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**Applying a Human Rights-  
Based Approach to Long-term  
Care for Older Persons:  
A Toolkit for Care Providers**

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# Executive Summary

## **Introduction**

This report aims to help care providers throughout Europe to understand their human rights obligations to older persons in need of long-term care by demystifying human rights and how to apply them in care settings. This will help to embed a human rights-based approach in everyday practices in long-term care settings for older persons. The report draws on monitoring work of the human rights situation in the long-term care sector carried out by members of ENNHRI in six European states to highlight how a human rights-based approach to long-term care can help care providers to meet their human rights obligations.

## **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 human rights-based approach 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. It is a useful and effective way of helping care providers to meet their obligations under human rights national and international legislation. It has many benefits for staff and service users alike and has 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. 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.

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## 1. Introduction

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

George Bernard Shaw, Irish playwright



The population of the world is ageing rapidly. People aged 60 and older make up over 11 per cent of the global population, and by 2050, that number will rise to about 22 per cent. In Europe alone, the population aged 65+ will more than double over the next 50 years.

This growth is a true cause for celebration: older persons are living longer because of better nutrition, sanitation, health care, education and economic well-being. Moreover, population ageing creates countless opportunities. Older persons (aged 65+) already contribute to society in a number of ways - volunteering, care of children and dependent older persons, transmitting their institutional memory and wisdom and contributing to the “silver economy” (spending on goods and services related to the needs and opportunities of ageing). With the right measures in place to secure health care, regular

income, social networks and legal protection, population ageing gives older persons a chance to contribute to society in more meaningful ways.

At the same time, population ageing is resulting in increased demand for long-term care. Older persons in and seeking LTC across Europe face challenges accessing and using these services. Policy-makers fear that these challenges may become more pronounced as they seek to cater for higher numbers of service-users with finite resources. Moreover, in spite of commitments to various human rights conventions, the human rights standards and situation of older persons are not well known or understood.

This report aims to help care providers throughout Europe to understand their human rights obligations to older persons in need of long-term care by demystifying human rights and how to apply them in care settings. This will help to embed a human rights-based approach in everyday practices in long-term care settings for older persons. The report draws on monitoring work of the human rights situation in the long-term care sector in six European states to highlight how a human rights-based approach to long-term care can help care providers to meet their human rights obligations.

Section 2 of the toolkit introduces ENNHRI and its project on *The Human Rights of Older Persons and Long-term Care*. Section 3 explains what human rights are, while Section 4 clarifies what a human rights-based approach is and its underlying principles. Section 5 sets out the case for a HRBA while Section 6 offers guidance on how to support the implementation of a HRBA in the day-to-day operations of a residential care setting. Section 7 offers a brief summary and draws some conclusions.

## 2. Background

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

Nelson Mandela, South African Politician and Philanthropist

ENNHRI is the European Network of National Human Rights Institutions. ENNHRI comprises 40 National Human Rights Institutions (NHRIs) from wider Europe. NHRIs are state funded institutions, independent of government, with a broad legislative or constitutional mandate to promote and protect human rights. Accredited by reference to UN Paris Principles (1993), 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 June 2017, the goal of the project is to improve the human rights protection of older persons in long-term care, with particular emphasis on residential care.

One of the key elements of the Project was the monitoring of the current human rights situation of older persons in and seeking long-term care in six representative EU Member States: Belgium, 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.<sup>1</sup>

The monitoring work showed that most care workers instinctively used a person-centred approach to inform their work. However, several practices identified in relation to the full protection of the human rights of older persons in care homes 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 on how to respect the autonomy of each individual resident while protecting them from harm. One of the biggest reasons for the challenges care providers faced was that they were not always sure what their human rights obligations were towards their older residents, and how these should be put into practice.<sup>2</sup>

### 3. What are Human Rights?

*Iniquum est conlapsis manum non porrigere; commune hoc ius generis humani est. (It is wrong not to give a hand to the fallen; this law is universal to the whole human race.)*

Seneca the Elder, Orator/Philosopher

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<sup>1</sup> UNIA, the Interfederal Centre for Equal Opportunities, Belgium; The Office of the Ombudswoman of the Republic of Croatia; The German Human Rights Institute; The Office of the Commissioner for Human Rights Hungary; The Seimas Ombudsmen's Office of the Republic of Lithuania; and The Romanian Institute for Human Rights.

<sup>2</sup> ENNHRI, 2017, "*We have the same rights:*" *The Human Rights of Older Persons in Long-term Care in Europe*. [www.ennhri.org](http://www.ennhri.org)

### 3.1 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 or ethnic origin, colour, religion, language, or any other status.

The basic objective of human rights is to empower individuals to fulfil their full potential by giving them the authority, capacities, capabilities and access needed 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. Their wishes must be respected and safety considerations only take priority over an individual's autonomy in limited circumstances.

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

### 3.2 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. These include the nine binding United Nations (UN) human rights conventions.<sup>3</sup>

Every state that has ratified a UN human rights treaty must report to UN treaty bodies on the implementation of the human rights obligations contained within the relevant treaty. Some treaties also allow for individual complaints to the UN body.<sup>4</sup> 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.

The most recent UN convention, the CRPD, is important for older persons in LTC. About 60% of Europeans aged 75 years and over reported limitations in daily activities due to a health problem<sup>1</sup> and 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 a different perspective on a number of human rights issues than older treaties. For example, guidance on

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<sup>3</sup> <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx>

<sup>4</sup> In some cases, this depends on the ratification of an Optional Protocol.

Article 14 issued by the CRPD Committee (the treaty body tasked with monitoring compliance with the Convention) in 2014 firmly endorses the absolute prohibition of detention on the basis of disability. As such, it is contrary to Article 14 of the Convention for any state to force any individual to live in an institution against their will. Similarly, the 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.

The Council of Europe's **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 defined in the Convention. 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.

