2) CRPD (Article 3) ECHR (Article 14) RESC (Part 5, Article E)	<ul style="list-style-type: none"> • Develop a Positive Ageing/Long-term Care National Strategy, developed in consultation with care providers, older persons and advocacy organisations, to raise the profile of older persons and protect against discrimination. • Ensure older persons have adequate access to long-term care, particularly those with limited financial resources and on the basis of need. This is particularly the case for older women. • Ensure older persons have access to healthcare on an equal basis with other groups, paying attention to their health needs. • Provide for adequate access to justice and redress in cases where individuals feel they have been discriminated against (on the basis of age or on multiple grounds). 	<ul style="list-style-type: none"> • Refrain from enacting care home policies and practices with a discriminatory content, or in a discriminatory way, towards staff, volunteers and residents. • Facilitate the needs and wishes of minority groups. • Ensure equity in out-of-pocket payments for care homes.
ACCESS TO JUSTICE, EFFECTIVE REMEDY, REDRESS	ICCPR (Article 3) CRPD (Article 13) ECHR (Articles 6, 13)	<ul style="list-style-type: none"> • Ensure older persons in or seeking long-term care have access to information about their rights, the complaints procedure, how to make a complaint and support for doing so. • Ensure complaints cases are dealt with within a reasonable timeframe. • Establish an independent third party advocacy service for older persons. • Support for NHRIs to facilitate and support access to justice. 	<ul style="list-style-type: none"> • Provide 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. • Deter conduct that would infringe human rights. • Provide effective avenues for complaint that allow individuals to report breaches of their human rights or well-being without fear of reprisal. • Respond to complaints within a reasonable timeframe. • Provide residents with access to independent third party advocacy services.
PALLIATIVE CARE AND EXIT FROM LTC	RESC (Article 23)	<ul style="list-style-type: none"> • Put appropriate care arrangements in place for individuals currently living in residential LTC to live independently in the community if they wish. • Ensure individuals at the end of their lives have access to palliative care and pain relief. 	<ul style="list-style-type: none"> • Ascertain that older persons living in residential LTC wish to remain there on a regular basis. • Ensure individuals are spared avoidable pain and enabled to die with dignity. • Provide adequate palliative care services. Access to pain treatment is an absolute human right.

Note

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