### 3.3 Human Rights Obligations

Human rights create both rights holders and duty bearers. As States ratify human rights conventions, they have primary responsibility to uphold them. This includes any organisation providing services on behalf of the State, including a residential care setting providing long-term care services for older persons. Rights holders are all individuals who have entitlements under a particular human rights convention. The guiding spirit of the application of human right standards is that their enjoyment is not limited to citizens of States parties. They are available to all individuals, regardless of nationality or statelessness, such as asylum seekers, refugees, migrant workers and other persons who find themselves in a State party's territory or subject to its jurisdiction.<sup>5</sup>

The obligations of duty-bearers varies, depending on the human right in question and the resources available to the state. Some human 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 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 only if there is a clear legal basis with a

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<sup>5</sup> [http://www.biicl.org/files/5930\\_building\\_human\\_rights\\_into\\_practice\\_-\\_english.pdf](http://www.biicl.org/files/5930_building_human_rights_into_practice_-_english.pdf)

legitimate aim and the restriction is proportionate, as outlined in greater detail in Section 3.2 below.

States have a duty to take deliberate, concrete and targeted steps, as “expeditiously and effectively as possible”, towards the full realisation of economic, social and cultural rights according to the maximum of available resources (known as the principle of “progressive realisation”). However, 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 fulfill 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 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. Section 2.4 below seeks to show care providers examples of areas where they are expected to prioritise resources in order to fully comply with their human rights obligations.

### 3.4 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.<sup>6</sup>

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

- Access to long-term care (Equal access to affordable health services for all persons; choice of long-term care 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

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<sup>6</sup> ENNHRI: *Human Rights of Older Persons and LTC Project: The Application of International Human Rights Standards to Older Persons in LTC*, forthcoming.

- 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 redress<sup>7</sup>

Although the binding human rights conventions do not include a specific right to LTC, nor the right to have a choice of LTC service,<sup>8</sup> the Committee on the Rights of Persons with Disabilities has confirmed that persons with disabilities have a right to choose the type of care, including residential, home or community care, and so older persons with a disability should not be admitted into residential care against their will.

However, there are also important limitations:

1. There is no automatic right to receive long-term care services, nor to choose the provider or care setting.
2. Many rights are interpreted differently by different treaty bodies and courts, particularly around autonomy, e.g. 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 prioritises an individual's right to make decisions others may not agree with.

A body of “soft law” also guides the treatment of older persons. The UN's Principles for Older Persons,<sup>9</sup> the Madrid International Action Plan on Ageing<sup>10</sup> and the Council of Europe's Recommendation on the Promotion of Human rights of Older Persons<sup>11</sup> gives guidance to duty bearers on the rights of older persons and how to implement them.

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<sup>7</sup> Annex X sets out the conventions providing for each of these rights and Annex X shows which European states have ratified each treaty, and thus accept responsibility for implementing them.

<sup>8</sup> See ECtHR Judgement: H.M v Switzerland, 26 February 2002, (no.39187/98), ECtHR Judgement Watts v. the United Kingdom, 4 May 2010, (no.53586/09).

<sup>9</sup> UN Principles for Older Persons, 1991, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

<sup>10</sup> Madrid International Plan of Action on Ageing, 2002, [www.un.org/en/events/pastevents/pdfs/Madrid\\_plan.pdf](http://www.un.org/en/events/pastevents/pdfs/Madrid_plan.pdf)

<sup>11</sup> Council of Europe, Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons, <https://wcd.coe.int/ViewDoc.jsp?id=2162283&>

### 3.5 LTC Care Providers Human Rights Obligations in Practice

Along with an understanding of human rights obligations in practice (outlined in Section 2.3) and the human rights relevant to long-term care, determining how duty-bearers are supposed to realise their human rights obligations requires an understanding of how human rights bodies interpret binding human rights law in practice. Annex X provides an overview of the obligations under each human right relevant to long-term care settings, as interpreted by relevant UN treaty bodies and the ECtHR. This overview table is based on a review carried out by ENNHRI as part of *The Human Rights of Older Persons and Long-term Care Project*. The table is not meant to serve as an exhaustive account of care providers' obligations, but to provide guidance on key priority areas.

## 4. What is a Human-Rights Based Approach?

### 4.1 A Human Rights-Based Approach

*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

A human rights-based approach (HRBA) to service delivery is a model that places the principles and standards of human rights as central to all aspects of service planning, policy and practice. A HRBA has the following key elements:

1. all key stakeholders are empowered and can participate in achieving the realisation of rights;
2. the rights promoted are explicitly linked to national and international human rights law (set out in Annex One);
3. accountability is clear; and
4. the most discriminated against, marginalised or excluded people are prioritised.<sup>12</sup>

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<sup>12</sup> British Institute of Human Rights (2008) *Changing Lives*, Second Edition.  
<https://www.bihar.org.uk/changing-lives>

The key element of a HRBA is that it ensures that care becomes a right which all individuals (rights-holders) can claim, and places responsibilities on governments and their agents, including care providers (duty-bearers), who are accountable for fulfilling their legal obligations to protect and promote the human rights of all individuals within their jurisdiction.

A HRBA is underpinned by five key human rights principles, known as the PANEL principles:<sup>13</sup>

- **Participation:** older persons in receipt of care should participate in all decisions about the care and support they are receiving.
- **Accountability and Transparency of duty-bearers to rights-holders:** those involved in the provision, commissioning and policy-making of long-term care have a responsibility to ensure that the standards of accountability and transparency for human rights are as high as possible, as well as providing effective remedies when breaches do occur.
- **Non-discrimination and equality:** older persons also have different identities based on their gender, ethnicity, religion and many other grounds. Each of these identities should be respected when receiving care and support services.
- **Empowerment of rights holders:** all older persons in receipt of care should understand what their rights are and how they can claim these rights. Achieving this may require the provision of appropriate advocacy or other communication support.
- **Legality – public authorities and care providers must be sure that their practices and procedures are grounded in human rights law and must not breach the human rights of anyone.**

A human rights-based approach 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.

Essentially, in order to put human rights laws and principles at the heart of policy making and service delivery for long-term care, staff and residents must be empowered with knowledge on human rights and leadership in order to be

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<sup>13</sup> Scottish Human Rights Commission, 2012, Care About Rights? Human Rights and the Care of Older People Information Pack, <http://www.scottishhumanrights.com/careaboutrights>. The rights underpinning a human-rights based approach were also adopted as [the values of ENNHRI](#) as a network: Respect of International Human Rights Standards; Transparency; Co-operation; Accountability; Participation; Non-discrimination; and Independence.

able to understand how best to implement all human rights, paying particular attention to vulnerable individuals and groups.

#### 4.2 A Human Rights-Based Approach to Decision-Making

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 within limits. 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 liberty and security of person
- The right to freedom of assembly and association
- The right to protection of property

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

When faced with a difficult decision, staff may find it useful to think about how the individual's rights will be affected by the outcome. Care providers 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: Example I**

Mary, aged 78, has Alzheimer's Disease and uses a stick to help maintain her balance when she walks. She has been moved into a care home and her family have asked staff to pay attention to make sure she does not fall. When sitting near the window one day, she becomes agitated as she wants to go out into the garden. The care worker is busy and is unable to accompany her and so is forced to prevent her. Mary becomes increasingly agitated.

At the next care team meeting, the team discuss

**which rights are at stake?** The right to respect for private and family life; the right to liberty and security; the right to freedom of movement.

**Can these rights be legally restricted?** It is legally valid to restrict these rights for the safety of Mary herself and for others.

**What is the justification?** The justification in this instance is that the restriction is for Mary's own safety.

**Is not allowing Mary out proportionate?** It would appear however that not allowing Sheila outside is a disproportionate restriction and there may be other ways to deal with the issue which are a lesser restriction on Sheila's rights. For example, she can be accompanied outside and plants can be put inside for her for times when she can't go out.

**Source: Scottish Human Rights Commission: Care About Rights**

<http://www.scottishhumanrights.com/health-social-care/care-about-rights/>

### **Making Decisions Using a HRBA: Example II**

Olive and Joe got married in 1940. They were a very close couple - they hardly ever had a cross word between them. At age 70, Joe developed Alzheimer's. As the disease progressed, Olive reluctantly agreed to put Joe in a nursing home as she couldn't cope anymore. 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”.

*ALTERNATIVE VERSION: A Human Rights-Based Approach*

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 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 is 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.

Human Rights and Older People in Ireland, 2013<sup>14</sup>

#### 4.3 A HRBA in LTC in Practice

Residential care homes for older persons have existed in many Western 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 nurses, 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.

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<sup>14</sup> <https://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/ASI-HROP-A4-Online-Report.pdf>

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.

Thus, 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.<sup>15</sup> The following account of a model of care developed in the United States over the last ten years helps to illustrate how a person-centred works in practice in long-term care settings.

#### **The Green House Model**

The Green House Project is an American national non-profit organisation dedicated to creating alternative living environments to traditional nursing home care facilities. The project was first developed by geriatrician William H. Thomas (physician) in 2003, with the goal of personalizing elder care by redesigning nursing homes “from scratch” to provide residents more privacy and control over their lives. The organisation aims to create caring homes to allow residents to have a more meaningful life than they would have in a traditional nursing home.

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WeDo, 2012, European Quality Framework for Long-term Care Services,  
[http://wedo.ttp.eu/system/files/24171\\_WeDo\\_brochure\\_A4\\_48p\\_EN\\_WEB.pdf](http://wedo.ttp.eu/system/files/24171_WeDo_brochure_A4_48p_EN_WEB.pdf)



The main characteristics of a Green House home are:

- Smaller facilities (10-12 residents) in the middle of existing communities; the homes are built to blend in with surrounding houses and neighbourhoods;
- Homes are designed for the purpose of offering privacy, autonomy, support, enjoyment, and a place to call home;
- A real home environment with an open kitchen, great room, and easy access to the outdoors;
- Residents do not have strict schedules and are encouraged to interact with staff and other residents, plus visitors (pets and family members). Their personal preferences are respected;
- The homes offer an opportunity for continued growth and development. Residents are known as creative, resourceful and whole people, who deserve meaningful lives;
- Relationships are the cornerstone of the model; all staff members and residents develop personal relationships with one another because of the small community and home atmosphere;
- A vertical organizational chart, with individual staff given greater autonomy to care for residents according to their individual needs and rights;
- Staff members in Green House Project homes are broken up into four different roles: the Shabaz, the Guide, the Sage and the Clinical Support Team. The Shabaz is the versatile worker who provides

personal care, prepares meals and performs housekeeping for the residents. The Guide is the supervisor of the Shahbaz and is responsible for the operations of the home. The Sage is a local elder who volunteers to be a mentor and advisor to the work teams in The Green House Project home. The Clinical Support Team comprises nurses, therapists, services, activities and dietary professionals who work with the Shahbaz to provide individualized care for each resident;

- Policies and procedures for dealing with grievances and complaints, which are similar to the system for more traditional care homes – firstly, speaking to the person who has caused the grievance in the first place. If this is not possible, calling on the Guide to intervene, and/or supporting residents to use formal complaints procedures within the jurisdiction.

Research has shown that, compared with traditional nursing homes, Green House residents have a higher quality of life, improved quality of care (maintained self-care abilities longer, lower rates of depression). Staff report higher job satisfaction, with lower turnover rates. Green House receive higher direct care time (23–31 minutes more per resident per day) than traditional nursing homes and more than four times as much staff engagement with elders outside direct care activities.<sup>16</sup> Studies indicate that capital costs are higher for Green House homes than traditional ones, although there are some opportunities for savings, through a lower staff turnover, fewer risks and better resident outcomes.<sup>17</sup>

Since the first Green House home opened in 2003, the project has spread to 26 states, with 86 Green House homes open in 15 states and another 125 homes in development or construction in an additional 11 states.

Source: <http://www.thegreenhouseproject.org/>

Many human rights experts and care clinicians suggest that 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 human rights-based approach is underpinned by an

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<sup>16</sup> 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.

<sup>17</sup> Jenkins, R., Sult, T., Lessell, N., Hammer, D. and Ortigara, A., 2011, Financial Implications of THE GREEN HOUSE® Model, *Seniors Housing and Care Journal*, 19(1), 3-22.

objective legal framework, reflecting the binding international human rights treaties which states have agreed to uphold.

## 5. The Case for a HRBA

*What we need is a radical reinterpretation of longevity that makes elders (and their needs) central to our collective pursuit of well-being.*

Bill Thomas, Founder of the Green House Model

### 5.1 The Legal Case

All member states of the CoE have ratified the ECHR, along with other binding UN and CoE conventions, and as such, have a duty to comply with all of the human rights standards they elucidate. This means governments, and care providers acting on behalf of the State, need to ensure that they uphold all of the rights relevant to long-term care outlined in Section 2.2. The focus in a HRBA on human rights principles set out in international legislation helps to support care providers to meet their human rights obligations towards older persons seeking/in receipt of long-term care.

### 5.2 The Practice Case

Research on a HRBA suggests that organisational processes can become more **consistent and efficient**, as there is greater clarity about the objectives and expected outcomes. This in turn can lead to a better organisational culture. Adopting a human rights based approach may **improve risk management**, through improved stakeholder relations, reduced risk of service user complaints, greater transparency and accountability, and enhanced organisational reputation. Protecting the human rights of employees leads to **increased productivity**, as workers who are treated fairly and with dignity and respect are more productive, suffer less stress and thus have lower rates of absenteeism. Finally, a human rights based approach had resulted in improvements in service delivery standards in mental health, general healthcare, criminal justice, disability and carer services, housing, and emergency services.<sup>18</sup>

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<sup>18</sup> UK Audit Commission (2003), *Human rights: improving public service delivery*. <https://www.justice.gov.uk/downloads/human-rights/acrep03.pdf> ; Victorian Equal Opportunity

Studies show that a HRBA in the area of long-term care can help to lower some of the costs associated with long-term care, while improving clinical outcomes (quality of life, fewer behavioural and critical incidents and a decrease in pressure sores), better relations between staff and residents as well as reduced staff turnover and absenteeism.<sup>19</sup>

## 6. Implementing a HRBA in LTC Settings

*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

### 6.1 Introduction

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. 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. 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. Annex 1 provides more guidance on care providers' obligations with respect to each human right relevant to long-term care.

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and Human Rights Commission, (2008), *From principle to practice: implementing the human rights-based approach in community organisations*,

<http://www.humanrightscommission.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>.

<sup>19</sup> 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.

### **5 key steps to a human rights-based approach for service providers**

1. Ensure the organisation's board understands the role of human rights and commits to a human rights-based approach.
2. Incorporate human rights into the strategic objectives of the organisation and develop a Single Equality and Human Rights Scheme 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.
3. Write action plans, with responsibility clearly designated, and monitor progress on a regular basis.
4. Develop tailored training programmes and guidance 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. Empower staff to propose changes in their own work and suggestions for the organisation to protect human rights.
5. 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.

Source: Age Concern UK, 2008, On the Right Track<sup>20</sup>

### **Implementation of a HRBA in The State Hospital, Scotland**

An account of the implementation of a HRBA in The State Hospital, a high security forensic mental health hospital in Scotland, is helpful in understanding the process involved in moving to this model. The State Hospital was prompted to change its model of care delivery following a critical report by the Mental Welfare Commission into the treatment and care of a particular service-user. An evaluation of the implementation and outcomes of the process by the Scottish Human Rights Commission helps to show how long-term care settings can apply a human-rights based approach.

Overall, The State Hospital's implementation approach had three stages:

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<sup>20</sup> [http://www.ageuk.org.uk/documents/en-gb/professionals/research/on%20the%20right%20track%20\(2008\)\\_pro.pdf?dtrk=true](http://www.ageuk.org.uk/documents/en-gb/professionals/research/on%20the%20right%20track%20(2008)_pro.pdf?dtrk=true)

## 1. *Planning*

- Establishment of a Human Rights Working Group (HRWG) led by senior management and involving clinical and non-clinical members of staff;
- Training for the HRWG with a human rights expert to identify specific human rights relevant to The State Hospital.
- Assessment of all policies and practices using a Traffic Light assessment tool:
  - 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.

Following the policy and practice review, one of the issues which demanded the most immediate attention was ensuring that policy and practice on the management of violent incidents complied with human rights legislation. The review revealed that prior to the development of a human rights-based approach, the manner of dealing with service-user violence was a through a “blanket policy” of procedures rather than a process which took proper account of the context and individual circumstances of each individual. The blanket policy approach had been adopted to ensure effective risk management and protect the rights of other service-users, staff and others as relevant, but did not take enough account of the individual in question.

## 2. *Service Delivery*

The rollout of the HRBA involved putting in place a number of key actions:

- The development of a training programme for staff and tools for the assessment of future policy and practice by the HRWG and an external human rights expert.
- The establishment of a forum for staff, service-user, and carer involvement in decisions.
- The creation of an Equality, Diversity and Human Rights Group to ensure a human rights approach to the delivery of equality duties.
- The development of a Human Rights Best Practice Guide for staff, which outlined 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.

- Development of education and awareness-raising programmes for all staff, which explored the motivations behind the human rights-based approach and made use of realistic case studies to bring human rights issues to life for staff.
- Steps to facilitate residents to participate in policy planning and service provision, including suggestion boxes in all clinical areas; service-user group meetings; feedback posters; extensive information points on wards and a weekly newsletter; monthly ward meetings; annual survey of residents to capture views on treatment and care; establishment of key worker system for each service-user. Service-users were also invited to attend their periodic case reviews.
- Development of a Human Rights Charter for everyone (staff, service-users and carers): formal explicit statement about the human rights of all groups in the hospital.

### *3. Review and Continuous Improvement*

Once The State Hospital had fully implemented the HRBA, it set about putting in place a plan to review how successful it was, and how to ensure the approach could be improved on a continuous basis:

- The Human Rights Group and Hospital Management Team were tasked with monitoring compliance with human rights standards;
- A service-user complaints system was established, with staff given information on how to facilitate complaints and made aware that service-users may need support to understand their right to complain;
- Service-user complaints: all service-users were provided with a flowchart setting out local and national complaints mechanisms;
- All complaints were recorded and reviewed;
- A Freephone number was made available to all service-users to access advocacy services to help them make a complaint;
- Periodic re-training to ensure human rights stays central to hospital practices.

### *4. Success Factors*

The following elements were seen as crucial to the success of the State Hospital's experience:

- top level buy-in and vision from the Board, Chief Executive and senior management
- clear executive leadership in implementation by a senior management team
- involvement from an early stage of human rights expertise to support the development and tailoring of a HRBA
- a participatory diagnostic process, 'the human rights audit', involving staff and stakeholders of an organisation help create a culture of care
- investment of appropriate time and resources
- a proportionate approach, consistent with human rights principles itself, so that the HRBA effort reflects the significance of the issues
- an approach which focuses on the rights of everyone affected: staff as well as service-users and their carers
- the HRBA promoted understanding of everybody's rights, and how to balance one person's rights against those of another, as well as how to justify limitations of rights.

Source: Scottish Human Rights Commission, 2009, op cit.

## 6.2 Dignity and the Prohibition of Torture/Abuse

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”.<sup>21</sup> Dignity is the basis of human rights. Even if it is rarely protected in its own right in binding human rights treaties, 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.

Findings on the right to dignity varied widely amongst the six countries, often due to staff shortages or inadequate training on how to protect each individual resident’s dignity. This included insufficient attention to the privacy and dignity of residents, such as personal care tasks being carried out with doors wide open or not using curtains/ screens; transporting residents in a state of undress; inappropriate clothing; bathing several residents at the same time; providing meals of an inadequate temperature, quantity and quality; and an inadequate physical environment, resulting in areas being blocked off from residents or in undignified forms of transport. Even in homes where care providers had made considerable effort to develop a reputation as care homes that placed residents’ right to dignity at the centre of everyday practice,

<sup>21</sup> [http://www.age-platform.eu/images/stories/22204\\_AGE\\_charte\\_europeenne\\_EN\\_v4.pdf](http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf)

managers spoke of “slippery slope”, whereby allowing minor questionable practices to go unchallenged led to them becoming commonplace, which in turn allowed other, more serious issues to emerge.

The overall lack of respect for dignity seemed to stem from workers or their managers not thinking about the older person as an individual who needs to be accorded dignity and respect for their personal privacy, and may indicate that a wider cultural attitude which fails to focus on dignity and human rights. In addition, low staff ratios meant workers felt unable to dedicate time to ensuring the dignity of each resident.

At the same time, monitoring of care teams found ample evidence of good practice. This included the development and implementation of a confidentiality policy in some care homes; ensuring dignity is a central part of staff training and everyday practice; and taking care of each resident’s unique needs.

<b>Training for Care Workers Focusing on Dignity</b>
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<p>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.</p>
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<p>Examples of upholding residents’ dignity and human rights in the LTC context given by interviewees included enjoying freedom of movement without restrictions (all Homes), and having a free choice of activities during the day (all Homes) to very specific ones, like, ‘having breakfast in pyjamas’ (Home 1), and ‘keeping pets, smoking or having a glass of wine before going to bed’ (Home 3).</p>
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<p>German Institute for Human Rights, Human Rights of Older Persons in Long-Term Care: National Report</p>
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<b>Protecting the Right to Dignity: Useful Resources</b>
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<p>AGE Platform Europe, Dignity and Well-Being of Older Persons in Need of Care, <a href="http://publications.age-platform.eu/opcare-toolkit/">http://publications.age-platform.eu/opcare-toolkit/</a></p>
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Department of Health, UK, With Respect: Dignity in Homecare Training Programme, <https://www.ukhca.co.uk/pdfs/DHTP3TutorsGuide.pdf>

EUSTACEA, 2010, European Charter of the rights and responsibilities of older people in need of long-term care and assistance, [http://www.age-platform.eu/images/stories/22204\\_AGE\\_charte\\_europeenne\\_EN\\_v4.pdf](http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf)

First Steps for Care Assistants, Preserving People's Dignity, <http://rcnhca.org.uk/equality-diversity-and-rights/preserving-peoples-dignity/>

IsQua: Guidelines and Principles for the Development of Health and Social Care Standards: <http://www.isqua.org/accreditation-iap/reference-materials>

Social Care Institute for Excellence: Dignity in Care, <http://www.scie.org.uk/publications/guides/guide15/index.asp>

### 6.3 Safety v Liberty and Autonomy

Partly as a result of the lack of clarity in how the right to autonomy is interpreted by different human rights organisations, care homes in all six countries experienced challenges in balancing residents' right to choice and autonomy with ensuring their safety.<sup>22</sup> For example, residents often had little opportunity to input into their care plan or daily routine, decorate their own bedrooms/private space and lacked information about the way life in the home was organised. In addition, many residents were subject to restraint by staff either out of a deliberate (well-meaning) attempt to protect their safety while they engaged in other duties or unconsciously failing to understand that the resident was restrained (e.g. placed in a low armchair out of which the individual could not move without assistance).

Care homes in several countries managed this tension by focusing on creative ways of balancing the right to autonomy while at the same time ensuring residents were kept safe. Technological aids, such as alarm mats, alarm bracelets, wheeled walkers, protection trousers and other devices, were used to avoid restraining residents.

Care homes that successfully maximised each resident's autonomy were those that prioritised ways of maintaining and supporting personal autonomy even when the resident's physical abilities were declining due to old age. This included a focus on rehabilitation and empowering and facilitating residents to

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<sup>22</sup> 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.<sup>22</sup> 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).

take part in the daily life and running of the care home – including peeling potatoes and making their own beds where possible. When staffing ratios allowed, many care homes also developed a flexible daily schedule in order to allow residents to live according to the routine they had followed before moving into the care setting.

Although national/regional regulations and guidelines can clash with the care homes' preferred way of responding to residents' individual needs, several care homes sought to find creative approaches whereby they catered for residents' wishes while still complying with the rule. For example, in one care home in Germany, residents preferred to be engaged in activities that made a practical impact in the home, rather than those provided simply to pass the time (e.g. bingo or watching movies). However, stringent rules on food safety made it difficult for staff to allow residents assist in cooking their own meals. However, the care home overcame this challenge by doing ample preparation to allow residents to cook simple things by themselves (which was permitted).

#### **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.

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.

### **Protecting the Right to Autonomy: Useful Resources**

ADASS, Safeguarding Adults: National Framework,  
<https://www.adass.org.uk/adassmedia/stories/publications/guidance/safeguarding.pdf>

Frontline Care Solutions: Maintaining Documentation in an Aged Care Environment - It Doesn't Need to be Hard,  
[http://www.frontlinecaresolutions.com/blog/Frontline\\_Blog/post/maintaining-quality-documentation-in-an-aged-care-environment-does-not-need-to-be-hard/](http://www.frontlinecaresolutions.com/blog/Frontline_Blog/post/maintaining-quality-documentation-in-an-aged-care-environment-does-not-need-to-be-hard/)

Mersey Care, Human Rights Joint Risk Assessment and Management Plan,  
[http://www.humanrightsinhealthcare.nhs.uk/Library/az/human\\_rights\\_joint\\_risk\\_assessment\\_plan.pdf](http://www.humanrightsinhealthcare.nhs.uk/Library/az/human_rights_joint_risk_assessment_plan.pdf)

NHS Lanarkshire: Sample Nursing Home Safeguarding Policy with Care Act, [www3.lancashire.gov.uk/corporate/web/viewdoc.aspx?id=125808](http://www3.lancashire.gov.uk/corporate/web/viewdoc.aspx?id=125808)

NHS Derbyshire: Writing Good Care Plans, A Good Practice Guide  
[www.corecarestandards.co.uk/EasySiteWeb/GatewayLink.aspx?allId=3487](http://www.corecarestandards.co.uk/EasySiteWeb/GatewayLink.aspx?allId=3487)

Aged Care in Australia, Sample Care Plan,  
[https://swsi.moodle.tafensw.edu.au/pluginfile.php/451321/mod\\_resource/content/2/Individualised%20Plan.pdf](https://swsi.moodle.tafensw.edu.au/pluginfile.php/451321/mod_resource/content/2/Individualised%20Plan.pdf)

Alzheimer Scotland, Charter of Rights for People with Dementia and their Carers in Scotland,  
[http://www.alzscot.org/assets/0000/2678/Charter\\_of\\_Rights.pdf](http://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf)

SCIE, Total Transformation of Care and Support,  
<http://www.scie.org.uk/future-of-care/total-transformation/vision>

## 6.4 Participation

The right to participation places an obligation on care providers to provide or facilitate access to recreational activities and events for their residents, as well as for each resident to participate in decisions affecting their daily lives and care. While care homes in all six countries typically sought to provide a wide range of activities to residents, some had a more limited range of activities which tended to be only offered during office hours. Many care homes used volunteers to engage with residents and provide and facilitate activities.

### **Feeling Valued: 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 many care homes in Croatia 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.

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.

### **Protecting the Right to Participation: Useful Resources**

Alexander Port et al, Engaging Nursing Home Residents in Meaningful Activities: the Prior Activity Preferences Questionnaire  
<http://www.managedhealthcareconnect.com/article/engaging-nursing-home-residents-meaningful-activities>

Eden Alternative, Strong Communication Skills: Step One to Building a Participatory Culture, <http://www.edenalt.org/strong-communication-skills-step-one-to-building-a-participatory-culture/>

Mansbach W. E. (2014). MemPics™: People, places, and events (1st ed.)  
<https://www.thebcac.com/mempics>

Communication with Persons with Dementia: Talking Mats and Dementia, Training Programme for Care Staff, <http://www.talkingmats.com/wp-content/uploads/2013/09/JRF-dementia-training-final-report.pdf>

## 6.5 Privacy

The right to respect for privacy and family life is enshrined in the ICCPR (Article 17), the CRPD (Article 22), the ECHR (Article 8). The right to privacy has been interpreted more broadly by the ECtHR to include the right to respect for one's dignity and personal autonomy, and the right to respect for social relationships.

Care homes in all six countries had a high proportion of residents living in shared rooms. The lack of individual private rooms (and bathroom) hindered residents' right to privacy in several ways. Not only did it compromise residents' modesty when carrying out personal care tasks, it also prevented them from personalising their bedroom (e.g. bringing their own furniture), protecting their personal belongings to a greater extent, offering a constant space to speak privately, including with visitors, and informing a culture of respect for privacy amongst staff. In some care homes in Hungary and Croatia, a higher number of residents than allowed for in national regulations shared a room. However, as outlined in the box below, one care home in X used innovative and creative ways to make use of the limited space in order to protect residents' right to privacy.

### **Investing in Privacy: the Use of EU Structural and Investment Funds in Lithuania**

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.<sup>23</sup> 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.

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

### **Protecting the Right to Privacy: Useful Resources**

Advocacy Centre for the Elderly, Privacy Issues in Long-term Care, [http://www.advocacycentreelderly.org/appimages/file/ACE\\_Summer\\_Newsletter\\_Vol10\\_No1.pdf](http://www.advocacycentreelderly.org/appimages/file/ACE_Summer_Newsletter_Vol10_No1.pdf)

SCIE, Dignity in Care: Privacy, <http://www.scie.org.uk/socialcaretv/video-player.asp?v=privacy>

Sample Privacy Policy Template: <http://www.ngh.on.ca/privacy-policy.html>

The Care Certificate, Module 7: Privacy and Dignity  
<http://www.skillsforcare.org.uk/Document-library/Standards/Care-Certificate/Standard%207%20CC%20Workbook.pdf>

## **6.6 The Right to the Highest Attainable Standard of Health**

The international human rights framework provides for the right to the highest attainable standard of physical and mental health, requiring health facilities, goods and services to be made available, accessible, affordable, acceptable, and be of good quality for older persons without discrimination. Access to high quality healthcare services proved challenging for care providers in all six countries; staff shortages in care homes can have implications for ensuring personal care tasks are carried out. This in turn can have implications for overall hygiene and health. Moreover, in several countries, medical and health practitioners can also be in short supply, which can impact on the ability of

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<sup>23</sup> 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.

care homes to As staffing ratios and the supply of healthcare practitioners depends on government policies and funding, care providers often have limited control over their ability to meet their obligations in relation to the highest attainable standard of health of residents. As outlined below, several care homes in Romania have developed strategies in an endeavour to do what was possible within the constraints they face.

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

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 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 a rehabilitation surgery.

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.

### **Protecting the Right to the Highest Attainable Standard of Health: Useful Resources**

NHS, 2010, Essence of Care,  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216691/dh\\_119978.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216691/dh_119978.pdf)

<http://www.berliner-projekt.de/> (in German)

<http://www.sima-akademie.de/> (in German)

## 6.7 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. All six monitoring teams noted that access to justice was one of the most challenging rights for care homes to fulfil, given that many older persons may be reluctant to complain for various reasons, including a fear of reprisal. They suggested that care homes would therefore need to have a highly-developed complaints system that takes these issues into account. In Hungary, residents had access to an external advocate who visited the care home to assess the quality and organisation of care and to ensure all residents were happy with all aspects of their care and make complaints/enquiries on their behalf when necessary.

### **Independent Broker: the Use of External Advocates in Hungary**

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.

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.

### **Protecting the Right to Access to Justice: Useful Resources**

Age Platform Europe, Older Persons' Self-Advocacy Handbook on human rights, <http://www.age-platform.eu/publications/older-persons-self-advocacy-handbook-human-rights>

Age UK, Older People and Human Rights: A reference guide for professionals working with older people, [http://www.ageuk.org.uk/documents/en-gb/for-professionals/equality-and-human-rights/older\\_people\\_human\\_rights\\_expert\\_series\\_pro.pdf?dtrk=true](http://www.ageuk.org.uk/documents/en-gb/for-professionals/equality-and-human-rights/older_people_human_rights_expert_series_pro.pdf?dtrk=true)

American Psychological Association, Elder Abuse and Neglect: In Search of Solutions, <http://www.apa.org/pi/aging/resources/guides/elder-abuse.pdf>

British Institute of Human Rights, Your Human Rights: A Guide for Older People, <https://www.bih.org.uk/olderpeopleguide>

European Patients' Forum, Patient Empowerment, <http://www.eu-patient.eu/campaign/PatientsprescribE/>

National Committee for the Prevention of Elder Abuse (USA), Elder Abuse Training Resources, <http://www.preventelderabuse.org/elderabuse/additional/additional2.html>

## 6.8 Addressing the Causes of Human Rights Concerns

The monitoring work carried out by ENNHRI suggested that the main causes of the human rights concerns described above were primarily:

- limited funding for care homes
- a lack of understanding of the human rights of older persons by care managers and staff
- unattractive conditions for care workers

Although the financial resources available to care homes are often outside of their control (due to their reliance on statutory contributions), our findings also showed that creative thinking can go some way to ensure the provision of a HRBA to long-term care. As such, training on human rights for care staff is vital for ensuring that care providers meet their human rights obligations to care staff.

The Scottish Human Rights Commission has developed a training programme for care workers, available online that can help care workers think in a human rights way.<sup>24</sup> Other publications are also available for healthcare workers.<sup>25</sup>

## 7. Summary and Conclusions

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

Robert G. Ingersoll, American Lawyer and Political Leader

Human rights reflect the minimum standards necessary for people to live with dignity. 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

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<sup>24</sup> <http://careaboutrights.scottishhumanrights.com/>

<sup>25</sup> <http://www.osce.org/odihr/105053?download=true>,  
[http://www.humanrightsinhealthcare.nhs.uk/Library/good\\_practice/WHO%20Toolkit.pdf](http://www.humanrightsinhealthcare.nhs.uk/Library/good_practice/WHO%20Toolkit.pdf)

State, including a residential care setting providing long-term care services for older persons, have a responsibility to protect and promote human rights.

A HRBA is a useful and effective way of helping care providers to meet their obligations under human rights national and international legislation. It has many benefits for staff and service users alike and has the potential to save resources through better health-related outcomes, reduced staff turnover and critical incident rates.

A human rights-based approach 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 long-term care, 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.

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.

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: Relevant Human Rights Standards

Right	Obligations in Practice	Relevant Restrictions
<b>Access to Long-term Care</b>	<ul style="list-style-type: none"> <li>• Ensure each individual has given informed consent to LTC and provide them with the choice of where to receive long-term care.</li> <li>• Waiting lists for care should be maintained on the basis of fairness, urgency and transparency, according to evidence based medical criteria which include the individual's condition and risk factors, emotional and psycho-social criteria and their quality of life.</li> <li>• Need and urgency should never be determined on the basis of race, religion, gender or other non-medical status. It should not be acceptable to buy or exert influence to move up a waiting list.</li> <li>• Patients and consumers of health care are entitled to have information on waiting lists and waiting times in specific settings generally as well as individualised information about their own ranking on waiting lists.</li> </ul>	There is no specific obligation to provide older people with the right to long-term care, though there are provisions on the right to equal access to affordable healthcare services and on the right to a choice of long-term care setting.
<b>Right to Life</b>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Carry out an independent investigation if a death occurs in which the state may be implicated.</li> </ul>	Can only be restricted under specific essential conditions, including to stop an individual carrying out <b>unlawful</b> violence or escaping <b>lawful</b> detainment.
<b>Freedom from Torture, degrading or inhuman treatment; violence and abuse (incorporates the right to</b>	<ul style="list-style-type: none"> <li>• Prevent all individuals from being subject to torture, violence or abuse (intentional OR unintentional treatment that causes the individual harm), or allow others to do so under any circumstances.</li> <li>• Provide an adequate number of trained staff to ensure residents' needs and wishes are met in a timely manner.</li> <li>• Put oversight mechanisms in place to monitor the situation of older persons in nursing homes and manage risks that may arise.</li> </ul>	Must never be restricted under any circumstances.

<b>an effective remedy)</b>	<ul style="list-style-type: none"> <li>• 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 them to report abuses to competent authorities.</li> </ul>	
<b>Liberty, freedom of movement and restraint</b>	<ul style="list-style-type: none"> <li>• Do not detain/restrain anyone against their will.</li> <li>• unless it is necessary and proportionate, for the purpose of protecting the person in question from harm or preventing injury to others (must be last resort, for the shortest appropriate period of time, and must be accompanied by adequate procedural and substantive safeguards established by law).</li> <li>• Make alternative community-based services available in order to provide less restrictive alternatives to confinement.</li> <li>• 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.</li> <li>• 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.</li> </ul>	<p>Traditionally, human rights law allows for circumstances of detention in the field of mental health as long as it is "necessary and proportionate, for the purpose of protecting the person in question from harm or preventing injury to others".</p> <p>More recent legislation and interpretation suggests that any restraint on people with disabilities, including seclusion, even for a short period of time, may constitute torture or ill-treatment.</p>
<b>Choice, Autonomy, Legal Capacity and Equal Recognition before the Law</b>	<ul style="list-style-type: none"> <li>• Care providers must recognise that each residents 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.</li> <li>• Develop policies and practices to facilitate supported decision-making, rather than substituted decision-making.</li> <li>• Facilitate individuals' involvement in decisions affecting their life and healthcare.</li> </ul>	<p>Must never be restricted under any circumstances.</p>
<b>Dignity</b>	<ul style="list-style-type: none"> <li>• Respect for and protection of each individual's physical, sexual, psychological, emotional, financial and material welfare and protection from neglect and abuse. Provide an adequate complement of trained staff and resources to ensure each individual's dignity and choices are respected.</li> </ul>	<p>The restriction of another right must never impinge on the right to dignity.</p>

	<ul style="list-style-type: none"> <li>• Ensure each resident's potential is met and fulfilled.</li> <li>• No unnecessary restraint.</li> <li>• No incontinence pads when the individual can access the toilet with support.</li> </ul>	
<b>Privacy and Family Life</b>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Respect each individual's personal choice as to their preferred mode of dress and address.</li> <li>• 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.</li> <li>• Ensure privacy of correspondence, data and discussions about care are also protected.</li> <li>• Provide each individual with information about their human rights if it is clear that their rights are at risk.</li> </ul>	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.
<b>Participation and social inclusion</b>	<ul style="list-style-type: none"> <li>• Facilitate the right to take part in the conduct of public affairs and to vote.</li> <li>• Provide or facilitate access to a range of recreational activities and events.</li> <li>• Facilitate individuals' involvement in decisions affecting life and healthcare.</li> </ul>	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.
<b>Freedom of expression, freedom of thought,</b>	<ul style="list-style-type: none"> <li>• Refrain from taking actions which would interfere with thought, conscience and religion</li> </ul>	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

<p><b>conscience: beliefs, culture and religion</b></p>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Facilitate the right to worship or assemble in connection with a religion or belief and to establish and maintain places for these purposes.</li> <li>• Provide reasonable access to the foodstuff in accordance with dietary requirements of a religious faith.</li> <li>• 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.</li> </ul>	<p>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. The right to hold religious and non-religious beliefs cannot be restricted.</p>
<p><b>Highest attainable standard of physical and mental health</b></p>	<ul style="list-style-type: none"> <li>• Provide timely and appropriate health care.</li> <li>• 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.</li> <li>• Ensure the participation of each individual in all health-related decision-making</li> <li>• Respect each individual's right to refuse treatment.</li> <li>• Make health facilities, goods and services available, accessible, affordable, acceptable insofar as possible.</li> <li>• The provision of an integrated model of care, combining elements of preventative, curative and rehabilitative health treatment.</li> <li>• 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.</li> </ul>	<p>Not to be understood as a right to be healthy but as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable standard of health. Includes at a minimum access to health facilities, goods and services available in sufficient quantity to all without discrimination.</p>
<p><b>Adequate standard of living</b></p>	<ul style="list-style-type: none"> <li>• Provide the basic essential levels of care, such as the provision of adequate food and water or medical assistance. Provide an adequate number of trained staff to ensure adequate living conditions.</li> </ul>	<p>No relevant restrictions possible. The right provides for minimum core obligations (adequate food and</p>

		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.
<b>Equality and non-discrimination</b>	<ul style="list-style-type: none"> <li>• Refrain from enacting care home policies and practices with a discriminatory content, or in a discriminatory way, towards staff, volunteers and residents.</li> <li>• Facilitate the needs and wishes of minority groups.</li> <li>• Ensure equity in out-of-pocket payments for care homes.</li> </ul>	In some circumstances, measures that are necessary to assist or recognise the interests of particular disadvantaged groups in the community ('special measures') will not be regarded as prohibited discrimination provided that they do not lead to the maintenance of separate rights for different racial groups and that they are not continued after the objectives for which they were taken have been achieved.
<b>Access to Justice, effective remedy, redress</b>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Deter conduct that would infringe human rights.</li> <li>• Provide effective avenues for complaint that allow individuals to report breaches of their human rights or well-being without fear of reprisal.</li> <li>• Respond to complaints within a reasonable timeframe.</li> <li>• Providing residents with access to independent third party advocacy services.</li> </ul>	The right to a fair trial and an effective remedy is absolute and cannot be limited.
<b>Palliative care</b>	<ul style="list-style-type: none"> <li>• Ensure individuals are spared avoidable pain and enabled to die with dignity.</li> <li>• Provide adequate palliative care services.</li> </ul>	Access to pain treatment is an absolute human right.